Exploring the Patient Journey: a collaborative approach to patient-centred improvement in healthcare.

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Abstract: Exploring the Patient Journey: a collaborative approach to patient-centred improvement in healthcare: Susan E M Baron

Despite widespread endeavours over many years, patient-centred care continues to evade some areas of healthcare. This can be clearly evidenced by regular reporting of sub-standard care and the findings of national patient experience surveys which repeatedly highlight a number of common contributory factors. Amongst these include a predominant culture of secrecy and blame rather than openness and support; failure to listen and respond to staff or patient issues; workloads and time constraints; fragmented teamwork; an overriding focus on targets rather than people; in addition to varying perceptions and interpretations of, and expectations and priorities for patient-centred care (PCC). These occur between patients, staff, educationalists, policy-makers, healthcare managers and the public. These factors, which are further reinforced by this study's review of empirical studies of patient-centred care, strongly indicate that new approaches to improvement, that involve service providers as well as service users, are called for.

Addressing this call was an interest of this study. Action research was selected because this promotes a collaborative and democratic approach to research-based organisational, social and cultural change and improvement. In this study, which was also underpinned by the philosophy of patient-centred care, action research was combined with the Patient Journey. This is a patient-centred improvement, and, or, practice development process developed and tested by Campbell et al (2004) at the City Hospitals Sunderland NHS Trust. By combining the action research and Patient Journey (PJ) processes, this enabled the generic potential and effectiveness of the approach to be concurrently investigated and established as will be explained.

Through the collaborative efforts of a participating 25 member Vascular Patient Journey project team, data was gathered during the process through team discussions, mapping and interviews with 17 service users. 75 issues were identified using inductive thematic analysis; 34 of which emerged from the data of service users, 35 from service provider data, and a further six jointly emerged from both datasets. These provided powerful catalysts for change and points of learning which the team, empowered by their involvement in the process, used as the evidence-base from which to action change, as discussions in this thesis will demonstrate. They will also illustrate why more should be done to involve multidisciplinary teams as well as service users in improvement.

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Introduction

This action research study has explored the *Patient Journey*, a structured and collaborative approach to service improvement and practice development that had been claimed to be "…*explicit, different and making a difference to patients*" (Campbell et al, 2004, p. 15). Campbell et al (2004) developed the *Patient Journey* by way of response to the UK's Department of Health's (DH) programme of National Health Service (NHS) modernisation. The team, from the Nursing Practice Research Centre (NPRC) at the City Hospitals Sunderland NHS Foundation Trust (CHS) were specifically responding to the Government's call for the NHS to *"be redesigned to offer a personalised service through patient-centred healthcare delivery"* (DH, 2000a, p. 17). This was outlined in the White Paper "*The NHS Plan: a plan for investment, a plan for reform*" published in 2000.

Campbell, then Head of Nursing Research and Development, together with Gibson and Bremner, as former and current Chief Executives of the CHS Trust, and Watson, and Husband as Principal and Senior Lecturers from a local University, identified shortcomings in a number of healthcare quality improvement initiatives, many of which had been introduced since 1997 to support NHS modernisation. These were intended not only to improve patient experience but also safety, efficiency, quality and continuity of care. Amongst these measures include integrated care pathways, continuous quality improvement, evidence-based practice, clinical audit, Plan-Do-Study-Act (PDSA) cycles (Langley et al, 1996, DH, 2003) and Discovery interviews (DH, 2003). Campbell et al (2004, p.15) were concerned that Discovery interviews, for instance, as a similar approach to Patient Journeys, did *"not have a systematic approach to sampling"* (Campbell et al, 2004, p.15). They were also concerned that many of the existing improvement measures were unlikely to address power differentials between healthcare staff and patients, or hierarchical differences amongst clinicians. It also seemed that none would effectively enable the *"insider perspective of the illness experience"* to be acknowledged, or patients' experiences to be contextualised as integrated journeys that cross organisational and health and social care boundaries (Campbell et al, 2004, p.16).

Campbell et al (2004, p.17) explained that their Patient Journey (PJ) approach aimed *"to rebalance the power relationships when developing patient care"*, such as those that might arise from integrated care pathways. These are usually only determined by health professionals. The Patient Journey, by comparison, was developed to enable the perspectives of service users and service providers to be considered alongside each

other when reviewing a current service for the purpose of improvement. As Table 1-1 illustrates, Campbell et al describe the Patient Journey as a six-step process. This begins with the identification of key stakeholders who are interested in reviewing and improving a current patient journey, and the recruitment of a PJ project team associated with that journey, who are to become actively engaged in the change process. The process is led by an external PJ project facilitator.

The Patient Journey

1. Identify Patient Journey and recruit Patient Journey project team
2. Stakeholder sampling and mapping of current patient journey
3. Recruit and interview patients
4. Collate and analyse data from mapping and interviews
5. Identify issues and solutions; plan actions for change
6. Implement change, monitor, evaluate, plan further change

Figure 1-1: six key stages of the Patient Journey (adapted from Campbell et al, 2004)

The first Patient Journey was piloted in CHS in 2002. Prior to the start of this study, sixteen Patient Journey projects had been completed (Table 1-2) and a further four were in progress. As Table 1-2 indicates, these had been used to investigate the patient journeys of adults and children living with acute or long-term conditions.

Patient Journey projects completed by 2004

Acute coronary syndrome	Lung cancer (2 projects)
Prostate cancer	Percutaneous endoscopic
Cholecystectomy	gastrostomy (PEG)
Laryngectomy	Ovarian cancer
Acute myocardial infarction	Head injury
(AMI)	Epilepsy
Acute childhood admissions	Strabismus
Fertility	

Figure 1-2: completed Patient Journey projects prior to start of this doctoral study

It was the outcomes of these sixteen PJ projects that enabled Campbell et al to claim that their approach was "…*explicit, different and making a difference to patients*" (Campbell et al, 2004, p. 15). These results had also been indicative of the wider potential of the model. However, because all PJ projects had been run 'in house' and overseen by those who had developed the model, it was recognised that independent verification was required before claims about its wider and generic potential could made. This led to the proposal for this funded doctoral study which would enable an outsider to

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Campbell et al's team, and the City Hospitals Sunderland NHS Foundation Trust, to independently investigate, implement and evaluate the Patient Journey process. The method selected for conducting this investigation, as already indicated, was action research. The methodology is explained in Chapter 3.

Study context

This action research (AR) study was structured around the Patient Journey (PJ) approach to improvement and practice development developed by Campbell et al (2004). As explained, prior to the start of this study, sixteen PJ projects had been implemented and completed for a variety of patient groups who had journeyed through the services of the City Hospitals Sunderland NHS Foundation (CHS) Trust based in northern England. The CHS Trust provides a wide range of services to a local community of around 350,000 residents; has around 904 acute hospital beds; an annual income of approximately £309.55 million; and employs just over 5,000 staff.

By comparison, this AR study, which investigated a Vascular Patient Journey (VPJ), was set within a vascular specialty which provides care, treatment and services to patients diagnosed with vascular disease. This forms part of the surgical directorate of an acute NHS hospital Trust based in southern England. This Trust, which will be referred to as the SE Trust to respect anonymity, serves a population of over 340,000; has an annual budget of approximately £246.7 million; nearly 800 beds, and employs more than 4,000 staff. At the commencement of this study, the SE Trust was undergoing a programme of modernisation and had expressed a keenness to develop high quality patient-centred healthcare services.

As action researcher, external Patient Journey project facilitator, and author of this thesis, prior to the start of this study I had no previous affiliation with the CHS Trust or with the SE Trust where this study was subsequently set. I was a true outsider at the outset in every sense; to the CHS team, the participating NHS hospital trust, and the CHS Patient Journey approach. During the implementation of this study's AR Vascular Patient Journey service improvement project, I worked concurrently as a staff nurse in a separate and unrelated acute NHS Trust located in a different part of southern England. In the latter part of the study I became a lecturer in nursing.

Background to the Patient Journey approach

Because the City Hospitals Sunderland's (CHS) Patient Journey approach (Campbell et al, 2004) was developed by way of response to the UK's NHS modernisation agenda, a

brief introduction to the *patient-centred* care (PCC) element of NHS reform follows. An overview of additional PCC policy drivers is provided in Appendix 1.

Key drivers behind NHS patient-centred reform
Significant failings
During the late 1980s and early 1990s a series of failings in paediatric cardiac surgery, at the Bristol Royal Infirmary (BRI) in England, UK, resulted in numerous infant deaths. When these failings came to light, this sparked intense media, public and political debate, both in the UK and internationally. This caused a sea change in attitudes towards professional regulation, clinical competence and quality improvement in healthcare (Walshe and Offen, 2001).

Complaints and cost to the NHS
More than 38,000 complaints had been made between 1998 and 1999 about all aspects of healthcare services, at a cost to the NHS of around £400 million. This was in addition to an estimated £2.4 million in liability already outstanding for existing claims (DH, 2000b). Moreover, a UK pilot study found that adverse events were costing the NHS an estimated £2 billion a year in extended hospital stays; some five times more than clinical negligence claims (DH, 2000b). Approximately 850,000 adverse events (affecting approximately 10% of in-patients) occurred annually in NHS hospitals; about half of which were thought to have been avoidable (Vincent, 2000, Vincent, 2001, Vincent and Coulter, 2002, DH, 2000b).

An endemic culture of secrecy and blame
A culture of secrecy and blame was identified as a contributory factor to healthcare failings. This was encouraging staff to "*conceal errors rather than report them and risk retribution*" (DH 2000b, p. ix) despite their professional, moral, ethical and legal duties to do so. In turn, this was adversely impacting on patient safety, collaborative teamwork, quality improvement and the implementation of patient-centred care (DH, 2001; Coulter, 2002).

Incident analysis, not only in healthcare but also wider society, had become focused on human acts or omissions and attributing blame rather than learning from errors, adverse incidents or accidents (Coulter, 2002, Walshe and Shortell, 2004). In healthcare this culture was further exacerbated by a lack of collaboration between frontline staff and managers as also highlighted by Kennedy (2001), Dimond (2002), and Ahern and McDonald (2001).

An internal market system

These issues were partially attributed to performance measures associated with an internal market system that permeated the NHS. These measures *"failed to reflect the breadth of what patients expect of the service, and of what staff want to provide"* (DH, 1997, p.8); and were further exacerbated by a corresponding principal duty placed on NHS organisations. This had been financially driven rather than focused on people and their experiences.

NHS reform: the NHS to be redesigned to be patient-centred

By way of response, in 1997 a programme of National Health Service (NHS) patient-centred reform was launched by the UK government (Department of Health [DH], 1997). This called for the NHS to be *"…redesigned to be patient-centred – to offer a personalised service"* (DH, 2000a, p. 3, 17); the directive that led Campbell et al (2004) to develop their Patient Journey model. The goal was for the NHS to become *"a health service designed around the patient"* (DH, 2000a, p. 4); where patients would be given a *"real say in the NHS"*; and provided with *"new powers and more influence over the way the NHS works"* (DH, 2000, p. 6). These reforms were necessary to *"...to fight the failings in the system"* and *"the toughest issues that have been ducked for too long"* (DH, 2000a, p. 15).

Ten fundamental principles of reform made clear that the needs and preferences of *"individual patients, their families and carers"* were to be taken into account in the provision and re-design of services (DH, 2000a, p.4, 5; DH, 2004d). Healthcare and services were to be developed according to the "*patient's point of view*" and able to respond effectively to the "*different needs of different populations".* The reformed NHS would "*work to continuously improve quality services and minimise errors*". It would also *"value and support its staff"* who would need to "*work together with others"* to provide a *"seamless service"* for patients (DH, 2000, p.4, 5; DH, 2004d). The Government acknowledged that attaining high quality healthcare and services was dependent upon "*every member of the team and every part of the system working effectively and in harmony with the rest"* (DH, 2004e, foreword). These quotes are used to emphasise policy level recognition of the importance of finding new ways to enhance and improve collaborative, multi-disciplinary teamwork.

Measures introduced to guide quality improvement and patient-centred care

The Quality Framework

The *"Quality Framework"* (DH, 1998) (Figure 1-3) was set up to drive quality into all areas of the NHS as part of the government's programme of reform.
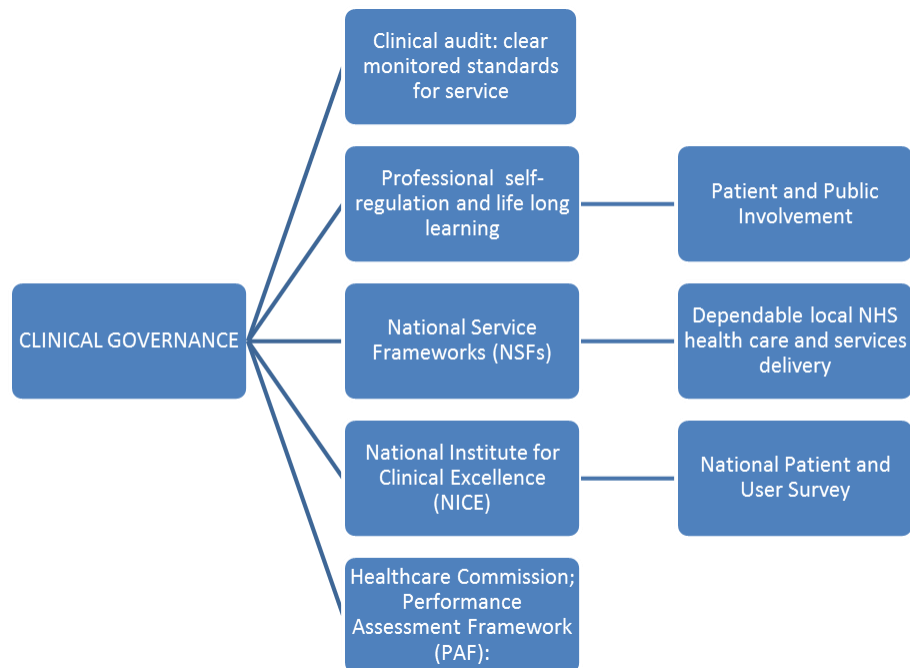
Figure 1-3: the Quality Framework
Adapted from "A First Class Service, Quality in the New NHS" (DH, 1998)

This saw the introduction of clinical governance, National Service Frameworks (NSFs), the then National Institute for Health and Clinical Excellence (NICE), renamed in 2013 as the National Institute for Health and Care Excellence (NICE), the Performance Assessment Framework, clinical audit, and independent monitoring of healthcare organisations.

The requirement for independent monitoring and review of healthcare was introduced through the Health Act in 1999. The aim was to verify each organisation's adherence to clinical governance; and the implementation of NICE and NSF guidelines and twelve patient-focused benchmarks introduced through *"The Essence of Care"* (DH, 2001b). Independent monitoring was initially undertaken by the Commission for Health Improvement (CHI). Since 2009 the Care Quality Commission (CQC) has acted as the independent regulator of health and social care in England. This organisation continues to monitor healthcare performance and patient experiences through inspections and national patient and user surveys. The results contribute to publicly available,

performance ratings for healthcare organisations first introduced by *"The NHS Plan: a plan for investment, a plan for reform"* (DH, 2000a).

Since its inception "*The Quality Framework*"(DH, 1998) (Figure 1-3) has aimed for the delivery of clinical excellence through the efficient, effective synchronisation of the systems and processes of risk management, performance management, quality improvement, information giving, accountability and communication (Craig and Smyth, 2002; McSherry and Pearce, 2002; Bauman et al, 2003). Each NHS organisation, and its employees, has a statutory duty to ensure that quality standards are upheld and maintained through *clinical governance* (DH, 1997); this Vincent (2000, 2001) described as the cornerstone of NHS modernisation.

Conversely, Duffy and Irvine, (2004), Swage (2004), Peak et al (2005) McSherry and Pearce (2002) reported that clinical governance *"had often led to fragmented pieces of work"* because the concept and its operationalisation was not readily understood (Duffy and Irvine, 2004, p. 141, McSherry and Pearce, 2002). Peak et al also identified that, even eight years after its introduction, the organisational view of clinical governance frequently differed to the perceptions of clinical staff. Moreover, a fundamental element of clinical governance*," innovation",* was being suppressed by a greater emphasis placed by NHS management on accountability (Peak et al, 2005). These factors are also indicative of a lack of collaboration between policy-makers, healthcare managers and frontline staff.

Patient and public involvement
As Figure 1-3 illustrates, patient and public involvement and national patient and user surveys were included as integral elements of clinical governance and thus the quality framework.

The Health and Social Care Act (DH, 2001); *Learning from Bristol* (DH, 2001) and *Involving Patients and the Public in Healthcare* (DH, 2001) introduced the building blocks for the greater involvement of patients and the public in every aspect of healthcare. These people were to have their voices heard, and their feedback used appropriately as catalysts for future change and improvement.

Commission for Patient and Public Involvement in Health
The Commission for Patient and Public Involvement in Health was set up to support involvement. One of its key functions was to collate information retrieved by Patient Advice Liaison Services (PALS); Patient and Public Involvement Forums, other local patient networks, and disseminate any trends or concerns in annual reports. In 2004

"*The NHS Improvement Plan: Putting people at the heart of public services*" (DH, 2004a) reaffirmed that *"responsive"* and "*personalised services*" would be embedded across the whole of the NHS (DH, 2004a, p. 8).

Professional duty to engage with patients and multidisciplinary teamwork

The duty to engage with patients, and with other members of the multidisciplinary team, was also explicit in professional codes. In more recent times in the UK, for example, Domain 3 of '*Good Medical Practice'* provided by the General Medical Council (GMC, 2011, 2013) makes clear that doctors are required *"to work in partnership with patients, to listen to and respond to their concerns and preferences"* and *"to work with colleagues in the ways that best service patients' interests"* (GMC, 2013). Doctors also have a duty to *"work collaboratively with colleagues, respecting their skills and contributions"* (GMC, 2013, p.14). These duties are also reiterated in the Nursing and Midwifery Council's (NMC, 2008) *'The Code'*, and The Health and Care Professions Council's (HCPC, 2012, p.8) *'Standards of conduct, performance and ethics'* who regulate the practise of sixteen groups of allied health and care professionals.

Involving service users in change management

A change management *"Briefing Paper"* by the NHS Service Delivery and Organisation R&D Programme (SDO) (NHSSDO, 2004) provided guidance for managers on helping service users to bring about change in the NHS. This was based on a summary of two systematic literature reviews, commissioned by the SDO, to examine best ways of involving service users in organisational change. Guidance for improvement leaders was published a year later by the NHS Modernisation Agency (DH, 2005). This made clear to improvement leaders that frontline staff, clinicians and managers (service providers), in addition to patients, should be involved from the beginning of the improvement process and empowered to contribute and share their knowledge, experiences and ideas. This was acknowledged as imperative, not only in terms of relationship building and reducing anxieties, but also because when the different perspectives and experiences of patients and staff are shared, these can produce catalysts for change (DH, 2005). These recommendations will be reinforced by the finds of the literature review in the next chapter.

Several factors found to impede meaningful patient involvement, as identified from the two systematic literature reviews, were also highlighted in the NHS SDO Briefing Paper (NHSSDO, 2004). Amongst these included organisational and professional resistance to change or to learning from service users. A lack of understanding of power differentials in healthcare, perhaps most notably between managers, doctors, nurses and patients, was also identified as a contributory factor. Guidance emphasised that

these factors were exacerbated by managers who set out to build an alliance with service users, or simply obtain their feedback, yet failed to recognise that for effective change to happen, this also required the engagement and empowerment of frontline staff (NHSSDO, 2004, DH, 2005).

The guidance also made clear that the aim of service user involvement must be explicit from the outset. The approach must be open and honest; information should be clear and readily understood by all, the potential for distress recognised and steps taken to prevent this, and service users informed of the outcome of their involvement. Securing organisational commitment and ownership for change was recognised as essential (NHSSDO, 2004, DH, 2005). This guidance was followed before and during this study's Patient Journey project.

Partnerships with service users; staff understanding of each other's roles
"National Standards; Local Action: Health and Social Care Standards and Planning Framework 2005/06-2007-08" (DH, 2004d), set out seven Domains of Core and Development Standards to guide the planning, commissioning and delivery of NHS healthcare and social services. One of the domains, Patient Focus, again reiterated that healthcare was to be *"provided in partnership with patients, their carers and relatives"*. Healthcare organisations were to use feedback from patients, carers and relatives to continuously improve the patient experience (DH, 2004d, p. 31). However, as the NHSSDO (2004) and Modernisation Agency (DH, 2005) guidance highlighted, finding out what service users wanted was relatively straightforward. The Patient Focus domain failed to make clear that the challenge would lie in achieving change once the data had been gathered. Core Standard C2 restated former recommendations that all health and social care staff gain an understanding of the roles and responsibilities of other professionals (DH, 2004d). The aim of which was to improve inter-professional communication, working and patient care.

10 high impact changes for service improvement
"10 High Impact Changes for Service Improvement and Delivery: a guide for NHS leaders" (DH, 2004e) introduced rare examples of real-time piloted improvement initiatives. The NHS Modernisation Agency described how the thinking behind the development of *"10 High Impact Changes"* (HICs) differed to more usual approaches to NHS improvement. This was because these changes were based on everyday experiences and the achievements of *"thousands of frontline clinical teams, right across the NHS"*. They were *"not the products of academic theory, or an isolated group of experts"* (DH, 2004e, foreword), but the results of the efforts of over 150,000 NHS staff who had been involved with the work of the NHS Modernisation Agency between 2001

and 2004. NHS staff had been *"actively engaged in re-shaping service delivery"* so that the NHS might move closer to achieving its ambition for patient-centred, individualised care. These 10 HICs were based on three underpinning principles

(i)   Change, informed by empirical evidence that is tested and evaluated in practice, in "*real life NHS settings",* has the best chance of success.

(ii)   A high quality service is dependent on every member of the multi-disciplinary team and every part of the system *"working effectively and in harmony with the rest"* (DH, 2004e, foreword)

(iii)   Health care and services need to be viewed "*through the patient's eyes".* Patients' experiences involve a journey and one "*which sometimes lasts for the rest of their lives. Such care is not only physical: it is emotional, psychological and spiritual, and encompasses the needs of the whole person."* (DH, 2004e, foreword)

These principles reflect the philosophy of the Patient Journey approach (Campbell et al 2004). However, no guidance or examples accompanied the 10 HICs to illustrate how they could be implemented at local level. Nevertheless, these made clear that the Patient Journey approach was closely aligned with political expectations and seemed to offer an effective means by which to address the following *"need"*:

> "...We need to help frontline staff to develop ownership about how to do things differently and provide a culture to encourage change at grass roots with all healthcare staff. We need to empower staff to have the courage to break with ingrained habits plus the energy and perseverance to meet the challenges of transforming healthcare which is patient-led." (DH, 2004e, p. 4)

"10 High Impact Changes" (DH, 2004), the SDO *"Briefing Paper"* (NHSSDO, 2004) and the NHS Modernisation Agency (DH, 2005) guidance for improvement leaders, which offered evidence-based policy guidance for initiating change, and involving service users and providers in quality improvement initiatives, contributed to the underpinning rationale for this study.

Organisational duty to involve

In 2006, Section 242 of the consolidated NHS Act placed a duty on NHS trusts, primary care trusts and strategic health authorities to involve or consult patients and the public during service planning and developing proposals for change. Guidance to support this was subsequently provided in *"Real Involvement: working with people to improve health services"* (DH, 2008).

NHS modernisation, patient-centred care and this study's proposal

Since the launch of NHS '*patient-centred*' modernisation more than a decade ago, the systems and processes of the NHS, particularly in relation to quality improvement and patient and public involvement, have undergone radical change, as these introductions illustrate. Yet despite best intentions, and considerable effort, the findings of a subsequent public inquiry (Francis, 2010, Francis, 2013), more recent regulatory body inspections and media reports have continued to make clear that sub-standard, dehumanised healthcare still exists, at least in some pockets of the NHS (Healthcare Commission, 2009; Care Quality Commission, 2008, 2011a, 2011b, Patients Association, 2011). Indeed many of the recommendations of the Bristol Royal Infirmary inquiry (Kennedy, 2001, DH, 2001) are repeated in the final report of two subsequent inquiries into serious failings at the Mid Staffordshire NHS Foundation Trust that occurred during 2005 and 2008 (Francis, 2010, Francis, 2013).

These reports provide evidence that the blame culture continues to permeate many healthcare organisations preventing staff from being open and sharing their views (Coulter, 2002; Attree, 2007; Brandom et al, 2011; Francis, 2013). Francis (2010, 2013), for example, reports that patients and staff at Mid Staffordshire were not listened to; little if anything was done to rectify deficiencies when identified; the numerous agencies in healthcare failed to communicate effectively and share knowledge and concerns; and a negative culture existed amongst disengaged managers who tolerated poor standards. Managerial interest was focused on budgets and targets and achieving foundation trust status rather than people. Moreover, for more than fifteen years, these and other reports have provided evidence that staff shortages, lack of time and resources; poor communication and fragmented ways of working continue to adversely affect both patient and staff experiences (Coulter, 2002, 2006; Calkin, 2011; Francis, 2013). Additionally, a report by the Health Service Ombudsman revealed that during the period 2011 to 2012, the NHS had received 150,859 complaints, an increase of 1.3% on the previous year, and 112,859 more than the period 1998 and 1999 (Parliamentary and Health Service Ombudsman, 2012).

These findings indicate that the NHS has not fully learnt from past mistakes and that disparity continues to exist between the views and expectations of policy makers, NHS managers, frontline staff and patients about the key determinants of high quality, safe, *patient-centred* care and how these can be operationalised (Coulter and Cleary, 2001; Coulter and Ellins, 2006, DH, 2009e, DH, 2010d, DH, 2010e; Moore, 2007; The Health Service Ombudsman (HSO), 2011; and Wheldon, 2005). They also provide evidence that, although significant inroads have been made to involve patients and learn about

their experiences, the findings are not being routinely used to inform change and improvement. This may be due, in part, to a failure by managers to recognise that frontline staff, those who directly interact with patients, are best positioned to identify solutions to issues raised by service users and implement changes in practice (DH, 2005). This suggests that more needs to be done to actively involve service users, frontline service providers and managers in quality improvement initiatives, thus also promoting multi-disciplinary teamwork and enabling shared learning (DH, 1997, DH, 2000a, DH, 2004e, NHSSDO, 2004, DH, 2005). More recently, the NHS Constitution (2013, p.13) includes pledges that support this, one of which specifies a commitment to ensure that all staff are *"empowered to put forward ways to deliver better and safer services for patients and their families"*.

This study: a response to issues identified
Recognition of these issues and an interest in finding ways to address them underpins the rationale for this study and its investigation into the Patient Journey approach to service improvement developed by Campbell et al (2004). This was to examine how the Patient Journey, as a multi-disciplinary, collaborative approach that involves services users and providers in the review of services, can impact on and improve the delivery of patient-centred care.

Consequently, the following chapter, Chapter 2, offers a critical review of literature associated with patient-centred healthcare. This aimed to address the lack of underpinning empirical evidence found in healthcare policy directives and the paper by Campbell et al (2004). These failed to clearly explain the rationale for PCC and what this approach entailed, or how PCC improvement might be attained in practice. The review will also highlight a number of gaps left by former empirical investigations into PCC. By so doing, the findings of the literature review will explain the underpinning rationale and philosophy that influenced this study's design, the methods selected, and the approach taken towards enabling patient-(person)-centred change and improvement to a current patient journey. They will also explain how the aim and objectives for this study, listed at the end of Chapter 2, were determined.

Introduction

This review examined the empirical roots of *'patient-centred care'* (PCC) and *'patient-centredness'* and associated frameworks of care to explain why these are core concepts promoted by NHS modernisation and an international movement for PCC. This included a critical review and analysis of empirical studies that have specifically investigated PCC or patient-centredness. The findings provide an evidence-base for PCC and improvement, whilst also offering insights into associated healthcare concepts, theories and underpinning philosophies. In turn, these provide justification for the engagement of service users and multidisciplinary service providers in this study's independent investigation into Campbell et al's (2004) Patient Journey process and the approach taken in this action research study.

As explained, this study was set up to explore the City Hospitals Sunderland NHS Trust's (CHS) *Patient Journey* (PJ) model (Campbell et al, 2004); a localised, yet potentially generalisable, collaborative and patient (person)-centred approach to quality improvement/practice development. Campbell et al (2004) had identified shortcomings in a number of current improvement measures, many of which had been introduced since 1997 to support patient-centred NHS modernisation. These aimed not only to improve patient experience, but also safety, efficiency, quality and continuity of patient-centred care (PCC) but commonly lacked clear guidance or failed to reveal their evidence-base to explain or support the approach advocated. Moreover, as Campbell et al (2004) identified, none of the existing improvement initiatives appeared to offer a means through which power differentials between healthcare staff and patients, or hierarchical differences amongst clinicians could be addressed. Nor did they generally enable the *"insider perspective of the illness experience",* to be acknowledged*,* or patients' experiences contextualised as integrated journeys that often cross organisational and health and social care boundaries (Campbell et al, 2004, p.16). These factors are considered fundamental to the attainment of PCC improvement as will be explained.

Literature search strategy

The strategies used to structure this review of literature evolved from guidance offered by Aveyard (2007), Bell (2005), Dixon-Woods et al (2005), Fink (2005), and Hawker et al (2002). Advanced searches for peer reviewed, full-text empirical literature published in English Language were usually undertaken using the comprehensive electronic

discovery service provided by EBSCO (this includes key health and social care databases such as MEDLINE, Science Direct, Ovid, CINHAL® (Citation Index for Nursing and Allied Health Literature) and Web of Knowledge) and the Cochrane Library.

Search terms are included in Table 2-1. These emerged as the review progressed. Although the original intention had been to solely focus on *patient-centred* and *patient-centredness*, it soon became apparent that the empirical foundations, philosophy and determinants of PCC should be contextualised with other theories, concepts, models and frameworks that also influence professional practice and patient care. This is explained separately.

Concepts and terms used for literature searches		
Patient-centred and patient-centredness	**Existing frameworks of care**	**Patient engagement/ involvement**
patient-cent*	patient care	patient-cent* AND
health care	care pathway	patient involv*
patient care	multidisciplinary inter-professional	service user/carer/staff involv*
patient experience	model/framework	patient/carer/family/ and or staff engage*
patient-cent*care	theoretical/conceptual	patient voice
defin*	philosophical	patient narrative
measur*	model of healthcare	quality improvement
outcome*	frameworks of care	service improvement
healthcare	holis*	patient journey
improv*	human*	change
service	biopsychosocial	model
	person-cent*	multi-disciplinary
	life-world	service user
	compassionate	service provider
	relationship-cent*	healthcare staff
	caring	professional
	digni*	

Table 2-1: Literature review core concepts and search terms

Searches often brought extensive results, for example 246,551 for *'patient centred care'* (Figure 2-1 below). This presented a significant challenge to a sole reviewer, and several modifications were required to reduce the results to a more manageable number. This was generally achieved using different combinations of terms; adding more limiters, applying Boolean logic, truncation and so forth (Aveyard, 2007; Bell, 2005; Fink, 2005). Not all revisions significantly reduced the results; on these occasions only the first 200 were scanned for relevant titles and abstracts.

On occasion this strategy led to an unexpected increase in results and advice was sought from a librarian. For example a search using *'patient involve'* to *'patient cent* AND health care'*, yielded 354,020 results (Figure 2-1). Adapting this search in accordance with guidance reduced the results to 103, by using (healthcare) and (service* improvement*) AND (patient experience* OR patient journ*). A record of the number of new and modified searches undertaken during this review was not kept.
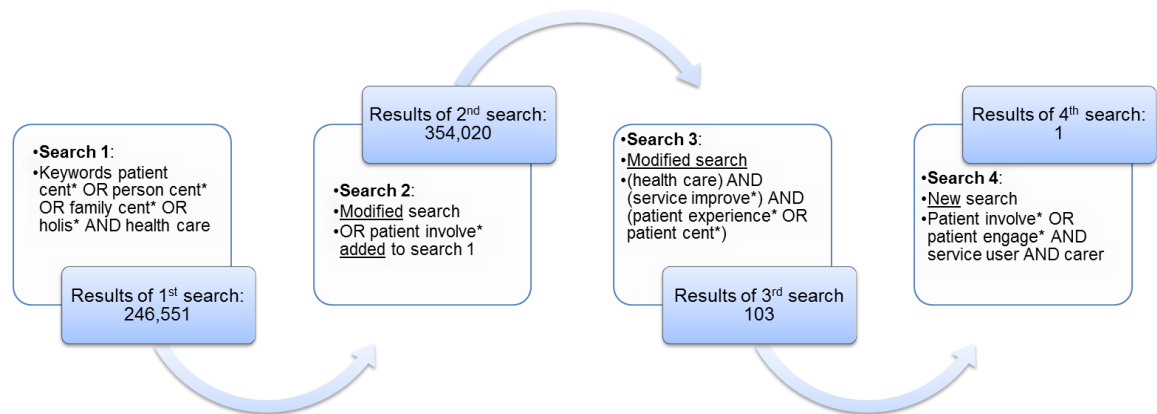
Figure 2-1: Example of application of search strategy

Hand searches of reference lists and citations in empirical literature revealed additional theoretical, conceptual or philosophical concepts and frameworks of care that have been associated with PCC. Journals and books; networking and serendipitous finds provided further articles (Whittemore and Knafl, 2005, Foster and Ford, 2003). A number of these and grey literature, including publications from the Department of Health, Picker Institute, King's Fund, the Care Quality Commission, the Institute of Medicine and the Institute for Healthcare Improvement, were retrieved via Google™ and Google Scholar™. Ad-hoc searches were also undertaken as required to retrieve further seminal works revealed by the literature.

Appraisal and data extraction

All shortlisted empirical studies were critically appraised in accordance with guidance offered by Aveyard (2007) and by using relevant checklists provided by the Critical Skills Appraisal Programme (CASP) (www.casp-uk.net, 2007), Oxford, UK. These can be used for appraising quantitative and qualitative research and literature reviews. They are tailored to the specific research paradigm, for example to appraise reliability and validity of quantitative research, or to determine the authenticity and generalisability of qualitative methods.

Irrespective of research paradigm, appraisal included consideration of study aim and design; setting; background literature review (to also identify key sources of influence); methods, participants, findings and limitations. Where relevant and available, additional elements were also assessed, including sampling strategy; ethical issues; researcher/ participant relationship if identified; data collection method; method of analysis, any undue bias on results, researcher' perception of limitations (Example appraisal matrix included as Appendix 2). Prior to final selection, the relevance, generalisability and potential contribution of each paper to this study was established (Aveyard, 2007).

Once selected, papers were read and re-read to affirm understanding; identify and extract key points, and enable relationships between studies to be identified. Highlighter pens and memos aided this process. Sometimes, but not always, pertinent data were extracted and stored in tables according to emerging theme (see example Appendix 3: table of associated concepts). This allowed more detailed cross-referencing and analysis. Every effort was taken to ensure that each stage of the iterative review process was conducted systematically and with rigour, to mitigate the risk of bias or error, and enable findings to be presented authentically. The inclusion criteria are detailed in Table 2-2 below.

What is the empirical evidence-base for patient-centred care and patient-centredness?	
Inclusion criteria	Exclusion criteria
- Patient-centred or patient-centredness (UK and US spellings) only - Peer reviewed, published, empirical studies only - Date of publication 1998-May 2007 (extended to 2010 to allow contemporary perspective when writing up thesis) - Healthcare, health care; any setting (acute, rehabilitative, end of life, primary care) - Any country - Any professional discipline - Any health condition, any patient group - English language - Full text - Service user (patient, carer, relative) involvement - Service provider (single or multi-disciplinary) involvement - Fulfilled appraisal criteria - Content must be relevant to proposal for this study. This includes establishing underpinning philosophy, identification of research method and justification for study.	Empirical studies using terms other than patient-centred

Table 2-2: Inclusion criteria for empirical studies associated with patient-centred care

Empirical literature was automatically excluded if it did not include the term *'patient-centred'* or *'patient-centredness'* or was not fully relevant to the proposed aims and objectives for this study. No paper was excluded on the basis of participant health condition, diagnosis, age-group, gender or ethnicity. Studies were not restricted to any specific discipline, healthcare setting or country in view of the multi-disciplinary nature of this study and perceived generalisability of the Patient Journey model. Date parameters varied according to the purpose of the respective element of the review; for example when establishing context and evidence-base prior to the implementation of the new Patient Journey in May 2007, or to enable contemporary perspective when writing up this thesis. Only papers that fulfilled the criteria are discussed in this review.

Tenets of the integrative review and narrative inductive method of analysis
Patient–centred care (PCC), as this review will illustrate, has been investigated through a broad variety of quantitative, qualitative and mixed research methods; from different theoretical, philosophical, professional and conceptual standpoints; and usually to examine different aspects of PCC. This reflects the complex and subjective nature of PCC, understanding and attainment of which is influenced by many factors, including individual perception and experiences; availability of resources; environment; human factors (Leonard et al, 2004); societal and organisational culture; and healthcare systems and processes. Not all of these could be explored or discussed during this review, rather an overall sense of most significant influences is provided.

In recognition of the varied evidence-base and complex nature of PCC, the principles of the integrative review and narrative inductive method of analysis have been followed, as proposed by Whittemore and Knafl (2005), Dixon-Woods et al (2005) Mays and Pope (1995), Mays et al (2005) and Greenhalgh et al (2005). Through these methods, data analysis techniques, including thematic analysis and narrative summary allow evidence from qualitative, quantitative, theoretical and conceptual origins to be integrated and presented in *"narrative juxtaposition"* (Dixon-Woods et al, 2005, p.47). Consequently, this review is presented as a critical analysis interspersed with summary tables to highlight key points (Greenhalgh and Peacock, 2005, Greenhalgh et al, 2005).

Literature review findings
Patient-centred care (PCC) initially became the focus of this review principally because, as explained, this is the term consistently used by the British Government to describe its vision of UK healthcare (DH, 1997, 2000a, 2008). However, as review will illustrate, this vision is not exclusive to the UK, nor is '*patient-centred'* the only term that reflects a persistent and international endeavour by behavioural and social scientists,

philosophers, theorists, healthcare professionals and patient advocates, to improve, humanise, personalise and demystify patient care.

This multitude of separate endeavours has resulted in an abundance of differently termed concepts, theories, models and frameworks of care.   Some of those most commonly related to PCC include person-, client-, relationship-, or family-centred care; holistic, biopsychosocial, caring, dignity-conserving and compassionate. Many of these terms are also used interchangeably (Mead and Bower, 2000, 2002, Reid Ponte, 2004, Freeth, 2006, Price, 2006, DiGioia III et al, 2010); a practice that is commonplace in healthcare and often causes confusion.

To prevent misunderstanding or confusion from being a barrier to improvement in this study, a brief introduction to commonly affiliated concepts will be included. This is integrated within the discussions in this review. A summarised synthesis of these interrelated concepts is also presented in Figure 2-2, and an additional narrative summary to introduce yet more related concepts, theories and models is provided in Appendix 3.

The foundations of patient-centred and humane approaches to care
According to McWhinney (1980), a co-contributor to the development of one of four dominant models identified by this review (Stewart et al, 1995), two schools of thought have co-existed in medicine since the time of Ancient Greece. The first, the *"conventional and academic"* school, gave rise to the traditional biomedical model. This is built on a disease classification system and, as such, is relatively easy to measure, *"articulate and communicate"*, at least by physicians (McWhinney, 1980, p.1096). The model focuses medical practice on pathology, diagnosis and treatment. It pays little regard to human and subjective elements or broader influences on health or illness.

The second, the *"natural or descriptive school",* was aligned by McWhinney (1980, p.1096) to the beliefs and practice of Hippocrates, a Greek physician and *"natural"* diagnostician who did *"not separate disease from the man, or the man from his environment".* This is explained further by Peabody (1927) who, almost a century ago, made clear to Harvard medical students in the US, that the effectiveness of diagnosis, treatment and care, is heavily reliant on the personal nature of the doctor-patient relationship. He also explained that the *'science'*, the biomedical aspects of medicine, and *'art'* of medicine, the human component, should not be considered as *"antagonistic but supplementary"* to each other (Peabody, 1927, p. 876). Each patient should be

viewed and respected as a person, not merely a set of symptoms for diagnosis, and their illness or wellness assessed and responded to in the context of their everyday life.

Early influences on patient-centred care

This review acknowledges that some of the most enduring early influences on PCC originate from the fields of medicine (Peabody, 1927, Engel, 1977, McWhinney, 1980) and behavioural and social sciences, for example through the contributions of Rogers (1951), Maslow (1954), Balint (1957). It also acknowledges long-term recognition in nursing of the importance of the whole person approach to care. This can be evidenced through nursing theory, and includes contributions offered by Roper (1976), Roper et al (1985) from the UK, and Watson (1985) Orem (1980) and Roy (1984) in the US. A brief introduction to some of these theories is included in Appendix 3.

Models of patient-centredness and patient-centred care

Unlike the majority of healthcare models, frameworks and concepts, the foundations of three of four models of PCC identified by this review are built on empirical evidence. Most importantly, this evidence has been gathered from service users (patients, carers, relatives and lay people) and, or service providers (multidisciplinary staff; clinical and non-clinical); those with first-hand experience and knowledge of healthcare.

Each of these models has been a significant influence not only towards the global movement towards PCC, healthcare policy directives and practice, but also more recent research into PCC through which these models were identified. Significantly, the development of these three empirically-based models triggered a concerted effort to improve patient care and healthcare experiences according to the perspectives of those with first-hand experience. Correspondingly, as ensuing discussions will demonstrate, these also provide the underpinning philosophy, principles and blueprint for future PCC healthcare improvement.

Models of patient-centred care (PCC)

The following two models focus on patient-centred care from first point of contact, recognising that healthcare requirements may extend beyond primary care. Patient-centred care embodies the philosophy and core determinants of the total patient care continuum; the patient's journey through healthcare.

The Planetree Model of patient-centred care

The earliest model of PCC, the Planetree model (Martin et al, 1998, planetree.org. 2014), was introduced in 1978 in Connecticut, US, by Angelica Thieriot. This model promotes a multidisciplinary and collaborative approach to healthcare. It also

emphasises the importance of supportive, nurturing organisational cultures towards the well-being of patients, their families and staff; healthcare environments where human beings care for other human beings. According to Frampton and Guastello the partnership that develops between patients and staff, or more specifically nurses, is viewed as *"the cornerstone of patient-centred care"* (2010, p.51). Nursing practice in hospitals that have been awarded Planetree patient-centred designation, as Frampton and Guastello (2010) explain, is often, but not exclusively, influenced by Watson's (1985) framework of human interactions and relationship-centred caring. Other influences stem from Swanson's (1991, 1999) empirical studies and theories of caring (1991, 1999) and the Tresolini Pew-Fetzer Task Force's (1994) work on relationship-centred care (Frampton and Guastello, 2010). These theories and frameworks help to facilitate the operationalisation of PCC through their emphasis on the human and relational element of PCC.

In 2014, the Planetree organisation reported that membership had exceeded 500 organisations across eight countries including Canada, the Netherlands, Brazil and Japan (planetree.org. 2014). The Planetree organisation is also affiliated with the Picker Institute, another world leader in PCC whose roots lie in the empirical foundations of a model of PCC offered by Gerteis et al (1993).

Gerteis et al (1993): "Through the Patient's Eyes: understanding and promoting patient-centred care"

The Picker Institute of the US institutionalised and built on the philosophy and determinants of PCC first identified through eleven research projects. These had been used to gather the perspectives of over 6,000 recent patients and 2,000 family and friends (care partners) about care they had experienced in one of sixty-two hospitals across the United States (Gerteis et al, 1993). Data from staff had also been gathered and subsequent analysis of this service user and service provider data led to the identification of seven core dimensions of PCC (Gerteis et al, 1993). These, similar to the components of the Planetree model, aimed to make the *"experience of illness and hospitalisation more humane"* (Gerteis et al, 1993, p. xxii). The findings were disseminated in a seminal text *"Through the Patient's Eyes"* by Gerteis, Edgman-Levitan, Daley, and Delbanco in 1993.

The seven dimensions of PCC were institutionalised by the Picker Institute when it first opened in 1986 in Massachusetts, US. An eighth dimension, access to care, was added the following year. Importantly, these dimensions, which have remained virtually

unaltered, embody the philosophy and principles of PCC as identified by service users and providers. These are:

i)   respect for patients' values, preferences, and expressed needs;
ii)   coordination and integration of care;
iii)   information, communication and education;
iv)   physical comfort;
v)   emotional support and alleviation of fear and anxiety;
vi)   involvement of family and friends;
vii)   transition and continuity; and
viii) access to care (pickereurope.org, 2014).

Although the Picker Institute in the US ceased operation in January 2013, its work is continued by the Institute for Patient- and Family-centred care in the US, and the Picker Institute Europe in Oxford, England (pickereurope.org, 2014, Richards and Coulter, 2007).

Gerteis et al (1993), like Thierot and Planetree (Martin et al, 1998; planetree.org. 2014), also aimed to transform healthcare systems and cultures so they provided positive environments and experiences for staff, not just patients. Yet, none of the current Picker Institute principles actively promotes this. This oversight, although not verified, is attributed to Gerteis et al's endeavours to *"consciously adopt the patient's perspective"* (1993, p. 5). However, there is concern that by doing so this creates the potential to diminish the significance of others actively involved in patients' healthcare journeys. This includes staff, family, friends and carers, who support and interact with patients and influence their experiences. Although no empirical evidence was found during this review that explicitly supports this suggestion, this is implicit not only amongst review findings, but also in reports of public inquiries and healthcare watchdogs, and the results of patient experience surveys.

Models of patient-centredness
Unlike the models by Planetree and Gerteis et al, the two following models focus more closely on the human and relational aspect of PCC, and facilitating patient-centredness, predominantly in primary care practice. Nevertheless, because these models aim to deepen care providers' knowledge and understanding of human factors, so that patient-centredness becomes an integral element of every stage of the PCC continuum, they are adaptable to any discipline and healthcare setting.

Stewart et al (1995): "Patient-Centred Medicine; transforming the clinical method"
The first PCC model to specifically focus on *patient-centredness* was developed by Stewart et al and published as a core text in 1995. The *Patient-Centred Clinical Method,*

which originates from Canada, was initially developed to transform family medicine by promoting *patient-centredness* in doctor-patient consultations.

Stewart et al (1995) initially identified six interactive dimensions of patient-centredness:

i. exploring the disease and illness experience
ii. understanding the person as a whole and what it means to be human
iii. finding common ground
iv. prevention and health promotion;
v. enhancing the doctor-patient relationship; self-awareness, compassion, healing, power, transference and countertransference;
vi. being realistic about time, resources, teamwork, personal limitations (Stewart et al, 1995, p.35).

Dimensions ii, v and vi, highlighted the importance of also recognising the doctor (healthcare professional/care provider), not just the patient, as a person; a factor this review highlights as a fundamental element of PCC. Unfortunately, the emphasis on doctor (healthcare provider) as person was omitted from a more recent edition of the model published in 2003. Although the reason for this remains unclear, a potential explanation may be attributed to Stewart et al's acknowledgement, similar to Gerteis et al (1993), that only *"the patient should be the judge of patient-centred care"* (Stewart, 2001, p.444); and thus the focus should remain on the patient. This deletion is regrettable as without specific dimensions to emphasise the significance of staff towards patients' experiences, or the importance of also seeing staff as individual human beings, there is potential for this group to experience dehumanisation and depersonalisation. Indeed, the endemic culture of blame and secrecy that continues to permeate healthcare organisations throughout the western world is indicative of the dehumanisation and depersonalisation of staff.

The foundations of Stewart et al's (1995) PCC clinical method, like Gerteis et al's (1993) model, is also built on empirical evidence. This was gathered from a number of observational studies undertaken in family practice in Ontario, Canada, by co-authors McWhinney (1972, 1986), Brown et al (1995), Levenstein (1984) and Levenstein et al (1986). It is also informed by a systematic review of sixty-nine internationally published peer-reviewed papers (Stewart, 1995). Stewart (1995) explained that review findings showed that patient-centredness requires *"a balance between the objective and the subjective, a bringing together of body and mind"* (Stewart, 1995; p.35). An analysis of medical interviews undertaken in a study by Mishler (1984, p.192), one of the works reviewed by Stewart (1995), had explained *patient-centredness* in terms of two voices; the "*scientific"*, the objective and detached voice of medicine due to its focus on

diagnosis, and the "*voice of the life-world*". The latter, Mishler suggested, reflected a *"common sense view of the world"* as derived from the person's social context, the personal meaning of illness, and concern about how illness might impact on everyday lives and goals (Mishler, 1984, p. 192). Mishler's contribution is specifically mentioned to enable acknowledgement of a further influence on PCC identified through this review; the philosophical perspective. In particular, the philosophies of the lifeworld and lived experience as explored by Habermas (1984), Husserl (1936), Heidegger (1962), Mishler (1984), Barry et al (2001), Charon (2001, 2006) and Galvin and Todres (2008) (For brief introduction to related theories and concepts see Appendix 3).

Mead and Bower (2000): a conceptual model of patient-centredness

Mead and Bower (2000b), by comparison, developed a conceptual model to clarify which aspects of doctor-patient relationships constituted *patient-centredness.* In a former observational study (Mead and Bower, 2000a), analysis of 55 video-taped consultations between 24 volunteer GPs and adult patients recruited from 13 practices across Birmingham, Manchester and Exeter in the UK, revealed that each observation-based instrument measured different elements of patient-centredness. Consequently, disparity was found amongst findings, a broad range of interrelated variables were exposed, and the effect of subjectivity on observer assessment was apparent. Mead and Bower (2000a) suggested these inconsistencies were further exacerbated by the lack of a universal definition of PCC, variances between concepts promoted by theorists and their application in practice, and differences in how the concept of PCC was interpreted and operationalised. These findings are similar to those also reported by Klein et al (1961) some forty years earlier in relation to the measurement of PCC, and more recently by Smith et al (2013) with regard to the biopsychosocial model (Engel, 1977, 1980). Because none of the three elements of the latter model could be measured in a consistent way Smith et al (2013) criticised this for being "*unscientific and untestable*" (Smith et al, 2013, p265)

Despite Mead and Bower's (2000b) intentions, the findings of this review indicate that their model, without introduction or context, may still cause confusion. For example, the fourth dimension '*biopsychosocial perspective',* signposts Engel's (1977) biopsychosocial (BPS) model. Yet, this is a distinct approach that, like PCC models, was also developed to address deficits of the biomedical model (Engel, 1977, 1980; Borrell-Carrió et al 2004). Consequently, if the biopsychosocial model is not explained or understood in this instance in the context of Mead and Bower's conceptual model this may trigger confusion amongst healthcare staff about what model of care they should be following. Additionally, the fifth dimension *'therapeutic alliance',* derived from Rogers'

(1951) client-centred theory, introduces terms and three integral elements i) empathy; ii) unconditional positive regard; and iii) congruence (Mead and Bower, 2000b). These require translation to everyday practice if clarity and consistency of understanding is to be ensured.

Core determinants of PCC and patient-centredness

Despite differences due to country of origin, healthcare system, evidence-base, philosophical influence, language used, and target audience (primary care doctors versus hospital staff) similarities are clearly recognisable between each of these models of PCC and patient-centredness. These have been synthesised and the resultant core dimensions presented in Figure 2-2 to enable a clearer overall perspective.
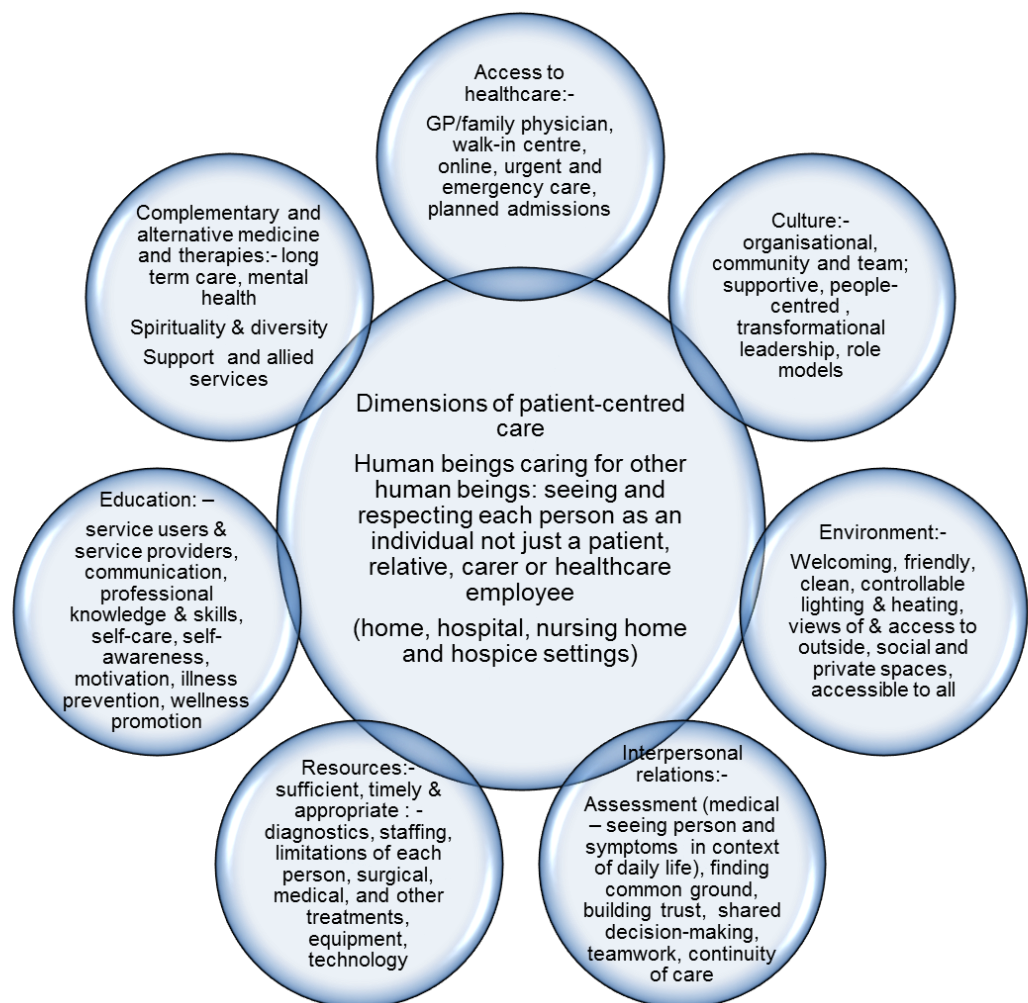
Figure 2-2: Synthesis of core determinants of patient-centred care based on Gerteis et al (1993), Stewart et al (1995), Planetree (Planetree.org, 2014) and Mead & Bower (2000b)

.

Each of the summary dimensions emphasises the complexity of PCC, and each may be broken down into further components and contributory and influencing factors. Although each dimension has been identified as an integral element of PCC, not all of these will be relevant to every episode of care and every patient on every occasion. Nonetheless, as the review of PCC models made clear, and the main circle of this diagram illustrates (Figure 2-2), PCC, at every level, is dependent upon humaneness, and the relationships that develop between service users and service providers. Perhaps most importantly, the dimensions in Figure 2-2 reflect the collective perspectives and experiences of patients and healthcare staff gathered throughout several decades. Yet these only came to light after individual perspectives had been gathered and findings analysed. This is significant because, as a US study by Klein et al (1961) and others in this review will illustrate, even staff from the same discipline, with similar roles commonly hold different perspectives and priorities for patient care. This in turn can impede the delivery of PCC and hinder multidisciplinary teamwork.

In the study by Klein et al (1961), for example, interviews with 24 hospital leaders from six out-patient departments in Boston, US, even after secondary analysis of interview data, led Klein et al (1961, p. 140) to conclude that PCC could not be defined as a *"unitary concept"*. Yet sixteen components of patient care had also been identified from the same data set. More recent studies, including UK studies by Wilkes and Mills (2001), Douglas and Douglas (2005), Webb (2007), a US non-experimental longitudinal prospective study by Radwin et al (2009) and a Canadian descriptive correlational design study by Poochikian-Sarkissian et al (2010), reinforce the finds of Klein et al (1961). These too provide evidence of long-standing differences, but also similarities, between the perspectives of patients and staff. Findings which support the view that improvement should be informed by patient and staff experiences as Campbell et al (2004) also recognised. They also indicate that if uniformity of understanding amongst multidisciplinary staff is to be attained, as is a fundamental requirement for improvement and PCC, opportunities should be provided for healthcare teams to come together and share their perspectives so that they might collectively identify and agree common goals for improvement.

What evidence is there that models of patient-centred care and patient-centredness make a difference?

In order to establish if PCC philosophy and associated models might also provide a blueprint for improvement, empirical studies that investigated the outcomes of patient-centred models of care prior to the start of this study's Patient Journey project were also reviewed. In keeping with the complex nature of PCC, each of the empirical studies

critiqued, despite sharing a common interest in PCC, investigated PCC from a different perspective, or to address different aims and objectives. Consequently, each study is presented in *"narrative juxtaposition"*, to enable authentic representation (Dixon-Woods et al, 2005, p.47). Each included study fulfilled CASP appraisal criteria (www.casp-uk.net, 2007).

The impact of Planetree PCC philosophy and training on patients' experiences
Martin et al (1998) discuss the effect of the Planetree PCC model on hospital patients' experiences in the US. In a randomised controlled trial (RCT) outcomes for 315 patients randomly assigned to a general medical-surgical Planetree Model hospital unit, were compared to those for 445 patients from four non-Planetree general medical-surgical units. The units were based in the California Pacific Medical Centre in San Francisco which offers a broad spectrum of medical services including bone marrow, kidney, liver and heart transplantation (Martin et al, 1998).

Martin et al (1998) briefly explained how the original eight integral components of the Planetree model (rather than subsequent 10 components) had been applied in the participating hospital unit. However, they did not clarify if the *"Planetree philosophy"* had been disseminated to all multidisciplinary staff, rather than just nurses, to ensure consistency of practice (1998, p.126). Nor did they explain if the results showed that patients' perceptions of PCC were aligned with components of care identified by the Planetree model. Nevertheless, Martin et al (1998) reported that the responses of 273 patients revealed an overall satisfaction rate of 70% with the Planetree unit environment compared to 67.7% by 345 patients of non-Planetree units. Whilst this result does not indicate a significant difference, and the percentages relate to different sample sizes, 70% of 273 as opposed to 67.7% of 345, it is nonetheless suggestive that Planetree PCC improved patient satisfaction. Further results also reinforced this. For example, Planetree patients' satisfaction of technical aspects of care (these elements were not defined) was rated at 86.5% compared to 81% by non-Planetree patient respondents. The personalised and nurturing elements of care provided by Planetree (patient-centred) nurses scored an overall 81.6% compared to 76.4% for non-Planetree unit patients. Patients also reported feeling more involved and better educated following discharge (79.2% versus 74.6%); more satisfied with the education they received (73.5% versus 65.1%), but little difference was found between patient control over health (73.6% versus 74%) and coping strategies (62.3% versus 62.2%) at three month's post discharge. No obvious explanations for the latter two outcomes were identified by Martin et al (1998) but had been investigated. Even so, overall, the results showed that patients, who had experienced PCC according to the Planetree Model, felt more

involved, learned more about their illnesses and were *"significantly more satisfied with their hospital stay"* (Martin et al, 1998; p.130).

The impact of Planetree PCC designation and in-patient quality outcomes

A more recent retrospective quasi-experimental US study, also explored the effect of the Planetree approach on inpatient quality outcomes (Stone, 2008). Stone, a former chief nursing officer and chief operating officer at the Sharp Coronado Hospital in California, had engaged nursing staff in meeting Planetree designated criteria (as detailed in Frampton and Guastello, 2010). Once more, it was not made clear how these criteria were disseminated to ensure consistency and clarity of understanding and approach to patient care. This was a study of five separate cohorts of a total of 869 hospitalised adult patients grouped by calendar year. All patients had recently undergone elective total-knee or total-hip replacement surgery. Data in relation to patient demographics, patient satisfaction, length of stay, cost-per-case were gathered and retrospectively examined from two comparable medical-surgical units, one of which followed the Planetree approach.

In each of the five one-year cohorts studied, Stone (2008) found that the Planetree unit consistently revealed shorter lengths of stay; statistically significant lower costs per case; higher than average overall patient satisfaction ratings; higher satisfaction ratings in almost all patient-centred dimensions. This study, similar to the RCT by Martin et al (1998), showed the positive effect of PCC on patients' experiences when delivered according to Planetree criteria (see Frampton and Guastello, 2010). The outcomes also led to the recommendation to those *"seeking to improve the inpatient hospital experience"* to consider implementing the Planetree PCC model (Stone, 2008, p. 68). The Sharp Coronado Hospital subsequently became the first hospital in California, and one of the first five in the US, to be recognised as a Designated Planetree Patient-Centred Hospital.

Although the collective findings represent the experiences of more than 1,000 patients, it is recognised that the studies by Martin et al (1998) and Stone (2008) were undertaken in the US, where the healthcare system is different to the UK, and patients are more widely regarded as consumers. Nonetheless, the ever-increasing, international membership of the Planetree organisation, outside of the US in eight countries including Canada, the Netherlands, Brazil and Japan (planetree.org. 2014), is indicative of widespread recognition of the merits of this PCC approach and its potential transferability to other healthcare systems (planetree.org.2014). Moreover, as highlighted previously during the introduction to the Planetree PCC model, the Institute

of Medicine (IOM, 2001) in the US demonstrated that their goals for healthcare reform were fundamentally the same as those of the Department of Health in the UK (DH, 2004e), despite the differences in healthcare systems, and irrespective of whether service users are viewed as consumers or patients.

The impact of training according Stewart et al's (1995) PCC model on PCC practice

Kinmouth et al (1998) also used an RCT, but this time to examine the impact of PCC training in primary care on patient outcomes in England, UK. Forty-one GP practices from a health region in southern England were involved; 21 in the intervention group with 142 patients, and 20 in the comparison group with 108 patients. Participants' ages ranged from 30-70 years; all patients had been recently diagnosed with type II diabetes. Study methods included pragmatic parallel group design and randomisation between practice teams to PCC (intervention group) and routine care (comparison group). Baseline data from each group were compared with data gathered one year later using interviews, questionnaires and self-reporting by patients on satisfaction with treatment, approach to care, lifestyle and communication with practitioners.

Unfortunately, once again, detail of the training, which was based on Stewart et al's (1995) model, was not included. This would have helped Kinmouth et al (1998) to explain in what way practice was being influenced and whether this involved just doctors and practice nurses, or whether a multidisciplinary approach was also being promoted. Nevertheless results showed that PCC resulted in *"significantly improved communication, wellbeing, and satisfaction amongst patients with newly diagnosed diabetes"* (Kinmouth et al, 1998, p. 1207). This is consistent with findings of Martin et al (1998), Stone (2008) and a more recent Canadian study by Poochikian-Sarkissian et al (2010) which investigated the impact of patient-centred education in acute care settings.

However, unlike other studies, Kinmouth et al (1998) found an unanticipated adverse effect of PCC. A *"significantly higher"* body mass index (BMI) (n=66/133) was identified amongst patients in the intervention group one year after diagnosis. Kinmouth et al (1998) partially attributed this to patients' better adherence to treatment, as this had previously been found to correlate with positive outcomes of PCC in former RCTs (Roter, 1977, 1989, cited Kinmouth et al, 1998). Patients in Kinmouth et al's (1998) study had been treated with hypoglycaemic agents, a common side effect of which is weight gain.

Kinmouth et al (1998) also suggested that practitioners in the intervention group may have been overly focused on diabetes treatment and management, rather than preventative measures to reduce risk of cardiovascular disease through weight gain. This was not verified. Moreover, this suggestion can be challenged as illness prevention and health promotion should have been an integral element of the training these practitioners received. This is because health promotion is one of the dimensions of PCC identified in Stewart et al's PCC model (1995). Nevertheless, Kinmouth et al provided a cautionary reminder that patient-centred consulting should not *"lose the focus on disease while paying attention to the unique experience of illness of each patient"* (Kinmouth et al, 1998, p.1208).

The impact of Stewart et al's PCC model on patient-centred communication

Stewart et al (2000) used an observational cohort design to investigate patient-centred communication and outcomes on patient health and use of medical care in Canada. Understanding of PCC was again derived from Stewart et al's (1995) model. Thirty-nine (47%) family physicians (general practitioners) and 315 adult patients were randomly selected from 250 family physicians' practices in and around Ontario, Canada. Presenting problems were identified as respiratory, digestive, musculoskeletal and other. Data were collected at 5 points during a two month period through a variety of quantitative and qualitative measures, including audiotaped patient-physician encounters, 4 measurement instruments (measure of patient-centred communication score; patient perception of patient-centredness; patient recovery from discomfort and concerns; and patient health status), assessment of medical care post-audiotaped encounter by 3 medical doctors, and telephone interviews with patients at two-month's post-consultation.

Analysis revealed that of the patients who had perceived their visit to be patient-centred, just 4.1% of the group underwent diagnostic tests during the two-month period, compared to 25.4% amongst the group who believed they had not established common ground (a determinant of PCC) with their physician (component 3 of Stewart et al's clinical method). Referrals were 6.1% compared to 14.9% in the non-patient-centred group. A limitation is that the data lacked detail about which specific aspects of doctors' skills and behaviours positively influenced patients' perceptions. This might have helped to explain why no similar result was revealed by a measure given to patients to rate their perceptions of how well their doctor had explored their illness experience (component 1 of Stewart et al's clinical method). This limitation was also acknowledged by Stewart et al (2000) who recommended that future researchers use qualitative methods when seeking information about patients' perceptions and experiences.

Relationship was also found between patient perceptions of patient-centredness, the efficiency of care, and positive health outcomes. These included lower levels of post-consultation discomfort, concern, and a six-point improvement in recovery (measured on a 100 point scale) were reported. However, insufficient detail was included by Stewart et al (2000) to enable effective critique. No findings were reported in relation to component 2 of the model, 'whole person', despite this being cited as a focus of the investigation. Nevertheless, the finds were sufficiently robust to support the recommendations by Stewart et al for wider recognition of the importance of PCC and for healthcare organisations to promote and facilitate this through *"meaningful"* educational programmes (2000, p.780). Stewart et al (2000 p. 800) specifically advocated communication skills training to enable doctors to understand how they can become a *"responsive partner for the patient"* and the importance of this to patient outcomes. A shortfall is that, similar to other studies discussed in this review, including Martin et al (1998), Stone (2008) and Kinmouth et al (1998), detail of the recommended training was not included or signposted. Nor was there any mention of whether this training should be offered to other members of the multidisciplinary team who also interact with patients, rather than just doctors.

Nevertheless, overall Stewart et al (2000) provided evidence that greater efficiencies can be achieved in medical care through PCC. They also verified the significance of patient-centred communication and establishing common ground towards patients' well-being and recovery. This is achieved when interactions with doctors are perceived by patients to be patient-centred. The latter finding demonstrating similarity with Martin et al (1998) and Kinmouth et al (1998), and perhaps contradicting those of empirical studies by Little et al (2001) and Swenson et al (2004) which indicated that not all patients want PCC, as some, particularly older patients, appeared to prefer a more paternalistic, directive consultation style. However, because of the adaptable nature of PCC, which is tailored to meet individual need, these preferences can still be accommodated and thus PCC is still appropriate.

The impact of Stewart et al's PCC model on physician interaction style
Epstein et al (2005) also investigated outcomes of PCC in the US. Their observational cross-sectional study design examined *'physician interaction style and its relationship to diagnostic testing costs'* (Epstein et al, 2005, p. 415). Data were collected from varied sources, including a survey, claims data and two impromptu, covertly recorded standardised patient visits with 93 physicians. The findings of Epstein et al, similar to Stewart et al (2000), also showed PCC related efficiency savings in diagnostic testing.

There were, however, a number of limitations to Epstein et al's (2005) study. These included *'standardised'* patients; the potential influence of payments for 'standardised' patient visits and the collection and forwarding of survey instruments. Other limitations include recruitment of physicians to the study by colleagues; and the ability of physicians to identify 40% of standardised patients. Nevertheless, Epstein et al reported that these factors had been recognised as potential issues and adjustments made during the study.

A summary of evidence-based outcomes of models of patient-centred care

The findings of these varied investigations into the outcomes of different aspects of patient-centred care are summarised in Table 2-3.

Evidence-based examples of positive outcomes of patient-centred care since 1998	
Outcome	Source of evidence (providing signposting to additional sources of evidence)
More personalised, individualised care, more nurturing nursing care, patient preferences addressed	Martin et al (1998), Little et al (2001), Radwin (2003), Swenson (2004)
Better, more effective communication between service users and providers, being kept informed	Martin et al (1998), Kinmouth et al (1998), Webb (2007)
Partnerships, shared understandings	Borrell-Carrió et al (2004), Douglas and Douglas (2004)
Authentic self-representation – patients honest and truthful accounting of self and symptoms	Radwin et al (2009)
Improved adherence to treatment/medication; improved patient responsibility for self-care	Kinmouth et al (1998) (in this study this resulted in a negative outcome for patients with recently diagnosed diabetes type II), Robinson et al (2008), Poochikian-Sarkissian et al (2010)
Lower levels of anxiety, discomfort, concern and improvement in recovery	Stewart et al (2000), Webb (2007)
Optimism, improved sense of well-being and quality of life	Kinmouth et al (1998), Stewart et al (2000), Reid Ponte et al (2003), Radwin et al (2009), Webb (2007)
Patient reports of feeling better informed pre and post-discharge	Martin et al (1998), Poochikian-Sarkissian et al (2010)
Improved functional status for patients	Poochikian-Sarkissian et al (2010)
Increased patient satisfaction	Martin et al (1998), Wolf et al (2008), Stone (2008), Sidani (2008), Poochikian-Sarkissian et al (2010)
Increased job satisfaction (doctors and nurses), empowerment of nursing staff	(Delbanco, 1992), Chaaya et al (2003), Johnson (2005), Brown et al (2006), McCance et al (2009)
Improved quality of care	Martin et al (1998), Stone (2008)
Improved general atmosphere in healthcare environments	Douglas and Douglas (2005), Poochikian-Sarkissian et al (2010)
Cost effective way to improve health outcomes; reduced length of hospital stay, reduced cost per case; reductions in referrals and diagnostic testing	Stone (2008), Stewart et al (1995), Stewart et al (2000), Martin et al (1998), Epstein et al (2005), International Alliance of Patients' Organizations (2005), Bensberg (2007)

Table 2-3: **Evidence-based positive outcomes of patient-centred care**

Table 2-3 contains evidence-based outcomes which were identified from included studies. These emphasise the significance of healthcare staff, or in this context doctors and nurses, towards patient outcomes and experiences, and the efficient workings of healthcare organisations. They also strongly indicate that because these outcomes were achieved through practice underpinned by the philosophy and principles of PCC; PCC also provides a blueprint for improvement in healthcare. Further evidence in support of this is offered in discussions that follow.

What does research tell us about the phenomenon, nature and implications of patient-centred care?

Despite the existence and ease of access to these PCC models, widespread promotion of the principles and philosophy of PCC, and evidence that this approach makes a difference in healthcare, evidence has continued to emerge of significant failings, unacceptable standards, and distressing experiences for patients (chapter one). This is also in spite of a broad range of improvement initiatives introduced through NHS patient-centred reform (DH, 1997, 2000a, 2008, 2013) (chapter one). Regulatory body reports and outcomes of public inquiries already provided evidence that explained why more widespread delivery of PCC might be proving problematic (chapter one). However, because this review was specifically focused on PCC, related empirical literature was explored in search of any additional evidence-based barriers that might impede PCC improvement, or be addressed, in this study.

Each of the following primary research studies has examined patient-centred care (PCC) or patient-centredness. As anticipated in light of the complex and diverse nature of PCC, each employed different methods to explore different aspects or perspectives of PCC; expressed different aims and objectives, and each involved different 'types' of participants (for example, health condition, specialty, staff role).

Differing perspectives, interpretations and expectations of patient-centred care
Although the majority of included studies highlighted differences in perspectives of PCC and priorities for patient care between service user and service providers as an issue, only two studies specifically examined how PCC is interpreted and understood. One of these, a UK qualitative interview study by Gillespie et al (2004), investigated how PCC was understood by those involved in "*translating the concept from a theoretical idea into a practical application*" (2004, p.143). Gillespie et al's awareness of different viewpoints had been heightened by a previous patient involvement project (Gillespie et al, 2002); UK Department of Health publications and a review of research into shared decision-making in primary care (Elwyn, 1998, and Elwyn et al, 1999 cited Gillespie et al, 2004,

Farquhar et al, 2005). Although it appeared generally well understood that PCC involved placing patients at the centre of the care process, Gillespie et al (2004) had been concerned that what this actually meant was not being well-articulated or understood.

In Gillespie et al's (2004) study, semi-structured interviews were conducted by one interviewer with 47 lay, professional and managerial participants recruited from healthcare affiliated organisations in and around London, UK (10 from health agencies; 15 from Royal Colleges; 12 from educational institutions; and 10 from patient and user groups). Analysis of interview transcripts revealed considerable diversity amongst study participants' interpretations and expectations of PCC (Gillespie et al, 2004). For example, health professionals most closely aligned their interpretation to the biomedical model of care, through which patients' needs are generally determined by professional priorities. Although Gillespie et al (2004) did not elaborate further, the findings from this review offer a number of possible explanations for their result. Amongst these include that i) organisational and managerial philosophy did not support PCC; ii) these professionals had not been introduced to PCC models through under, or post-graduate education; iii) the principles of NHS healthcare PCC reform had not reached those at the frontline; iv) that health professionals were not routinely made aware of findings from patient satisfaction and experience surveys; or v) that they were not supported to deliver PCC.

Patient and user group participants described PCC in the context of a whole person or social approach to health, although few related this to the care of individuals. Rather, they viewed PCC in terms of their involvement in the planning and delivery of healthcare services (Gillespie et al, 2004). A finding potentially indicative of role bias; for example, the role assigned to participants through patient involvement may have caused this group to tailor their responses according to what they believed was expected of them; rather than offering a personal, perspective grounded in experience (DH, 2004, NHSSDO, 2004). As advocates for PCC, these people should have been able to articulate that PCC is principally concerned with humanising experiences and care at the individual level.

Participants from educational institutions generally reduced PCC to the teaching of communication skills, and appeared to neglect other significant, contributory elements such as shared decision-making. This is despite the existence of PCC models, theoretical frameworks of care, professional codes of conduct, and healthcare policy directives (DH, 2000a, 2004e) which emphasise the importance of these elements, and with which this group should have been familiar. In contrast, managers predominantly

focused on quality assurance and measurement of care; their understanding of PCC at the individual level was also vague, despite their *'duty to involve'* (DH, 2004e, 2005a, NHS Act, 2006). This latter finding also reflects reports of public inquiries and investigations into healthcare failings which commonly cite a managerial focus on targets and budgets as one of a number of common barriers to PCC. At policy level, PCC was mostly viewed as public participation in health services and healthcare policy, including patient advice and liaison services (PALS), patient advocacy, and patient forums (Gillespie et al, 2004); a finding similar to that of patient groups and respondents from Royal Colleges. Again, these groups failed to consistently acknowledge the individual level of PCC or the patient-centredness of *"face-to-face encounters"* (Gillespie et al, 2004, p.146). Correspondingly, Gillespie et al (2004, p.147) concluded that *'patient-centred'* was merely being used as a *"sound bite"*.

Goodrich (2009) reinforced the findings of Gillespie et al (2004) when reporting on research conducted for the King's Fund' Point of Care programme, also based in London, UK. She too reported that PCC was commonly used as a *"buzz word"* (Goodrich, 2009, p.16). Focus groups and in-depth interviews were conducted with around 30 staff drawn from four NHS trusts in England to find out how the language of policymakers and academics was understood by those in practice. Although Goodrich (2009) reported that the study involved nurses, doctors, porters, consultants, domestics, administrative staff, middle managers and trust executives, she, similar to Gillespie et al (2004), did not disclose how many participants represented each discipline or trust. This data could have helped to pinpoint if the mixed perceptions and misinterpretations were more prevalent amongst specific groups or organisations, clinical or non-clinical staff, qualified or unqualified healthcare staff.

Further data might also have clarified whether these differing viewpoints, interpretations and priorities had also been influenced by factors other than the language and terminology of academics and policy-makers; such as lack of familiarity with healthcare policy directives, insufficient 'in-house' education, the interchangeable and varied use of terms, alternative models and frameworks of care, discipline specific priorities, or lack of leadership and role modelling or trust engagement with PCC philosophy. These were highlighted as issues during the course of this review (Mead and Bower, 2000a, 2000b, Institute of Medicine, 2001, West et al, 2004, Reeves et al, 2005, Webb, 2007).

Nevertheless, Goodrich (2009) reported that the phrase *"seeing the person in the patient"*, *"resonated positively with all participants"* (p.16). This is interesting as this indicates that those at the frontline of care were at least familiar with the philosophy of

PCC. *"Seeing the person in the patient'* and seeing the service *"through the patient's eyes"* are messages widely promoted by Gerteis et al (1993), Stewart et al (1995); the Institute of Medicine (IOM, 2001), the Planetree organisation (planetree.org, 2014), and the Picker Institute Europe (pickereurope.org, 2014) in the UK. These are also phrases endorsed by the Department of Health (DH, 2000a, DH, 2004e, forward) and the King's Fund Point of Care programme, with which Goodrich is associated (Cornwell and Goodrich, 2009, 2010, Goodrich and Cornwell, 2009); the latter providing an alternative explanation for the positive affiliation she reports (Goodrich, 2009). Even so, and importantly, Goodrich (2009) reiterates the point that NHS staff prefer the use of everyday *"human"* words such as respect, dignity, gentle, kind, caring, welcoming, comfort, smile, sensitive, and compassion, to describe patient care (Goodrich, 2009, p.16).

Yet, conversely, this review found that some of these everyday terms may also cause confusion. This is because commonly used terms such as dignity, compassion, and caring also represent separate philosophical, theoretical, conceptual and or empirical frameworks developed to guide professional practice.

Related concepts and theoretical and conceptual models and frameworks

Because of their potential to cause confusion, a few of these alternative, yet related concepts are introduced to enable PCC to be contextualised within the wider healthcare and educational arena. (See Appendix 3 for further interrelated concepts)

As mentioned, some of the most commonly found terms and concepts associated with PCC during this review of primary research papers, include dignity, holistic, biopsychosocial, compassionate, caring, and person-centred, many of which are used interchangeably. Yet, despite their similarities and clear links with PCC as will be illustrated, similar to nursing frameworks and models, the majority of these have been influenced by, or reflect a different perspective; evidence-base; dimension of patient experience; model of professional practice, or specific discipline. Consequently, even everyday terms such as dignity and caring will have differing connotations according to the communicator's knowledge-base, lived experience and expectations. So, although Goodrich (2009, p.16) reports that NHS staff prefer everyday *"human"* words to describe patient care, correcting language as a stand-alone measure, would be unlikely to eradicate confusion.

Dignity

Dignity, for example, one of the everyday words highlighted by Goodrich (2009), may be simply understood by lay people and healthcare support workers (non-health

professional graduates) as a *"state or quality of being worthy of honour or respect"* (oxforddictionariesonline.com, 2013). By comparison, doctors, nurses and allied health professionals will understand dignity as a human quality they have a duty to respect, maintain and protect for each of their patients (General Medical Council (GMC), 2013; Health and Care Professions Council (HCPC), 2012; Nursing and Midwifery Council (NMC), 2004, 2004, 2008, 2010). Professional understanding is also likely to be deeper and further advanced as a consequence of knowledge gained from theory, practice and research (Davies et al 2000; Chochinov, 2002, 2007, Chochinov et al, 2002, Gallagher and Seedhouse, 2002, Gallagher, 2004, Woolhead et al, 2004, Baillie, 2008).

A Canadian cross sectional cohort study by Chochinov et al (2002), for example, contextualises dignity in end of life care. The study involved 213 terminally ill cancer patients with a life expectancy of less than 6 months. This showed that for patients receiving end of life care, dignity was highly correlated with how they looked and how they thought they were perceived by others (Chochinov et al, 2002). A separate Canadian study by Chochinov et al (2002), in which 50 patients with advanced terminal cancer were interviewed, found that for patients with greatest debility *"life without dignity was described as a life no longer worthy of living";* and for those more able *"a personal sense of dignity was inseparable from life itself"* (Chochinov et al, 2002, p.441).

These studies provided the empirical evidence-base for the *'ABC and D model of 'Dignity Conserving Care'*; Attitude; Behaviour; Compassion and Dialogue (Chochinov, 2007). This too, like PCC, emphasises the importance of seeing the person for who they are or were, rather than just the illness they have. It promotes compassion as an integral determinant, rather than a separate concept (Schantz, 2007) and highlights to healthcare staff that dignity in end of life care is about *"having one's human value and worth acknowledged"* (Johnston et al, 2010, p.11). To achieve this, it makes clear that *"dying with dignity means different things to different people"*, and that individual meaning is influenced by each *"individual's historical, social and cultural perspectives"* (Johnston et al (2010, p11), thus reiterating the importance of seeing each patient as a person. But, this model only promotes dignity in the context of end of life care. Thus, unless it is introduced and its transferability to other settings and interrelatedness to other models explained, this may cause confusion. Dignity, as a concept, has also been examined by Davies et al (2000), Gallagher and Seedhouse (2002), Gallagher (2004), Woolhead et al (2004) and Baillie (2008) who offer varying perspectives to Chochinov (2007).

Holistic

The foundations for and interpretations of the concepts holism and holistic care, by comparison, are far more complex. Holism, like PCC, may also be traced back to the time of Ancient Greece. It too, like PCC and BPS (Engel, 1977, 1980) models, focuses on the patient as person in the context of lifespan and thus may cause practitioners to question which approach they should be following.

In mental health nursing, the holistic model emphasises the importance of attending to the patient's spiritual, social, intellectual, physical and emotional needs (Beck et al, 1993). These are recognised as inter-connected aspects of the whole person, not merely the signs and symptoms of disease, injury or illness. Holism, like PCC, also emphasises the interrelationship between the person, events and environment; of giving full attention to another; being aware of attitudes and behaviours of self; the role of technology; understanding the meanings that people attach to their illness or disease. And, similar to the Planetree PCC model, holistic nursing practice may integrate alternative and complementary therapies like music therapy, pet therapy and aromatherapy; as these are recognised as influential towards caring and healing (Dossey et al, 2004). Yet each is usually, but not always, presented to one professional discipline as a separate model, philosophy and approach to practice. To further illustrate this point two brief extracts from competencies for medical practice are included. These are sourced from the European Academy of Teachers in General Practice/Family Medicine (EURACT) (2002) and explain to doctors that:

> "Family medicine deals with people and their problems in the context of their life circumstances, not as impersonal pathology or "cases". The starting point of the process is the patient. It is as important to understand how the patient copes with and views their illness as dealing with the disease process itself. The common denominator is the person with their beliefs, fears, expectations and needs…a person-centred approach, orientated to the individual, his/her family, and their community." (EURACT, 2002, p.5)

EURACT (2002) also advises doctors that the

> "Holistic approach includes the ability to use a bio-psycho-social model taking into account cultural and existential dimensions" EURACT (2002, p8)

Without analysis these competencies seem relatively straightforward; yet collectively they signpost three distinct models of healthcare practice; *person-centred*, *holistic* and *biopsychosocial*. Consequently, this may cause doctors to question whether this means they are to incorporate all approaches in their everyday practice, or alternatively, follow specific models. For example, the biopsychosocial model as Engel (1997) proposed; holistic care according to Beck et al (1993), EURACT (2002), Dossey et al (2004) and,

or, Bradshaw (2011); and, or, person-centred care according to Nolan et al (2001, 2004), and, or McCormack (2004). Furthermore, as each doctor and healthcare worker has the potential to interpret the messages from these models according to their own predispositions, experiences and knowledge-base, this may give rise to further confusion, misinterpretations and differing perceptions (Klein et al, 1961, Mead and Bower, 2000b, Gillespie et al, 2004, Goodrich, 2009). An example of this is provided by Warner, a nurse of many years' experience who in contrast to the definition offered by EURACT (2002), perceives "*holistic care*" to be associated with *"wind chimes"* and *"calming blue lights"* (Baron and Warner, 2004, p.21). A misconception which has also been found in medicine, and one that McWhinney (1980; p. 1096) attributed to common use of *'holistic'* by *"unorthodox groups of healers"*.

Caring

Interestingly, a concept analysis of caring by Sourial (1997) in the context of mental health and learning disabilities nursing in London, UK, indicated that this was a part of holism. Sourial (1997) considers holism a more comprehensive concept because it is more clearly defined, better understood and scientifically based. But not everyone shares this view:

> "Holism dictates we spend time discussing the concept of self in relation to intravenous cefuroxime. Unfortunately, as more nurses embrace this approach, other matters become less important, such as, their knowledge of the therapeutics, contraindications and potential adverse effects of any drugs they administer…" (Baron and Warner, 2004, p. 21)

Sourial refers to Gordon (1990) who stated that holistic medicine incorporates humanistic medicine; an aspect of holism that respects relationships and the personal development of staff as well as patients. Like those who have investigated PCC, BPS and holistic approaches to care, Sourial identified numerous meanings and interpretations of caring, and recognises that this is another term not only used by professionals but also lay people (Sourial, 1997). Caring has also been explored by Berg and Danielson (2007), Fredriksson and Eriksson (2003), Halldorsdottir (2008), Larson (1984), McCance et al (1997, 2009), Mathes (2011) who links this with relationship-based care, Quirk et al (2008); Steele-Moses et al (2011), Trojan (2003); Watson (1985, 2006, 2007) who associates this with PCC; and Eriksson (2002) from the Department of Caring Science in Finland (Appendix 3). Fredriksson (1999, p 1173) explained that caring entails

> "…attempting to participate in the inner feelings of another while remaining objective, to see the world from the other's perspective with as much understanding as possible…to understand the lived experience of another, we must begin by listening."

Fredriksson's (1999) statement provides evidence of long-standing similarities between perspectives of caring and PCC. Roach (1984, 1992, 1997), by comparison, defines seven C's of caring, i) compassion, ii) competence, iii) confidence, iv) conscience, v) commitment, vi) comportment, and vii) creativity. She describes caring as an action that nurtures, fosters growth, recovery, health, and protects and empowers recipients of care. Roach (1992, p.18) explains that *"with compassion one becomes a colleague of humanity"*. Compassion is once again considered an integral element of caring, as it has been with PCC and Dignity; although this too has been explored as a separate concept by von Dietz and Orb (2000, 2001) and Schantz (2007) amongst others. Thus, caring, like other concepts associated with PCC, will have different meanings according to communicator knowledge, experience and context. It is, for instance, also viewed as a human trait, a moral virtue; a naturally occurring phenomenon. Additionally, as Roach (1992, 1997) points out, the origins of caring theories lie in theology, philosophy, anthropology, human sciences and metaphysics. These are often informed by humanistic knowledge and hermeneutics which evolved from understandings of human love and caritas, the natural motive for caring. Thus they are not always readily relatable to everyday practice.

Swanson (1991), somewhat unusually, offers five empirically-based, rather than theoretical or conceptual, categories or processes of caring; i) knowing; ii) being with; iii) doing for; iv) enabling, and v) maintaining belief (1991, p. 163). The findings of three separate phenomenological investigations in the US, two into 39 women's experiences of caring in maternity services, and the third into care providers' experiences in a neonatal intensive care unit, further advanced Swanson's epistemological and empirical understandings. Her findings, together with those of meta-analysis of 130 studies and influence from Watson (1985, 1988), led to the identification of five hierarchical levels of nurse caring knowledge, and three conditions that significantly affect caring in nursing; i) leadership; ii) compensation and reward and iii) professional relationships, including culture (Swanson, 1999).

More recently, Tonges and Ray (2011, p.374) explained that Swanson's caring model (1999) provides a *"coherent explanation of the links between caring and patient well-being"* and can effectively help to bridge the gap between nursing theory and practice. Interestingly, Swanson's (1999) model, as one built on evidence gathered from service users and service providers, also emphasises the significance of multidisciplinary staff involvement, recognition and well-being and teamwork towards caring and PCC practices. Elements also identified by this review as central to attaining PCC. Swanson's (1991, 1999) and Watson's (1985) caring theories have been used to support patient-

centred nursing practice in Planetree designated hospitals (Frampton and Guastello, 2010).

Person-centred

According to Nolan et al (2001; 2004, p.46), person-centred care, like PCC, is another *"often quoted but ill-defined concept"* (Nolan et al, 2004, p.46). Person-centred, according to the findings of this review, is generally used in the context of nursing practice, perhaps most notably by Kitwood (1997) and McCormack (2004). Kitwood (1997, p.8) defines person-centredness in the context of dementia nursing as

> *"…a standing or status that is bestowed upon one human-being, by others, in the context of relationship and social being. It implies recognition, respect and trust."*

Kitwood explains this definition was influenced by the work of Swiss psychologist Tournier (1999) and the philosophies of Buber (1984) and Rogers (1961).

McCormack (2001) drew on Gadamer's (1993) philosophy in his hermeneutic study carried out in Northern Ireland. This investigated the meaning of autonomy for older people in hospitals (McCormack, 2001). He also examined how the word *'person'* translated into person-centredness and person-centred practice through a review of 110 papers and philosophical analysis (McCormack, 2004). Four core concepts were identified which according to McCormack (2004) represent the heart of person-centred nursing; i) being in relation ii) being in a social world iii) being in place and iv) being with self. These concepts emphasise the significance of relationships in healthcare and nursing practice, and were also influenced by philosophies of Buber (1958), theoretical models for nursing, including those by Peplau (1952, 1988), Watson (1985) and Johns (1994). As mentioned, the latter contributions have also been influential towards the development and operationalization of PCC, and theoretical models of caring, providing a further indicator of the interrelatedness of associated concepts.

McCormack selected the term person-centred, because terms such as relationship, as introduced by Tresolini and the Pew-Fetzer Task Force (1994) in *'relationship-centred care'*, only represent one component of personhood; the others being context, place and self. *'Person-centred'*, McCormack (2004) suggests, is more inclusive as this enables regard to also be paid to sustaining relationships that are nurturing, not only to patients, their relatives or carers, but also to staff. This is further explained in a framework for person-centred nursing offered by McCormack and McCance (2006, 2010) and through further discussions in McCormack et al (2010a, 2010b).

The findings of this review of PCC empirical literature, despite their focus on *'patient-centred'* reinforce McCormack's view that the term *'person-centred'* most accurately reflects the ambition for humane and personalised healthcare. Indeed, *person-centred* was, and remains, the preferred term for this doctoral study. As explained, it was not used because *'patient-centred'* is the term promoted by UK healthcare policy directives, Campbell et al (2004), and the global movement towards PCC. Yet, as explained, this review of PCC strongly suggests that by focusing only on the patient, as the term *patient-centred* implies, this adversely affects the experience of others, particularly those who support and directly interact with patients as carers, family members, and healthcare staff. This is perhaps most evident from the findings of studies that investigated service user and service provider experiences of PCC, discussed later.

A synthesis of concepts most commonly related to patient-centred care

Collectively, dignity, caring, holistic, compassionate, biopsychosocial, as interrelated concepts, theories and models, embody the core determinants of humanised, PCC healthcare. Together they also impart a clear message that relationships between patients *and* staff are central to attaining this. Individually, the summarised elements illustrate that every concept is essentially focused on the same goal; to improve patient care and patient and staff experiences. This is represented in Figure 2-3 (below).

Figure 2-3 illustrates that PCC is the only model that clearly links the care continuum to patients' healthcare journeys. This is attributed to differences in evidence-base. PCC is built on the experiences and perspectives of service users and providers. In contrast, related concepts and frameworks, which feature the interpersonal element of patient care, with a few exceptions (Chochinov, 2007, Swanson, 1999, and Roper, 1976), are generally philosophically and theoretically-based. Yet, whilst their differing foci, terminology or evidence-base may initially trigger confusion, the messages of any can deepen understanding of the relational and interpersonal aspect of care. To reflect this, each of the outer relational dimensions in Figure 2-3 has been overlapped with the central element of PCC. It should be acknowledged, however, that each of the outer dimensions provides signposting to a range of models and frameworks of care that can help to facilitate the operationalization of PCC. But, this only became apparent during this investigation of empirical research into PCC. Correspondingly, this supports the view that, where models and frameworks are to be used to guide practice these should be contextualised, introduced and explained not just to doctors or nurses, but all multidisciplinary staff to ensure clarity and consistency of understanding and approach to practice.

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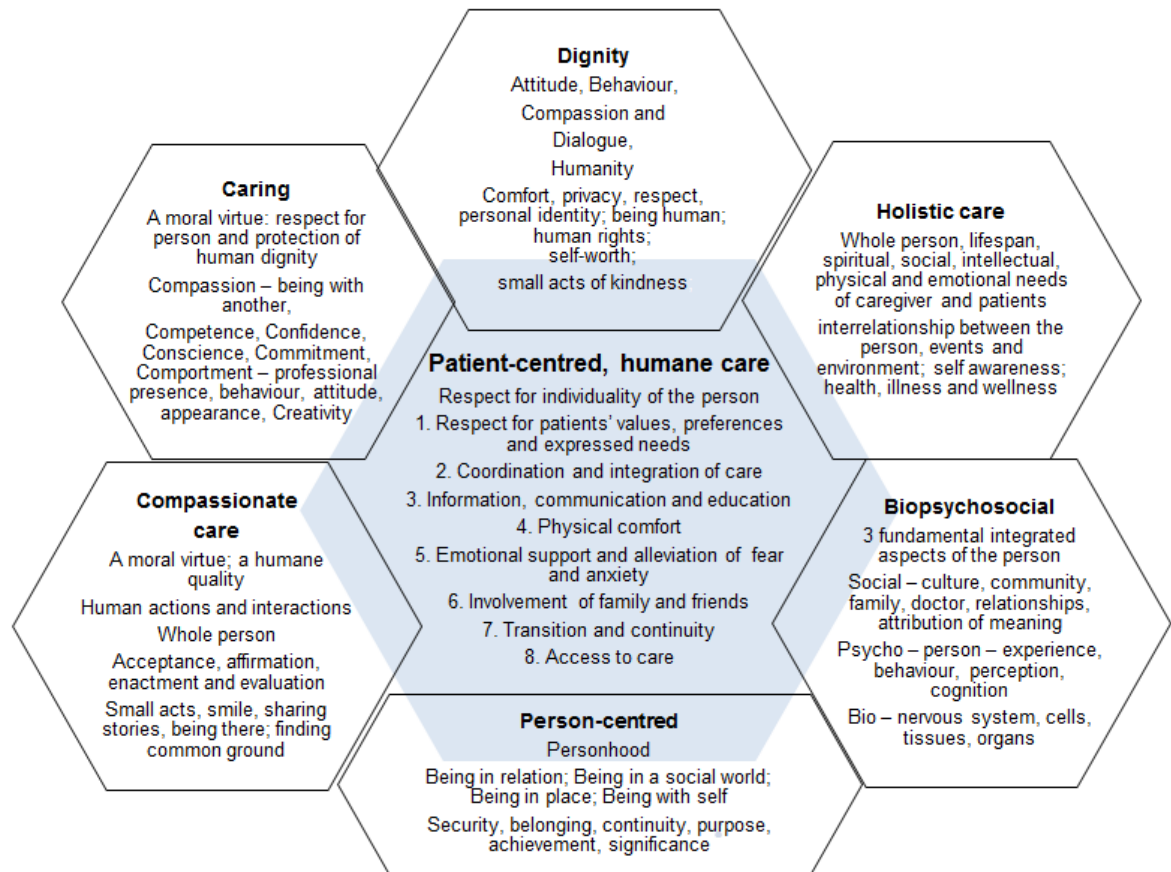
Figure 2-3: Patient-centred care and interrelated concepts

These interrelated models and frameworks reflect a long-term, widespread, yet somewhat fragmented endeavour to improve the experiences of patients and healthcare staff. This has resulted in varied perspectives and interpretations of contemporary approaches to care, the confusion and misunderstandings from which have been found to impede the widespread implementation and smooth delivery of PCC. The singular focus on one profession by the majority of these models and frameworks, and their failure to explicitly emphasise the importance of also valuing and respecting the healthcare provider as a person, towards PCC, are now identified as contributory factors which impede multidisciplinary teamwork and PCC practice. Further barriers are identified from the following studies that have investigated service user and service provider perspectives of PCC

Service users and service providers perspectives and experiences of PCC

Four studies, by Gillespie et al (2004), Douglas and Douglas (2005), West et al (2004) and Reeves et al, 2005 who report on the same study, and Webb (2007), specifically investigated service user and, or, service provider perspectives of PCC, the findings from which provide more recent perspectives of PCC. These have been contextualised

with the *Innovation in Practice* report in which the Patient Journey (PJ) improvement method is introduced (Campbell et al, 2004). The purpose is to illustrate why Campbell et al's contribution warranted further investigation.

As previously discussed, the UK qualitative interview study by Gillespie et al (2004, p.16), provided evidence that policy writers, educationalists, healthcare professionals, managerial and lay participants rarely associated PCC with individual experience. It also showed significant variation in interpretation and understanding about the concept. Although these findings only reflected 47 participants from London, these were people who should have been able to explain what PCC entailed through their positions. For example as healthcare policy writers, educationalists, professionals, managers, or patient-centred care advocates.

In PJ projects, Campbell et al (2004) suggest this issue can be addressed, at least locally, by bringing clinicians and managers together as a team to share and discuss their perceptions and priorities for care and improvement. The team, collectively, also map the current patient journey through their service. This, according to Campbell et al (2004) brings better understanding of each other's roles and the service; understanding which Atwal and Caldwell (2006) identify as a fundamental requirement of multidisciplinary (MDT) teamwork. Yet, bringing a team together as Campbell et al (2004) suggested, would preclude the involvement of non-clinical members. As a consequence, other issues that may compromise teamwork, such as differing perceptions of teamwork; different skill levels and characteristics of team members; and medical dominance might remain unresolved (Atwal and Caldwell, 2006). These were identified as barriers by Atwal and Caldwell (2006) from an analysis of interviews with 19 nurses and 21 recorded observations of multidisciplinary interactions in a UK qualitative study.

Service user groups in Gillespie et al's (2004) study also spoke of disparity of power between health professionals and patients, and the persistent resistance by some professionals to adopt a patient-centred approach (Gillespie et al, 2004). These are issues also identified by Campbell et al (2004), and ones they purposely aimed to address when developing their improvement methodology. As a consequence the PJ approach to sampling differs from *"traditional forms of redesign"* and improvement project development (Campbell et al, 2004, p. 21). Firstly, sampling is based on a *"stakeholder perspective"* (Campbell et al, 2004, p.22) which not only promotes team engagement, but also receptiveness to learning about the impact of their own practices and services on their patients' care and experiences. The team decides the group of

patients whose experiences they want reviewed, and determine the criteria for their selection. Secondly, patients and carers are interviewed in their homes, rather than an unfamiliar or clinical setting. Thirdly, interviews are carried out by an outsider to the clinical team to mitigate bias. Campbell et al (2004; p. 21) found from CHS PJ projects, that this approach to patient involvement and interviewing is more likely to encourage participants to *"tell us how it is".* Campbell et al (2004) suggest, this enables specific issues experienced by patients (including those from socially disadvantaged or minority groups) to be freely reported without fear of repercussion, or impact on future care (Campbell et al, 2004). This is significant as in Gillespie et al's (2004) study, service users' financial status, and social, cultural or language differences had been identified as barriers to PCC, shared-understanding and decision-making (Gillespie et al, 2004).

Health professionals in Gillespie et al's (2004) study had also cited a climate of underfunding, low staffing levels and low morale as significant barriers to PCC; they also generally perceived PCC as expensive (Gillespie et al, 2004). Awareness, particularly of low morale, and other barriers reported by staff, was important, particularly as an aim of the PJ projects is to empower staff to overcome barriers and identify and implement solutions to problems reported by their patients. It was not clear, however, to what extent any of these specific issues were a problem in Gillespie et al's (2004) study as no supporting statistical data or additional explanatory information were provided. This would have been useful as staff perceptions about these barriers, despite relating to a different NHS trust and region of the UK, could affect staff willingness to be involved in this study.

Interestingly, the negative perceptions about costing that Gillespie et al (2004) found, contradict those of Gerteis et al (1993), Stewart et al (1995), Martin et al (1998), Stewart et al (2000) and, more recently, Campbell et al (2004), Epstein et al (2005) and Stone (2008), who suggest that PCC does not increase costs, but leads to more efficient and cost effective care. In the context of PJ projects, Campbell et al (2004) explain that these are *"based on a premise of there being no cost to the organisation"*, although they emphasise that project teams should also include a business or directorate manager.

Although Gillespie et al (2004) identified numerous barriers to PCC; they make no mention of their findings being used to influence improvement. This reflects a trend amongst included studies, the only exception to this is an action research study by Curry (2005), discussed separately. It is acknowledged, however, that this was not an explicit aim of included studies which generally only sought current perspectives of PCC. Campbell et al (2004) and Curry (2005), by comparison, indicate how research can

support improvement by revealing current perspectives and experiences that can provide the impetus for meaningful, sustainable, localised change and PCC improvement. Further discussions will elaborate.

Patients' perspectives of the hospital environment

Similar to Campbell et al (2004), Douglas and Douglas (2005) undertook their study by way of response to NHS patient-centred modernisation (DH, 1998, DH, 2000a, DH, 2004). This mixed-methods study comprised a survey of 785 former patients; an autophotographic study by 35 in-patients; interviews with a further 50 in-patients from surgical (21), medical (9), care of the elderly (9) and maternity (12) units; and focus groups with hospital staff, architects and surveyors. The setting was an NHS hospitals trust in Greater Manchester, UK. The hospital had been selected by Douglas and Douglas (2005) because of the trust's planned redevelopment programme, a possible indicator of that organisation's commitment to change.

Douglas and Douglas (2005) specifically focus on patients' perceptions of their healthcare environment. (Environment is one of the core determinants of PCC). Analysis of interviews with 50 patients, and a large scale survey of a further 785 former patients, exposed several *"depersonalising"*, disempowering, and unfriendly aspects of hospital environments (Douglas and Douglas, 2005, p66-67). These included loss of independence, freedom and control; no outside view; minimal consideration for specific needs of physically disabled people; limited or no choice of accommodation (single room versus 4-bed bay); insufficient space between beds; limited seating for visitors; no refreshments on ward for patients or visitors; restrictions to normal ways of living in every aspect, including being able to adjust heating, lighting and noise. Ward *"regime"* and *"general atmosphere"* were also found to significantly impacted on patients' feelings and experiences (Douglas and Douglas, 2005, p66-67).

Survey results largely reiterated the findings of interviews but included lack of *"bedside entertainment"* as a separate issue, perhaps as a consequence of questioning (Douglas and Douglas, 2005, p.271). Auto-photographic data from a further 35 in-patients, showed that perceptions of ward atmosphere and hospital environment were strongly influenced by nursing staff. This was evident from photographs that patients had taken of nurses to illustrate their view of a patient-friendly environment. Although study findings re-emphasised the importance of environment, and inter-personal relationships as determinants of PCC, a criticism of this study is that because the staff perspective is missing the findings could not be contextualised within the reality of everyday practice.

Nurses' perspectives of delivering patient-centred care in acute hospital settings

By way of contrast, another large-scale UK study, reported in two papers by West, Barron and Reeves (2004) and Reeves, West and Barron (2005) only examined the perspectives of nurses. A closed questionnaire was used to determine whether nurses experienced barriers when delivering PCC. The questionnaire was a modified version of a prototype developed for healthcare employees in the US, and piloted by the Picker Institute (Weinberg et al, 2000 cited West et al, 2005). The design was influenced and structured according to the original seven dimensions of PCC identified by Gerteis et al (1993). (This is mentioned to demonstrate the continued and wider influence of Gerteis et al and Picker, despite its origin from the US and use in a different healthcare system.)

Nurse participants were recruited from 19 acute and one specialist hospital located around London, UK. A total of 2880 healthcare assistants, enrolled nurses, qualified staff nurses, senior staff nurses, ward sisters, unit managers, nurse specialists, nurse practitioners and modern matrons completed the questionnaire. Of these, 1153 were graduates, 1582 non-graduates, 267 were male nurses, 1523 were white, 615 Afro-Caribbean, and 590 worked part-time. Unfortunately, similar to the studies by Gillespie et al (2004) and Goodrich (2009), West et al (2004) did not indicate if these socio-demographic factors were notable in the results, nor did they specify how many nurses from each grade or hospital had participated. This is significant because healthcare assistants are not prepared for practice in the same way as healthcare professionals; registered nurses will have different levels of experience and skills; and senior sisters and unit managers may not be so closely involved with the day-to-day provision of PCC. Additionally, gender and ethnicity have the potential to be further influencing factors; and wards and hospitals may perform differently.

Nevertheless, the results of the survey of 2880 'nurses' echoed many of those found from patient data in Douglas and Douglas' (2005) study. For example, 53% of respondents also identified inability to adjust temperature, light or noise levels in their environment as a problem. Nurses, similar to patients, also highlighted lack of space as an issue. This prevented them from working effectively with patients (29.9% of respondents) and maintaining privacy when giving information to patients and relatives (37.7%). For patients, lack of space not only impeded privacy but also visiting (Douglas and Douglas, 2005).

Other problems reported by nurses included, 40.7% only sometimes had the right resources to treat their patients, and even when "*desperately short of staff*", 28.5% nurses wasted time trying to locate or borrow equipment (West et al, 2004, p.440). The

latter are just two examples of many barriers to PCC that are unlikely to be identified by patients and might otherwise remain hidden without consultation with staff. Almost two-thirds of nurses, 64.6%, had too much to do (West et al, 2004). Adverse effects of this included 51.9% of nurses only sometimes had enough time to address patients' anxieties and fears because of workload pressures; 44.1% only sometimes had enough time to treat patients' symptoms and conditions; 65.2% were often too busy to respond to call bells. Less than half (41.7%) were always, or nearly always, able to help patients at mealtimes, and barely half (53.3%) reported always or nearly always being able to implement measures to reduce risk of pressure sores. Significantly, when comparing studies, the concerns raised by nurses commonly appear to echo or provide possible explanations for those identified by patients in Douglas and Douglas' (2005) study. This is despite differences in study focus and setting.

Lack of education was also highlighted as a problem in West et al's (2004) study. Education is also fundamental to PCC as determined by staff and patients in the foundational studies associated with PCC (Gerteis et al, 1993, Picker Institute, 2012, Planetree, 2014, Stewart et al, 1995, Mead and Bower, 2000b). Survey findings highlighted that only 56.5% of nurse respondents received sufficient training to effectively monitor the side effects of medication; just 54.2% in *"watching for danger signals"* (these were not specified) and 59.8% in pain assessment. West et al (2004, p. 441,435) also stated that a *"high proportion"* of nurses wanted more training in the interpersonal and social aspects of PCC, but failed to offer specifics in terms of numbers and grades of nursing staff. This would have helped to clarify where current shortfalls exist so that they might be resolved. They also reported that 14.2% of nurses had not received any training in addressing patients' anxieties and concerns. This, and lack of training in managing aggressive behaviour, are further examples of issues identified by nurses, but not by patients. Almost half (41.6%) of nurses had not received any training, yet 43.9% reported being verbally abused and 13.7% physically assaulted by patients or relatives. West et al (2004) once again, did not specify if these results related to all grades of nursing staff.

Reeves, West and Barron (2005) in their separate paper, highlight that survey findings showed a clear relationship between the barriers to PCC experienced by nurses and their intention to leave their current employer. Significantly, almost one-third planned to leave within three years (Reeves et al, 2005). Findings which strongly indicated lack of awareness at senior level, not only of the significance of the relationships patients build with nurses towards patient outcomes and overall experiences, but also of the value of eliciting feedback from nurses as well as patients towards improvement and

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organisational efficiency. These factors were viewed by Reeves et al (2005) as emphatic evidence that employers should better support nurses to deliver high quality PCC; this should also be reflected in working conditions and pay (Reeves et al, 2005). This reinforced former similar proposals by Swanson (1999), McCormack (2004) and UK healthcare policy directives (DH, 2000a, 2004e).

Reeves et al (2005) also recommended that staff surveys that are similar to those of patients should become routine. The survey in their study was an adapted version of one developed for healthcare employees and piloted in the US by the Picker Institute (Weinberg et al, 2000 cited West et al, 2005). However, the findings of this review, whilst supporting this suggestion, also indicate that a staff survey as another stand-alone measure may not necessarily lead to action, or improved relationships between managers and staff. This is further implied by reports from investigations into healthcare failings (Kennedy, 2001, Colin-Thorné, 2009, Francis, 2013) which demonstrate that despite numerous patient involvement initiatives introduced since the start of NHS modernisation, patient feedback and survey results are still not being routinely, or effectively, acted upon. The reports also indicate that additional measures are needed to ensure that issues identified by patients and staff are not only raised but also attended to, resolved wherever possible, with outcomes reported back to patients and staff. These factors were also highlighted in guidance offered to improvement leaders by the NHS Modernisation Agency (DH, 2005).

Impact of barriers to patient-centred care on nurse retention and patient care
Further evidence in support of greater recognition of staff, albeit once more in relation to nursing, is offered by Aiken et al (2001, 2012). More than a decade ago, a large-scale, cross-nation survey gathered 43,329 registered nurses' perspectives of staffing, organisation and outcomes in 711 hospitals in five countries (Aiken et al, 2001). The sample comprised 13,471 nurses from the United States; 17,450 from Canada; 5,006 from England; 4,721 from Scotland, and 2,681 nurses from Germany. The results showed similar issues and barriers to PCC were being reported in every country, despite differences in healthcare systems. In terms of nurses' well-being, the negative impact of these barriers manifested in low morale and self-esteem, burnout, lack of autonomy and job satisfaction, as well as intention to leave the current employer or profession (Aiken et al, 2001). Interestingly Aiken et al (2001, p.51) emphasised that reorganisation undertaken by hospital managers largely followed an approach more akin to *"industrial models of productivity improvement"* rather than one that would enable nurses', or other staff', concerns to be aired and addressed. Consequently, Aiken et al (2001, p. 51)

suggested, healthcare organisations would continue to have *"limited success in terms of retaining nurses or improving patient outcomes."*

The findings and recommendations of Aiken et al's (2001) study have since been reinforced by those of more recent, large-scale cross-sectional surveys by Aiken et al (2012). On this occasion nurses and patients were surveyed; 33,659 nurses and 11,318 patients participated from 488 acute care hospitals in 12 European countries; and 27,509 nurses and more than 120,000 patients from 617 hospitals across the US. Results showed that deficits in care quality and work environments not only continued but were commonplace in all countries. They also revealed widespread lack of confidence in hospital management to resolve problems identified in patient care. Conversely, results indicated managerial scepticism that nurses' complaints represented objective observations of care quality; despite nurses' complaints being substantiated by patient data. Factors indicative that improvements in organisational culture, managerial attitudes, and receptiveness to learning from nurses (staff) as well as patients are required if effective organisational transformation is to be achieved and better work environments, improved nurse retention, and safer, more cost effective, patient-centred care attained (Aiken et al, 2012).

The perspectives of patients, visitors and staff of non-clinical patient-centred care in acute hospital settings

A qualitative research study, undertaken in 2006 by Which? an independent not-for-profit consumer organisation based in the UK, examined the perspectives of patients, visitors *and* multi-disciplinary frontline staff. The study is reported on by Webb (2007) who explains that in-depth qualitative interviews were carried out with 27 recent hospital in-patients and 22 visitors from seven sites across the UK. Five of these sites, Manchester, Leicester, Plymouth, Wimbledon, and Newcastle were affiliated with NHS England; one, Cardiff, represented NHS Wales; and another site in Glasgow, NHS Scotland. (This is highlighted because NHS England, NHS Wales and NHS Scotland and NHS Northern Ireland, have been administered independently since devolution of the NHS in 1999. Thus they are often reported on separately.) The sample also varied by hospital type, location and emergency or planned admission.

In-depth interviews were also conducted with a variety of 42 front-line staff in addition to the 49 service-user participants. These were recruited from the same seven sites and included nurses, allied health professionals, healthcare assistants, doctors, administrative and auxiliary staff, managers and 7 agency staff (4 nurses, 3 administrative). As with each of the studies reviewed, specifics about the numbers of

different staff involved, their grades, or location, were not included. Rather the results were generalised to all groups and settings. Again, lack of explanatory detail prevented meaningful understanding. For example Webb (2007) reports that variation in individual experience was found in patient and visitor data but, overall, *"most"* reported *"reasonable"* experiences in relation to the non-clinical aspects of NHS hospital care (Webb, 2007, p.63). More detail would have clarified what was meant by *"most"* and *"reasonable"* and if this related to all settings. Nevertheless, analysis of staff, patient and visitor data revealed four determinants of positive experiences; i) ward environment; ii) organisation of care, iii) being kept informed; and iv) attention from caring staff (Webb, 2007, p.64).

Commonalities are clearly evident between these finds and those of Douglas and Douglas (2005) and West et al (2004) and Aiken et al (2001). For example, Webb (2007) also found that patients identified key aspects of environment as lighting, temperature, noise, cleanliness, and, similar to Douglas and Douglas (2005), timing of meals, food quality, and assistance with meals were also important features. Staff, by comparison, recognised that the ward environment, particularly cleanliness, was important to patient well-being and recovery, but were generally less aware of the importance of environmental factors, such as lighting and noise, to patients.

In terms of organisation of care, patients valued timeliness, speed of response; continuity of care; efficiency and professionalism. They also emphasised the importance of attention from caring, friendly staff; of positive staff attitudes and good manners. Patients wanted to be kept informed, and notified of impending delays. Findings also showed that patients disliked being repeatedly asked by different members of staff for the same information. Importantly, they also emphasised that *"staff have the capacity to make or break a patient's stay"* (Webb, 2007, p. 66). The latter has also been indicated by all studies included in this review of PCC literature.

Staff also recognised information-giving was important to the well-being and experiences of patients and their families. However, experience of hospital systems, environment, and team-working, provided them with a different perspective. Staff understood the reality of practice, and the real reason why providing information in a timely manner, and proactively, might at times be problematic. Consequently, they recommended that patients be advised to proactively seek information as and when they required it (Webb, 2007). However, it was not clear if this recommendation reflected the views of all staff as, similar to the majority of studies reviewed, no explanatory detail was included (Webb, 2007).

Other issues identified by staff included poor communication between teams and limited availability of staff; reinforcing finds of West et al (2004) and Atwal and Caldwell (2006), amongst others. This frequently inhibited the provision of the smooth, delay-free care that patients expected. Patients, by contrast, reported that some staff appeared *"disconnected from their work"*; which *"instilled a real sense of a lack of care"* (Webb, 2007, p.67). One possible explanation may be attributed to a result which showed that staff found some patients *"particularly demanding"* (Webb, 2007, p.68); with unrealistic expectations about the amount of attention they, and their visitors, should receive. Due to other constraints on nurses' time, these expectations were challenging to fulfil. However, this review identifies further possible explanations in terms of understaffing, workload, lack of time, insufficient education in communication and PCC skills; different cultures and ethnicities, or lack of support as also highlighted by Gillespie et al (2004), West et al (2004) and Reeves et al (2005), Aiken et al (2001, 2012). Significantly Webb (2007) emphasised that staff generally appeared accepting of issues reported by patients as merely problematic. This apparent indifference may relate to another result which showed that the majority of staff, although keen to see improvements in patient care, felt powerless to influence change. Unfortunately, Webb (2007) does not clarify whether this find related to all staff, or specific grades. However, although not mentioned by Webb (2007), this is a notable barrier to improvement also emphasised by Aiken et al (2001, 2012), Ahern and McDonald (2002), Attree (2007) and Jackson et al (2010a 2010b).

The impact of negative organisational culture and unresolved barriers to patient-centred care on staff experience

Empirical studies of nurses' experiences of whistleblowing in the UK and Australia undertaken by Ahern and McDonald (2002), Attree (2007), Jackson et al (2010a, 2010b), reinforce finds not only reported by Webb (2007) but also Aiken et al (2001, 2013), Reeves et al (2005), and Atwal and Caldwell (2006) who investigated nurses' experiences of multidisciplinary teamwork. Collectively, these studies provide strong evidence that long-standing barriers to PCC and negative organisational and team cultures significantly impact on nurses' experiences, well-being, morale, motivation and practice and thus patients' experiences and care. These can damage inter-professional relationships; suppress openness; create climates of fear; facilitate bullying and exclusion; and instil feelings of disillusionment, moral distress and withdrawal (Attree, 2007, Webb, 2007, Jackson et al, 2010a, 2010b). These barriers, and the corresponding culture of blame and secrecy, have also been found to impede improvement, through lack of effective, supportive collaboration between managers, clinicians and frontline staff. This in turn, has been found to negatively impact on the

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experiences of patients and staff at all levels of healthcare organisations (Kennedy, 2001, Colin-Thorné, 2009, Francis, 2013).

Turning patient and staff involvement from rhetoric into reality

An action research study by Curry (2005) demonstrates how research can be used to meaningfully engage patients and staff in local service review and improvement. In the study, an action research project was run in parallel to the introduction of a new nurse-led urgent care team in Sunderland Teaching Primary Care Trust (TPCT) in England, UK. This was similar to the aim of this study in which action research would be run in parallel with a new Patient Journey project.

Curry (2005, p. 438) explains that action research (AR) *"underpins most of the current approaches to planned organisational change"*. It promotes innovation, can bridge the gap between theory and practice, and enables staff from all levels of an organisation to learn new knowledge about their own service through their involvement in the research process. The principle aim of AR is to empower staff to collectively diagnose current problems, identify solutions and take action to implement change and improvement (Curry, 2005). This method, which reflects the philosophy of PCC and this study, was also deemed most appropriate for investigating and evaluating this study's Patient Journey. As such, it will be introduced and discussed more fully in chapter three.

In Curry's (2005) study in-depth interviews with 11 patients with chronic obstructive pulmonary disease (COPD) were conducted in patients' homes to gather their perspectives and experiences as service users. Although similar to Campbell et al's (2004) PJ approach, a key difference is that patients in the study by Curry (2005) were invited to participate by UCT clinicians, rather than through stakeholder/matrix sampling. Campbell et al's (2004) method aimed to mitigate risk of practitioner bias, whilst also promoting engagement. The criterion for patient involvement in Curry's study was diagnosis of COPD.

Interview data were analysed and categorised according emerging themes. Again different to Campbell et al's (2004) PJ approach, in which thematic analysis and authentic reporting of emergent data is used, interpretation of data was influenced by Maslow's (1950) hierarchy of needs (1950) and Donabedian's (1992) structure, process and outcome model (cited Curry, 2005, p.439). These theoretical frameworks helped to focus analytical thinking on patients' needs (Maslow, 1950) and service improvement in terms of structure; complexity, points of access, timing and responsiveness; process which, prior the introduction of the UCT service, was described as "systems-focused",

and outcomes; which commonly resulted in in-patients being frequently moved between wards; insufficient opportunity to build relationships with staff ; poor continuity of care; lack of information to enable self-management on discharge, and inequity with other patient groups in terms of access to care. Patients with COPD, due to the nature of their illness and physical restrictions, were heavily reliant on family or friends for support and gaining access to care. As a consequence, Curry (2005) reports that patients often felt disempowered, marginalised, and believed their needs and experiences, as patients with COPD, were less important to healthcare providers than those of other patients. These findings echo those of Gillespie et al (2004) who also highlighted that patients from minority and lower profile groups experience barriers to PCC.

Similar to Campbell et al (2004), findings were discussed with a multidisciplinary team recruited from the related service. In Curry's AR study this included *"practitioners, managers, nurse leaders, a consultant physician, a social worker and a patient and public involvement representative"* (2005, p. 438). This group was set up to review patient feedback, identify solutions and ensure change happened; like the envisaged role of the multidisciplinary team in Campbell's PJ projects. This group, similar to teams in PJ projects, had also mapped the current *"patient journey across the urgent care pathway"* and met six times during the six-month active research period (Curry, 2005, p.444).

Findings of Curry's (2005) study were consistent with other PCC studies reviewed and once again emphasised the importance of ensuring patient-centred processes were contextualised with the patient's journey (including quick and convenient access, timely and appropriate responses), nursing competency, up-to-date equipment, multidisciplinary teamwork, emotional support for patients and family members, education of staff patients and families, and active engagement and partnership in their care. Importantly, unlike other studies reviewed, data in the studies of Curry (2005) and PJ projects by Campbell et al (2004), which had been derived from patients and staff, provided catalysts for local, effective change. These resulted in real-time improvements to local patients care. For example, Curry (2005) reported that access to COPD services had been highlighted as an issue by service users. This was addressed by providing care at home through the introduction of a nurse-led urgent care service. Safety and security risks identified by both service users and service providers, in relation to gaining access to patients' homes, was resolved by installing digital locking systems.

More generalised outcomes of the study were reported by Curry (2005) as improved multi-disciplinary learning and communication; seamless patient care; and consistency of approach in policy development across teams. According to Curry (2005, p.445) the multidisciplinary and collaborative nature of action research had moved *"patient and public involvement from rhetoric into reality"* by enabling patients' views to be captured, responded to, and appropriate changes implemented (Curry, 2005, p. 445). This was also the intention of Campbell et al (2004) and this study.

Chapter overview

This review has pinpointed robust evidence that not only supports the rationale offered by Campbell et al (2004) for the development of their Patient Journey model, it also substantiates the involvement of service users and service providers in patient-(person)-centred quality improvement initiatives. Included empirical studies demonstrate that both service users and service providers consistently identify common and distinct, current and long-standing barriers to PCC. This can be evidenced through studies of patients' perceptions of the hospital environment by Douglas and Douglas (2005); nurses' experiences of delivering PCC by Aiken et al (2001, 2012), West et al (2004) and Reeves et al (2005) and Gillespie et al (2004); patient and multidisciplinary staff experiences of non-clinical aspects of PCC by Webb, (2007); of nurse whistleblowing by Ahern and McDonald (2002), Attree (2007), Jackson et al (2010a, 2010b), and differing perspectives of PCC discussed by Gillespie et al (2004) and Goodrich (2009). Their collective findings provide evidence that not only patients but also staff voices are still not always heard, nor their concerns routinely acted upon. A factor suggestive not only of an unresolved 'disconnect' between healthcare policy-makers, regulators, managers, patients and frontline staff, but also that patient (service user) involvement may still be largely tokenistic (Gillespie et al, 2004). This is because the aim of patient engagement and patient-centred care initiatives was to provide patients and lay people with a stronger voice, and empower them, in partnership with staff, to take a role in shaping future, patient-centred health care and services, both locally and nationally (DH, 2005).

The studies by West et al (2004), Aiken et al (2012), Reeves et al (2005), Webb (2007) and Curry (2005), in particular, demonstrate how staff data complements that of patients by enabling fuller understanding of the reality of current issues in healthcare. Moreover they reveal that not all issues are common to each group; and that patients and staff often have different perspectives and priorities about the same aspects of care. They also emphasise that power imbalances between staff, and patients and staff, poor teamwork, lack of recognition, feeling undervalued, can demotivate and demoralise staff

who become accepting of current issues as merely problematic, rather than attempting to address them (Webb, 2007, Attree, 2007, Aiken et al, 2012).

Additionally, findings indicate that the multitude of models and theoretical, conceptual and philosophical frameworks of care, if not contextualised and introduced, may give rise to confusion and misconceptions about which approach to practice should be followed (Roper, 1976, Mead and Bower, 2000b). They may also encourage fragmentation of teamwork due to their emphasis on one discipline, as opposed to multidisciplinary or interprofessional working; this includes more recent, modified versions of PCC models (Gillespie et al, 2004). And further confusion can arise from the interchangeable use of broad-ranging terminology and concepts associated with patient care, some of which are not readily translatable to those at the frontline of care (Roper, 1976, Goodrich, 2009). Moreover, not all staff are health professional graduates. Thus, not everyone who interacts with patients will have had their understanding of the significance of building interpersonal relationships in patient care transformed through deeper investigation into the meaning of human experience.

These factors, as Campbell et al (2004) also identified, indicated that current improvement initiatives introduced through NHS modernisation required rethinking and further development. They also suggested that the current emphasis on patient as person, *patient-centred,* may be promoting depersonalisation of staff and thus may warrant revision. Importantly this evidence is derived from research that investigated the perspectives, experiences and desires of patients and staff; the collective findings from which laid the foundations for contemporary models of PCC; informed the underpinning philosophy and core determinants of PCC, and continue to inform current research, practice and education as well as the global movement towards PCC. As studies into outcomes of PCC demonstrate, PCC is an approach that not only makes a difference to patients and staff, but also brings cost benefits and improvements in organisational culture, systems and processes.

Even so, the majority of these investigations into PCC, irrespective of whether these have been large-scale and used quantitative research methods, or smaller scale using qualitative methods, lacked fundamental detail to enable truly meaningful understanding of results. For instance, other than the innovation report by Campbell et al (2004), and the action research study by Curry (2005), many failed to explain if or how PCC training or philosophy had been implemented; or specify what grades of staff, particularly nursing, were involved; how resolutions to current issues might be achieved; or if the data would be used for improvement. Moreover, in studies that report improvement,

insufficient detail was offered to explain what aspects of PCC, or patient or staff data, had influenced improvement, for example the reduction in diagnostic costs, enhanced well-being of staff and patients, and better outcomes in terms of patient recovery. This is significant because this detail might have helped to inspire PCC improvement in other healthcare teams or organisations. Additionally, by generalising results and omitting the detail, particularly in relation to issues that negatively impact on patient and staff experiences or PCC, the findings can be depersonalised by local multidisciplinary healthcare teams who may otherwise perceive their care and services to be of high quality and patient-(person)-centred; or may not feel sufficiently empowered or motivated to act because the findings do not specifically relate to their own service or practice.

Collectively, the evidence revealed by this review established that the empirical foundations of PCC embody the underpinning principles and philosophy, or the blueprint, for healthcare improvement. As mentioned, advocates of PCC not only recognise and valued the perspectives of patients and staff, but also partnerships between staff and patients as central towards achieving positive outcomes in health, and thus also improvement.

Study aim and objectives
Building on the Patient Journey approach to service improvement and practice development by Campbell et al (2004)

Review findings were indicative of two aspects of Campbell et al's (2004) model that might be developed yet further by this study. Firstly, similar to each of the studies discussed, Campbell et al (2004) appear to focus Patient Journey projects on identifying current issues with patient care. For example, Campbell et al (2004, p. 24) explain that interviews with patients usually open with the question *"Can you tell me your experience of care at CHS?"* Although this allows for positive feedback, they also state that project teams generally want questions asked about *"contentious issues"* they want resolved, which has the potential to focus thinking on negative aspects of care. The findings of this review strongly indicate that a neutral stance should be adopted, to enable patients to provide an authentic account of their experiences, the good and the bad. Learning and improvement can be acquired from both types of feedback, but most importantly, staff morale and motivation can be enhanced by learning about the successful aspects of their endeavours, merely than only where improvement is required. By retaining focus on the negative, this has the potential to perpetuate the culture of blame and issues such as lack of recognition and feeling undervalued; factors that are known not only to

adversely impact on staff morale and motivation and patient care, but also impede opportunities to learn from best practice.

Secondly, Campbell et al imply that only senior members of the clinical team, *"lead clinician, clinical nurse specialist"* (2004, p. 24), and a directorate and, or, business manager, participated in PJ projects. Yet, the findings of this review (Aiken et al, 2001, Campbell et al, 2004, Gillespie et al, 2004, Curry, 2005), reports from public inquiries by Kennedy (2001), Colin-Thorné (2009), Francis (2013) and Berwick (2013), and UK Department of Health (2004) guidance for improvement leaders, emphatically indicate that all members of staff who interact with patients, rather than merely a *"full multi-professional team"*, have the potential to make a difference to patients' experiences. Thus they should be empowered to contribute their feedback and ideas in service review and improvement. Consequently every effort would be made to include representatives from all levels of the participating multi-disciplinary team, including clinical and non-clinical staff, when recruiting to this study's Patient Journey project. These intentions are reflected in the study aim and objectives.

Aim

Using action research, to explore and evaluate the Patient Journey approach to patient-centred healthcare improvement (Campbell et al, 2004) following the philosophy and principles underpinning action research (AR) and patient-(person)-centred care (PCC).

Objectives

1. Meaningfully engage a multidisciplinary healthcare team in a review of their own patients' journey to explore their collective perspectives, as service providers, about what is currently working well or not so well with the current journey, and how this might be improved as described by those who participate.

2. Explore patient and care partner perceptions, as service users, of what is currently working well, or not so well with the same patient journey, and how this might be improved as described by those who participate.

3. Working with service providers (the AR Patient Journey project team), identify issues from the insights offered by service users and providers, and possible solutions that may help to improve the current patient journey as collectively determined by those who participate.

4. With service providers, create a plan for sustainable change and improvement as defined and determined by those who participate.

5. Explore and explain how data from service users and service providers, does or does not lead to patient-(person)-centred (PCC) change and improvement

6. Evaluate service user and service provider perceptions of the Patient Journey process as experienced through their involvement in this action research Vascular Patient Journey study.

7. To extend beyond this small scale project and gather wider opinion about the potential of the action research Patient Journey PCC improvement process through dissemination.

Action research and the data collection and analysis methods that enabled the aim and objectives of this study to be addressed, are discussed in the next chapter, Chapter 3.

Introduction

This chapter provides the philosophical and empirical justification for action research. It also explains the thinking, methods and processes that led to the implementation of this study's independently run, combined action research (AR) and Vascular Patient Journey (VPJ) project. It will also explain the methods used for data collection and analysis.

Context

This AR VPJ study was conducted in collaboration with twenty-five core members from a multidisciplinary vascular team drawn from the surgical directorate in the SE NHS Trust introduced in Chapter 1. This team was responsible for providing services and care to eleven patients and six care partners who, during this AR VPJ study, shared their stories of their experience of the current vascular patient journey. Each of the patient participants lived with a diagnosis of with peripheral vascular disease (PVD) and had undergone surgery for a femoral-popliteal bypass graft in the preceding three months.

Methodological considerations

According to van Manen (1990) the fundamental assumptions and characteristics which determine the approach to be taken in pursuit of the knowledge being sought should be reflected in the methodology. This action research study, from its outset, was focused on an independent investigation of the City Hospitals Sunderland NHS Trust's (CHS) *Patient Journey* (PJ). As explained, the PJ provides a framework for facilitating patient-(person)-centred change and improvement, or, practice development (Manley and McCormack, 2003, Manley et al, 2005, McSherry, 2004, McSherry and Bassett, 2002), through collaborative effort. The PJ is an approach specifically developed by way of response to the UK government's calls for *patient-centred* NHS reform (DH, 2001a). Thus, these factors should also be acknowledged by and reflected in the methodology.

Findings from the critique of empirical studies of PCC strongly emphasised that the approach to this investigation should follow the principles, characteristics and philosophy of AR. As will be explained in more detail later, this is a method that promotes a participatory, democratic and collaborative approach to research. Its purpose is usually to enable a team, group or community to work together to collectively identify new knowledge about an aspect of their social world, and from the new learning acquired to become empowered to change and improve that world. Limitations identified from critiquing quantitative and qualitative studies of PCC had also indicated this was the

route of investigation to follow if similar shortfalls in this AR study were to be prevented. The varied limitations of former PCC research methods are discussed in detail in the literature review in Chapter 2. Most commonly these were identified as the lack of explanatory detail provided in study findings to enable meaningful understanding or inform improvement; a failure to consider the perspectives of both service users and providers of healthcare; and no indication of whether the findings had been acted upon to influence change and improvement. It is acknowledged, however, that these shortfalls were identified in empirical studies that used more traditional research methods; methods that aimed to fact-find rather than improve PCC. Even so, these were limitations that those studies had also indicated were adversely impacting on PCC, or understanding of PCC. As such, an endeavour to address these shortfalls became an objective for this AR PJ study.

Review findings also indicated that in this combined AR study, the dominant philosophies that underpin qualitative research and action research in particular, should be explicitly linked with the philosophy and principles of PCC. The primary purpose of this would be to allow open acknowledgement of PCC values and principles, but also to enable these to be followed, practiced and promoted during the AR and PJ improvement processes. This, in turn, should ensure that the improvement process in this AR study would not only be aligned with NHS 'patient-centred' healthcare modernisation directives (DH, 2001a) as Campbell et al (2004) intended, but also the global drive towards PCC. The literature review indicated that the empirical foundations of PCC provided a philosophy and set of underpinning principles, or the blueprint, to guide AR studies in healthcare. It also suggested that, by following a PCC approach, this might also make it possible for a number of current issues in healthcare to be addressed. These had not only been identified by the literature review, but also highlighted by reports of investigations into healthcare failings. Examples of these include varied perceptions and priorities for PCC; fragmented teamwork; hierarchical boundaries; lack of clarity about PCC; the terminological quagmire of healthcare; workloads and time constraints; a culture of secrecy and blame; and demoralised, de-motivated or disempowered staff. These are issues that the review indicated could also impede the progress and outcomes of an AR study in healthcare, if not addressed. Thus these were further factors that required consideration when designing this study as following discussions will further explain.

The nature of qualitative research and its relevance to this investigation
Action research sits within the paradigm of qualitative research. This, Parahoo (2006) explains, is commonly used as an umbrella term that encompasses a broad variety of

differing research methods. However, each of these methods, are underpinned by philosophies such as constructivism, interpretism and phenomenology that, unlike those in the quantitative paradigm, are focused on exploring human experience, or specific, aspects of experience such as motivation, behaviour, emotions, beliefs and perceptions (Holloway, 2005). Qualitative exploration, like PCC, but unlike quantitative inquiry, is, as Parahoo suggests, *"holistic"* (2006, p. 63). It is also inductive, subjective and interactive, thus methods of data collection and analysis are usually flexible and reflexive (Parahoo, 2006). This description can also be aligned to the evolving, interactive and holistic nature of action research, which, as will be explained, is not only informed by reflexive methods of data collection, but encourages reflexive practice amongst participants. These are also characteristics of the Patient Journey process developed by Campbell et al (2004), thus demonstrating the compatibility of both methods for integration as intended in this study.

Importantly, the underpinning principles and philosophies of qualitative research methods, and thus AR, like those of PCC and related healthcare concepts, philosophies and theories identified in Chapter 2, acknowledge that people cannot be separated out from the world in which they live, or work; it studies people in their natural settings. For example, interpretivism, one of the dominant underpinning philosophies of the qualitative paradigm, acknowledges that people are unlikely to interpret or experience phenomena the same way; thus an individual cannot claim to understand the experience of another by simply relating this to their own experience (Ross, 2012). This is because interpretists, like action researchers, and advocates of patient-(person)-centred care also recognise that each person's experience, and perspective of that experience, is shaped by a broad variety of factors, including past experiences, interpretations and expectations. Fundamentally, qualitative research, like PCC, acknowledges and respects that experience is individual to each person.

These similarities between qualitative research and PCC can be evidenced by through the qualitative methods critiqued in the literature review, for example by Gerteis et al (1993), Douglas and Douglas (2005), Curry (2005) and Webb (2007). The philosophies of interpretism, similar to constructivism and PCC, also respect the view that people, unlike objects, attribute meaning to events (Schwandt, 2000, Gallagher, 2004, Quirk et al, 2008), and that reality, if it is to be understood, may be subject to a broad range of influencing factors which stem from each person's experience of their being in the world (Gerteis et al, 1993, Chochinov, 2007, Schantz, 2007, Youngson, 2010). These human factors can be further explained, as the literature review illustrated, not only through the findings of empirical studies into PCC, but also the philosophical and theoretical

Knowledge claim positions influencing Action Research Patient Journey study

Interpretisim
Interest in how the social world is interpreted, understood and experienced (Ross, 2012)
Subjectivity and multiple realities – interpretation of experience influenced by individual perceptions and past experience
Absolute truth does not exist as humans interpret phenomena differently
Humans cannot simply step inside another's experience and expect to understand this on the basis of their own experience
Other person's experience is individual to them; high internal validity, faithful description of own lived experience (Laverty, 2003)
Researchers aim to make connections between experiences, perceptions and actions
Researchers listen to narratives, observe and interact with participants and data and aim to report how participants have felt and lived that experience as closely as possible.
Researcher as instrument; integral and necessary to the process. Personality, communication skills and ability to gain trust of participants is crucial to data collection.

Constructivism
Individuals seek understanding of the world in which they live and work – emphasis on context rather than person
Multiple participant meanings due to varied interpretations
Social and historical construction – humans construct reality through experience, language and concepts to make things make sense (Ross, 2012)
Naturalistic inquiry (Lincoln and Guba, 2000, Schwandt, 2000) – data is contextually sensitive
Subjective, constructed interpretations and meanings of experience directed towards objects or things.
Constructivism - goal of research – *"to rely as much as possible on the participants' views of the situation being studied"* (Creswell, 2001, p.8), BUT, context focused
Researcher builds up a picture of participant's reality of experience until it makes sense; enables them to view the depth and complexity of individual experience (Ross, 2102)

Advocacy/Participatory
Political – an action agenda for reform that may change the lives of participants, the organisation in which they work or live, and the researcher's life. In this instance NHS modernisation.
Empowerment issue-orientated
Collaborative approach
Change-orientated, transformative as indicated by literature review and reports of healthcare failings
The voice of participants becomes a *"united voice for change and reform"* (Creswell, 2001, p.10)
Advocacy provides the voice for participants, raises their awareness through new insights and learning, and produces an action plan for change to improve service user and service provider experiences.

Patient-(person)-centred care
Political – an action agenda for reform that aims to improve and humanise patient care, service user and service provider experiences, healthcare services and organisational culture and efficiency.
Historical and social construction – ongoing evidence of healthcare failings, inhumane care, inefficiencies in healthcare, endemic culture of secrecy and blame, unsatisfactory experiences for service users and providers
Values-based
Person-centred - individuality of experience; seeing through the eyes of the other, a holistic perspective. Awareness of individually constructed meanings and interpretations
Recognises experience as catalysts for learning and improvement – contextually sensitive data
Empowerment – of marginalised healthcare staff and, or, service users by giving them a voice
Collaborative, democratic approach – to facilitate sustainable, change and improvement
Goal of PCC - to humanise care and healthcare cultures, and improve efficiency

Researcher
Background, particularly as patient and nurse, on study design, data collection, and interpretation and analysis of data
Past experience, influence from own culture, social world, communities, including as patient, care partner, nurse, non-clinical and clinical roles in NHS; customer service trainer and service improvement facilitator in global communications organisation
Researcher intent: to demonstrate why experiences and perceptions of service providers *and* service users should inform change and improvement in healthcare
Characteristics of researcher – interested in people and their experiences, advocate for patient-(person)-centred care, democratic, facilitative and inclusive approach, realistic, determined

Table 3-1:   Knowledge claim positions influencing this action research study

perspectives linked with PCC and humanised approaches to care (Appendix 3). Table 3-1 provides a summary of the knowledge claim positions that most strongly influenced the design of this qualitative AR study.

Patient-centred care: an underpinning philosophy for action research in healthcare

The review of PCC empirical literature and associated concepts, theories and philosophies (Appendix 3), indicated that the philosophy and principles of PCC, and the CHS Patient Journey process (Campbell et al, 2004), provided a philosophy and framework for conducting action research in healthcare.

PCC philosophy, like that of AR, emphasises the importance of involving those with first-hand experience of a healthcare service in a review of their current state for the purpose of improvement (Douglas and Douglas, 2005, Curry, 2005, Webb, 2007). It also promotes recognition and appreciation of each participant as a unique and valued human-being, and of understanding and acknowledging others' perspectives and roles (Gerteis et al, 1993, Stewart, 1995, planetree.org, 2014, McCormack, 2001, 2004). Additionally, PCC philosophy recognises the significance of rapport building and establishing common ground between service users and providers (Stewart et al, 1995, Gillespie et al, 2004, Goodrich, 2009). Each person should feel able to openly express their perceptions and ideas, needs and preferences so that common understandings and shared-decisions can be accomplished, and relationships enhanced (Balint, 1957, Borrell-Carrió et al, 2004, Reeves et al, 2005, planetree.org, 2014). PCC review findings also indicated that, if patient-(person)-centred change and improvement is to be achieved, in line with the aim of healthcare reform and this AR study, individuals and teams must feel sufficiently empowered and motivated to change (Reeves et al, 2005, Johns, 1994, 2009, Atwal and Caldwell, 2006). These are also key requisites for supportive, effective teamwork, positive experiences and PCC (Maslow, 1954, von Dietz and Orb, 2000, Aiken et al, 2001, 2012, Atwal and Caldwell, 2006). They are also fundamental to action research.

As will be explained, action research, like PCC improvement philosophy, also seeks a real-time view of local healthcare as seen through the eyes of those who are a part of a culture, organisation or community. In this study this would be service users and providers (Gerteis et al, 1993); those with first-hand experience of the care continuum associated with a specific patient journey. These people's insights, experiences and authentically reported accounts would provide the catalysts for change and improvement, where indicated, to their current patient journey.

Action research: using research to inform action for the purpose of improvement

Over the last decade, action research (AR) has been gaining increasing recognition as an effective means to facilitating change within business organisations, educational establishments, and more recently within the NHS (Parkin, 2009; French et al, 2011; Koshy et al, 2011). Reason (2001) describes this as an approach that enables groups to become empowered to solve problems within their own environments through participative, collaborative inquiry; critical reflection; consciousness-raising and the acquisition of new knowledge (Table 3-1). Change happens, Parkin (2009) suggests, because AR facilitates local ownership and responsibility for change, as opposed to change being imposed by centralised policymakers, or organisational managers. Those, who are often far removed from the reality of day-to-day custom and practice. Parkin (2009) is specifically emphasising the relevance of AR to the NHS and healthcare in this context, as former discussions have also intended. AR, as Carr and Kemmis (1986) and Koshy et al (2011), also point out, is values-based, democratic, situational and participatory, and specifically focused on enabling research to bring about change through the involvement of others.

The origins of action research

The origins of action research lie in America where, according to Hart (1996) it first emerged as a form of rational social management. It soon became closely associated with the work of Kurt Lewin (1890-1947), a social psychologist who used this anti-positivistic experimental method to investigate a range of social issues including industrial unrest, racism, and low morale amongst military personnel (Hart, 1996). There is some debate, however, about the extent to which Lewin and his followers were manipulative or democratic in their approach to social change (Kemmis and McTaggart, 1982; Hopkins, 1985; Hart, 1996). Nevertheless, Kurt Lewin is regarded by many as the 'father' of action research (Coghlan and Jacobs, 2005); his ideas initially emanating from studies conducted at the Center for Group Dynamics, Massachusetts Institute of Technology in Boston in the USA (Morton-Cooper, 2000).

Democratic participation rather than autocratic coercion

In the late 1930s Lewin, together with his students, carried out a number of situated quasi-experimental studies in factory and community settings. These investigated the effect on human behaviour and productivity of *"democratic participation rather than autocratic coercion"* (Adelman, 1993, p.7). Findings indicated that the *"average manufacturer holds highly distorted views about what makes a work-team 'tick'"* and that several factors were influential in preventing practical, first-hand experience from

"leading to clear insight" (Lewin, 1947, p. 9). These finds enabled Lewin to challenge existing post-war theories about managing people and organisations (Lewin, 1946, 1947a, 1947b). Yet, the democratic and participatory approach advocated by Lewin was directly opposed to existing theories such as *'scientific management'*, an approach founded on the work of Frederick Winslow Taylor in the United States in the late 1800s and early 1900s. The '*Taylorist'* approach, favoured by governments in post-war years, was based on the assumption that workers were driven mainly by economic reward and best controlled through authority. Consequently, post-war employment became characterised by centralised control of work practices and minimal worker autonomy (Morton-Cooper, 2000).

Conceptualisation of change as a three stage process

Coghlan and Jacobs (2005, p. 445) suggest that Lewin's research with women in Iowa led to his conceptualisation of change as a three stage process. Lewin empowered the women to explore their own resistance to change, and to challenge long established meat-eating habits of their families. Prior to this the women had been reluctant to experiment with cheaper forms of meat which they considered inferior and, as such, refused to provide for their families. Through the collaborative process of action research, experimentation and change had been enabled. The outcomes demonstrated to Lewin that change was more likely to occur in conditions where the factors hindering or restraining change were reduced or removed, rather than when the forces driving change are increased (Coghlan and Jacobs, 2005). The finds also led to Lewin's identification of three key phases of change. These were expressed as *"unfreezing"* (recognising and accepting the need for change), followed by *"moving"* (a move to new behaviours and values; the change) and *"refreezing"* (stabilising the change in normative behaviour) (Coghlan and Jacobs, 2005, p. 445). These phases are illustrated in Figure 3-1.
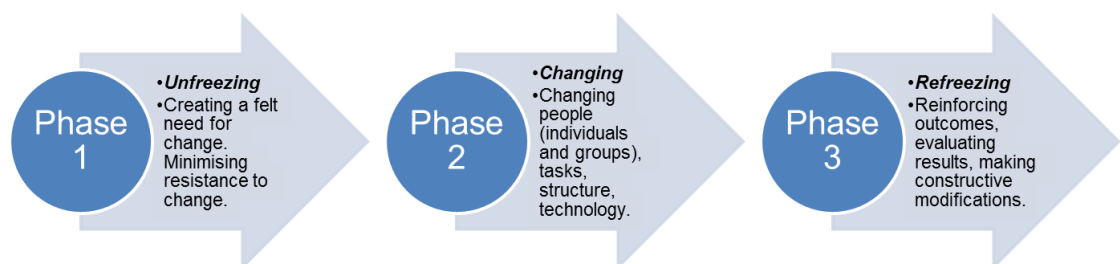
Figure 3-1: Lewin's three phases change (French et al, 2011, p. 586)

In this action research study, these stages were not consciously followed. Rather, these brought researcher awareness of phases this action research study might transition

through during the endeavours to bring about change. Figure 3-2 illustrates how these loosely related to the combined AR and PJ processes in this study.

1 • Fact-finding and preparatory phase

2 • Preparing for implementation/recruiting the project team (Phase 1 Action Research: *unfreezing* – recognising and accepting the need for change; creating a felt need for change; minimising the resistance to change)

3 • Engaging with the Patient Journey process (Phase 1: unfreezing)

4 • Data collection (Phase 1: unfreezing)

5 • Data analysis (Phase 1: unfreezing; start of Phase 2: changing/moving - a move to new behaviours and values; changing people (individuals and groups; tasks; structure, systems; technology)

6 • Identification of issues and solutions (Phase 2: changing/moving

7 • Action planning and implementing change (Phase 2; start of Phase 3: Refreezing – reinforcing outcomes, evaluating results, making constructive modifications; stabilising the change in normative behaviour)

8 • Evaluation (Phase 3: refreezing)

9 • Extending beyond the small-scale project

Figure 3-2: the relationship between the change, action research and Patient Journey processes (based on Lewin, 1946; and Lewin 1946 cited Kemmis and McTaggart, 2000, French et al, 2011 and Campbell et al, 2004)

Quality of work–life issues

It was not until the 1970's when quality of work-life (QWL) issues began to interest social science researchers that greater emphasis was placed on worker participation. Influenced by democratic values and concerns about autocratic management, social scientists, building on the contributions of Lewin (1946, 1947a, 1947b), began to explore the notion of worker participation in decision-making, and the potential of their involvement to bring greater efficiency.

Action research: supporting organisational and cultural change and personal and professional development

Since then, Hart and Bond (1985), Morton-Cooper (2000), McSherry and Pearce (2002), Wright and Hill (2003) and more recently Parkin (2009) and Koshy et al (2011) report that action research has been effectively used to initiate organisational change and improvement in industry, education and healthcare; in human relations theory, and as a means through which personal and professional development and practice might be improved. Indeed, in Curry's opinion (2005, p. 438), action research now *"underpins most of the current approaches to planned organisational change"*. It can bridge the gap between theory and practice, and makes it possible for staff from all levels of an

organisation to become involved in diagnosing problems and developing strategies that lead to improvement (French and Bell, 1999, French et al, 2009, 2011). As Kemmis (1985), Carr and Kemmis (1986), Meyer (1993, 1995, 2000) and Reason and Bradbury (2001, 2008) suggest, the democratic and dialogic nature of this approach can help to breakdown the hierarchical boundaries that may be found amongst healthcare professionals, between healthcare staff and patients, and healthcare researchers and participants.

These factors, which are further explained through the contributions of Lewin (1946, 1947a, 1947b) and others including Coghlan and Brannick (2001), Gummesson (2001), Iles and Sutherland (2001), Iles and Cranfield (2004), Hughes (2008) and Koshy and Millett (2008), Koshy (2010) and Koshy et al (2011), verified that action research was an appropriate means by which to conduct this investigation. This was already indicated by the PJ approach promoted by Campbell et al (2004), the action research study by Curry (2005), the principles and philosophy of PCC, and wider finds of the review of patient-centred literature.

Three practices of action research

Reason and Bradbury (2001) suggest that if action research is to provide a compelling and enduring contribution, an action researcher should engage with three practices. The first of these is first-person AR which requires an action researcher to *"cultivate an inquiring approach"*. This is to enable the researcher to make sound decisions and contextualise the AR process within a much wider arena (Reason and Bradbury, 2001, p. xxvi). First-person practice is aligned with the preparatory stage, a fact-finding, knowledge-development stage which, in this AR VPJ study, included the critical review of PCC literature. Engagement with second-person AR requires an action researcher to facilitate effective dialogue with, and between, others and actively engage them in the action research process. In this study this was fulfilled through engagement with the SE Trust and interactions with participants and key stakeholders. Second-person practice relates most closely to the setting up and implementation of the AR Vascular PJ project. Engagement with third-person AR practice requires an action researcher to extend beyond the small-scale project. This was achieved through an evaluation of the PJ process by those who participated in the process (Chapter 5), and dissemination of study findings through presentations and publications (Chapter 6).

Action research and the Patient Journey

In the current study, the original six steps of the PJ process (Chapter 1, Table 1-1) were modified to include preparatory and evaluation stages. Other than these stages, the

Patient Journey process provided the framework for this AR study. This is illustrated by Figure 3-3. By integrating the two methods, action research could also be used to enable each step of the PJ process, once implemented, to be reviewed and evaluated by those actively engaged in the change process.
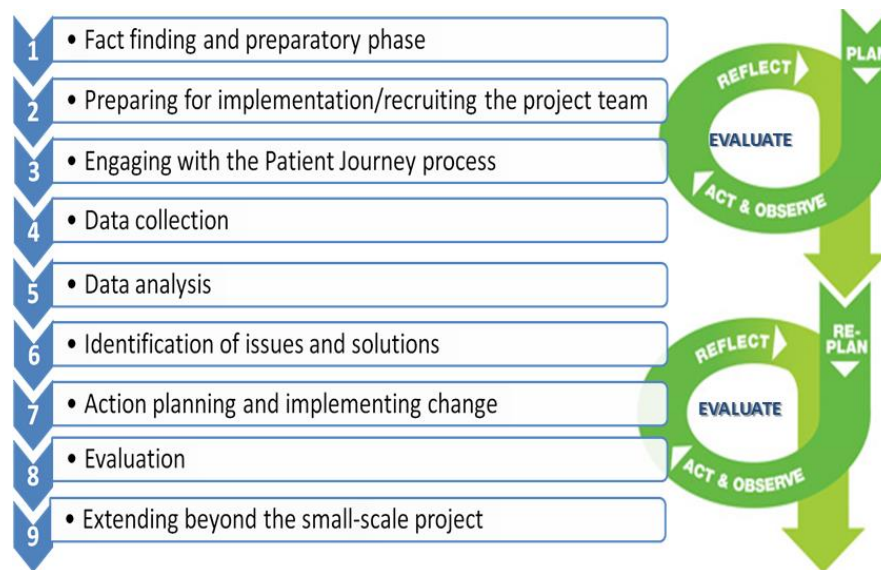
Figure 3-3: nine stages of combined action research Patient Journey process based on Campbell et al (2004) and Kemmis and McTaggart (1988)

To clarify, in this AR study the original PJ process (Campbell et al, 2004) became integrated with AR at stage 3 as illustrated in Figure 3-3. Each of the stages between 3 and 7 also represents a Patient Journey project team meeting when the VPJP team became involved in AR through the actions of planning, acting and observing, reflecting and re-planning as proposed by Lewin (1946) and Kemmis and McTaggart (1988, 2000).

Modifications to the CHS Patient Journey

In accordance with the aim of the current study, the Vascular Patient Journey was mostly implemented according to the guidance of Campbell et al (2004). However, as mentioned, modifications were necessary to enable this independently run PJ project to be contextualised within this action research study. These are as follows:

1. The Vascular PJ approach and stance of external PJ facilitator, and thus action researcher, in this study were aligned with the principles and philosophy of patient-centred care in addition to NHS Modernisation directives (DH, 1997, 2000a, 2008).

2. The findings of the literature review indicated that membership of the PJ project team should be extended to include multidisciplinary clinical and non-clinical staff. In the CHS PJ projects, Campbell et al (2004) implied that only clinicians and a directorate or business manager generally participated.

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3. The literature review also required me, as external facilitator and action researcher, to follow the philosophy and principles of PCC. This would include facilitating open and frank reporting of service user and service provider perspectives and experiences when gathering data, and removing the emphasis on *"contentious issues"* often sought in CHS PJ projects (Campbell et al, 2004, p.24)*.*

4. Experience as an action researcher and external PJ project facilitator, required the preparatory stage in action research to be acknowledged in this investigation of the Patient Journey. When introducing and setting up an action research study in parallel with an independent Patient Journey project for the first time, essential, preparatory groundwork is required.

5. The emphasis on following *"established tenets of integrated care pathway methodology"* as suggested by Campbell et al (2004, p.16), was removed so as not to restrict the potential of this PJ project. In this study, although it was recognised that a new care pathway might be developed, or evolve, as a consequence of the Vascular PJ project, this was not identified as an aim for this independently led PJ project.

Action researcher and external PJ project facilitator

In keeping with the philosophy of AR and PCC, the role of an action researcher and external PJ project facilitator, is to gain trust and to create a felt need for change within PJ project participants. Key aims for this role, which reflect the principles and philosophy of AR and PCC, as they were applied in this study, are outlined in Figure 3-4.

1. Instil a shared sense of belief amongst the project team that change can, and will, happen and has the potential to benefit all
2. Endorse a non-judgemental, democratic approach; a neutral and supportive environment; respect for each other's knowledge and views
3. Stimulate a shared passion and enthusiasm for the delivery of high quality, safe, patient-(person)-centred (humanised) care
4. Encourage openness to hearing, and acting upon, views from the frontline (of patients and staff) and all members of a multidisciplinary team
5. Emphasise the value of multi-disciplinary/inter-professional learning: facilitate willingness to learn from and about each other
6. Facilitate preparedness and enthusiasm for change and commitment to accept responsibility/ownership for ensuring change happens
7. Emphasise potential advantages in terms of personal and professional development, enhanced relationships and improved experiences

Figure 3-4: approach and aims of action researcher as external Patient Journey improvement project facilitator

Data collection methods

Three principal methods of data collection were already integral to the Patient Journey approach; thus these also became integral elements of this study's combined action research and PJ processes. These are mapping of a current patient journey, stakeholder and matrix sampling, and qualitative interviews. These methods will be discussed in the context in which they arose during the implementation of this study's Vascular Patient Journey.

Stages of action research

The stages of the AR VPJ process identified in Figure 3-3 provide the structure for explaining and reporting on the methods and activities that informed the change process in this study. It is acknowledged, however, that none of these stages, other than the preparatory phase, had a precise start or end point. Rather these stages provide a framework by which to conduct an action research Patient Journey improvement project in healthcare.

Action research stage 1: groundwork

Prior to the implementation of an action research study or Patient Journey project there is a preparatory stage during which essential groundwork must be undertaken by action researchers vis-â-vis external PJ project facilitators. The preliminary phase in this study began in October 2005. This was when the foundations for this combined action research and PJ project implementation were laid.

As mentioned, the original six steps of the Patient Journey process identified by Campbell et al (2004) did not provide an accurate depiction of the actions required by an action researcher and thus external PJ project facilitator. As this study now acknowledges, it is not possible for an 'outsider' to an organisation to simply recruit a Patient Journey project team, or implement a Patient Journey project without some initial preparation. These preparations included fact-finding, participant observation, networking with potential key stakeholders, which often led to further introductions and enabled wider dissemination of the proposal for this AR study and affiliated PJ improvement project. Steps were also undertaken during this period, as Coghlan and Jacobs (2005) advised, to identify potential barriers to AR PJ project implementation. The aim was to minimise resistance to a change project when networking, and after the AR Patient Journey project had been launched (French et al, 2011). Alertness to the significance of preventers or drivers of change had been heightened by knowledge of the phases of change first identified by Lewin as reported by French et al (2011) and illustrated previously in Figure 3-1.

Knowledge building

During this preparatory stage knowledge was also furthered in preparation for the roles of action researcher and PJ change project facilitator within an NHS setting. This was aided through the critical literature review but also by keeping abreast of UK healthcare policy directives and literature associated with the advancing global movement towards PCC; and attending researcher development workshops, Masterclasses, and seminars.

Enabling fair testing and evaluation: gaining an informed understanding of the City Hospitals Sunderland NHS Trust's Patient Journey approach

To ensure that the interpretation and understanding of how a Patient Journey might be implemented and facilitated in this study was consistent with that of Campbell et al (2004), a visit was undertaken to the CHS trust in Sunderland in late March, 2006. This visit, whilst enabling clearer understanding, also yielded two additional unpublished, in-house reports about the CHS Patient Journey process. This better understanding informed the Research Protocol Flowchart for this current study (Appendix 4).

Action research stage 2: setting up

The following discussion provides an overview of activities undertaken when setting up this action research study and introducing the CHS Patient Journey improvement approach to the SE NHS Trust (Campbell et al, 2004). As mentioned, every stage of the action research process can also be aligned with steps of the modified Patient Journey process (Figure 3-3).

Establishing a credible identity as a researcher: introductions and networking

Between January and June 2006 networking began in earnest with key stakeholders and lead clinicians within the SE Trust. From the outset, the priority had been to secure 'buy-in' from the participating Trust's management team. During this period numerous meetings were attended, for example with the Director and Assistant Director of Nursing Services who initially became key contacts; the SE Trust's then Acting Chief Executive, the Service Improvement Lead, Medical Director and Head of Learning and Development (HLD). A meeting of Divisional General Managers (DGMs) was also attended, during which participant observation brought useful insights into relationships, group culture, current issues and future plans for the SE Trust, as well as providing introductions to key nursing personnel. Further one-to-one meetings were also held when scoping or following possible leads for a PJ project, for example with a Cardiac Rehabilitation Specialist Nurse, a consultant in pain medicine and management, a Consultant Clinical Psychologist, a Stroke Co-ordinator and lead clinician from the

stroke specialty, amongst others. In June 2006, the Patient Journey approach was introduced more widely to SE Trust staff during an in-house conference when two representatives from CHS provided overviews of a Stroke PJ and Lung Cancer PJ. These early endeavours helped to raise my profile as action researcher, and create awareness of this AR study and the PJ approach, but did not initially lead to the identification of a setting in which to implement a Patient Journey project.

Facilitating access

A Patient Journey Steering Group (PJSG) was established in June 2006. Membership comprised the Trust's Acting Chief Executive (CE), the Deputy Director of Nursing (DDNS), Medical Director (MD), Head of Service Improvement (SI) and me as action researcher and prospective external PJ facilitator. This was in keeping with the *"general project management approach..."* advocated by Campbell et al (2004, p.17). This group assisted with raising the profile of the Patient Journey project; acted as additional auditors of the PJ and action research processes; and reported on PJ project proceedings to the Trust's Executive Board. The PJSG also demonstrated to prospective PJ participants that this study had managerial and executive level support, thus also promoting the credibility of the proposed study.

Ethical approval and risk assessment

Full LREC approval was granted on 26th March, 2007 (Appendix 5).   Research and development approval was received from the SE Trust's R&D Consortium on 28th March, 2007 (Appendix 6). A risk assessment, also approved by LREC, is attached as Appendix 7. Strategies for reducing risk, particularly in relation to risk of potential distress to participants during interviews, or from any ethical or moral issue that might arise during the study, were detailed in both documents. These also considered risk from coercion; disclosure of sensitive information; or to researcher as lone-worker. Strategies identified for protecting participant and data anonymity and confidentiality were also included.

Research monitoring and review

The standard, quality and rigour of the action research process was routinely monitored, assessed and audited by PhD supervisors and through annual monitoring of post-graduate researchers. Annual reports were also provided for LREC and the SE Trust's Research and Development department. Independent opinion and peer review during the study was also obtained through presentations at international conferences in Berlin, Vienna and in the UK in Bournemouth, London, Edinburgh and Cambridge and through dissemination in a variety of publications, as listed in Appendix 33.

Peer-review and collaborative agreement

In negotiation with SE Trust management administrative support was provided with distributing information to the project team via SE Trust email, and recording notes of VPJ team meetings. This provided a further independent audit trail of the research process. Additionally, and in keeping with the collaborative nature of action research, PJ project team members reviewed and approved all written accounts. This includes meetings notes, reports of mapping exercise, report of qualitative interviews with service users; evaluation reports, PJ PowerPoint presentations, and articles published in the SE Trust's newsletter. A number of these documents are included as appendices, albeit with personal identifiers removed, and will be introduced in context later.

Identification of Patient Journey; approval to proceed

Approval to proceed with PJ project implementation was not achieved until the second year of this study. At this stage, two potential PJ journey projects had been identified; one from the SE Trust's urology specialty, the other from the vascular speciality. Final approval, from the PJSG, that this action research study could investigate a Vascular Patient Journey project was obtained in January 2007, nearly sixteen months after the start of this AR study. This reflects time constraints on stakeholders' time, which commonly delayed meetings. It is also representative of additional barriers identified during the literature review, which indicated challenges might be encountered when trying to introduce and implement a change project in the NHS.

Establishing a consensus view; building shared visions and goals

Findings from the literature review, and personal experience indicated it was imperative that central figures of the VPJP team, in this instance a lead Vascular Consultant Surgeon (LVC), Assistant Director of Nursing Services (ADNS), Vascular Nurse Practitioner (VNP) and me as external VPJ project facilitator, established a common understanding of the PJ approach (Campbell et al, 2004) to enable effective implementation and fair testing. This was facilitated through a second visit to CHS in April, 2007, the insights from which were reported back to the LVC who had not been able to attend.

Preparation for Vascular Patient Journey project launch, April 2007

Information about the Vascular Patient Journey (VPJ) study, in the form of the Research Protocol Flowchart (Appendix 4), an invitation to participate letter (Appendix 8), Participant Information Sheet (Appendix 9), participant consent form (Appendix 10), proposed action plan (Appendix 11) was forwarded by email to a member of SE Trust management administrative staff for onward distribution via SE Trust email to

prospective team members in mid-April, 2007. As mentioned, this provided an independent audit trail and enabled confirmation that each VPJT team member had received information. This was a cost-effective, readily accessible and timely method for disseminating and gathering information to and from the VPJP team.

Action research stage 3: integration with the Vascular Patient Journey

The first meeting, on 8th May 2007, marked the point of Vascular Patient Journey project implementation. It is also the point at which AR became fully integrated with the Patient Journey process (Figures 3-3) and mostly followed guidance provided by Campbell et al (2004) with the exception of modifications previously highlighted. These included multidisciplinary membership, approach to interviewing, and removal of emphasis on the development of an integrated care pathway.

The inaugural meeting was attended by sixteen members of the vascular team, all of whom duly consented to participate (Appendix 10). By the second meeting in June, a core group of twenty-five multidisciplinary project team members had been established (Appendix 12). Six full VPJP meetings took place between 8th May and 29th November, 2007. VPJ issues and solutions action-group and additional ad-hoc meetings continued to be held until my withdrawal from the SE NHS Trust in February 2009.

Vascular Patient Journey: assigning key roles and responsibilities

In line with the recommendation of Campbell et al (2004), four key roles were assigned during the first meeting. These, and recommendations for PJ project membership, are explained in Appendix 13. The following roles were also recorded in the notes of the meeting (Appendix 14).

- Clinical Champion - lead Vascular Consultant Surgeon (LVC)
- Local Vascular Patient Journey facilitator - Vascular Nurse Practitioner (VNP)
- External VPJ facilitator – action researcher
- VPJ chair - Acting Director of Nursing (ADNS) (temporary appointment)

The ADNS also assumed responsibility for reporting on the PJ project to the Trust's Executive Board. Interestingly, although this was the only time that these roles would be mentioned, each post-holder, other than the ADNS, became crucial to the progression and outcomes of the Vascular PJ.

As action researcher and external PJ project facilitator my stance, as previously outlined in Figure 3-4, followed the principles and philosophy of patient-(person)-centred care. The literature review and personal experience made emphatic the importance of building strong relations with the team, adopting a neutral stance, and promoting a supportive, open and positive team culture.

Action research stages 4 and 5: data collection and analysis

The main methods of data collection included those already integral to the Patient Journey process developed by Campbell et al (2004); these are mapping, matrix sampling and qualitative interviews. Data was also collected through Vascular Patient Journey project team meetings, participant observation, field notes, a researcher journal, qualitative evaluation interviews and questionnaires. These methods are discussed in the following section. They are also summarised in Table 3-2 below.

Data collection method 1: Vascular Patient Journey project team meetings

Data collection methods for VPJ project team meetings included field notes, meetings notes and participant observation. The latter occurred whilst also acting as chair and facilitator of VPJ meetings, and was used to gain an insider perspective of the participating project team, their working relationships, hierarchical boundaries, beliefs, knowledge-base, expertise, and perceptions of their patient journey and current working practices, and vision for their future (Ross, 2012). As passive observer the intention was to gain an understanding of what made that team 'tick'; through fact-finding, knowledge-building and relationship-building with the VPJ team. This also brought familiarity with the group's language, their service and specialty, knowledge that also facilitated the process of fitting in and gaining the VPJ team's trust. Participant observation also helped with the identification of any potential threats, for example from SE Trust politics, and enablers to project progression, particularly in terms of project team members.

During every VPJP team meeting notes were taken, sometimes by a secretary from the SE Trust, sometimes by me, and later written up in a word document. Examples are included as Appendices 14 and 19. Appendix 14, the notes of the first meeting, provide an example that illustrates that notes were also used to record emergent data from the VPJP team. In this instance, the first draft list of sampling criteria. Sensitive data and personal identifiers, other than staff roles, have since been removed from these notes, and any other documents included as appendices in this thesis. Staff roles have been retained to verify and reflect the multidisciplinary and interactive nature of a Patient Journey project. This is consistent with the terms of ethical approval and agreement with the VPJP team. All meetings notes and documents related to this AR VPJ study have been verified as accurate by the VPJP team.

Data Source	Method of Data Collection	Method of Analysis	Research Objective Met
SE Trust stakeholders	Participant observation, 1-1 and group meetings; snowballing, field notes, reflective and reflexive journaling	Descriptive, thematic content, or conversation analysis	Mainly 1
SE Trust Stakeholders Vascular Patient Journey project (VPJP) team (25 members)	Biographical and demographic data Participant observation, snowballing, field notes, meetings notes, emails	Descriptive and thematic content analysis	1,3,4,5,6
SERVICE PROVIDERS (VPJP team)	MAPPING	Collaborative or individual inductive conversation, content and thematic analysis	Mainly 1 and 3 but also 4 and 5
SERVICE PROVIDERS (VPJP team)	MATRIX SAMPLING Identification of sample using demographic, biographical and medical data	Collaborative inductive thematic analysis Medical Data Index coding	Mainly 2
SERVICE USERS (patients diagnosed with peripheral vascular disease (PVD) and care partners)	SEMI-STRUCTURED INTERVIEWS	Inductive thematic content analysis of field notes and 11 interview transcripts	Mainly 2, 3 and 5
MAPPING & SERVICE USER INTERVIEW REPORTS*	Content analysis of data reports for Issues and Solutions action planning for change document*	Content analysis	1, 2, 3, 4 and 5
ISSUES AND SOLUTIONS DOCUMENT*	Content analysis to identify issues for action		1, 2, 3, 4 and 5
* The data contained in these reports is the equivalent of findings in traditional research methods. However, although reported in the findings section in this AR VPJ study these provided the catalysts and impetus for change, thus were integral to the research process.			
SERVICE USER & SERVICE PROVIDER PARTICIPANTS**	Evaluation interviews and questionnaires**	Descriptive analysis	Mainly 6*
** Not part of the AR VPJ change process, but integral to the aim of this AR VPJ study so reported separately under findings			

Table 3-2: Data collection and analysis methods

Analysis of data collection method 1: VPJP team meetings

Generally, data collection in this context was concerned with gathering evidence about key stages of development, decisions made and planned actions agreed by the VPJP team and ensuring these were accurately interpreted and recorded. These were viewed as an additional data source that could be used to inform AR research objectives 1, 3 and 4. However, other than checking for accuracy, a specific method of analysis was not followed.

Data collection method 2: mapping

Preparation for mapping, in addition to sampling, also began during the first meeting in May. This method was used to gather the service provider, as in the VPJP team's perspective of the current service and any strengths or weaknesses. This would provide one of the main data sources for improvement and thus contribute towards fulfilling the aim of this study and AR objectives 1,3,4,5 and 6.

Mapping is introduced by the team at CHS in an undated guidance document, the PJ Manual/Toolkit, as

> "...the initial process, whereby the team draws out the current service to be able to see clearly and possibly for the first time, the service as it stands... There's a whole science to mapping...However, the key is to be able to communicate the major steps of the PJ to all concerned...The level/detail of the mapping is all important, e.g.: the patient goes to the GP, is admitted to CHS (name changed) and is discharged - is a Patient Journey, but doesn't deliver sufficient detail...A map that describes which member of staff to provide the post-op drink is probably so detailed as to get in the way, rather than act as a vehicle for communication" (PJ Manual/Toolkit, ca. 2007, p. 6)

Additional information about mapping patients' journeys was acquired from Fraser (2002) prior to embarking on the exercise in this study.

In this AR VPJ project, all team members were invited to contribute to the mapping exercise either through sessions set up specifically set up for this purpose, or by email. The first of the mapping sessions was held on 22nd June as recorded in notes of the third PJ meeting held on 12th July, 2007 (Appendix 19). The activity involved team members writing their stage of involvement with their vascular patient's journey, and any associated strength or weakness, on post-it notes and placing these in the appropriate location on a roll of lining paper. Post-it notes enabled stages and comments to be rearranged until consensus was reached about correct order. This activity continued until the VPJP team were satisfied that all stages of the current journey, and any related issues, from start point to completion, had been accurately recorded. Eighteen VPJ team members contributed either in person, or by email. Amongst these included a

clinical nurse specialist (CNS) from primary care, medical staff, nursing staff, diagnostic staff, pharmacy, NHS Trust management and service improvement. A consultant anaesthetist, unable to attend the sessions in person, forwarded his perspective of his involvement and issues by email (Appendix 15).

Support with the mapping sessions was provided by the SE Trust's then Service Improvement Lead (SIL). The SIL had former expertise of mapping services in the NHS and insider knowledge of the vascular service and thus could help to ensure accuracy of recording of the stages and flow of the current patient journey. As an activity that provides an opportunity for a PJ team to work together to review their service, the role of action researcher role in this instance was as participant observer and co-ordinator.

Analysis of data collection method 2: mapping

Inductive, content analysis as described by Bowling (2002), Patton (2002, 2002a), Parahoo (2006) and Ross (2012), was used by the VPJP team to identify each stage of the current VPJ, and any associated issues as these emerged from the data.
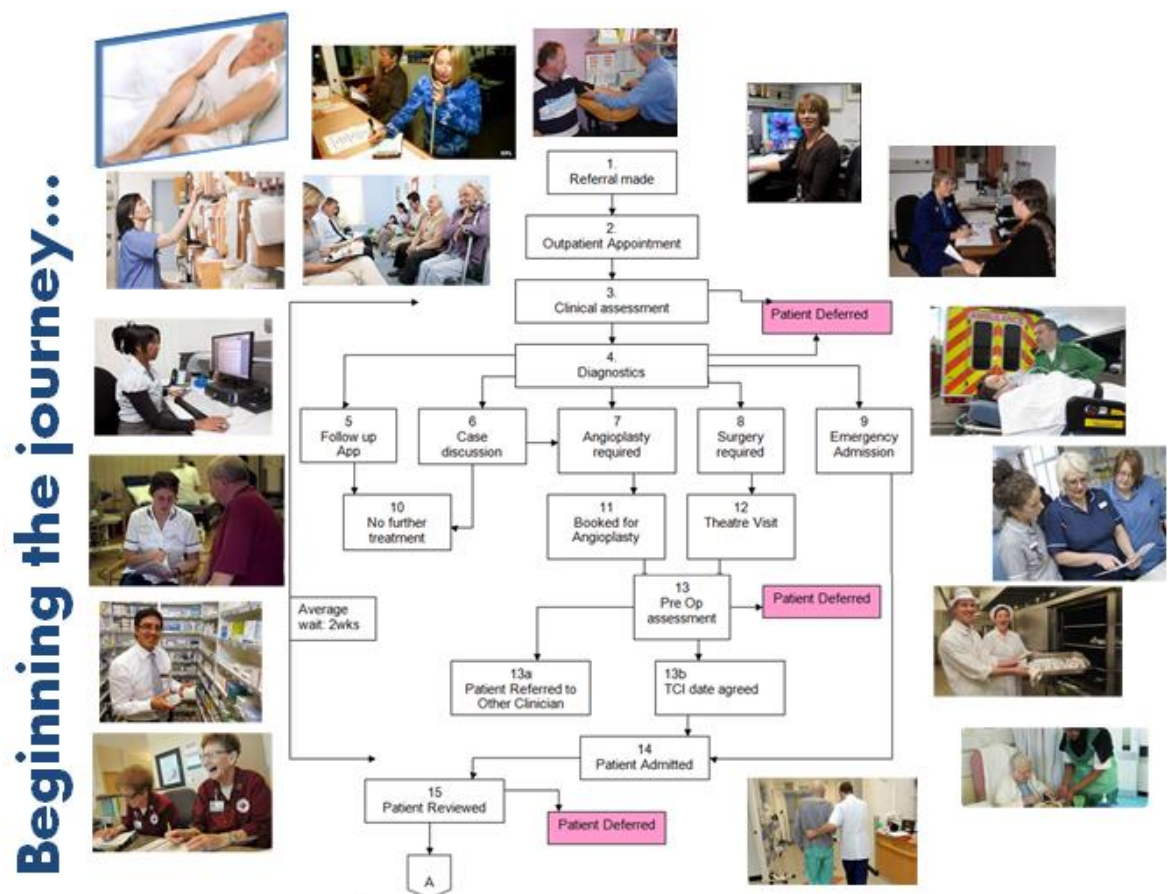
Figure 3-5: first 15 stages of the Vascular Patient Journey, flow-chart format

Once consensus had been reached that data collection and analysis were complete, the findings were presented in narrative and flow-chart format in a word document by the SIL with support from the IT Department. Figure 3-5 illustrates the VPJP team's collective perspective of the first 15 stages of the current vascular patient journey. Once consensus had been reached that data collection and analysis were complete, the findings were presented in narrative and flow-chart format in a word document by the SIL with support from the IT Department.

The full version of the process map comprises 25 stages of the vascular patient journey and 35 related issues. Two drafts of the *'Patient Pathway'* mapping report were produced dated 20th September and 3rd November before the VPJP unanimously agreed that the third draft dated 3rd December, 2007, not only accurately depicted the current patient journey but had also identified all known associated issues. An anonymised version of the full 'Patient Pathway' mapping report is included as Appendix 16.

Examples from mapping exercise

Three examples, drawn from the narrative, rather than flow-chart element of the final AR VPJ *Patient Pathway* document, are included to demonstrate the type of data and insights that can be acquired from a multi-disciplinary team. The first in Figure 3-6, from page 4 of the report in Appendix 16, reveals VPJP team members' perspective of the start of the vascular patient's journey. This is represented by step 1 which staff generally agreed began from the point of referral to the SE Trust.

2.1 Process Narrative and Issues

The key steps in the patient's journey are set out in the Process Narrative and the Process Map below. In mapping the patient's journey, staff have raised a number of issues which are detailed below.

Step #	Step Description and Issues
1	Patient referred: • By a range of clinicians including GPs, Vascular Nurses, Orthopaedic Consultants, A&E, MAU, Endocrinologists, Care of the Elderly Team, other hospitals, Community Leg Ulcer Clinics
2	Outpatient Appointment • Patient attends – Consultant team/Nurse appointment at SE Trust or community hospital (20 x 10min appointments per clinic) Vascular nurse assessment clinic • *Significant delay due to repeat appointments between Vascular Nurse, Consultant, Duplex scan* • *Patients assessed by Community CNS seen by SE Trust CNS before consultant – Community CNS to refer direct to consultant?* • *Delays when patients transfer between XX and ZZ hospitals*

Figure 3-6: Extract from AR VPJ mapping document to illustrate team perspective of start of Vascular Patient Journey and issues identified

Figure 3-6 also shows that, by working together, the VPJP team had collectively identified, and agreed, where issues with their service or patients' care currently existed. Issues are highlighted in italics. Figure 3-7, also from page 4 but this time drawn from Step 4 of the current VPJ, begins to reveal the range of issues that were identified by the VPJP team; these are also highlighted in italics. This, and Figure 3-6, also demonstrate that the involvement of a multi-disciplinary team reveals problems that are unlikely to be identified by service users, yet these may still significantly impact on patients' experiences.

2.1 Process Narrative and Issues

The key steps in the patient's journey are set out in the Process Narrative and the Process Map below. In mapping the patient's journey, staff have raised a number of issues which are detailed below.

Step #	Step Description and Issues
4	Diagnostics • Investigations. Notes and results sent to requesting clinician • Imaging capacity for 1-2 Duplex scans per OP clinic • *Imaging demand for 3-8 Duplex scans per OP clinic* • *2 week wait for Urgent Duplex, 6 week wait for Elective Duplex* • *No access to full range of diagnostics in peripheral clinics*

Figure 3-7: Extract from VPJ mapping document providing further examples of issues identified by multidisciplinary staff

Figure 3-8 below is an extract from step 15 on page 6 of the report, which is roughly midway through the current vascular patient journey. This illustrates that, at almost every step, the team identified a specific problem, or problems, that were unlikely to be identified by service users.

2.1 Process Narrative and Issues

The key steps in the patient's journey are set out in the Process Narrative and the Process Map below. In mapping the patient's journey, staff have raised a number of issues which are detailed below.

Step #	Step Description and Issues
15	Patient Reviewed • Surgeon consents/marks the patient • Discussion with family • Anaesthetic review evening before surgery • *Sometimes difficult to find the patients (ward of admission)* • *Order of Theatre list confirmed from 4pm day before surgery* • *Wards not aware of the order of Theatre lists*

Figure 3-8: Issues identified by the multidisciplinary team at step 15, midway through the current vascular patient journey

The issues highlighted in Figures 3-6, 3-7 and 3-8, together with others identified in the mapping document (Appendix 16) together with those revealed by service users during interviews, were amalgamated into an '*Issues and Solutions'* document . This is the AR VPJ action planning for change document which will be discussed in context later.

Unforeseen benefit of mapping

An unexpected but significant benefit of the mapping exercise, which was introduced during the first meeting, was its positive effect on teambuilding at an early stage in the change process. The activity provided a somewhat rare opportunity for the team to meet, network and build or enhance relationships with each other, and discover what each person already contributed to their service. This immediately provided new insights and understandings of each other's role. It also enabled the team to collectively identify their perspectives of positive and negative aspects of their current PJ, and where duplication might exist as Figures 3-6, 3-7 and 3-8 illustrate. As the issues began to be revealed they also, on occasion, began to open up new channels of communication. For example, an issue raised in Figure 3-6 had not previously come to light. This required discussion between the clinical nurse specialist (CNS) in primary care who first identified this as an issue, and a vascular nurse specialist working in the SE Trust. Email correspondence to verify this is included as Appendix 17.

Data collection method 3: sampling

Sampling, like the mapping exercise, is another integral method of the AR Patient Journey process as highlighted in Figure 3-3. This activity also commenced during the first VPJP team meeting on 8th May as recorded in the notes (Appendix 14).

As with the mapping exercise, this AR VPJ study also found that sampling, as an evolving fact-finding exercise, was subject to ongoing, inductive analysis and peer review. This activity was undertaken during VPJP team meetings, rather than separate sessions, and required several meetings to complete. Sampling, like mapping, although aligned with specific stages of the AR VPJ study (Figures 3-3) is discussed here in its context as a data collection method.

Clarifying the sampling method

Campbell et al (2004, p.21) ask *"What makes the City Hospitals Sunderland NHS Trust patient journey process different?"* They explain that

> "Although the overall process for project development is similar to many others, there are two specific ways in which the patient journey approach differs from traditional forms of re-design. The first lies in the way in which the patients are

interviewed and their views incorporated in the project; the second is the way in which these patients are sampled" (Campbell et al, 2004, p. 21)

According to Campbell et al (2004, p. 22) their method is "*based on a stakeholder perspective* (Ovretveit, 1998, 2003, Ovreteit et al, 2002) *and uses matrix sampling*" (Reed et al, 1996); a method which they also align to purposive sampling. This, they explain, means that

> "...the guys whose practice will be changed – lead the choosing of the patients – feel in control of it – and therefore are signed into their contribution to the process – and have greater faith in the sample being right" (PJ Manual/Toolkit, ca. 2007, p. 8).

Guidance also recommends that a PJ project team consider the following

> "What kind of patients do you think should be interviewed?
> Which patients would you be disappointed if they weren't interviewed?" (PJ Manual/Toolkit, ca. 2007, p. 7)

However, in this study's Vascular PJ, although the ADNS (PJ Chair), had recently undertaken a Master's programme in research; and a consultant anaesthetist was concurrently researching pre-operative assessment clinics (POAC), no-one had prior experience of matrix sampling. This indicates the importance for an external PJ project facilitator, and thus action researcher, to build a good understanding of the method prior to its use. The following is included to illustrate how knowledge of sampling was developed prior to and during the application of the method in the Vascular Patient Journey.

Sampling in qualitative research

Charmaz (2006) asserts that, as it is the aims and purpose of a study which provides the driver for project design, so it is that they must also provide a key influence on sample selection and size. However, as Coyne (1997, p. 623) points out *"sampling is a very complex issue in qualitative research as there are many variations...and much confusion and overlapping of types."* This confusion, Morse (1991) suggested, has arisen as a consequence of a lack of clear guidelines on the principles of sample selection within the paradigm of qualitative research. Moreover, as Coyne (1997) highlights, this confusion may inhibit a researcher's ability to clearly explain how a sample has been selected. This may, in turn, adversely affect wider perspectives of the nature and quality of the research. Lack of detail, as the review of empirical studies into PCC emphasised, makes it difficult for others to interpret research findings; gain useful understanding, or replicate a study. Concerns also expressed by Kitson et al (1982) and Knafl and Howard (1984). Thus every endeavour would be undertaken to provide sufficient detail in this VPJ study.

Defining the sample

Parahoo (2006, p. 256) defines a sample as a *"subset",* or "*a proportion"* of a population; and a *"population as the total number of units from which data can potentially be collected".* Theoretically, according to Parahoo (2006), all the units of a population (also termed the theoretical population) could participate in a study. In this context, this would have meant all patients with a diagnosis of peripheral vascular disease (PVD) would need to be interviewed, which, for a number of reasons, would have been unrealistic. Instead, as Parahoo (2006) suggested, the VPJP team was to be encouraged to identify units they considered most relevant for recruiting a sample of patients most representative of their current patient journey.

Initially it seemed this might be a relatively straightforward exercise. The VPJP team quickly and unanimously agreed with the proposal put forward by the lead Vascular Consultant (LVC) and Vascular Nurse Practitioner (VNP). This was that sampling units include patients with a diagnosis of PVD (individuals) who had undergone surgery for a femoral-popliteal by-pass graft (individuals and event) within the last three months (event) at the SE Trust (organisation). These became core sampling units to which additional inclusion criteria would be applied before being presented in a final matrix. It was recognised that these, as individual sampling units, were unlikely to be homogenous. For example, patients diagnosed with PVD, as with any other diagnosis, differ in characteristics and variables such as age, gender, mobility, co-morbidities, route of admission to hospital. Thus these characteristics would also need to be considered when determining the selection criteria to be included in the VPJ sampling matrix.

The praxis of Patient Journey sampling; an evolving, multidisciplinary activity

As mentioned, prior to the first VPJP meeting the *"kind of patients"* to be interviewed had already been discussed with the LVC and the VNP and subsequently agreed by the team at the first VPJP team meeting on 8th May, 2007. During the meeting, additional sampling units, or criteria, also began to emerge from team discussions as recorded in the notes (Appendix 14).

However, as subsequent discussions will illustrate, the praxis of sampling presented a greater challenge than initially anticipated. Suggestions from VPJ team members not present at the meeting were also invited by email. Their contributions and those from the first meeting were amalgamated into a matrix using Microsoft Excel software (Table 3-3); software that is also readily accessible in NHS organisations.

Patients With Peripheral Vascular Disease	Elective Admission		Emergency Admission	
Inclusion Criteria	Male	Female	Male	Female
>40 years				
Employed				
Not employed				
Retired				
Smoker				
Previous Smoker				
Non-Smoker				
Own Home no support				
Own Home - family support				
Own Home with State Carer				
Residential Home				
Nursing Home				
Independent Funding				
State Funding				
Diabetes				
Ischaemic Heart Disease				
Mental illness				
Stroke				
Venous disease				
No tissue loss				
Tissue loss - ulcer				
Tissue loss - gangrene				
Previous angioplasty				
Pre-op amputee				
Independent Pre-op				
Dependent Pre-op				
Independent Post-op				
Dependent Post-op				
Full mobility Post-op				
Mobilising with aide Post-op				
Not mobile Post-op				
Surgical outcome - graft/repair				
Surgical outcome - amputation				

Table 3-3: first draft of action research Vascular Patient Journey sampling matrix

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Due to concern about the overly large size of this matrix (Table 3-3), guidance and a possible solution was sought from CHS by email in May 2007, as recorded in the following extract from the PhD journal.

> After drawing up the draft I forwarded a copy to CHS for comments and advice. XX was going on leave for a couple of weeks but gave his valued support as usual...He confirmed the matrix was along the right lines but seemed rather medically biased. He recommended the inclusion of some additional holistic/social factors (Extract from PhD Journal, year 2)

The following is a copy of the email dated 16th May, with personal identifiers removed in accordance with LREC approval.

16.5.07
Sue, sorry forgot to do this.

Every group's matrix has to be theirs and so it is difficult to make comment without understanding the dynamics of the group.

That having been said, I let XX see it as well – so our combined comments are:

Looks very complicated – do all of these cells really exist? Are you expecting that some patients will fulfil many cells?
Looks very medically dominated – surely there are some contrasting social or holistic factors that are important to the way in which patients go through their journey.

I fly off on annual leave til 5th June today. XX is about. And XX can fix you a phone call with me if we need to talk.

All the best, very exciting, XX

It was unclear how the inclusion of holistic and, or social factors, as had been suggested, would reduce the size of the current matrix. Nevertheless, three example PJ matrices that were also forwarded brought useful insights. Each of these, from an Acute Coronary Syndrome (ACS) Patient Journey, Stroke PJ and Parkinson's disease PJ, was much smaller than the first draft of the AR VPJ matrix and contained a range of differing sampling units. Although these examples did not clarify how the current draft matrix might be reduced, they confirmed there was no rigid framework or formula to adhere to. These verified that each matrix had been uniquely designed to meet the specific requirements of each PJ team.

The guidance from CHS was acknowledged and fed back to the VPJ project team via email after the first meeting in May when the first draft of the AR VPJ matrix was also circulated. VPJP team views and comments were requested in response to the guidance. A separate update was also forwarded to the Vascular Nurse Practitioner (VNP) and her ideas sought (Appendix 18).

An ever-expanding matrix

Patients With Peripheral Vascular Disease Post Surgery	Elective Admission				Emergency Admission		
Inclusion Criteria	Male	Female	Total		Male	Female	Total
>40 years							
Employed							
Not employed							
Retired							
Smoker							
Previous Smoker							
Non-Smoker							
Alcohol abuse							
IV Drug Abuse							
Diabetes							
Rheumatological Disorder							
Renal Disease							
Ischaemic Heart Disease							
Mental illness							
Stroke							
Venous disease							
Hypertension							
Hypercholesterolaemia							
No tissue loss							
Tissue loss - ulcer							
Tissue loss - gangrene							
Pre-op amputee							
Lives alone							
Own Home - family support							
Own Home with state carer							
Residential Home							
Nursing Home							
Homeless							
Change of residence on discharge							
Independent with ADLs pre-op							
Dependent pre-op							
Full mobility pre-op							
Mobilising with stick pre-op							
Mobilising with frame pre-op							
Mobile with wheelchair pre-op							
Not mobile pre-op							
Independent with ADLs post-op							
Dependent post-op							
Full mobility post-op							
Mobilising with stick post-op							
Mobilising with frame post-op							
Mobile with wheelchair post-op							
Not mobile post-op							
Outcome - angioplasty + graft/repair							
Outcome - graft/repair							
Outcome - 1st amputation							
Outcome - further amputation							
In-patient rehab							
Community hospital rehab							
Domiciliary rehab							

Table 3-4: second draft of action research Vascular Patient Journey sampling matrix

Unfortunately, VPJP team responses rather than reduce the size of the matrix as had been hoped, resulted in a second matrix containing more than 50 variables (Table 3-4). This was unworkable because if the matrix remained in that format 200 patients would need to be recruited. This is because each cell in a PJ sampling matrix represents at least one participant. Thus, if there were 50 criteria for male and female elective admissions; plus 50 criteria for male and female emergency admissions, this equals 200 participants. This was clearly an unrealistic target for this study. Nevertheless, everyone's contribution had been recorded and openly acknowledged in keeping with the PCC approach of Patient Journey projects and stance adopted as PJ facilitator.

Data analysis method 3: sampling

Unable to identify an immediate solution to effectively reduce the size whilst still retaining core sampling units, guidance was sought from the research supervisor. By gaining a fresh perspective and experienced researcher's opinion of the problem, a solution was found. At his suggestion, the VPJP team were simply asked to prioritise their criteria into two categories, essential and desirable (of interest). This was achieved at the second meeting of the VPJP team held on 7th June when the second and unworkable matrix (Table 3-4) was reviewed, and essential criteria, identified, confirmed and agreed with the VPJP team (Table 3-5).

Representativeness of sample

The matrix in Table 3-5 contains the criteria for recruiting the patient participant sample in this AR VPJ study. This sample would, according to the VPJP team, provide a representative view of their current vascular patient journey.

Patients with peripheral vascular disease (PVD)	Elective admission male/female ≥ 40 years	Emergency admission male/female ≥ 40 years	TOTAL
MDI diagnosis code I70.9* (ALL)			
Diabetes (Type I or II)			
Hypertension			
Cardio-vascular disease			
Discharged home			
Discharged other			

Table 3-5: action research Vascular Patient Journey sampling matrix

The sampling units (Table 3-5) were identified as male and female patients, over the age of 40 years, with a diagnosis of peripheral vascular disease (PVD) who had undergone surgery for a femoral-popliteal bypass graft within the preceding 3 months, between March and June, 2007, at the SE NHS Trust. The units, displayed as column headers, and the first row, represent 'essential' criteria, as categorised by the VPJP team. The remaining rows contain a prioritised selection of 'of interest' criteria as also identified by the VPJ project team. These were included because patients diagnosed with PVD commonly have co-morbidities that also require treatment and management. As such, the team believed this data might be useful at a later stage.

The matrix in Table 3-5 illustrates that *all* participants in the AR VPJ sample would initially be identified through diagnosis code I70.9. This indicates they had a diagnosis of peripheral vascular disease and had undergone surgery for a femoral-popliteal bypass graft. These are codes and categories listed in the SE Trust's General Surgery, Diagnostic/Operative Medical Data Index (MDI) used by the SE NHS Trust for recording patient data for auditing and funding purposes. The use of codes for selection followed the guidance of an information analyst from the SE Trust. After introducing and explaining the sampling matrix, the analyst suggested this would be the most effective, reliable, and least easily influenced method for identifying participants who would meet the matrix criteria. This would mitigate the risk of any undue influence from the VPJP team at this stage, a number of whom were familiar with the majority of patients who journeyed through their services.

To fulfil each of the additional sampling cells, patients were further identified according to relevant other medical, biographical or demographic data. For example, once a potential participant had been identified through code I70.9 a further search was undertaken to establish to co-morbidity and place of discharge. A sampling cell was complete when a patient was found to have the correct MDI diagnosis code, and they were female or male, aged 40 years or over, either a planned or emergency admission, and met at least one of age of the other categories. For example they also had 'hypertension'. The matrix in Table 3-5 indicates that a minimum of 10 patients, with varied criteria, would need to be identified if all sampling cells were to be completed.

Appropriateness of proposed sample size
Sample sizes in previous PJ projects had ranged between 8-24 service users (patients and carers). It was understood from CHS reports and the PJ manual, that sample sizes in previous studies were determined by the prevalence of the specified diagnosis amongst target populations, and availability of suitable participants. For example, in the

Parkinson's disease PJ just 28 patients were found who met the selection criteria, and only a combined total of 13 patients *and* carers had been interviewed. In this AR VPJ study, as explained, the matrix indicated that the sample size should be around 10 patient participants. This was consistent with former PJ projects at CHS.

Applying the matrix: selecting the sample

The process of selection began after the second VPJP team meeting in June, when the essential criteria was identified and agreed. The search for suitable participants was undertaken by the information analyst from the SE Trust. Initial searches undertaken using through MDI diagnostic code ICD10 (peripheral vascular disease) combined with a sub-category code of I70.9 (femoral-popliteal bypass graft) as agreed with the VPJP team. The analyst, who worked part-time, took just under two weeks to collect the data. Disappointingly only 14 patients were identified by using this combination of codes (ICD10 and I70.9).

The results were discussed at the third VPJP team meeting on 12th July (Appendix 19), when it was confirmed that 14 results was lower than had been anticipated. Further discussions by the VPJP team highlighted that this result may have been inadvertently skewed. There was a possibility, for example, that some patients may not have been revealed because their operation and diagnosis had been categorised differently. The VPJP team were aware of inconsistencies between clinical teams in how these MDI codes were being interpreted and applied. In light of this, after the July VPJP team meeting, the information analyst conducted another search of the MDI Coding Book (2006). The identification of a further 8 sub-codes confirmed this notion. These were found under MDI diagnostic (ICD10) and Operative Procedures (OPCS4) codes "Grafts for Occlusive Disease" and "Extra-anatomic by-pass"; L583, L592, L593, L595, L601, L603, L653, T555. These additional codes were used by the analyst in the second search which was completed by mid-July, 2007.

This revised and final search revealed 37 initial results. These were listed in a password protected Microsoft Excel document which was only forwarded to me. Out of the 37 results, 4 were double entries reducing the list to 33 and one patient was under 40 years of age thus did not meet the selection criteria. Further analysis of the list reduced the numbers for selection to 28 patients, 10 females and 18 males, as, after obtaining verification from the VPJP team, Operative Procedures codes for 5 patients, which were different to those identified, were not compatible with the matrix selection criteria.

At no time during this process did any member of the VPJP team have sight of the data spreadsheet containing patients' identifying details. This was to respect and protect the confidentiality of patients. By so doing this also ensured that the process of selection adhered to the conditions of ethical approval, research governance and mitigated any risk of undue bias.

Data collection method 4: interviews

Recruitment of service user participants

Having identified eligible participants, recruitment began on 26th July, 2007. At this stage the list of patients was further reduced to 25 for the following reasons:

- Female patient recently deceased (aged 97 years)
- Male patient – inpatient as at 27.07.07
- Male patient – did not meet coding criteria

In this AR study's Vascular PJ the Vascular Nurse Practitioner (VNP), as a central figure of the team and one who was known by most patients, made the initial contact with prospective participants by telephone (in accordance with CHS guidance). If interest in participating was expressed, with the patient's permission, the call was handed over to me (a variance from the CHS approach). Thus I was introduced to each potential participant by one of their service providers, which, in turn, had also enabled each participant to hear my voice and speak with me prior to a follow-up telephone call to arrange their interview. Moreover, this approach allowed an immediate response to any queries or requests for further information thus mitigating the risk of any undue anxiety and saving time. It also provided each person with reassurance that I was a bona fide researcher and interviewer working in affiliation with the SE Trust's vascular team.

This reassurance was considered imperative given that potential participants were expected to meet with me in their own homes. Nevertheless, it was recognised this approach introduced a potential for bias that up to this point had been avoided. The VNP gained knowledge about which patients might be interviewed. This issue was addressed by not disclosing who had been interviewed and by removing codes assigned to participants from the final report of patient interviews.

It had not been possible to contact 3 female patients from the shortlist of eligible participants on 26th July, and despite further attempts by the VNP at a later date, no contact would eventually be made. A 79 year old female patient was put on a reserve list at this stage because of the travelling distance involved. Of the male patients, 3 were no reply on telephoning, 1 had an incorrect number listed, 1 was Chinese and spoke no English but was also added to the reserve list; and a further three patients in their 70's

were held in reserve (as by this stage 3 out of 7 already recruited were in their 70's). 1 male patient had no contact number listed. An impromptu telephone interview was conducted with one patient as he was to undergo surgery within the week at another hospital but wanted to comment on the care he had received from the VPJ team. The notes from that interview are included as Appendix 20. During recruitment an attempt had been made to ensure that at least one patient from each age group after 40 years, had been recruited, and that the male to female ratio was balanced as fairly as possible. By the end of the day, a total of 14 possible patient participants, 6 females and 8 males had been recruited.

Setting up interviews

Details about the study were subsequently forwarded to the 14 patients who had expressed an interest. This information included the Participant Information Sheet (Appendix 9), and an Expression of Interest letter (Appendix 21). Out of the initial 14 selected, when telephoned to confirm their continued interest and to arrange an interview with them, approximately 10 days later, two male patients felt unable to participate due to deterioration in their health. One female patient had, unfortunately, since passed away. This left 11 patients, between the ages of 45 and 80 years (6 males aged 46, 59, 64, 67, 69 and 72 years, and 5 females 45, 63, 66, 72 and 80 years of age) who consented to be interviewed (Table 3-6).

Patients with peripheral vascular disease (PVD)	Elective admission male/female ≥ 40 years	Emergency admission male/female ≥ 40 years	TOTAL
MDI diagnosis codes ICD10, I70.9 &, or OPCS4 (ALL)	5	6	11
Diabetes (Type I or II)	4	3	7
Hypertension	4	3	7
Cardio-vascular disease	2	1	3
Discharged home	4	5	9
Discharged other	1	1	2

Table 3-6: completed action research Vascular Patient Journey sampling matrix.

Although initially disappointed by this result, 11 patients and 6 care partners, or 17 service users, was accepted as a realistic sample size for the following reasons:

1. The smallest sample size amongst CHS Patient Journeys was 8.
2. There had only been a maximum of 25 eligible patients in the original target group to recruit from.

Table 3-6 also shows the numbers of patients who met 'of interest' data. This was collected for 10 of the 11 patients; no co-morbidity (diabetes, hypertension or cardiovascular disease) was revealed for the remaining patient, either during their interview, or in the data spreadsheet. In the two remaining rows of the matrix (Table 3-6) relating to discharge destination, *'other'* represents transfer to a community hospital for rehabilitation. Eight out of the 11 participants revealed during their interviews that they had previously been smokers, 2 stated they were non-smokers; 4 male patients reported having leg ulcers which had been treated by district or practice nurses from their GP surgery; none of the sample had received care from a Primary Care Team (PCT) leg ulcer clinic. All recruited patients were initially identified using MDI codes ICD10, I70.9 and OPCS4; each had a diagnosis of peripheral vascular disease and all had undergone a femoral-popliteal by-pass graft at the SE Trust between March and June, 2007.

Integrating action research with the PJ method

The team at CHS recommended that:

> "the interviews are about the patients/carers having the opportunity to comment on the service they received – the good and the bad. Most of the interviews conducted so far have been highly spontaneous, with the participants taking full opportunity to talk to the researcher...Opening questions are important, and some of the following are good ways of opening the interview, bearing in mind that they will already have had the information leaflet about the project:
>
> - We are interested in improving the care of patients with X, can you tell me about your experiences?
> - How did you get on when you were diagnosed with X?
> - What did you like and dislike about the care you received for X.
> - Most patients want to tell their story in some chronological order, but want to bring attention to specific strengths and weaknesses of the service. Therefore all of the above openings are good ways of allowing the patients/carers to give their impressions of the services, without any structure to constrain them." (PJ Manual/Toolkit, ca. 2007, p.10)

When evaluating the transferability of the modified CHS PJ approach, particularly as a framework for conducting AR in healthcare, the above appears to provide clear guidance that explains the essence of the PJ method of interviewing. Yet, this is perhaps too simplistic. This is because the guidance fails to acknowledge the significance of the skills and approach of an interviewer towards the collection of rich, frank and deep data as will be explained (Jones, 1985, Guest et al, 2006).

Preparation for AR VPJ qualitative interviews

For instance, as Bowling (2002), Guest et al (2006) and Mason (2010) recognise, in qualitative research it is the richness and depth of data gathered during interviews which is most significant, rather than numbers of interviews conducted or whether a point of saturation has been reached. This is significant because in prior Patient Journey

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projects samples had traditionally been small, varying from 8-24 service user participants. In this AR VPJ study the sample size would be similar as the sampling matrix had indicated that a minimum of 10 patients would be interviewed, and an unspecified number of care partners (spouse, partner, son or daughter). Thus, it was considered essential that my skills as AR VPJ interviewer were are sufficiently developed to ensure the richness and depth of each person's experience was authentically narrated, captured and reported (Mason, 2010). As Mason (2010) points out 13 interviews conducted by a skilled interviewer are likely to yield richer data than 28 interviews by an inexperienced and, or inept interviewer (Mason, 2010). A view also shared by Patton (2002, 2002a), Miles and Huberman (1994a, 1994b), Sandelowski (1993, 1995, 2004) and Bowling (2002) amongst others.

By way of preparation for interviews in this AR VPJ study, in addition to a brief review of associated literature, a two day qualitative interviewing training course at Oxford was attended in June 2007. This course was run by researchers involved with the Database of Individual Patient Experience (DIPEx, 2007). These researchers had expertise of interviewing patients to find out about their experiences. (This organisation has since been renamed to Healthtalkonline and youthhealthtalk.) Attendance at this course helped to affirm that the interviewing skills and experience gathered from nursing practice and past employment should enable the objective for interviewing in this AR VPJ study, objective 3, listed at the end of Chapter 2, to be fulfilled.

Interview questions

Just three simple questions were used to frame the interview in this AR Vascular PJ study.

1. Tell us about your care.
2. What do we do well?
3. How could we make it better?

These three questions, which were approved by the VPJP team, were considered sufficiently structured to enable rich and detailed data to be gathered from service users about their perspectives and experiences of the current vascular patient journey. In addition, they should provide sufficient focus for data analysis at a later stage, as DiCicco-Bloom and Crabtree (2006) suggested. The loose structure provided by these questions, which is characteristic of a qualitative, semi-structured interview, was also deemed sufficient to focus the interview whilst also allowing the interviewer to become *"attuned to each participant"* as intended and as Knox and Burkard (2009, p. 567) advise. This was important in a study influenced by the underpinning philosophies and principles of AR and PCC. As Ross (2012) suggests, the semi-structured approach to

interviewing is the most democratic as this enables both parties to have some element of control over the content. This also reflects the principles and philosophy of AR and PCC. The rich, deep narratives from these interviews would provide the data source for research objective 2, and contribute towards objectives 3, 4 and 5 listed at the end of Chapter 2.

Stance as action researcher an Vascular Patient Journey interviewer

As AR VPJ interviewer, but also nurse, and as already indicated, I was already interested *"in understanding the experience of other people and the meaning they make of that experience".* This, explains my stance which Seidman (1991, p.3), Arksey and Knight (1999) and Bowling (2002) suggest is aligned with the purpose of a qualitative interview. Figure 3-4 provides a more detailed, yet summarised, overview which also demonstrates AR researcher' and AR VPJ interviewer' affiliation with the principles and philosophy of patient-(person)-centred care.

The purpose of the interviews in this AR VPJ, as explained, was to gather patients' and their care partners' frank perceptions and honest opinions about the current patient journey according to their first-hand experiences of that journey. This was their opportunity, as service users, to share their stories for the purpose of improving the experiences of other patients. This included highlighting those aspects that had made a positive difference to them. These stories would reflect the service as seen through the eyes of these participants (Gerteis et al, 1993), and described in their words, thus their personal accounts must remain authentic and free from researcher bias (Arksey and Knight, 1999, Bastian, 1995, Jack, 2008, Ross, 2012). As a nurse, I recognise the importance of making people feel at ease, building a rapport, finding common ground and ensuring they feel safe and able to talk openly and freely (Gerteis et al, 1993, Stewart et al, 1995, Gaskell, 2000). However, I am also deeply aware that these elements of PCC are fundamental to building trust and respect in healthcare relationships. Thus, the experiences these people recounted to me were treated with utmost respect to protect that trust, whilst also adhering to the terms of informed consent and ethical approval.

During interviews, although remaining "*neutral and objective"* as Jack (2008, p. 58), Hoddinott and Pill (1997) and Hiller and Diluzio (2004), amongst others, advise, this does not imply that a critical distance was maintained or that I remained aloof (Ross, 2012). Whilst I remained vigilant of my potential to inadvertently coerce participants, or influence or 'steer' associated discussions (DiCicco-Bloom and Crabtree, 2006), I remained mindful that authentic accounts of participant's experiences and perceptions

were sought. In keeping with the philosophies of PCC, interpretism and constructivism the aim was to enable storytelling to reflect the reality of healthcare experiences from the speakers' point of view, and according to that person's construction of the reality of their own healthcare journey (Ross, 2012). The role of interviewer was, therefore, facilitative not directional.

It is believed that my own insights and understandings as a nurse, and patient, enabled a connection to be made between interviewer and interviewee that fostered trust and openness. My knowledge, experiences and insights when shared demonstrated that I was a bona fide qualified nurse, and researcher as claimed. Participants accepted I was a 'true' outsider to the team, and the SE Trust that provided their treatment and care (Bartunek and Louis, 1996). My stance as genuine 'outsider', but one who also possessed 'insider' knowledge as a nurse and patient, may also have enabled each participant to talk frankly and openly about all aspects of their healthcare experience safe in the knowledge that their comments would not offend me. As a consequence participants' story-telling, and our conversations, usually remained focused, constructive and impartial. Even so, there were times when information was shared that challenged my vow to keep my role and duty as nurse separate to that of researcher (Sword, 1999, Jack, 2008). An example will be explained in context later.

AR VPJ interviews with service users

The AR Vascular PJ interviews took place between August and November, 2007. Nine patients and six relatives participated in home interviews which lasted between 40 minutes and 1 hour 17 minutes. Two telephone interviews were conducted at participants' requests because of the impracticalities of a home visit and because these patients wanted the opportunity to have their views heard.

A Participant Information Sheet (Appendix 9) and reply slip (Appendix 22) had been sent to patient participants following initial telephone contact and in advance of their interview. A letter to each participant's general practitioner had also been sent to notify them of their patient's forthcoming involvement in the study (Appendix 23). This was by of courtesy but also in the event that retelling a healthcare experience caused undue distress for which further medical advice or support was required. Each person was also telephoned by me, on the day prior to their interview to confirm that I was still expected and they were still happy to participate. Written, informed consent was obtained on the day of the interview (Appendices 24 and 25), when each participant was also reminded of their right to withdraw from the study at any time. A PJ interview schedule (Appendix

26), which had been prepared when applying for LREC approval and contained additional interview prompts, was also taken to each interview but was not required.

Each participating patient's (service user's) home was approximately a two hour car journey away from my base. On one occasion three interviews were undertaken on one day; otherwise usual practice was for one in the morning and one in the afternoon, to allow sufficient time for travelling and an unhurried interview. The average time allowed for each interview was two hours. Six of the eleven patients also had their spouse, partner or relative present; thus insights into a total of 17 service user' experiences were gathered. Other than telephone interviews, each home interview was recorded using a digital recorder, as also advised by Britten (1995), Bauer and Gaskell (2000) and Stockdale (2003). This was unobtrusive, silent, had extensive recording time and caused no distraction as it captured, first-hand, the entire story as it unfolded (Hiller and Diluzio, 2004, Fernandez and Griffiths, 2007). Brief notes were also taken during the interview, but only to capture salient points when possible to do so without disrupting the flow of the interview. Field notes were written up after the interview on the same day.

All service user participants were very welcoming and openly shared their healthcare experiences with me. Although one male participant became tearful as he recounted his journey, this had not given rise to undue concern. This was because the patient and his wife told me they had become accustomed to these occasional, yet still necessary, emotional releases. These, they both assured me, were short-lived and could be contextualised. Nevertheless, these emotions were reflective of the psychological impact of his care experience and would subsequently be highlighted as an issue. This will be demonstrated in Chapter 4. The couple also told me that having the opportunity to speak to someone about their experiences, in the hope that it might help other patients, had been therapeutic and much valued by them both. The therapeutic effect of qualitative interviews is also recognised by Shami (2003) who used this method to investigate patients' experiences of treatment, and Overcash (2004) who used narrative research to find out about cancer patients' experiences.

All interview recordings, field notes and transcripts were assigned a code, from P01-P011 which represented the order in which the interview had been undertaken. Each recording was transcribed by me. This was a lengthy, iterative process that involved repeatedly listening to each speaker and becoming immersed in their story-telling to ensure their narrative was recorded verbatim. Transcripts were subsequently also checked and re-checked for accuracy against the recording. All participants were offered the opportunity to review transcripts of their interviews, but this was declined.

Copies of all recorded interviews were stored in a media file on a password protected laptop. An additional copy of each recording was also kept on a compact disc and stored in a locked cabinet. These were available for independent verification of interview transcripts in the event any concern had been expressed by the VPJP team about the validity, authenticity or accuracy of the reported findings.

The notes from two telephone interviews were, however, forwarded to those participants for member-checking and approval. This was because these notes could not be checked for accuracy against a recording. These were duly returned, after being approved by interviewees, in the postage-paid enveloped provided.

Analysis of data collection method 4: interviews

Inductive, thematic content analysis
Field notes from each interview were written up after the interview, sometimes immediately by hand, otherwise typed a few hours later in a word document. (An example, the field notes of interview P02 is included as Appendix 28.) Writing field notes, as those such as Patton (2002a), Parahoo (2006) and Ross (2012) advise, enabled me to capture an overall sense and context of the interview, and quickly record any key issues, or compliments, that had come to light during the interview.

Points or issues that seemed most noteworthy were initially highlighted, usually by using different colours. The same initial practice was repeated with interview transcripts as Figure 3-9 illustrates (Appendix 27). Thought was also given at this stage as to which aspect of the current patient journey these comments and issues related. The first section highlighted in blue in Figure 3-9 could, for example, indicate an emerging theme that would contain issues or compliments relating to environment, or healthcare delivery, as could the following sections highlighted in pink. Or, those pink sections could indicate an emerging theme containing issues and compliments about health professional practice, or healthcare delivery. The comments in green, just below, a theme about transport, and those highlighted in grey at the bottom of Figure 3-9, by comparison, could be suggestive of an emerging common issue, or theme, about entertainment. Thus, the first stage of inductive analysis had begun whilst *"...trying to make some kind of (abstract) sense ...of the raw reality one is encountering"* (Lofland, 1971, p. 121).

Figure 3-9: extract from P05 interview transcript in which four potential emerging themes are identified

By overlapping the phases of data collection and analysis, at an early stage, it had been possible to gain a sense of the issues of greatest importance to these patients and start grouping these into themes as they emerged. This initial stage is also referred to as 'open coding' , or *"opening up the data"* Parahoo (2006, p.393) during which commonly found, or most significant emergent issues may begin to be categorised according to terms, words, and phrases found in, or implied by the data (Bowling, 2002, Patton, 2002a). These embryonic themes were later compared, tested and checked for appropriateness and relevance with each subsequent interview in accordance with guidance from those such as Jones (1985), Easterby-Smith et al (1991), Strauss and Corbin (1990), Miles and Huberman (1994a, 1994b) and Marshall and Rossman (1995). The field notes and findings of the first stage of analysis also aided accuracy of verbal reporting back on preliminary finds from interviews to the VPJP team.

The complex, diverse and varied nature of vascular patients journeys: a challenge of analysis

Identifying the most encompassing themes from the data proved challenging due to the complex, diverse and individual nature of interviewees' experiences. Figure 3-10, also drawn from the P05 interview transcript, illustrates the breadth of information that can be acquired from just one interview.

Figure 3-10: extract from P05 interview transcript to illustrate range of information revealed by one interview

In Figure 3-10 'I' represents interviewer (myself) and 'P' the patient. This example also illustrates that if extracts are not presented in context, they have the potential to impart an incorrect message. When taken in isolation, the account captured in Figure 3-10 is strongly indicative of a serious failing. However, when contextualised with subsequent comments made by the same patient, as illustrated in Figure 3-11, this clarifies that although this was a significant issue, it had since been addressed by the vascular team and resolved to the satisfaction of the patient and his wife.

Figure 3-11: extract from P05 interview transcript "no complaints"

As the story-telling progressed, the patient and his wife (W) revealed more detail about the *"disagreement"* and *"bed sores"* which verified the statement *"no complaints"* in Figure 3-11. This is evidenced by the comments in Figure 3-12:

I "Did that cause you quite a lot of anxiety the next time you went in, having had that?

P "Um, no because I had the special mat (laughs). They have never told me anything that wasn't true."

W "As he said to you, people were saying to him why didn't you sue, and I said to them what were they supposed to do – lift his leg up while they've got him open and say "Oh, look he's gettin' a bed sore, let's stop? You can't do it." (laughs).

I "It's a nice way to look at it. I mean with the best will in the world they would never have intended, ever, for that to happen."

P "He, what he did on that occasion, he repaired the aneurism in the aorta and he also did a bi-femoral. Right. You're a nurse (lifts up his shirt to show me his operation scar) – the only thing he didn't do – he didn't give me a smiley face, he gave me a miserable one!" (all laugh)

I "Did you tell him about that? He'd enjoy that as well, wouldn't he?" (All laugh)

P "Actually, I think you did (looking at wife)" (laughter).

Figure 3-12: extract to illustrate depth of insight and explanatory detail provided by in-depth, semi-structured, qualitative interviews

The patient's comments in Figure 3-12 also suggest that my background as a nurse, which had been disclosed, appeared to be appreciated. In any event, the extracts in Figures 3-9, 3-10, 3-11 and 3-12 provide examples of the nature, richness and diversity of data collected during the interviews.

An example of ethical and moral challenges faced when analysing interview data
However, the extracts in Figures 3-9, 3-10, 3-11 and 3-12 also highlight a challenge that was often faced when interviewing this group of patients about their healthcare experiences. Firstly, the narration in Figures 3-10 and 3-11 could have related to a current issue of serious concern, which, if not already being addressed would have been my duty, not only as a nurse but also ethically and morally as a researcher, to have reported with the patient's permission. This concerned human experience, and highlighted an aspect of healthcare practice that had made a significant and long-term impact on that person's experience. Had it not been resolved, the patient would also have been advised to report this.

But, this incident occurred during a previous admission. From a research perspective, this was not within the timeframe for inclusion in this AR study's Vascular PJ investigation, thus it should otherwise be discounted. Consequently, the finding was

informally fed back to the team, but not included in the *'Report of Patient Interviews'* (Appendix 29). This action had also been agreed with the patient and his wife. However, issues were subsequently raised about different aspects of pressure area care as a result of the stories narrated by other participants. For patients diagnosed with PVD, their circulation and healing is already compromised and this places them at high risk of developing pressure ulcers.

The process of analysis

Returning to the process of analysis, after highlighting key points during the first stage, descriptive annotations were added, sometimes immediately, sometimes after re-reading the text several times. These comments were generally added to the margin of each field note and transcript and provided indicators of possible emerging themes or categories. An example of this activity is illustrated in Figure 3-13. This represents the second stage of inductive, thematic content analysis as it was applied in this study in accordance with the suggestions of those such as Bowling (2002), Denzin and Lincoln (2005) and Green and Thorogood (2004) amongst others. When doing this, consideration was given to which aspect of patient care or the patient's journey each highlighted section might provide an example of, and how the data indicated this might be categorised. The focus of analysis remained consistent with the focus of the interview and this study which was to find out what was currently working well or not so well with the current vascular service, and how this might be improved. The example in Figure 3-13 is taken from field notes written after interview P02 which took place on 9th August, 2007 (Appendix 28).

Figure 3-13: early stages of inductive, thematic analysis of field notes from interview P02

The process illustrated in Figure 3-13 was applied to all field notes and interview transcripts. When determining the nature of these emergent themes and what they might represent, it was recognised that the terms used to categorise these must be readily relatable to the vascular patient's journey, everyday practice and the goal of improvement. This had been made explicit by the aim of this study, the focus of the interview, and findings of the literature review (Klein et al, 1961, Gillespie et al, 2004, Goodrich, 2009). These had also emphasised that all issues and compliments that emerged from the data must be articulated and encapsulated using terms and language common to all study participants (Goodrich, 2009). Significantly, the purpose of the data here was to enable understanding of what aspects of healthcare currently worked well, and where improvement was needed as 'seen through the eyes' of patient and care partner participants (Gerteis et al, 1993). This would be achieved by using verbatim quotes.

Familiarity with the data

Familiarity and an overall sense of the data was gained by becoming immersed in the whole interview dataset, that is 9 interview scripts, 2 summarised accounts of telephone interviews, and field notes, by repeating the processes already described with each record. Once this had been achieved, and once satisfied that all key issues and compliments had been highlighted, emergent themes and associated verbatim extracts were further compared and contrasted (Bowling, 2002, Quinn Patton, 2002). During this stage a number of possible main themes or categories emerged which seemed more representative and inclusive of the findings from all eleven interviews. Even so, the complex and varied nature, often very personal, but sometimes commonly experienced aspects of vascular patients' journeys presented a significant challenge when trying to establish from the data what these key themes actually were. Another challenge was rooted in an understanding that, due to the subjective nature of human experience, and varying interpretations, perceptions and priorities for healthcare, my interpretation of the themes was likely to be different to any other researcher, of member of the VPJP team, if they examined the same dataset. This had been strongly emphasised by the findings of the literature review (Klein et al, 1961, Gillespie et al, 2004, Goodrich, 2009).

External, unbiased assistance with coding and analysis

Consequently, assistance with coding and theming, and feedback on the process, was obtained from two colleagues from the university. All data had been anonymised prior to seeking their opinion to protect confidentiality in accordance with LREC approval. The aim of external advice was also to minimise the risk of personal bias, and facilitate comprehensive and thorough analysis. The VPJP team were deliberately not invited to participate during this stage principally to protect participant identity and respect

confidentiality, but also to mitigate the risk of any undue influence on data analysis or reporting. VPJP team opinion and approval was, however, sought for final themes proposed for the report of interviews. The point of this was to ensure these themes were representative of those that the VPJP team had envisioned in relation to their vascular patient journey and their quest for improvement.

Assigning numerical codes

After gaining feedback, numerical codes were also assigned to each main theme to reflect, as closely as possible, each stage of the vascular journey and the main issues or compliments associated with that stage. For example, code 1 was allocated to a theme representative of GP to consultant referral time. This had been identified by several patients as the start of their journey. It was also a period in their journey when issues were experienced and thus improvement was required. Codes 3, 5 and 7, identified in the first comments box in Figure 3-14 below, by comparison, related to possible main themes concerning communication, relationships with healthcare professionals and healthcare delivery, respectively. Because these most commonly related to the admission phase of the vascular patient journey this was reflected in the numerical ordering. The assigning of codes to data themes, albeit not necessarily numerically, is also advocated by Bowling (2002), Quinn (2000a) and Gill et al (2008).

Figure 3-14: extract from interview transcript P05 to illustrate data analysis process. Theming and coding of data

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Refining analysis

However, as mentioned, and as Figure 3-14 illustrates, many of the highlighted sections in interview transcripts did not have a clearly defined boundary which made precise theming challenging. As a consequence, during the next and final stage of analysis when the data extracts were copied and pasted into a separate word document, when uncertain about the most appropriate theme, the same extract might be copied several times into a number of differently themed sections. This document formed the first draft of an interview report for the AR VPJP team.

Although this process initially led to duplication of extracts across the differently themed sections, this also helped to refine each category, or aspect of the vascular patient journey. As these extracts began to be pulled together this gave a more complete and comprehensive sense of the relevance or appropriateness of the corresponding theme. The key driver behind this stage, as with every stage, was a commitment to ensuring that the verbatim accounts from the stories of patients and their care partners were accurately and authentically represented in the final report of patient interviews. These extracts represented issues identified by service users according to their first-hand experiences and shared for the purpose of improving the experiences of others.

Codes and themes; providing a structure for reporting

As explained, the purpose of codes in this study had principally been to enable the narrative and sequence of participating patients' journeys to be retained, and any corresponding issues and compliments highlighted in context. A similar approach had been used for reporting the analysis of the mapping data, albeit in a different format (process and narrative maps). Sixteen main themes finally emerged from the interview data as illustrated in Figure 3-15.

The ordering of these themes loosely reflects the chronological order of the vascular patient journey. It also represents the order in which the issues and compliments were reported in the final *'Report of Patient Interviews'* provided for the VPJP team (Appendix 29). Structuring the report of interview findings in this way not only retained the context of the vascular patient journey. It also made the next stage of the AR VPJ process more manageable. As will be explained, this involved amalgamating the issues identified through mapping and interviews in a single document. This would be used by the VPJP team to identify solutions, where possible, that would lead to improvement.

	Theme
1.	Time from initial GP appointment to Vascular Consultant appointment
2.	Telephone contact with SE NHS Trust Hospital
3.	Communication and information
4.	Short notice/emergency admission
5.	Relationships with healthcare professionals
6.	Nurse workloads
7.	Healthcare delivery
8.	Privacy and dignity
9.	Cleanliness/infection control
10.	Hospital catering
11.	Patient-line
12.	Visiting
13.	Car parking
14.	Discharge
15.	Transport
16.	Outpatient appointments/follow up care

Figure 3-15: sequential coding and main themes emergent from service user interview data analysis

Because each of the themes in Figure 3-15 relates to experience, the size of each section in the corresponding '*Report of Patient Interviews'* does not necessarily reflect the significance or poignancy of the data. (An anonymised version is included as Appendix 29.) For instance, theme 4, *Short notice/emergency admission*, which only appears on page 12, contains a narrative which, when verbally reported to the VPJP team, led to an immediate change in the vascular team's short-notice admissions policy (Figure 3-16).

"…the technician who did it said the vein was underperforming, a restriction - that something would have to be done and he contacted the consultant by phone…He told me if I had any pain over the weekend to seek medical help. When we arrived home…fair old drive …someone had already phoned but there wasn't a number we could ring back and eventually, about 5pm or something, another lady phoned to say that provision had been made for me to be in hospital first thing in the morning (a Friday). Couldn't make it for two or three reasons…made to feel guilty…message coming through about how urgent this had to be done… Basically we was told that this could cost me my leg…spent weekend feeling extremely worried…"

Figure 3-16: service user catalyst for change

This was that all future calls of a similar nature would only made by a clinical member of the vascular team who was qualified to answer patient's medical concerns.

The most commonly occurring and often interrelated themes were

1. Time from initial GP appointment to Vascular Consultant appointment
3. Communication and information
5. Relationships with healthcare professionals; and
7. Healthcare delivery

With hindsight, and more time, themes 3, *communication and information;* 5, *relationships with healthcare professionals;* 6, *nurse workloads*, and 7, *healthcare delivery*, would have benefitted from being analysed yet further in light of the now apparent lack of clear distinction between these themes. This can be evidenced from the interview report (Appendix 29). It is also acknowledged that had the focus of this study been differently aligned, then other themes which would enable powerful and poignant insights into a greater number of additional issues associated with the experience of living with PVD could have been made more explicit. For example, what it means to live with a low-profile, debilitating and painful long-term condition; or to experience a life threatening event; and the impact of these on quality of life, the sense of self, psychological well-being, relational, and other aspects of life, including employment. By so doing, the rich, poignant data could be more widely drawn on by the VPJP team for educational purposes or policy shaping, for example, as discussions in Chapter 6 will explain. It is acknowledged, however, that the focus of this AR VPJ study was to facilitate change and improvement within a local vascular service through the identification of issues. It had also been to ensure that the positive aspects of vascular patients' experiences were identified and reported.

A balanced perspective

Integral to the aim and objectives of this AR study, and the CHS PJ approach (Campbell et al, 2004), was an intention to address a current trend for negative reporting in healthcare. This continued focus on errors and issues, as the literature review explained, can lower staff motivation and moral and adversely impact on patient care (Aiken et al 2001, 2012, Kennedy, 2001, Reeves et al, 2005). By comparison, the approach taken in this AR VPJ study enabled the positive aspects of the current vascular patient journey to also be reported, as described by service users. The extracts in Figure 3-17, which illustrate this point, are taken from page 13 of the Patient Interview Report (Appendix 29). These also highlight the significance of the relationships and interactions service users experience with healthcare staff. This was

identified during the literature review as the most significant aspect of PCC and patient's experiences (Gerteis et al, 1993, Stewart et al, 1995). As Webb (2007, p.66) also recognised, *"staff have the capacity to make or break a patient's stay"*.

ii. (Patient) *"...the nurses were absolutely fantastic...I didn't want for anything...they were absolutely run off their feet...you could see that they were struggling...there was just so much ...I used to have a good laugh with the nurses...the nurses, and the doctors, do a fantastic job...some of them could be grumpy but when you saw what they got to put up with...you'd be surprised that people want to do the job (nursing)...but to me they're worth their weight in gold."*

iii. (Patient) *"...even though ...hospital is nearer to me I would rather go back to XXX for my care because they know me. I know... is across the road from me...but XXX was very good and I never wanted for anything..."*

iv. (Patient) *"...I had a social worker there...anything you needed she got it for you, she was very good..."'*

v. (Patient) *"...a very quiet voice in my ear said 'how are you going ...I woke up and there's our lad, Mr..., the surgeon, kneeling down, he said 'How's it going?' I said oh fine, he said 'How's the leg?' I said marvellous, you know, I said it's great, no pain in my leg, you know I couldn't get away from it I said, and the foot's lovely...so he said 'How do you feel about going home this afternoon?'...and I said do you want me to start singing Hallelujah? 'Alright I'll have a word with sister and you can go out this afternoon' he said."*

vi. (Patient) *"...I thought I was treated respectfully by all staff... I didn't know how to address staff nurses, I didn't feel it was right for me to say hello whoever...I would sooner say 'staff' or something like that...(spouse) '...it's the generation you were brought up in".* Patient was referring to respect for hierarchy and ranking and believed that using first names for certain 'ranks' of staff might be disrespectful.

vii. (Patient) *"The way Mr ... treated us was really first class"* (spouse) *"On the day of the operation I was told to ring at 3pm and ...wasn't back. I rang at 5pm and couldn't get anyone...I got through at 5.30 pm and I was told that ... had been taken back in which obviously I was very worried about...was told somebody from surgical team would ring me and actually Mr ... himself phoned me about 7pm...and I thought that was really very, very nice...when we go to the clinic he's always very good to me as well, I don't feel like I'm in the way or anything, he's always inclusive, isn't he?"* (Patient) *"Oh yes...he's a super man."*

Figure 3-17: anonymised verbatim extracts from service user data to illustrate positive aspects of vascular patient journeys - patients and care partners' relationships with staff

Although these extracts (Figure 3-17), and others, would not be included in the AR VPJ action planning document, because these were not issues to be addressed, their inclusion in the Report of Patient Interviews for the VPJP team was essential. This was required to fulfil the aim and objectives of this study which also sought to address gaps, or issues identified during the literature review. During the mapping exercise, when service provider data was being gathered, the VPJP team, consistent with usual practice in healthcare, had only focused on identifying issues when mapping the stages and flow of the current vascular patient journey. Yet, findings from the literature review had indicated that negative reporting was one of a number of contributory factors that can lower morale and motivation and impede improvement in healthcare (Attree, 2007,

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Webb, 2007, Jackson et al, 2010a, 2010b). Consequently, this was an issue this AR VPJ study had addressed by also reporting the positive effects of team members' contributions to the current vascular patient journey in the interview report. VPJP team perspectives on this more balanced approach to report are included in Chapter 5, which reports of the evaluation of this AR VPJ study.

Data collection method 5: analysis of mapping and interview datasets

The next stage, stage 6 of this AR VPJ study, identification of issues and solutions (Figure 3-3), was informed by the findings from the analysis of service provider (mapping) and service user (interview) data. These datasets once amalgamated into a single *'Issues and Solutions'* would provide evidence-based catalysts for change and improvement to the current vascular patient journey. Due to the significance of this document and stages 6 and 7 of the AR VPJ towards the change and improvement processes in this AR VPJ study, these are discussed separately in the next chapter, Chapter 4.

Data collection method 6: evaluation interviews and questionnaires

As indicated in Table 3-2 the summary of data collection and analysis methods, the evaluation of service user and service provider perceptions and experience of their involvement in this AR VPJ study, was not part of the AR VPJ change process. Consequently, the methods used during evaluation, and the findings are discussed separately in Chapter 5.

Chapter overview

This chapter has introduced and discussed the philosophical underpinnings of this action research Vascular Patient Journey study. It has illustrated how the philosophies and principles underpinning the qualitative research paradigm, action research and PCC have been adhered to and applied in the methods used. The introductions to these philosophies, in addition to evidence gathered during the literature review, have also explained the thinking behind the study design and the processes of, and approach taken to AR VPJ project implementation and team-working, and during data collection and analysis. Additional supporting evidence, both in the text and as separate appendices, has offered deeper insights into process and practices associated with AR, the significance of engaging collaboratively with a multidisciplinary project team, whilst also providing a verifiable audit trail of the first five stages of this AR VPJ study. By doing so, this has also addressed a common deficit found amongst PCC studies reviewed. As explained in the literature review, these commonly lacked supporting or explanatory detail which, in turn, prevented meaningful understanding and interpretation

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of methods or results. It was recognised that if the generic potential of the CHS PJ process (Campbell et al, 2004) was also being investigated, in line with the aim of this AR VPJ study, then sufficient detail and explanation should be offered to enable replication.

In light of this, an insight into some of the challenges faced has also been offered to illustrate the reality of implementing an action research project as an outsider Patient Journey project facilitator to a healthcare organisation. These were perhaps greatest in the early stages of this AR VPJ when transitioning through the preparatory and setting-up phases prior to VPJ project launch. During these times, prior knowledge and experience of the ways of working in the NHS, and of the change process, prepared me, as the action researcher, for a number of the challenges that were encountered and thus strengthened my resolve to address and overcome them.

The activities undertaken during the first five stages of the AR VPJ process discussed in this chapter paved the way for Stages 6 and 7. As will be explained in Chapter 4, during stage 6 the VPJP team were engaged in '*the identification of issues and solutions'* in preparation for Stage 7 '*action planning and implementing change'*. These two stages were informed by the findings of data collected from service users (vascular patients and their care partners) and service providers (the multidisciplinary VPJP team). The discussions in the following chapter, Chapter 4, will also show how research findings from data gathered from service users and service providers can be used to drive localised change and improvement in healthcare.

Introduction

This chapter discusses Stage 6, *'identification of issues and solutions'* and Stage 7, *'action planning and implementation of change'* of the action research (AR) and Vascular Patient Journey (VPJ) process as it was applied in this study (see Figure 3-3 in Chapter 3). In light of the significance of service user and service provider data to the AR VPJ change and improvement processes, this chapter is dedicated to illustrating how the findings from both datasets provided catalysts for change to improve the current vascular patient journey. This will also address objective 5, as listed with this AR VPJ study's aim and objectives at the end of Chapter 2. This specified a requirement to

> "5. Explore and explain how data from service users and service providers does or does not lead to patient-(person)-centred change and improvement".

Whilst it is acknowledged that every point and every issue highlighted by service users and service providers warrants inclusion in this chapter, this is not practical given the constraints of word counts. In addition, because this chapter is focused on illustrating how issues identified by these groups became catalysts for change, the findings that are included tend to focus on the negative aspects of vascular patients' journeys (VPJ); as is the nature of change. Thus to enable acknowledgement of what was already working well with the current VPJ, the three core data documents associated with this study, albeit with personal identifiers removed, are included as Appendices 16, 29 and 30. These, and in particular the '*Report of Patient Interviews'* in Appendix 29, enable a more balanced perspective to be constructed of the current VPJ as described by those with first-hand experience. The verbatim narrative extracts contained within the Report (Appendix 29) also provide rich, poignant and detailed insights not only into the vascular patient journey but also the experience of living with peripheral vascular disease (PVD).

Action research stages 6 and 7: identification of issues and solutions and planning and implementing change

Although the identification of issues and solutions, and planning and implementing change are separated into two stages, 6 and 7, in Figure 3-3 in Chapter 3 which provides an overview of the AR PJ process, in this AR VPJ project there was no clear boundary between these stages. This is because, in some instances, solutions to issues were identified, and change quickly implemented, in response to feedback provided to the VPJP team on emergent findings. Consequently, these two stages have been combined in this chapter, rather than separated, to reflect this. Preparation for these stages of change began with data collection method 6 as follows.

Data collection method 6: analysis of mapping and interview datasets

Content analysis (Ross, 2012) was used to identify and extract issues from the *Report of Patient Interviews* (Appendix 29) and the *Vascular Patient Journey mapping report* (Appendix 16). These were then integrated into a single *'Issues and Solutions'* (IAS) action planning for change document. This was a variance to the guidance offered in the PJ Manual/Toolkit (ca. 2007, p. 11) which recommended that;

1. "The local facilitator needs to produce a complete list of the issues that the clinical team require to be part of the redesign.
2. The PJF will have already produced a list of the issues that patients and carers require within the new PJ.
3. The Clinical Champion needs to identify the requirements from the vision, as well as more objective issues from the available evidence.

All of the above are pulled together into a composite list, usually by the PJF. The general experience is that there is a lot of cross over between these three lists, and that the themes identified from the interviews with patients/carers can help to organise the list. This assists in ensuring that the patients/carers' views are set as the priority for redesign..." (PJ Manual/Toolkit, ca. 2007, p. 12).

As illustrated in Chapter 3 in Figures 3-6, 3-7 and 3-8, in this AR VPJ study, Steps 2 and 3 as recommended by CHS in the above quote, had already been addressed. In this AR VPJ study this had been achieved through collaborative and multidisciplinary VPJP team effort during mapping exercises. Consequently, in this study, neither the local facilitator (the vascular nurse practitioner), nor the clinical champion (lead vascular consultant surgeon), were required individually to spend time constructing the lists recommended by CHS. After analysis, the findings from three mapping sessions were recorded in the '*Vascular Patient Journey patient pathway*' mapping document (Appendix 16). In addition to providing an overview of the steps of the current VPJ, any associated issue identified by the VPJP team is also highlighted in italics in this document.

Issues and Solutions planning for change document

The *"composite list"*, an '*Issues and Solutions*' (IAS) document (Appendix 30), was, however, compiled by me as action researcher and VPJ facilitator as CHS guidance suggested. This was also to maintain project momentum in recognition of other constraints on VPJP team members' time. It was also reasonable as interview findings had already been reported to the team, verbally at VPJP meetings as they emerged, and following analysis, in the *Report of Patient Interviews* (Appendix 29). Thus, as with all reports and documents, the IAS document was subject to peer review, verification of accuracy, and approval by the VPJP team. The construction of the IAS document

entailed copying issues highlighted by service providers in the mapping report and pasting these into an appropriately sequenced section in table format (Figure 4-1).

VASCULAR PATIENT JOURNEY Issues and Solutions		
Issues	**Primary Evidence**	**Solution**
1. Some patients report lengthy delays between initial visits to GP to consultant referral at XXX Hospital.	Patient interviews	
2. Some patients appear to 'fall through the net' when being referred from YY to XXX Hospital (SE NHS Trust).	Patient interviews Mapping	

Figure 4-1: exemplar from first Issues and Solutions action planning document dated November 2007 to illustrate data presentation

Consistent with the first two reports (Appendices 16 and 29); the sequencing of the amalgamated issues in the IAS document (Appendix 30) was structured by the vascular patient journey. This process was not, however, quite so straightforward when amalgamating findings from the interview data. Firstly, because the verbatim extracts in this report also included compliments rather than being solely focused on issues, and, secondly, because of the complexity of many of these issues, some of which would require different solutions to resolve; whilst others might be unresolvable. Even so, this data had already been analysed, themed and presented in sections that equated to steps of the vascular patient journey. This aided transfer to an appropriate section in the IAS document. In the first version of this document, which was produced in November 2007, the *'solution'* column was left blank in readiness for the identification of solutions and action planning by the VPJP team (Figure 4-1).

The completed Issues and Solutions (IAS) document contained 75 issues as identified from the analysis of the reports in Appendices 16 and 29 and during VPJP meetings. These issues were reviewed by the VPJP team, accepted as accurate, and the process of identifying solutions (Stage 6), planning action for and implementing change to improve the current vascular patient journey (Stage 7) began.

Acknowledging different perspectives and priorities
One of the reasons for including a '*primary evidence*' column in the *'Issues and Solutions'* document (Figure 4-1, Appendix 30) was to allow the different data sources to be recorded and openly acknowledged. By so doing, this also enabled the types and

numbers of issues highlighted by patients and their care partners (service users), and the multidisciplinary VPJP team (service providers), to be clearly identified. This had been indicated to be necessary from the review of literature where lack of sufficient explanatory detail, including about data sources, often prevented clear understanding about how to improve the current state (Douglas and Douglas, 2005, West et al, 2004). The review had also made emphatic that differences in perceptions, experiences, interpretations and priorities for patient care existed between service users and service providers, and between different hierarchical groups associated with PCC (Webb, 2007, Gillespie et al, 2004)

As a consequence, this now provides one form of evidence that can begin to explain why service users *and* service providers should be involved in service review as this AR VPJ proposed. As Table 4-1, for example, illustrates, of the 75 issues identified, 34 of these were sourced from service user (patient and care partner) interview data, 35 from service provider (multidisciplinary staff) mapping data, with just 6 issues common to both groups. The details of these issues are available in the IAS document in Appendix 30.

Steps 1-25 of Vascular patients' journey Issues identified – GP referral to post-discharge				
Steps of journey	Patient/ relatives	Staff	Patients & staff	Total
1-13 GP referral	4	9	1	14
14-22 Admission	24	14	3	41
23-25 Post-discharge	6	12	2	20
TOTAL	34	35	6	75

Table 4-1: numbers of issues raised by service users and service providers during different stages of the vascular patient journey

Table 4-1 clearly indicates that both service users and service providers are able to readily identify issues in healthcare. However, their different perspectives, as supporting documents and ensuing discussions will also illustrate, led to the identification, usually, of different issues. In this study the issues raised by the VPJP team often provided explanations for issues raised by patients, or were issues that patients would not have identified due to a lack of insight into the practical reality of frontline healthcare practice. This finding is consistent with those reported by Webb (2007) from a qualitative study that investigated the perspectives of service users and providers. The difference in this

AR VPJ study is that this amalgamated data was subsequently used to inform change and improvement to the vascular patient journey, as will be explained

Involving service providers – enabling instant change

By the time the first version of the IAS document was presented to the VPJP team on 29th November, 2007, steps had already been taken to resolve a number of issues. These had previously been revealed during the mapping sessions and patient interviews. This quick action demonstrates a further advantage of involving a multidisciplinary team in improvement and of keeping the VPJP team informed as data emerged. The following, an extract from the PhD journal, explains:
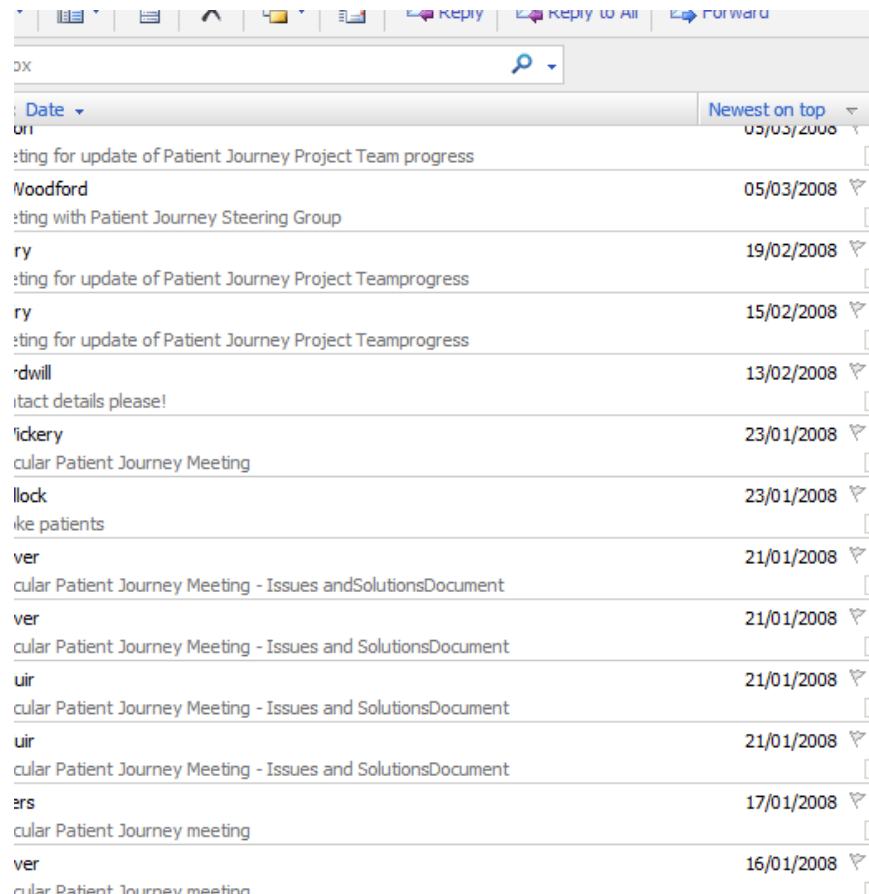
> "At the Vascular Patient Journey Project Team meeting on 1st November I learned of the changes already being put in place as a consequence of findings from the mapping exercise and patient interviews, and work the team had already undertaken. The most notable of these were as follows:
> - Nurse Practitioner (NP) advised that POAC (Pre-operative assessment clinic) times had been re-arranged to 3 sessions per week to coincide with clinic appointments. This would allow patients requiring surgery to have their pre-op assessment on the same day (to avoid repeat hospital visits for patients and potentially reduce waiting times)
> - Psychologist has now agreed to make time available - primarily for amputee referrals...
> - Only medical staff would contact patients in future when short notice admissions were advised. Waiting List Co-ordinator and admin staff notified.
> - Consultant cardiologist has agreed to give 2 sessions per month for cardiology reviews for vascular patients in an attempt to reduce waiting times...
> - Changes have been made to the admission/pre-op care of diabetic patients – reducing the need for day before admissions...
> - Vascular Specialist Nurse and Service Improvement Manager (x 2) and ... have been working on 18 week targets.
> - The Nurse Practitioner met with Occupational Therapists and Physiotherapists to discuss where improvements might be made in service provision – on-going....
>
> The next meeting of the team will be held at the end of November, earlier than expected but everyone felt that they wanted to keep the momentum going and a couple of people would be absent at the beginning of December." (Extract from PhD Journal, 2007-2008, p.3)

Between 29th November, 2007 (the date of the meeting that equated to the sixth and last stage of the integrated PJ process) and 23rd February, 2008, five versions of the original Issues and Solutions document had been produced to take account of issues as they were resolved, reported, or 'parked' for action at a later date. An anonymised copy of version 5 is included as Appendix 30. Versions in this context were initially related to an updating of the document, which occurred roughly every three weeks. Version 5 also reflects actions taken up to 23rd February, 2008. By that stage, as the following copy of an edited email trail in Figure 4-2 indicates, VPJP team members had become

accustomed to communicating any changes as they occurred and forwarding these for recording in the main IAS document.

Figure 4-2: edited copy of email trail to demonstrate collaborative teamwork and regular interaction and updating with regard to VPJP project progress

To ensure that the information was current, accurate, and that outstanding issues also received attention, each revised version of the document was also distributed to and reviewed by the VPJP team. An additional benefit of this action was that all members of the VPJP team were provided with a tangible, up-to-date record of progress already made. This in turn, as they would later report during the AR VPJ evaluation, had continued to fuel their motivation.

Promoting sustainability

From January 2008, meetings were held specifically for the purpose of working through the IAS document to enable solutions to issues to be identified, action collaboratively agreed and the way forward planned. These meetings continued after the sixth stage advocated by Campbell et al (2004) who suggested that PJ projects take six months to complete. This was because, in this VPJP project although six months was sufficient time to build the team, gather and analyse data, report on the findings and begin to implement change, this was insufficient time to promote and ensure the sustainability of

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the project. This VPJ team would no longer have a PJ project facilitator, or support from a lead group who *"govern the development and evaluation of the project"* (Campbell et al, 2004, p.17) after my withdrawal from the SE Trust, unlike those at CHS. Moreover, by this stage although 40 of the 75 issues had been discussed, and possible solutions found, many of those 40 still needed to be actioned upon. Furthermore, the remaining 35 issues awaited discussion. In light of other demands on each team member's time, as had been clearly evident throughout the project up to that point, it was recognised that there was a high probability that withdrawal from the project at that stage, would impede the continued progress of the change and improvement process.

Consequently, on 20th March 2008, in preparation for withdrawal from the AR VPJP project and the SE NHS Trust, a meeting was held with the Patient Journey Steering Group. Attendees included the Trust's acting Chief Executive, the Director of Nursing, Service Improvement Manager, lead Vascular Consultant and Vascular Nurse Practitioner. A verbal report of the progress of the Patient Journey project was given and discussion took place as to how the work of the VPJP team might continue to be built upon, and sustained, following my departure. The following extract from the PhD journal explains

> "The meeting went well...a broad overview of the discussions revealed a positive and enthusiastic response to the Patient Journey with interest expressed in adopting the model for use elsewhere within the Trust...The meeting concluded with an agreement that issues with the highest priority for resolving, from the perspective of the vascular team, the Trust, and the patient, would be identified and details forwarded to the Director of Nursing. A new Chief Executive was expected in post with effect from 1st April..." (Extract from PhD journal, 2007-2008)

An email was subsequently circulated to the VPJP team in late March, 2008, asking for their top priorities for change out of those, as yet unresolved, issues, to be categorised as follows:

1. Issues which the vascular team could resolve, prioritising order of importance
2. Issues outside of the control of the team (organisational/strategic), prioritising order of importance
3. Issues considered of most importance to patients, prioritising order of importance.

Nine responses were initially received. The following, which is a direct quote from an email received on 16th April 2008, provides an example of how the issues in the main IAS document (Appendix 30) were prioritised by one of these nine respondents. The remarks in the email also draw attention to the complexity of patient care, and the challenge associated with identifying specific issues for improvement. They also provide

a poignant insight into the significant impact of wider organisational, resourcing and systemic issues on healthcare delivery that are beyond individual, or team control.

16/4/08

"Sue - Sorry for the delay. I didn't get to all my emails before I went on leave. I have looked through the Issues and Solutions list and come up with some priorities under the headings you requested. I have tended to group them as many of the issues are inter-related and cross boundaries.

Vascular Issues/Priorities

Communication

This includes patient communication with us (14), our communication with the patient (9, 13, 36, 65), and our communication with other teams (9, 24, 33, 42)

Information

This is mainly about information for patients, including global information about service/conditions, team, etc, as well as specific information about conditions/operations/ pathways, including their 'place' in the process (35, 36, 37, 39, 41, 42)

POAC

Unfortunately, solution has not worked (unsure why at moment) but this workload is vast and is essential to working of firm. (10)

Duplex

More sessions required (5)

'The pathway'

Sounds like a cop out, but streamlining whole pathway, ensuring it works whatever the situation and whoever is present, has got to be one of main priorities. It touches many areas of report and involves close working with Trust/Organisation.

Organisation Priorities

Sorting out computer system and access to notes This is the main problem. The new computer system has made the whole administrative process slower, inefficient and inaccurate. Consequently a system that was OK but needed work, is in meltdown, creating huge stress on secretaries. (11, 24, 2, 61, 65)

Nursing Levels/workload (75)

Orthotics (55, 56)

Access to service (1, 2)

Discharge issues (58, 59, and 60)

Availability to ITU/HDU beds/level care (34)

Day case angioplasty (19)

Portering (20, 21)

Co-ordination of investigations (4)

Patient Priorities

Cleanliness

No doubt major concern for patients (52, 53)

Information

See above

'Knowing where they are in process and having faith it works'

This is source of numerous phone calls and is worse since new system in place. Links closely to communication issues under vascular (1, 2, 4, 9, 12, 15, 65)

Nursing Levels/workload (75)

Intra and Peri-hospital Transport (68, 69, 70, 71)

Our patients are not the most mobile!

Delayed orthotics
Perennial problem (55)
Have tried to prioritise, but difficult. Could discuss more on Friday"

A final email request was sent at the end of June, 2008, for the VPJP team's IAS priorities to which one further response was received during the first week of July. This highlights, once again, one of the main challenges of this project; delays in progress caused by competing demands on team members' time.

Although only 10 responses, out of a possible 25 were received, these were considered sufficient to inform a revised and refined prioritised IAS document. From the outset of the AR VPJP project there had been an agreement with the team that a nil response would not delay progress. It had also been made clear that this would be taken as an acceptance of any current proposal or update. Between March and July, 2008, Version 5, continued to be used as the main IAS working document. In July, 14 months after the launch of the AR VPJ project, and eight months since the culmination of the six step PJ process, a *"Prioritised Issues for Action"* document was produced. Dated 22nd July 2008, this document contained 31 (out of the previous 75) issues for further action; fourteen of which were an amalgam of 2 or 3 issues from the original document.

Issue	Key Points	Action Required	Lead	Timescale
11. Patient notes not always available. (It has been reported that as at May 2008 it is not possible to view patient correspondence from other specialties using Cerner – which can be a problem when patients under shared care. Tracking of diagnostic results is also reported to be a problem)	New IT system, Cerner, recently implemented but problems still encountered, resulting in appointment delays, patient misinformation, and creating 'huge stress on secretaries', etc. Recognised as Trust wide issue.	To improve the use of the Cerner queue (notes tracking) and review the courier service. Subject to ongoing review and monitoring by the Silver Team – call centre now set up to deal with increased patient complaints (approx 20%).	Silver Team, LL, Executive Lead	
12. Delayed access to Cardiologist opinion.	2 additional review sessions per month were agreed with cardiologist but limited improvement reported by Vascular Nurse Practitioner. During POAC patients seen by Anaesthetist and VNP are assessed with greater emphasis on whether a cardiology or more holistic review by care of the elderly would be more appropriate, to ease pressure on cardiology referrals.	Ongoing review – MC reports that access to cardiologists remains an issue. MC reports that elderly care have been approached but are unable to attend POAC. Ongoing.	VNP, Anaesthetist	

Figure 4-3: example to illustrate layout and content of prioritised issues for action document

This prioritised list detailed what action was required; who the action had been assigned to, and the proposed timescale for action (Figure 4-4). The purpose was to make explicit where improvement still needed to be made, and provide a means by which the change process might be sustained. This had been viewed as essential. Not only in terms of my proposal to withdraw, but also because, by this stage, most of the original, supporting stakeholders had left their posts, or been reassigned to different roles within the SE

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NHS Trust. In April, 2008, there had been a re-shuffle of key members of the SE NHS Trust Management Team which meant that only one member of the Patient Journey Steering Group, the Head of Service Improvement, still represented Trust Management (by August, 2008, this person would also leave). The acting Chief Executive, formerly the Medical Director and a keen advocate of this AR PJ model and patient-centred service provision, had also returned to a former post in radiology.

Despite these preparations, active engagement with the VPJP team and the SE NHS Trust continued until February 2009. By that stage visits to the Trust were no longer deemed necessary, changes had been implemented, and the evaluation of participants' perceptions of their involvement in this AR VPJP project completed. Contact was mainly by email, or telephone, for the purpose of updating. Consequently, almost two years after launching the AR VPJ project the time seemed right to withdraw from the field. Ensuing discussions in this chapter and the next will explain the change, improvement and evaluation processes as they occurred in this AR VPJ study.

Service user and service provider data as catalysts for change
In this AR VPJ study, as previously explained, the change and improvement process was structured around, contextualised within and informed by data drawn from the current vascular patient journey. To reflect this, and consistent with the data reports, the following discussions follow the structure and themes of the *Report of Patient Interviews* (Appendix 29), beginning from Step 1 as identified by both groups. This allows each section to be predominantly informed by the interview data, which by way of contrast to that gathered during mapping, produced narratives that provide rich and detailed descriptions of service user experiences. Consequently, each of the following themed sections includes verbatim narrative extracts that offer poignant insights into participants' experiences as seen through their eyes and described through their words. This also reflects the philosophy and principles of PCC. Additionally, and consistent with the focus of this chapter, each of these themed sections also includes examples to illustrate how an issue was addressed, where possible, after it had been identified from the stories narrated by service users or through the collective efforts of service providers.

Theme 1: Referral time from initial GP appointment
Eleven patients living with peripheral vascular disease (PVD) recalled their journeys during this AR VPJ study. As previously explained in Chapter 3, their recorded narratives were assigned a code ranging from P01-P011, transcribed verbatim, anonymised, analysed and reported upon, and the original data files stored safely.

However, after the data was transferred to the Report of Patient Interviews the codes were removed. At this stage it became apparent that the use of codes could lead to the identification of patients by the VPJP team. This was due to the individual nature of at least one element of every patient's experience.

The following verbatim extracts, from pages 4-6 of the Report, offer an insight not only into the personal nature of the experience of living with PVD, but also the commonly shared and complex aspects and the impact of PVD. None of these narratives have been critiqued or interpreted, other than to identify an issue or compliment, thus the authenticity of the original spoken word has been retained as intended.

1. "… November of last year (2006) I caught an infection in my toe, I'd scratched my toe, don't know how… and went to see the doctor because it wasn't healing…saw GP again beginning of March 2007, because infection continued with extreme pain and possible gangrene in toe…was seen in clinic and admitted as an emergency."

2. "…saw my doctor…had terrible pain in my legs and I said my toes feel cold … (doctor) wrote a letter there and then and phoned up local hospital and that same day (6th July 2006) I was up the general hospital and saw a consultant who said 'yes you've got problems here' …the next thing was they did an MRI …August...then saw consultant at local hospital on ... October… then nothing.' …at end of April (2007) saw doctor for some more pain killers … I was having to get up about every 3 hours during the night having to take a couple of pain killers … when I saw doctor he said 'what do you want more for?' …he said 'haven't you had your operation yet?' … of course when we phoned up direct we found out …been missed off the list"

3. Patient consulted GP in February 2007 for advice after sustaining a small skin tear on top of their foot when falling in the shower. "…had had ulcers before so thought it was prudent to go round to the local surgery to get it looked at and properly dressed…and get in the system if you like…well, weeks went by and the ulcer was treated but it was getting bigger, and bigger and bigger and bigger until we got to April time when the surgery referred me, put me on a list to go and see a surgeon…I had a letter from, I don't know where…, which said I was to report to … hospital (local - added) to see a surgeon early in May…had a phone-call from … hospital (local - added), …a day or two before we were actually due to go there cancelling this appointment, and I then had an appointment with Mr …a month later which was here (SE NHS Trust -added)... He looked at my leg and done some tests...and he concluded that there was no pulse, or very little pulse in the bottom end of my leg, foot, whatever. And he made arrangements over the phone while we were there for me to go into SE NHS Hospital Trust the next day… The swiftness of the admission was amazing…the way Mr … treated us was really first class"

4. "…been going to doctor (GP since retired -added), oh, we loved him…with these legs for years…five years … with the pain, he used to tell me to walk through the pain barrier and it was getting harder and harder, I just couldn't do it anymore … and the nurse said…couldn't get any pulse in there …has he done anything about these yet?...and I says 'no'… God, she said, because he should have done … then I went to the new doctor and within a week I got a letter from the hospital and two weeks after that I went in and had the operation"

5. "…went to the GP in the February 2006 because I knew I'd got a slight problem there and I thought maybe if they put a flue brush through there I'd be alright! …I wanted to go …for a holiday so I thought I had better get it checked out… had vascular scans on my leg…came up with a partial blockage on that leg...when I went in with a DVT (August 2006), that was while I was waiting for treatment for this leg, for a bypass…waiting for an angioplasty…they couldn't do it, they wouldn't do it because they discovered that not only had I got the DVT in that leg, I had an embolism and an aneurism in the graft (other leg)…the old graft I had had in 2001…"

6. "…I found that I couldn't get comfortable in bed...I was getting quite bad stinging pains in the feet and lower legs when I was laying down...I found I could get relief from the stinging by sleeping in an easy chair with my legs more or less vertical…the result of that was that the legs started to swell…not a good way of spending the night either…sleeping in a chair…this went on for at least 2 months… I had had an ulcer on the lower leg…for about 7 months…I was getting very desperate in that time that no-one was seeing…Dr- (GP) eventually suggested I went to the hospital for an overnight stay for intravenous antibiotics" (nurse had asked GP to look at the ulcer -added) (Interviewer) "…Why did you not get to see the GP?" (Spouse) "It's something that's come into being over the last 2 years and they've lost a lot of people, and we're not terribly happy with the situation…we have a phone consultation initially, supposedly, and then if they think they need to see you obviously they say well come in tomorrow, but you cannot ring up and say I need to see the doctor…the doctor will phone you back and discuss the situation…hadn't been able to walk anywhere…even as far as the end of our road to the surgery, for nearly 18 months…because of the pain, the claudication pain or whatever they call it…getting more and more immobile…"

7. "…saw chiropodist for routine appointment at local hospital. Discoloured big toe with pain in same leg…chiropodist made telephone call to doctor at same hospital for immediate referral…transferred to SE NHS Hospital Trust same day."

These rich descriptions from first-hand experience make emphatic, from the outset, the challenging and complex nature of PVD. Perhaps most notable is the evident impact of peripheral vascular disease (PVD) as a painful and debilitating condition, on each person's and their family's life. These extracts also suggest that a number of potentially avoidable issues were further impacting on these service users' experiences. In terms of healthcare, the issues of greatest significance at this point, related to unacceptable delays in referral to treatment time and ineffective inter-professional and, or, inter-hospital communication. Although from a different perspective, and albeit more commonly contextualised as contributory factors, delays at the beginning of patients' journeys had also been identified by service providers. Figure 4-4, which is copied from page 4 of the Vascular Patient Pathway mapping report (Appendix 16), shows how these delays were identified as issues by the VPJP team.

Process Description/Narrative

Process Narrative and Issues
The key steps in the patient's journey are set out in the Process Narrative and the Process Map below. In mapping the patient's journey, staff have raised a number of issues which are detailed below.

Step #	Step Description and Issues
1	Patient referred: • By a range of clinicians including GPs, Vascular Nurses, Orthopaedic Consultants, A&E, MAU, Endocrinologists, Care of the Elderly Team, other hospitals, Community Leg Ulcer Clinics

2	Outpatient Appointment
	• Patient attends –
	      Consultant team/Nurse appointment at SE Trust or community hospital (20 x 10min appointments per clinic)
	      Vascular nurse assessment clinic
	• *Significant delay due to repeat appointments between Vascular Nurse, Consultant, Duplex scan*
	• *Patients assessed by Community CNS seen by SE Trust CNS before consultant – Community CNS to refer direct to consultant?*
	• *Delays when patients transfer between XX and ZZ hospitals*

Figure 4-4: Issues at start of vascular patient journey as identified by service providers

The bulleted points highlighted in red italics in Figure 4-4 (Appendix 16, p. 2) also emphasise that, although patients, or their care partners, revealed issues that might lead to an investigation or service review, only members of the VPJP team, the service providers, had knowledge of the issues highlighted in Figure 4-4. In this example, none of the patients attributed the delays they experienced to a lack of resources, or duplication of assessments in primary care clinics and out-patient clinics, or poor inter-hospital communication and administrative issues. These were contributory, and explanatory, factors only identified by staff.

The examples thus far illustrate that the data of service users and service providers, when reported separately can provide deeper insights and better understanding about healthcare experiences; in this instance in relation to the vascular patient's journey. Yet, these findings, when presented in standalone reports, may not create the impetus that leads to change. As mentioned, this had been identified as a significant gap when critiquing former empirical studies of PCC. These too had revealed insights and knowledge about PCC, but seemingly none had resulted in PCC change and improvement. Consequently, this was a shortfall that this AR VPJ study intended to address. Firstly, by following and applying the philosophy and principles of action research and patient-(person)-centred care to this AR VPJ study's approach to improvement. Secondly, by using the collective findings from service users and providers as points of learning and catalysts for change. Figure 4-5 shows how issues raised by both parties were amalgamated in the IAS document. This also shows how any action taken by the VPJP team was reported. In this example these actions had

occurred before the end of February 2008, and included the purchase of additional diagnostic imaging equipment and a change to assessment policy. The example in Figure 4-5 is taken from page 2 of an anonymised Version 5 of the document dated 23rd February 2008 included as Appendix 30.

Issues	Primary Evidence	Solution
3. Duplication of clinical assessment of patient by Community Clinical Nurse Specialist and nurse team at XX prior to consultant appointment.	Mapping	**Issue resolved:** Patients who have been assessed by the Clinical Nurse Specialist in the Community Leg Ulcer Clinic, and for whom assessment forms have been completed, may now be referred direct to consultant clinic. Patients who have not been assessed by the Community CS will continue to be referred to XX as at present. **VSN/CNS**
4. Several patients had a considerable distance to travel to XX and would appreciate same day appointments e.g. consultant appointment, pre-op assessment, duplex scanning.	Patient interviews	**Ongoing:** Same day, drop-in, pre-op assessment commenced 5/12/07 but has not proved successful for patients with PVD. Several patients declined opportunity due to time factor. **Ongoing:** Same day appointments for 4 key diagnostic tests under review through **No Delay/18 week** project **VCS/IPM**
5. Imaging demand for 3-8 Duplex scans per OP clinic, imaging capacity for 1-2 Duplex scans per OP clinic. 2 week wait for urgent scans, 6 weeks wait for elective scans.	Mapping	**Issue resolved** Portable head for duplex scanner ordered, **VCS/BM**. **Ongoing:** **VCS/BM** also to explore possibility of purchasing additional portable Duplex scanner **Ongoing:** **VCS/BM** to look at possibility of recruiting trainee/junior grade sonographer and/or increasing medical staff input to provide one-stop scanning for patients in clinic.

Figure 4-5: examples of issues, 3 and 5, only raised by service providers and action taken

Figure 4-5 also illustrates that the IAS document provided an audit trail of the change process as it occurred. In this instance, although issues 4 and 5 had not been completely resolved by 23rd February 2008, their inclusion in this document ensured these issues would remain under review until a satisfactory outcome had been reported. When revisiting this document during the writing up phase of this AR VPJ study, it became clear that if each solution comment had been dated this would have enabled greater clarity in terms of timescales. Even so, despite this omission, a general sense of timing was still attainable from different versions of the document. As previously explained, these usually required updating approximately every three weeks, for example 10th January, 31st January, and 23rd February 2008. Furthermore, by that stage VPJP team members had become accustomed to regularly forwarding updates via email which provided an additional and dated audit trail.

Theme 2: Telephone contact with the SE NHS Trust

The following examples from pages 6 and 7 of the interview report (Appendix 29) provide brief insights into two patients' experiences of telephoning the SE Trust and how these became catalysts for change:

1. "...When you phone that number up you get a computer answer you, ask you for the name of department, or number of the ward, but I want to speak to Mr… secretary, so I say that, and the machine doesn't understand of course, so it

says it doesn't understand...so how do you get from that position … Then I got an operator …then it's done within 5 seconds…so that machine they got answering the telephone is an absolute pain for anyone that don't know exactly who they want to talk to… not had to use it before only ever had direct numbers … go try it… I insist! That turned out, I think to be the most annoying thing out of all of everything" (p.7)

2. "…to start with it was an automated thing and that didn't seem to know, understand what I was saying, so then I got from a plastic woman or man to a human one…somebody then gave me a direct number…" (p.7)

In the Report (Appendix 29), at the end of each themed section of verbatim extracts, the VPJP were asked to consider a number of the most notable points identified from that section. For example, under this theme the VPJP team were asked.

- "How effective is the automated voice recognition system? Does it help or hinder the patient experience?
- Should appropriate contact numbers be included on all correspondence?" (Appendix 29, p.7).

By way of response and by 23rd February 2008, the VPJP team agreed to ensure all future correspondence with patients would include appropriate, and direct, contact numbers for the team (Figure 4-6).

Issues	Primary Evidence	Solution
14. Automated hospital telephone answering system had caused frustration to a few of the participants –voice recognition was reported to be the main problem. Direct contact numbers were important.	Patient interviews	**Issue resolved:** Provision of direct contact numbers. Patient correspondence now includes contact numbers. **Ongoing:** VCS reported there was possibility for contact via an on-call mobile phone if necessary in future. **Ongoing:** VCS also considering including email address on future patient correspondence. **Ongoing:** VNP look at possibility of dedicated phone line for patient access to Vascular NP

Figure 4-6: example of issue only identified by service users and action taken by VPJP team

The above comments and others in the Report (Appendix 29) highlighted contact with the SE NHS Trust, or the vascular team as an issue. They also explained the reasons why. As a result these, and other extracts in the Report, provided a rationale and the evidence to support change; in this instance the installation of a direct telephone line to the team. This was something the VNP had tried, for 7 years to achieve without success. This direct line would give patients direct access to the VNP in the event of cause for concern. Evidence of agreement to install the line is reported in the following anonymised copy of an email from the VNP in Figure 4-7. This also provides an insight into the VNP's perspective of the VPJ project.

Sent: 15 April 2008 11:59
To: Sue Baron

The rest of it I am happy with. As I said I have found the project very useful for me. It has given me access to management and has helped me get some improvement for our patients. The telephone answering machine has been given the go-ahead by [ ]r at a cost of £300 for installation. Once installed, the patients can phone up and leave messages and I can get back to them at the end of the day.

The patient point of view has been very interesting and in a lot of cases verified how I felt the service was delivered.

I would think that this project could be transferrable to other patient pathways and be useful to other clinicians.

Figure 4-7: email update verifying funding for installation of phone line and opinion of AR VPJ project

Evidence that the phone line had subsequently been installed is provided in Figure 4-8 below, in the solution comments to Issues 14 and 65. Figure 4-8 also provides an example of ongoing and individually reported updates; in this instance by using an edited version of the master document. VPJP team members often completed these if they had several updates to report. These updates were forwarded to me by email and subsequently recorded in the main IAS document. Figure 4-8, as an abbreviation version, also shows other examples of issues identified, and resolved, or actioned by the team, one of which, issue 68, had been jointly identified by patients and staff. On this occasion the issue had been identified during a VPJP team meeting rather than mapping.

Additionally, Figure 4-8 makes it possible at a glance to gain a sense of the different types of issues raised by patients and staff. The issues raised by patients, for example, are indicative of factors more likely to cause an emotive response due to their impact, in some way, on their experience. By comparison, those identified by multidisciplinary staff appear to be more service than experience orientated. The latter group were generally more focused on highlighting resource, system, organisation, technical and resource type issues as the mapping report indicates (Appendix 16). Yet, despite this, analysis of their data commonly revealed possible explanations for issues raised by patients.

Comments from XX – General Manager/Surgical Specialities		
Vascular Patient Journey		
ISSUES AND SOLUTIONS – Version 5		
Issues	Primary Evidence	Solution- **Additional comments**
5. Imaging demand for 3-8 Duplex scans per OP clinic, etc etc	Mapping	Additional costs fro scanner being identified. To be included in next Divisional Capital Plan.
9. Sequence of theatre booking and pre-op assessment – requires a lot of phoning to arrange.	Mapping	Bid for system in IT programme 08/09.
14. Automated hospital telephone answering system etc etc	Patient interviews	Additional phone installed (SO).
22. Sometimes difficult to find the patient (ward of admission)	Mapping	System under consideration for IT programme 08/09.
32. One patient recounted her discomfort at being surrounded by male patients on a mixed ward and opposite…etc etc	Patient Interviews	New mixed sex policy approved.
39. Several patients reported that they would have liked more help etc etc.	Patient Interviews	Information shared with vascular team.
52. Cleanliness – some patients had reported observing inadequate cleaning.	Patient Interviews	National Deep Clean Programme completed successfully.
55. Delayed orthotic assessment and supply.	Mapping	Current wait reduced to 4 months.
61. Secretarial support for production of MDI discharge summaries.	Mapping	'Medical Office' project will replace MDI.
65. Some patients reported delays in their out-patient follow up, or no follow up appointments.	Patient Interviews	Possible solution – MM to liaise with Communications and Electronics manager with regard etc etc.after this sentence. Phone now installed.
68. Hospital transport not turning up when booked through central booking system – etc etc	Patient interviews Project Team	Issue raised with PALS Manager
69. A number of patients recalled the long distance from the car park/entrance to the ward etc.	Patient Interviews	Issue raised with PALS Manager
70. Wheelchairs for patient use not always available.	Patient Interviews	Issue raised with PALS Manager
Additions/alterations in red.		

Figure 4-8: example of an individual update for inclusion in main Issues and Solutions (IAS) document

Theme 3: Communication and information

In Chapter 3, when discussing the methods of data collection and analysis, reference was made to a patient who had become distressed during his interview. Consequently, in this section it seems pertinent to illustrate how his story became a trigger for change. Thus an insight into his experience is included. During the interview, the couple provided a moving and compelling account of their journey and the varied challenges they had encountered along the way. For instance, in this first extract from page 8 of the Report (Appendix 29), the spouse clearly indicates that both she and her husband would have welcomed more information about the forthcoming surgery:

"…you did have that booklet about bypass… British Heart Foundation…two booklets … they actually said about what you were going to have done…'cos we'd never heard of it, every time you say somebody's had a bypass you think it's the heart…I think it's quite new, I don't know…"

This patient had been given an information booklet from a friend who had received treatment at another NHS hospital. This booklet, he suggested, had been invaluable as it answered many of the questions previously left unanswered by the information

provided by the SE NHS Trust. As such this was identified as an issue for inclusion in the IAS document (Appendix 30, p.9) as Figure 4-9 illustrates.

35. A few patients would have liked more information about their plan of care, future prognosis, adverse effects of anaesthesia (including possible psychological effects) the do's and don'ts of post-operative recovery.	Patient interview	**Ongoing:** plan for Vascular Team to re-write patient information leaflets and provide a Vascular information website. **VCS/Vascular Team.**

Figure 4-9: example of communication issue raised by service user and action taken

The patient also described how he had received

"…no written information about the possible after effects of having anaesthesia...blockage and bypass surgery explained very clearly but didn't say about afterwards…separate compartments all doing their own jobs but no connections…they've all done a good job – the surgical side, the hospital side, excellent; but the psychological side nobody tells you about the sense of isolation, the highs, the lows, the mood swings...the possible after effects of anaesthesia and surgery..." (Appendix 29, p.10)

Retelling this part of journey triggered distress in this patient and as his story unfolded two aspects of care, and three key issues, were revealed. The first, the psychological impact, is expressed as two issues, 37 and 38 (Appendix 30, p.10) because different contributory factors had been identified. This is illustrated in Figure 4-10,

37. One male patient felt that psychological and physical care should be of equal importance. He gave details of a booklet, supplied by another NHS Trust, that had provided the 'turning point' for his post-op recovery	Patient interviews	**Ongoing:** Currently being reviewed by nurse practitioner, physiotherapist, occupational therapist – **VNP/P/OT.** **Ongoing:** Patient Information Leaflet **VCS/Vascular Team**
38. Limited clinical psychology input (principally for amputees)	Mapping Patient interview	**Issue resolved/review:** VNP has negotiated with Psychologist additional input primarily for amputees, as required.

Figure 4-10: example of issues associated with psychological impact of care and action taken as identified by service users and providers

Another aspect of care related to fragmented multidisciplinary teamwork. This was an issue commonly highlighted by patients as they retold their stories, as further evidenced by the interview report (Appendix 29). Although in this context the experience of fragmented teamwork was themed under communication and information, the varied nature of the impact of this could be related to every section. The following extracts from three different patients, illustrate this point, and provide examples of different ways in which patients' experiences can be affected.

1. "…I got a bed blister on the back of my ankle of my remaining leg but, obviously if…I get an infection in here, in this one, I can't have a by-pass they said they'd have to straight remove… I woke up in the morning and I had above my bed 'Nil By Mouth' and I'm thinking hold on I've already had me operation me leg's been removed, everything else, but nobody's told me 'nil by mouth', and they were saying 'yeh, … you've got to go for an operation. I thought well, between the people that were on the ward we could have a bit of a joke, a bit of a banter between some of the patients, you know… so they was going - Somebody's got up in the middle of the night and changed the card over… so we thought they were having a laugh, or whatever, you know? …so I was going - Come on who's changed the card?' …Until the nurse came over and said '...that's right …you've got an operation', and I'm thinking come on tell me about it, what operation? I've had me leg removed, I can't have any more done…eventually the doctor came and saw me…had to go to the other side of the hospital to have an injection in my back to open up my veins…they classed this as an operation." (Appendix 29, p.8)

2. "This was of major concern to us, wasn't it? …for the first 10 days it was a case of Mr… coming and having a look and wanting me to show some improvement in the ulcer before he would discharge me. Then he decided that he wanted to put a VAC pack on my ulcer…to help it heal...that was done by the vascular nurse… every three days this dressing was changed. The basis of the problem was that I was getting told by one team, the doctors, that this was heading for me staying in for a long time to have a skin graft; I was told by the vascular nurse that basically I would have to stay in there until the ulcer healed completely, but I was being told by Mr … that all he was interested in was seeing some major improvement in it before he was going to discharge me. So towards the end of my stay in hospital I was getting these three different stories so I asked the staff nurse to find out…what exactly was happening…disjointed information." (Information finally clarified satisfactorily with consultant. Patient recounted how the indecision about the hospital stay had also impacted on their spouse.) (Appendix 29, p.9)

3. "…lack of communication between groups…they came down to take me to put this line in my neck but I didn't know I was going for it. So, I wasn't ready, I didn't know I was going to have it…it was just lack of communication somewhere there I think…if I'm going to go down for that sort of thing I want to know about it…the thing was it was visiting time, my mother had just turned up; obviously if I'd have known I'd have said well don't bother coming in mum…" (Appendix 29, p11)

The above verbatim narratives provide clear examples of the detrimental impact on patients and their care partners of isolated and fragmented ways of working in healthcare. They also provide poignant lessons, as narratives drawn from first-hand experience, for use in healthcare education and practice. Significantly, these examples, and numerous others in the report in Appendix 29, and the IAS document in Appendix 30, further strengthen the argument not only in support of multi-disciplinary working and learning, but also of providing opportunities, such as this AR VPJ study provided, that facilitate and promote multi-disciplinary, open and supportive team-work.

Narratives 1 and 2 in this section also illustrate the complex nature of PVD, and thus of vascular patients' journeys. Several issues can, once more, be identified from these

brief accounts. For example, as mentioned in the methods chapter, Chapter 3, when the challenge of analysis was discussed, a significant issue relating to pressure area care had been revealed. Although that example related to a healthcare experience outside of the timeframe for inclusion in this study, and concerned an issue that had since been addressed, narratives 1 and 2 in this section provide further examples by which the importance of pressure area care for this group of patients can be raised. Figure 4-11 demonstrates actions taken by the VPJP team since these issues came to light. Solution comments to issue 44 reveal that more resources had been made available and more accessible. Issue 75 includes a proposal for additional training to enable staff to be better informed and equipped to care effectively for patients with PVD, as patients with complex nursing requirements.

44. Pressure area care/availability of pressure mattresses	Patient interviews	**Issue resolved:** Situation improved. Air mattresses and a range of alternative devices were now readily available for use in patient pressure area care. **WS/BM/VCS**
75. Nurse staffing/workloads	Patient interviews Team discussion	**Ongoing: BM** reported that nurse staffing levels within the surgical directorate are currently under review. **Ongoing: VNP** felt that additional training should also be provided to enable nurses to care effectively and safely for patients with increasingly complex nursing requirements.

Figure 4-11: issue identified by service users and actioned by service providers

Contentious and sensitive nature of issues

These, and other potentially contentious issues in the report (Appendix 29), also demonstrate the significance of building strong relations in an AR PJ project from its outset. In this AR VPJ study, had this relationship not been established with the VPJP team, and if the focus of interviews had only been to report negative issues, it is believed this would have presented a significant challenge at this stage in the improvement process. As an action researcher and VPJ facilitator who felt accepted by the team, and who also had positive feedback to offer, this meant that I did not feel uncomfortable when reporting findings of a sensitive nature back to the VPJP team.

Examples of complimentary narratives are included at this point to illustrate how positive feedback enables a more balanced and perhaps fairer reflection of communication between service users and service providers. These were interspersed with negative narratives, rather than in sub-divided sections, as can be evidenced from the same section of the report (Appendix 29, p. 7-11).

1. "…communication …second to none…" (p.7)

2. "…had the same consultant all the way through, he was marvellous, and he explained everything clearly…he didn't talk down to you and spoke in a language we could understand…" (p. 8)

3. (Spouse) "Communication was very good, I was notified if anything went wrong or anything like that, even at 1 or 2 o'clock in the morning I had phone calls." (Patient) "…it was always fully explained to me and to you…nice and clear…very good communication…" (Spouse)… (Patient had been taken back into theatre) "…Mr—rang and left message on answer phone to say they were taking … back down (to theatre)... it was him that rung (consultant) …when … came out of the theatre he rung me, and then after… recovery …went to high dependency they rang me at 2 o'clock in the morning to say that … was in there…" (Patient) "We've always had good contact. Mr – always used to come in, sit down and explain everything…at times I wish he hadn't (both laugh) especially before the first one…to say I was a bit nervous would be understating the situation…like when they did an angiogram there's this possibility of stroke, death, blah, blah, blah and afterwards you find out they've never had a case of it in XXX (both laugh)" (p.9)

4. "…it's also if we get in touch with secretaries if we're not sure about something, we always get an answer back…no complaints with communication…whoever we've rung we've always ended up getting answers." (p. 10)

5. "…if I had any questions at all I would ask and I would always get a good answer…" (p. 11)

As the issues under this theme were mainly educational no absolute solution could be found. This is reflected in the actions taken as illustrated in Figure 4-12, copied from page 8 of the IAS document (Appendix 30). These five extracts also reiterate the multidisciplinary nature of patient care, providing further verification in support of the proposal to include a multidisciplinary team in this AR VPJ study.

40. More recognition of impact of previous negative care experience, the fear and anxiety of patient (e.g. central line had been associated with life-threatening infection on a previous admission)	Patient interview	**Ongoing/awareness raising:** It was felt that little could be done unless patient's notified medical/nursing staff of their anxiety/fear. Good communication and rapport with patients would facilitate disclosure. **WS/Nursing/Medical staff**
41. Inconsistencies in information - a couple of patients recounted variations in information received, and the feelings of frustration or anxiety this had caused them, and in some instances, their relatives.	Patient interviews	**Ongoing:** Suggested solution was for nurse representation at daily Vascular Meeting from 10-10.30 am **WS/VCS**.
42. Inter-professional communication – fragmentation of teams/care – some patients felt that the different health professionals did not communicate with each other	Patient interviews	**Ongoing:** Possible solution might be to provide patients with written information about the roles of health professionals who might be involved in their care during hospital admission **VSC/Vascular Team**

Figure 4-12: examples of communication issues and actions taken

Nevertheless, and partially by way of response to the feedback under this theme, inter-hospital communication was also investigated and a new system of documentation and

patient record transfer planned. This is verified in the following extracts in Figure 4-13 from an individually forwarded IAS update received from the SE Trust's service improvement team, via email on 20th May 2008.

2. Some patients appear to 'fall through the net' when being referred from YY to XX Hospital.	Patient interviews Mapping	Vascular Consultant clinics are now being held at YY. **LVC and Consultant** colleagues liaising with administrator for YY access codes to computer information systems such as PACS. Each site holds separate sets of notes for patients. In future 2 copies of each piece of patient information to be made and stored in both sets of notes. Consultant secretary currently dealing. Electronic Patient Record should improve this in future. All trusts are now required to develop an inter-provider referral form, including a minimum dataset. Trust lead to be identified and system implemented. This will mitigate the risk of patients falling through the net.
11. Patient notes not always available.	Mapping	New computer system CERNER currently being implemented with case note tracking module which should improve tracking and availability of patient records. Improve the use of the Cerner queue (notes tracking) and review the Courier service **(BB)**

Figure 4-13: examples of larger-scale response to communications issues raised by service users and providers

Theme 4: Short notice/emergency admissions

Although six of the eleven participants had experienced emergency admissions only two patients briefly spoke about this part of their journey. Of these, as also mentioned in Chapter 3, one patient specifically requested that their experience of being informed about a short-notice admission be recorded because of the anguish it had caused. As such, although lengthy, the verbatim narrative which recalled both the patient's and his wife's traumatic experience, and the strong emotions this had evoked, was included in full in the interview report (Appendix 29, p.12, Figure 4-14).

"…the technician who did it said the vein was underperforming, a restriction - that something would have to be done and he contacted the consultant by phone…He told me if I had any pain over the weekend to seek medical help. When we arrived home…fair old drive …someone had already phoned but there wasn't a number we could ring back and eventually, about 5pm or something, another lady phoned to say that provision had been made for me to be in hospital first thing in the morning (a Friday). Couldn't make it for two or three reasons…made to feel guilty…message coming through about how urgent this had to be done… Basically we was told that this could cost me my leg…spent weekend feeling extremely worried…"

Figure 4-14: anxiety caused by notice of urgent admission by non-clinical staff

The couple's concerns were also highlighted by the points for consideration included at the end of this section in the Report as follows:

1. The possible adverse effects of short-notice of urgent admission to patients.

2. Would it be more appropriate for patients to be notified of short-notice/urgent admission by medical staff or nurse practitioner?

3. The potential impact on the patient of being nil by mouth and cancelled for theatre, more than once, following an emergency admission. (Appendix 29, p.12)

As a direct consequence an immediate change was made to existing practice for notifying patients about short notice/emergency admissions. This had been actioned before 1st November 2007 as recorded in the PhD journal and notes of the VPJP team meeting held on 1st November.

> "At the Vascular Patient Journey Project Team meeting on 1st November I learned of the changes already being put in place as a consequence of findings from the mapping exercise and patient interviews, and work the team had already undertaken. The most notable of these were as follows:
> - Only medical staff would contact patients in future when short notice admissions were advised. Waiting List Co-ordinator and admin staff notified"

The action was also recorded in the IAS document, albeit the specific date is not included (Figure 4-15).

13. Patient reported great anxiety at not being able to attend for urgent, next morning, hospital admission for surgery, following phone call from XX.	Patient interview	**Issue resolved:** Patients to be contacted only by medical staff or nurse practitioner in the event of a short notice admission **(VCS/VNP)**

Figure 4-15: example of instant action to resolve issue raised by one patient

Since then the policy, at least within the vascular specialty, stipulated that any such call must only be made by a qualified health professional rather than a member of the administrative team as had been the experience of this patient.

This patient's narrative, which was also included in Chapter 3, illustrates the power of patients' stories. It also provides evidence that also substantiates the view that patients, and close family members (if appropriate), should be given opportunities to discuss their experiences openly and frankly. The information offered by this couple would otherwise have only come to light had they voiced their concerns in writing, as a complaint, which neither had felt they wanted to do. Up to this point the team had not been aware of any possible adverse effect arising from current practice; as such this was viewed as poignant and valuable learning.

This single issue subsequently received yet further attention from the SE Trust as illustrated by an update report in a prioritised version of the IAS document, dated 22nd July 2008. As mentioned, this report was produced as part of my preparation for withdrawal from the VPJP team and included prioritised actions as identified and forwarded to me via email by the VPJP team. The following extract from page 7 of that report (Figure 4-16), illustrates the action taken in response to the patient issue. It also shows that further actions were planned and that ownership for these actions had been assumed. This was in line with the key purpose of this document which was to promote sustainability of the improvement process after my withdrawal from the project.

Issue	Key Points	Action Required	Lead	Timescale
13. Short notice of urgent admission – impact on patient when they cannot attend.	In future patients will only be contacted by medical staff or nurse practitioner. Need identified for greater clinical engagement, particularly in relation suitability of patients for short notice admissions; better utilisation of bed spaces allowing for 'headroom' for admissions across the specialities.	To be considered as part of overall review of communication with patients being undertaken by MPH. Also to be considered under Bed Management policy review and No Delays	Associate Director of Communications and Marketing Director of Operations Service improvement	

Figure 4-16: example from the prioritised IAS document dated 22nd July 2008

Another issue raised in relation to emergency admissions is reflected in the following narrative (Appendix 29, p.12)

> (Patient) "…so I went in as an emergency but had a wait of about 3 or 4 days before anything was done.." Patient was admitted on 4th March and had surgery on 8th March. Was made nil by mouth on a number of occasions before finally having their operation which took 8½ hours.

The main issues that emerged from this narrative concerned the nil by mouth policy and repeated delays to urgent surgery; issues identified not only through the narratives of other patients, but also by the VPJP team through mapping as issues 9, 23 and 24 in Figure 4-17 illustrate (Appendix 30).

9. Sequence of theatre booking and pre-op assessment – requires a lot of phoning to arrange.	Mapping	**Ongoing:** Under review through **Theatre Strategy Group/No Delay/18 week (VCS/VNP/BM)** Further solution would be centralised /up-to-date information showing theatre lists/day surgery lists/ clinics and changes. **VNP** to contact xx manager
23. Order of theatre list confirmed from 4pm day before surgery	Mapping	**Issue resolved:** Theatre lists now confirmed by 11am day prior to list. Secretaries to prompt Consultants to ensure this will continue. **Secretaries/Consultants**
24. Wards not aware of theatre list sequencing on day of surgery	Mapping	**Ongoing:** Notification via electronic white board could alleviate problem in future. Not generally a problem in SAL (surgical admissions lounge). **Issue resolved:** Ward staff not to feed patients until 1st theatre case has gone ahead and theatre list confirmed – to include in Safety Briefing **VCS/VNP**

33. A number of patients reported delays in the timing of their operation – this ranged from surgery at the end of a day after being NBM all day to several days delay.	Patient interviews	**Ongoing/awareness raising:** Improved communication between medical and ward staff would help to alleviate this issue. **Medical/ward staff.**

Figure 4-17: issues related to nil by mouth policy and theatre delays as identified by service users and service providers

Figure 4-17 above is another example which reveals the different perspectives of service users and service providers. It also shows why both perspectives are valuable, with the solutions comments section providing further evidence in support of multidisciplinary teams in patient journey reviews for the purpose of improvement. In this instance, the VPJP team's involvement enabled them to take immediate steps to resolve these issues. One of which was simply to draw awareness to one of the consultant surgeons of the consequences of simply altering his operating schedule on the day of surgery after his list had begun. Other steps to resolve theatre delays, as the comments in issue 9 (Figure 4-17) illustrate, would involve larger scale changes. With regard to issue concerning confusion about the SE Trust's existing nil by mouth policy, this policy was revised and ratified on 10th January 2008. The revised, clearer guidance is illustrated in Figure 4-18.

Figure 4-18: revised nil by mouth guidance developed in response to issues highlighted by service users and service providers

Theme 5: Relationships with healthcare professionals

The review of PCC literature made emphatic the significance of interpersonal relationships in healthcare (Atwell and Caldwell, 2006, Curry, 2005, Douglas and Douglas, 2005). Indeed, as the philosophy and principles of PCC highlighted (Gerteis et

al 1993, pickereurope.org, 2014, Stewart et al, 1995, planetree.org, 2014), and as Webb acknowledged *"staff have the capacity to make or break a patient's stay"* (Webb, 2007, p. 66). The significance of interpersonal relationships is also acknowledged by the underpinning philosophies associated with the paradigm of qualitative research (Schwandt, 2000, Swanson, 1991, Gallagher, 2004), and thus action research, albeit in this context the impact of interpersonal relationships on team-working, change improvement (Lewin, 1947, Carr and Kemmis, 1986, Reason and Bradbury, 2001, 2008).

In this AR VPJ study positive and negative aspects of relationships experienced during vascular patients' journeys can, as previously mentioned, be evidenced in the *Patient Interview Report* (Appendix 29). Twelve extracts are included under this theme which can be found on pages 12-15. These reveal that all patients experienced, at least at some point, a relationship with one or more of the healthcare staff they encountered that made a positive difference to their experience. Their verbatim accounts also make clear that these relationships had been greatly valued. The opportunity to 'have a laugh' with their healthcare providers was important for many; whilst feeling supported, and being given sufficient, clear and appropriate and timely information was viewed by the majority as an essential part of an effective relationship. Factors also identified amongst the empirical studies of PCC reviewed, for example by Kinmouth et al (1998), Douglas and Douglas (2005) and Webb, (2007). The importance, and influence, of these one-to-one relationships on healthcare experience is clearly evident in these extracts; demonstrating consistency with the discussions and findings of the review of empirical PCC literature, and the philosophy and principles of PCC (Gerteis et al, 1993, Stewart et al 1995, planetree.org, 2014). They also support Webb's statement that *"staff have the capacity to make or break a patient's stay"* (Webb, 2007, p. 66). However, in this study, these patients' stories also indicated that each service user had hoped, and expected, to encounter friendly, thoughtful staff with whom they could build a relationship and who would make them feel involved. The following quotes and others in the Report (Appendix 29) provide insights that illustrate these points:

- "…the nurses were absolutely fantastic…I didn't want for anything…they were absolutely run off their feet…you could see that they were struggling…there was just so much …I used to have a good laugh with the nurses…the nurses, and the doctors, do a fantastic job…some of them could be grumpy but when you saw what they got to put up with…you'd be surprised that people want to do the job (nursing)…but to me they're worth their weight in gold." (p.13)

- "…I had a social worker there…anything you needed she got it for you, she was very good…" (p.13)

- (Patient) "The way Mr X treated us was really first class" (Spouse) "On the day of the operation I was told to ring at 3pm and …wasn't back. I rang at 5pm and couldn't get anyone…I got through at 5.30 pm and I was told that … had been taken back in which obviously I was very worried about…was told somebody from surgical team would ring me and actually Mr X himself phoned me about 7pm…and I thought that was really very, very nice…when we go to the clinic he's always very good to me as well, I don't feel like I'm in the way or anything, he's always inclusive, isn't he?" (Patient) "Oh yes…he's a super man." (p.13: this extract was also included under the communication theme)

- "…the only one…who didn't seem so friendly …was the one who did the scan on my legs… (Patient still had open wounds) 'She said, get these off…' (referring to wound dressings – added) 'I says they're open wounds, and they were, and she scanned all the way down them, and that was agony…I've got finger marks on the ceiling…that was agony." (Diagnostic imaging staff) (p.14)

- "…at night I couldn't get hold of the nurse…I rang the bell three times and nobody came…and I thought where are all the nurses at night? I had to get up to go to the toilet on my own, I didn't have anybody help me and I was very unhappy about it (normally uses a three wheeled support at home)… most of the nurses may I add were lovely, I'm not complaining about all nurses, but this one particular nurse, I've tried to speak to her quite reasonably …she was very impatient with me…then she said…'don't forget you're in an NHS hospital…this isn't a private ward…and I looked at her and said I didn't ask you that I just asked where the …so she said 'well, I've only got one pair of hands'…she was very bad tempered that night and that was upsetting for me…" (p.14)

- "The anaesthetist was very nice…he came round and had quite a chat with me…he even did a little sketch for me…" (p.14)

- "…I've been that happy with all of those nurses and anybody that works on ward - that I actually went out and I bought them all presents…34 of them…but, you know, if it wasn't for their care, etc, I wouldn't be here anyway…The good thing about ward - is I know where I am going, I know the people on there…and they're all wonderful…" (p.14)

- "…she's wonderful, if there's anything not done…she's a star (nurse practitioner – added). The last operation I went in for, I went in on a Sunday and she came in and did all my paperwork, to make sure it was all done, and done correctly. In fact, on occasions when I was down in the dumps after certain ops…she came in one evening to take me for a walk around the grounds, rather than me just sitting or being next to the hospital bed…she is a star, she's wonderful…" (p.14)

These extracts also emphasise the multidisciplinary nature of healthcare practice. For example, in this instance mention is made of interactions with an anaesthetist, radiographer, nurse, nurse practitioner, nursing team, social worker and consultant surgeon. Thus VPJP team awareness of the significance of their relationships with their patients was readily raised when reading the interview report as this was inclusive of all rather than focused on a single discipline. This was another shortfall identified from the review of empirical studies of PCC which commonly focused on the perspectives of

single disciplines and generally medicine or nursing (Kinmouth et al, 1998, Reeves et al, 2005).

In terms of identifying and raising issues for action from these extracts for inclusion in the IAS document, this had not been particularly straightforward due to the individual and often, one–off nature of experiences reported. Even so, albeit not necessarily overtly, relationship (and communication) issues are highlighted in the report through issues 25, 29, 31, 33, 35, 36, 39, 40, 41, 42, 47, 74 and 75 (Appendix 30). Issue 39, by way of example is illustrated in Figure 4-19.

39. Several patients reported that they would have liked more help with washing/personal hygiene, especially in the early post-operative days.	Patient interviews	Ongoing/awareness raising: BM/VNP reported that a plan/pathway had been introduced for orthopaedic patients which might assist in resolving this issue. VNP/BM/WS to follow up.

Figure 4-19: an example to illustrate how relationship issues were raised and attended to in this AR VPJP study

Subsequent follow-up action to issue 39 in Figure 4-19 contributed to the development of a new information leaflet in July 2008. The aim of this was to ensure that patients and staff were better informed about what to expect during a hospital admission for a femoral-popliteal bypass operation. This would also address issues raised under the themes of communication and healthcare delivery. A copy of the leaflet is included as Figure 4-20.

NHS Trust

DEPARTMENT OF VASCULAR SURGERY

YOUR TIMETABLE FOLLOWING A FEM-POP BYPASS OPERATION

DAY ONE	DAY TWO	DAY THREE	DAY FOUR
The Physiotherapist will show you exercises including breathing and leg exercises. Your wound will be checked and any drains may be removed. You will have a blood test today. Your drip will be taken down once you are drinking well. You will have regular pain control. You will sit out of bed and be able to use the commode for toilet purposes. You may be able to have a short walk today. You will receive a blood thinning injection once daily. It is important for you to keep your leg elevated when sitting and whilst in bed.	You will sit out of bed, and be able to mobilise to and from the toilet with supervision. Take regular pain relief. Doppler pressures (ABPI's) will be carried out by a member of the medical team. Over the next few days the Occupational Therapist will discuss your home situation, and make sure the correct equipment is provided. Your urinary catheter will be removed today if you are mobile enough. **Ensure you have planned your transport to take you home with your family or friends. You may be able to go home on Day 3 or 4 following your operation.**	If you are safe and the medical team are happy, you will be able to go home. You may dress in your normal clothes with advice from the Occupational Therapist. You will have walking practice with the Physiotherapist and/or nursing staff. It is important to mobilise regularly throughout the day. Continue doing your exercises. Take regular pain relief. The Occupational Therapist will assess your ability to transfer on/off the bed, chair and toilet with you. **Ensure you have planned your transport for taking you home.**	Most patients will be discharged home today Before leaving the Ward today your tablets, outpatient appointment and discharge letter will be arranged by the Ward staff. You will practice stairs prior to discharge (if you have stairs at home). Take regular short walks. Continue to dress independently using the appropriate aids. **Confirm your transport arrangements if you are going home.**

Figure 4-20: femoral-popliteal bypass information leaflet produced in response to issues reported by patients

Theme 6: Nurse workloads

Each patient and their care partner commented on nurse workloads, most commonly in relation to their impact on nurse-patient relationships. Correspondingly, because this is also an ongoing and commonly cited issue in reports of investigations into healthcare failings (Kennedy, 2001, Colin-Thorné, 2009, Francis, 2013) service user perspectives as described in this AR VPJ study are also included in the main body of this thesis.

Genuine concern was expressed by service users about the pressures under which nurses were expected to cope and still deliver an acceptable level of healthcare. The following narratives, from pages 15 and 16 of Appendix 29, illustrate this point.

1. "The nurses were absolutely brilliant you know, and you didn't want for anything and you could see that they were run off their feet, could see that, you know, they were struggling to keep with you like because there was just so much there…"

2. (Spouse) "…we thought the staff worked very hard, you know ...worked really, really hard…they were very busy…having worked in a care home I know the pressures…" (Patient) "…all the staff nurses gave the impression that they were in command of all situations that appeared to be in front of them…" (Spouse) "But you could tell how pushed they were…I kept saying I don't know how they remember to do it all…because they were like from one end to the other, weren't they, all the time…" (Interviewer) "…could have done with more staff?" (Spouse) "I think they could have done with more staff, yeh, but they did very well…"

3. "…every time I've been in, err, them poor nurses was run off their feet but they never moaned if you wanted them, they was there. That's what I felt with me, they were there…from the time I was in until I come out it was great. When I had my big operation…it seemed as though they was by my side 24 hours a day, they was always there, um, really nice…I wouldn't call them anyway unless it was an emergency (use of call bell) …I could see them rushing about, they'd got that much to do…when I did use it they was there right away…"

4. "…I really feel sorry for these nurses, from the time I opened my eyes at six o'clock they have been non-stop…the little one there has done a double shift, flat out and is still coping…"

5. "…I had to look after myself a bit…there was other people needing far more attention than me…I didn't get much individual attention…I didn't really feel looked after enough…"

6. "…the care itself has been wonderful, all round really…there's been the odd occasion where I've had to wait longer than I would have wanted for Oramorph (pain relief – added) when needed but, usually, I think the reason for that is the usual, they're short staffed, or shortness of staff at the time. As I say the overall care has been brilliant…"

7. "…I was also appalled at some of the nurses' behaviour on nights on ward -. It could be put down to, again, shortage of staff…"

8. "…but it was very busy in – ward, they were rushed off their feet…'

These few verbatim extracts clearly demonstrate the significance of the nurse/patient relationship and the perceived impact of nurse workloads on this relationship and patient care. Perhaps not surprisingly, nursing staffing and workloads were raised as an issue by both service users and providers as Figure 4-21 illustrates.

75. Nurse staffing/workloads	Patient interviews Team discussion	**Ongoing: BM** reported that nurse staffing levels within the surgical directorate are currently under review. **Ongoing: VNP** felt that additional training should also be provided to enable nurses to care effectively and safely for patients with increasingly complex nursing requirements.

Figure 4-21: nurse staff and workloads – an issue identified by patients and staff

As Figure 4-21 also illustrates this is an example of an issue not so readily resolved. Nevertheless, the findings of this AR VPJ study, which also provided evidence-based rationales from those who have first experience of the impact of constraints on nurses' time, strengthened the argument in support of a review. It also led to a proposal to provide additional training for nursing staff to ensure they were effectively prepared for caring for patients with more complex needs; in particular those associated with PVD.

The narratives in this theme, nurse workloads, and indeed all those included in the '*Report of Patient Interviews'* and this thesis, also demonstrate the potential of service user stories towards enhancing healthcare education and informing healthcare policy. Each of these statements comes straight from experience. There is no need for interpretation; the messages they impart are clear and there is no risk of confusion like Goodrich (2009) reported. For example, these make clear that some patients may not ring their call bell because of their concern for nurses who, they believe, are already too busy. The narratives also reflect concerns about workloads that are repeatedly identified by inquiries into healthcare failings (Kennedy, 2001, Colin-Thorné, 2009, Francis, 2013). These were also highlighted by the review of former empirical studies of PCC as discussed in Chapter 2, including those that have examined the nursing perspective by Reeves et al, (2005) and Aiken et al (2001, 2012). Findings which also clearly indicate that the following goal of UK healthcare policy-makers has yet to be fulfilled:

> "a vision of a renewed public service ethos, a system that values the dedication of staff and believes that trust is still the glue that binds the NHS together…with healthcare to be delivered by staff who…are not rushed off their feet and constantly exhausted (DH, 2000a, p. 17)..."

By late 2011 it appeared that finally this issue was being taken seriously. For example, the NHS Institute for Innovation and Improvement in the UK launched a Safer Nursing Care Tool (SNCT) in 2011; a tool which is claimed to be a *'simple way of assessing the safe number of nurses needed for a ward'* (Stephenson, 2011). Added to this, in the

UK, the Royal College of Nursing called for mandatory nurse staffing levels. In the UK between 2007 and 2011 the average number of patients per registered nurse was reputed to have increased from 6.9 to 8.4 (Calkin, 2011) (although personal experience brought evidence of significantly higher patient to nurse ratios than these). This may be compared to California USA, where minimum registered nurse to patient ratios were mandated by Californian legislation in 2004, setting a maximum ratio in medical-surgical wards of 5 patients to 1 registered nurse, with the highest ratio set at 6:1 in mental health settings, and the lowest at 2:1 in intensive care units (Aitken et al, 2010). Yet, as Coulter (2002), Jenkinson et al (200a, 200b), Ball (2010), the reports by Francis in 2010 and more recently in 2013 make clear, short-staffing continues to impact on patient experience, patient outcomes (mortality and adverse events) and the efficiency and quality of care, as the service user narratives in this study also affirm.

Theme 7: Healthcare delivery

This was the largest section of the interview report spanning from page 16 to 25, and containing 23 verbatim extracts which related to care experienced across several wards and including a medical assessment unit, at the SE NHS Hospital Trust. Locations were not identified in the Report (Appendix 29) to respect confidentiality and to prevent judgement. On the whole, the participants gave positive accounts of their healthcare delivery. In this context the following examples are included primarily to demonstrate the diversity of the issues discussed, but also to highlight their potential as catalysts for change or learning. The first extract, drawn from a patient's recollection of their fear of catching first sight of their newly amputated limb, could, for example, be used as a point for reflection on current practice.

> "…I was sat in the bed thinking do I look, or don't I look?...lucky enough a doctor came along, well I say lucky enough… and the first thing he did was pull back the sheets and I got to see it anyway without thinking about it…that initial shock wasn't really that bad to be honest…I got on very well with the doctor…explained everything and that everything had gone alright…"

The following extract represents the views of more than one patient who expressed a desire for physiotherapy sessions to also be made available outside of the ward environment

> "…would like to have done more exercise, or even… something better than the exercises I had…the physios would come round your bed…the nurses called them physioterrorists!…you'd get one of them come round and say ….fancy having a walk on the Zimmer frame, so you'd have a walk so far… I'd like to have gone somewhere off the ward to do something…"

Thus this was raised as an issue (Figure 4-22).

44. Patient would have appreciated greater variety of physiotherapy, with off ward activities such as use of gym or swimming following amputation	Patient interview	**Ongoing:** OT would look at possibility of providing alternative activities for amputees/patients with longer admission times

Figure 4-22: response to patient request for more varied physiotherapy sessions

The experience of the following patient, from which only a very brief insight is provided, might be used as a poignant, and clear, example to educate, or remind, health professionals about the importance of effective pressure area care

"…the worst thing that came out of the care that I had was ...because I had to stay in bed I developed a big sore on my heel, which is still being dealt with."

(Interviewer) "Do you think they could have done something else to prevent that?"

(Patient) "Well, I would have probably expected normal patient care to have been looking for signs or to prevent maybe…I don't know…putting a pillow under your leg or something... …the pump (VAC machine) …it made a hell of a difference…but there's a question over the politics of that pump because it made such a difference and I said well, am I allowed to have this thing out of here?…because the only reason, really, that I was in there for the last fortnight was to have this pump on me, there was no other treatment that I was getting…"

(Spouse) "…to us it seemed a waste of a hospital bed."

This patient developed a pressure ulcer which required on-going nursing care for several months. It later transpired (from an evaluation interview) that, unfortunately, approximately one year after this admission, the same patient had been re-admitted to hospital for a life-saving below-knee amputation. This was necessary because he had acquired a life-threatening infection in the limb which had spread from the ulcer (also discussed in the next chapter on evaluation). As previously highlighted, in this chapter and Chapter 3, other patients from this high risk group also reported developing pressure ulcers either prior to or during their hospital admission. Consequently their narratives collectively contributed to issues 44 and 75 raised in the IAS document with regard to pressure area. These were mentioned in earlier in this chapter under Theme 3, communication and information, and included as Figure 4-10. Solutions to those issues included additional resources and a proposal for additional staff training. However, three further issues were identified from this patient's narrative and included in the IAS document (Appendix 30) as Figure 4-23 shows.

63. One patient felt that he should have been able to continue with VAC therapy following discharge, or been discharged earlier with VAC therapy.	Patient interviews Mapping	**Issue partially resolved:** **VCS** reported that patients may now be discharged with portable VAC if PCT accepts.
64. Access to VAC therapy in PCT's	Mapping	**Ongoing:** **VSN** reported that Service Improvement Manager is currently looking at provision of VAC therapy following discharge with Trust commissioners/ procurement
65. Some patients reported delays in their out-patient follow up, or no follow up appointments.	Patient interviews	**Ongoing:** Possible solution – **VNP** to liaise with **BM** with regard to possibility of dedicated Vascular Nurse Practitioner phone line for patient access. **Ongoing:** **VNP** currently looking at improving follow-up for diabetic patients.

Figure 4-23: issues and responses related to pressure area care

Further reference to this patient's experience after his discharge from hospital, is made in the following chapter.

The next examples demonstrate how the hospital environment can significantly affect the patient's experience of healthcare delivery. This aspect of healthcare was the focus of a study by Douglas and Douglas (2005) the findings from which are critiqued in the literature review. Different issues were raised by the patients in this AR VPJ study, although several, like the patients in the study by Douglas and Douglas made reference to factors such as accessibility of the environment, importance of an outside view, and their lack of control over environment in terms of lighting, heating or noise.

1. "…we were in the annexe of that ward…the first thing that struck me about it was how poor the planning was, not by the people who now run it but by the people who originally built it, because it's one of those places where the only bit of daylight comes in – comes in from what I call factory type windows right up at the top…it's an old building... originally they were going to scrap all that and build new vascular units... Hopefully in the future that'll happen…"

2. (Spouse, talking about post-operative period) "…was at this rather noisy end…I think you were complaining a bit about it being very busy, people going passed the bed that you didn't know who they were or what they were and where they were going…eventually you were moved…I think you settled better then...it was a more serene end of the ward."

3. "…would like to have gone privately…I don't like sharing great wards…don't mind being in a ward of about 6 but when it's about 20, you know, long, oh I hate that …people snoring, coughing, I couldn't stand it…"

4. "…after a very short while, I was moved into a side room…I was told I'd be better there…the only thing I will say is that, although I'd had an operation, I wasn't ill…the hard bit of being in a side room, you might think it's going to be much more comfortable and luxurious, which in some ways it is, but there's another side of it which isn't so good and that is, unless a member of staff comes in to actually do something…check you over…supply meals…that sort of thing…you don't see a soul…you lose the human contact…it's not only limited visiting, it's limited visibility as well…it can be very interesting sometimes with things going on in the ward that you watch, you know? It's like a spectator sport...and I guarantee you that any patient, that's at all reasonably well, does it."

Although the structure of the building, as mentioned in Narrative 1, was not something which could be readily addressed by the VPJP project team, these findings were timely in light of proposals for a new-build in which the vascular specialty would be housed. The last extract also offers a poignant insight into the patient's experience of being in a side room. This was acknowledged and responded to as an issue (Figure 4-24) and offered a point for consideration in the new design.

30. Patients who had side rooms reported feelings of isolation at times	Patient interviews	**Issue resolved/review:** New surgical build contains single rooms with internal windows giving visibility of ward area so that feelings of isolation may be reduced. The windows will be provided with blinds to enable privacy when required. **VNP/WS**

Figure 4-24: addressing the issue of isolation in side rooms

A number of powerful messages were also offered about healthcare delivered by nursing staff, particularly in relation to post-operative care. Although only 4 comments are included they provide valuable points for consideration by those striving to strike the right balance between caring for and enabling independence in patients during the post-operative recovery phase.

1. "…they did sort of strip me and help me to wash…I think just the first day…I would have appreciated a bit more help…maybe that's just me being lazy or something but I just felt so drained…I think if they'd said… I'll stay here and I'll help you, I wouldn't have said no."

2. "…I think it was the day after I'd had it (operation) I was obviously very fragile, I didn't feel like doing, couldn't do anything…I wanted a wash…"

These two narratives contributed to the development of a new care plan for patients undergoing a femoral-popliteal bypass operation shown in Figure 4-20, and the identification of issue 39 illustrated previously in Figure 4-19 when discussed earlier in this chapter.

The following Narrations, 3 and 4, by comparison, illustrate the significant difference that staff can make to patients' experiences.

3. "It was a great blessing to me that I was encouraged to be up and on my feet within a short time…Had I not been able to get up and stroll about, I feel my recovery could have been longer, I think." (Spouse) "Not only physically but mentally…they do it for physical reasons but it has a good effect mentally."

4. "The thing that really sticks in my mind, immediately after the op, in the recovery room, was the dear lady who stayed with me, and listened to me blubbing...She was a great comfort and I'm very grateful to have had her there. I haven't a clue who she was except that that was maybe her job to look after people who had

just had an operation, but I do remember being very confused and saying the classic line 'where am I?'…I like to have my hand held…it is something I get great comfort from…subsequently, in the ward when I was recovering and had another blubbing fit and a nurse came and held my hand, again it was of great comfort…" (account from male patient)

There were several other issues highlighted by the extracts under this theme from which catalysts for change were also identified. However, many of those, like the ones identified from Narratives 1 and 2 above, were also common to other themes. Narratives 1 and 2, for example, also contributed to an issue also identified from those under Theme 5 *'relationships with healthcare professionals'*, and thus the development of a new post-operative care plan. This emphasises the interrelatedness of many individual elements that comprise patient care, and emphasises the challenge faced when trying to determine specific issues.

Fourteen points for consideration were also offered in the Report under this theme for discussion by the VPJP team. Some of these are listed here to enable a sense of the focus of the narrative included under this theme. Other discussions in this chapter will show that many of the issues these influenced had also been highlighted through other themes as illustrated in brackets below. This is also evident from Appendix 30, the IAS document.

- Communication skills, including attentive and effective listening. (issues 35, 36, 37, 41, 42)
- Consistency and accuracy of information (issues 35, 36, 37, 41,42
- Value of therapeutic relationships for patients and their families.
- Patient washes; early post-operative period (issue 39)
- Availability of pressure mattresses/pressure area care (issues 44, 75, 63, 64)
- Patient medication and pain management (issues 25, 26,27),
- Off ward physiotherapy sessions (issue 40),
- Side rooms – isolation or luxury? (issue 30)
- Location of patient on ward (issue 22)
- Releasing Time to Care - The Productive Ward, national initiative by the NHS Institute for Innovation and Improvement 2007

The latter point in the above list relates to The Productive Ward, an initiative launched by the NHS Institute for Innovation and Improvement in late 2007. This encourages ward staff to take responsibility for improving the efficiency of their ward with a view to freeing up more time to spend directly with patients whilst also cutting costs (discussed in more detail in Chapter Six). The findings of this AR VPJP study indicated that Productive Ward would provide an appropriate 'follow-on' model by which to enable nursing staff to address any ward level issues unearthed during a Patient Journey project. As such, it had been highlighted to the Trust following my attendance at a

launch event in Basingstoke in November 2007 (this was subsequently implemented at the SE NHS Trust).

Theme 8: Privacy and dignity

Respecting the privacy and dignity of patients is an issue that has received considerable attention in the media, by healthcare watchdogs, the Government, healthcare professional bodies throughout recent years (discussions in Chapters 1 and 2). It has also been investigated through empirical research, for example Chochinov (2007). Interestingly, only 5 patients in this AR VPJ study specifically commented on this aspect of their care, albeit without actually using the term 'dignity'. Of these, three had not encountered any problems; but two, regrettably, had uncomfortable experiences to recall. The first extract, which also reflects comments of other service users who participated, illustrates why it would be helpful to ensure that the name, role and grade of each member of staff is clearly visible to patients

- "…I don't know whether he was a doctor or a nurse…I'd got Jordan books… and he came the one day to wash me…the book was on the bed and he says why does anyone want big boobs like that? Would you like big boobs? And I thought no way are you washing me, I'm sorry, and I says to him…I can manage…he was doing his job but I didn't like him saying that, that to me was stay clear, I didn't like it so I removed the Jordan book."

- "What she did was, she undressed me, totally, and then she went off to do something else but, when she went off, she left the curtains ajar… there was a big gap in the curtains and I couldn't do anything. She didn't give me my bell, there were people walking up and down and I felt terrible…I felt terrified…I couldn't do anything…"

The second provides a poignant insight through which reflection on practice can be facilitated. At the conclusion of this section in the Report (Appendix 29), the points for consideration asked the team to think about the potential effect on the individual of not maintaining privacy and dignity; arguably a key requisite of patient-centred care. No specific issues were raised in the IAS document.

Theme 9: Cleanliness and infection control

Around the time of the interviews there had been extensive media coverage with regard to hospital cleanliness and hospital acquired infections. As such, it was encouraging that participants had not placed greater emphasis on this topic. Seven out of 11 commented and the majority of these praised current standards. Interestingly, one of the most positive comments was received from a patient who had contracted MRSA during a past hospital admission.

1. (Patient - previously MRSA+) "…I also noticed last time we looked, compared to quite a few of the hospitals ...they've got a lower incidence (MRSA) than many of

the others…"(Spouse) "...those old buildings … it is very hard for them to be kept clean…I've seen them going round with cloths on their hands, going round the screens and all that... (Patient) "…used to watch them every day…they'd be doing everything they could, they couldn't do more…in my honest opinion…The biggest problem I personally feel is the visitors coming in..."

2. "…educate, educate, educate...(patient was referring the public rather than staff – added) on the cleaning side of it... they had two…cleaners for want of a better term …and whenever a bed was empty you would see them come in and they'd look, there's this bed empty, and it might just be the patient just got out of the bed to go to the toilet and immediately they'd have the brakes off, wheel it out and wipe it all round…"

3. (Relative) "…what about that nurse that time that sneezed? …she didn't even bother to wipe her hands…and a student nurse, she sneezed on the back of her hand and she didn't bother to go and wipe her hands…. I mean every time I went into the ward, they've got them all over the place (alcohol gel)…you just wipe your hands…" (Interviewer) "…did you notice them hand washing; the nurses?" (Patient) "Yes, they were very good I noticed…she said she had hay fever, didn't she?" (Relative) "…but she was going in every bloomin' cubicle sneezing on people. I didn't think that was a good idea…"

These extracts reveal that patients and their relatives are natural observers of day-to-day healthcare practice and, as such, are in a position to provide well informed opinions about where improvements may be made. Issues for consideration at the end of this section included

- Alcohol gel dispensers
- Hand washing
- Education of visitors
- Consistency of thorough cleaning across all environments

Other service user narratives included in the Report also indicated they believe that more needs to be done to raise public awareness about the service user's role in preventing the spread of infection, particularly when visiting hospital environments. Their insights also led to the inclusion of issues 52 and 53 in the IAS document (Figure 4-25 and Appendix 30).

52. Cleanliness – some patients had reported observing inadequate cleaning	Patient interviews	**Issue resolved**: Improved during last 6-8 months with introduction of Rapid Response team
53. Availability of alcohol gel	Patient interviews	**Issue resolved**: No issue over availability. Responsibility of **ALL** to ensure that empty dispensers are replaced or reported.

Figure 4-25: issues related to infection control

Theme 10: Hospital catering

Patients, on the whole, indicated that catering provision at SE NHS Trust was satisfactory; the influence of individuality on perceptions was strongly evident in this

section. The first extract also provides evidence of some patients' wider knowledge about hospital services

1. "Lousy…when I went in, in 2000 …they had their own kitchens and were cooking their own food…recognisable and tasty…now, as I understand it, it's done on the hot baking system… they bring it in and obviously it's heated up in the hospital to a required standard, enough to kill anything that's in it, including the patient. The main trouble is, it is often unrecognisable and very often slop… obviously working to a low budget. …on the telly the other night…they'd been to the CXC hospital. They're allowed £2.60 per day, per patient for food, that's it. But they're dishing up new potatoes and god knows what and they're sourcing it all locally…it's not coming in from some….contractor. …an alternative, perhaps you could pay the hospital an extra £1.00 per day and get something better..."

2. "I'm not a big eater, the food I had was good enough for me…if I didn't like what was there I would have a sandwich…there was a choice…I said to my daughter I've had a very strange meal today but I've enjoyed it…don't know what it was. Only thing I could complain about was the tea…it came in a tiny cup and I have a bit of sugar usually but they wouldn't let me have it in there."

3. "…the food was excellent…I said compliments to the cook once or twice because they were so nice…I really enjoyed the food…"

4. "…generally speaking the grub was ok bearing in mind the difficulties of moving large quantities of ready-made meals, and there was a fair choice. Something which did irritate and cause concern was the fact that my diabetes advisers tell me I should inject myself about 20 minutes before a meal. In hospital, one never knew when it was 20 minutes before, and oft times I was using a needle only a couple of minutes before…as soon as the trolley appeared I would shove the needle in and that would only be about three minutes before eating…"

5. "…my favourite beverage is tea…at an early stage in my diabetes it was suggested that I should drink skimmed milk…this has now become a preference…Skimmed milk was never available in hospital…even Marvel would have been preferable…or little sachets…"

The penultimate extract highlights the significance of the timing of meals to diabetic patients. As Figure 4-26 illustrates this was an issue raised and attended to the VPJP team. Interestingly when the availability of skimmed milk (last extract) was first reported as an issue this was not considered significant by some members of the team. Nonetheless, when this was revisited at a later date, reassurance was given that skimmed milk or any other specific dietary requirement or preference would be provided if requested. A paragraph to this effect was subsequently included in revised patient information admission leaflets following a hospital-wide review. This issue also provides an example of a difference between the perspectives of patients and healthcare staff about what is important in healthcare.

47. A diabetic patient felt it would have been useful to know when meals would arrive so that he could have his injection as usual 20 minutes before he ate.	Patient interviews	**Ongoing/awareness raising:** Meals arrive at approximately same time each day on the wards. Possible solution – increase patient awareness during admission and in **patient information leaflet VNP/WS**
48. Several participants felt that the hospital food could have been better. They also reported that they did not always get the food they had ordered. Suggested looking at CXC Hospital 'in house' catering.	Patient interviews	**Closed but noted:** No immediate solution but it was generally believed that catering had improved since the time of patient interviews.
49. Tea trolley/urn for visitors to use was suggested, or option of buying a drink on the ward. Larger mugs were also requested.	Patient interviews	**Ongoing:** Larger mugs are now available on some wards. **WS** to liaise with **Matron/PALS/Housekeepers** to explore possibility of providing drinks for visitors.
50. Availability of skimmed milk for patients.	Patient interviews	**Issue resolved/awareness raising:** Housekeepers can obtain this for patients. **Ongoing: WS** to liaise with h/keepers and check Admission to Hospital leaflet with regard to information giving to patients who require special dietary requirements. **WS/VNP**

Figure 4-26: issues related to catering as raised by patients and attended to by staff

Theme 11: Patient-line (Hospedia since July 2009)

Patient-line, or more specifically the ability to make and receive calls at the bedside, was appreciated. Eight patients commented on this service and each considered it too expensive (Appendix 29, p. 27-28). According to one patient *"…Patient-line is an absolute rip off"*. Another patient suggested that all those who are eligible for free service should be notified of this. This patient, a former nurse, believed they were entitled because they were a healthcare professional. However, they had not discovered this until after their discharge from hospital. One patient remarked that the charges might have been more acceptable *"...if you knew the money was going into the NHS"*. Where pay phones were available some patients had reported difficulty in accessing these, either because of their location, or because they were surrounded by hospital equipment. Their location also caused issues in terms of maintaining privacy during telephone conversations. Although these issues were acknowledged by the team, current contractual obligations meant little could be done to improve the issues raised at that point in time as the response in Figure 4-27 illustrates.

51. Patient-line – complaints about cost, in particular calls into hospital. Patients would be more accepting if charges were benefiting hospital.	Patient interviews	**Closed but noted:** Until contract with Patient-line providers expires - no solution could be offered.

Figure 4-27: patientline, example of issue not immediately resolvable

Theme 12: Visiting

It was clear from listening to patients stories that visiting was often the highlight of their day. Generally the visiting times were acceptable and most patients were confident that if they had not felt well enough for visitors the ward staff would intervene and restrict

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visiting appropriately. Nine patients commented on their experiences and each was included in the Report. The significance of visiting had also been highlighted by Douglas and Douglas (2005) and Webb (2007) in addition to being acknowledged as one of the fundamental elements of PCC.

Where visiting had been limited, patients in this AR VPJ study had recounted feelings of isolation, loneliness and boredom. Their stories also revealed that the majority of these patients' relatives had at least half an hour to travel, some over an hour, which often impacted on the frequency and duration of visits. One travelled by train and explained how this took longer and was more complicated than necessary because

> "There's no direct bus from the train station to the hospital…you have to go from the station to the town and change buses to get to the hospital…"

Two relatives reported difficulty in visiting, either because of their own health (one had Parkinson's disease) or because they were also a carer for another close family member (a disabled daughter in this instance). Once more indicating why patient (person)-centred care must also involve and consider the impact on relatives or other care partners. Other issues raised, in this instance largely by relatives, included the following

> (Spouse) "I did think for me, as a visitor, the space between beds was horrendous" (Patient) "Especially in the far end of the ward" (Spouse) "I had to sit in front…you know? You couldn't get to the side…" (Patient) "…in some places the visitors had to sit out in the middle of the ward... very difficult for the staff…"

Bed space was also identified as an issue in the study by Douglas and Douglas (2005). This was raised as an issue in this AR VPJ study but was not immediately resolvable as Figure 4-28 shows

45. Space between beds was described as 'horrendous' – not enough room for patient/nursing staff or visitors	Patient interviews	**Closed but noted:** No solution to this problem other than ensuring minimum bed space criteria is met in accordance with infection control/health and safety regulations. New build has single rooms. **WS/VNP**

Figure 4-28: issue identified by service user insufficient space between beds

> (Spouse) "…from a visitor's point of view I had to walk to the café to get a drink …I would quite happily have paid for a coffee. They come round with a trolley for patients…long walk to the café…especially for older visitors…"

The indirect request in the last narrative for visitor access to drinks was also raised under catering; issue 49, in Figure 4-20. This is another issue that highlights the importance to patients of ensuring the well-being of their visitors.

Theme 13: Car Parking

Five patients, or their care partners, mentioned car parking and their narratives are also available in the interview report (Appendix 29). The main issue concerned cost, for example *"…the price of the parking…. £6.00 a day for 8 weeks…"* Similar to the comment about Patient-line, one patient had remarked that *"...if the money was ploughed back into the hospital I wouldn't mind..."* However, the multi-storey car park at SE NHS Trust meant finding a space to park was not an issue and this was valued. Two additional, separate comments were

- "(Patient)… it was a long way to walk, I must admit though on some occasions you've got the French doors from the day rooms that open right out onto a car park…"

- (Spouse) "…I ended up using the Park and Ride as often as I could, although it's not available on Sundays. Principally because I - generally speaking - was there for well over four hours, which was going to cost me £6.50, and Park and Ride was £1.50, so that worked quite well…although it was a bit of a nuisance when you were carting stuff around… there's a parking fee at all times…concessionary parking…doesn't occur now…"

Yet more issues for consideration had been highlighted (Figure 4-29). The AR VPJP team had agreed there was little that could be done about parking costs at the time, but the issues relating to concessions, the availability of Park and Ride on Sundays, and ways of improving access, for patients, or visitors, with reduced mobility, would be further explored.

69. A number of patients recalled the long distance from the car park/entrance to the ward (admission and discharge)	Patient interviews	**Ongoing: BM** to liaise with **PALS.** One possible solution might be provision of a volunteer driven electric buggy service between car park/hospital/clinic/ward
70. Wheelchairs for patient use not always available.	Patient interviews	**Ongoing: BM** to liaise with **PALS.**
71. No direct bus to hospital from train station.	Patient interview	**Issue closed but noted:** Unable to resolve as responsibility lies with local Council.
73. Patients and visitors felt the parking was expensive. Would be more accepting of the charge if some of the money was being utilised by the hospital.	Patient interviews	It is believed that some money does get paid back to the Trust by Q Park – **BM** to obtain further information

Figure 4-29: car parking and access issues reported by service users

Theme 14: Discharge

Patients' experiences of discharge varied considerably. Extracts from 6 patients were included in the Report (Appendix 29) as they provided specific issues which needed to be addressed. Amongst these included the availability of wheelchairs as one patient's friend had only been able to find a broken wheelchair when they had come to collect them. This had meant that the patient, with significantly reduced mobility, had to walk

the long distance from the ward to the car park. Issues highlighted here also contributed to those identified from the narratives themed under car parking as issues 69 and 70 (see Figure 4-29). Even so, the availability of wheelchairs is an example of an issue also identified by staff as Figure 4-30 illustrates.

54. Wheelchair provision	Mapping	**Ongoing:** Looking at long term wheelchair provision with EM Centre **(OT)**. **Issue resolved**: Short-term loan for inpatients has improved **(OT)**

Figure 4-30: issue identified by service providers

Conversely, another patient recalled

> "…no problems with discharge… just had to arrange for district nurse…came out in a wheelchair straight up to the car, no problem…so I came out in slippers, pyjamas and a dressing gown…".

Yet another told his story of how he had been discharged to another hospital, something which he described as a very negative experience and one which since then had strongly, and adversely, affected his perception of any future in-patient experience. He stated that he had

> "…hated the experience … had felt very lonely … the telephone and television had cost a fortune (£75 - added) … the family had been unable to visit because of the distance …the food had been awful … and no follow up referral had been organised for a district nurse visit after discharge".

The patient had to arrange the latter from home. He also mentioned that more support, both emotionally and psychologically would have been very welcome during this time.

72. A number of patients reported receiving poor care following transfer to other hospitals.	Patient interviews	**Issue closed/awareness raising:** Unable to resolve - other than to ensure patients are fully aware of reason for transfer and what to expect.

Figure 4-31: poor after-care, an example of an unresolvable issue

As Figure 4-31 illustrates, the issue identified from the patient's narrative in this instance was unresolvable. This was because it was out of the jurisdiction of the SE NHS Trust. Nevertheless, the VPJP team were also aware that issues existed in relation to patient transfers from SE NHS Trust to community hospitals as the issues in Figure 4-32 show.

57. Community hospital admission criteria limit access to amputees	Mapping	**OT** discrepancy over definition of *rehabilitation* for patients continues – no immediate solution. Problem generally arises because of patient social issues
58. Community hospital bed availability (delays discharge or transfer)	Mapping	**Ongoing:** Community hospital bed availability is an ongoing problem which is likely to remain unresolved because of probable future cuts in the number of beds by SHA/PCTs. Historic issues between Social Services and hospital regarding provision/funding/availability of longer term care also continue.
59. Unpredictable length of hospital stay (amputees)	Mapping	**VCS** reported that of SS Housing is currently looking into assistance for patients who have no fixed abode. **Ongoing/awareness raising: VCS** recommended that, whenever, possible details of patients who are likely to experience social problems on discharge be flagged up to **Discharge Liaison,** including prior to admission if possible

Figure 4-32: issues related to in-patient hospital admissions as identified by service providers

Another patient had felt they were

> "pushed out of the hospital far too quick…it was only a week, I think, I was in, but there was a lot of shuffling going on with the beds, a lot of shortages of beds, I think they'd closed down ward X but they hadn't stopped…the admissions that were coming in…"

Although this patient's experience did not result in a specific issue, this did relate to an aspect the current patient journey that had been identified as a problem (Figure 4-33) not only by the VPJP team but also the wider SE Trust.

60. Delayed/untimely discharges	Mapping	**Ongoing:** ongoing review on a Trust-wide basis through rolling Audit reviews. **Discharge Chaser/XX Trust Management/Matron, Surgical Directorate/Matron, Orthopaedics/Trauma**

Figure 4-33: issues concerning patient discharge identified by service providers

The contrasting narratives in this section, like those of others, once more reveal a variety of ways in which the vascular patient's journey can be influenced. They also clearly emphasise the depth of insight into hospital practices and services that many service users possess as a consequence of their first-hand experiences. This strongly indicates the value of listening to their stories when seeking improvement.

Theme 15: Transport

Five extracts were identified under this theme. Some of the issues raised also related to the section on visiting.

1. (Spouse) "The only downside we've got is transport." (Patient) "Yes, transport has got diabolical…it don't turn up…the system has been changed…it's now done from a call centre. For example, they said I could come home…that was 12 o'clock…we arrived here at quarter to half past nine in the evening…and that was in a regular taxi." (Spouse) "Well, the last time … was going in, it was

arranged that … had transport…the hospital rang at 11 o'clock in the morning…can you be in hospital by 2 o'clock we are operating on you today…transport booked…half past one they hadn't arrived…I rang them up, it's on the way…half past two it hadn't arrived…had to ring hospital to tell them …wouldn't be there for the operation so they had to re-alter all their lists again…"

2. "…my son or daughter has to lose time from work to take me…then they have to spend on petrol … appointments on all different days…I'd rather have my son or daughter take me because they can come in with me…what little bits I didn't understand or didn't quite hear, because I am deaf in the one ear...they listen and they know everything that's going on. If I'd have had public or hospital transport, which a lady was telling me about…, I wouldn't have had my daughters with me."

These issues later received attention from the VPJP team. Transport issues had already been highlighted to SE NHS Trust through other means, and the service was currently being reviewed. The team was also in the process of addressing the second issue, awareness of which already existed, by introducing, whenever possible, same day appointments through a new central booking system which was soon to be implemented within the Trust.

4. Several patients had a considerable distance to travel to XX and would appreciate same day appointments e.g. consultant appointment, pre-op assessment, duplex scanning.	Patient interviews	**Ongoing:** Same day, drop-in, pre-op assessment commenced 5/12/07 but has not proved successful for patients with PVD. Several patients declined opportunity due to time factor. **Ongoing:** Same day appointments for 4 key diagnostic tests under review through **No Delay/18 week** project **VCS/IPM**
68. Hospital transport not turning up when booked through central booking system – missed theatre slot; missed appointments.	Patient interviews Project Team	**Ongoing: BM** to liaise with **CEM** for possible solutions. **CVS** felt it would be useful if electronic records could have an indicator to identify those patients who rely on hospital transport

Figure 4-34: hospital transport issues as identified by service users and providers

Theme 16: Outpatient appointments/follow-up care

This final theme provides a somewhat rare insight into patients' experiences following their discharge from hospital. For this group of patients, who live with a long-term, debilitating and complex condition their journey was ongoing as these narratives, and others in the interview report will illustrate. Twenty extracts are included under this theme in the Report from pages 31-34 (Appendix 29). A selection of these is included to demonstrate, once more, the variations between and thus individuality of experience within one single theme. These narratives also provide an otherwise rare and poignant insight into patients' and their families' experiences of living with PVD.

1. (Patient) "…we had to have a nurse in every day to dress it (the wound)…keep an eye on it…still going backwards and forwards to SE NHS Hospital every other week just to check…"

2. (Patient) "…the hospital are so worried about that leg… me damaging it…(Consultant's – added) last words to me, me main doctor…he said 'wrap this other one up in cotton wool, that's the one that you've got to look after 'cos, he said, if you do something to that one there's no bypass or anything for that one.' (Partner) '…it is scary, it **is** scary…"

The patient in the narrative extract 2 was still coming to terms with an unexpected, emergency below-knee amputation of his good leg, and, very understandably, was keen to obtain further information about a spinal injection he had heard of from another patient which might prevent him from losing his remaining leg. The following extract also provides a very brief insight into how his health issues were significantly impacting on his life

"…I've gone back to the same scenario which I had before the leg was removed, even now…when I'm at – (local) hospital…I put my leg on and I walk so far then I've got to sit down…this foot will absolutely go white, it will only let me do so much…it's definitely a problem…' '…I'd like to go back to work if I could but I can't see it because the job…me damaging it..." (This patient was a carpenter)

Two of the 11 patients mentioned that they had acquired an infection

" …I was sent home with an infection…xx rang me and said that they'd had the results of a swab that they'd taken while I was in…it turned out that I had an infection…so I went on two doses of antibiotics at the same time…"'

"…when I went down with the MRSA our own GP came in and prescribed antibiotics…the leader of the district nurses at that surgery…she rang the vascular team up…told me the ambulance will be there by 5 o'clock…"

Other issues highlighted by the patients, or their relatives, included those such as the sourcing of mobility aids from the Red Cross, rather than the NHS; hospital waiting times for follow up appointments; the implications of repeat hospital visits on other family members, such as time off work, when patients require assistance; one patient missing essential regular check-ups at GP surgery because they could not afford the cost of travel; accounts of debilitating pain, including

"…I can walk to the supermarket, well nearly get there, just got to cross the road…I'm scared of crossing roads so I wait till there's a crowd there, then the pain's eased so I can dash along with them…It is a bit embarrassing when you won't cross the road and you've got your grandchildren and they say 'come on … it's clear now' and I have to say 'hang on'…"

"…I'm better with one leg…but I'm still waiting for treatment for the right, the right leg is getting worse all the time, in fact it's a lot worse now than when I went in hospital ages ago…I can hardly walk now…it's so painful…I don't like being so helpless and this leg is the only thing that's stopping me walking about."

Another patient revealed how his surgery had continued to strongly affect his way of life and well-being since returning home:

"…even now you get that sort of emotional thing, nobody had told me any of the effects…this is the annoying thing…the surgical side, great; psychological, nil. There was no follow-up at all on that. It was only by the grace of God he'd (a friend – added) had actually the same operation as me…that I knew then that all the things I had been experiencing... the sense of isolation…all the jobs that I used to do (and couldn't do post-operatively, friend gave booklets and patient started to keep a diary which helped – detail added) …you feel cut off, awful because everybody else is running round behind you…doctors 3 times a week for dressings…you feel so helpless."

This patient's experience, as previously mentioned had contributed to a number of issues being raised. These were still receiving attention several months later as the following example from the Prioritised IAS document, dated 22nd July 2008, in Figure 4-35 illustrates.

Issue	Key Points	Action Required	Lead
35. More written and verbal information for patients on plan of care, future prognosis, adverse effects including possible psychological adverse effects of anaesthesia and the do's and don'ts of post-operative recovery, etc. 36. Overall communication was good but at the bedside patients reported that the doctors sometimes talked over them to other members of their team, in a language they did not understand.	Good communication and information are recognised as central to delivery of high quality care. Despite patients speaking very highly of their overall perspective of communication, both verbal and written, it was felt that there were still some areas for improvement. XXX currently looking at possibility of introducing patient experience tracker, possibly from Dr Foster/Picker for gathering patient feedback following inpatient stay. It is envisaged that this would be a Trust wide initiative with monthly feedback of results to wards.	Review ward round procedure – possible solution suggested that doctors' discussions take place away from bedside, if practical. Review patient literature – VNP been asked to join patient info/consent group which aims to address these issues for XX. Trust to consider purchase of EIDO leaflets. Look at providing information website for vascular patients.	Medical staff VNP/Patient info consent group/consultant/IT Patient Experience Committee – DNS LVC

Figure 4-35: examples of ongoing issues and evidence of orientation to PCC in key point's column through reference to Picker Institute

Figure 4-35 also reveals evidence of the SE Trust's interest in following the principles and philosophy of PCC through reference to the Picker Institute Europe (2011, Sizmur and Redding, 2009) in the key point's column.

And, finally, an insight into the potential consequences which may arise if a patient fails to receive appropriate post-operative follow-up.

(Spouse) "…we went up and saw one of the team…he said, have you had your post-operative scan...we'll organise that and then I'll see you again…should get notification of the scan within 2 weeks. Well, we got notification but the scan wasn't

going to be done for another month, or more…I rang the scan people this time and said…I am certain that my husband should be having a scan within 2 weeks…checked the letter and came back to me saying, yes, you are quite right come up next week…went for the scan…part of it had occluded, it had narrowed anyway in a dangerous way…back in (hospital for further surgery) within the week…What worries me…if we hadn't actually made the move to say can this be checked, it would not have been found and, I'm afraid it would have been an emergency, so that's a little bit concerning, especially as after this second op, although everything appears to have gone absolutely smoothly…nobody's seen Dave (name changed), neither our GP nor anybody at the hospital, and that's since May, and I don't know if there is supposed to be any follow-up." (Interviewed in October 2007)

By way of response to the issues that had been highlighted by these narratives, the VPJP team produced new guidelines. These were ratified and introduced in February 2008. As Figure 4-36 illustrates, these make clear that all patients who had undergone surgery for a femoral-popliteal bypass graft, or other vein graft, required a post-operative check. These guidelines aimed to mitigate the risk of another patient experiencing a similar issue.

Vein Graft Surveillance Guidelines

- All vein grafts must have a 6 week post operative graft surveillance duplex scan.

- If the 6 week scan reports any abnormality, the consultant will review the report, organise any relevant treatment and request a further duplex scan.

- If the 6 week scan reports no abnormality the patient should be booked for a 2nd surveillance scan in 6 months by the Vascular Technologist.

- If the 6 monthly scan reports no abnormality the patient should be booked into the Doppler Clinic for 6 monthly ankle brachial pressure measurements.

- If the 6 monthly scan reports any abnormality the Consultant will request an appropriate follow up scan.

Figure 4-36: vein graft surveillance guidelines – a response to post-discharge issue reported by service user

Issues relating to the ongoing care of these patients had also been identified by the VPJP team, albeit of a different nature and from a different perspective. Figure 4-37 provides three examples.

65. Some patients reported delays in their out-patient follow up, or no follow up appointments.	Patient interviews Project team meeting	**Ongoing:** Possible solution – **VNP** to liaise with **BM** with regard to possibility of dedicated Vascular Nurse Practitioner phone line for patient access. **Ongoing: VNP** currently looking at improving follow-up for diabetic patients.
66. Delays in Vascular Nurse reviews	Mapping	**Ongoing: VSN** – from 3.3.08 clinic day changing to Tuesday in attempt to address problem. **BM/VSN** to confirm correct coding for non-consultant led clinics.
67. Nurse-led clinics in community hospitals	Mapping	**Issue closed but noted**: No immediate solution because of funding/resources but included in vision for future service improvement

Figure 4-37: examples of post-discharge issues identified by service providers

These few extracts and others contained within the interview Report (Appendix 29), in addition to further insights obtained when carrying out the evaluation, make emphatic the significance of ongoing support, care and treatment for patients living with PVD. Yet, no evidence was found when reviewing PCC literature of any study that had examined post-admission experiences, or the experiences of patients with PVD. Whilst this may be due to the focus of this study's literature review, which did not specifically examine PCC in terms of patients' post-hospital discharge experiences, these are now identified as two significant gaps in light of the findings of this AR VPJ study. The narratives captured in this study make clear that these patients' journeys did not end when they left hospital. Indeed, these stories indicated they will be life-long. Thus there is clearly much that still needs to be learnt from patients about this aspect of their journeys if healthcare and services in acute and primary care sectors are to be effectively improved and the principles and philosophy of PCC fulfilled.

Discussion

Limitations: strengths and weaknesses of methods

The richness and depth referred to in the literature in relation to semi-structured, in-depth qualitative interviews is clearly evident amongst the above themed sections. The diversity, individuality and richness of the findings also makes apparent and supports the view that the sample size in this AR VPJ study was adequate. This is further supported by evidence of the influence of these narratives as points of learning or catalysts for change, as was their purpose in this study. Moreover, as the process of analysis indicated, it might have been intensely challenging to attempt to keep interviewing until a point of saturation had been reached.

Nevertheless, a brief overview of each the methods used during this AR VPJ in terms of the strengths and weakness of each is provided to acknowledge potential limitations of this study, and this proposed action research patient journey approach to improvement in healthcare. The first, in Table 4-2, focuses on the three principal methods mapping,

sampling and service user interviews; Table 4-3 briefly examines the pros and cons of participant observation, project team meetings and written notes as the data sourced directly from the action researcher or Patient Journey project team; and Table 4-4 briefly summarises the pros and cons of the data analysis reports and IAS action planning document.

Strengths	Weaknesses
Mapping – Provides real-time insights into current patient journey – strengths and weaknesses Enhances understanding of each other's contribution and roles Enhances teamwork	Challenging in healthcare to bring all members of a group together Time constraints Requires participation of majority of group for accuracy and effectiveness May be disagreement amongst team members about issues identified Time required to analyse findings and produce as report
Numerical geographical and biographical data – Helpful for identifying specific criteria for patient sample, Enables key characteristics of participants to be acknowledged, roles, grade and so forth. Enables issues related to specific groups or disciplines to be revealed	Can be restrictive, e.g. either too much or too little data, challenging to prioritise for patients with complex conditions, when used for identifying patient sample. Challenging to depersonalise when used to identify participants' roles. Descriptive and explanatory, rather than evidence
Sampling – Enables identification and recruitment of representative patient group according to the service provider perspective. Sense of ownership, enhances involvement and motivation to participate - "our patients".	Challenging to reduce team contributions to a manageable and realistic sampling matrix May not take account of all team member's perspectives or priorities Potential to introduce bias if not closely monitored and facilitated
Individual Interviews – Enables rich, detailed and poignant insights into service user and service provider experiences and perceptions.	Participant may feel coerced by researcher, or may not feel able to disclose sensitive or personal data, or the truth as they see it. May fear consequences of negative reporting in terms of future impact on care. Richness and depth of data collected is reliant on the skill and approach of interviewer and their ability to interpret and analyse data without exerting undue influence. Data from healthcare experiences are complex, varied, individual and emerging themes commonly lack clear boundaries Interpretation by analyst (AR) is likely to be different to others due to varied perceptions, interpretations and priorities for patient journey

Table 4-2: strengths and weakness of principal action research Patient Journey data collection methods

Tables 4-2, 4-3 and 4-4, whilst highlighting potential limitations of this AR VPJ study are also intended to mitigate risk of pitfalls for any future researcher interested in conducting an AR PJ study.

Strengths	Weaknesses
Participant Observation - Gained from first-hand, real time experience Enables actioner researcher (AR) to gain a sense of the 'field', and develop 'insider knowledge'; essential for identifying key stakeholders, building relationships and gaining trust required for collaborative teamwork	Observer (AR) may introduce bias or influence Past experience and, or, knowledge claims may adversely influence understanding and result in misinterpretations, inaccuracies in reporting or study findings. If critical observer may prevent teambuilding
AR/PhD journal and field notes – Provide an audit trail of the AR PJ process as experienced and described by the action researcher. Detail of highs, lows, challenges, key milestones, the personal impact of the research experience. Field notes enable key points, themes, feelings, sense of occasion and experience to be quickly captured	A biased perspective. Personal to the researcher. Subjective. Anecdotal rather than empirical findings unless supported by other emergent data
VPJ team meetings – Knowledge building, team-building, empowerment, learning from and about each other, developing shared visions and goals, collective understanding of current patient journey, support, shared responsibilities for change Meetings notes – peer reviewed audit trail of PJ process. Captures key issues and points of discussion. Record of achievements and progress.	Existing team dynamics, organisational or group politics or culture, and/or hierarchical boundaries may impact on participation in or contribution to meetings. Facilitator may not be sensitive to these issues, or inappropriately biased in their approach Time constraints preventing attendance Meetings notes make it possible to identify key contributors – may not be appreciated by all Knowledge that points will be recorded may prevent some team members from contributing

Table 4-3: strengths and weaknesses of data produced by action researcher and Patient Journey project team

Tables 4-2, 4-3 and 4-4, whilst highlighting potential limitations of this AR VPJ study are also intended to mitigate risk of pitfalls for any future researcher who is interested in conducting an AR PJ study.

Strengths	Weaknesses
Mapping and Interview Data Reports Provide of real-time, detailed and meaningful insights into a current and local patient journey. Rich source of catalysts for change	Potential for AR or PJ project team to introduce bias when selecting issues from analysis reports of mapping or patient interviews and copying and pasting into Issues and Solutions document. However risk of this is mitigated through peer review of IAS document and interview and mapping reports
Issues and Solutions (IAS) Document Readily accessibly data source of current issues with current patient journey Action planning document Record of PJ team achievements and progress Motivational driver for change Sense of well-being when change attained	Negative emphasis due to its focus on issues to be resolved May cause frustration when change cannot happen Number of issues can seem overwhelming/ unmanageable Could be demotivating – all problems as ready reminders in one place

Table 4-4: strengths and weakness of data analysis reports and IAS action planning document

As such, in this context it is believed that the sampling, interviewing and analysis methods applied were appropriate and suited to their purpose in an AR PJ study. Methods which are integral to the Patient Journey model, as advocated by Campbell et al (2004). Although this was modified to fulfil the aim and objectives of this study listed at the end of Chapter 2, the findings and outcomes thus far of this AR VPJ, despite the challenges faced along the way, clearly verify the transferability of the Patient Journey as a patient (person)-centred approach to health care and service improvement and practice development (Manley et al, 2005, McSherry and Bassett, 2002, McSherry, 2004, Page and Hamer, 2002). The following final Table 4-5 highlights the strengths and weaknesses of the overarching method, the action research Patient Journey, as it was experienced in this AR VPJ study.

Strengths	Weaknesses
Combined action research and Patient Journey Involves those with first-hand experience of a local patient journey in the review and improvement of that journey. Promotes a collaborative, democratic and participatory approach to change and improvement in healthcare. Multidisciplinary and inclusive rather than single discipline and exclusive Promotes and enhances teamwork through better understanding of each other's roles and through collaborative working towards shared goals Fosters supportive and open culture Patient Journey element provides a patient-(person)-centred framework for conducting action research in healthcare. Enables real-time, detailed and meaningful insights into a current and local patient journey. Much improved understanding of service users' experiences, not only of services and care but also of living with PVD Reveals positive and negative aspects of current state; a more balanced perspective. Humbling, inspiring and poignant rich insights into current experience – potential to facilitate and inspire transformational learning Rich source of catalysts for change Enables solutions to be quickly identified and change quickly implemented, where this is possible, by those with first-hand insights, knowledge and experience of that patient journey as service providers Empowering, promotes ownership, leadership and responsibility Overwhelming sense of achievement when change happens; shared decisions and goals	(from perspective as genuine outsider AR PJ facilitator) Considerable preparatory effort – potential to fall at first hurdle Challenges associated with securing access, ethical approval Periods of stagnation, frustration, isolation Challenges with identifying key stakeholders and securing engagement Susceptible to existing barriers to change Susceptible to differing perceptions, interpretations or priorities, local politics, local cultures and hierarchies Heavy reliance on the active involvement and participation of AR PJ team members Time constraints and additional demand on team members' time Challenge in the NHS of bringing a multidisciplinary team together Heavy influence of organisational culture, systems and processes Heavy reliance on attitude, characteristics and approach of AR/external PJ facilitator Heavy reliance on attitudes, characteristics and approach of team members Susceptible to dynamics and collective motivation of PJ project team Subject to frequent changes in key stakeholder membership

Table 4-5: strengths and weaknesses of the Action Research Vascular Patient process as it was experienced by external AR VPJ project facilitator

Researcher journal: personal narrative

In keeping with the nature of this chapter a brief insight into my perspective as action researcher, VPJ project facilitator, but most significantly as interviewer in this context, is offered. The following is taken from my PhD journal in which many of the experiences, high and lows and major milestones associated with this study, and their impact during this period, were captured and reflected upon.

> "The interviews with the participants have been a humbling experience. They have broadened my understanding of what it must be like to live with peripheral vascular disease (PVD). This is evidently a highly debilitating, sometimes very frightening and intensely painful condition about which there is little information. I have found it hard to believe that PVD is not yet acknowledged as a chronic condition as there appears to be no escape from its effects.
>
> These patients had undergone complex surgery and, for some, traumatic experiences, but all appeared incredibly stoic as they recounted their healthcare journeys to me. I believe this was probably due to the fact that they had generally felt well supported and well informed pre and post-operatively. On the whole they were full of praise for the team, but particularly xx, xx and xx. Many had required a stay in intensive care or high dependency units; experienced critical and life threatening deterioration in their condition, yet were still determined to fight their way back to 'normal' lives, as far as their condition would permit. And, they retained a positive outlook.
>
> Their stories strongly highlighted the significance of good relations with their healthcare professionals. Not surprisingly, each participant commented on the care and support they had received, particularly from the doctors and nurses. It was clearly evident how much they had valued this and the support of their family and friends. Their stories also made very clear that having accessible and supportive health professionals was of paramount importance to both patient and their carers during difficult times. I feel privileged to have met these people and to be conducting a study with health professionals who are held in such high regard by their patients." (Extract from PhD Journal, 2007)

This personal narrative is included because the discussions in this chapter have focused on demonstrating how data from service users and service providers provide catalysts for change. As such, because the nature of change is to improve a current situation, and thus in this context to address the negative aspects of vascular patients' journeys, it is recognised that another's perception of these service users' experiences, based on the majority of the content in this chapter, is likely to be poor. This illustrates how negative reporting can, on occasion, adversely bias our perceptions. I was fortunate in this AR VPJ to gather both perspectives. This enabled me to also express to the VPJP team that despite some of the findings, overall their patients could not speak highly enough about them. The gratitude of these patients and their partners to this team for the positive difference they, with only a few exceptions, had made to their care and their lives, was unmistakeable. This positive reporting, as findings from an evaluation in the next chapter will affirm, was also valued and appreciated by the VPJP team.

Sixth modification to the CHS Patient Journey

Campbell et al (2004) advocate that to draw a Patient Journey project to a close, a consensus event should be held, as also noted on the action plan for this study (Appendix 11). The purpose of this is to bring the team together one more time so that they can review their position, collectively plan actions and assign ownership for ensuring sustainable change and improvement. This should, Campbell et al (2004) suggest, take place in the company of an outside facilitator who is also an expert from the same clinical field. Although this idea was proposed to the VPJP team, this was not considered necessary in this VPJ project. Instead, the team chose to continue to meet with me for more than a year after the official sixth, and thus last VPJP team meeting on 29th November, 2007, by which time the six steps of VPJ process had been completed. A follow-up 'away day' was however held in December 2008, when the VPJP team met together at an external venue, with additional colleagues not previously involved in the AR VPJ project, to review their current state. My involvement with the team ceased after February 2009.

Chapter Overview

This chapter has provided powerful and poignant insights into NHS patients' healthcare experiences. From these, the power of the patient's and their relative's voices, as a means to facilitating patient-centred healthcare improvement, and informing healthcare education is clearly evident. This is consistent with the views of Wilcock et al (2003) who also discuss the power of patient stories towards healthcare improvement. These peoples' stories are explicit. They need no further interpretation and, as such, cannot trigger misunderstanding and confusion. But they do need to be contextualised as the example in Chapter 3 illustrated. In addition, although the narratives are only drawn from a small group of patients and their relatives about personal healthcare journeys these, nonetheless, reflect the complex and diverse nature of healthcare. They also make explicit some of the broad and varied range of factors which impact on patients' healthcare journeys, at individual; team; organisational levels and beyond. Many of these findings are also reflected in the literature review, and discussions about the key constituents of patient-centred healthcare. Perhaps most importantly they illustrate the poignancy and richness of data that can be gathered from qualitative interviews and the potential power of the patient's voice as catalysts for change.

But as this chapter has also illustrated, without the active involvement and commitment of their service providers, the AR VPJP team, many of the issues that these service users had highlighted may have remained unresolved. Moreover, as the mapping data illustrates the insider knowledge of the organisational systems, processes, policies and

ways of working that this multidisciplinary team possessed, meant that explanations for many of the issues reported by patients were readily found. This, in turn, enabled effective and appropriate solutions to be more readily identified and actioned.

Fulfilment of research objective 5

The findings discussed in this chapter provide powerful evidence in support of the involvement of both groups in future endeavours to improve PCC. This is because they explain how data from service users and providers does provide catalysts for effective patient-(person)-centred change and improvement in healthcare. Thus these findings have also addressed research objective 5, which was to demonstrate how data from service users and service providers does, or does not, lead to PCC change and improvement.

In Chapter 5, the findings from an evaluation of service user and service provider perceptions of their involvement in this action research Vascular Patient Journey study, is discussed. The evaluation fulfils research objective number 6 of a total of 7 objectives listed at the end of Chapter 2.

Introduction

This chapter discusses the results of an evaluation undertaken during Stage 8 of this action research Vascular Patient Journey study (Figure 3.3, Chapter 3). This fulfilled research objective 6, detailed at the end of Chapter 2, which required an evaluation of service user and service provider perceptions of the Patient Journey process, as it was experienced during this action research Vascular Patient Journey study. The findings contribute towards fulfilling the aim of this study.

Action research Stage 8: qualitative evaluation

As demonstrated by the discussions and activities explained in previous chapters, evaluation is an ongoing and integral part of the action research process. Indeed, as Freshwater (2005) suggests, the largely self-evaluative nature of action research, as also demonstrated by its ability to effect change, is one of its defining characteristics. Nevertheless evaluation in this context related to evaluation of participants' perceptions of the AR VPJ process rather than an element or outcome of the AR change and improvement process. Participant responses should indicate whether, irrespective of any change or improvement secured through the AR VPJ process, they perceived their involvement to be worthwhile. Thus further guidance and clarification had been sought from the literature. Essentially, as Patton (2002), and the Swiss Evaluation Society (SEVAL, 2000) confirmed, this evaluation should only be undertaken if the findings would be useful, if it was feasible, particularly in terms of time and cost, and if it was conducted fairly and ethically.

In terms of usefulness, the aim of this evaluation was to strengthen the findings of this study by also providing the participant perspective of the AR VPJ process. It was feasible because it involved people who were already participants in this study. Cost was minimal, other than printing, postage and researcher time. The impact on participant time was kept to a minimum by providing different options for providing responses to a set number of open questions. As with all activities undertaken during the AR VPJ project by this stage, this evaluation was conducted fairly and ethically in accordance with the terms agreed for Local Research Ethics Committee (LREC) and Research and Development (R&D) approval.

As will be demonstrated, the responses, whether sourced through the evaluation questionnaire, or an interview, provide an authentic insight into the experience of participating in this action research VPJ project as a service user or service provider.

Service provider evaluation

The 6 questions used in the service provider evaluation were influenced by an unpublished '*Patient Journey Evaluation Report; Final Report'* produced by Campbell and Lloyd (2007) for the CHS Trust, a copy of which was forwarded to me by Campbell in March 2008. This is not included as an appendix because it was not informed by data from this AR VPJ study and it belongs to the CHS Trust. Nevertheless, this document included the findings of an evaluation questionnaire completed by 53 (46%) out of 116 CHS Trust staff who had previously been involved in one of sixteen completed PJ projects. In CHS these staff had been asked:

1. "What do you understand by the term Patient Journey?
2. How actively involved in the PJ project would you say you were?
3. What do you consider were the good aspects of the PJ Process?
4. What do you consider were the not so good aspects of the process?
5. How do you think we could improve things for the future?" (Campbell and Lloyd, 2007, p. 10)

In keeping with the central aim of this study, which had been to explore the Patient Journey approach to patient-centred healthcare improvement, it was considered reasonable to use the questions as this enabled consistency with the CHS method of evaluation. Moreover, these questions had already been tested. Use of the CHS method would also make comparison of evaluation findings possible at a later stage if time permitted. However, in this AR VPJ study, a sixth question had been included. This asked service user participants:

6. What was your overall impression of the Patient Journey?

The aim of this additional question was to encourage all VPJPT members to express their overall opinion of the Patient Journey process; which might not otherwise be expressed in answers to the first 5 questions. VPJP team member responses would be gathered either through a questionnaire (example Appendix 32), anonymously if preferred, or semi-structured interview based on the same questions, according to preference and in recognition of time constraints. This was in accordance with the terms of LREC approval.

Data collection

Questionnaires were distributed by email to the 25 VPJP team members on 13th May 2008 (Figure 5-1).
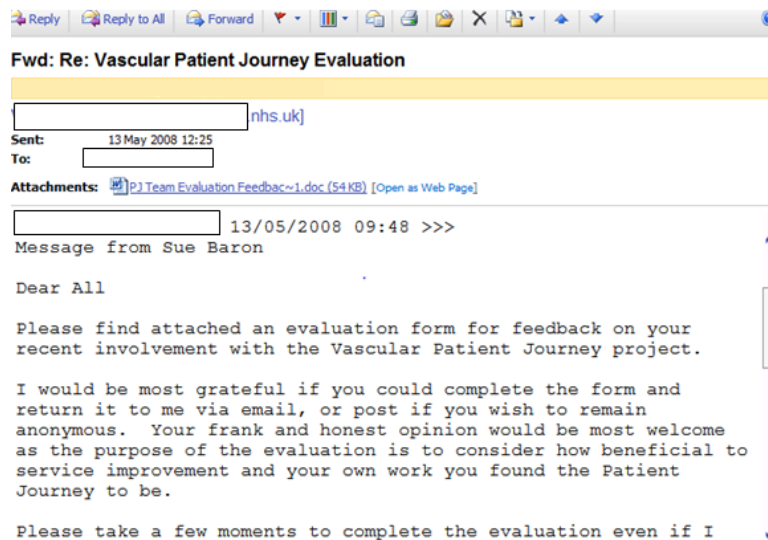
Figure 5-1: email request for evaluation on action research Vascular Patient Journey process

Six VPJP opted to complete questionnaires (example Appendix 32), none anonymously, and quickly returned these via email as Figure 5-2 illustrates. This also demonstrates minimum impact on participant time.

Figure 5-2: evaluation – quick to complete

A further 11 of the 25 VPJP team members opted to participate in a face to face interview, providing 17 evaluation responses (68%). Interviews took place between April and June, 2008 and were recorded using the same digital device used for gathering Vascular Patient Journey interview data. Interviews were held in various locations within the SE NHS Trust, to suit participants, and were conducted using an informal approach consistent with the underpinning philosophy of this study. The duration of the interviews ranged from 15 minutes to 1 hour and 7 minutes. All participants gave their written consent to participate and for their data to be shared (Appendix 31).

After each interview, the digitally recorded data was transcribed verbatim, by me, in accordance with earlier practice and ethical approval. Responses, in this instance, were

simply categorised according to the six evaluation questions. Inductive analysis was used but only to identify any common themes amongst the responses. A summary of the combined findings of interviews and questionnaire, which are not differentiated according to source but synthesised and structured by the questions and emergent common sub-themes, follows:

Q1. What do you understand by the term patient journey?

A process

Twelve of the 17 respondents readily aligned *'patient journey'*, at least initially, to a process, for which a variety of terms and descriptions were used including:

- "the whole pathway";
- "the way the patient processes through the treatment system"
- "patient package"
- "all stages of patient care"
- "the process in which a patient passes from initial contact/referral through to discharge from acute care"
- "the journey the patient takes..."
- *"GP referral – hospital – investigations – diagnosis – discharge".*

According to 8 of the respondents this journey begins at the point of GP referral; a finding consistent with those of the mapping exercise. Another respondent suggested this starts *"from the onset of symptoms".* Interestingly no-one described a pathway that extended beyond discharge. This supports an earlier recommendation for more research into the post-hospital discharge patient experience. As this study has demonstrated from the insights provided by just one small sample of patients, there is much that can be learnt from such data.

An experience – "seeing the patient as an individual"

Six respondents (including two of the 12 who defined this as a process) used the term *"patient experience"* to explain the patient journey. Their responses had been further explained by comments such as

- "patient used to be viewed as a commodity, now we are here for the patients...every aspect - a holistic view of the patient experience" (Lead Clinician/Lead Vascular Consultant)
- "how they get through the system and come out the other side" (Vascular Nurse Practitioner)

A Superintendent Radiographer elaborated yet further

- "The patient experience; right from the very start of their initial contact with the medical profession – their experience through the system physically and

emotionally. Patients are very different aren't they in the way they react – you know? Everything from hospital phobia through to complete confidence in the system...we must be aware of what patients are going through – how they perceive your area, your department – to perhaps make life easier for us all" (Superintendent Radiographer)

The latter comments are perhaps reflective of an increased recognition by the VPJ team that the patient's journey, at least in this context, had become more humanised and patient-centred. As one respondent's succinct response affirms; the patient journey was

- "…now about seeing the patient as an individual" (Vascular Nurse Specialist).

A response that is also indicative of the value of underpinning an action research healthcare improvement project with the philosophy and principles of PCC.

Q2. How actively involved in the PJ project would you say you were? Please explain the extent of your role.

Eight of the 17 respondents described themselves as actively involved in the PJ project and referred to the contributions they had made. The Lead Nurse Practice Development reported that she had held a *"minor and irregular advisory/consultative role"* (Appendix 32, Figure 5-3 and question 2)

1. What do you understand by the term patient journey?

The time from first symptoms and seeking help from GP to final resolution of the problem after surgery and full healing has occurred

2. How actively involved in the PJ project would you say you were? Please explain the extent of your role.

Minor and irregular advisory/consultative role in steering group meetings only

3. What do you consider were the good aspects of the PJ Process? Please list

Clarity about the process; clear progress notes after each meeting and objectives for future actions at each stage; adequate level of consultation involving many stakeholders; researcher listening and responding to concerns whenever they arose; clinician-led development. The defined patient group.

Figure 5-3: example of textual evaluation responses

One of the Vascular Consultants described himself as *"not very involved".* One of the Ward Sisters explained that she was

- "...not as active as I wished I could have been and feel I could have had a lot more to offer if I could have got away from the ward...always included in ward staff numbers..." (Ward Sister)

The explanation offered by the Ward Sister for her limited involvement is consistent with the findings of former empirical investigations into PCC highlighted during the review, and this AR VPJ study's analysis of service user narratives discussed in Chapter 4. These, together with findings from studies critiqued in the literature review (West et al, 2004, Reeves et al, 2005, Webb, 2007) repeatedly identified nurse workloads, staffing levels and time constraints as issues that negatively impact on healthcare delivery, patient care and patient and staff experiences. Significant issues which have been raised repeatedly since the introduction of the Labour Government's NHS modernisation agenda in 1997, as the introduction, literature review and patient interview and discussion chapters also highlight. Yet this issue has yet to be adequately addressed (Coulter, 2002; DH, 2008a, 2008b; DH, 2009b; Cornwell and Goodrich, 2009, 2010). As this Ward Sister pointed out this project provided her with an opportunity, which she missed, for her to be

- "...specifically looking at the role of the patient within the ward environment, and the nurses' and patients' perspectives" (Ward Sister)

Two further Ward Sisters, who had also set out to actively engage as VPJP team members failed to participate or provide evaluative data.

The replies to Question 2 also highlighted another group of frontline staff whose voices are rarely represented in healthcare reviews or redesign. Although every effort had been made to encourage administrative staff to actively participate in this project, out of the 4 representatives recruited only 1 had attended VPJP team meetings, and this had been to take minutes. Their responses defined the reasons for their absence as

- "...pressure of work" (Medical Secretary);
- "...work pressure too great to attend...struggle to keep up with emails...been working through lunch hours..." (Waiting List Co-ordinator).

A Vascular Consultant's secretary, who had commenced in post after the start of this project, attributed her non-attendance to

- "...time restraints – difficult to just drop everything and go to a meeting….Yes, I think we do get overlooked sometimes..." (Vascular Consultant Secretary)

The above comment about being *"overlooked"* related to the secretary's appreciation of the recognition of administrative and other support staff by this AR VPJ study, and the endeavours to involve them. Had this approach been more widely publicised across the Trust, and if these staff had been actively encouraged to participate as part of their

professional development, it is thought that they would have felt more able to justify their attendance.

Q3. What do you consider were the good aspects of the PJ Process?
Five main themes emerged from the responses to this question

1. Multidisciplinary/interprofessional working and learning
Each of the 14 responses received to question 3 (the 3 non-responses being from administrative staff), identified the benefit of the AR PJ approach in bringing everyone together in pursuit of service improvement. These also reinforce the view that multidisciplinary teamwork is a key contributory factor to patient-centred healthcare, as illustrated in the findings of this AR VPJ in addition to those by Atwal and Caldwell (2006), Webb (2007) and Aiken et al (2001, 2012), amongst others critiqued in the literature review. The following narrative extracts also indicate the importance and significance of multidisciplinary working is widely recognised and valued when this is effective:

- "...identification of issues that as a team we can try to put right for the benefit of patients" (Vascular Nurse Specialist)
- "...adequate level of consultation involving many stakeholders...teamworking and teambuilding" (Lead Nurse, Practice Development)
- "...involvement of different specialties and professionals...variety, etc" (Physiotherapist)
- "...improvement in efficiency of systems as a result of the multidisciplinary approach to systems analysis and capacity planning, using a model similar to FMEA..." (Failure modes and effects analysis – added) (Pharmacist)
- "...bringing teams together...a chance to stand back and look at the PJ from different perspectives..." (Director of Nursing/Executive Lead)
- "We all got together...all the different areas...that was a really positive aspect because we don't get together at all...would definitely like to see that sort of forum continue. We are very specific in our own little areas aren't we? Sometimes we don't appreciate what also goes on at the beginning or end of the journey." (Ward Sister)
- "...all people in the room discussing service issues...significant 'buy-in'" (Service Improvement Manager)
- "Getting everyone to talk together..." (Clinical Lead/Lead Vascular Consultant)
- "Multidisciplinary approach...key aspect" (Primary Care Nurse Specialist)
- "...it's opened up communication between other members of the team..." (Superintendent Radiographer)

2. Patient and spouse/carer involvement
Patient involvement had also been highly valued by members of the VPJP team who acknowledged for example, that in this context, it had enabled

- "...identification of issues that are important to patients...privilege of reading about the patients' experience... issues that as a team we can try to put right for the benefit of patients..." (Vascular Nurse Specialist)
- "...meaningful patient involvement..." (Director of Nursing Services)
- "Initially I thought...what's it going to do because we have played around before sitting in rooms doing patient pathways with post it notes... sitting there thinking so this is what we think...but nothing from patients at all. So this is the value because it gives you patients' views as well – it puts it all together – and – because you get feedback from the patient...it does demonstrate that even though we assume that we've put things in place that will work it doesn't mean they do work...you give people information sheets...they don't necessarily read them and it's good to appreciate that. And it's good to actually pick up and have someone come back because they (patients – added) don't tell us. They very rarely will stand up to us and say 'you're talking across my bed and I don't know what you're talking about' – they don't do that...we're the suits...they're in a vulnerable position – flat in a bed looking up and everyone's around them looking down...This is the chance for them (patients – added) to do it back...We've got some feedback from patients that we don't normally get – it's part of British culture not to complain if, overall, we are happy with the service we get..." (Clinical Lead/Lead Vascular Consultant)
- "'I liked to hear what the patients had to say. It confirmed a lot of things for me – it threw up a couple of new ones as well that I hadn't thought about and again, I kind of felt it was putting us in a privileged position. You know – you (researcher – added) were out there – and they (the patients – added) were in an unthreatened environment and I know what's come back from them has come back with no pressure – it's not me sitting beside them asking them, and it's their honest feelings about how we've been looking after them – and I think that's important. You can give them EXIT cards, and you can ask them but whether they are truly honest or not when it's you (their healthcare professional – added) that's doing the asking, and it's you who's doing the looking after them and that they know they're probably going to have to come back again – I sometimes wonder if they do answer it right. But I think they have here." (Vascular Nurse Practitioner)
- "...it's made me aware of the whole system. It also makes you aware of what the patient is going through in broader terms. I mean if you'd asked me a year ago, before we started this, I'd have said – arrival in hospital on the morning of their examination – but now I am more aware of the lead up to that and the lengthier follow up, so that makes a difference...it makes me want to follow up patients and see what's happening to them...I'm more motivated..." (Superintendent Radiographer)

The significance of patient involvement has been strongly highlighted throughout the discussions in this thesis. The value of this has been reinforced by the service user data gathered during this AR VPJ study, and the narrative extracts included in Chapters 3, 4 and 5. As the introductions to Department of Health modernisation directives in Chapter 1, Appendix 1, and the critique of empirical studies of PCC in Chapter 2, have affirmed, patient involvement has been one of the key goals of patient-centred healthcare modernisation for many years. This goal is one that is strongly supported by this study. As the findings from this AR VPJ study demonstrate when patients, their care partners, and a truly multidisciplinary team are actively engaged in health care and services review, significant, appropriate and relevant change happens.

3. Project management

A further factor which, up to this point, has not been specifically discussed, or explored, is the potential influence of a Patient Journey project manager/facilitator. This is, perhaps, best explained through the following quotes:

- "I think it was really good that we all came together and were able to, and felt quite happy, giving our viewpoints" (Ward Sister)
- "Quality of reports and data really helpful – grounded, real..." (Service Improvement Manager)
- "Thoughtful assessment of our activities..." (Consultant Vascular Surgeon)
- "Clarity about the process; clear progress notes after each meeting and objectives for future actions at each stage; adequate level of consultation involving many stakeholders; researcher listening and responding to concerns whenever they arose...outsider approach" (Lead Nurse, Practice Development)
- "What's good? The fact that it's been so complete, so thorough...I've been involved in these sorts of things before – everyone sits around a flip chart and scribbles things down for a couple of hours and that's it. I think the key thing about this is that it's been very thorough – much more thorough than I have ever experienced before – collecting of information, the meetings and feeding back..." (Consultant Anaesthetist)
- "Informal nature of meetings allowed frank and honest discussion. No element of blame, etc., whenever an issue, shortfall etc., was noted..." (Lead Vascular/ Amputee Physiotherapist)
- "...there's been a hell of a lot achieved in not that many meetings – but – it needed you, or you with the VNP's help...it would need that – you couldn't expect a committee to do it – I wouldn't have thought." (Superintendent Radiographer)

As action researcher and VPJ project facilitator and a key part of the VPJP team, although there were many challenges to overcome during the course of the Patient Journey project, the eventual success of the project in driving forward patient (person)-centred change, coupled with the openly expressed appreciation of the VPJP team, made these challenges worthwhile. In keeping with the narrative nature of this qualitative study, the following extract from the PhD journal provides an insight into some of my thoughts after the conclusion of the AR VPJ project, but during the period of evaluation:

- "…Those who work in healthcare should be helped and encouraged to improve their service, confident in the knowledge that their suggestions or efforts will be acknowledged and perhaps even rewarded. Encouraging employees to become involved in looking at how their own care and services might be improved; and to become effective team members should surely be a fundamental part of any successful organisation? This was certainly something I experienced in the commercial sector as an employee of a successful global, customer focused communications company.
- Why does the NHS have to be different? I have witnessed so much frustration and 'wasted' talent amongst the different types and grades of employees since entering nursing as a student and more recently since qualifying whilst working as a staff nurse and also undertaking this project; so many demoralised and de-motivated individuals who feel 'knocked back' or 'held back' by a lack of resources, a lack of recognition, time, or despondent managers, but it is difficult

to find the answer to how this might be resolved without creating a whole new ethos for working within the NHS. There seems to be an inherent attitude or pattern of working within the NHS that is challenging to change. It is almost as if people just give up because they have told themselves, or have learnt from experience, that it will require considerable time and effort to make any difference – just as I too have found in my experience. In order to have your voice heard or to create any positive change, as I have now learnt, you have to possess dogged determination. But you also need access to the right and effective stakeholders; to be interested in people and in promoting a supportive and open, collaborative teamworking culture. In addition, I also now believe that, despite the perhaps inevitable, early challenges I experienced as an 'outsider', being an outsider is an ideal and appropriate stance for a Patient Journey project facilitator..." (PhD Journal, 2008)

4. Generic potential of the Patient Journey process; role of facilitator

The following comments, made by the Lead Vascular Consultant, the key stakeholder in this AR VPJ project, during a face-to-face interview, were specifically related to my role, rather than project management as in theme 3.

- "The reproducibility of this is in part dependent upon the investigator or the person who's involved...the reproducibility of this as a tool – because it's qualitative – the person who does it is the key element... You know as well as I do that if you go to some meetings that are chaired by a very strong chair – it's good because you get through the meeting but you often feel like you are being railroaded into decisions and actions that you think - 'hang on a minute, we haven't discussed that' - but oomph it's gone. Whereas if you have the meetings where everybody says everything about everything then you don't get through the meetings and don't come up with anything of benefit. So it's that fine line – it's a line that has to be learnt…

  …Because of your approach – you don't give off the 'wrong vibes' – because you take that approach – you let it roll but still keep it driven – you create a situation of somebody that I think, from my point of view, I think 'right, I want to try and get this right; I want to do something; I want to make sure I engage...' Because you don't drive us too hard and because you don't give us grief and stuff, but do still keep pushing us through it creates a sense in us of wanting to do it and wanting to get it right. If the wrong person was doing that – it just takes a couple of sharp little comments and you think – 'ah well, sod you!'...Getting everyone to talk together through a relaxed approach..." (Clinical Lead; Lead Consultant)

These comments provide evidence which indicates that the aim and objectives 1, 2, 3, 4, 5 and 6, of this action research Vascular Patient Journey, as listed at the end of Chapter 2, had been fulfilled. They also demonstrate that a personal objective as AR VPJ facilitator, to facilitate the development of an open, supportive, teamworking culture had been achieved (Figure 3-4, Chapter 3). Moreover, the LVC's comments make emphatic that the qualities and attributes of Patient Journey project facilitators can significantly impact on project outcomes.

5. Impact of project participation on personal and professional development

According to a Consultant Anaesthetist, another 'good' aspect of this AR VPJ study was that although he had been

- "...aware of some issues before - the PJ has had the effect of putting it down in black and white – it's not something we can ignore as much – I suppose it's given us the impetus to sort it out" (Consultant Anaesthetist)

According to the Superintendent Radiographer, his involvement in the Patient Journey project had since

- "...opened up all sorts of doors..."

Additional, perhaps less obvious benefits are poignantly highlighted in the following verbatim extract from an interview with the Vascular Nurse Practitioner (VNP). The VNP held a central role in this AR VPJ; her insider knowledge of the vascular patient journey and contributions were invaluable. The VNP had been assigned the role of Local Facilitator of this Vascular PJ during the first meeting in May 2007 which she did not attend. Her comments provide a frank insight into her perspective and experiences as an active and crucial participant:

- "The suits in the Trust – although they acknowledge you as general people and they know that the Trust couldn't function without all these wee ants rushing around doing what we do – it's nice now and again for somebody to actually know who we are and acknowledge that you exist. That's been quite nice from a selfish point of view for me – you know you can trudge away and do stuff and nobody knows till you're not there what you do – felt that for years – nobody's fault it's just what happens…Because of this – the PJ – I'm known in the corridor now by people who would have never known me before.
  Different departments – when you go to them - they suspect that you've the knowledge and the skills to be able to do stuff – but without turning up with your CV and portfolio... they don't really know... All of a sudden it seems to have actually made it clear that no – she's actually got a very active part in it (the vascular patient journey - added) and knows the majority of the patients from the beginning to the end – I find that they're coming to me now.… You know – they used to ask half a dozen doctors – who'd never even met the patients – about somebody I'd have seen...to make a decision – a clinical decision without even meeting the patient - they don't do that anymore – they bleep me... I think this has improved patient care. It's not increased my patient workload at all because, ultimately all that happened before was that the junior doctors wouldn't want to make a decision and, if the consultant wasn't available; they would come to me anyway. So, no, it hasn't increased the workload. I think it's just made it a wee bit easier for the patient – they're not hanging around waiting ...also if you haven't met the patient (junior doctors - added) how would you know what to do?
  My role is now better identified – my involvement with the PJ has improved my working life and my profile. I'm no longer an anonymous processor – they're now recognising what I do – they're interested in my opinion.
  It has also given me a better insight and understanding of other roles. I hadn't appreciated before the amount of paperwork and the going backwards and forwards of patients' notes – poor secretaries, admissions and medical records – they're going backwards and forwards and I'm not surprised they're (the notes) lost half the time – if you think of how many times those notes move around this

hospital and who's tracing them/who's tracking them then I'm not surprised they get lost as often as they do – I'm surprised they even get where they're supposed to be going...I think as well – the duplex girls – before – not meaning to sound rotten about them – but I thought, expected them to just process the data. But, actually, they do a lot more than that, and they talk to the patient and explain the findings and things like that to them...

This (the PJ) was something different to do – the patients were ok – I'm not indispensable, they can function without me. Nice to get away from what you're doing all the time...I have a very reactive job...bleep going off all the time. This is just nice. I wouldn't shy away from it in the future and I wouldn't take so long to make my mind up like I did this time and have to be dragged half way up north to prove a point! I suppose I was very sceptical because everything we'd tried before just didn't seem to work but, this to me, has shown that if you've got a structure...you can't ignore it. It's almost like – oh – you have to do it now, don't we? We've gone and got 11 patients to say it so we've got to do it. So I would never shy away again from it...I would definitely do it again."

The VNP was pivotal to this project's success. Her insider knowledge of the setting, the team, their current practices and ways of working, gained through her role as a Nurse Practitioner, were invaluable. Her dedication and commitment to her patients, and her role, was inspiring. Knowledge, qualities and attributes ideally suited to the role of local Patient Journey facilitator. Yet, despite all this, and her advanced clinical knowledge, this quote provides evidence that her participation in this AR VPJ study had brought fresh insights and new knowledge. It also provides further verification of the value of bringing a multidisciplinary team together for the purpose of improvement. Particularly when using a method that allows the team to learn from their own patients and each other about what is currently working well, or not so well, and empowering them to collectively make decisions about where change and improvement is required.

Q4. What do you consider were the not so good aspects of the process?

Two of the 14 responses received stated "none" (Vascular Nurse Specialist and a Consultant Vascular Surgeon). A further 3 had commented:

- "Difficult for me to say, maybe time" (Executive Lead/Director of Nursing)
- "I don't think there are any not so good aspects. I think it is very difficult to get all those people together at one time on a regular basis but I don't know what the best way is to get around that" (Ward Sister)
- "Nothing comes to mind...didn't find any not so good aspects. Despite extra work it has value and is worth doing...it crystallises the issues." (Clinical Lead/Lead Vascular Consultant)

Other responses included:

Time constraints; bringing a project team together

- "Difficulty in getting stakeholders together especially during the mapping phase...no easy or immediate access to researcher" (Lead Nurse, Practice Development) (Researcher based in different county some 2 hours car journey

away; also working concurrently in clinical practice in different NHS Trust – comment added) (Appendix 32)

- "Despite variety, continuity of staff was not always apparent...other commitments" (Physiotherapist)
- "Vast number of issues highlighted by process requiring additional demands on time...wonder if there is a more manageable way? (Service Improvement Manager – joined project at sixth VPJ meeting)
- "Peripheral time commitments restricting ability to contribute/commit as would have liked. There were so many issues – no light and shade (75 – added)...difficult to see what would happen...very open ended" (Service Improvement Lead)
- "Difficulties of becoming involved as an outsider" (Primary Care Nurse Specialist)
- "You've probably had a nightmare trying to organise everybody..." When asked if time had been an issue "No, not really because there's been a hell of a lot achieved in not that many meetings – but – it needed you, or you with the NP's help...it would need that – you couldn't expect a committee to do it – I wouldn't have thought." (Superintendent Radiographer)

Trying to bring a team together in a timely manner had, undoubtedly, been one of the greatest challenges of this project.

Perceptions about sustainability

- "...keeping the work going and maintaining the momentum – somebody needs to take it all forward - who leads that – I don't know." (Vascular Nurse Practitioner)
- "No clear actioning for the completion of the 'to do' list – that's what we're often very bad at doing...other thing to bear in mind – you can't do a project like this and think it will be finished...I think what we have to work for is TQM (total quality management – added) and to always improve on what we have – and that is a challenge. Need to build acceptance that we need to continually change into the way we work – then I think we can do it." (Consultant Anaesthetist)

Conversely, the concern about sustainability was perhaps somewhat premature, because, at the time of this evaluation, which took place between April and June, 2008, plans for ensuring sustainability were still ongoing. This was mentioned in Chapter 4, and will also be referred to in Chapter 6. My continued involvement with the SE NHS Hospital Trust until early February 2009, despite beginning preparations for withdrawal in early 2008, was for this purpose. This enabled the work to be continually pushed forwards, and responsibility and ownership for sustainability to be gradually handed over to key stakeholders.

Total Quality Management (TQM), Continuous Quality Improvement (CQI) and the Patient Journey process

The Consultant Anaesthetist's proposal (see quote above) to work towards a total quality management (TQM) approach, or Continuous Quality Improvement (CQI), as Ovretveit (2003) might describe this, emanated from his own efforts to improve theatre efficiency and services. During the period of his engagement with the AR VPJ, this Consultant had been undertaking his own study in affiliation with the Institute of

Healthcare Improvement. The focus of this work was also on improvement, but through a quantitative approach identified as PDSA (Plan, Do, Study, and Act) (Langley et al, 1996). This required statistical analyses of theatre operations, such as throughput of patients; theatre lists; operation times; outcomes of surgery; workloads of individual surgeons; income and expenditure, for example. TQM also places an emphasis on training, learning and ensuring consistency of purpose. This can be achieved by engaging managers in an on-going quality improvement programme, and placing an expectation on them to continually seek to improve the supervision, training and retraining of their staff as part of the process (French et al, 2008). The Consultant Anaesthetist suggested that combining TQM (and/or CQI) with the Patient Journey approach would provide an effective means by which to achieve on-going quality improvement.

Cost implications of a Patient Journey
With regard to the concerns about the cost of the PJ process, according to Campbell et al (2004, p. 24)

- "The system is based on a premise of there being no cost to the organisation of the re-design; this is achieved by asking the business manager (directorate) to chair the regular meetings of the team. However, in one major instance, the business manager has taken advantage of this work to present a business case for changes to the service."

In this project, other than discussions amongst the VPJP team about securing funding for new diagnostic imaging equipment, any other associated costs had not been disclosed. As such, this aspect cannot be accurately assessed or evaluated. Nevertheless, as external facilitator of the AR VPJ project, it is possible to verify that other than the additional demands on time, financial implications had only been openly considered by one member of the VPJP team.

- "Resources...could be costly to run? Estimate approximately 12 hours' time commitment for active members (Service Improvement Manager)

Costs associated with running this Vascular Patient Journey project, which generally only included administrative (email), travel and occasionally catering (tea or coffee), had been kept to an absolute minimum.

Q5. How do you think we could improve things for the future?
A broad range of suggestions were offered under this section and were themed as follows

Organisational issues

- "We must act on the findings and not let this become a paper exercise. The Trust/Division should set up a group to frequently review what we are doing to correct the issues identified." (Vascular Nurse Specialist)
- "...share the methodology and the outcomes locally to enable all staff to understand the value of the approach...an article in the weekly staff bulletin or the...(SE NHS Trust's - added) newsletter as well as presenting in more formal settings. It would be good to have practice development input for the surgical specialty as currently none exists." (Lead Nurse, Practice Development) (Appendix 32)
- "I think there has been huge engagement from the team, but not so sure of the wider divisional management team. Executive lead changes may not have helped though we are looking actively to share and learn from this work – not only for vascular patients but all patients across the trust." (Director of Nursing and Patient Services)

By way of response to the second quote, an article was subsequently published in the SE Trust's newsletter in October 2008, and further presentations undertaken. One of these was to the SE Trust's Patient Experience Committee in August 2008, the responses to which are briefly commented on in Chapter 6. Other comments are above also echoed in the discussions in Chapter 4 with regard to the sustainability of this VPJ project. They also provide evidence of increased recognition amongst team members of the benefits of this way of working, through which collaborative, multidisciplinary, cross care boundary relationships had been, and were being, developed.

- "Improve communication between primary and secondary care – to improve working relationships and avoid duplication of work...this would improve service provision and cost effectiveness" (Primary Care Nurse Specialist)

Issues concerning teamwork and communication between primary and secondary care, particularly with regard to patients 'falling through the net' between services, had also come to light during patient interviews. These were discussed as issues in Chapter 4.

- "...courage to acknowledge those issues which just have to be 'parked'. Find ways to ensure ward nurses get involved..." (Service Improvement Lead)
- "More corporate by-in; obviously the Trust knew about it but I think this sort of thing should be given top billing...this is a priority...this has to be reported on and we have to make sure that we are achieving something from it. I think it's a really good project and it could have had a higher profile – maybe it has and I don't know about it? This is something we could use elsewhere" (Consultant Anaesthetist)

The above responses to question 5 indicate that the effectiveness and value of the AR VPJ approach was recognised and welcomed. They also indicate that the generic potential of the CHS PJ process (Campbell et al, 2004), with relatively minor modifications, had been clearly established through wider recognition of its merits, thereby fulfilling the aim and objectives of this AR VPJ study.

Recommendations for future Patient Journey projects

- "I can't think of any other way of running it differently – I think it's really good – excellent really – because it was there – you joined in, you hopped off – but it happened..." (Superintendent Radiographer)
- "As a process – no suggestions; enjoyed participating" (Vascular Nurse Practitioner)
- "Perhaps having a list of all dates and times way in advance that would have been helpful" (Ward Sister) (this had been given at the first meeting of the team, which the Ward Sister had not attended. However, meetings still had to be rearranged – comment added)
- "...invite individuals who are part of the MDT (multidisciplinary team – added) to discuss aspects of their care/issues at specific times on a 3-hour afternoon agenda, for example." (Consultant Anaesthetist)
- "Perhaps break up the journey into stages and run a mapping exercise for each stage to allow the relevant people to attend." (Physiotherapist) (Conversely, other team members commented on the value of the insight their involvement in this activity had afforded them of each other's roles and of the whole patient journey – comment added)

The responses in this section perhaps demonstrate once again why gathering feedback data from project team participants had been considered so important. Whilst commonalities are to be found amongst the resultant data, the qualitative approach to interviewing made it possible for individual opinions and thoughts to also be expressed and shared. As such the findings have provided a comprehensively informed, contextualised and authentic overall view of the AR Patient Journey process as it was experienced in this study.

Q6. What was your overall impression of the Patient Journey?

Although this was included as the sixth and final question, in some interviews this was replaced by "Any other comments?" The reason for this was because, despite earlier thoughts to the contrary, previous questions had enabled an overall impression to be elicited. Four of the 17 respondents had no further comments to add (Vascular Nurse Specialist, Consultant Surgeon, Executive Lead/Director of Nursing Services, Primary Care Nurse Specialist); 6 gave an overall view and 7 offered additional points for consideration. As such the report of findings in this section is divided accordingly.

Overall impression of the Patient Journey model

- "...A welcomed change to improving patient safety and overall patient care." (Pharmacist)
- "A good model – helped everyone draw out the issues and bring them all together. However, staffing and time constraints are a major drawback." (Ward Sister)
- "I wouldn't shy away from another PJ in the future – I suppose I was very sceptical at first because everything we'd tried before just didn't seem to work but this has shown to me that if you have a structure – you can't ignore it – particularly as we have had our patients tell us their experiences – so we've got to do it. I'm not an academic (a personal view despite her extensive clinical

knowledge and expertise, and an MSc – added)...I was worried that I was going to get into something that was far too highfaluting – but I have enjoyed this and would definitely do it again. I would also recommend that other nurse practitioners get involved if they get the chance." (Vascular Nurse Practitioner)

- "...despite extra work this has value and is worth doing, it crystallises the issues. Patients want one thing, doctors and stuff want another and then the service needs another thing. A good team will try and address as many of these issues as possible and, if each of these 3 groups feel that the issues of the other groups are their issues as well, then everyone pulls together in the same way. Patient Journey data should become a key part of service review as it incorporates corporate, clinician and patient requirements; 3 key areas considered as part of a whole. Scientific numbers...I would like interviews on every patient – what if we missed a number of key points out there that we should address for other patients? I want to know everything that's going on...I understand sampling sizes ...it's not a fault of how it was done...but I don't think there's any other way of doing things – I realise it has to be this way...Would have liked more time – but still feel length and timing of meetings were right given the circumstances. Don't think anything could be changed to improve it...Reproducibility of this approach is very dependent on the investigator/researcher and their ability to project manage and to secure the engagement of the team..." (PJ Clinical Lead/Lead Vascular Consultant)

These verbatim statements, which provide authentic insights into the perceptions of the service users who had participated in this AR VPJ study, reinforce other empirical findings reported in Chapter 2 and by the findings thus far. These, in addition to the numbers of different issues raised by each group, and the team's ability to quickly attend to these, provide clear evidence that service users should be involved in improvement. They also demonstrate the significance of adopting a patient-(person)-centred, democratic and collaborative approach as promoted by this AR VPJ study.

The last comment, made by one of the Trust's busiest Consultants (as previously emphasised by the VPJ Steering Group), demonstrates that, even for those with highly demanding workloads, active involvement in an action research PJ project is achievable and was valued.

The qualitative versus a quantitative approach to service improvement
In light of wider, sometimes negative perceptions of qualitative research, particularly amongst the medical profession, the following views, expressed by the Lead Vascular Consultant Surgeon, had been welcomed. This former sceptic eloquently articulated his initial and subsequently changed perception of qualitative research. It also provides a somewhat rare insight into the perceptions, experience and training of a surgeon:

- "You can put together a patient questionnaire to say 'are you happy with the service we are providing you?' but you can get whatever answers you like depending on how you put the questionnaire together...the Government's agenda is driven on questionnaires which they design to get the answers they know they can deal with...This is open – Tell us about the journey; tell us about

what happened, what you liked, what you didn't like, what worked, what didn't work. This gives you a lot more.

The thing is – from the medic's side, the scientist's side if you like, it's much more qualitative than quantitative and we are much more comfortable with quantitative research. Give us a set of numbers...80% success rate - we know where we stand. This is qualitative research and it's much, much harder for us to appreciate and, although we all go away and get taught in our research there's quantitative and qualitative and these are different things – we mutter 'qualitative – fluffy physiciany stuff''...an attitude to be found particularly amongst surgeons, but also amongst medical doctors. The way we work as surgeons – with so much coming at you, you have to compartmentalise and so you have to have knobbly bits to hang on to – that's what hard facts provide you with – 'I know that I should do this operation for you because you've got the following situation' – fine I've stopped thinking now – the decision's made...whereas this is much softer. But actually, when you break it down, and you read through it... it's crystallised into areas and patterns and things... So what I've got at the end of it is; A, I feel slightly more comfortable with qualitative research ideas now; and, B, I'm coming out thinking this is a very good process that we should be constantly doing – and it's not just a process that we should be doing in the NHS.

..as I began to realise what we've got from it, just how much we've got from it, I wondered if we should do this every 5 years? Just to see...Now I think...every team should do it every 5 years." (Excerpts from recorded interview with PJ Clinical Lead/Lead Vascular Consultant)

When meeting two stakeholders from the SE NHS Trust, at a King's Fund Conference after my withdrawal from the Trust, it was disclosed that this consultant was proposing to run another of these VPJ reviews within the next 12-18 months.

Link with integrated care pathway (ICP) methodology

Interestingly, although Campbell et al (2004) link the CHS Patient Journey approach with integrated care pathway (ICP), or care pathway, methodology, only the Superintendent Radiographer (extract below), had commented

- "We've done care pathways before but actually nothing really seems to come of it, certainly not in that depth."

Although an integrated care pathway had not been a goal of this study, a 4 day post-operative femoral-popliteal bypass graft patient pathway was developed. An image of this is included in Chapter 4 as Figure 4-20. The Superintendent Radiographer also added:

- "...you can make suggestions to Trust management about changes to service but they disappear – whereas this seems to be a bit more staff-solved problems – if you know what I mean? ...this has been an exercise based on experience if you like and any problems that have come up from that...then we've discussed - as a team – how to solve all these problems for the benefit of patients and the running of the service – not for any cost cutting...Patient feedback was very interesting – some a bit bizarre but that makes more interesting reading...I feel privileged that we've been the only ones in this hospital so far to have been involved – it's been great. I hope Trust Management would say that they'd do it for every service really" (Superintendent Radiographer)

These remarks yet again demonstrate the value of data gathered from experience. They also provide further evidence in support of this collaborative approach to health care and services review.

Additional suggestions

A number of 'one off'' suggestions were also offered by VPJP team members as points for wider consideration. Amongst these included:

- "...opportunity for academic accreditation of local facilitator roles?" (Lead Nurse, Practice Development)
- "The Patient Journey versus patient focus groups; or both?" (Service Improvement Lead)
- "For you (researcher) to explore professional development opportunities, including secondment with IHI" (Institute for Healthcare Improvement, Massachusetts, USA) (Consultant Anaesthetist)

The last point had been particularly valued on a personal level as it symbolised an acknowledgement of my credibility and abilities as action researcher and external AR VPJ facilitator.

Involvement and engagement of pivotal frontline staff in service improvement initiatives

Informal discussions with 3, of the 4 administrative staff (1 had left the SE NHS Trust since the start of the Patient Journey) who were acknowledged as VPJ team members but had not actively voiced their views, brought affirmation of a previously held belief that these members of staff should also be consulted when seeking to improve and increase efficiency of healthcare services.

A Waiting List Co-ordinator (WLC), for example, provided explanations, and valuable suggestions for ways by which some of the failings that had been unearthed during the PJ process might be addressed. Particularly those relating to communication between hospital staff, inter-hospital sites and patients. Insights were also offered into issues not previously identified by the VPJP team during mapping. However, although they had highlighted availability of High Dependency or Critical Care beds as an issue, this was not specifically in relation to reserving these beds for the immediate post-operative care of high risk vascular patients when co-ordinating surgical admissions. As a consequence of new information gathered from the WLC, the priorities Issues and Solutions (IAS) list was updated (Figure 5-4).

Issue	Key Points	Action Required	Lead
34. Access to and availability of ITU/HDU beds.	Ongoing problem – impact also on admissions. Sometimes difficult for waiting list co-ordinator to contact xx when arranging admissions. Proposal for ITU/HDU ward round time to change to enable discharges to be identified sooner.	Patient flow/capacity planning to be addressed by Bed Utilisation Group? Difficulties were also reported to be under review by xx – outcome to be followed up.	

Figure 5-4: information update by Waiting List Co-ordinator recorded in prioritised Issues and Solutions document – July 2008

The WLC also expressed views on the recently introduced IT system which had significant 'teething problems'. Related issues were, once again, reported back to the VPJP team for further discussion and review, demonstrating how evaluation had also become another data source for the AR VPJ change and improvement process.

Issue	Key Points	Action Required	Lead
11. Patient notes not always available. (It has been reported that as at May 2008 it is not possible to view patient correspondence from other specialties using Cerner – which can be a problem when patients under shared care. Tracking of diagnostic results is also reported to be a problem)	New IT system, Cerner, recently implemented but problems still encountered, resulting in appointment delays, patient misinformation, and creating 'huge stress on secretaries', etc. Recognised as Trust wide issue.	To improve the use of the Cerner queue (notes tracking) and review the courier service. Subject to ongoing review and monitoring by the Silver Team – call centre now set up to deal with increased patient complaints (approx 20%).	Silver Team, LL, Executive Lead

Figure 5-5: example of additional data sourced during evaluation

The Medical and Consultant's Secretaries reiterated many of the concerns voiced by the Waiting List Co-ordinator, whilst also revealing a range of additional problems with the new IT system; giving examples in relation to hospital correspondence with patients. These were integrated with the comments of the WLC, fed back to the VPJP team and contributed to the update in the IAS document (Figure 5-5). The secretaries also offered pertinent insights, and pragmatic recommendations for improving efficiency in current services, particularly with regard to difficulties associated with accessing and tracking patients' notes; tracking of diagnostic test results; booking of appointments for which a centralised system was recommended. As Figures 5-6, 5-7 and 5-8 illustrate these issues were also receiving ongoing attention by the VPJP team and the wider SE NHS Trust.

Issue	Key Points	Action Required	Lead
2. Some patients appear to 'fall through the net' when being referred from YY to XXX.	TT reported that patient information has been duplicated for patients attending both XXX hospital and YY since May/June 07. AA also confirmed consultant access to IT radiology and duplex results across both sites for approx 12 months. Vascular Consultant clinics now being held at YY. Electronic Patient Record (EPR) should reduce risk of patients 'falling through the net' in future.	Ongoing monitoring and review Development of inter-provider referral form should mitigate risk of patients 'falling through the net'. ? Trust lead. EPR	

Figure 5-6: continuing improvement process - communication and records

Figure 5-7 below shows that the existing courier service was to be reviewed

11. Patient notes not always available.	Mapping	New computer system CERNER currently being implemented with case note tracking module which should improve tracking and availability of patient records. Improve the use of the Cerner queue (notes tracking) and review the Courier service **(BB)**

Figure 5-7: continuing improvement - review of courier service

Figure 5-8 illustrates that the perspectives of administrative staff had been acknowledged by the VPJP team. It also shows that the possibility of a centralised Patient Booking Centre was being considered by the SE NHS Trust.

4. Several patients had a considerable distance to travel to XXX and would appreciate same day appointments e.g. consultant appointment, pre-op assessment, duplex scanning.	Patient interviews	Same day, drop-in, pre-op assessment commenced 5/12/07 but has not proved successful for patients with PVD. Several patients declined opportunity due to time factor. Same day appointments for 4 key diagnostic tests under review through **No Delay/18 week** project TT/BB The Admin Processes Review and potential development of a Patient Booking Centre is intended to synchronise hospital appointments and reduce visits

Figure 5-8: example of VPJP team ongoing improvement endeavours

Discussions with administrative staff also drew awareness to the widely spread locations of team members across the Trust, rather than in one centralised location, which, in their view, contributed to team fragmentation and access issues for patients. For example, when patients required Doppler, or duplex scans, these were performed in a separate location some distance from the main vascular clinic. As the PJ interviews had revealed, for this group of patients, walking, even a short distance, always exacerbated pain and frequently posed a significant challenge.

The administrative staff had offered additional highly pertinent perspectives of the whole Patient Journey. Their discussions provided evidence that their lack of involvement in

the project had left a notable gap, thus also supporting a strong personal belief that frontline staff, clinical and non-clinical, must be helped to recognise the value of their views, and be given opportunities, through projects such as this, to make their voices heard. The discussions above perhaps exemplify why gaps and inefficiencies in some aspects of health service provision continue to exist, and why patients' experiences associated with continuity of care continue to be variable. They also provide evidence, that in spite of the former Labour Government's directive, that...

> " There need to be changes in how the system works, how people behave and a change in culture…becoming patient led means thinking about the whole person…it also means giving those working closest with patients – frontline staff-more autonomy and authority to act. They are best placed to be able to understand patients' needs and act accordingly." (DH, 2005a, p. 24)

...there is still much to be done if this is to be achieved.

Perspective of Local Vascular Patient Journey project facilitator

In light of her pivotal role within this project and the vascular team, the following comments from the Vascular Patient Journey's Local Facilitator/Vascular Nurse Practitioner, are drawn upon as final points which sum up her overall view - as a nurse and frontline healthcare professional - of the Patient Journey, and to conclude this section of the evaluation.

- "...this (the Patient Journey/pathway – added) can definitely lead to change. This has done more in a year than I had managed to do in the six years before this came along – there's no two ways about it – and I think that's all to do with people actually recognising that there is a need for something...before I would say the patient's telling me...but, they want more evidence of that yet they don't tell me how to go about getting it. At the end of the day I'm a nurse, I'm not a researcher – I don't know how to go about these things. So, this to me was an ideal opportunity – a channel for the patients to add support to what we've been saying all along. Having the patients' views is important – everything is driven by what the patients' needs are...at the end of the day – if you've got happier patients, you've got happier staff." (VPJ Local Facilitator/Vascular Nurse Practitioner)

Overview of service user evaluation

The findings of the service provider evaluation are self-explanatory. They also provide strong evidence in support of the involvement of service providers in improvement, or more specifically, action research Patient Journey projects. Moreover, they demonstrate that the collaborative and patient-(person)-centred approach to involvement and the change and improvement process were valued by the VPJP team despite the additional demands this placed on their time. Thus, these findings together with changes

implemented during the AR VPJ project, verify the generic potential of this approach to change and improvement in healthcare.

The majority of data for this first stage of the evaluation had been gathered by late June, 2008, which is why the findings from administrative staff could quickly be amalgamated into the prioritised Issues and Solutions (IAS) document published in July 2008. Once the service user evaluation had been completed, attention turned to collecting service user perceptions of their involvement with the AR VPJ process.

Service user evaluation

Part two of the evaluation focused on gathering the perspectives of the service users who had participated in this study. In light of the aim, objectives and nature of this AR VPJ study, it was imperative that an insight into the experience of retelling healthcare journeys for the purpose of improving other patients' experiences was gathered. The service user evaluation, similar to that of service providers, was not concerned with how the findings from the Patient Journey project might have improved services, or care, for service users during the 12 months since their initial interview. As objective 6 at the end of Chapter 2 specified, evaluation in this context was to be focused on service user perceptions of the AR VPJ approach as this had been experienced by them through their involvement.
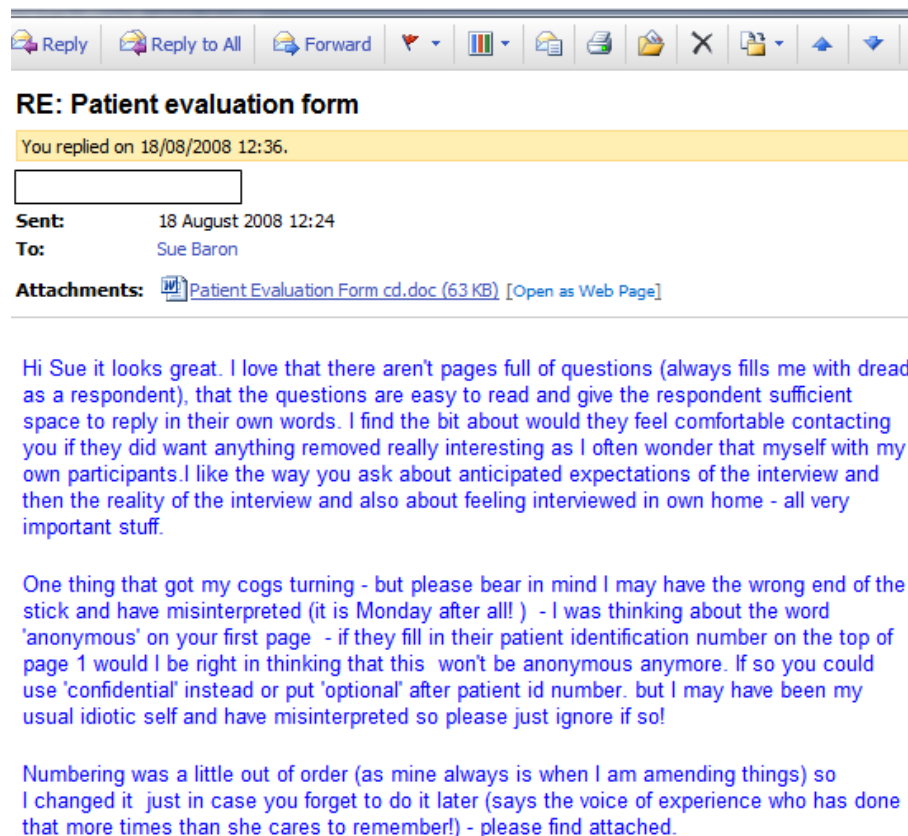
Figure 5-9: email providing feedback on draft evaluation questionnaire for service users

Consequently, it was from this perspective that the service user evaluation for this AR VPJ study was structured. Because this was a newly developed evaluation questionnaire, external opinion was sought from a university colleague (Figure 5-9). Following guidance, the questionnaire was revised (Appendix 32) prior to forwarding to service users by post in August 2008, together with an AR VPJ update letter and a report on VPJ project progress. The updates were produced by way of response to guidance offered in a change management *'Briefing Paper'* by the NHS Service Delivery and Organisation R&D Programme (NHSSDO, 2004) and *'Guidance for improvement leaders'* published by the NHS Modernisation Agency (DH, 2005). This suggested that service users should be notified of the outcome of their involvement.

Data collection

Evaluation data was collected between August and October, 2008. As before, the following report from the findings of the evaluation has been categorised according to the questions asked. Nine responses were received to the 11 postal requests; a 53% response rate (9/17 participants).

Q1. How did you feel about being asked to take part in an interview at home to talk about your healthcare experience?

Five patients and 2 care partners (in this context spouse, partner, son or daughter) stated that they had *"welcomed the opportunity"* to participate in this project.
A further 2 of these reported that this study had interested them. One replied that they were

- "Perfectly happy …quite confident about being seen at home".

Overall, the informal approach to interviewing in a familiar environment had been welcomed by all. No concerns with regard to personal safety from allowing a stranger into their homes had been voiced. This was partly attributed to interview preparation and prior contacts by telephone when rapport building had begun.

One wife, whose husband had been readmitted to hospital at the time of our conversation and was currently very unwell, briefly commented that she and her husband had valued opportunity to talk to someone independent, not family, not part of the healthcare team, about their care, their experiences. She stated it was

- "…nice to have someone to talk to and get things off your chest..."

This statement supports the views of Shami (2003) and Overcash (2004) about the therapeutic effect of qualitative interviews.

Q2. Did you feel able to say everything you wanted to say about your healthcare experience during the interview?

All respondents answered "yes" to this question with some elaborating further through comments such as

- "...was able to free range as much as I wished." (Patient)
- "Sue (researcher – added) had a good attitude – we are both straight and open people." (Patient)
- "I feel we covered all the ground that we wanted to discuss" (Patient and wife)
- "It was a very relaxed interview and I could say exactly how I felt about my healthcare while in hospital." (Patient)

These responses also highlight the significance of the AR PJ interviewer's approach to the interviewee experience.

Q3. Can you remember how you felt immediately following the interview, for instance: relieved it was over, or, enjoyed the experience?

Five respondents stated that they had

- "enjoyed the experience"

The majority elaborated further through the addition of comments such as

- "I felt pleased that I was actually able to say what I wanted to say, and I felt it had gone well. In addition to which, very simply, I felt I was able to give a very good account of my experiences instead of just knocking the NHS all the time. Was able to give praise where it was due." (Male patient)

The above comment perhaps demonstrates that the approach to interviewing had enabled participants to feel able to offer a genuinely informed, frank and more rounded view of their insider experience

- "...we thought the questions were good and fair." (Son speaking on behalf of mother - the patient. The son was referring to the 3 questions used at the start of the interview; i) Tell us about your care? Ii) What do we do well? and, iii) How could we make it better?
- "I think it did xxx good to talk about it. The more he talked about things the easier it seemed for xxx to accept it…amputation, what he had been through." (Female partner)
- "...I said everything that I thought was right, said what was on my mind…felt good about it..." (Female patient)
- "…not a lot of other outside contact so this was like a social occasion as well" (Female patient)
- "...an opportunity for a patient's point of view." (Female patient and former nurse)
- "I found it helpful as my husband had just been into hospital." (Spouse)
- "I suppose that in a way I did enjoy the experience and hoped that some good would come from it." (Female patient)

The above responses are once more indicative of the therapeutic effect of participation in Patient Journey interviews. As mentioned in Chapter 3, this therapeutic effect is also recognised by Shami (2003) who investigated patients' experiences of treatment, and Overcash (2004) who explored cancer patients' experiences.

Q4. Would you have felt comfortable contacting the researcher, following your interview, if you had wanted to remove or add any information you had/had not disclosed during the interview?

No concerns were voiced about contacting the researcher should the need have arisen to modify or retract their response as the following quotes verify

- "Yes, indeed, no inhibitions at all as far as that was concerned"
- "I would have been quite happy to contact Sue."
- "I found my interview with Sue very relaxed and had I wanted to contact her at a later date would have had no qualms what-so-ever."
- "Yes, you are a very nice person."

The last quote was an indicator that some of these responses might not be entirely frank. It was possible that some respondents might provide complimentary answers because of the rapport that had been developed during the interview.

Q5. What do you consider was good, or not so good, about collecting information from you in this way?

In light of the individuality of the answers to this section, all responses to this question have been included

- "I felt face to face was the right way. You could talk to a person rather than putting thoughts down on paper and hoping they would understand them."
- "Everything was asked and answered as we would like it"
- "It is more informal to be able to talk in your own home."
- "It was better someone coming – you could talk freely rather than writing things down which I'm not good at and I would forget most of what I wanted to say anyway – also you wouldn't be able to understand my writing...not good at spelling, handwriting. This way gives opportunity to meet somebody different...I'm at home a lot on my own...this way I got to meet someone new."
- "Good – we didn't have to make any effort – normally have to travel miles to do anything...less disruption."

It was clearly evident from these replies that participants had welcomed the opportunity to be interviewed in the comfort and safety of their own homes. The additional security afforded them by their familiar environment is thought to have enabled participants to more freely and openly share their frank, poignant and, at times, intensely private experiences of healthcare.

- "Very good to get the patient's opinion"

- "We just hoped it would help other people in the future. Anything that makes life easier for other patients has to be a bonus."
- "Being able to discuss the poor treatment I received on two occasions." (Although this patient had done this, only their account of the healthcare experience relevant to this study had been included in the data presented to the VPJP team. This was highlighted as an example in Chapter 3)

The respondents' awareness of the importance of having their voice heard, through a means such as this, was also apparent.

Q6. Having taken part in an interview, would you be prepared to participate in a similar interview again?

All respondents confirmed that they would be prepared to participate again. However, one carer had suggested that in light of his mother's failing health, another option might be more appropriate. Interestingly, further contact had not been declined. As with previous answers, some additional comments had also been offered as follows

- "...Would be happy to take part again. Totally at my choice...no strange thing to take part in an interview...often had medical students conduct in-depth interviews with me during my stay...I'm one of those people often picked out for a case study."
- "An interview would be fine. No problem with time."
- "Yes we would be." (Spouse was then asked if they had appreciated being included) "I think it was essential to have both of us there…emotions involved…can't always stand back and see what has happened, or speak out for themselves. Sometimes in order to cope, people cut out the worst bits so don't really remember what it was like."
- "If I could be of any help then, yes, I would take part in another interview."

The last quote here perhaps reflects the principal reason why these patients had participated in this study; an altruistic desire to improve the healthcare experiences of others. Berg (2001), Hiller and DiLuzio (2004) and Lowes and Gill (2006) suggest this is one of the key motivators for engagement.

Q7. Please use this space to add any other comments or suggestions about your participation in this project.

Suggestions about how the Patient Journey approach might be improved were also invited to which a variety of responses had been received. The following extracts demonstrate their individual nature. The first response appeared to be more related to improving future experience rather than how the approach to improvement promoted by of the PJ might be enhanced:

- "Very difficult to say as I had a positive experience of my healthcare...only comment – perhaps surgeons are now too graphic in their descriptions. I was scared before the first major op."

Other participants contributed their perspectives of the PJ improvement process:

- "...an excellent opportunity for a patient to give his point of view in an impartial way...and that the information can improve care..."
- "Thank you for the opportunity to discuss my husband's time in hospital."
- "It was good and 'right' that we both were there and had both been included in the interview" (Patient's wife had her own personal experiences as well – and had raised issues during the PJ interviews - such as the cost of parking, non-availability of season ticket; variation of visiting times from one ward to another.)

These quotes provide further evidence that demonstrates the close involvement of family members in healthcare experiences. Findings such as these strongly emphasise that those who live with patients are the true partners in healthcare, and as such, should receive greater recognition and support for the part they play.

- "…we valued the opportunity to try and help other patients. However, J still has problems with the prosthetic limb (xxx centre) – which has got him down/made him feel low – now at last about to try a new one (this Friday) – has remained in wheelchair most of the time since his amputation...We have moved house since the interview – now have a bungalow and J can be more independent. Just needs prosthetic limb so that he can start to walk again." (Partner of patient)

The above quote reflects lengthier, poignant telephone discussions in relation to the wider reaching impact of living with peripheral vascular disease (PVD); a sense of which is enabled by these comments, from the patient's partner. For example, life with PVD for this person, the youngest participant in his forties, had adversely affected his psychological well-being through the effect of surgery and his isolation due to significantly reduced mobility and resultant confinement to home. It also had a profound effect on his socioeconomic status. Unable to return to work as a carpenter he was now totally reliant on benefits. Experiences, which had also significantly impacted on his partner's, and his family's and friends' lives, and, as such, strengthen the argument for individualised care planning and multidisciplinary, interprofessional and inter-agency collaboration.

In light of the above insight, and in keeping with an intention of this AR VPJ study which was to give service users a voice, the following summarised accounts of field notes written during three follow-up telephone conversations are included. Whilst it is acknowledged that these are anecdotal accounts rather than empirical evidence, the somewhat rare insights they provide into subsequent experiences, which were freely offered, indicated these should not be excluded from this thesis.

Rare insights – post-discharge experiences

On-going nature of healthcare: Experience 1

This first account was relayed by a female patient, a widow in her early sixties who lived alone but with close family nearby. She explained how, since our meeting last year, severe leg pain had continued to dominate her life. She was now only able to walk short distances for a couple of minutes at a time. An electric mobility scooter would have been welcomed but she had no idea how to apply for one. She did not want a wheelchair because of her perspective about what this meant. Psychological and socio-economic factors were significantly impinging on her quality of life and her health. PVD and the additional co-morbidities she lived with, require regular monitoring and intervention. However, due to financial, mobility and social issues, these essential appointments were frequently missed. This was not only affecting her current health but also her future prognosis. This lady lived in fear of an exacerbation of her condition which she had been warned would be likely to lead to amputation, possibly of both legs. Yet, despite these, and other more personal concerns, she expressed heartfelt gratitude to the vascular team for the care she had received.

On-going nature of healthcare: Experience 2

Since his discharge from hospital following emergency surgery, this male patient who was in his late sixties and lived in his own home with his wife, had not received any further follow-up. His wife told me that they had, at least, expected a scan to check that the by-pass graft was performing effectively. However, because her husband was the patient and was fearful of further investigations, he chose to wait until an appointment was sent to him. As his wife, she had felt concerned and frustrated that she did not have the authority to chase this, despite her niggling worries about him.

This wife's anxiety had been triggered and intensified by a past experience which she recounted to me. That had resulted in her husband's emergency hospital admission. The lasting impact of that experience had caused her husband's current reluctance to push for a follow-up appointment. Since their participation in the PJ interview, the only out-patient 'follow-up' had been with their practice nurse. Consequently, her husband had made the assumption that because no appointment had been sent, none was required and all must be well. As such there was no need for him to take further action. In light of the potential risk to this patient, made clear from the information disclosed to me, and the duty of care and responsibility placed on me through my role as a nurse, the VNP was contacted to alert her that this gentleman may have 'fallen through the net'. As Figure 4-36 in Chapter 4 illustrates, new vein graft surveillance guidelines ratified by the VPJP team in February 2008, stated that all patients should have a follow-

up consultation after their surgery. Thus these guidelines, published after this patient had been discharged in May 2007, had not been available in time to increase vigilance to prevent the current experience of this gentleman and his wife. Consequently, his details were disclosed to the VNP so that an appointment could be arranged. Confidentiality was not considered to be breached as this action addressed a concern of considerable risk to the patient. An appointment letter would be sent and the patient could make the decision whether or not to attend. This incident also verifies that the introduction of new guidelines was warranted.

On-going nature of healthcare: Experience 3

The experience of this patient in this third scenario was recounted to me by his wife. This gentleman was in his late fifties. He had been re-admitted to SE NHS Hospital Trust at the end of July 2008; some 14 months after the admission discussed in his PJ interview. Six days after his latest admission, a below-knee amputation had been performed because of an infection which had not responded to treatment. He was currently very unwell as the amputation had subsequently failed to halt the infection, despite on-going intravenous antibiotic therapy. Now an above knee amputation was being considered as life-saving treatment. However, prior to that the plan, as his wife recounted to me, was to introduce Vacuum Assisted Closure (VAC) therapy, hopefully that day. This treatment promotes healing by delivering negative pressure, causing a vacuum at the wound site through a patented dressing. This negative pressure draws out infectious materials and promotes granulation, a stage of healing at cellular level that enables deep wound healing from the base upwards.   VAC therapy had previously been demonstrated to be effective for this patient during the admission that he recounted during his interview. However, cross-boundary issues concerning funding and resources for ongoing treatment of patients at home resulted in VAC therapy being stopped before full effect had been achieved. The demand for beds had also meant that the patient could not remain in hospital. The cause this had caused to the patient and his wife as discussions, and interview extracts in Chapters 3 and 4 also highlight, led to an issue being raised. At the time of this evaluation this issue was receiving ongoing attention. This illustrated by an IAS update from the SE Trust's Service Improvement Lead, dated 20th May, 2008 (Figure 5-10).

64. One patient felt that he should have been able to continue with VAC therapy following discharge, or been discharged earlier with VAC therapy.	Patient interviews Mapping	VAC therapy to be raised (again) with Deputy Director of Provider Services. XXXt PCT **(SIL)**
65. Access to VAC therapy in PCT's	Mapping	
66. Some patients reported delays in their out-patient follow up, or no follow up appointments.	Patient interviews	Review of Outpatient demand and capacity will include follow-up appointments and delays **(SIL)**

Figure 5-10: cross-healthcare boundary issue regarding VAC therapy

During the telephone call, this patient's wife also took the opportunity to also tell me about the challenges she now faced as a consequence of her husband's on-going condition. She was extremely concerned about her husband's recent deterioration, and was fearful of losing him. She was also struggling to cope with the additional demands and responsibilities placed on her. For example, visiting responsibility fell solely to her because it was too far for family and friends to travel. For her this involved 2 hours' driving for each visit. She previously travelled by train but this had become impractical because of the time required and because the couple had two dogs. Once more the psychological and socio-economic impact of the illness experience was clearly evident. In this instance, this wife had given up employment to become the main carer for her husband. He was no longer employable because of this condition. She described feeling 'hugely concerned' about their financial status and, at the time of our conversation, explained that she was very worried about missing a deadline for submission of a claim for invalidity benefit. Yet, due to the severity of her husband's current health status neither had the strength nor desire to complete a lengthy and complicated form. Furthermore, whilst her husband was in hospital he was not eligible to claim. Access to a coordinator/support worker who could advise them about their rights/completion of forms etc. and support them through an already difficult time would have been greatly welcomed.

This experience, once more, reiterates the significance of multidisciplinary, interprofessional and inter-agency collaborative working in health and social care. It also provides another example that clearly demonstrates why those closest to the patient must also be considered when seeking to deliver patient-(person)-centred healthcare. This couple's distressing experience provides a poignant point for reflective learning which has since been used in nurse education. It is one, of a number of real life examples used to encourage student nurses to reflect on, and discuss current practice,

in this instance in relation to pressure area care. This example enables students' attention to be drawn to the importance of pressure area care, and assessing the patient risk of developing a pressure sore appropriately. As previously mentioned, for this group of patients, circulation and skin integrity was already compromised through their diagnosis of PVD. This example is also used to raise awareness of potential longer-term implications for the patient and family, when pressure area care has not been effective, or when funding or healthcare policy issues have prevented much needed treatment.

Discussion

Patient Journey project evaluation data – wider relevance

Some might argue that the insights into these three on-going healthcare experiences should not be included. Firstly, because these are narrated by the action researcher, rather than verbatim accounts, thus may not be viewed as empirical evidence. Secondly, they may also be perceived to be biased. Yet, by this stage in the thesis the nature and bias of the researcher should be clearly evident, as one concerned with ensuring authenticity. Thirdly, these stories are not related to the purpose of the service user evaluation of their engagement in the AR VPJ process. But, an intention of this action research study was to give patients, and frontline staff, a voice so that healthcare, and healthcare experiences, might be improved. This indicated their inclusion was warranted. Moreover, these additional insights were freely offered during project evaluation, thus should be acknowledged in keeping with the overall nature of this study and to support future recommendations. They also symbolise the unpredictability and further reaching consequences of healthcare and the impact of PVD.

Qualitative methods and healthcare review

The findings of this AR VPJ study clearly emphasise the value of action research and qualitative data collection methods when seeking change and improvement and points of learning in healthcare. However, it is acknowledged that a drawback of qualitative methods, particularly interviews, is that the processes of data collection, transcription, analysis and reporting are time intensive. They are also open to researcher bias, although in action research this risk is minimised through ongoing peer-review and validation of accuracy and authenticity of reports and findings by research participants. Consequently, despite their limitations, the worth of the methods used in this AR VPJ study is clearly evident. The service user narratives epitomise the depth and poignancy of information that can be acquired when giving patients, and their care partners the opportunity to talk freely about their experiences. They also provide real-time insights into the experience of living, in this instance, with a long-term, debilitating condition.

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The data gathered from service providers completed the story. As the findings discussed in Chapter 4 revealed, without their contributions many issues may have remained unresolved. Moreover, their active involvement enabled a number of issues to be quickly addressed. As this study has also demonstrated service users and service providers have different perspectives and priorities care, they also have different experiences, knowledge and insights. This was illustrated in Table 4-1 in Chapter 4 which shows that of 75 issues identified, 34 were identified by service users, 35 by service providers, and only 6 were common to both groups. This finds has reinforced those revealed in the literature review of widespread variations in perceptions, interpretations, experiences and priorities in healthcare (Klein et al, 1961, Gillespie et al, 2004 and Goodrich, 2009). Thus, the findings of this AR VPJ strongly support the view that service users and multidisciplinary service providers should be involved when a review of healthcare is undertaken for the purpose of improvement.

Key attributes of the action research Vascular Patient Journey process
1. Interprofessional working and learning
As the evaluation interview findings demonstrate, each member of the team valued the opportunity to learn with, about and from each other during the Patient Journey process as they worked collectively to improve the experiences of their patients. The importance of multidisciplinary, but particularly interprofessional education towards the delivery of high quality, patient-(person)-centred healthcare is also recognised and promoted by The Centre for the Advancement of Interprofessional Education (CAIPE, 2002), the World Health Organisation (WHO, 2000, 2010). Additional discussions in Chapter Six will elaborate further.

This AR VPJ study provides evidence that multidisciplinary involvement in the action research Patient Journey process of service improvement, despite the challenges, led to more effective and better working relationships; increased staff visibility and had a positive effect on personal and professional development. Through this collaborative approach, frontline voices, the voices of experience, were heard and person-centred (as it now might be termed) change and improvement happened.

2. Giving patients and their relatives a voice
The rich data gathered during the interviews had a powerful impact on even the most sceptical, including those who had previously viewed qualitative methods as 'fluffy'. The data provided potent and poignant catalysts for multidisciplinary and interprofessional learning and change. This aspect of the Patient Journey process also provides strong evidence in support of the engagement of patients in on-going health services review

and redesign as advocated throughout this study, and actively promoted by successive UK Governments (DH, 2006, DH, 2009e) (See also Appendix 1).

3. Patient engagement: valued by patients

Patients, and their relatives, reported valuing the opportunity to openly share their healthcare experiences through a face to face, informally structured interview in their own home. The chance to improve the experiences of other patients had been the predominant driving force behind engagement. For some, the chance to speak freely to an 'outsider', but especially one with 'insider knowledge' of healthcare who could demonstrate an informed understanding of their lived experiences, was also reported to have brought therapeutic gain (insider/outsider stance discussed in Chapters 3, 4 and 6).

4. Facilitated by an outsider to the multidisciplinary team

This study supported the view that

- "…being external is an important aspect of the role of facilitators as patients' views are brought to the clinical team, and facilitators are able to present data on behalf of the patients, based on interviews. In many ways facilitators are patients' advocates...The background of facilitators is not just important because they have the skills to carry out the interviews, but also so that they are trusted by the clinical teams. There are limitations as to how clinical teams will accept data collected by colleagues from their own team because individuals may be trying (or be perceived to be trying) to represent data in a way which achieves their own ends" (Campbell et al, 2004, p. 21).

As a Patient Journey facilitator, it is suggested that the role holder must

- have a keen interest in people and possess well developed interpersonal skills
- be democratic, diplomatic and non-prejudicial
- be organised and methodical
- have a good understanding of the dynamics of teamwork and traditional health professional hierarchy
- to be able to motivate others
- be passionately committed to ensuring the success of the project
- possess patience, yet be able to sustain momentum
- be able to instil belief in others that change can and will happen
- ideally, possess some knowledge of clinical, organisational and political influences in healthcare
- be passionately committed to improving healthcare experiences and outcomes by making sure that what really matters to patients, and frontline staff, is voiced and clearly heard.

As an outsider no preconceived ideas had been held about the team or the service under review. There was, however, a commitment to ensuring that whoever engaged in

this project understood from the outset that this review was concerned with finding out about the strengths and weaknesses of current services, as identified by patients, relatives and staff. This was not however, about fault finding and blame, but about enabling a balanced perspective with credit being given when it was due. As external project facilitator, the goal had been to facilitate patient (person)-centred improvement by fostering the development of a friendly, supportive and open project team culture.

5. Change happens

Improvements to existing practice/service provision began to be made almost as soon as the data began to emerge. This in turn helped to sustain motivation and enthusiasm amongst VPJT members. Changes were made possible for the following principal reasons

- Engagement of a motivated, dedicated team who held a shared passion for improving the experiences of their patients
- Involvement and support of NHS Trust management and lead clinicians who brought credibility to the change process
- Involvement of budget holders; this enabled funding for additional diagnostic imaging equipment to be secured thereby addressing an issue highlighted by patients and staff.
- Voices from the frontline – patients, carers, and NHS staff – were heard. The Patient Journey process, and the data, empowered frontline staff, in addition to NHS managers, to initiate and implement appropriate and effective change, sometimes almost immediately. This supports the political view that NHS systems should be "giving frontline staff more autonomy and authority to act" because they are more closely involved and thus better positioned to understand what patients really need and want (DH, 2005a, p. 24).

Examples of change/improvement include

- Short notice admissions only to be offered to patients via healthcare professional
- Pre-operative assessment clinics increased to 3 sessions per week
- Patient pre-operative medication, admission information revised
- Nil by mouth policy reviewed and updated
- Theatre lists and sequencing of operations now agreed prior to commencement of lists
- Skimmed milk available, patients just need to be made aware by ward staff. Note to patients about placing requests for specific dietary requirements also added to patient information leaflet
- Times of meals included in revised patient information leaflets
- Dedicated phone line installed, for patient access to nurse practitioner as appropriate
- Funding secured for portable head for duplex scanner
- Day case angioplasties and angiograms commenced April 2008

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Details of further changes are also highlighted in Chapter 4, and the Issues and Solutions document in Appendix 30.

Key challenges of the action research Vascular Patient Journey process

- Time constraints – arranging timely meetings continually proved to be problematic.
- Sustaining team motivation/prompting responses/active participation.
- NHS Trust targets, such as 18 week, No Delays and application by the SE NHS Trust for Foundation status placing greater demands on project team members' workloads.
- Influence of past experience – 'brick wall' effect/Trust politics
- Minimal involvement of ward staff, particularly nursing staff
- No active participation by clerical staff.
- Loss of numerous key stakeholders who left to take up new appointments and could no longer be affiliated with the study, including the SE Trust's Chief Executive; Director of Nursing; Assistant Director of Nursing; Director of Nursing's PA, Service Improvement Lead, and the absence, on long-term sick leave, of a General (business) Manager.

Conclusions from the evaluation of this action research Vascular Patient Journey project

Evidence of the impact and value of the Vascular Patient Journey process is clearly apparent from the evaluation data. As the discussions in Chapters 3 and 4, and the findings from service user and service provider evaluation data in this chapter, make emphatic, the Patient Journey process can provide powerful catalysts for patient-(person)-centred changes to existing health care and services. According to the data, it can also provide an effective means through which multidisciplinary and interprofessional teamworking and staff morale may be promoted and enhanced.

According to the findings of this AR VPJ study, it seems fair to conclude that the Patient Journey has the potential to be applied in any healthcare setting and to any patient journey. A conclusion which is drawn from the effectiveness of the AR VPJ, not only in providing catalysts for change, but also through the empowerment of staff who through collaborative working can use those catalysts to improve the current journey for their own patients. A conclusion subsequently reinforced by the findings of service user and service provider evaluation data.

Extending beyond the small scale project (1)

Having completed a comprehensive local evaluation, and in order to extend beyond the small scale project as planned (Reason and Bradbury, 2001, 2008), two further actions remained:

1. To return to the evaluation report of the first 16 Patient Journeys, prepared by the Nursing Practice Research Centre at CHS, and compare the findings.
2. To present the Patient Journey model to external audiences in order to gain a wider perspective and gauge potential interest.

Action 1 which relates to evaluation is discussed in this chapter; action 2 will be discussed in Chapter 6.

Patient Journey evaluation by the City Hospitals Sunderland NHS Foundation Trust (CHS)

In the five years since the first Patient Journey project was launched in CHS, 18 Patient Journeys had been completed across a variety of clinical settings and patient groups; 16 of which were included in an 'in house' evaluation conducted during late 2006, early 2007.   As part of this process an audit had been undertaken to establish the consistency of the Patient Journey process. For this data had been collected about group membership, mapping, action plans and end of year reports. A two-part questionnaire, to capture more qualitative aspects of data, had also been distributed by email to 116 PJ team participants, and 53 responses (46%) received. The response rate between each PJ varied from 13% to 80%. In this AR VPJ study the rate was 68% (17 out of 25). As had been the experience in this study, group sizes during the course of a PJ had fluctuated and been subject to change; some members had left the Trust, and new people joined. PJ project team membership ranged from 9 to 25 members, the mean was 14. The VPJ team in this study comprised 25 members.

Part 1 of the CHS questionnaire contained 5 questions which, with an additional question, had been used for the service provider evaluation in this AR VPJ study. This was deliberate to enable the findings to be explored for similarities, or differences, between CHS and the AR VPJ results. The aim was to enable a more comprehensively informed perspective to be offered of the generic potential of the Patient Journey process. The following sections discuss the findings.

CHS: Q1. What do you understand by the term patient journey?

Lloyd and Campbell (2007) identified a clear consensus amongst the CHS respondents, much like those in this study, that the PJ is about *"the patient experience"*, is *"patient*

focused" and *"fitting the needs of patients"*. The overall view was that the term 'patient journey' implied the "*whole experience from presenting complaint to diagnosis and treatment"* (p.10). However, the CHS responses, unlike those in this evaluation, also linked this term with the CHS Patient Journey as a structured process for modernising services, perhaps because of the higher profile of this approach as a trust-wide initiative.

CHS: Q2. How actively involved in the PJ project would you say you were? Please explain the extent of your role.

Comments with regard to involvement with the PJ process indicated that, much like this study, this had ranged from *"very little involvement"* to *"fully involved"*. Interestingly, and similar to empirical studies reviewed in Chapter 2, no detail about staff grade or role had been included. This would have indicated whether Ward Sisters, for example, also experienced difficulty in participating at CHS. This lack of detail was considered surprising given that this report had been written for the CHS, not publication.

CHS: Q3. What do you consider were the good aspects of the PJ Process?

Similar to the AR VPJ evaluation several themes emerged from the responses by CHS PJ participants to this question. These, once more, largely reflected the views of this study's PJ participants. The responses to this question are perhaps the most crucial in terms of establishing wider and generic potential of the PJ process. Four key attributes were identified from the evaluation of 16 completed PJs.

- **Opportunities**

  Opportunities included ability to discuss the patient journey with the full professional team. In many PJs this was the first time the full team had worked collaboratively to identify problems and solutions in a "*non-confrontational"* way (p.12). The opportunity, to gain a real-time perspective of the entire patient journey was welcomed, as it was in this AR VPJ study. Opportunities to raise the profile of a specific condition, and reveal the complexities of individual roles had also been appreciated.

- **Teamwork**

  The value of teamwork was also inferred under *'opportunities'*, but was specifically identified as a separate theme and a strong and widely valued aspect of the PJ process. This in CHS, as in this AR VPJ study, was reported to have *"strengthened teamwork"* through closer relationships, improved communication and better understanding of each other's roles (p.12). These factors have been identified previously in Chapter 2 as key to the delivery of PCC.

- **Organisation**

  Participants at CHS had valued the structured approach provided by the PJ which provided clear direction and a predetermined route to follow to achieve change. Having an external project facilitator was valued.

- **Patient focus**

  This was considered the most crucial element of the PJ process, and the most significant theme. Participants valued the powerful insights the interviews had provided, with some participants reporting a perception that change was easier to achieve when it was driven by data sourced from patients.

Interestingly, despite the positive feedback to Question 3, which was consistent with that received in this AR VPJ study, one CHS respondent stated they were *"not sure"* and another that they had *"failed to see any good points from the journey"* (p.11). The latter had not been a finding of this AR VPJ study.

CHS: Q4. What do you consider were the not so good aspects of the process?

The findings question 4 were categorised into three themes; group meetings, time, and implementation. Although specific numbers were not revealed, several respondents were reported to have replied *"not sure"* or *"no comment"* to this question, with 2 (of 53; 3.8%) who had considered everything to be good and helpful. By comparison, 5 (36%) out of the 14 who responded to this question in this AR VPJ, these stated *"none"* (2), "*difficult to say, maybe time"* (1); *"I don't think there are any not so good aspects"* (1) and *"nothing comes to mind...didn't find any not so good aspects"* (1).

Time

This was identified as a major theme, consistent with the findings of this AR VPJ study. Some CHS respondents had commented that the PJ process had *"seemed to take a long time to get going"*. Whilst this comment resonated with me as external VPJ Facilitator, it had not been found amongst the VPJ responses, probably because the majority of the VPJ team had only been involved from the point of VPJ project launch in May 2008 which is now defined as Stage 3 of the AR PJ process.

Implementation

Comments under the theme *'implementation'* were predominantly focused on the PJ action plan. Some PJs had influenced considerable change whereas others had achieved very little. It was evident that sustainability, as in the VPJ, had also been an issue of major concern in CHS. Some replies cited a *"lack of support"* and *"lack of engagement to implement changes after design"*, and *"unable to get support from PCT"*,

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as significant issues. Comments in relation to implementation, which had not been highlighted in the VPJ evaluation, included *"gaps identified, but there were no resources to alleviate them"*, *"lack of money"* and *"lack of funding to implement changes"*. In addition some reported that it was *"difficult to changes things due to constraints"* and that the *"financial implications were not clear from the outset"* (p.14). The latter comments were surprising given the suggestion by CHS that the PJ is a cost neutral approach; *"The system is based on a premise of there being no cost to the organisation of the re-design..."* (Campbell et al, 2004, p.24). One PJ had reported *"no changes as a result of the work"* and *"no common themes and therefore no outcome"*, which had been attributed to a too diverse patient group.

Group meetings

The theme 'group meetings' was not one which emerged from the findings of the VPJ evaluation although the comment *"difficult to get people together"* had been a common thread. Challenges with continuity, or completion of some CHS PJs, were attributed to the departure of key staff in the middle of a project and/or a high staff turnover. Although these issues had also presented challenges within the VPJ project they had, nonetheless, been overcome. For some, the lack of involvement of a Business Manager was also reported to have created difficulties.   Other comments, not found in the VPJ evaluation, revealed that some considered there were *"too many people involved"* and how they *"sometimes had to fight to be heard"*. Issues such as *"reluctance to finalise the group"*, *"poor communication"* and that *"the process became orientated to a small group doing the work"* were also reported. Maintaining motivation, enthusiasm and focus had proved to be challenging for some respondents, a view which perhaps might have been reiterated by some participants, including myself, in the AR VPJ. However frustrations caused by *"trying to change fixed ideas"* or *"getting staff on board who were reluctant to change the way they work"* had not been a specific concern of VPJP team respondents unlike those at CHS.

CHS: Q5. How do you think we could improve things for the future?

Once more, the CHS evaluation brought new points to consider. These were presented in three themes, *right team*; *PJ process management*; and *monitoring of implementation*. The findings revealed requests to ensure that the right members are recruited to a PJ from its outset; with the suggestion that the PJ process is chaired by a Business (or Deputy) Manager. Other suggestions included a call for a smaller, locally owned dedicated group, yet this contradicted another respondent's view that where this had occurred this had not been a positive aspect of the PJ process. There had also been a call for more involvement of frontline staff; this had also been identified as a need from

this study's Vascular PJ. With regard to management of the PJ process, some CHS respondents called for

- more appropriate time allocation, with greater flexibility and extended timescales
- a system for informing new staff about the PJ; the provision of education/ awareness sessions for all staff involved in the process
- getting the right people involved
- improved groundwork prior to commencement of a PJ
- patient involvement in mapping
- to spend more time on how service should be, and on implementing the changes
- needs to be a specific patient group; works best where there is national best practice available (although lack of best practice had not created an issue in this PJ)
- highlight research project focus rather than 'how can we improve things' project

Again, apart than the first point, no others had been raised by VPJ respondents. The suggestion to include patients in mapping was interesting but considered unrealistic. This was primarily because of the nature of the exercise, the unfamiliar environment, but also because of the individuality of each person's journey. Furthermore, as this AR VPJ study demonstrated, this data can be gathered through patient interviews. The last of the above points, which called for a focus on research than improvement was unclear. For instance, as this study demonstrates, even if the focus is on research, the most appropriate approach, in the context of a PJ, is action research the focus of which is still concerned with how 'things' can be improved.

Under the *'monitoring of implementation'* theme respondents offered a number of different points of interest in this AR VPJ study. These included recommendations such as a six monthly evaluation of changes and update of action plan; clearer and regular progress reporting; clearer outcome measures; better follow-up and annual post-action plan meetings. In the VPJ, these recommendations had largely been addressed. For example, an action plan, the regularly updated Issues and Solutions (IAS) document, was used to drive change and improvement forward. This was discussed, with examples provided, in Chapter 4 (Appendix 30).

Part 2 of the CHS questionnaire had been divided into three sections; *consensus event*; *implementation group* and *action plan*. Interestingly the evaluation report did not provide any indication of how many consensus events had been held. As action researcher, and external PJ project facilitator, in light of the decision not to hold a consensus event in the VPJ, it would have been interesting to know how many other teams considered this necessary. Lloyd and Campbell (2007) also reported that a number of implementation groups had been set up to deliver the action plan after completion of the

six month Patient Journey process. Although a specific implementation group had not been set up in this AR VPJ, the VPJP team were still meeting regularly, albeit in a smaller group, at the point of my withdrawal in February 2009. These meetings had regularly taken place after the last of six meetings associated with the Patient Journey process had been held in late November 2007. The subsequent meetings were focused on ongoing and unresolved actions, reviews of changes already implemented, progress updates, implementing further change and maintaining sustainability. These actions also reflect the nature of action research as defined in Chapter 3.

Interestingly, and somewhat surprisingly in light of the strong emphasis Campbell et al (2004) had placed on patient involvement, CHS did not include patients and carers in the evaluation.

Limitations of evaluation

Whilst there had been a 68% return rate for PJ project respondents in the Vascular PJ evaluation, this had only been 46% in the CHS PJ evaluation. As a consequence it is acknowledged that the findings from CHS might not provide a wholly accurate representation of the majority view. Nonetheless, because the responses resonate largely with those of this AR VPJ study, and because they were drawn from 16 completed Patient Journey projects, this provides sufficient evidence upon which to draw a concluding consensus view.

Exploring the Patient Journey: findings of this action research study

This action research Vascular Patient Journey study, and the evaluation of 16 Patient Journey projects at the City Hospitals Sunderland (Lloyd and Campbell, 2007), have enabled the generic potential of the PJ process to be realistically and fairly assessed. As the discussions in Chapters 3 and 4 and this chapter illustrate, the Patient Journey has been demonstrated to be a process through which powerful catalysts can quickly trigger patient (person)-centred changes to a current and local patient journey. Regardless of the challenges that have been highlighted by Chapters 3, 4 and this final, overall evaluation, this AR VPJ study provides robust evidence that the AR PJ improvement process is effective, readily adaptable and achieves considerable results. This claim is substantiated by the evidence provided in Chapters 3, 4 and 5, which include findings from the AR VPJ project and the changes secured, and the findings of the service user and service provider evaluation data, in addition to those of PJ project participants at CHS. It is further reinforced by evidence that Patient Journey projects continued to be implemented, in CHS, throughout the duration of this study.

Further verification of the generic potential of the AR PJ process comes from my stance as action research and external Patient Journey Facilitator, with first-hand experience of implementing a Patient Journey. As evident, this was an independent project, carried out in a different NHS Trust remote from CHS and facilitated by someone with no prior knowledge or experience of the PJ process. There was no readily available guidance or accessible support available from the lead group who *"...govern the development and evaluation of the projects..."* in CHS (Campbell et al, 2004, p. 17). Nor did this project have access to *"...appropriate research leadership from the Nursing practice Research Centre"* unlike CHS PJ projects. As such, it might be argued, that the generic potential and effectiveness of the Patient Journey process has been fairly and comprehensively tested and evaluated by this action research study and established.

Wider implications of the Patient Journey process
A framework for action research
This action research study has also demonstrated that the CHS Patient Journey provides a framework for conducting improvement research in healthcare. Figure 3-3 and the discussions in Chapters 3 and 4, in particular, illustrate how the combined processes can be implemented to bring about change and improvement to current patient journeys. This chapter provides evidence of how involvement in an AR PJ study is perceived by service users and service providers.

A method for Practice Development
Campbell et al (2004) introduce the Patient Journey approach in the journal '*Practice Development in Healthcare'.* However other than their article title, they make no further reference to this discipline which has also played a role in modernising the NHS (Page, 2002). Rather, terms such as modernisation initiative, service development or project development are used. Practice development, offers another approach to improvement to that can be aligned with action research (Manley et al, 2005). It is usually contextualised within clinical nursing practice, and is also one that has been gaining increasing recognition since its introduction to the UK by the nursing profession in the late 1970s. Thus its focus is also on modernisation and enabling patient-centred, quality improvement in services, practice and care (Manley and McCormack, 2003, McSherry and Warr, 2006). Consequently, a brief mention to align the PJ process to Practice Development (PD) is offered. Further understanding of PD can be obtained from the literature offered by Elwyn (1998), McCormack et al (1999), Page and Hamer (2002), McSherry and Bassett (2002), McSherry and Driscoll (2004), McSherry and Warr (2006), McCormack et al (2007), and Volante (2009).

McSherry and Warr (2006) and McCormack et al (2007) suggest that practice development, like action research and the PJ, also promotes a participatory approach. The PJ as a structured framework for conducting action research places a specific emphasis on patient-(person)-centred, quality improvement. As this AR VPJ study has demonstrated, the PJ model enables

- knowledge to be shared, new knowledge acquired, and findings to be used as catalysts for further learning and change
- stakeholders, service users and multidisciplinary service providers to be involved in the change and improvement process
- collaborative engagement, active participation, team and relationship building, supportive culture, empowerment, leading to shared ownership for change
- an understanding of what really matters to service users and service providers so that patient-(person)-centred change and improvement can be secured and sustained.

Many of these elements are also central to PD as McCormack et al (2007) explain through findings of a synthesis of empirical evidence. The Patient Journey process also incorporates a number of characteristics and attributes which McCormack et al (2007, p. 77) suggest are central to PD projects. Although not explicit, these are reflected in the key principles and components of the PJ approach as outlined in Figure 5.11, below.

The Patient Journey: a person-centred approach to service improvement Key principles and components
Agreed ethical process; adheres to research governance; structured framework within action research paradigm
A project culture where openness is welcomed, people are valued, and ideas can flourish
Active engagement of key stakeholders (service providers and users); support of CEO and Trust Management and Executive Boards
Multi-level stakeholder analysis through participative and reflective, collaborative, multi-disciplinary engagement; promotes shared ownership
Values determined, clarified and collaboratively agreed; shared visions identified
Workplace culture analysis; critical reflection (mapping and interviews, multi-disciplinary project meetings) reflective multi-disciplinary learning
Genuine, rather than token, person-centredness; voices heard and acted upon
Integral, ongoing peer review of PJ process and progress; formally reported upon
Reporting, formally and informally, on change as it happens; sustaining motivation
Overall evaluation; dissemination of learning

Figure 5-11: key principles and components of the Patient Journey approach

Generic service improvement process

Past employment experience in the private sector in a global communications company, indicates that the principles of the PJ process could be applied in any organisation where the focus is on improving customer services. Similar opinions were also expressed by the Lead Vascular Consultant, Consultant Anaesthetist and Superintendent Radiographer, each of whom could envisage the wider potential of this model beyond the NHS setting. This view is reinforced by literature associated with organisational behaviour and management, and organisational change, for example by those such as French et al (2011) and Martin and Fellenz (2010).

Chapter overview

This chapter has offered a broadly informed evaluation of the Patient Journey model. Data gathered from patients, the care partners and the multidisciplinary project team in this Vascular Patient Journey have been compared with an unpublished evaluation report by Lloyd and Campbell (2007) of 16 completed CHS Patient Journeys. By so doing it is now possible to support the claim by Campbell et al (2004, p. 15) that *"the City Hospitals Sunderland notion of Patient Journeys is explicit, different, and is making a difference to patients"*.

The potential of the Patient Journey as a generic approach to service improvement has been recognised. It is evident from these findings that, for those who are determined and motivated to make a difference to the healthcare experiences of others, the Patient Journey process can effectively facilitate this. Not only in terms of local outcomes, but also in terms of the wider insights it enables into the healthcare experiences of NHS patients and frontline staff. As the findings have demonstrated service users and service providers see and experience the patient journey from different perspectives thus they can identify different issues. In this instance, as the findings in Chapter 4 showed, 34 issues emerged from service user data, 35 from service providers and 6 joint issues from both datasets. This illustrates that both sets of data are required to enable effective and appropriate change. Thus, these findings provide clear evidence which demonstrates why the views and well-being of service users and multidisciplinary, rather than just service users, or just interprofessional, service providers must be taken into account when seeking the delivery of high quality, safe, individualised and humanised care. Findings which also indicate that 'person-centred' as a more encompassing term, rather than 'patient-centred' which directs focus only on the patient, should become the predominant, or umbrella, term to define contemporary healthcare delivery.

The final chapter, Chapter 6, addresses the last action identified for this AR VPJ study as part of Stage 9 of the combined AR and VPJ processes. The required the PJ approach to be presented to external audiences to gain a wider perspective.

Introduction

This chapter will draw this action research Vascular Patient Journey to its conclusion by first providing an insight into the wider perspective of this approach to healthcare improvement. This was acquired during a period of active dissemination whilst preparing for final withdrawal from the VPJP team and the SE NHS Trust.

The discussions in this final chapter will also include recommendations for future research, practice, healthcare education, and AR PJ projects as indicated by the findings of this action research Patient Journey study.

Extending beyond the small scale project (2)

Having completed the evaluation of the AR PJ process and compared this to the CHS evaluation, one final action remained:

- To present the Patient Journey model to external audiences in order to gain a wider perspective and gauge potential interest.

As explained by the aim and objectives listed at the end of Chapter 2, the primary aim of this study involved exploring the wider and generic potential of the City Hospitals Sunderland (CHS) Patient Journey process (Campbell et al, 2004). Because of this it was considered appropriate to engage in third-person action research practice, which, as Reason and Bradbury (Chapter 3) explain, entails *"extending beyond the small-scale project"* to gather an impartial opinion (Reason and Bradbury, 2001, p. xxvi). Through dissemination it was hoped that not only might an external opinion be acquired but also that any previously unforeseen political, intellectual or cultural concerns (Reason and Bradbury, 2001, 2008) associated with the revised and amalgamated action research Patient Journey process would be revealed and, if possible, addressed. The aim was to offer a *"compelling and enduring"* research contribution offered at this study's conclusion (Reason and Bradbury, 2001, p. xxvi).

Correspondingly, whilst still engaged with the AR Vascular Patient Journey (VPJ) project team, dissemination of completed project findings commenced. Although by this stage, August 2008, this study had been presented to audiences in Berlin, Vienna and the UK, and had been well received, those presentations had only contained progress reports of the AR VPJ in the SE NHS Trust (see also Appendix 37, for summary of dissemination). Now an evidence-based overview of the whole VPJ project, with a comparison to 16

CHS PJs could be offered the intention was to gain wider opinion.   This would enable more fully informed discussions and recommendations to be offered at this study's conclusion.

Dissemination: seeking an external viewpoint

The first of the post-project presentations took place on 12th August 2008 to the SE NHS Trust's Patient Experience Committee, when an overview of this project met with an enthusiastic response. Two of the key attributes of the PJ process, as previously identified in the discussions about findings in Chapter 4, and the evaluation in Chapter 5, the patients' voice and the collaborative, multi-disciplinary and inter-professional approach to service improvement, were quickly recognised and their merits acknowledged. For example; just four short quotes from patients (Figure 6.1 below) sparked a variety of personal and professional responses, enquiries, and disclosures of similar experiences, some of which perhaps had not been anticipated. Rather, service, organisational or clinician orientated responses had been expected, more akin to those voiced by the VPJP team.

Figure 6-1: Slide from dissemination presentation

After the presentation a number of emails were received, extracts from two of these are included by way of example. These were from people who were already keen advocates for patient-(person)-centred care, particularly for people living with long-term conditions, as their enquiries indicate.
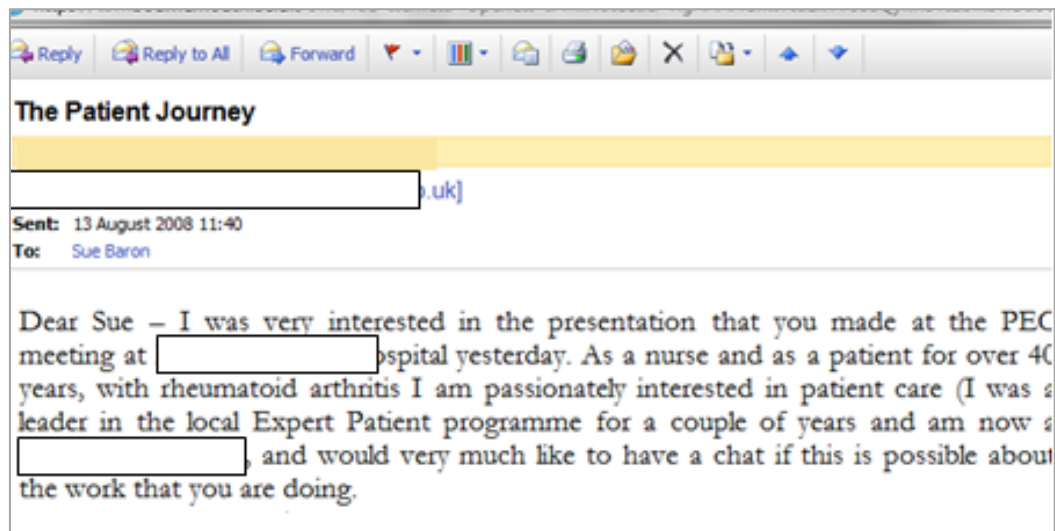
Figure 6-2: example of email enquiry following presentation to patient experience committee
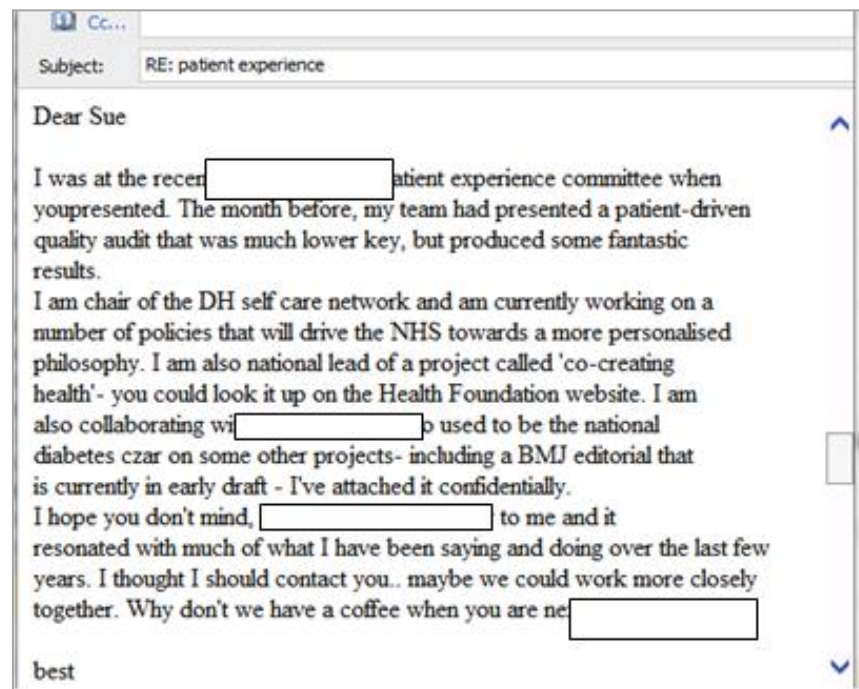
Figure 6-3: further example to demonstrate wider interest in the action research Patient Journey process

A précis of the presentation was also recorded in the minutes of the Patient Experience Committee meeting. This is included as Figure 6-4 by way of additional supporting evidence. Each of the extracts included in these figures can be verified can be verified through access to SE NHS Trust records or researcher's email account.

> ## 4. Vascular Patient Journey Research Project
>
> Sue Baron, PhD Student/Research Assistant, Bournemouth University, and XX, Nurse Practitioner for Vascular Surgeons, attended the meeting to tell the committee about a piece of research into patient experience that Sue had carried out (a paper on the research had been circulated to the committee prior to the meeting). The objectives of the research (a model which was developed in Sunderland) had been to make healthcare more patient-centred by carrying out in-depth interviews in patients' homes with patients that had undergone vascular treatment at XX. The interviews were set up by XX, inviting patients who were selected by a set of criteria that was established by the vascular care team. Sue Baron carried out the interviews (which were taped) and then fed back the findings to XX and the team so that learning and improvements in patient care could be achieved.
>
> XX reported that significant changes in behaviour had been made directly because of this research e.g.
> - Patients are now contacted prior to coming in for surgery to find out when a good time of day would be for them to arrive (instead of expecting them to arrive very early in the morning)
> - It is now explained to patients why they are required to sleep in beds once they arrive at hospital when they have been used to sleeping in chairs at home
>
> The committee were impressed by this piece of work and were keen to establish how it could be used more widely to improve patient experience. XX and Sue felt that it would be essential for any type of research of this kind to be 'owned' by the specific team in question and that establishing the correct criteria for the patients interviewed was very important. This would ensure that it would only be necessary to interview a small sample (only 11 patients were interviewed in this instance). It would also be necessary to ensure that the whole multi-disciplinary team were involved and engaged; a lack of engagement of nursing staff due to lack of time had been a challenge for this project. It was suggested that this type of work could be incorporated into the Productive Ward Live initiative that XX is planning to implement and/or as a progression of the planned electronic methods of obtaining patient feedback.

Figure 6-4: evidence of dissemination at Patient Experience Committee on 12th August 2008

Further positive and enthusiastic responses were also received during and following additional conferences and events (Appendix 12). For instance, when presenting at Bournemouth University's 7th International Qualitative Research Conference in September, 2008, the suggestion was made by a senior NHS Manager from central England, that the findings of this study should be reported in three arenas

> "A delegate yesterday suggested that I needed to ensure that I have access across the three disciplines – policy making, education and healthcare – why not contact Lord Darzi (the then Parliamentary Under-Secretary of State at the Department of Health, and current leader of NHS reform - added) direct, she suggested." (Extract from PhD Journal, 2008)

Around the same time, as part of the endeavour to more broadly disseminate this work, a synopsis of this study was sent to a national nursing journal for patient-centred healthcare. This was by way of response to their request for improvement initiatives. Figure 6-5 is an extract from the subsequent reply dated 21st November 2008.
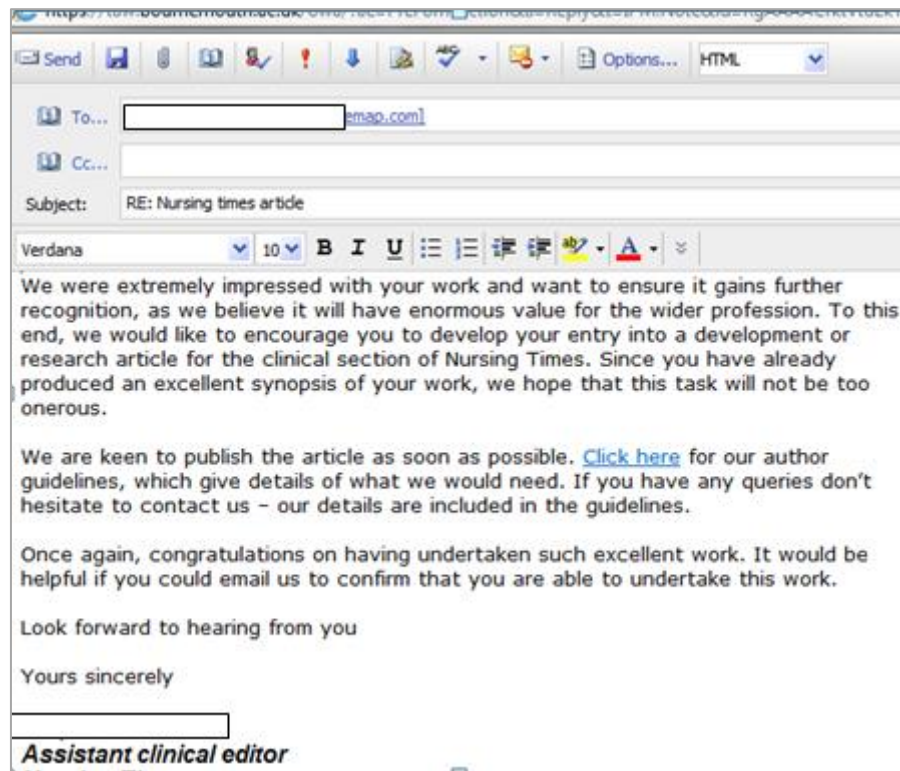
Figure 6-5: example of wider interest in the AR VPJ improvement process

The article referred to in Figure 6-4 was published in June, 2009 (Baron, 2009b). Other examples of interest at that time also include an enquiry from a senior healthcare manager in Saudi Arabia, and the Lead Consultant Surgeon from the VPJ project in January 2009 (Figure 6-6).
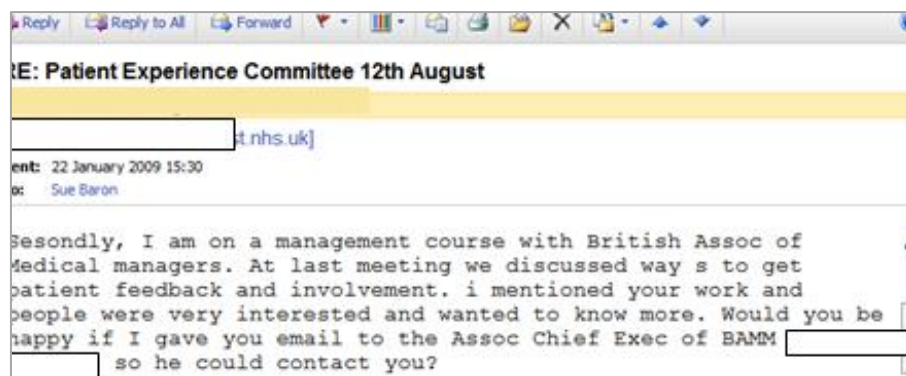
Figure 6-6: further example of wider interest in AR VPJ

Endeavours to reach wider audiences continued during late 2008, early 2009, with two additional research reports being published, one in an independent publication of the SE NHS Trust (Baron, 2008), and the other in a University review of School projects (Baron, 2009a). These too brought further enquiries and expressions of interest (example Figure

6-6, Figure 6-7). These email extracts reflect the enthusiastic responses received when presenting this study to professional, clinical, academic, educational and lay audiences.
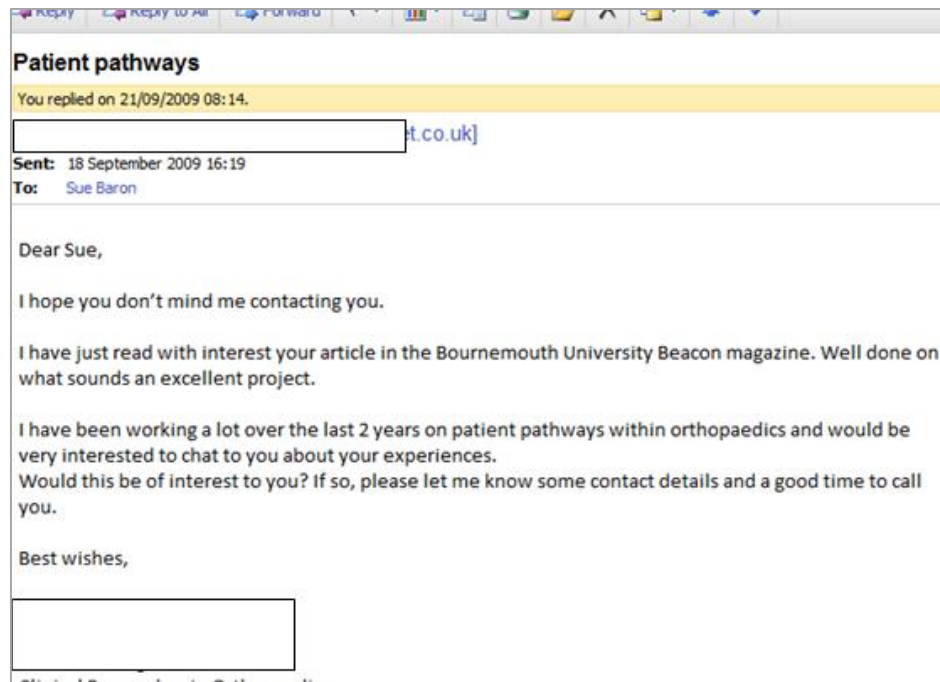
Figure 6-7: response to local publication

.
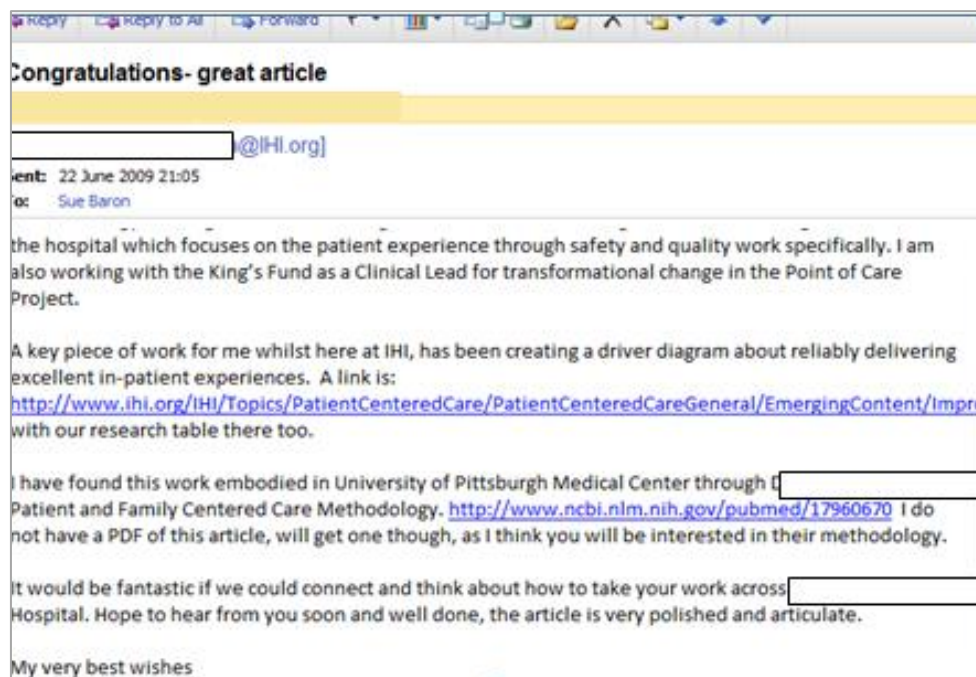
Figure 6-8: example of interest in AR VPJ from overseas

Figure 6-8 provides an example of overseas interest in the AR VPJ study. Although this person was affiliated with organisations in the UK, at the time of contact they were working with the Institute of Healthcare Improvement (IHI, 2011), in the US. This is one

of a number of international organisations actively promoting PCC. The extracts in these figures can also be verified.

An impartial opinion: concluding the study

The findings from dissemination provided the impartial opinion that was sought in order to bring this study to its conclusion. This is affirmed by the examples that have been included from some of the enquiries and feedback received. The views and interest expressed in these email extracts are further reinforced by the discussions and evidence provided in Chapters 4 and 5. These findings fulfil the aim of this study which was to explore the CHS Patient Journey approach and evaluate its wider potential as a generic, patient-centred and collaborative approach to change and improvement. Perhaps most significantly the findings support the view that service users and multidisciplinary service providers should be involved in healthcare services review and improvement initiatives. The discussions thus far, and in Chapters 4, 5, have also fulfilled objectives 1-6 listed at the end of Chapter 2. However, one final objective, 7, required recommendations to be made on the basis of the findings of this study. These are offered amongst the discussions in the final part of this concluding chapter.

Closing discussions and recommendations

Political concerns

Throughout this study every endeavour has been made to keep abreast of emerging policy directives, initiatives and quality and service improvement measures associated with what might now be defined as the global movement towards patient-centred healthcare. The purpose has been to ensure that a contemporary, politically aware, contribution, of broader interest, might be made to the existing body of evidence at this study's conclusion. It has also enabled new, politically driven, national NHS modernisation initiatives to be compared with the modified action research Patient Journey model (Campbell et al, 2004) and recommendations made.

The Productive Ward - Releasing Time to Care Initiative

One of the most notable, national NHS modernisation developments since 2005 was launched by the NHS Institute for Innovation and Improvement in 2007 (NHS Institute for Innovation and Improvement, 2007). In NHS England this is referred to as the *Productive Ward*, whereas in NHS Scotland the term *Releasing Time to Care* is used; both being shortened versions of the full term applied by the NHS Institute *'The Productive Ward – Releasing Time to Care'.* (In NHS Wales this initiative is included within the *'Transforming Care Programme'* also a national, ward based improvement

programme and part of NHS 1000 Lives Plus (2011), a national improvement programme.)

Since its introduction, *The Productive Ward – Releasing Time to Care* has been described as a '*phenomenon*'; it has also been claimed to have *'revolutionised care'* (Fradd, 2009). Its aim has been to support and empower frontline staff to review their current working practices, giving them the responsibility for finding ways in which improvements, at ward level, can be made, through clear and workable strategies. Time is released and protected by management so that ward staff can actively engage with the programme. This has also been recommended for AR PJ projects as inferred in the extract from the Patient Experience Committee minutes (Figure 6-4). By late 2011, 85% of NHS acute hospitals (139 acute Trusts) were reported to have downloaded the Productive Ward toolkit from the NHS Institute website demonstrating widespread interest.

A Rapid Impact Assessment of Productive Ward, undertaken by the National Nursing Research Unit, King's College, London, of nine NHS Trusts in England, found that, although progress was reported as variable (thought to be partially due to the use of varying evaluation strategies), it seems the initiative has increased staff satisfaction and improved patients' experiences (NHS Institute for Innovation and Improvement, 2011; Robert, 2011). Amongst additional benefits reported are an *'increase of 41.6% in direct patient care time',* and financial returns, which averaged from £8.07 for every £1 spent on implementing Productive Ward (NHS Institute, 2011).

However, the key emphasis is on just one, albeit perhaps the most significant aspect of a patient's healthcare journey, the hospital ward. As such, this leaves some notable gaps in relation to other aspects of their journey which, as the findings from this study indicate, could be bridged by the AR Patient Journey process (Campbell et al, 2004). It is suggested, therefore, that if an action research Patient Journey study and Productive Ward were run in succession, those issues identified during the PJ process could be handed over for action as part of the Productive Ward initiative.

Experience Based Design
In March 2009 another initiative emerged from the NHS Institute for Innovation and Improvement which also appears to have the potential to 'follow-on' from, or enhance, a Patient Journey project. *The Experience Based Design (EBD) Approach* (NHS Institute for Innovation and Improvement, 2009), holds a number of similarities with the Patient Journey. This might be attributed, in part, to the involvement in its development of a

former member of the team from the Nursing Practice Research Centre at CHS. This person had also co-authored the paper on the CHS Patient Journey in which it had been stated that

> "Re-designed processes, such as those resulting from the patient journey process, need to have appropriate data collection loops that tell the clinical team how well it is achieving the new processes. Our vision is to incorporate such 'hot spot' data collection and variance analysis by having the patient journey as part of the hospital information system." (Campbell et al, 2004, p. 24, 25).

Both approaches have also been claimed to be making a difference:

> "…the project should be different and should make a difference. Indeed it was different and has made a difference" (NHS Institute for Innovation and Improvement, 2009, p. 7)

> 'The City Hospitals Sunderland notion of patient journeys is explicit, different, and is making a difference to patients' (Campbell et al, 2004, p. 15)

The EBD (NHS Institute, 2009) approach offers four key steps to service improvement defined as

> *"Capture:* getting patients and staff involved, and helping people tell their stories
> *Understand:* identifying emotions, mapping emotional 'highs' and 'lows', finding touch-points
> *Improve:* co-design turning experience into action
> *Measure:* evaluating and sustaining the improvement" (NHS Institute for Innovation and Improvement, 2009, p. 17)

Steps, which it is thought could be used to build upon and help to sustain the work undertaken by a PJ project team. The EBD approach offers *"…an improvement approach… there is no 'textbook' way that has to be strictly followed…the range of tools and steps presented here are designed so that they can be used flexibly"* (NHS Institute, 2009: 16). But, the guidance offered about interviewing and filming patients raised concern based on the experience of interviewing in this study:

> "The National Research Ethics Service has advised that no formal ethical review is needed prior to using the EBD approach and other experience based co-design methods (as long as the work is conducted for service improvement purposes…However, you will still need to apply good ethical principles to your work, including getting full, informed consent from all the people who share their experiences and stories." (NHS Institute, 2009, p. 15).

As evidenced by the discussions and narratives in Chapters 3 and 4, interviewing patients about their experiences requires a sensitive approach. Their narratives have also shown that significant ethical issues may be uncovered during the process. As such, it is strongly recommended that ethical approval should always be obtained when there are intentions to interview or film patients about their experiences. The only advice

currently given in the Institute's EBD Guide and Tools booklet, is to "*Make sure that they* (patients – added) *feel OK before they leave"* (NHS Institute, 2009, p. 59), which is perhaps somewhat disconcerting. Experience in this AR VPJ study strongly indicates that awareness of the potential issues associated with interviewing should be heightened through ethical review. Interviewers should also be appropriately prepared and possess the right skills for interviewing.   In spite of my own background as a nurse, I had not fully appreciated the all the possible implications associated with interviewing patients prior to undertaking this study. An example of this was provided in Chapter 3 which illustrated how a patient's disclosure about a pressure sore sustained whilst receiving in-patient care triggered ethical concerns. Whilst it is appreciated that securing ethical approval can be a lengthy process, and it might impede innovation during the research process, as it did during the latter part of this AR VPJ study, ethical approval is nonetheless consideration crucial to protect the well-being, safety and confidentiality of those involved.

The ethical issue that caused frustration in this AR VPJ study relates to an idea that arose from discussions with the Vascular Patient Journey Steering group in 2008. This was after the period of data collection. The proposal was to use clips from the recordings of patient interviews as points of learning and reflection for hospital staff. The intention was to incorporate these media clips into short films, involving actors, that the SE Trust could us as part of an 'in house' educational package for all staff. When the possibility of this was further explored with LREC, the idea had to be shelved. This is because as Figure 6-9 illustrates this would have required a *"substantial amendment"* which time constraints did not allow.
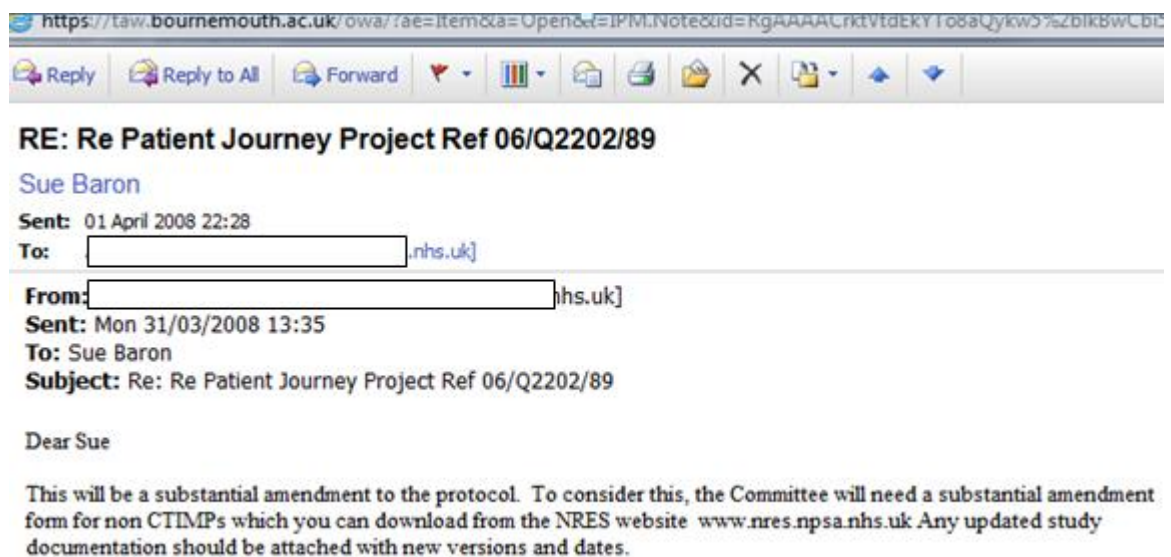
Figure 6-9: exploring potential for educational films

The experience in this AR VPJ highlights a disparity between service improvement measures such as EBD, and research, which might warrant further investigation.

Wider political concerns

Whilst national guidelines are available to promote patient (person)-centred healthcare, and advances have undoubtedly been made in some areas of the NHS, on-going reports of failings have continued to indicate that much still needs to be done, not only in terms of improving services, but also changing the current blame culture (Colin-Thorné, 2009, Francis, 2013). Currently NHS organisations and their employees, particularly nurses, are all at risk of being viewed as uncaring, unsafe and of delivering inhumane care. This is somewhat unfair given the commitment and dedication of many who strive to ensure that their patients are well looked after, feel safe and who always endeavour to provide their patients with good healthcare experiences, as this study also demonstrates. An example slide which was used to illustrate this point in a more recent research seminar is included as Figure 6-10.

Continuing cause for concern in 2012

Nurses 'are losing their sense of compassion' (Daily Telegraph, 9th January 2012)

"Nursing needs to improve" (David Cameron, 6th January 2012)

Nurses in the NHS too often lack ability, compassion or even the simple desire to work in the profession

In some cases staff lack basic skills, have a poor grasp of maths and do not understand the values of the health service, according to the NHS Future Forum (2012)

"...patients — in particular the elderly — are suffering from poor standards of nursing care as they are ignored or mistreated on wards."

"...the core part of nursing is caring for people when they are at their most vulnerable." (Professor Steve Field, GP, chairman of the NHS Futures Forum, 2012)

"Medical staff should treat patients as individuals and treat them with dignity..." (National Institute for Clinical Excellence [NICE], 2012)

Figure 6-10: examples of continued focus on negative reporting

Whilst it is imperative, and right, that any failings or instances of sub-standard care are exposed, as they have been through the reports referred to in this thesis, it is suggested that these should be better contextualised. This has also been strongly indicated by the findings of this study as the Report of Patient Interviews in Appendix 29, and discussions in Chapters 4 and 5 illustrate. For example, the report by the Patients Association (2011), included first-hand, disheartening accounts of the shameful care and treatment of 16 mostly older people, across the NHS. A report that has been widely publicised by the British media, but without an accompanying caveat to explain that, although such failings are completely unacceptable for just one person, the findings cannot provide a true reflection of all care and treatment provided by the NHS. When

placed in context, the NHS is said to provide services for approximately 1,000,000 people every 36 hours; with around 3 million people being treated in NHS England every week (NHS Choices, 2009, 2011). It is possible to argue that by only focusing on failings, the British media and the UK Government are helping to perpetuate the blame culture, rather than enabling a more balanced perspective by also reporting on the successes of healthcare employees and the NHS. This, in turn, can lead to scaremongering which, perhaps inevitably, is also likely to increase anxiety amongst current and future patients, and lead to a demoralised and demotivated workforce. The impact of the latter on patient care and staff retention was also made evident by the findings of empirical studies into PCC critiqued in Chapter 2.

These factors provide further evidence in support of this AR PJ study's recommendation that more opportunities should be provided for patients, their relatives *and* staff to routinely provide feedback on their experiences, to raise concerns, suggest ideas and give credit where this is due. Action research studies that are framed by the Patient Journey process in the manner tested in this study provide one means of achieving this. This has shown the benefits of collecting data from both groups, and of learning about the positives as well as negative aspects of current patient journeys. It has also provided evidence of the benefits and challenges, of involving multidisciplinary teams in the improvement process. Perhaps most significantly in this cultural context, it has demonstrated what can be achieved when a multidisciplinary team can come together and work together in an environment where the fear of being judged, ostracised or labelled as a trouble-maker, or not being listened to is dispelled. The impact and value of this approach is reinforced by the outcomes reported in Chapters 4 and 5.

Linking research to education and practice

Interprofessional Education (IPE)
According to the Centre for the Advancement of Inter-Professional Education (CAIPE) inter-professional education (IPE) occurs when *"two or more professions learn with, from, and about, each other to improve collaboration and the quality of care"* (CAIPE, 1997, 2007). In 2010, the World Health Organisation (WHO, 2010) changed the emphasis of this definition and advocated that the focus of IPE should also be targeted at improving health outcomes, rather than solely on quality of care. Each of the three factors, inter-professional collaboration, quality, and health outcomes is promoted during the AR Patient Journey process. As this AR VPJ study has demonstrated, when a multidisciplinary team or interprofessional group work in collaboration, shared learning occurs, common goals can be identified, and a range of skills fundamental to the

delivery of safe, high quality and patient-(person)-centred care can be further enhanced. Barr (1994, 1998, 2000a, 2000b) and Milburn and Colyer (2008, p. 319) suggest these skills include communication, negotiation, problem-solving, teamworking and conflict management skills. The findings of this study have shown that engagement in collaborative working and becoming empowered through the improvement process can enhance any of these skills. This is perhaps verified most strongly by the service provider evaluation in Chapter 5, but also through the steps of change discussed in Chapter 4.

Interprofessional education and multidisciplinary collaborative practice

Improved collaboration between health and social care professionals, one of the main goals of interprofessional education (IPE), has been viewed as a priority since the 1960's by successive UK Governments (Forman and Nyatanga, 1999). IPE can also be aligned to this study's multidisciplinary focus, as one that promotes improved collaboration between health and social care professionals but also others of the healthcare team. As the ethos of the AR PJ team membership suggests, this should include not only healthcare professionals but also, administrative and support staff, healthcare assistants, managerial and other clinical and non-clinical staff, and staff from across care boundaries if possible (primary care, acute care, social services). According to Barrett et al (2005, p. 18), collaborative practice occurs when there is a

> "...common purpose of developing mutually negotiated goals achieved through agreed plans and monitored and evaluated according to agreed procedures. This requires pooling of knowledge and expertise to facilitate joint decision-making based upon shared professional viewpoints."

This collaborative practice is promoted through the revised AR Patient Journey process; as the findings of the CHS PJ evaluation in Chapter 5 demonstrate. It has also been emphasised by publicly reported failings, amongst which include the death of Victoria Climbie (Lord Laming, 2003; DH, 2003d); and failings at the Bristol Royal Infirmary (Bristol Royal Infirmary, 2001; Coulter, 2002; DH, 2001d; DH, 2003c; DH, 2010) and Mid Staffordshire NHS Foundation Trust (Francis, 2010, 2013); and *Care and Compassion"* report in 2011 by the Health Service Ombudsman, reports by the Patients Association (2005, 2008, 2009, 2010, 2011, 2013). These investigations poignantly strengthened the argument in support of multidisciplinary collaboration and interprofessional education (IPE). This is further supported by the findings of the literature review in Chapter 2, which highlighted the impact of single profession education, theoretical models and frameworks of care, and research focus on fragmented perspectives and ways of working. This topic can be explored further and through the literature of Barr (1994,

1996, 2000a, 2000b), Parsell et al (1998) Hale (2003) and Milburn and Colyer (2008) and a variety of healthcare policy directives (DH, 2001d, NHS, 2003).

As the findings of this AR VPJ study indicate, it seems there is still a long way to go before multidisciplinary and IP collaborative practice, IPE, and a patient (person)-centred and open healthcare culture, becomes embedded throughout the NHS. Arguably a significant issue, but, nonetheless, one which the findings of this study suggest the AR PJ process could help to address.

Self-awareness

A further factor emphasised this AR VPJ, is the importance of self-awareness (Jack and Smith, 2007) towards PCC, patient care and experiences, interpersonal relationships and teamworking, and securing improvement in healthcare. The following three extracts from the Report of Patient Interviews (Appendix 29) illustrate this point:

- '…I spilled some water…so I called…all of a sudden this one comes flying in…we're still handing over, wha, wha, wha, bang and out…I thought she didn't even ask me what the problem was…I could have been ruddy dying for all she knew" (p.15)
- "I'm not complaining about all nurses, but this one particular nurse, I've tried to speak to her quite reasonably …she was very impatient with me…then she said…'don't forget you're in an NHS hospital…this isn't a private ward…and I looked at her and said I didn't ask you that I just asked where the …so she said 'well, I've only got one pair of hands'…she was very bad tempered that night and that was upsetting for me…" (p.14)
- "…I don't know whether he was a doctor or a nurse…like I said I took my own books and I'd got Jordan books…and he kept saying to me 'oh, she's got big boobs' and things like this and he came the one day to wash me…the book was on the bed and he says why does anyone want big boobs like that? Would you like big boobs? And I thought no way are you washing me, I'm sorry, and I says to him…I can manage…he was doing his job but I didn't like him saying that, that to me was stay clear, I didn't like it so I removed the Jordan book." (p.24)

Although these extracts relate to ward-based, inpatient care, self-awareness and self-insight is recognised as a multidisciplinary concern. Harris (1997, p. 591), for example, in the context of social work, defines this as a person's

> "...ability to look at and recognise oneself – not always nice, and sometimes judgemental, prejudiced and non-caring".

A definition which, when applied to any of the above scenarios, suggests that the healthcare staff who interacted with these patients were not self-aware, or at least not during those points of interaction with patient. This is significant as the lack of self-awareness in these situations, even if only momentarily, caused a situation that left an

adverse lasting impression on the patient involved. These examples also demonstrate why those such as Ellis (1999, p. 296) suggest that:

> "the first step in providing patient-centred care is awareness and acceptance of what motivates action and intervention. These fundamental elements are the starting point for providing true holistic care, increasing self-awareness and promoting personal and professional development. Reflection and experiential learning provide the means to access the potential of both HCPs (healthcare professionals – added) and patients."

The quotes from Harris (1997) and Ellis (1999), together with the three verbatim extracts from patients, illustrate why opportunities to enhance self-awareness through healthcare education should be offered. This is a core characteristic of patient-centred practice fundamental to building positive and therapeutic interpersonal relationships. It was first acknowledged in nursing, medical and counselling practice some fifty years ago as briefly mentioned in the literature review. After the end of the Second World War a paradigm shift amongst these professions started to occur and those such as Peplau (1952, 1988) in nursing, Balint (1955) in medicine, Rogers (1951, 1957) and Maslow (1943, 1950, 1954) in counselling, began to emphasise the importance of self-insight and awareness towards the building of therapeutic relationships between the professional and their patient (client). Not only in terms of better outcomes for the patient, but also in terms of better work satisfaction for themselves (Kjeldmand et al, 2004). More recently Eckroth-Bucher (2001, 2010, p. 297) has suggested, on the basis of findings from a review of literature associated with nursing, education, social work, sociology and psychology, that self-awareness is

> "...a dynamic, transformative process of self. Ultimately, self-awareness is the use of self-insights and presence knowingly to guide behaviour that is genuine and authentic to create a healing interpersonal environment"

By encouraging self-awareness in healthcare education and practice, multidisciplinary staff, not just healthcare professionals, can be supported to more fully consider their position in the world, and explore what shapes their beliefs, values, feelings and opinions. Through an improved understanding of 'self' the healthcare provider can reflect on how their 'self' might affect relationships, and the feelings, perceptions, actions and their reactions to and interactions with others, or to different situations.

From the nursing perspective, self-awareness has not only been aligned to the development of therapeutic relationships between the nurse and their patient, but also to enhanced professional competence (Burnard, 1984, 1986; Rungapadiachy, 1999; Freshwater, 2002, 2005; Freshwater and Rolfe, 2001, Jack and Smith, 2007). Solon, a

Greek philosopher, is reputed to have suggested that knowing thyself can *"profoundly affect how we experience another person's humanity"* (Smoyak, 1999, p. 64) *"as one can only understand in another what is understood in self"*, a view shared by Peplau (1952, 1988) and Arnold and Boggs (2007) and Eckroth-Bucher (2010, p. 297) who adds

> "Creating an interpersonal environment that heals – one that is empathetic and compassionate and permeates the senses as well as meets health care needs – is believed to be possible only if self-awareness is built into the communication process"

Real life examples, like the three included above, can be also used in healthcare education as a starting point to encourage reflection on practice. This is simply defined by Spalding (1998) as a way in which we can learn from experience, our own or another's. Through this, self-awareness can also be enhanced. As these examples and others in Appendix 29 illustrate, understanding of how thoughts, beliefs, emotions, attitudes and so forth can impact on our own behaviours, is one of a number of fundamental characteristics crucial to the development of positive and supportive interpersonal relationships in healthcare. It is also a trait that can facilitate positive teamwork through enhanced relationships and improved ways of working, which in turn can contribute towards transforming the culture of the NHS towards one that is more people-centred. More detailed understanding of reflection in and on practice and examples of theoretical models may be gathered from Dewey (1933), Polanyi (1967), Schon (1983), Benner (1984), Kolb (1984), Boud et al (1985), Gibbs (1988), Higgins (1997, 1989), Johns (2000, 2009), Jasper (2005) and Fleming (2007).

A cohesive, national message rather than specifically focused

The findings of the literature review in Chapter 2 and those from this AR VPJ study, particularly in Chapters 4 and 5, have demonstrated that single profession perspectives, condition-focused initiatives, such as the NSFs, the terminological quagmire in healthcare, a failure to listen to service users and service providers, or involve them in improvement, are amongst many factors that have impeded the delivery of equitable and seamless, patient-(person)-centred healthcare. However, these findings have also demonstrated that many of these issues are readily resolvable when insights into the perspectives and real-time experiences of service users and service providers are acquired. Just one account, from one person's experience, as the data in this study demonstrates, can provide a catalyst for long-awaited change, and poignant learning. As this AR VPJ has emphasised, these narrative accounts from a multidisciplinary team's own service users, enabled clearer understanding of their own patients' journeys and a common understanding of the concept of patient (person)-centred healthcare.

But, it was only the team's involvement in the change process, and collaborative working that enabled these narratives to become catalysts for effective change. Through involvement and working in partnership, as the findings in Chapter 4 demonstrate, the team were empowered to quickly act to resolve current issues to improve the experiences of their future patients, the efficiency of their service and their interactions and working relationships with each other.

What do patients really want?

Figure 6-11 (below) represents a synthesis of the elements of vascular patient journeys found to be of greatest significance during this AR VPJ study. These are consistent with many of those also identified by former empirical research into PCC in Chapter 2.

As the literature review confirmed, much of what the UK Government is striving to achieve in NHS healthcare today in terms of patient-centred healthcare, and ensuring better continuity of care, has been discussed before. It has also become clear that patient (person)-centred healthcare is not a new concept but one which has existed under a variety of guises since the dawn of medical history. Nonetheless, it is a concept which is diverse and complex, and influenced by a broad range of factors, including single profession perspectives, which can trigger misconceptions and confusion. Yet, fundamentally, this is an approach that is simple to follow if basic humanistic principles and values, such as dignity and respect; honesty and integrity; kindness and compassion, are promoted and adhered to; and if each person is recognised as an individual human being with their own set of beliefs, values, influences and ways of being. Even so, as the reports of NHS failings have indicated, despite its relative simplicity, and evidence of increasing recognition its value in healthcare, the patient-(person)-centred approach is still being suppressed in some pockets of the NHS. As the reports suggest, this is particularly notable in areas where there is an overriding focus on fulfilling Government imposed targets and achieving financial cutbacks; where the organisational culture and associated leadership are not person-centred or blame free, and where there is a lack of clarity about the concept, which have led to misconceptions about its significance to healthcare. For instance, that this approach is less efficient, more time consuming and that it detracts from the medical model. Yet, on the contrary, as the findings from this study have indicated, the patient-(person)-centred approach, can lead to more effective treatment and care, more streamlined services and cost benefits, better experiences and greater satisfaction. It can also improve staff morale and motivation, and lead to improved ways of working amongst healthcare staff.

Patient-Centred Healthcare – What Patients Really Want
To have quick access to and receive best possible, individualised, timely, advice, treatment and care, delivered by friendly, competent, trustworthy, healthcare staff
To be treated as individuals, with dignity and with respect for their culture, lifestyles, values, and beliefs and existing support networks.
Respect and consideration for, and involvement of, family/carer/friend as appropriate
To have their voice heard and to be able to exercise real choice, if they so desire, about treatments and services
To receive high quality, readily understandable information (verbal and written), about their condition and possible treatment, given in an honest, timely and sensitive manner at all stages of the patient journey
To be kept informed
To experience good face-to-face communication, and to be able to build therapeutic relationships with health and social care staff
To feel safe
To receive an apology and an honest explanation when promises are not kept, or when things go wrong
To have any pain effectively treated and managed
To feel confident that their individual dietary and nutritional requirements will be fulfilled when this is necessary
To have their fundamental needs - such as elimination and personal hygiene – attended to in a timely, dignified and respectful manner when assistance is required
To undergo only those interventions for which informed consent has been given
To know that their physical symptoms will be managed to a degree that is acceptable to them and is consistent with their clinical situation and clinicians' current knowledge and expertise
To receive psychological/emotional/spiritual support, as appropriate, from professionals who listen and have the skills and attributes to provide this support
To know that services will be well co-ordinated by multi-disciplinary/inter-professional teams; no risk of 'falling in the cracks' between professionalisms or care boundaries
To not feel abandoned after discharge from hospital
To know what options are available to them under the NHS, voluntary and independent sectors, including access to self-help and support groups, complementary therapy services and other information; guidance to achieve optimum quality of life
When the time comes, and where possible, to die in the place of their choice

Figure 6-11: Patient-centred healthcare: a synthesis of core determinants as identified from findings of this action research Vascular Patient Journey study

For this patient-(person)-centred approach to become endemic throughout the NHS, leaders must embrace this concept and play their part in fostering the development of a cultural shift towards one which is people focused, open and supportive. Greater emphasis needs to be placed on developing an NHS-wide, common understanding of patients', and NHS employees, wants and expectations. The ways of working promoted through this action research Vascular Patient Journey study can help with this.

As this exploration into the Patient Journey approach now demonstrates, not only does this provide a route through which poignant and powerful catalysts for patient (person)-centred, effective change in healthcare practice and service improvement can be unearthed; this is a process through which the seeds of cultural change may also be sown. When a team actively engages, this approach promotes open and supportive ways of working, and enhances collaborative, multi-disciplinary and inter-professional teamwork. Through the Patient Journey the benefits of working together, listening to and learning from each other, are quickly acknowledged. Furthermore, by ensuring the involvement of a broad spectrum of disciplines from across the NHS hierarchy in the change process, a more comprehensive and real-time view of healthcare provision and practice, and the practicalities of change, is enabled. Firstly from those with first-hand experience of the services under review; those who understand what is currently working well or not so well and who have a keen interest in improving the experiences of others. And, secondly, from those who understand the systems, processes, financial and other targets imposed on healthcare organisations. Thus their combined knowledge and expertise and new found common understanding can quickly lead to change as evidenced in this study.

Limitations

The limitations of this AR VPJ study and the methods used are discussed and summarised in Figures 4-2, 4-3, 4-4 and 4-5 in Chapter 4, they are also indicated in the findings of the evaluations of this study and those of the 16 Patient Journey projects undertaken at CHS discussed in Chapter 5. These have indicated that time, existing long-term barriers, negative perceptions about the ability to bring about change arising from past failed attempts, organisational and team culture and ability to sustain motivation will all influence whether a Patient Journey can be implemented and become effective. This heavy reliance on people is perhaps the greatest limitation of this approach. Yet, conversely, this, as this study has demonstrated, is perhaps also its greatest strength as it is through their engagement in the AR PJ process that change and improvements to patients experiences and care can quickly and effectively be achieved.

In terms of methodology, any limitations in terms of undue influence from researcher bias, for example, are largely mitigated through the collaborative and democratic approach, which also ensures that all findings and other related documents are peer-reviewed and subject to consensus agreement of accuracy, reliability and authenticity.

Limitations of external Patient Journey facilitator role

The findings of the service user evaluation indicated that the role of external PJ facilitator is significant towards the progress and outcomes in an action research PJ study. In light of this, a brief insight into my experience of that role is offered using extracts from my PhD journal. These also help to explain the starting point of this investigation, the associated voyage of self-discovery, and why this study is unique.

- February (2006)"...my liaison with the Trust was a new venture for the university... I was likened to a 'guinea-pig'. This, in itself, did not worry me and perhaps served to explain some of the issues that had arisen so far. I had already become aware that, within the nursing profession, it is extremely unusual for a newly-qualified nurse to embark on a PhD. I was informed that, traditionally, this has been considered appropriate only for those with many years' experience. Also, during a recent meeting of Divisional Managers (in SE NHS Trust – added) I had overheard the comment 'I always wanted to do a PhD but couldn't get the funding'. There was no overt animosity directed towards me, but …
  As February progressed my motivation and enthusiasm dwindled. I felt like I was banging my head against a brick wall and going nowhere fast. I was looking for progress and direction and becoming more and more frustrated with trying to find a focus, or more specifically a client group, around which my study could be centred...." ((Extract from PhD journal, February, 2006, p.8, Year 1).

This extract illustrates the importance of recognising, as an AR PJ facilitator, how first impressions about the role holder may affect access when aiming to set up an AR PJ project. It also reflects the challenging nature of conducting action research, as an outsider, in an NHS organisation. This was strongly influenced by existing barriers, many of which had been anticipated from personal experience of working in the NHS, but also those highlighted during the literature review (Chapter 2). For example, the most significant barrier encountered during introductory meetings was an almost widespread scepticism about the chances of success for an improvement project of this type. A number of lead clinicians, for example, explained that this was because they had become cynical about attempts to improve services based on their own experiences. One consultant described how they felt as if they had been '…coming up against a brick wall…', another blamed their failed endeavours on a lack of support from Trust management or financial constraints; they also believed part of the problem could be attributed to NHS leaders '…trying to provide a Rolls Royce service when it could only afford a mini...'. But there were further barriers to overcome in terms of time

constraints from workloads, as the second part of the above extract indicates. Thus this brief insight reinforces the suggestion that the greatest limitation of the AR PJ process concerns its heavy reliance on the nature, characteristics and skills of its participants.

Final conclusion

This action research study has considered and discussed many issues in relation to the multi-faceted and complex concept of patient-centred healthcare. The introductions in Chapter 1, and the critical review of empirical PCC literature in Chapter 2, highlighted a number of reasons why PCC might continue to evade many sectors of healthcare and the NHS. These include varied perceptions of, priorities for, and misunderstandings about the concept of patient-centred care and patient-centredness; the emphasis on single profession frameworks and theoretical models of care and focus on single disciplines in research; a lack of focus on multi-disciplinary and inter-professional working and education; and an endemic culture of secrecy and blame. As the findings of this AR VPJ can now demonstrate these have been long-standing issues that still remain despite the PCC modernisation directives issued by the Department of Health, and widely publicised reports of public inquiries into healthcare failings.

A number of these issues were also highlighted during this AR VPJ study. But the difference in this context was that, through the active and collaborative engagement of a multidisciplinary team who were interested in improving their patients journeys, change happened as a consequence of what their patients and care partners told them, and what they, collectively, as a team identified as issues to be addressed about their service. As mentioned in Chapters 4 and 5, 34 of these issues emerged from service user data, 35 from service provider data and 6 joint issues from both datasets, highlighting 75 aspects of the current patient journey that warranted attention. A number of the changes that occurred by way of response, and how they were informed, have been offered as examples in Chapter 4. The VPJP team's motivation and morale, as the evaluation findings in Chapter 5 indicate, was sustained through their engagement in the AR VPJ process, because they also learnt how they had made a positive difference to their patients. Additionally, through their more frequent face-to-face interactions with each other, and through working more closely together, they started to build more supportive and open relationships by learning from and about each other. By so doing, they evolved into a stronger, more collaborative multidisciplinary team who became empowered and took responsibility to improve their own service.

As such, the contribution of this action research study to the existing body of knowledge, as one that has involved and drawn on evidence from those with first-hand experience

of NHS healthcare, is considered to be *"compelling and enduring"* (Reason and Bradbury, 2001, p. xxvi). Recommendations have been offered throughout this thesis which not only aim to clarify the concept of PCC, but also provide evidence-based explanations and examples to illustrate how patient-(person)-centred healthcare might be facilitated. The data derived through the Vascular Patient Journey project has clearly demonstrated the significance of involving those with first-hand experience of healthcare, as service users and service providers, in the change and improvement processes. It has also brought evidence of further gaps in existing knowledge to light which would be beneficial to explore. For example, the longer-term implication of a hospital admission; the impact of national guidelines and initiatives that focus only on high profile long-term conditions on those who live with a low profile conditions like PVD. In addition, the findings from this AR VPJ study strongly suggest that the Patient Journey process provides a readily adaptable, generic, structured framework for facilitating patient (person)-centred change and improvement in healthcare; a process that can also be used for practice development and as a tool of clinical governance.

As this study indicates, Patient Journey projects are not without challenge. Central to achieving success is determination, hard-work, effective leadership and a shared passion and commitment amongst project team members to work collaboratively on improving the experiences of their patients, and each other. The collection of frank and open accounts of patients' healthcare journeys, whilst time consuming, not only provide valuable, authentic, blame free insights into what is working well, or not so well with existing services. They also enable a much clearer understanding of the patients' experience of their whole journey through healthcare, often across care boundaries, and of living with specific conditions.

The Patient Journey effectively places patients (and their relatives), and healthcare staff, at the heart of healthcare and service review and improvement, thus also enabling appropriately informed efficiency savings, improved working relationships, and much deeper insights into complete healthcare experiences to be attained. Added to this, the open, supportive and blame free ethos which has now been aligned to the Patient Journey approach is refreshing, motivating and, as has been demonstrated, is one which through which the seeds of cultural change can be sown (see final quote, below). It is, therefore, offered as an approach through which the UK Government's vision for a personalised, patient-centred NHS may be clarified and fulfilled, and new ways of thinking and working initiated. The following copy of an email update in Figure 6-12 below, received from a key stakeholder at the SE NHS Hospital Trust in November,

2011, concludes this chapter and thesis by revealing the longer-term impact of just one Patient Journey project.

RE: Transforming Patient Experience Annual Conference

Sue Baron

Sent: 23 November 2011 19:38

[st.nhs.uk]

Sue, it was great to see you at the conference, we have had a lot of interest since which has been really good.

As we talked through where we are now is due to the foundation work we did 5 years ago and the patient-centred improvement journey work in vascular was a key part of that. As I said in my presentation it takes time and we are on a journey. So the work you led really helped to start our thinking in a more constructive way around what is it like to be a patient in our hospital. Reviewing clinical care pathways is a priority driven by efficiency but what that early work did was start to shift our thinking around what is it like from the patient perspective and if you do that the efficiencies still come. There were great examples in the work you did of truly understanding the pathway and making it more patient focussed but also safer and more efficient . It is also about the cultural shift across the hospital and by clinical teams leading the work with facilitation as you did gets great staff engagement and satisfaction in the work.

Figure 6-12: wider impact of an action research Patient Journey project

Policy document	Key directive(s)
The NHS Plan: a plan for investment, a plan for reform (Department of Health (DH), 2000) (White paper)	▪ The NHS must be redesigned to be patient-centred – to offer a personalised service. ▪ NHS to become a health service designed around the patient based on 10 core principles ▪ Patients to be given a real say in the NHS and provided with new powers and more influence over the way the NHS works. The patients' voice is high on the governmental agenda. ▪ New Care Trusts to be set up to commission health and social care in a single organisation – aim to prevent patients from falling in the cracks between the two services or being left in hospital when they could be safely cared for in their own homes.
An Organisation with a Memory (DH, 2000)	▪ To provide a safer NHS ▪ To address the blame culture ▪ Identification of the true causes of failure ▪ Improve incident handling
The Health and Social Care Act (DH, 2001)	Statutory duty placed on all NHS organisations to consult patients and the public at an early stage when planning and organising services
A Commitment to Quality; a Quest for Excellence (DH, 2001)	▪ UK Government and medical profession jointly called for an end to the NHS blame culture ▪ 7 pledges in support of a more supportive and open culture ▪ Patients' right to expect services which are responsive to their needs, which are delivered to a consistently high standard ▪ Patients' right to be treated with respect and be provided with good information
The Essence of Care: Patient focused benchmarking for healthcare professionals (DH, 2001) (updated 2010)	12 benchmarks to support localised, quality, patient-focused improvements in specific aspects of care delivery (continence bladder and bowel care; personal and oral hygiene; food and nutrition; pressure ulcers; privacy and dignity; record keeping; safety of clients with mental health needs in acute mental health and general hospital settings; principles of self-care)
The Expert Patient: A new approach to chronic disease management for the 21st century (DH, 2001)	'My patient understands their disease better than I do.' Patients to become key decision makers in the treatment process. Patients with long-term conditions to be empowered to self-manage and work in partnership with their health and social care providers.
Building on the Best: Choice, responsiveness and equity in the NHS (DH, 2003)	▪ The NHS will listen to how patients want to be treated ▪ Everyone to have their own HealthSpace linked to their electronic health record, allowing individuals to make their preferences known to the clinical team ▪ Increase choice to a wider range of services ▪ Increase choice of where, when and how to get medicines ▪ Enable people to book appointments at a time that suits them, from a choice of hospital (up to 5 by 2005). Those waiting over six months for surgery to be offered faster treatment at alternative hospital ▪ Widen choice of treatment and care, greater choice in maternity and end of life care ▪ Ensure people have the right information, at the right

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	time, with support to use it (Commission for Patient and Public Involvement in Health (CIPPH) set up in January 2003 – an independent, non-departmental public body sponsored by the DH. Its role was to make sure the public is involved

The Commission for Patient and Public Involvement in Health (CIPPH) was set up in January 2003 – an independent, non-departmental public body sponsored by the DH. Its role has been to make The Commission for Patient and Public Involvement in Health (CIPPH) was set up in January 2003 – an independent, non-departmental public body sponsored by the DH. Its role has been to make sure the public is involved in decision making about health and health services in England. A report by the Commission for Health Improvement 'Unpacking the Patients' Experience: Variations in the NHS patient experience in England (Feb, 2004) showed that involvement rarely changed practice or services despite the intentions and much work still needed to be done. In 2011 there were over 400 Patient and Public Involvement (PPI) Forums, one for each NHS Trust in England. Patient Advice and Liaison Services (PALS) and Independent Complaints Advocacy Service (ICAS) were also launched in 2003 – these replaced Community Health Councils.

The NHS improvement plan: Putting people at the heart of public services (DH, 2004)	▪ The next stage in the NHS journey is to ensure that a drive for responsive, convenient and personalised services takes root across the whole of the NHS and for all patients ▪ Better support for people with long term medical conditions ▪ Each patient to have access to HealthSpace (also DH, 2003, above)
Patient and Public Involvement in Health: The Evidence for Policy Implementation (DH, 2004)	A summary of the results of the Health in Partnership research programme
10 High Impact Changes for Service Improvement and Delivery: a guide for NHS leaders (DH, 2004)	Every single patient to receive the best possible care, every single time – take a process view, following the patient journey through the health and social care system. 1. Day surgery, rather than inpatient surgery, to become the norm for elective surgery 2. Improve access to diagnostic tests thereby improving patient flow across the whole NHS system 3. Reduce the length of hospital stays by managing variation in patient discharge 4. Manage variation in the patient admission process 5. Unnecessary patient follow-ups to be avoided, with those that are appropriate to be delivered in the right care setting 6. Advocate a care bundle approach to improve reliability of therapeutic interventions 7. Apply a systematic approach to care for people with long term conditions 8. Reduce waiting times and improve patient access 9. Use process templates to optimise patient flow-through and reduce bottlenecks 10. Redesign and extend roles in line with efficient patient pathways to attract and retain an effective workforce
Creating a Patient-Led NHS: Delivering the NHS Improvement Plan (DH, 2005)	▪ Patient and public involvement should be a part of everyday practice in the NHS ▪ Change the whole system so that there is more choice, more personalised care, real empowerment of people to improve their health – a fundamental change in our relationships with patients and the public ▪ Move from a service which does things to and for its patients to one which is patient-led where the service works with patients to support them with their health needs

	▪ Stronger standards and safeguards for patients ▪ Improvement in the ability of NHS organisations to understand the needs of patients
Now I Feel Tall. What a Patient-Led NHS Feels Like (DH, 2005)	▪ Make the NHS more aware of the importance of improving patients' emotional experience ▪ There need to be changes in how the system works and how people behave, and a culture where everything is measured by its impact on patients and the benefits to people's health

Patient involvement service improvement initiative: Discovery interviews (DH, 2005) (comparison to Patient Journey in Chapter Two)

Our Health, Our Say, Our Care: A New Direction for Community Services (DH, 2006)/A Stronger Local Voice (DH, 2006)	To promote greater patient independence, choice and control building on existing patient involvement philosophies – to make sure that the needs, preferences and involvement of local people, including those that are seldom heard, are central to the planning, development and delivery of local services

Section 242 of the consolidated NHS Act 2006 placed a duty on NHS trusts, PCTs & strategic health authorities to make arrangements to involve patients and the public in service planning and operation; and in the development of proposals for changes.
In 2007 **Local Involvement Networks (LINks)** were set up to provide everyone in the community – from individuals to voluntary groups – with an opportunity to give their views on local health and social care services. However, the lack of clarity about the role and structure of LINks had caused concern, particularly to the Chair of the CPPIH, that the disbanding of CIPPIH and the 400 plus PPI forums already established, would lead to the patients' voice slipping away quietly (DH, 2007). The document *'Local Involvement Networks Explained'* (DH, 2007) included the recommendation that 'clinical staff and staff involvement in developing proposals is critical; we need greater involvement of clinicians, staff and their representatives in the process at a local, regional and national level.'

Our NHS, Our Future: Next Stage Review (DH, 2008)	Five pledges aimed at enabling the NHS to make world class quality of care a reality for all: Pledge 4: The local NHS will involve patients, carers, the public and other key partners. Those affected by proposed changes will have the chance to have their say and offer their contribution. NHS organisations will work openly and collaboratively.
High Quality Care for All: NHS Next Stage Review Final Report (Darzi, 2008).	"The NHS touches our lives at times of basic human need, when care and compassion are what matter most. Over the past 60 years, it has been a vital friend to millions of people, sharing their joy and comforting their sorrow. One million people are seen or treated every 36 hours, and nine out of 10 people see their family doctor in any given year. In 2008, the NHS will carry out a million more operations than it did just 10 years ago." Key steps to achieving high quality care for all: ▪ High quality care for patients and the public – personalising services: making services fit for everyone's needs – change locally-led, patient-centred and clinically driven – a nationwide process. "If quality is to be at the heart of everything we do, it must be understood from the perspective of patients." (2008: 47) ▪ Quality at the heart of the NHS – clinical care to be safe and effective; patients to be treated with compassion, dignity and respect...empowering patients, more rights and more control. ▪ Bringing clarity to quality – "Many bodies undertake standard setting, and what is desirable versus what is mandatory is often too hard to understand. In addition,

	NHS staff tell us that the knowledge and information they need to deliver excellent care can be too hard to find" (2008: 49).
	▪ Working in partnership with staff – frontline staff to be empowered to lead change that improves the quality of care for patients "...unlock local innovation and improvement of quality through information – information which shows clinical teams where they most need to improve, and which enables them to track the effect of changes they implement (2008: 49).
	▪ The first NHS Constitution – setting out the extensive set of patients' legal rights in relation to the NHS.

Health and Social Care Act (2008) – Established a new integrated health and social care regulator – the Care Quality Commission – to replace previous monitoring and inspection bodies.

'Voices into Action' (2009) - aimed to provide health and social care service users a greater say in how their services are run (through surveys, consultations and LINks)
The Health Act (2009) – personal health budgets for people with long-term conditions

The Engagement Cycle: a New Way of Thinking about Patient and Public Engagement (PPE) in World Class Commissioning (DH, 2009)	Key patient and public engagement activities: ▪ Engaging communities to identify health needs & aspirations ▪ Engaging the public in decisions about priorities & strategies/continued…
The Engagement Cycle: a New Way of Thinking about Patient and Public Engagement (PPE) in World Class Commissioning (DH, 2009)	▪ Engaging patients in service design & improvement ▪ Patient centred procurement & contracting ▪ Patient centred monitoring & performance management Customer Insight: Each of the Patient and Public Engagement activities should generate data about what matters to patients. This data can be 'patient-derived' (i.e. comes *from* patients directly or indirectly) or 'patient experience data' (i.e. is *about* people's experiences of services).
Putting Patients at the Heart of Care (DH, 2009)	Sets out vision for public and patient engagement and experience
Understanding What Matters: a guide to using patient feedback to transform care (DH, 2009)	NHS Trusts to collect feedback from patients to drive service improvement. Guide sets out best practice in terms of collecting, analysing and using patient data to transform services. ▪ individual feedback: seeking feedback from patients on the quality of care that they have experienced, their needs and preferences ▪ collective perceptions from the public: obtaining intelligence on what matters to local populations.
Helping the NHS Put Patients at the Heart of Care (DH, 2009)	Discusses Department of Health support programme to help services engage the public and patients
The NHS Constitution (DH, 2009, updated 2010)	Sets out rights and privileges for patients, public and NHS staff
Equity and Excellence: Liberating the NHS (DH, 2010)	Sets out the Government's long-term vision for the future of the NHS. The vision built on the core values and principles of the NHS - a comprehensive service, available to all, free at the point of use, based on need, not ability to pay.
Equity and Excellence: Liberating the NHS (DH, 2010)	▪ put patients at the heart of everything the NHS does; focus on continuously improving those things that really matter to patients - the outcome of their healthcare; and empower and liberate clinicians to innovate, with the freedom to focus on improvement
Patient-centred NHS a step closer to reality: Health and Social Care	Under the new measures there will, for the first time, be a defined legal duty for the NHS and the whole care system to improve continuously the quality of patient care in the areas

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Bill published. (DH, January, 2011)	of effectiveness, safety, and - most importantly - patient experience.Plan to improve the NHS in five key ways: • patients to be more involved in decisions about their treatment and care so that it is right for them – there will be 'no decision about me without me'; • the NHS to be more focused on results that are meaningful to patients by measuring outcomes such as how successful their treatment was and their quality of life, not just processes like waiting list targets; • clinicians to lead the way – GP-led groups will commission services based on what they consider their local patients need, not on what managers feel the NHS can provide; • there will be real democratic legitimacy, with local councils and clinicians coming together to shape local services; and • they will allow the best people to deliver the best care for patients – with those on the front-line in control, not Ministers or bureaucrats.

Example of literature analysis also showing disparate nature of empirical studies of patient-centred care

Source/ model of patient-centred care	Study design	Sample/ control group or intervention	Measurement and outcomes	Distorting influences	Completeness/ recommendation
Campbell et al (2003) UK study No model cited	Mixed methods In-depth interviews & RCT	20 patients diagnosed with patella-femoral arthritis Physiotherapist Independent interviewer – not a healthcare professional. Intervention: 9 treatment sessions, exercise, posture correction, footwear advice	Primary outcome measure; 10 cm visual analogue pain scale; function subscale of Western Ontario and McMaster University's osteoarthritis index (WOMAC) In-depth interviews at patients' homes	Level of concordance between interview and questionnaire data was less than 50% No detail of questions used included by researchers to facilitate clear understanding of outcomes	Inconclusive outcome regarding effectiveness of PCC intervention due to inconsistencies in findings. Discrepancies between results of standard patient based measurements and patients' interview narrative led to recommendation that quantitative outcome measures should also include patient narrative

Example of literature analysis also showing disparate nature of empirical studies of patient-centred care

Source/ model of patient-centred care	Study design	Sample/ control group or intervention	Measurement and outcomes	Distorting influences	Completeness/ recommendation
Stewart et al (2000) Canadian study Model: Patient-centred medicine (Stewart et al, 1995)	Observational cohort study: Focus on The impact of patient-centred care Examined patient –centred communication and patients' perceptions of the patient-centredness of the visit to their physician.	39 family doctors 315 patients	(1) Visual analogue scale on symptom and discomfort used to assess patients' health (2) Self-report of health using Medical Outcomes Study Short Form-36 (3) Chart review of medical care utilisation variables of diagnostic tests, referrals visits to family physician Focused on 3 of 6 interactive components of patient-centred concepts of Stewart et al (1995) model	Questionable reliability of patient's self-reports.	Findings indicated that patient-centred communication, and patients' positive perceptions of common ground between themselves and their physician, improved health status and reduced need for diagnostic tests and referrals.

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Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
Patient–centred	**Field of origin: Medicine** **Evidence base**: Picker/Commonwealth Patient-Centered Care (PCC) Program Gerteis et al (1993); the Picker Institute (2011); Institute of Medicine *Crossing the Quality Chasm* (2001) (Stewart, 1995, 2001, Stewart et al, 2000, 2003) (Gerteis et al. 1993) *Through the Patients Eyes; understanding and promoting patient-centred care.* **Introduces 8 dimensions of patient-centred care** – i) treating patients as individuals, ii) co-ordinating care and integrating services, iii) overcoming the barrier of words iv) innovations in patient-centred education v) enhancing physical comfort, vi) providing effective emotional support, vii) involving and supporting family and friends viii) facilitating the transition out of hospital. It also offers **three dimensions of promoting a patient-centred health care environment**, i) culture, leadership and service in the patient-centred hospital, ii) promoting the doctor's involvement in care, iii) rebuilding public trust and confidence. Dimensions determined from evidence gathered during the Picker/Commonwealth Program for Patient-Centred Care established by the Commonwealth fund and Delbanco (1992). **Contribution:** comprehensive empirical exploration of patient centred care and contributory factors. **Perceived limitation:** Focus on medical profession and health care in USA, therefore, anticipate perceptions of irrelevance/or restricted access by other health professional groups working in different healthcare organisations. **The Picker Institute** opened in 1994 in Maine, USA established by Harvey Picker, supported by the Picker/Commonwealth PCC Program, and inspired by his wife's experiences as a patient. Margaret Gerteis and co-editors of *Through the Patient's Eyes*	Seeing through the patient's eyes – an approach that adopts the patient's perspective. Picker Institute's eight principles of patient-centred care: 1. **Respect for patients' values, preferences, and expressed needs** – including quality of life, involvement in decision-making; dignity, needs and autonomy. 2. **Coordination and integration of care** – of clinical care, ancillary and support services; frontline patient care 3. **Information, communication and education** – clinical status, progress and prognosis; processes of care; information to facilitate autonomy, self-care and health promotion 4. **Physical comfort** – pain management, help with activities of daily living; surroundings and hospital environment 5. **Emotional support and alleviation of fear and anxiety** – related to clinical status, treatment and progress; impact of illness on self and family; financial impact of illness 6. **Involvement of family and friends** – are recognised and accommodated; involved in decision-making, are they supported as caregivers; are their needs recognised? 7. **Transition and continuity** – information; co-ordination and planning, support (clinical, social, physical, financial) 8. **Access to care –** to be able to access care when it is needed and in a timely manner.

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Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	were amongst the founder members. 8 dimensions of patient-centred care were developed into 8 principles of patient-centred care in 1997 based on findings from additional focus groups with patients, family members, physicians and non-physician hospital staff, and literature, as analysed and defined by researchers from Harvard Medical School. The Picker Institute Europe, a UK based charity, was launched in 2000. **Contribution/recommendation**: aims to make patients' views count in healthcare and ensure high standards of patient experience.	
Patient-centred	**Institute of Medicine (IOM)** (US) Committee on Quality of Health Care in America. Crossing the quality chasm: a new health system for the 21st century. Washington, DC. Committee sought to further address issues raised in earlier report *"To Err is Human: Building a Safer Health System"* published in 1999. This highlighted that tens of thousands of Americans were dying each year as a result of preventable mistakes in their care. Crossing the Quality Chasm offered a comprehensive strategy for reforming healthcare, fostering innovation and improving the delivery of care for the forthcoming decade. **Contribution/recommendation:** identified "quality chasm" (gap) in modern healthcare that must be bridged by implementing patient-centred practices that also address the psychological and social dimensions of patients health concerns. **Perceived limitation:** Focus on medical profession and health system in the United States (US).	Institute of Medicine (IOM) (2001), USA. Defines patient-centred care as **"Healthcare that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care"** The Institute of Medicine (IOM) also offers Six Domains of quality: 1. Safety 2. Effectiveness 3. Patient-centredness - providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. 4. Timeliness 5. Efficiency 6. Equitability Takes a whole system approach – considers strategy for change, funding, environment, information technology, evidence-based decision-making, knowledge sharing and freely flowing information; safety from a systems perspective, preparing the workforce adequately to enable smooth transitions through healthcare, reduction of waste, transparency. Care to be based on continuous healing relationships and customised according to patients' needs and values with the patient at the centre.

Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
Patient-centred	**Medicine:** **(Stewart et al, 2006)** Patient-centred Medicine; transforming the clinical method, 2nd ed. Evidence base – empirical studies (including Stewart, 1995, 2001), clinical experience and literature reviews – predominantly Canada. Co-author Ian McWhinney (1980, 1986) was born in Lancashire, educated at Cambridge and St Bartholomew's Hospital Medical School, and acquired 14 years' experience of UK GP practice, prior to being appointed Foundation Professor of Family Medicine at the University of Western Ontario in 1968 so also has knowledge and experience of UK healthcare. **Other related links**: McWhinney co-author of Gerteis et al (1993) Through the Patient's Eyes and member of Picker Institute **Contribution/recommendation:** case studies and practical explanations for patient-centred clinical practice and education. **Perceived limitation**: focus on medical profession. Primarily informed by research undertaken in Canada	*"Patients want patient-centred care which explores the patient's main reason for the visit; seeks an integrated understanding of the patient's world – that is their whole person, emotional needs, and life issues; finds common ground on what the problem is and mutually agrees on management; enhances prevention and health promotion; and enhances the continuing relationship between the patient and the doctor"* (Stewart, 2001, p445) Six components of the patient-centred clinical method: 1. Exploring the disease and the illness experience 2. Understanding the whole person 3. Finding common ground 4. Incorporating prevention and health promotion 5. Enhancing the doctor-patient relationship 6. Being realistic
Patient-centred/patient-centredness	**Literature Review**: Mead and Bower (2000), 'Patient-centredness; a conceptual framework and review of the empirical literature, UK: a review of conceptual and empirical literature for purpose of developing a model of the various aspects of the doctor-patient relationship that are encompassed by the concept of patient-centredness and methods of measurement **Limitations**: focus on GP practice and measurement of patient-centredness in doctor-patient relationship from doctor's perspective. Patient perspective not gathered.	Doctor-patient relationship and measurement of patient-centredness. Elements/concepts identified as • Biospsychosocial perspective • Patient as person • Sharing power and responsibility • The therapeutic alliance • The doctor as person
Patient-centred	**Medicine** Delbanco (1992,1993, 2005) and Gerteis et al (2005) (as above for PCC)	*"Nothing about me without me"*; healthcare that continually seeks improvement based on the effective engagement of lay people and health professionals.
Biopsychosocial	**Medicine** **Theoretical model**: Engel (1977, 1980) identified 3 aspects of medical thinking: i) viewing the body as machine and separate from the mind; ii) the reductionist and materialistic orientation of	A theoretical model offered by George Engel (1977, 1980). Proposed 3 fundamental, integrated aspects of the person to be acknowledged during doctor-patient consultation Social – culture, community, family, doctor, relationships, attribution of meaning

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Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	medical thinking, and iii) the omission of the human dimension due to the objectivity of the doctor-patient relationship. Borrell-Carrió et al (2004): *Critical review of 20 years of the biopsychosocial model.* **Limitations:** open to misconceptions and misinterpretation, for example - the compartmentalisation of a person's illness/health into *Bio* – attended to by doctors; *psycho* – by mental health practitioners and *social* by social workers – rather than interrelated parts of the whole person. Challenging to define and apply in consistent way for every patient therefore effectiveness difficult to measure.	Psycho – person – experience, behaviour – perception, cognition Bio – nervous system, cells, tissues, organs Borrell-Carrió et al (2004: 578): The physician's role is to come to a *"shared understanding of the patient's narrative with the patient".* Broadened physician thinking beyond simply seeking biomedical diagnosis. For example – in the medical model the disease may be diagnosed as an occluded artery whereas the biopsychosocial model considers factors influencing illness and recovery e.g. bio – hypertension, atherosclerosis; psycho – anxiety, stress, and social – e.g. family or employment situation, environment, previous family history of death from cardiac disease, age
Caring	**Nursing** Larson (1987) Comparison of cancer patients' and professional nurses' perceptions of important nurse caring behaviours See also Henderson (2001) and Mann (2005)motional labour in relation to nursing and caring work	50 elements of caring categorised under six themes; **Accessible** - e.g. frequently approaches patient, does little things for patient; encourages patient to call, responds quickly. **Explains and facilitates** - informs patient re treatment & support systems; how to self-care; suggest questions to ask of doctors; is honest **Comforts -** e.g. provides basic comfort measures – warmth light, noise; provides encouragement by finding positive elements; is cheerful; sits with patient; uses touch; listens and talks to patient; involves family A**nticipates** - e.g. anticipates; night times can be difficult for patients; difficulty/shock relating to diagnosis; perceptive of patients' needs and acts accordingly e.g. timely medication to prevent/manage pain, or nausea; challenges of first-times for patients; knows when patient has had enough. **Trusting relationship** -e.g. listens to and shows interest in that patient; puts patient first; allows patient to express feelings; gets to know the patient as an individual M**onitors and follows through -** professional in appearance; is well organised, calm, possesses high quality technical and physical care skills; knows when to call doctor; makes sure others know how to care for patient.
Caring/caring theory	**Nursing and midwifery: USA** Swanson (1991, 1999) 3 studies USA- perceptions of women who miscarried, neonatal intensive care and high risk mothers – and personal experience, as a mother and nurse - led to Swanson's Caring Theory and five caring actions or processes; knowing,	Five Caring Processes of Nursing: 1. **Knowing** – striving to understand an event as it has meaning in the life of another; understanding what the other might be going through but avoiding assumptions (includes acknowledging and responding to the pathological/biomedical elements/thorough assessment/seeking

Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	being emotionally with, doing for, enabling and maintaining belief, proposed in 1991. Also influenced by Watson, who supported her as doctoral student, and Delores Gaut, a nurse philosopher. Swanson, based on her experiences as a researcher (during the three studies with women), nurse and patient suggests that maintaining belief (see next column) might also be viewed as the beginning of caring. She suggests that people enter nursing because of their belief in people, their ability to hold them in esteem and see them as persons of dignity and worth and also because of their belief in themselves, and their want, to make a difference to others.	cues/also knowing in the context of self as the care-giver) 2. **Being with** – the engagement of two human beings/being emotionally present/sharing feelings but not burdening the patient with their account of a similar experience/being self-reflective/knowing personal limits/being self-aware 3. **Doing for** – doing for the patient what they would do for themselves if they were able within the boundary of supporting them to maintain independence/comforting and anticipating needs/preserving dignity by acting in such a way that their personhood is saved as well as their body. 4. **Enabling** – facilitating the other person's passage through difficult events and life transitions/informing/explaining what is going on/supporting/allowing people to just be where they are/educating – putting the patient back on centre stage and facilitating their control over their own illness/recovery/life/preparation for dying/empowering individuals, people and communities to know how to care for themselves. 5. **Maintaining belief** - helping find meaning; sustaining faith/optimism and hope/creating memories/helping people find peace, alleviate guilt/demonstrating belief that the other can get through this.
Caring/caring theory	**Nursing: Colorado, US** Watson (1979,1997,1988, 2002 2006, 2007) Jean Watson, founder of the Watson Caring Science Institute (formerly the Center for Human Caring) in Colorado, researched the philosophy and science of caring with view to solving a number of conceptual and philosophical issues about nursing. Ideas drawn freely from the work of Carl Rogers in relation to self; phenomenological-existential influences. Watson (1988, p.55) describes a person as *"the experiencing or perceiving organism"* that has 3 elements mind, body and soul, all of which are influenced by self. Seminal works by Watson include the human caring theory developed in the late 1970s; *Nursing: Human Science and Human Care* (1985) *New Dimensions of Human*	Watson (1985) defined caring as *"the process by which the nurse becomes responsive to another as a unique individual, perceives how the other feels and sets that person apart."* Watson's 10 carative factors (Watson, 1985, p. 75) 1 Humanistic-altruistic system of values 2 Faith and hope 3 Sensitivity to self and others 4 Helping and trusting, human care relationship 5 Expressing positive and negative feelings 6 Creative problem-solving caring process 7 Transpersonal teaching and learning 8 Supportive, protective, and/or corrective mental, physical, societal and spiritual environment

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	Caring Theory (Watson 1988) *Nursing; human science and human care; a theory of nursing* (Watson 1999). Watson (2002) ***Assessing and Measuring Caring in Nursing and Health Science:*** a seminal text based on literature review, empirical studies, associated theory and philosophy to offer a series of instruments for understanding and measuring caring. Acknowledges caring as a complex human phenomenon. Draws attention to philosophical and theoretical bases of caring including reference to the Rogerian science of Unitary Human Beings (Smith, 1999 cited Watson, 2002) including (i) **Manifesting intentions** (e.g. person-centred intention; preserving dignity and humanity; being with; feeling compassion…) (ii) **Appreciating pattern** (e.g. placing value on the other; cherishing the wholeness of the human being…) (iii) **Attuning to dynamic flow** (e.g. sensitivity to self and other; belonging and interconnected…) (iv) **Experiencing the infinite** (e.g. transcends physical and material world…) and (v) **Inviting creative emergence** (e.g. holding hopeful orientation; growing in capacity to express caring…). The above, and a meta-analysis of 130 empirical studies, also enabled outcomes of caring and non-caring research to be highlighted. **Findings for patients** (feelings of humiliation, fear, out of control, helplessness, despair alienation, vulnerability and long-lasting bad memories; adverse effect on healing), **and for nurses** (hardened; oblivious, depressed, frightened, worn down) (Swanson, 1999 cited Watson, 2002)	9 Human needs assistance 10 Existential-phenomenological-spiritual forces (11.Medically supportive care – added by Schroeder and Maeve in 1992) Watson (1988, p.29) suggested that nursing is a holistic practice and that *"human caring involves values, a will, a commitment to care, knowledge, caring action and consequences"* Watson (2002) Findings in relation to outcome of non-caring environments: **Patients:** feelings of humiliation, fear, out of control, helplessness, despair alienation, vulnerability and long-lasting bad memories; adverse effect on healing **Nurses:** hardened; oblivious, depressed, frightened, worn down (Swanson, 1999 cited Watson, 2002) **Limitations**: Watson's theory has been criticised for almost excluding the physical and technical aspects of care, and questioned as to whether the depth of relationship advocated is realistic in many situations (e.g. Morse et al, 1990; Schroeder and Maeve, 1992; Sourial 1997).
Caring	**Nursing: mental health and learning disabilities, London, UK** Sourial (1997) An analysis of caring. Paper aimed to clarify understanding about the concept of caring using Walker and Avant's (1995) method for concept analysis.	Eight uses of the concept 'caring' were identified and the paper affirms the existence of contrasting views about the concept. Key factors highlighted: **A moral stance** – a moral virtue; includes respect for persons and the protection of human dignity; in nursing these are also associated with competence.

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	Limitations: Analysis conducted using keywords *caring* and *holism* Sourial suggests that perhaps the concept of holism, rather than caring, is preferable, firstly because *"holistic nursing care is a more comprehensive concept than caring"* and caring seems to be a part of holism. Secondly, she suggests holistic is more clearly defined, understood and scientifically based. However, perhaps, as the following quote illustrates, others would challenge this view: *"Sounds wonderful – a mixture of applied intuition and creative evolution, Moody Blues lyrics and concepts of goodness and wholeness not seen since Shredded Wheat was first launched…When I was training, we were taught that the medical model of nursing was the bees' patella. These days, it is not enough to give the right drug to the right patient at the right time. Holism dictates we spend time discussing the concept of self in relation to intravenous cefuroxime. Unfortunately, as more nurses embrace this approach, other matters become less important, such as, their knowledge of the therapeutics, contraindications and potential adverse effects of any drugs they administer…"* (Baron and Warner, 2004, p. 21)	**Two dimensions of caring** – instrumental and affective **Human trait of caring** – discusses the use of phenomenology which highlighted differences between nurse and patient perceptions of caring. Findings indicate that physical care is more important to patients whereas nurses emphasise psychosocial care; the latter Sourial suggested may be because nurses take physical care for granted. **Holism** – two meanings identified. One is associated with the biopsychosocial model; it advocates a whole person approach that encompasses more than a person's physical or biomedical care. Caring was identified as a fundamental part of holistic nursing practice. The second is at variance with the traditional view of Western healthcare as it includes alternative therapies, such as therapeutic touch, and focuses on healing and therapeutic interventions. Sourial quotes Gordon (1990) who considers holistic medicine to include humanistic medicine; an aspect of holism that respects relationships and the personal development of staff as well as patients. **Bureaucratic systems –** these challenge the ability of the nurse to enact human caring because of their economic, rather than people focus. **Patient outcomes** – Sourial suggested that Attree's (1993) classification of the attributes/characteristics of quality nursing care could be readily applied to the caring concept. This would help address gaps left by researchers who attempt to examine the concept of care by exploring patient outcomes and who do not pay sufficient attention to the structural components of caring or the relationship of care to patient outcomes. Sourial concludes that 'caring' as a concept has numerous interpretations which are all considered under the same umbrella. It is not a concept solely specific to nursing; it may be used by lay people and other professionals, for instance by mothers, parents, social workers, doctors
Caring theories	**Nursing: various countries** Roach (1984) McCance et al (1997, 2009) Department of Caring Science, Finland: Katie Eriksson (Eriksson 2002) Theoretical studies Human caring theory advocates that care/caring is the ethical	Example: Roach's 7 Cs (Roach, 1992, 1997) Roach (1992). *The human act of caring: a blueprint for the health professions.* Caring is the vehicle through which nurses interact with patients and assist them to cope with suffering, to find meaning in their experiences, to promote health and wellness and to die with dignity. Caring is the action that nurtures; action that fosters growth, recovery, health and protection of those who are

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	principle or standard by which treatments or interventions are measured; a moral ideal with recommendation for this to become a philosophical basis for nursing. Involves a transpersonal process and is concerned with preserving human dignity and restoring and preserving humanity in fragmented, technological, medical cure dominated systems. Caring science is a humanistically orientated approach informed by humanistic knowledge and hermeneutics that evolved from leading historical conceptions of caring – compassion and human love, that is, caritas (see below) the basic motive of caring. Caring is basically seen as something natural and primordial. A caring relationship that arises in an unselfish relation with another and from a genuine desire to alleviate suffering. Involves respect for the absolute dignity of the human being. In the relationship between the patient and the caregiver, the patient is seen as a unique human being, an entity of body, soul and spirit. The principal idea of caring is to alleviate human suffering and preserve and safeguard life and health Origins of caring theory – theology, philosophy, anthropology, human science and metaphysics See also Finfgeld-Connett (2008)	vulnerable. Caring is the empowering of those for whom care is given (Roach, 1997) and includes: **Compassion**: A way of living born out of an awareness of one's relationship to all living creatures; engendering a response of participation in the experience of another; a sensitivity to the pain and brokenness of the other; a quality of presence which allows one to share with and make room for the other. *"With compassion one becomes a colleague of humanity."* (Roach, 1992, p.18) **Competence**: The state of having the knowledge, judgement, skills, energy, experience and motivation required to respond adequately to the demands of one's professional responsibility (cognitive, affective and psychomotor domains of learning) **Confidence**: The quality which fosters trusting relationships; and confidence of the patient in the roles of the nurse as caregiver, advocate, educator, counsellor, leader, manager, researcher, competent, skilled and safe practitioner. Self-confidence to create safe, caring environments and experiences (knowledge and experience) **Conscience**: A state of moral awareness; a compass directing one's behaviour according to the moral fitness of things; directs moral, ethical and legal decision-making.(sense of accountability, responsibility and leadership) **Commitment**: A complex affective response characterised by a convergence between one's desires and one's obligations, and by a deliberative choice to act in accordance with the standards and obligations of the nursing profession and to ensure that caring is a part of every nurse-patient interaction. **Comportment**: professional presentation of the nurse to others in behaviour, attitude, appearance, dress and language that communicates a caring presence. (self-awareness; accepting responsibility for actions; responsibility for environment and others who contribute to it) **Creativity**: having a vision of how nursing should be, and where improvements could be made. (thinking critically, reflectively and imaginatively; qualities of risk-taking, openness and resourcefulness; ability to individualise care and embrace change)
Client-centred therapy/client-centred	**Psychotherapy**: **Chicago, Illinois, US**. Rogers (1942, 1951, 1957). Client-Centred Therapy. Rogers (2003). Client-Centred Therapy. Its current practice,	Roger's seminal work explores the suffering and hope, the anxiety and satisfaction that fill therapists' counselling rooms. It concerns the uniqueness of the relationship between therapist and client and the common elements that

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	implications and theory. Based on prior research and experience in practice involving clients (men, women and children), thus enabling theory to be built upon close, intimate and specific, recorded observations of man's behaviour in a relationship.	are to be found amongst all these relationships; the highly personal experiences of each one of us; about one person trying to perceive another's experience in terms of the meaning, the feelings and sense it has for them; about human fallibility to gain an understanding of another; about the privilege of the emergence of self as a person; the philosophical orientation and attitudes of the counsellor; *"about life as life vividly reveals itself in the therapeutic process – with its blind power and tremendous capacity for destruction, but with its overbalancing thrust toward growth, if the opportunity for growth is provided.*" (Rogers, 2003, preface)
Compassionate care, compassion	**Nursing: Australia** Von Dietze and Orb (2000) Compassionate care: a moral dimension of nursing. An analysis of the concept of compassion using dictionary definitions and informed by a **literature review** of seminal works including Nouwen et al (1982). This review also considers the alignment of compassion to sympathy and empathy (including discussion and dictionary definitions for each), which are often used interchangeably with compassion. However, as Von Dietze and Orb point out, unlike compassion, neither empathy nor sympathy *"make claims on a nurse's motivation and behaviour"* as they simply seek to offer an appropriate professional response to a person's needs (p.167). The paper also discusses potential barriers to the provision of compassionate care. Citations include Beck (1991) and Souriel's (1997), *An analysis of caring,* in which eight uses of the concept of caring are identified and include ethics, instrumental and affective; traits, patients' and nurses' perceptions of caring; holism, humanism, organisational and quality. The citations help to illustrate threads of interrelatedness between definitions and concepts associated with health care practice.	*"In a moment of crisis a compassionate person will be physically present, acknowledge the need to be there and offer solidarity, consolation and support. It is this sense of solidarity – one's willingness to enter into the problem, confusion or question of another person <u>together</u> with that person that is the core of compassionate care"* (quote from Dietze and Orb, 2000, p.170) (underline added) Defined as an *"essential morale value of the caring role"*. Von Dietze and Orb suggest that this is inextricably linked with actions such as listening, educating, comforting, and that it is the way in which these actions are carried out that demonstrates compassion. Compassion is more than an emotion; it revolves around the ways in which we relate to other people and demands that we act (p.168). They suggest, by way comparison, that: "…empathy can (often for good reasons) put a distance between ourselves and the patient, whereas compassion implies that there is a deeper level of participation in the suffering of another person. Compassion can blur our understanding of professional boundaries and professional objectivism." (p.169) **Barriers** • When decisions about patient care are determined by cost. • A changing system, changing practices and diminished resources places immense pressure on compassionate nursing care.

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
		• The ethos of competition; including competition between nurses resulting in lack of support and compassion for one another. Unhealthy competition isolates, destroys and divides people' healthy competition creates unity, solidarity and closeness. • Nursing culture and the stereotypical image of nursing • Moral conflict between the patient and the nurse, or the nurse and the healthcare system or organisation.
Compassion	**Nursing: Pennsylvania, US** Schantz (2007). Compassion: a **concept analysis**. **Literature review** of articles published between 2004-2005 using key words 'compassion' and 'concept analysis'. The concept of *'compassion'* had concerned Schantz since her entry to nursing. She discusses the 'reality shock' experienced as a novice nurse *"making her debut in the hardly nurturing milieu prevalent in the real world of the healthcare establishment"* (p.49). Schantz cites MacIntyre (1984) who asserts that the rigid rules and conditions that govern the real world of nursing are "the external goods" that guarantee economic profit for hospitals, healthcare institutions and healthcare administrators. This economic-controlled agenda influences the dynamic of nursing practice and the nursing ideals acquired from nursing education, as these commonly conflict with organisational or senior staff agendas. **Limitation:** no clear definition is provided as a consequence of the analysis which draws predominantly on the work of von Dietz and Orb (2000), but also personal experience as novice nurse and a film *Wit* (Edson, 1999) as an exemplar of depersonalisation rectified through compassion. Other citations include Leininger (1991) – see caring theories above.	A concept that is neither clearly defined nor widely promoted in everyday nursing practice; furthermore the word is used interchangeably in nursing research with caring, empathy, sympathy, compassionate care, implying such terms are synonymous, despite their subtle differences. Compassion may be understood in terms of the definition offered by Dietz and Orb (2000, 2001) (see also above), which they recognise as a *"moral virtue"* (Von Dietz and Orb, 2000, p.172). For compassion to flourish this requires acceptance, affirmation, enactment and evaluation. Through these the nurse and patient make the congruent connection between "reasoned justification and morally driven action" (Dietz and Orb, 2000, cited Schantz, 2007, p.53). Compassion is enabled when nurses develop relationships built on trust and confidence with their patients. These enable patients' emotional, spiritual and other needs to be effectively addressed; and these in turn promote healing. Simple and small acts, such as a smile, sharing stories, can demonstrate compassion.
Compassion	**Medicine: New Zealand** Youngson (2007, 2008, 2009). Compassion in healthcare.	Abstract: *"As an engineer, turned anaesthetist, I was interested in how the different parts*

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	Evidence base: personal experience as an anaesthetist and father of patient. Founder of **Hearts in Healthcare** Cites, and builds on work of **Kenneth B Schwartz Centre** for Compassionate Healthcare in Boston, US and **Schwartz Centre Rounds** – multidisciplinary forums in which caregivers discuss their experiences, thoughts and feelings about different topics and the emotional or social challenges of caregiving. **Professor Johanna Shapiro** – author of ***Walking a mile in their patients' shoes*** – a comprehensive review of the psychological and emotional responses to the traumas of clinical training and practice, demonstrating how a more humanistic approach can strengthen empathy and the capacity for compassionate caring. Youngson advocates that all health professional bodies should read this article when reviewing codes of practice. Compassion see also Davison and Williams (2009a, 2009b), Schwartz 1995); and Stevenson (2002) who links with PCC	*of a hospital worked as a system. When examined from the patient's perspective I found unbelievable duplication, disco-ordination and haphazard service. But when our daughter broke her neck and endured three month's spinal traction on an acute ward, I finally understood how a system focused on clinical care can profoundly neglect the basic human needs of patients."* Article highlights systemic failures; staff shortages; a system incapable of responding to simple human needs; hospital culture; the cost of being a relative of a patient (e.g. car parking); 'inhuman' working hours; extreme fragmentation of care; societal expectations; patients as enemies just looking to complain or sue; health professionals feeling beleaguered and threatened. Youngson defines compassion as *'the humane quality of understanding suffering in others and wanting to do something about it'* (p.7) Steps for strengthening the heart of healthcare • Declare compassion as a core value • Reward rather than punish compassionate caring • Hone communication and relationship skills • Create a safe space for deep conversations in the workplace (acknowledging personal vulnerability, personal fears; the spiritual nature of practice; opportunities to discuss the emotional and social issues that arise in caring for patients; personal healing for health professionals (cites • Challenge models of professionalism – particularly the biomedical model which underpins Western medicine (cites Shapiro, 2008) • Hard-wire new behaviours into the organisation
Dignity	**Nursing**: **UK** Davies, Brown, Wilson & Nolan (2000). (see also person-centred care) *Excellence in the care of older people: case reports.* Dignity on the Ward campaign carried out in partnership with Help the Aged between 1999 and 2001 in the UK. Case reports. Setting for case study 3: Mary Ward and Victory Ward at Queen Alexandra Hospital, Portsmouth. Both wards provide acute medical care for men and women who are generally over 65	Studies 3 and 4 (4 in total) investigated Patients experiences Bedside handover Medication review programme Ward environment Partnerships in care Teamwork Developing staff Developing practice

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	years of age. Setting for case study 4: Kidderminster General Hospital, Ward A1 – a 28-bed women's acute medical ward; Ward A2 a 32-bed men's equivalent of A1. **Limitations** – no discussion of methods included; not clear whether aspects highlighted had been revealed of significance by these studies due to insufficient detail; no reference lists.	Leadership Maintaining dignity Transition between hospital and home Studies strongly highlighted the benefits of collaboration between patients, local people, NHS staff of different disciplines and status when seeking improvement and excellence in healthcare. Four key principles for creating a positive culture of care: 1. Giving priority to essential care needs of older patients. Senior staff as role models 2. Ensuring same access to services as younger people 3. Creating values that involve patients and make their choices central to ward activity 4. Creating a stable ward team which encourages staff initiative Outcomes included publication of pocket guides specifically targeting nursing care of • Older people from ethnic minorities • Dying • Pain and older people
Dignity	**Nursing: UK** Gallagher and Seedhouse (2002). *Dignity in care: the views of patients and relatives* Pilot study to evaluate the impact of an educational intervention related to dignity in practice in 3 older care practice settings in England. Included qualitative interviews with staff, 9 patients and 7 relatives Gallagher (2004, 2010)	Findings revealed 5 core elements: **Respect** – self-respect and being treated with respect Link between independence/dependence and dignity To be treated equitably – not discriminated against because of age **Privacy** – ensuring no unnecessary exposure /private conversations Maintaining self; e.g. grooming, cleanliness, dress **Staff** – attitude and approach; sensitivity and reflection Environment – impact of curtains and mixed sex wards; the importance of a pleasant environment **Resources** – staffing and continuity of care **Seeing and knowing the patient as a person**
Dignity	**Nursing: UK** Gallagher (2004) *Dignity and respect for dignity - Two key health professional values: implications for nursing practice.*	Analysis identified dignity in nursing practice as two key professional values: **other-regarding** by respecting the dignity of others, and **self-regarding** by respecting one's own dignity or self-respect Dignity in practice concerns the nature of practice; people; the environment and

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	Literature review to investigate what dignity means.	processes. Taxonomy of dignity violations – 4 categories (i) not being seen (ii) being seen but only as a member of a group (iii) violation of personal space (iv) humiliation. Gallagher advocates that all nurses and other professionals need to listen carefully, look justly and compassionately, respond sensitively and act for improvement when necessary, learn from experience.
Dignity	**Nursing: UK** Baillie (2007, 2009) *Patient dignity in an acute hospital setting: a case study.* **Multi-method qualitative case study -** to investigate the meaning of patient dignity, threats to patients' dignity, and how patient dignity can be promoted in acute hospital settings. **Unstructured interviews** conducted with 24 patients (34-92 years), 13 ward-based staff, and 6 senior nurses, and **participant observation** in a 22-bedded surgical ward in an acute hospital in England, UK. Citations include Chochinov et al (2002), Gaut (1983), McClement et al (2004), Seedhouse and Gallagher (2002), Woolhead et al (2004). Baillie draws on their work, and that of others, to provide further evidence of the importance of dignity whilst also highlighting that this is another healthcare concept that has been described as *"an ambiguous, vague concept"* (p.24). The literature review indicated that further research into dignity in acute hospital settings was needed as the few studies that had already been undertaken were generally small scale, and had commonly used surveys and phenomenology. Although these had identified that staff behaviour and hospital environment affected patient dignity these aspects had rarely been studied by observation.	*"Patient dignity is feeling valued and comfortable psychologically with one's physical presentation and behaviour, level of control over the situation, and the behaviour of other people in the environment."* (p.33) Also offers model to illustrate how patients' dignity is promoted or threatened in hospital. Patients are vulnerable to loss of dignity in hospital. Staff behaviour and the hospital environment can influence whether dignity is upheld or lost. Key findings: • Dignity is associated with feeling comfortable, in control and valued; with physical appearance and behaviour from others. • Lack of environmental privacy threatened dignity • Staff being curt, authoritarian and breaching privacy threatened dignity • Patients' impaired health and/or old age rendered them vulnerable to a loss of dignity. • Patients promoted their own dignity through their attitudes (rationalisation, use of humour, acceptance), other patients' support, a dignity promoting culture, developing relationships with staff, retaining ability and control. • Staff promoted dignity through their interactions with patients, making patients feel comfortable, in control and valued, and by promoting their dignity when under threat. • Findings concurred with previous research that identified dignity as an internal quality and that its meaning is concerned with feelings – in particular self-esteem and self-respect (Matiti, 2002) **Limitations** noted – e.g. one ward in one English hospital; relatives' views not gathered; patients and staff may have changed their behaviour when being

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
		observed.
Dignity conserving	**Medicine/nursing/psychiatry:** (Chochinov 2007). *Dignity and the essence of medicine; the A, B, C, and D of dignity conserving care.* British Medical Journal, 335, 184-187: Analysis paper, based on Canadian studies, which presents an empirically-based framework to relocate humanity and kindness in the culture of patient care (Mcclement et al. 2004). Mcclement et al (2004) derived understanding of the concept of dignity from the perspectives of 50 palliative cancer patients (see Chochinov et al, 2002, above). Builds on seminal work offered in 1927 by Sir Francis Peabody in his landmark paper *"The care of the patient".* Peabody advocated that the secret of the care of a patient is in caring for the patient. It also builds on previous empirical studies (see above) by Chochinov et al (2002, 2002) and Chochinov (2004) *Dignity and the Eye of the Beholder.*	A whole person approach focused on kindness, humanity and respect. A focus on Attitude; Behaviour: Compassion; Dialogue – the ABCD of dignity conserving care. Seeing the person for who they are or were, rather than just the illness they have, is more likely to uphold a patient's sense of dignity. Affirming personhood, self-worth, dignity, respect; finding sense and meaning; small acts of kindness, a deep awareness of the suffering of another and a wish to relieve it; the bringing together of humanity and compassion in the treatment of disease.
Holistic/holism	**Nursing: notable works include** Nightingale (1860) Mental health nursing: Beck, Rawlins and Williams (1993). Mental Health-Psychiatric Nursing: *A Holistic Life Cycle Approach.* Dossey (2000) Florence Nightingale: Mystic, Visionary, Healer. Dossey, Keegan and Guzzetta (2004). Holistic Nursing: a handbook for practice Frisch (2001) American Holistic Nurses Association (AHNA)	Views the person as a whole across the lifespan: considers the patient's spiritual, social, intellectual, physical and emotional needs. Recognises the inter-connectedness of these elements; focuses on the whole person not merely the signs and symptoms of disease, injury or illness. Acknowledges the interrelationship between the person, events and environment; of giving full attention; being aware of attitudes and behaviours of self; the role of technology; understanding the meanings that people attach to their illness or disease. Includes consideration of the importance of alternative and complementary therapies such as music therapy, pet therapy and aromatherapy towards caring and healing. **Contribution:** medical and nursing care that focuses on the whole person **Perceived limitations**: misconceptions about the concept. For example Baron and Warner (2004, p.21) provide example of opposing views – Warner's interpretation makes reference to *"wind chimes"* and *"calming blue lights*
Holistic	**Nursing/Public Health: Norway** Berg, Hedelin and Sarvimäki (2005). A holistic approach to the	Two main aspects were uncovered in informal dialogues: • biomedically orientated

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promotion of older hospital patients' health. Descriptive and exploration design entailing participant observation of 5 nurses over 6 month period and informal dialogues with 4 of those nurses. Each of the nurses worked in an infection unit in Norway. Content analysis and hermeneutic interpretation of 80 pages of field notes and text from dialogues. Theoretical framework: a holistic-existential perspective which enables nursing to be based on a multidimensional view of man and health, with a focus on people's life-world and their 'being in the world'. Draws on the work of Heidegger (1989); Merleau-Ponty (1962/1995); Van Manen (1997, 1990). It also builds on a former study by Berg and Sarvimäki, (2005) which gave rise to the following definition: *"Health promotive nursing is planned nursing actions designed to meet the needs of individuals, families and communities in their efforts to deal or cope with health challenges that they presently encounter in daily life or that might appear in the future. . . . The aim of holistic nursing is to support human beings in their need of knowledge and to offer practical assistance in order to cope with illness experiences and suffering and thus to stimulate healthy living"* (Berg and Sarvimäki 2005, p. 390). The statement is supported by 5 conditional statements: 1. A fundamental positive and respectful attitude in regard to the values of every human being, their integrity, autonomy, human rights, and possibilities. 2. A holistic approach in nursing, which implies a view of man as being a whole, consisting of a physical, psychological, social and spiritual dimension. 3. A multidimensional view of health and illness, including a focus on the individual human being and the human being in social context, which promotes a comprehensive view on health and illness. 4. An existential approach that focuses on 'the-human-being in-	• holistically orientated Nurses' interpretation of health promotion was closely connected to their interpretation of health and holistic nursing; they tended to balance between holistic and biomedical perspectives. This, Berg et al suggest, made it difficult to find a clear focus on health promotion. It seemed that nurses found it much easier to discuss health, illness/disease, treatment and prevention of complications than discussing promotion of the patient's health. The interpretation of health promotion was also linked to facilitating the patient's ability to cope with illness. Furthermore the context of nursing is dynamic and constantly changing, and nurses are expected to meet different approaches and attend to people with different demands, perspectives and goals that affect the conditions for health promotion. Nurses expressed a dilemma between being a part of the biomedical treatment culture and the idealistic nursing culture; they talked of "walking on a tightrope". Health promotion was almost missing in the culture of their ward; the focus appeared to predominantly lie with diagnosis and treatment of current illness rather than the more complex situation associated with older patients' illness and health deficits. This study also discusses the phenomenon of **'waiting'**, for instance nurses' frustration at waiting for doctors, and the differing reactions to this. Berg et al state that time is an individual, contextual and relational concept. Waiting, as a phenomenon is something that nurses, patients and relatives experience differently in hospital. Time, they acknowledge, has a profound effect on people's lived lives. Meaningless waiting, the time spent on an action and the timing of it conveys messages about such things as importance and status. Waiting is a phenomenon that Berg et al suggest might be an interesting issue to investigate further.

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	the-world', which emphasizes individuals' experiences of the world as well as their understanding of their being and the meaning they give their life. The dialogue between the individual and the nurse is an essential part of this condition. 5. The public health perspective guides the direction with regard to strategies, knowledge and the focus on health. Health promotion strategies and empowerment are important issues in this condition (Berg & Sarvimäki 2005, p. 390).	
Holistic	**Medicine**: Freeman (2005) Towards a definition of holism. Discussion of brief **narrative review of medical and non-medical literature**. Referred to use of different definitions of terms holism and holistic which resulted in confusion and misunderstanding about the concept e.g. in relation to complementary or alternative medicine; nursing practice; spirituality in health, allopathic approach to care as promoted by biopsychosocial model. **Perceived limitations**: misconceptions about the concept which McWhinney (1980; p. 1096), for example, suggests arise from common use of the term by *"unorthodox groups of healers".* The approach has potential to be misused for prying into every aspect of patients' lives irrespective of whether this is necessary, and for patients' lives to become medicalised. See also McWhinney (1986, 1997) and link, and contribution to PCC	Freeman (2005) suggested that the holistic approach, at least in family medicine/GP practice, relates most closely to definition provided by the European Academy of Teachers in General Practice/Family Medicine (EURACT, 2005). This approach requires physicians to acknowledge that people are complex; their lives and associated communities are complex and form part of a complex world; each aspect has the potential to affect the health of an individual. *"Physicians must respect the whole and each of its parts and consider the synergies these create as they act together."* (Freeman, 2005, p. 154)
Holistic approach	**Medicine:** Allen et al (2005) European Academy of Teachers in General Practice/Family Medicine European Academy of Teachers in General Practice/Family Medicine (EURACT) (2002). Core competencies for general practitioner/family doctor:	"Family medicine deals with people and their problems in the context of their life circumstances, not with impersonal pathology or "cases". The starting point of the process is the patient. It is as important to understand how the patient copes with and views their illness as dealing with the disease process itself. The common denominator is the person with their beliefs, fears, expectations and needs…" (p.5) "k) Deals with health problems in their physical, psychological, social, cultural and existential dimensions." (p.6) "3.6 Holistic approach includes the ability to use a bio-psycho-social model taking into account cultural and existential dimensions" (p.8)

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
Knowing/ Knowing the patient	**Critical care nursing: England, UK** Crocker and Scholes, 2010. Weaning from ventilation needs to be tailored to individual patients and involve them. **An ethnographic study**; fieldwork conducted in a large teaching hospital over six months. Data was collected through participant observation, focused interviews, field notes and documentary analysis of weaning protocols and educational packages. Data analysed using content analysis. Participants – nurses caring for patients who were being weaned off ventilation. Built on previous work by Scholes (1998) *'Therapeutic use of self: a component of advanced nursing practice'* and an earlier publication by Crocker and Scholes (2009) *'The importance of knowing the patient in weaning from mechanical ventilation'*. Cited works specific to the concept of *'knowing'* include Sandelowski (1998), Luker et al (2000), Ball and McElligott (2003), Henderson (1997), Tanner et al (1993), Radwin et al (1996). **Limitations**: small scale study in one critical care unit where the researcher worked. See also Barrie (2010) A Different Way of Knowing using Patient Stories as an Educational Resource	Crocker and Scholes (2010, p.19) state that *'Knowing the patient has been defined as characteristic of expert nursing. To be truly patient-centred, nurses need to address the barriers that prevent them from getting to "know" their patients.'* Four themes emerged from the data – knowing the patient; the division of labour in weaning; nursing visibility; the nursing technology relationship. Knowing the patient, the theme discussed in this paper had 3 sub-categories; ways of knowing: continuity of care; patient's role in weaning. Nurses implied that knowing the patient was central to delivering individualised care. They also felt they knew their patients differently to other professionals. The following quote was included to illustrate this point: "…nurses are more holistic. Doctors come along and they see the organs and the rate and the numbers; as nurses we see the overall picture, we see the psychological, emotional and all that kind of stuff…" (p.20) The findings indicated that more experienced nurses were better able to 'know' their patients and practice truly patient-centred care. Junior nurses generally relied on biomedical facts, the patient's illness and medical history; even advanced beginners' ways of knowing were limited to those that are technologically framed and depicted by biomedical data. One possible contributory factor for this was the use of weaning protocols which encourage nurses to be task orientated and thus prevent them from acquiring the expertise to devise individualised weaning programmes that take account of patients' psychological readiness to wean. Continuity of care was also limited due to 12 hour shifts and lack of time. The latter, and multiple caregivers, had also been found to inhibit knowing the patient. With regard to the patient's role in weaning, analysis of field notes revealed minimal involvement of or partnership with, patients. This was attributed to nurses' views of patient' progress as a weaning trajectory. Scholes and Crocker advocated that staff rotas in critical care should enable advanced beginners to learn from more experienced nurses; and ensure schedules are organised to enable nurses to begin weaning at a time when they can offer the patient continuity of care.	

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
Humanisation/ Lifeworld-led care/lived experience	Philosophy: Todres, Galvin and Dahlberg (2007). Lifeworld-led healthcare: revisiting a humanising philosophy that integrates emerging trends. Medicine, Health Care and Philosophy, 10 (1), 53-63. Draws on philosophy of lifeworld-led care as examined by Husserl; other citations include Habermas (1990) Merleau-Ponty (1962); Heidegger (1962, 1966); phenomenology and hermeneutics dominate. Evidence base also includes former qualitative study by Galvin, Todres and Richardson (2005) *'The intimate mediator: a Carer's Experience of Alzheimer's'* and Todres, Fulbrook and Albarran (2000) *On the receiving end: A Hermaneutic-Phenomenological Analysis of a Patient's Struggle to Cope while going through Intensive Care.* Linked to Department of Health NHS modernisation agenda. DH (2002) Shifting the Balance of Power and DH (2005) Creating a Patient-Led NHS: Delivering the NHS Improvement Plan. Limitation: Accessibility and discourse which may limit transferability to everyday healthcare practice. See also Galvin and Todres (2009)	To avoid person-centred trends in healthcare being directed towards consumerism, Todres et al offer a philosophical basis from which endeavours to humanise healthcare can be more deeply considered. Intention also to address the potentially dehumanising and depersonalising effect of technological advances in healthcare – for example *turning humans into commodities with their value determined by how efficiently they fit into larger impersonal systems and processes* (p.54) Promotes citizenship – all in this together – therefore all have responsibilities as well as rights (Turner, 1990). Participatory democracy more meaningful — *a bottom-up approach that is responsive to human concerns on the ground* (Barns et al., 1999). Responds to directive in NHS Modernisation agenda to involve patients in processes and methodologies for monitoring quality improvement cycles in the NHS. Partnership between professionals and service users recognised as a central feature of UK and Swedish healthcare policy. Recognises the 'what' of relationships as Temporarility – time as it is experienced by humans Spatiality – the environing world; places and things that bring a meaning to living Intersubjectivity – being understood in a world with others, interactions – the social world Embodiment – how each person bodily lives in ways that are meaningful to themselves, the world and others. The concrete 'here' of ourselves Mood – this acknowledges that lived experience is "coloured by mood". This interprets other dimensions of the life-world in varying ways. These dimensions are constituents of the life-world and can be used to explain lived experience. Integrative framework that encompasses the core life-world values: Core Value – a humanising force that moderates technological progress. Core Perspectives – i) grounded in qualitative experiences of people ii) lifeworld constituents: temporarility, spatiality, intersubjectivity, embodiment, mood. Indicative Methodologies: i) phenomenological and narrative studies ii) otherness-centred reflective practice

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
		Benefits: i) humanised credibility ii) bottom-up participation.
Person-centred	**Medicine: European Academy of Teachers in General Practice/Family Medicine (**Allen et al, 2005) European Academy of Teachers in General Practice/Family Medicine (EURACT) (2002). Core competencies for general practitioner/family doctor: c) *develops a person-centred approach, orientated to the individual, his/her family, and their community.* *"…Each contact between patient and their family doctor contributes to an evolving story, and each individual consultation can draw on this prior shared experience. The value of this personal relationship is determined by the communication skills of the family doctor and is in itself therapeutic."* (p.5)	*"3.2. Person-centred Care: Includes the ability:* • *to adopt a person-centred approach in dealing with patients and problems in the context of patient's circumstances;* • *to develop and apply the general practice consultation to bring about an effective doctor-patient relationship, with respect for the patient's autonomy;* • *to communicate, set priorities and act in partnership;* • *to provide longitudinal continuity of care as determined by the needs of the patient, referring to continuing and co-ordinated care management"* (Alen et al, 2005, p.7)
Person-centred	**Medicine/education: Europe** Allen, Gay, Crebolder, Heyrman, Svab and Ram (2005). The European Definitions of General Practice/Family Medicine; The Key Features of the Discipline of General Practice; The Role of the General Practitioner; and A description of the Core Competencies of the General Practitioner/Family Physician. Utrecht; European Academy of Teachers in General Practice (EURACT)	Person-centred care requires the physician's to • adopt a person-centred approach in the context of each patient's circumstances • enable an effective doctor-patient relationship which respects autonomy • communicate, set priorities and become partners • ensure continuity of care as determined by needs of patient In addition to balancing the health needs of individuals with those of the community and available resources, doctors are also expected to promote health; act as patient advocates; co-ordinate care with other professionals. To enable this doctors are required to be aware of Contextual aspects – including impact of socio-economic factors; local community; geography and culture on the workplace and patient care. Attitudinal aspects - awareness of their own capabilities and values – able to identify ethical aspects of clinical practice (prevention/diagnostics/ therapy/factors influencing lifestyles); - self-aware: possess an understanding that their own attitudes, and feelings are important determinants of how they practise - able to justify and clarify personal ethics; - be aware of the mutual

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
		interaction of work and private life and striving for a good balance between them Scientific aspects – including continuing learning, quality improvement and scientific research (EURACT, 2005, p 7, 8).
Person-centred/person-centredness	**Gerontological nursing (nursing older people) and dementia care** (McCormack, 2003, 2003, 2004) McCormack (2004, p.32,33) draws on a **philosophical analysis** of the word 'person' to explain, in this sense, that it aims to capture *"those attributes of persons that represent our humanness and the factors which we regard as most important and the most challenging in our lives…it is the 'moral personality that gives persons status and it is this 'humanity that distinguishes persons from other species, i.e. our personhood…each person has an intrinsic, inalienable, unconditional and objective worth or dignity as a person"*	McCormack suggests that, if accepting Kitwood's (1997) definition of person-centredness (above), which acknowledges that each person has a 'context' in which their personhood is manifested, then it is possible to extract four core concepts. These, he argues, are the heart of person-centred nursing: i) Being in relation – this means knowing the older person in their social context; relationships. Care plans include others significant to the older person and the needs of the community of formal and informal carers. McCormack suggests that being in relation entails sustaining a nurturing relationship between older person and nurse which requires moral integrity, knowing and valuing of self and others; reflective ability and flexibility derived from reflection on values and their place in the relationship. ii) Being in a social world – respect for the person's narrative that 'reflects the Kantian ideal of respect for the intrinsic worth of persons'. Persons are social beings. iii) Being in place – the context in which care is provided; persons have a context through which their personhood is articulated. iv) Being with self – the primacy of self; respect for values is central to person-centred practice.
Person-centred	**Gerontological nursing (nursing older people) and dementia care: England, UK** Nolan et al (2004) – acknowledge the pioneering work of Tom Kitwood (1997) and colleagues at the Bradford Dementia Centre and McCormack (2004). Person-centred care, they state, is described as *"an oft quoted but ill-defined concept"* (Nolan et al, 2004, p.46). Nolan et al offer an alternative vision – one beyond person-centred care - based on Tresolini et al's (1994) relationship-centred care and The 'Senses Framework' (Nolan, 1997, Davies	The Senses Framework (Nolan et al,2001): Senses of • security (to feel safe within relationships) • continuity (to experience links and consistency) • belonging (to feel part of things) • purpose (to have personally valuable goals) • achievement (to make progress towards a desired goal or goals) and • significance (to feel that you matter). Each of these senses should be experienced by all parties involved in caring –

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	et al, 1999, Nolan et al, 2001, 2002). This vision *"captures the subjective and perceptual dimensions of caring relationships and reflects both the interpersonal processes involved and the intrapersonal experiences of giving and receiving care."* (Nolan et al, 2004, p.49).	staff, patients and families. Consideration should also be given to *"types of supportive social conditions (MacDonald, 2002) or to the milieu of care (Pryor, 2000)"*.
Person-centred	**Nursing education: Royal College of Nursing Institute, London, UK** Price (2006) Exploring person-centred care. Article offered in frontline nursing journal to help nurses to conduct their own investigation of person-centred care in their practice by asking the question - "how do I work with this concept in my day-to-day care of patients? - as part of their continuing professional development. Price builds on previous research (2002) Laddered questions and qualitative data research interviews. Citations include Berg et al (2005) holistic care; Larson and Ferketich (1993), Watson (1999), Smith (1999) Kirpal (2004) Brilowski and Wendler (2005) caring; Hochschild (1983, 2003) and McQueen (2004) – emotional intelligence. **Limitation:** suggestion that the person-centred approach is presented in stark contrast to the medical model. These perhaps instead be considered as models at opposite ends of the same continuum of healthcare delivery – with the ideal approach encompassing both.	Price states that "many nurses describe their care as holistic, individualised, patient or person-centred…an approach they believe permits patients to get involved in the decisions made about practice. This approach is presented in stark contrast to the medical model…" Price acknowledges that sometimes a tension can arise between the competing approaches (citing Jones 1999, 2005 from mental health nursing); and highlights the potentially immeasurable nature of care that requires an understanding of patients as individuals, and helping them to relate to their situation, lifestyle and needs. Price structures the *'Learning Zone'* reflective exercise around the following dimensions of person-centred care **Care ideology** – person-centred care is part of the ideology of nursing but it is an approach that can raise tensions for the nurse **Knowing the person** – discusses the challenge of knowing which aspects of the person the nurse should or can know about, whether it is always realistic or appropriate to try to understand the patient in physical, social, psychological and spiritual (holistic) terms; types of knowledge involved; the meanings that persons ascribe to their experiences or situation. Knowledge building requires a series of interpersonal skills i) a sincere and professional interest ii) active listening iii) asking questions in a sensitive way. **Therapeutic relationships –** which requires i) working with feelings and attitudes; ii) accepting the other; iii) dealing with variability iv) purposeful action v) emotional intelligence. **Acting in a person-centred way** – involves critical thinking and three key skills i) negotiation; ii) equitable allocation of personal resources; iii) interprofessional working **Taking stock** – clarifying own values and attitudes ii) considering priorities and what constitutes purposeful care iii) understanding group philosophies.

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		Price concludes: "…person-centred care is a powerful concept in nursing…it is a concept big in intent but limited in practical application. There have been difficulties translating the concept into practice and developing measures that demonstrate this approach in action…for person-centred care to work…it has to become a concept defined and owned by a range of healthcare practitioners…it has to be explored by the practitioners rather than simply disseminated by the theorist."
Psychosocial	**Medicine: primary care physicians** Sobel (1995) Rethinking Medicine: Improving Health Outcomes with Cost-Effective Psychosocial Interventions. California, USA. Kaiser Permanente Medical Care Programme Various patient groups including 3,500 senior citizens over 7 year period; 7,000 adult patients with osteoarthritis of the knee; 500 families who visited physicians with a feverish child under 13 years; 109 patients with chronic pain; 68 patients with malignant melanoma **Literature review of studies using psychosocial interventions and outcomes, including;** Kroenke & Mangelsdorff (1989) study of more than 1000 patient records in which aetiological causes were found for less than 16% of 14 most common symptoms reported to family physicians (GPs) (chest pain, fatigue, headache, dizziness, oedema, back pain, dyspnoea, insomnia, abdominal pain, numbness, weight loss, impotence, cough, and constipation). Finds suggested that symptoms could be attributed to psychosocial factors. Studies by Lorig et al (1989) and Lorig, Mazonson & Holman (1993) Holman and Lorig et al (2000) on self-management programmes for patients with arthritis indicated that factors such as sense of control, positive outlook, perception of self-efficacy were key indicators in reports of improvement in arthritic	Psychosocial health: calling for a shift in medical culture to one which also focuses on addressing the mental, emotional, behavioural and social dimensions of illness or disease. Key themes identified in review: (i) **Beyond medical disease** – and view of patients as 'mindless machines'; understanding their need and demand for medical services. (ii) **Beyond behaviour change and risk reduction** –consideration of the impact on health status and physiological functioning of shared determinants such as socioeconomics, personality traits, beliefs, sense of control, perceptions, self-efficacy and optimism. (iii) **Beyond medical interventions** – developing cost-effective psychosocial interventions – rather than targeting specific disease aiming to influence core set of attitudes, moods and beliefs – including optimism, self-efficacy, happiness, sense of control, sense of coherence; sense of connectedness, hardiness. Studies reviewed in the latter theme considered impact of such factors on childbirth, surgery, cancer and cancer survival, psychosomatic and stress related disorders, chronic pain and chronic disease, self-care for minor injuries and acute illness

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	symptoms. Cummings & Vanden Bos (1981) concluded from a 20 year study by Kaiser Permanente that more than 60% of visits to family physician were by 'worried well' i.e. no diagnosable condition, and 25-50% are for symptoms arising from psychosocial triggers	
Relationship-centred care	Tresolini, C.P., and the Pew-Fetzer Task Force, 1994. Health Professions Education and Relationship-centred Care. San Francisco, CA: Pew Health Professions Commission Relationship-centered Care. Report of Pew-Fetzer Task Force. Pew Health Commission, San Francisco, USA. Re-printed in 2000. The Task Force proposed a new conceptual model for advancing psychosocial health education and healthcare delivery in the US – 'relationship-centred care' based on evidence gathered through a **literature review, semi-structured interviews with 22 experts in the field, and telephone interviews and surveys of faculty staff and students in a number of medical, allopathic and osteopathic schools in America and Canada**. An aim was to draw attention to the 'importance of interactions amongst people as the foundation of any therapeutic or healing activity'. Widespread debate in the US during the early 1990's with regard to future of American healthcare - arising from growing concerns about failure of the healthcare system to address the demands arising from chronic illness and the needs of a diverse and multi-cultural society. This led to the setting up of the Pew-Fetzer Task Force to consider a different approach to healthcare based on the interdependence of psychological, social and biological factors. Also builds on and cites the work of Peplau (1952), Polyani (1958) and personal knowledge; concepts of the biopsychosocial and patient-centred care models (Engel, 1977; Levenstein, 1988,	Primary focus on 3 fundamental relationships: 1. Patient-practitioner relationship: information, communication, comprehensive biomedical care; critical reflection on practice, self-awareness, caring and healing ethic, preserves dignity and integrity of patient and their family, listening and communicating openly and effectively, seeks to eliminate abuses from power inequalities arising from race, sex, education, occupation and socioeconomic status, active collaboration of all parties in all aspects of healthcare. 2. Community-practitioner relationship – the context of health or illness. Individuals belong to multiple communities formed by their neighbourhood, culture, work, social network and personal circumstances such as illness or injury (e.g. hospital). Practitioners need to understand broad social, political, cultural, economic and political determinants of health; recognise and act in accordance with the values, norms, social and health concerns of the community 3. Practitioner-Practitioner relationship: "*Effective, empathic care requires a community of practitioners working together to serve the complex matrix of individual's needs in health and illness*" (2000, p27). This involves: • Teamwork • Shared values • Mutual trust • Collaboration • Humility • Learning from and making use of expertise of others • Helping others learn and develop • Integrating services and individual and systems levels • Setting aside issues of hierarchy, specialism and privilege

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	McWhinney, 1989), Aaron Antonovsky (1987) *Unraveling the mystery of health: how people manage stress and stay well* (1987), Watson (1985, 1988), and Tressolini (1994). Also cites the Picker Institute, Kenneth B. Schwatrz Center but not Gerteis et al (1993) *"Through the Patient's Eyes, understanding and promoting patient-centred care"* despite the evidence for this seminal text being provided by the Picker Commonwealth Patient-Centred Care Program. See also Polanyi (1967,1969)	• Relationships which serve the needs of practitioners as well as patients, • Communities that enable healthcare providers to care for one another and give and receive support and encouragement. Included recommendation that *"Health professions education must help developing practitioners become reflective learners and professionals who understand the patient as a person, recognise and deal with multiple contributors to health and illness, and understand the nature of healing relationships"*…in order… "*to form caring, healing relationships with patients and their communities"* (p.39). The Report is offered as a *"…useful framework for program development"* (p. 49) by which students can learn a relationship-centred approach to care.
Humanisation	**Philosophy**: **Bournemouth, UK** Galvin & Todres (2008) UK Philosophical influences include: Husserl's (1936) notion of the lifeworld; Heidegger's (1962) contemplations about ownness, being with others and human freedom and Merleau Ponty's perspectives about body subject and body object. Limitation: perceptions of relatedness to/readiness of understanding amongst frontline practitioners	A conceptual framework that defines what Galvin & Todres mean by the term *"humanisation"*; includes eight dimensions of humanisation: 1. agency 2. insiderness 3. uniqueness 4. togetherness 5. sense-making 6. personal journey 7. sense of place 8. embodiment
Lived body v Cartesian dualism	**Philosophy/medicine: London, UK** Gold (1985). Cartesian dualism and the current crisis in medicine - a plea for a philosophical approach: **discussion paper**. Draws on Merleau Ponty's (1945, 1961) notion of **embodiment** as the **'lived-body'**; the experience of the human body which cannot be objectified; Sartre (1957) and Camus (1958) view of existentialism; and Jaspers (1931) German philosophical anthropology; Husserl's (1954) **'Lebenswelt' or lifeworld**.	Gold, a dental surgeon, discusses the current 'crisis in medicine' and the need for a philosophical enquiry. However, also points out that philosophical theory, such as that put forward by Descartes, can adversely affect the practice of medicine, Gold suggests it is time to consider a new 'concept' of the body that has arisen out of existentialism, philosophical anthropology, and phenomenology. He suggests that human bodies *"can be better and more realistically envisaged as multiphasic, experiential beings of finite freedom"* (p.664)
Lived experience of illness	**General medicine: New York; USA** Charon 2001. *Narrative Medicine: A model for empathy,*	Acknowledges that illness unfolds in stories; that our bodies are more than machines…that they perform our lives, carry our scars, our bliss, our

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narrative medicine	*reflection, profession and trust* Charon, 2006 *The self-telling body.* Medical practice informed by narrative inquiry. Cited authors include Mishler (1981, 1984), and Frankel	memories, simultaneously both limiting and expanding our lives. Narrative medicine recognises that the central events of healthcare are the giving and receiving of accounts of self. Honouring stories not just for their biological content but also for the news they give of the person in whom the illness dwells; they unite the story teller and the listener in a shared world either recalled or imagined. "Finally, we are coming around to understanding that our tasks include the duty to bear witness as others tell of trauma and loss. The narrative practice of medicine — or, as I have come to say, the practice of narrative medicine — unites a host of neighbouring concerns and approaches…accurate diagnosis depends overwhelmingly on taking a good story, and above all on listening to the patient; not only for what she or he thinks is wrong and how it all started, but also how it is told and the kind of person that tells it. We cannot understand the disease without under-standing the patient."

Lifeworld	**Medicine, Primary care; UK**
	Barry, Stevenson, Britten, Barber and Bradley (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice.
	UK study: **35 case studies (from an initial 62 involving 62 patients), comprising 35 patients (17 male and 18 female) visiting 20 doctors in the midlands and south-east England**. Each case study consisted of patient interviews before and after a consultation, doctor interviews about these consultations conducted by a psychologist and sociologist. The method for investigating indicators of the success of the consultation included ten "mainly patient-centred, endpoints"
	Draws on Habermas' (1984) theory of Communicative Action and Mishler's (1981, 1984) voices of medicine and the lifeworld (p.489), and the Unremarkable Interview, which represents a unit of structured discourse used in doctor-patient communication that can silence the voice from the patient's lifeworld.
	Cited works also include Balint (1957), Charon (1993), Brown,
		"The voice of the lifeworld refers to the patient's contextually-grounded experiences of events and problems in her life. These are reports and descriptions of the world of everyday life expressed from the perspective of a ''natural attitude''. The timing of events and their significance are dependent on the patient's biographical situation and position in the social world. In contrast, the voice of medicine reflects a technical interest and expresses a ''scientific attitude''. The meaning of events is provided through abstract rules that serve to decontextualize events, to remove them from particular personal and social contexts." (Mishler, 1984, p.104.cited Barry et al, 2001)
		Findings revealed four broadly different patterns of communication:
		   1. Strictly Medicine
		   2. Lifeworld Blocked
		   3. Lifeworld Ignored
		   4. Mutual Lifeworld
		The analysis revealed that participating doctors tended to change their communication strategy according to whether they considered the patient to be presenting with psychological or physical problems; e.g. Strictly Medicine for acute physical problems. So long as the patient had no underlying concerns, the exclusion of the lifeworld did not prevent a good outcome for the

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	Stewart and Tessier (1995), Brody (1992), Illich (1976), Stewart et al (1995), Broyard (1992), Byrne and Long (1976). **Limitations:** terminology, discourse, and ease of understanding/ transferability of the concept of lifeworld for healthcare practitioners. Study was funded by Department of Health as part of the Prescribing Research Initiative.	consultation. However, for patients with long-term conditions, their physical conditions were a lifeworld issue. Yet evidence indicated that doctors remained focused on the physical aspects and the voice of the lifeworld was commonly 'blocked' or 'ignored'. This led to a recommendation for doctors to become sensitised to the importance of addressing concerns of the lifeworld – particularly for patients who have psychological and/or chronic physical conditions. GPs notions of success to not only be informed by technical considerations but also whether their patient feels understood, listened to and treated like a whole and unique human being.
Mind-body dualism (Cartesian Dualism)	**Philosophy/medicine/psychology:** Gold (1985); Dental surgeon. Based in London, UK, building a case for unity between mind and body in his discussion paper. Mehta (2011) *Mind-body dualism: A Critique from a Health Perspective.* A Revised and peer reviewed version of a paper read at an International Seminar on Mind, Brain, and Consciousness, Thane College Campus, Thane, India, January 13-15, 2010. Mehta is clinical psychologist and Associate Professor in Psychology based in Mumbai, India. Rene Descartes (1956-1650) French philosopher, mathematician and scientist (mind-body split)	Cartesian dualism or mind-body dualism is a view of human beings as two separate parts – mind and body. In the 17th century Descartes advocated that human beings comprised two dissimilar substances that could not exist in unity. Mind and body dualism represents the metaphysical stance that the mind was an immaterial but thinking substance whereas the body was a material but unthinking substance. Additionally the mind was free from mechanical laws, unlike the body. Ryle (1949, p11-12) cited (Mehta, 2011, p. 201) suggests *"A person…lives through two collateral histories, one comprising of what happens in and to the body, the other consisting of what happens in and to his mind…The events in the first history are events in the physical world, those in the second are events in the mental world."* The dualistic stance of human nature and analytical method determined the biomedical model. Through this human beings are viewed as biological organisms (materialism), to be understood by examining their constituent parts (reductionism) using the principles of anatomy, physiology, biochemistry and physics.
Mind-body	**Mind-Body Medicine; Calgary/Canada** Bakal, Steiert, Coll and Schaefer (2006) An experiential mind–body approach to the management of medically unexplained symptoms. Paper discusses an experiential mind-body framework for	Framework builds on the biopsychosocial model in an endeavour to make the model more practical by adopting a treatment framework based on structural causality. *"Structural causality recognizes the multifaceted nature of a symptom or illness but proposes a linear treatment plan reflecting the intervention that is likely to*

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Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	understanding and treating patients with medically unexplained symptoms. The model relies on somatic awareness, a normal part of consciousness to resolve the mind-body dualism inherent in conventional multidisciplinary approaches.) Citations include Borrell-Carrio et al (2004)	*give the greatest chance of success. Somatic awareness is ideally suited to serve in this capacity.*" (p.1445) Somatic awareness is defined as "*the sense of the psychological condition of the whole body. Brain structures have been identified which have directive involvement in the awareness of inner bodily processes."* (p.1445) *"Somatic awareness is supported by modern theory in neurobiology and serves as an experiential probe into the critical aspects of MUS development and maintenance. In addition, it recognizes the existence of inner mind–body healing processes and serves to direct physician and patient in the collaborative discovery of these resources. "Unexplained'' symptoms are no longer mysterious medical events and are investigated and treated within a holistic paradigm."* (p.1447)
Narrative medicine	Charon (2001) Narrative Medicine: a model for empathy, reflection, profession and trust. Paper introduces a case study essay to partially illustrate the concept of narrative medicine, acknowledging that nursing, law, history, philosophy, anthropology, sociology, religious studies and government, has come to realise the importance of narrative knowledge. Narrative knowledge is that used to understand the meaning and "*significance of stories through cognitive, symbolic and affective means"* (p.1898). Builds on biopsychosocial and patient-centred medicine to look broadly at the patient and the illness. Cited works include Balint (1957), Engel (1977), Laine & Davidoff (1996), Body (1987) Swenson et al (2004) Mishler (1986)	*"Narrative considerations probe the intersubjective domains of human knowledge and activity…those aspects of life that are enacted in the relations between two persons"* Requires narrative skills such as close reading, reflective writing and authentic discourse. Charon concludes that by bridging the divide between physician and patient, the self, colleagues, and society, narrative medicine can help physicians to offer accurate, engaged, authentic and effective care of the sick
Unitary theory	Broom (1997) *Somatic illness and the patient's other story. A practical integrative mind/body approach to physical illness for doctors and psychotherapists*. Broom (2000). **Medicine** and story: A novel clinical panorama arising from a unitary mind/body approach to physical illness.	Unitary theory challenges mind/body dualism which dominated medical education. Enables the mind and body to be viewed as two sides of the same coin rather than opposing parts. Illness or health may be influenced by a range of interacting factors. For instance when treating pain, factors such as origin of the pain, previous history of pain, site, emotions, thoughts, mood, perceptions, attitudes, coping strategies, relationships, environment, safety, economic status, employment status, healthcare professional-patient relationship, education, any medical-legal issues.

Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
Unitary science of human beings	Rogers (1970) *An introduction to the theoretical basis of nursing.* Rogers (1994) *The Science of Unitary Human Beings: Current Perspectives.* "Talking about nursing as a noun, as an organised body of knowledge. The *practice* of nursing is not nursing. Rather it is the use of nursing knowledge for human betterment. It is important to distinguish between a body of knowledge versus learning skills or techniques or ways of using knowledge." (p.34) "I think we make a big mistake when we try to categorise everything. This seems to be a characteristic of the western world. Some of the categorizations actually do nursing a disservice…research has been largely qualitative and quantitative. One needs to look at the phenomenon under study and determine the best ways to get at it, rather than mix whatever methods are necessary to hopefully answer the question with the least amount of effort…"good" research…does take creative ideas and a great deal of commitment" (p.34) Rogers views nursing as *"an independent science, an independent discipline with its own unique phenomena, unique in terms of any other field, which is generating principles and theories, the purpose of which is promotion of health…"* (p.34) The science of unitary human beings provides the knowledge for imaginative and creative promotion of the well-being of all people.(p.35) Limitations: open to interpretation and misconceptions; not readily understandable or transferable to those in healthcare practice.	Five basic assumptions: 1. "The Human being is unified whole possessing an individual integrity and manifesting characteristics that are more than and different from the sum of their parts". (That is the characteristics of an individual are what give him his identity as a human being. Human beings are just not characterised by body parts, but by mass, structure, function and feelings.) More than holism, psychology, sociology which Rogers regarded as parts not the unitary whole of a human being or their environment 2. "The individual and the environment are constantly exchanging energy with each other and the human being is visible only when particulars disappear from view". (Implying - everyday life experiences illustrate how an individual affects, or is affected by, the world around him/her. People are connected to the natural world.) 3. "The life process of human beings evolves irreversibly and unidirectionally along a space time continuum". (That is conception, birth, infancy, childhood, adolescence, adulthood through to old age and death; sequential stages of development.) 4. "Identifying individuals and reflecting their wholeness is life's patterns". (Implying man's ability to self-regulate himself in spite of the continuous change or new patterns in his life and the environment.) 5. "The human being is characterized by the capacity for abstraction and imagery, language, thought, sensation and emotion". (Man is different and unique from other living forms because he is able to think for himself.)
Whole Person	Healthcare (nursing) education: US Donadio (2005). Improving Healthcare Delivery With the Transformational Whole Person Care Model. See also Mount (1993) Pilot study involving 50 patients from the cardiac rehabilitation	After the completion of the study the principal investigator, stated "As a physician, I find that whole health educators are incredibly supportive in my attempt to help patients regain or maintain wellness. The educators reinforce knowledge, motivate patient behavior, and have the time to help remove barriers to wellness" (p.77)

Healthcare related concepts, theoretical models, and philosophies associated with patient-centred care		
Term/concept	**Source, evidence base and perceived limitations**	**Core dimensions, attributes and principles**
	department at Union Hospital, a 132 bedded community hospital. Patient participants completed a validated survey instrument - commonly used to measure quality of life (SF-36, Medical Outcomes Trust, Boston, Massachusetts) - initially and again after six months. During the six month period patients had a series of 6 one-to-one sessions with a whole health educator (6 participated in study). Whole health educators: the Whole Person Care curriculum comprises 24 classes (72 contact hours) which promote nurses' personal and professional self-reflection and growth. The curriculum, which is endorsed by the American Holistic Nurses Association, enables each learner to understand the whole picture of health – including physical, emotional/social, nutritional/chemical, environmental and spiritual aspects of health and disease. Behaviours that affirm the sacredness of life – respect, integrity, compassion and equity are the foundation of Whole Health Education, a multi-dimensional whole person Links to other works: paper cites the Pew-Fetzer Task Force (1994) – use of terms holistic, whole person, relationship centred Potential limitation: study funded by the Union Hospital and the New England School of Whole Health Education (NESWHE). Principal Investigator was the Medical Director of the Department of Cardiac Rehabilitation at Union Hospital, and cardiologist in private practice.	"The NESWHE pilot study demonstrated that Whole Health Education is not only valuable but also desirable in the journey of cardiac patients toward wellness. The qualitative data, collected in the form of patient exit interviews, staff interviews, and unsolicited notes and letters, was positive. Patients with behavioural problems became cooperative and related to staff in a better manner. This study also recognised that the outcome of any best practice is dependent upon the dedication and hard work of the individuals and organisations that attempt to integrate practice into their culture. The findings, together with those associated with a model of Whole Person Caring, affirmed the need to ensure organisation wide, systemic agreement about an organisation's mission statement and values if optimal success is to be secured.

A Study to Explore the Patient Journey Approach
To Patient-Centred Healthcare Delivery

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1. Set up Patient Journey Steering Group to identify and agree clinical setting for implementation of Patient Journey. Group will also discuss and make recommendations for the potential membership of the Patient Journey Project Team.

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2. Recruit membership of the Patient Journey Project Team from relevant clinical area – to include primary and secondary care settings. Invitation to participate will be by telephone call, face to face contact or letter as appropriate. Information leaflet will be provided.

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3. Start Patient Journey based on The City Hospitals Sunderland approach. Six, monthly meetings (1) establish membership of Patient Journey Project Team, allocating roles of Clinical Champion, Patient Journey Chair, Local Facilitator. Patient Journey Facilitator will be Sue Baron, Principal Researcher, (2) mapping of current services (3) matrix sampling (4) patient interviews (5) redesign of patient journey (6) action plan.

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4. Patient interviews will take place during month 4 of the Patient Journey process. Patients will be selected according to the criteria for selection as determined and agreed during matrix sampling in month 3. The interview matrix will be made up of clinical and social factors to ensure that the cohort of patients to be interviewed enables a fair representation of the target population. Patients will be contacted in the first instance by a clinician from their specific clinical setting and later by Sue Baron, Principal Researcher.

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5. Information leaflets will be given to potential participants. The patients who are agreeable to taking part in the study will be asked for their written consent prior to their informal, recorded interview with Sue Baron. Sue will have made prior telephone contact with the patient to agree a convenient date and time for the interview, reconfirming the patient's interest in the study, and ensuring the patient is comfortable with being visited at home. Patients will be able to have a representative with them if they wish.

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6. Recorded patient interviews will be informal with a few prompts available, if required, based on the City Hospitals Sunderland approach. The interview will open with Sue Baron inviting the participant to speak freely about their experiences of their recent health care from GP, through secondary and primary care. Examples of prompts, as used in the Sunderland PJ approach, are as follows:
   * How did your health problem start?
   * What sort of changes, if any, could have been made to improve your care through the different stages?
   * How involved did you feel in the decision making process of your care and treatment? When did you feel most involved, if at all? Did you have enough information to make choices?
   * What other aspects of care, if any, would you like to have been less/more involved with?
   * Did you have enough information/feel supported enough to make decisions about your care? How did you receive information and or support?

7. Interviews will be transcribed and analysed using simple thematic analysis determined according to categories commonly applied, or readily understood by particpants.

↓

8. Thematic analysis from the interviews will be fed back to the fifth meeting of the Patient Journey Project Team and the data used to inform the design of a new Patient Journey for patients within that specific clinical setting. This information will not stand alone. The development of services will also take account of staff perceptions, feedback from focus groups (if relevant) and current and future targets set by Government and or other professional bodies. Redesign is to be supported with latest evidence relevant to clinical setting.

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9. Month 6 of the Patient Journey process will incorporate discussion on the vision for the new Patient Journey, and negotiation for the development of a detailed project plan for the implementation of the new Patient Journey.

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10. Implementation of the new Patient Journey.

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11. In accordance with the aims and objectives of the study, the efficacy of the patient journey process will be analysed and evaluated. Following its implementation, the new Patient Journey, will be subject to evaluation. This will require further interviews with a new group of patients, from the same clinical setting, who will be selected using the same criteria as for the first cohort. As before, this data will be used in conjunction with other relevant information in the form of staff perceptions, focus group meeting feedback for instance.

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The cyclical and constantly evolving nature of *action research* closely echoes the Patient Journey Process. Through collaborative teamwork and regular analysis and review of the process, it is envisaged that the aims and objectives of the study, which primarily is to evaluate the effectiveness of the Patient Journey approach to patient-centred healthcare delivery, will be met. A report of the findings, and the new knowledge acquired, will be used to develop further Patient Journeys thereby facilitating the delivery of patient-centred, evidence-based healthcare, in line with government directives. Copies of the report will be available for participants on request.

All patient data will be anonymous, stored securely in a locked cabinet or on a password protected computer at Bournemouth University, as appropriate, and destroyed after 10 years in accordance with University policy. Any data shared with the clinical teams will also remain anonymous.

COPY (1659)

NHS

Somerset Research Ethics Committee
RDSU
Taunton & Somerset Hospital
Musgrove Park
Taunton
Somerset
TA1 5DA

Telephone: 01823 344799
Facsimile: 01823 342780

SB/ac/06/Q2202/89

20 March 2007

Mrs Susan Baron
Research Assistant
Bournemouth University
Institute of Health and Community Studies
1st Floor, Royal London House
Christchurch Road, Bournemouth, Dorset
BH1 3LT

Dear Mrs Baron

Full title of study: A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

REC reference number: 06/Q2202/89

Thank you for your letter of 27 February 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered at the meeting of the Sub-Committee of the REC held on 20 March 2007. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised. This includes the additional consent forms for the patient journey project team members and the patient's friend/relative/carer. Information sheets and consent forms for the participant observation group and the second patient group should be forwarded for sub committee review in due course, if applicable.

With regard to the participant information sheet for patients, it was felt that the sentence referring to professional misconduct (page one, paragraph three) is rather complex. It would be advisable to remind patients at the start of the interview that it is not a forum intended to elicit complaints and caution should be exercised in naming individuals and discussing their conduct, however if a complaint arises then it will be followed up appropriately. This action could be included in point 1 of the interview schedule – please email a copy of this updated document for our file.

An advisory committee to South West Strategic Health Authority

Ethical review of research sites

The Committee has designated this study as exempt from site-specific assessment (SSA. There is no requirement for other Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document		Version	Date
Application	✓		14 September 2006
Investigator CV	✓	2.0 Susan Baron	
Protocol	✓	1.0	01 September 2006
Covering Letter			21 September 2006
Summary/Synopsis	✓	1.1	27 February 2007
Letter from Sponsor	✓		12 September 2006
Peer Review	✓		29 May 2006
Compensation Arrangements	✓	UMAL	01 August 2006
Interview Schedules/Topic Guides	✓	2.0	27 February 2007
Letter of invitation to participant	✓	2.0	27 February 2007
GP/Consultant Information Sheets	✓	1.0	27 February 2007
Participant Information Sheet	✓	2.0	27 February 2007
Participant Consent Form - patient	✓	1.1	27 February 2007
Participant Consent Form – patient's carer/relative/friend	✓	1.0	27 February 2007
Participant Consent Form – PJ project team	✓	1.0	27 February 2007
Response to Request for Further Information	✓		27 February 2007
Letter from Professor K Galvin			19 June 2006
Letter from Professor S Campbell			05 September 2006
Health & Safety risk assessment	✓	1.0	01 September 2006
Reply slip 2	✓	2.0	27 February 2007
Reply slip 1	✓	2.0	27 February 2007
Letter to prospective patient journey team member	✓	1.1	27 February 2007
Honorary contract	✓	Susan Baron	11 January 2006
CV		Professor Iain Graham	
CV		Dr Jerry Warr	18 September 2006

R&D approval

You should arrange for the R&D office at all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain final approval from the R&D office before commencing any research procedures.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for
Research Ethics Committees (July 2001) and complies fully with the Standard Operating
Procedures for Research Ethics Committees in the UK.

06/Q2202/89	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

pp.

Dr Simon Bolam
Chair
Somerset Research Ethics Committee

Email: alison.courtney@tst.nhs.uk

Enclosures: *List of names and professions of members who were present at the*
                          meeting and those who submitted written comments
                          Standard approval conditions

Copy to: *Dr J Warr, Practice Development Unit,*
                          Institute of Health and Community Studies,
                          Bournemouth University
                          Christchurch Road
                          Bournemouth, BH1 3LT

                          Dr J Allen
                          Research & Research Governance Facilitator
                          Taunton & Somerset Hospital

Somerset Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 20 March 2007

Committee Members:

Name	Profession	Present?	Notes
Dr Simon Bolam	Consultant Haematologist	Yes	REC Chair
Mr Alan Hopper	Lay member	Yes	REC Vice Chair

Also in attendance:

Name	Position (or reason for attending)
Mrs Alison Courtney	REC Co-ordinator

NHS

Mrs S Baron
Research Assistant
Bournemouth University
Institute of Health and Community Studies
1st Floor, Royal London House
Christchurch Road
BOURNEMOUTH BH1 3LT

26 March 2007

Dear Mrs Baron

RE: A STUDY TO EXPLORE THE PATIENT JOURNEY APPROACH TO PATIENT-CENTRED HEALTHCARE (1659) [S]

The conditions set out in the R&D Executive Group's letter to you dated 9 November 2006 have now been met. As a result the Group is happy to grant R&D approval on behalf of

Approval is given subject to the following standard conditions:

a)   Compliance with conditions specified by Ethics Committee(s)
b)   All amendments to the project to be notified to the R&D Executive Group
c)   Full co-operation with requests for information for monitoring purposes, including possible audit of the project to assess compliance with research governance standards
d)   There is an intention to publish, whatever the results
e)   Notification of local study specific SAEs (Serious Adverse Events) and SUSARs (Suspected Unexpected Serious Adverse Reactions) to the R&D Executive Group
f)   Compliance with the Research Governance Framework for Health and Social Care
       (For information and guidance on the Research Governance Framework for England, please see http://www.dh.gov.uk/PolicyAndGuidance/ResearchAndDevelopment/ResearchAndDevelopmentAZ/ResearchGovernance/fs/en)

Page 1 of 2

Yours sincerely

Chair
R&D Executive Group

Enc.   List of documents reviewed

Patient-Centred Healthcare Delivery Using a Patient Journey Approach

As part of my research I, Sue Baron, am required to regularly travel to XXX NHS Hospital Trust which is providing the setting for the study, a distance of approximately 75 miles from Bournemouth University. Additionally, during the course of the study, I will be required to conduct interviews in patient homes, with the patient, and a relative or carer if appropriate, within the locality of the affiliated NHS Trust.

In order to ensure my personal safety when travelling to the study setting the following measures have been put in place:

- A hire car is used for the journeys, due to the mileage involved and unreliability and age of my own transport.
- In the event of a breakdown, the hire company provide a contact number for assistance.
- I will always carry a mobile phone for use in the event of an emergency.
- I always ensure that family and colleagues are informed of the date and anticipated duration of my visit.
- Whenever I visit the Trust I always ensure that someone is expecting me, at a specific time.
- My contact details, including my mobile telephone number, are issued as appropriate.
- As the visit usually requires a full day, I notify my family when I arrive at and leave my destination.
- I would cancel a journey in the event of extreme, adverse weather conditions.

To ensure my personal safety when conducting interviews with patients and their relative or carer in their homes, the following measures will be put in place:

- A pre-arranged date and time will be agreed with the patient, leaving a contact number for them to use should the date become inconvenient.
- The patient will be telephoned on the day of the planned interview, to confirm that they are expecting me.
- The interviews will be conducted during the daytime.
- The date, time and location of the interview will be publicised to colleagues as appropriate to ensure my personal safety whilst respecting the anonymity of the participant.
- I will notify colleagues of my arrival at and departure from the address by mobile phone.
- In the unlikely event of there being no mobile service available, I would ask the patient's permission to make a call, offering to pay the charge, in order to confirm my whereabouts.
- I will inform the patient and their relative/carer, if appropriate, prior to commencing the interview, that if I feel intimidated, threatened or in any personal danger at any time, I will terminate the interview and leave the property.
- I will ensure that I am completely aware of the closest and safest exit from the property.
- Interviews will always be conducted in a main room, such as living room, dining room or kitchen.

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- Interviews will be restricted to the patient and their named relative/carer only, as agreed when arranging the interview.
- As the interviews are to be taped, I will ensure that the electrical equipment has been subjected to the appropriate health and safety checks by university staff.

Due to the nature of the study which will be constantly evolving, there may also be a requirement to conduct interviews within the hospital setting. In this instance, the above measures will be adapted but will also include:

- Awareness of the hospital's fire safety procedure and the location of the nearest fire exit for the safety of myself and the participant.
- Appropriate choice of accommodation for interviewing, preferably with telephone contact, enabling privacy whilst maintaining safety.
- Notification to colleagues of location of interview room, commencement time and expected duration of interview.

To ensure the personal safety of the patient and their named relative/carer, if appropriate, when conducting interviews in their own homes the following measures will be put into place:

- The patient will be made aware of the purpose of the interview and the nature and aims of the research. Their role in the research process will be clearly explained to both the patient and their relative/carer if appropriate.
- Verbal consent will be obtained from the patient, prior to the commencement of the interview, and all questions and queries answered to ensure the patient is giving informed consent and is clear about the purpose of the interview.
- I will contact the patient prior to the interview to check that they are still happy to be visited and that the date and time are convenient.
- I will reconfirm who will be present with the patient.
- I will reconfirm that the interview will be taped using my own equipment.
- I will also seek permission to take notes throughout the interview to support the taped interview.
- On the day of the interview, to check understanding and reconfirm informed consent, the patient will be asked to sign a form prior to the commencement of the interview. I will check again that the patient is still happy to proceed.
- Adequate time will be made available for the interview. Anticipated duration is 15-30 minutes but due to the nature of the interview it is acknowledged that more time may be required.
- The patient will be advised that the information given during the interview will remain completely anonymous and will only be used for research purposes as agreed, including dissemination.
- I will ensure that the patient and their relative/carer are aware that they may terminate the interview at any time, or remove unwanted data from the study at any point.
- I will ensure that the patient and their relative/carer are aware that they can refuse to answer any questions or discuss any topic or issue that they feel uncomfortable with.
- Due to the potentially emotive nature of personal reflection on healthcare experiences, I will clarify with the patient and their relative/carer, if appropriate, prior to interview, how they would like me to respond should they become upset or distressed.

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- I will ensure that the patient knows that, regardless of the information disclosed, no judgement or pressure will be made on them.
- In the event that the patient discloses information which indicates that they may benefit from further specialist support, I will have a list of additional services available, such as counselling services, support groups.

In the event that any interviews are held within the hospital, the above safety measures would still apply but would also include:

- Ensuring that the participant is aware of the nearest fire exit and what the fire procedures are.
- Ensuring that access to the interview room is appropriate for all interviewees, some of whom may have mobility problems or other disability.
- Making sure that the interview accommodation is comfortable, has adequate light, ventilation, seating and room temperature.
- The location of the nearest toilet facilities is made known.

To ensure the safety of the university, and the NHS Hospital Trust associated with the study, the following measures will be observed:

- I will ensure that the university and the NHS Trust are fully aware of the purpose of my research.
- I will ensure that the NHS Trust is in full agreement with the Patient Journey approach and gives consent for service mapping, matrix sampling and interviewing before they commence.
- In accordance with my honorary contract with the NHS Trust all data and information collected during the course of this study from the Trust will be treated confidentially.
- I will work in collaboration with the university and the Trust, keeping both clearly informed of the progress and requirements of the study, working in agreement with both throughout the course of the project, and in accordance within the terms and conditions of my contracts.

2nd April 2007

Dear

Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

I am writing to inform you of an independent action research study which is to be undertaken by Bournemouth University in collaboration with XXX NHS Hospital Trust.

The principal aim of the study is to explore the Patient Journey approach to patient-centred healthcare delivery, which The City Hospitals Sunderland NHS Trust, who initiated the process, claim is *"explicit, different and making a difference to patients".* To facilitate this, the Patient Journey process will be introduced into the vascular specialty in agreement with xx, Vascular Consultant, and the XXX NHS Hospital Trust. An overview of the study is provided in the attached flowchart for information.

The study has been approved by Trust Management and the Local Research Ethics Committee.

Multi-disciplinary membership of the Patient Journey Project Team is invited from individuals involved in the provision of healthcare services for patients with peripheral vascular disease in the acute setting. If you are interested in taking part in this study and working as part of the project team on the development of patient-centred services please contact Sue Baron by email, telephone or in writing at the address below for further information.

Thank you for taking the time to read this letter and the attached information.

Yours sincerely

Sue Baron

Research Assistant/PhD Student/Patient Journey project facilitator

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

TELL US ABOUT YOUR CARE. WHAT DO WE DO WELL? HOW COULD WE MAKE IT BETTER?

Would you be interested in talking about your recent health care experience? If you answer 'YES' to this question XXX NHS Trust would like to invite you to take part in a research study being undertaken with Bournemouth University which will involve you in answering some questions during an *informal* interview. Please take time to read the following information and discuss it with your family and friends if you wish. If you would like any further information Sue Baron, research student at Bournemouth University, would be happy to provide this for you. Her contact details are provided at the end of this leaflet.

What is the purpose of the study?

XXX NHS Trust is currently looking at a number of ways in which services for patients may be improved. As part of this initiative, the Trust has linked with Bournemouth University to find out about patients' recent health care experiences as part of a study looking at the *Patient Journey Approach* to improving services and care. To do this we would like to interview you. This will probably last for about 15-30 minutes and will be done in an *informal manner* by Sue Baron from Bournemouth University. Sue is also a nurse.

Sue will make notes during the interview which will be recorded. The information collected at interview will be given a number to make it unidentifiable by name. The nameless findings from the interviews will, in the first instance, only be made available to the study team. An exception to this would be in the event of information about professional misconduct or malpractice when, in the interest of patient safety, it would be necessary to inform Trust management of the disclosure. At a later date because this is a research study, it is likely that the findings from the project will be published in professional journals or included in conference presentations.

Please be assured that if, ***at any time***, you regret the disclosure of any information this may withdrawn by contacting Sue by telephone, email or post. A transcript of your interview will be made available to you on request.

The information collected during the course of this study will be stored by Bournemouth University for ten years, either in a locked filing cabinet or on the University's password protected computer hard drive as appropriate.

The answers you provide will help the XXX Trust to develop patient-centred services for future users and may also help to improve services for patients within other hospital Trusts. The content of the interviews will not be used to identify individual members of staff or for management purposes, with the exception of information about poor practice or misconduct as mentioned previously.

During the interview we would welcome your honest opinion of the service you received during your recent episode of care. Your contribution is extremely valuable to us as it will help us to understand not only what we currently do well but, more importantly, where and how improvements might be made.

Why have I been chosen?

You have been chosen because you have recently experienced an episode of health care as a patient in XXX Hospital, XXX NHS Hospital Trust. There will be approximately 15-19 other patients who will also be invited to take part in the study.

Do I have to take part?
The decision to take part, or not, is up to you. Please be assured that you can withdraw from the study AT ANY TIME and that your withdrawal will in no way influence the quality of future care you receive from the XXX NHS Hospital Trust.

What will happen if I take part?
If you decide you would like to take part in this study, your permission is needed for Sue Baron, from Bournemouth University, to be given your contact telephone number. Sue can then ring you to arrange a time to come and talk with you at your convenience. If you would prefer not be visited at home, it will be possible to arrange an alternative venue.

You may wish to have a relative or carer with you at the informal interview and, if this is the case, please let Sue know. This is welcomed but please consider if you would be happy for this person to hear everything you might say during the course of the interview.

Before the start of the interview Sue will ask you to read and sign three copies of a consent form, one copy for you to keep with this information leaflet, one for your medical notes and one for Bournemouth University. The recorded informal interview will probably last about 15-30 minutes, during which it is likely that Sue will also make notes. The informal chat is to give you the opportunity to tell Sue about your recent episode of health care, what you found good and/or bad about your experience and if there was any way we might have been able to improve the care you received.

Although unlikely, you may find that talking about your recent health experience causes you distress.   If this happens, and if appropriate, Sue will be able to provide you with a contact number for further support.

What are the possible benefits of taking part?
The information you give on your recent experience of health care will help us to find out ways in which our services can be improved for future patients.

Will my taking part in the study be kept confidential?
The recording and notes of your interview will be given a participant number to ensure that you will not be identifiable by name. The information will be stored securely in a locked cabinet within Bournemouth University and destroyed after 10 years. A copy of the interview transcript will be available to you on request.

The content of the interview will not be used to identify individual members of staff, or for management purposes, and will remain strictly confidential. As mentioned previously, the exception to this would be a disclosure about poor practice or misconduct details of which, in the interest of patient safety, would be forwarded to Trust management as appropriate.

If you choose to be accompanied by another person during the interview please consider if confidentiality is likely to be an issue.

What will happen to the results of the research study?
The results of this study will be used to help us to gain a better understanding of patients' health care needs and expectations, building information collected into the future development of high quality, patient services. It is probable that the results of the study will be written up and published in a professional journal, within the next five years, and may be presented at relevant conferences.

A copy of the report will be available to you on request.

Who is organising the research?
The study is being jointly organised by Bournemouth University and XXX Hospitals NHS Trust with advisory input on the Patient Journey Process by The City Hospitals Sunderland NHS Hospitals Trust as required.

Who has reviewed the research?
XXX Local Research Ethics Committee and the Institute of Health and Community Studies School Research Committee, Bournemouth University.

Contact for further information
Should you require any further information please call Sue Baron on xxx or email Postal address Institute of Health and Community Studies, Royal London House, Christchurch Road, Bournemouth, Dorset, xx.

If you would like independent information about the study, or in the unlikely event that there was something about the interview you were unhappy about, please contact XX, Institute of Health and Community Studies, Royal London House, Christchurch Road, Bournemouth, Dorset xx, telephone, email

Thank you for taking the time to read this information leaflet.

Project Team Participant Identification Number   REC Ref No 06/Q2202/89

…………………………………Appendix 10   Consent Form

Title of Project: A study to explore the Patient Journey Approach to Patient-centred Healthcare Delivery

Principal Researcher: Sue Baron

Please read each statement and initial the box

1. I have received and understood information about the above research project and give my consent to participate as a member of the Patient Journey Project Team.

2. I understand that the information collected is for the purpose of the above research project and remains confidential within the PJ Team.

3. I understand that my participation in the study is voluntary and that I may withdraw at any time without explanation.

Name ……………………………….… Designation …………………………..……...

Contact address ………………………………………………………..…………….

…………………………………………………………………………………………

Telephone …………………………....Email …………………………………………

Signed ……………………………………................. Date …………………..………

Signed (Researcher) ……………………………….. Date …………………………

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

VASCULAR PATIENT JOURNEY – MAY 2007

ACTION PLAN

ACTION	KEY STEPS	TIMESCALE
1. Set up Vascular Patient Journey Project Team.	Confirm membership of group – assign key roles at initial meeting	May 2007
2. Map out current process and analysis of the patient journey	Agree the approach with Project Team. Identify key people and set up sub-group(s) for mapping exercise Consult and confirm outcomes of mapping exercise with main Project Team.	May-June 2007
3. Identify patients to take part in interviews	Develop a matrix sample from views of Project Team. Local PJ facilitator to make contact with potential patients for verbal consent.	June/July 2007
4. Interview patients	Patient Journey facilitator to interview patients	July/August 2007
5. Redesign Vascular Patient Journey	Identify gaps/blockages in existing map. Map new Patient Journey using information from patient interviews and evidence of best practice.	September/October 2007
6. Consensus event	Develop an action plan for the delivery of the new Patient Journey. Plan the way forward.	October/November 2007

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

VASCULAR PATIENT JOURNEY PROJECT

MEMBERSHIP LIST

Lead Vascular Consultant Surgeon

Vascular Consultant Surgeon x2 (by email)

Consultant, Care of the Elderly x2 (by email)

Anaesthetists x 2

Acting Director of Nursing (until 3rd meeting; reporting of subsequent meetings to new appointee)

Vascular Nurse Practitioner

Superintendent Radiographer

Acting General Manager, Surgery (first part)

General/Business Manager (latter part)

Lead Service Improvement Team

Specialist Pharmacist

Practice Development Lead Nurse

Vascular Specialist Nurse

Matron

Ward Sister x2

Clinical Nurse Specialist, PCT Leg Ulcer Clinic

Social Worker (temporary)

Occupational Therapist x2 (1 temporary)

Physiotherapist

Medical Secretaries (x2)

Waiting List Co-ordinator

25 core members + external action researcher/PJ facilitator

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

PATIENT JOURNEY PROJECT TEAM

Guidelines for Group Membership

The Patient Journey Project Team must include representation from all members of the multi-disciplinary team involved in caring for a specific group of patients from the point of entry to acute services through to discharge back into the community.

For the purpose of this study, the identified group of patients will be drawn from the vascular specialty and will have a diagnosis of peripheral vascular disease. Below is the membership list of the **Stroke Patient Journey** which was run in City Hospitals Sunderland NHS Foundation Trust, as an example:

Consultants from specialty (3) – 1 as Clinical Champion
Consultants from associated specialties (2) – e.g. A&E
Professor of Nursing Practice
Doctor – Neuro Rehab
Practice Development Nurse
Business Manager
Professional Head of Occupational Therapy
Head of Speech and Language Therapy
Speech and Language Therapist
Charge Nurse (1) Sister (2)
Staff Nurse
Stroke Nurse Specialist
CHD Specialist Nurse
Matron
CT Section Head, Radiology
Community Panel Representative (2)
Team Manager, Planning & Development Social Services (1)
Team Leader, District Nursing
GP (1)
Patient Journey Project Team – membership guidelines/continued

The above list is only a guide and may be expanded to include other disciplines. For example to include non-clinical staff, including representatives from admissions, secretarial and other support services, as appropriate/possible. This is the proposal for the Vascular Patient Journey project.

Key Roles

Once the team membership has been agreed, four key roles need to be assigned which are central to the Patient Journey process. These are:

The Patient Journey Chair: manages the development of the Patient Journey process and ensures its smooth progress, dealing with any blockages or issues as they arise. Manages the project overall and sets the agenda for the PJ meetings with the PJ

Facilitator. This role requires an individual, ideally a Business Manager, who has in-depth knowledge of the specialty; a keen motivation for service improvement and the ability to develop a business case should the need for extra resources be identified.

The Clinical Champion: the natural leader of the service/team ideally a consultant physician who holds ideas/vision for the development of the service that the team are likely to support. They are responsible for bringing leadership and vision to the group and are able to draw upon high quality evidence and best practice guidelines to support the need for change, as appropriate. The clinical champion should be able to stand back and see where the need for change exists, from the patients' perspectives as well as a service perspective.

The Local Facilitator: a nurse/practitioner who brings a picture of the current service to the group. They represent the service needs and have an in-depth knowledge of the Trust. Between meetings, the local facilitator will act on behalf of the PJ team to ensure the team are engaged in the work. They will lead the initial mapping of the current service and will help to find patients for interview. The local facilitator will be able to offer options for the redesign of the service.

The Patient Journey Facilitator: brings patient and carer involvement to the group by conducting the interviews with patients and carers (if appropriate) and reporting the thematic, anonymous findings back to the group. They are an external person to the clinical team who will facilitate the appropriate and timely development of the PJ, meeting with the PJ Steering Group/Acting Director of Nursing to report on progress. The PJ Facilitator ensures that the right patients are interviewed and conducts the interviews on behalf of the PJ team. The sampling follows the principles of qualitative research, using a purposive approach. It is expected that the sample size will be between 10 and 20 patients/carers. This role would be undertaken by Sue Baron, researcher from Bournemouth University.

The Patient Journey Process

Once potential members of the Vascular Patient Journey Team have been identified, they will be contacted by Sue Baron who will provide further information about the Patient Journey study; request consent from each member as participants in a research study, and notify the date of the date of the first meeting.

At the initial meeting a six month action plan will be agreed. The process will commence with mapping the current patient journey for the identified group of vascular patients. During the Patient Journey process it is expected that monthly full team meetings will be held with meetings of sub-groups as required.

Preliminary Action Plan:

Month 1 – Agree membership of group/assign roles. Begin mapping current services.
Month 2 – Progress report of mapping current journey – illustrate with flow diagrams.
Month 3 – Matrix sampling of patient group.
Month 4 – Recruitment of participants and commencement of patient interviews.
Month 5 – Feedback to group of preliminary findings from patient interviews. Discuss initial proposals for improved Patient Journey.
Month 6 - Action plan for implementation of recommended changes.

NOTES OF THE VASCULAR PATIENT JOURNEY PROJECT TEAM
8 MAY 2007

PRESENT: Chair/Acting Director of Nursing
                Clinical Champion/Lead Vascular Consultant Surgeon
                Action Researcher/External Patient Journey Project Facilitator
                Superintendent Radiographer
                Occupational Therapist
                Consultant Anaesthetist
                Physiotherapist
                Vascular Nurse Specialist
                Service Improvement Team Lead
                Lead Nurse Practice Development

APOLOGIES: Consultant Care of the Elderly
                Consultant Surgeon
                Local Patient Journey Facilitator/Vascular Nurse Practitioner
                Medical Secretary
                Waiting List Co-ordinator
                Acting Divisional General Manager Surgery
                Clinical Nurse Specialist, Primary Care

The Chair welcomed all to the first meeting and explained the purpose of the meeting which was to introduce what a Patient Journey (PJ) is and how it would be developed. Sue Baron had already been working on the project for a year in preparation for project implementation. Papers also distributed via meeting for information. The Chair explained that several specialties had expressed an interest in taking part; however the Vascular PJ was selected. Sue Baron (SB), together with PJ Chair and Local PJ Facilitator visited Sunderland in April. This provided valuable insight into the Patient Journey process. This has been tested in Sunderland through more than sixteen separate PJ projects run over the last 5 years in conjunction with the university. The work had been led by Campbell and colleagues.

1. **BRIEF OVERVIEW OF THE PATIENT JOURNEY PROCESS**

   The protocol flowchart (previously circulated) was tabled and discussed and points noted:
   - Step 1 – Recruit team
   - Step 2 – Identify routes into the hospital, point of entry and how patients follow through the current service
   - Step 3 – team to decide on group of patients to be interview and criteria for sampling, e.g. age, social situation, disabilities etc.
   - Step 4 – The local PJ facilitator would provide first contact between the Trust and patients selected by SB via matrix sampling, for interview.
   - Step 5 – SB to undertake interviews
   - Step 6 - Identify issues and find solutions/possible redesign of current Patient Journey
   - Step 7 – Action plan for implementation of changes identified

It was anticipated that a consensus event with an external facilitator would be held at project conclusion to review work done, evaluate the process and consolidate. This was in keeping with Campbell et al's (2004) approach.

2. **ASSIGNMENT OF TEAM ROLES**
    The following were agreed:
    Vascular Patient Journey Chair – ADNS in the interim, with either potential for business managers to take over when ADNS leaves current post
    Clinical Champion – Lead Vascular Consultant Surgeon
    Local Patient Journey Facilitator – Vascular Nurse Practitioner
    Patient Journey Facilitator – Sue Baron

3. **GROUP MEMBERSHIP**
    The Group's membership was discussed with the following suggested additions:

    Consultant Anaesthetist
    Consultant Psychologist
    Consultant Cardiologist
    Consultant Care of Elderly
    Senior Social Worker Assistant (cover ward X)
    Social Worker (cover ward Y)
    Additional Ward Sisters to be invited (Sue Baron to discuss with VNP/LPJF)
    SB.

4. **PROCESS MAPPING**

    SR reported that mapping exercise undertaken 2 years ago for angioplasty and angiograms. SR also stressed importance of getting everybody in the room together. The Head of Service Improvement (HSI) volunteered to co-ordinate session(s). Agreed to move on with this quickly, and with as many from the team as possible involved; CC and HSI to liaise regarding suitable dates. **HIS & CC**
    The group discussed criteria for possibly 2 pathways (the list is not exhaustive)

5. **MATRIX SAMPLING**
    The team discussed criteria for possibly 2 pathways. Initial suggestions for sampling criteria included:
    Male/female
    Age range – 40+
    Employment status
    Dependency – nursing home, residential home, self-care at home
    (independent/with support from family or state)
    Pre-op mobility
    Tissue loss (leg ulcer, gangrene)
    Pre-existing amputations/outcome amputations
    Outcome – amputation/further amputation/graft
    Diabetes
    Ischemic heart disease
    Venous disease
    Stroke
    Mental Health
    Smoking

    SB will put the above into a matrix for circulation and comments. Emails will be forwarded via current PA to Acting Director of Nursing. **SB**

6. **ACTION PLAN**
Outline action plan presented.

7. **CONSENT AS RESEARCH PARTICIPANTS**
SB asked all members for their written consent to be a participant in the concurrent action research study. This was obtained from those present via a consent form.

8. **ANY OTHER BUSINESS**
It was noted that Sunderland have offered their support with any stage of the process or attend meetings, if this is required. Gratitude was expressed by SB and the PJ Chair for this.

9. **DATE OF NEXT MEETING**
7 June 2007 at 10.30 a.m., provisionally in the XXXX (the venue may be subject to change).

Contents of email sent 15.6.07 by xxx Consultant Anaesthetist, prior to mapping meeting on 22nd June 2007

Dear Sue,

I am sorry that I will be unable to attend the patient journey meeting, please accept my apologies. I would like to give you details about the anaesthetic involvement.

There are 3 anaesthetists who have an interest in vascular surgery. They cover most of the elective lists.
In line with recommendations from CEPOD it is important that there is a system for the anaesthetist to review major cases pre-admission. This happens several ways:
1) Surgeon sees patient in clinic and deems him/her a high risk. A direct referral is made to anaesthetist who can review and advise about risks, further investigation etc.
2) patient listed for AAA repair. We have an agreed guideline - all of these patients are referred to the cardiologists for an Exercise Tolerance Test. If that is equivocal they may proceed to a Dobutamine Stress Echo or an angiogram. When this has occurred the patient is listed. Consultant Surgeon will often send me the notes and ask if it is ok to proceed.
3) VNP sees patient in POAC. I have a fixed session in POAC on a Friday morning when VNP is there. We work closely together and I will see all of the AAA patients and any others that she is concerned about. In other words all of the problems should be resolved before the day of admission.

Emergency patients are reviewed by request. If a patient needs an ITU or HDU bed this is booked by VNP or vasc team. There is a guideline for the use of HDU beds for AAA patients.

I think that there are problems with patients being pulled off waiting list and listed without going through POAC. This may be to fill the list but if so there is a greater chance that they will be cancelled on the day.

Could I have a look at the patient journey and add when I get back in first week of July.

Thanks

Consultant Anaesthetist

>>> xxxx 05/31/07 2:48 pm >>>
Director of Operations and Practice Development Lead Nurse

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PATIENT PATHWAY

Vascular patient journey

Version	3
Date of Issue	3 December 2007
Status	Final version
Authors	Vascular Patient Journey Project Team
Approved By (Print name)	
Signature	
Approval Date	
Approved By (Print name)	
Signature	
Approval Date	

Table of Contents

Amendment History

Version	Prepared By	Date Issued	Notes	Status
1	HSI	20/09/07	First Draft	Draft
2	HSI	03/11/07	Second draft	Draft
3	HSI	03/12/07	Final version	Final

Distribution

Copies of this document will be distributed to the following people for review.

Person	Title
XX	Researcher
XX	Consultant Surgeon
XX	Physiotherapist
XX	Senior Social Worker
XX	Nurse Practitioner
XX	PA, Director of Nursing
XX	Consultant Surgeon
XX	Occupational Therapist
XX	Sister
XX	Superintendant Radiographer
XX	Lead Nurse – Practice Development
XX	Service Improvement Programme Manager
XX	General Manager
XX	Medical Secretary
XX	Consultant Anaesthetist
XX	Director of Nursing
XX	Clinical Nurse Specialist, Primary Care
XX	Occupational Therapist
XX	Vascular Nurse Specialist
XX	Specialist Pharmacist

Process overview

This document describes the process for the management of patients with peripheral vascular disease in an acute trust and associated issues or causes of delay.

The process begins with referral by a clinician and finishes with patient discharge.

Process Description/Narrative

Process Narrative and Issues

The key steps in the patient's journey are set out in the Process Narrative and the Process Map below. In mapping the patient's journey, staff have raised a number of issues which are detailed below.

Step #	Step Description and Issues
1	Patient referred: • By a range of clinicians including GPs, Vascular Nurses, Orthopaedic Consultants, A&E, MAU, Endocrinologists, Care of the Elderly Team, other hospitals, Community Leg Ulcer Clinics

2	Outpatient Appointment
	 • Patient attends –
	      Consultant team/Nurse appointment at XX or community hospital (20 x 10min appointments per clinic)
	      Vascular nurse assessment clinic
	 • *Significant delay due to repeat appointments between Vascular Nurse, Consultant, Duplex scan*
	 • *Patients assessed by Community CNS seen by XX CNS before consultant – Community CNS to refer direct to consultant?*
	 • *Delays when patients transfer between YY and XX hospitals*

3	Clinical Assessment • Patient history, examination, ABPI's, request Duplex scan, risk factors • Leg ulcer: bandaging, dressing, swabs
4	Diagnostics • Investigations. Notes and results sent to requesting clinician • Imaging capacity for 1-2 Duplex scans per OP clinic • *Imaging demand for 3-8 Duplex scans per OP clinic* • *2 week wait for Urgent Duplex, 6 week wait for Elective Duplex* • *No access to full range of diagnostics in peripheral clinics*
5	Outcome 1: Follow up Appointment • Life, limb, lifestyle choices discussed with patient • Repeat follow-up appointment/s arranged • Patient decision re future treatment options
6	Outcome 2: Case discussion – re angioplasty • Options discussed • 90% of patients: Angioplasty booked • 10% of patient: Surgery
7	Outcome 3: Angioplasty required • *Capacity: 2 Angioplasties per list, 5 lists per week 09.30-12.30*
8	Outcome 4: Surgery required • Bilateral or aneurism disease: staging (avoids early pre-admission delays)

	• *Waiting list forms not always available in Outpatients*
	• +/- Angiogram
9	Outcome 5: Emergency Admission
10	Outcome 6: No further treatment required at this stage
11	Booked for Angioplasty

12	Booked for theatre by consultant
	• *Sequence of Theatre booking and pre-operative assessment*
	   Weds: List from DI to CNP of patients for following week
	   Fri: Patients pre-assessed by CNP
	   Mon-: Patients admitted for Angiogram or Angioplasty
	   Thurs (requires a lot of phoning to arrange admissions)

13	Pre Op assessment • CNP assesses patients referred from all clinics (including periphery) • Patient completes pre-assessment questionnaire • CNP examines, takes history including drug history, advises re medication, health promotion, requests additional investigations • CNP consents patients for Angiograms/Angioplasties • Patient screened for MRSA • Positive MRSA screen – CNP refers patient to GP for antibiotics and re-screening arranged • CNP writes treatment guide for ward staff • Notes returned to POAC reception – patient ok to book • *Sometimes patients not pre-assessed due to insufficient clinic spaces and CNP time*

13a	Patient referred back/on to another clinician
	• CNP refers for Anaesthetic opinion as necessary
	• CNP assesses cardiac status:
	   Patient cancelled
	   Patient referred back to Vascular Surgeon who:
	       Refers to Cardiologist for assessment
	       Delayed access to Cardiologist opinion
	       Refers back to GP to manage blood pressure, and to arrange 3 BP measures in primary care before returning to Pre-assessment clinic
	       CNP calls Admissions – patient ready for surgery

13b	TCI date agreed
14	Patient Admitted to ward (i) Elective • If diabetic patient requires sliding scale, admitted day before operation • Patient starved for 6 hours before operation • Sliding scale types 1 and 2 diabetes • Antiseptic bath, etc. • Amputee checklist started • OT and Physio referral pre-operatively for amputees • OT wheelchair assessment • IV fluids prescribed as appropriate • +/- ECG • Pre-op checklist completed at time of collection of patient from ward for Theatre • Patient collected by Theatre Porter for transfer to Theatre • *Bulk of Emergency / Urgent Angioplasty requests made during Thursday ward round, leaving Friday morning to carry out the*

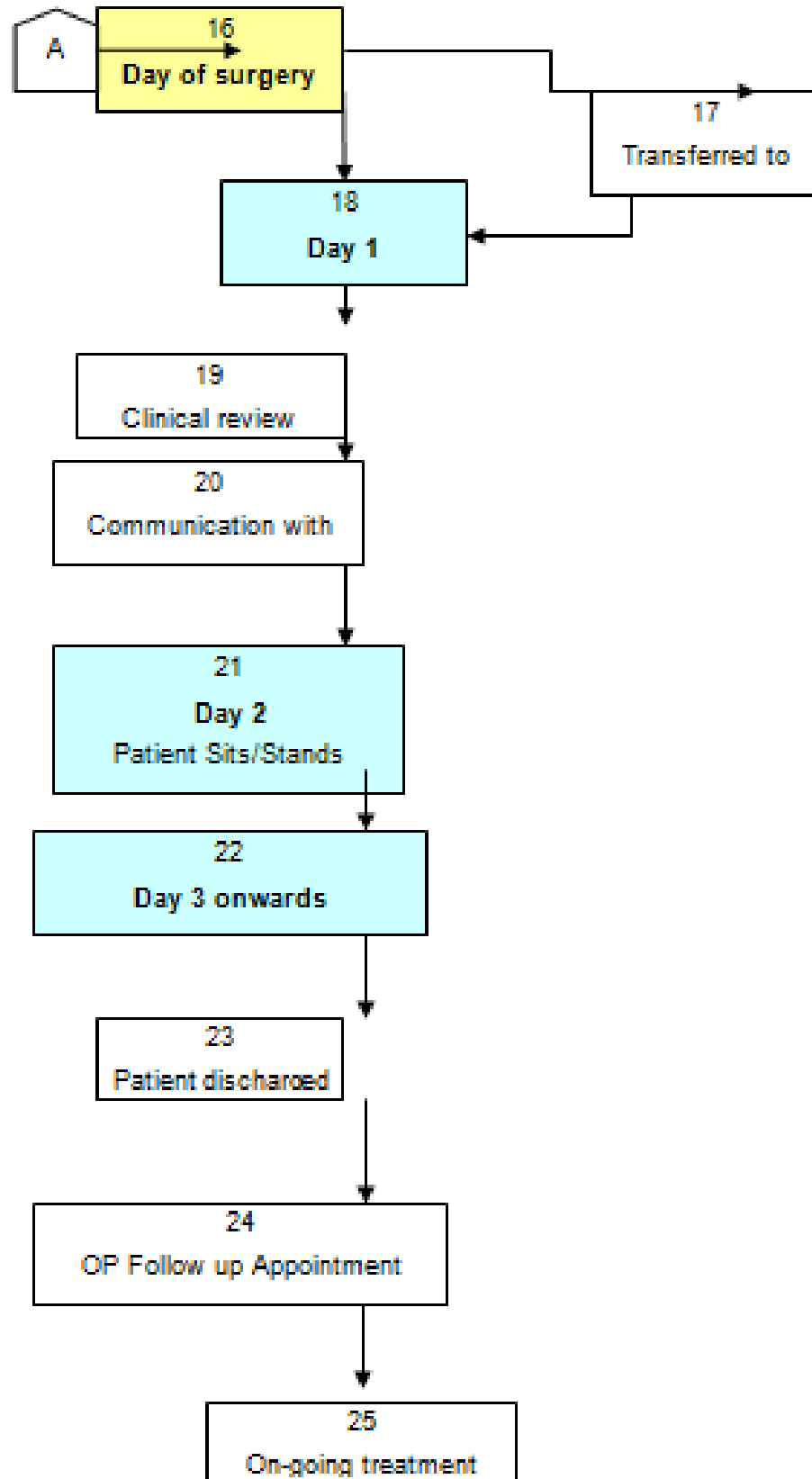|	
	requests
	• *All patients for Angioplasty admitted as Inpatients (50-60% could be treated as day cases)*
	• *Shortage of X-ray Porters to transfer patients for Angioplasty*
	• *Patients identified for Surgical Admissions Lounge are sometimes admitted to the Ward*
	• *No shower available on Ward*
	• *Lack of side rooms for isolation*
	• *Shortage of Theatre Porters*
	(ii) Admission direct from Outpatient Clinic
	• Duplex same day/tomorrow
	• Urgent Angiogram (0-2 days)
	• Decision re: palliative care/conservative treatment, angioplasty, surgery
	• Patient clerked, examined, assessed, bloods, ECG, medication
	• MRSA screened – decolonisation, isolation if required
	(iii) Patients transferred to/from BB and YY hospitals
15	Patient Reviewed
	• Surgeon consents/marks the patient
	• Discussion with family
	• Anaesthetic review evening before surgery
	• *Sometimes difficult to find the patients (ward of admission)*
	• *Order of Theatre list confirmed from 4pm day before surgery*
	• *Wards not aware of the order of Theatre lists*
16	Day of surgery
	(i) Angioplasty (in Imaging Department)
	• Consent confirmed by Radiologist
	• Clip, check pulses, cannulate (20 mins)
	• First patient arrives at 9.00
	• Procedure time: 1-2 hours
	• Recovery: 30-40 mins (in Diagnostic Imaging)
	(ii) Surgery
	• Patient arrives in Anaesthetic Room
17	Transferred to ward/ITU/HDU
	• Ward management
	• Analgesia, fluids, post-op obs
	• Food / hydration
	• Medication: Obs/PAR score, check drugs restarted, check drug history and document in notes, amend drug chart, document safety issues, review blood results, antibiotic review
	• All amputees and patients with PCAs, epidurals and nerve catheters reviewed daily by acute pain team
	• *Difficult to access ITU/HDU beds*
18	Day 1:
	• Drains out
	• Referrals: Pain Management Team, +/- Vascular Nurse, Physio, OT, Exeter Mobility Centre
	• Amputees: OT/Physio review – chest check, bed exercises, sitting balance work, ADL, family support, etc
	• *Some GPs tell patients not to bring own drugs*
	• *Some patients bring drugs in blister packs*
	• *Generally patients referred to OT at pre-op assessment*

	• *Friday Theatre lists: 2 days when patient is not reviewed due to weekend*
19	Clinical review • Surgical review • Bedside Dopplers / surgical outcome
20	Communication with Family and or Carer
21	Day 2 Patient sits/stands • OT issue wheelchair and pressure cushions • Physio: Sitting/balance +/- standing • Transfer bed to wheelchair • Hoisting, liaising with nursing homes re slings • Nurses or OT raise social issues with Medical Social Worker • On-going wound care, nutrition, obs, monitoring pressure areas, provision of mattresses, VAC therapy where required • Referrals: Vascular Nurse, Dietitian • *Wheelchair provision*
22	Day 3 onwards (i) For amputees only: Mobility • OT assessments and treatment, washing, dressing, kitchen • Patient commences gym sessions (jointly with OT) • When staples/stitches out: Patient commences PPAM-aiding and stump shrinker supplied • Wheelchair mobility practise with OT • Attend Outpatient appointment with EM Centre at XX • Review of existing prosthetic limbs by EM Centre • Review of existing prosthetic limbs by EM Centre • OT home visits (ii) All patients: • Provision of walking aids, where indicated, and OT equipment • Referrals: Discharge Liaison Team, community hospital waiting list, 'handovers' to community hospital staff, Social Services OT • Physio referral to Orthotist, if appropriate • *Orthotists need to document input/provision of footwear in patient's notes* • *Community hospital admission criteria limit access to amputees* • *Limited clinical psychology input (principally for amputees)*

	Patient discharge
	(i) Amputees • OP Physio appointment organised at XX or community hospital, as indicated • OP appointment/s with EM Centre (amputees only) (ii) All patients: • 1-stop pre-emptive discharge prescribing • Stair assessment with Physio as needed/directed • *Unpredictable length of stay* • *Delayed discharges* • *Delayed Orthotic assessment and supply* • *Community hospital bed availability (delays discharge or T/F)* • *Secretarial support for production of MDI discharge summaries* • *MDI discharge summaries not always being copied to Somerset PCT Community Leg Ulcer service*
24	OP follow – up appointment • Angioplasty: 4 week Doppler nurse review • Surgery: Diabetics with amputation or not straight forward – consultant review in 2 weeks • Surgery: other – review in 6 weeks with Vascular Nurse • Graft: 6 week duplex scan and consultant review • Discharge to community teams, including District Nurse • *1-stop consultant review with scan required* • *Delay between initial assessment and follow-up (3-4 months) requires full repeat assessment* • *Nurse-led clinics in community hospitals* • *Patients for Angiograms and palliative care to move to nurse-led clinics* • *Delays waiting for Vascular Nurse review due to current Trust workload* • *Access to VAC therapy in the community*
25	On-going treatment (i) Amputees • OP Physio sessions commence • Continue to attend EM Centre
	Patient Deferred

1.1 Process Map

A

16
Day of surgery

17
Transferred to

18
Day 1

19
Clinical review

20
Communication with

21
Day 2
Patient Sits/Stands

22
Day 3 onwards

23
Patient discharged

24
OP Follow up Appointment

25
On-going treatment

Samples of email communication with Clinical Nurse Specialist, Primary Care illustrating approach to interactions with team members

```
Hello Sue
Would love to meet up sometime. This has obviously been a huge
piece of work that you have undertaken. I am currently evolving
into a new post but still within Tissue Viability / Leg
Ulceration!!! I can be contacted either by e-mail or 01000 0000 or
work mobile 07000007
Best wishes
CNS, Primary Care
>> Sue Baron <sbxxx@boxxx.xxuk> 27/05/2008 10:49 >>>
Hi TT

Just to say that it was good to meet you at last on Friday and to
thank you for your time and your views on the PJ model.  Much
appreciated.

Hope you had a good weekend and that you enjoyed….

Best wishes
Sue
```

Samples of email communication with SE Trust Vascular Specialist Nurse – opening channels of communication between primary and acute care whilst also highlighting potential issues

```
From: VSN[xxx@xxx.nhs.uk]
Sent: 03 July 2008 09:39
To: Sue Baron
Subject: Fwd: Re: Patient Journey Update

>>> VSN 03/07/2008 09:32 >>>
Dear Sue

Thank you for the update on the vascular patient pathway. Sorry
not to have been able to meet up as yet.

As for the issues you raised in no 3 I feel I need to clarify that
there is not a duplication of clinical assessment.
Patients with leg ulceration are referred throughout the county
and the patients referred by CNS are a small proportion of these.
We offer the same service to all patients referred to us from the
vascular surgeons.

The consultants ask the vascular nurses to see the patients in the
first instance so that we can assess the condition of the leg
ulcer on its first review in the Trust. During this consultation
there may be a repeat of some clinical procedures but there will
also be additional tests and procedures carried out. Our aim is to
heal the ulcer for the patient. Based on our assessment we will
usually recommend a different treatment regime, e.g. modified
```

compression. This is a decision that we make in clinic based on our clinical assessment of the patient. It is a decision that the referrer has not been able to make, hence the reason for referral. It would be very difficult to do this without seeing the patient first. As registered nurses we are accountable for our actions and there will be times when we need to repeat procedures for our own clarity. We would then see the patient in 6 weeks or sooner if needed, to assess if the ulcer is healing. If the ulcer is healing and the patient has no other vascular symptoms the aim is to heal the ulcer without further investigation or intervention. If the ulcer fails to respond we then organise the relevant vascular investigation or refer onto another clinician for further advice. Following the investigations the patient will see the consultant. The consultant then has all the information that they require to further assess the patient.

I therefore do not agree that there is a duplication of the clinical assessment.

The second point you raise is that discharge summaries are not always available to the leg ulcer clinic.
The vascular nurses always copy the assessment following their review and send this to the clinic. This is usually followed up with a phone call to the clinic. I am aware that the discharge summaries sent from the surgeons do not always go to the clinics. However, they are sent to the GP. This is an issue that the Trust does need to review but communication between the leg ulcer clinic and GP also needs to be reviewed to improve the patient experience and vascular pathway.
I hope that this clarifies my thoughts on the issues raised. Would be happy to further discuss.

LL
Vascular Specialist Nurse

Re: Patient Journey Update

>>> Sue Baron <sbaron@bxxxth.xx.uk> 03/07/2008 15:00 >>>
Dear LL (VSN)
Many thanks for your comments and clarification which are greatly valued.
May I suggest that your email is also forwarded to CSN? I think it is important that the situation with regard to the perceived duplication of clinical assessment is also clarified with CSN. I am sure she would appreciate your views and would welcome the opportunity to talk with you and discuss/clarify perspectives about what services you both currently offer to vascular patients. I have also noted the comments on the second point, the communication issues associated with discharges, which I am happy to raise as appropriate. Again, it would be helpful if you felt you could discuss these direct with CSN to see if there is any …other possible resolution - she may not be aware of the difficulties you report in the communication between the leg ulcer clinic and the GP.I would be happy to then take anything forward..

Email to VNP who could not attend first VPJ meeting demonstrating approach to communication

> From: Sue Baron
> Sent: Wed 09/05/2007 15:01
> To: vnp@SE.nhs.uk; cies@XX.fsnet.co.uk
> Subject: VPJ meeting
>
> > Hi XX
>
> Hope all went well yesterday both with uni work and your ….>
> As I said yesterday you were greatly missed! You may already have been updated about what went on but here's the jist of it
>
> PJ Team roles – xx Clinical Champion, xx, PJ Chair, you local PJ facilitator and me PJ facilitator.
>
> Team membership - LVC suggested we also include the sisters from wards 00 & 00 but was not sure of who they were - are you able to find out/make contact with them? Neither the Sisters, nor the Matron, whom we had invited to the meeting turned up yesterday which was a bit surprising and no apologies either. Do you have any idea why?
>
> We also need to invite someone from Diabetes/Endocrinology and Social Services. VCS wondered if we needed anyone else in addition to CNS to cover PCTs, and SR mentioned to me that it might be appropriate to include a further couple of people from radiology (don't know as yet who he had in mind).
>
> Process Mapping - discussed what was involved in this yesterday. SIL and LVC agreed to liaise re arranging two sessions when the mapping exercise can be undertaken. I have emailed both today re this but would be grateful if you could also prompt LVC. If possible the mapping needs to start asap as Sunderland have found it can be quite a lengthy process.
>
> Matrix Sampling - discussed briefly what this entails and agreed with the team a set of criteria which needs to be represented in the patients selected for interview. LVC suggested that admission for patients with peripheral vascular disease is either elective or emergency and then we would need to make sure that there was representation amongst the group of the following: (These are same as in minutes of meeting and in thesis, so not included here)
> ………
>
> What are your views?
>
> Sorry it's such a huge email but there was quite a lot to tell you!>
> Look forward to hearing your comments, etc.
>
> [Notes of the Vascular Patient Journey Project Team - 8 May 2007.doc (43.1 Kb)]
> [excel programme - matrix VPJ May 07.xls (24.6 Kb)]
Email re draft sampling matrix
> Message Received: May 29 2007, 08:27 AM
> From: "Sue Baron"

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NOTES OF THE VASCULAR PATIENT JOURNEY PROJECT TEAM

12th JULY 2007

PRESENT: Vascular Nurse Practitioner
Consultant Anaesthetist
Lead Nurse, Practice Development
Physiotherapist
Vascular Nurse Specialist
Researcher

APOLOGIES: Lead Vascular Consultant Surgeon
Consultant Surgeon
Acting Director of Nursing
Director of Nursing
Service Improvement Lead
PA, Director of Nursing
Clinical Nurse Specialist
Occupational Therapist
Occupational Therapist
Superintendent Radiographer
Medical Secretary
Senior Social Worker
Specialist Pharmacist
Ward Sister
General Manager

1. NOTES OF THE LAST MEETING

The notes of the last meeting held on 7th June 2007 were agreed.

2. MATTERS ARISING

- **Group membership – participation from sisters**

WS had attended the mapping session on 22nd June and had sent apologies for this meeting. Sue and VNP confirmed that another WS had been invited to join the project team from the outset but had not yet actively engaged.

3. MAPPING – UPDATE

Process mapping commenced on 22 June, facilitated by SIL and attended by Ward Sister (x1), Vascular Consultant Surgeon (x1), VNP, Specialist Pharmacist, OT(x1) and Sue Baron, with a written contribution from Consultant Anaesthetist. This was a successful session during which the patient journey for elective and emergency admissions was mapped from the point of referral/admission through to 1-2 days post-surgery. As there were not enough members present to complete the mapping, it was agreed that another session would be arranged. The session would again be open to all members of the PJ team and, if possible, include representation from Social Services. The Vascular Specialist Nurse would forward

her involvement separately. SB to liaise with Service Improvement Lead re further session date; team preference was for a Wednesday early pm. **SB, HM**

4.   **MATRIX SAMPLING**

Copies of two matrices, 'essential' and 'desirable' had been circulated to the VPJ project team for comment and agreement. These were the final drafts which included amendments/additions as agreed at the last meeting; and further amendment following subsequent discussions with VNP (essential matrix) and OT (desirable matrix). The final matrix was now being used by an information analyst to identify eligible participants; only 14 had been found so far. It was suggested that the inclusion of specific theatre and consultant lists might bring more results as this number was not representative of patients treated within last three months.

Consultant Anaesthetist suggested that the 'desirable' matrix should have *cardiovascular disease* rather than separate diagnoses which was agreed with the group. The OT, not present, had recently forwarded a further suggestion to Sue that PADL's and DADL's be included. These were discussed with the group on behalf of OT. It was agreed that these would not be included in the 'desirable' matrix but if information in relation to this was offered at interview this would be reported back to the PJ group as appropriate.

The group approved the matrices.

5.   **ANY OTHER BUSINESS**

ADNS will no longer be part of the VPJ team as she is on a year's secondment to another Trust. It is hoped that a newly appointed Director of Nursing will join the VPJ at the next meeting.

CL will no longer be representing Social Services because she is to undertake a degree in social work. Sue is waiting to hear if anyone else will be able to represent social services.

6.   **DATE OF NEXT MEETING**

To be arranged.

73 year old male
Emergency admission 8.4.07
Referral from other NHS Hospital Trust
Date of surgery 8.4.07
Diagnosis code I74.3
Discharge 12.4.07

This was a brief impromptu telephone conversation as the patient was interested in taking part in the study but was due to have further surgery in his local NHS hospital on 31.7.07.

The main points about this patient's healthcare experience were recorded as follows:

- Patient had no visitors apart from his wife and son on the day after his operation because of the distance from home.
- His wife relied on his son, who lived 200 miles away, for transport to the hospital. At 76 years of age bus travel was "impossible".
- Despite living at their home or 13 years the patient did not like to ask friends to bring his wife to visit. One of his friends was disabled, the other in poor health.
- With regard to his in-patient care he reported that he '… had been looked after very, very well'.
- A 'senior male doctor' who examined him at tried to make him feel at ease.
- The patient commented that he had felt slightly 'isolated' on the ward, despite being reporting that his care had been good. He expanded on this by stating how he had two ill patients on either side of him – one patient receiving an IV infusion from what looked to him like 'sand-bags'. This patient was unable to go to the toilet and seemed very unwell. The patient on his other side couldn't move and needed full care. He reported that he had 'felt out of it' and at times 'stranded' because of the needs of these patients and the time their care demanded of the nursing staff.
- The patient recalled that he used a commode in his early post-operative period, then with assistance mobilised out to the ward toilet before finally managing on his own.
- Privacy and dignity had been maintained throughout his stay.
- The patient referred to a young female doctor as a 'waste of time' because she had attempted but not been able to take a blood sample.
- With regard to discharge, the patient had managed to get a friend to collect him. Unfortunately the only wheelchair available was broken and he had to walk from the ward to the car park which left him exhausted.

Despite not having written consent from the patient, his verbal consent was freely given for his comments to be included in the study.

REC Ref No 06/Q2202/89

Dear

Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

Thank you for expressing an interest in the above study.

Please read the enclosed participant information sheet which gives further details **about** the research project. After reading the information sheet please take time to think about whether you would still like to take part.

If you decide that you would like to take part in the study please telephone Sue Baron on **01202 000000** or complete the enclosed reply slip and return it in the envelope provided. You will then be contacted to arrange a convenient date and time for your informal interview.

Thank you for your interest and for taking the time to read this **letter and the attached information**.

Yours sincerely

Sue Baron
PhD Student/Research Assistant

Enc

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

REPLY SLIP

If you are interested in taking part in the above research project please complete this slip and return it in the envelope provided. You will then be contacted by Sue Baron from Bournemouth University who will answer any questions you may have before arranging a convenient date, time and place for your informal interview.

I have read the Participant Information sheet about the above study, and am happy to be contacted in order to discuss this further and to arrange a date for the informal interview.

My name is ……………………………………………………………………………...

My telephone number is ………………………………………………………………...

My email address …………………………………………………………………………

Signed………………………………………**Date**………………………………………

I would like to be accompanied by my relative/carer/friend and am happy for them to hear anything I might say during the interview. Their details are as follows:

Name ……………………………**Relative/Carer/Friend*** (delete as appropriate)

Address ……………………………………………………………………………………

………………………………………………………………………………..

Telephone number ………………………………………………………………………

Signed………………………………………………**Date**…………………………………

Dear Dr

Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

One of your patients (   ) has kindly agreed to participate in a research project which is exploring the Patient Journey approach to patient-centred healthcare delivery which, in this instance, will focus on patients with peripheral vascular disease.

Central to the study is the collection of patients' views and perceptions of their recent healthcare experience which will be obtained through informal, recorded interviews in patients' homes.   Patients may have a nominated family member or carer present if they wish. Consent will be obtained prior to the informal interview and patients will be made aware that they may withdraw from the study at any time, and may retract any data which they later regret disclosing.

In the event that, during the course of my research, I encounter a patient who is in distress they will be advised to contact their GP, the Patient Advice & Liaison Service (PALS) or the Vascular Clinical Nurse Practitioner at xxx, as appropriate.

Ethical approval for the study has been obtained from the Somerset Research Ethics Committee.

Should you require any further information about this project please do not hesitate to contact me by telephone on 0100 000000, email sXX@bouXXX.ac.uk or in writing to the address below.

If I do not hear further from you I will assume that you are happy for your patient to participate in the study.

Many thanks

Yours sincerely

Sue Baron

Research Assistant/PhD Student

Patient Identification Number   REC Ref No 06/Q2202/89

…………………………………

CONSENT FORM

Title of Project: A study to explore the Patient Journey Approach to Patient-centred Healthcare Delivery

Principal Researcher: Sue Baron

Please read each statement and initial the box

1. I confirm that I have read and understood the participant information sheet for the above study, dated **February 2007 (Version 2).**

2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without explanation, in the knowledge that my future health care or legal rights will not be affected.

3. I understand that the interview will be recorded and notes may be taken.

4. I agree to take part in the study.

5. **I would like to review a copy of the transcript of my interview.**

6. **I would like to receive a copy of the study findings.**

_____   _____   _____
Name of Patient   Date   Signature

_____   _____   _____
Researcher   Date   Signature

Care partner Identification Number   REC Ref No

06/Q2202/89

……………………………………

CONSENT FORM

Title of Project: A study to explore the Patient Journey Approach to Patient-centred Healthcare Delivery

Principal Researcher: Sue Baron

Please read each statement and initial the box

7. I understand that ………………………………. Is taking part in the above research study and I have agreed to accompany him/her.

8. I understand that ………………………………… may disclose private or personal information which is to remain confidential between ……………….., Sue Baron, researcher, and myself.

9. I acknowledge that the purpose of the informal interview with ………………… is to gather information on his/her personal and recent experience of healthcare.

10. I understand that the interview will be recorded and notes may be taken.

_____   _____   _____

Relative/Carer/Friend   Date   Signature

_____   _____   _____

Researcher   Date   Signature

INTERVIEW SCHEDULE

A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare

TELL US ABOUT YOUR CARE. WHAT DID WE DO WELL? HOW COULD WE DO IT BETTER?

1. Opening the interview:

- The date and time of the interview will have been previously agreed with the patient, and confirmed in writing. The patient will be contacted by telephone on the day before interview to confirm that the date and time is still convenient.
- On the day of the interview Sue Baron (interviewer), will check that the patient is happy to continue, has read and understood the information sheet, has provided written consent, and is happy to be accompanied by the nominated relative/friend/carer (if appropriate).
- Sue Baron will ensure that the patient (and their relative/friend/carer, if appropriate) is aware that the interview is not a platform for complaints, and that caution should be exercised in naming individuals and discussing their conduct. None-the-less the patient will be assured that in the event of a complaint arising this will be followed up appropriately.

2. The interview: Please tell me about your care. What was done well? How could it have been better?

The patient will be invited to recount their recent healthcare experience from the onset of illness, their hospital admission and discharge home. There will be no set questions. The prompts are based on The City Hospital's Sunderland Patient Journey (PJ) Approach and will only be used if required.

Examples of possible prompts (if required), based on the Sunderland PJ approach
- How did your health problem start?
- What sort of changes, if any, could have been made to improve your care through the different stages?
- How involved did you feel in the decision making process of your care and treatment? When did you feel most involved, if at all?
- What other aspects of your care, if any, would you like to have been less/more involved with?
- Did you have enough information/feel supported enough to make decisions about your care? How did you receive information and or support?

Throughout the interview Sue will use a range of communication skills to encourage free flowing conversation from the patient. Verbal attending techniques such as paraphrasing, reflecting, restatement/questioning, clarifying and summarising will be used by Sue to confirm her understanding of the patient's account of their health care experience (Egan, 1990, Burnard, 1992, McKinney, 1992, Munro & Campbell, 2000).

3. Closing the interview

The interview will close with the patient being asked what they considered to be the worst and best part of their care/treatment.

- At the end of the interview Sue will check with the patient that they are comfortable with the information they have disclosed. She will ensure that the patient is fully aware that any disclosure made during the interview may be withdrawn or rephrased at a later date and how to contact Sue if this is required.
- The patient will be asked if they would like to see a transcript of their interview when available.
- Contact numbers will be made available for further contact/support as appropriate.
- The patient will be thanked for participating in the study and offered further information about the study findings when available.

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TRANSCRIPT OF P05 INTERVIEW 14.8.2007

Start of recording – rapport building including general discussion about technology while the equipment is being set up to try and make sure participant is as relaxed as possible. Written, confirmed consent has been given and signed.

I "it is the 14th August… I don't give any names on here at all … you and I know what's being said but that information apart from quotes there is no name ever attached… anything that goes back is fed back to the team to help them with their improvements and is totally anonymous, alright?"

P "… yes, good"

I "that (digital recorder) will just carry on recording quiet happily on its own" "Right, so, really … going back to the information that I sent through to you, what I wanted you to do, if that's alright with you, is purely to tell me about your care, tell me about your experiences, particularly the more recent inpatient stay ….

P "yep"

I "…sort of how you got there, what is what like when you were in there (hospital), what was good for you and what wasn't so good for you, alright? So just feel free to tell me whatever you want, ok?"

P "Right. The first thing that happened on this occasion because they'd closed down wards 1 and 2 I believe, which were the two wards I was most used to … especially ward 1 but I'd also spent a couple of times in ward 2, so on this occasion it was ward 3, and we were in the annexe of that ward…. The first thing that struck me about it was how poor the planning was – not by the people who now run it but by the people who originally built it (laughs)..."

I "Right"

P "…. Because it's one of those places where there's only a bit of daylight comes in, comes in from what I call factory type windows right up at the top of the eaves (laughs)"

I "So really it's quite gloomy then is it? I mean I don't know the ward …"

P "obviously it's well lit, well lit

I "yes"

P "and I couldn't fault the staff and carers as far as that goes"

I "Right"

P "So, I don't want , it's just that it's an old building and frankly, it's a great shame but originally they were going to scrap all that and build new vascular units and everything apparently. Hopefully in the future that will happen.

I "yeh"

P "Um, after a very short while, I was moved into a side room."

I "ok"

P "I was told I would be better there because it was quieter. The only thing I will say, is that although I had had an operation I wasn't ill"

I "ok"

P "You know what I mean by that?"

I "Yes"

P "Yep, I felt ok in myself, and I was able to get up, after a very short time, and get up and move about. (Pause) The hard bit of being in a side room, you might think it's going to be much more comfortable and luxurious, which in some ways it is, but there's another side which isn't so good and that is – unless a member of staff comes in to actually do something …"

I "mm"

P "... check you over to make sure you are still ok, you are still in the land of the living and heart beating properly, etc., or supplying meals that type of thing …"

I "yeh"

P "… or you desperately need a nurse and you call one, you don't see a soul and it would be nice if somebody, right obviously if you're under what I call closed orders, i.e. you've got an infection like MRSA or C Difficile, um, you would expect them, obviously they've got to dress up every time they come in to see you …."

I "mm"

P "… so that's not so easy you see but, if you haven't it would be nice if every now and then you just got a head pop through the door and say "you ok" – you know what I mean?"

I "Yes"

P "A bit of human contact"

I "Were you on your own a lot in that side room?"

P "Yes"

I "you hadn't been put in there because of MRSA?" (Participant had told me that he previously been MRSA positive from an earlier hospital admission during our introductory chat)

- It was not possible to show inductive analysis as tracked changes were used to do this and this was not compatible with the formatting of this thesis

Field Notes/Themes/Issues identified from P02 Interview on 9th August 2007¶

46 year old, male patient¶

Emergency admission 4/3/07¶ — *Comment [SB1]: Possibly due to delays in referral process¶*

Referral from other NHS Hospital Trust¶

No tissue loss – infected toe on "good leg"¶

Date of surgery 8/3/07, graft failed – below knee amputation 17/03/07¶ — *Comment [SB2]: Impact on life/mobility¶*

Discharge 13/04/07 – hospital transport (ambulance) to home address¶

Diagnosis coding I70.9 (& M32.9: systemic lupus erythematosus, unspecified) Co-morbidity: Berger's Disease (diagnosed 5 years), hypertension¶

Non-smoker currently (partner smokes)¶

Council property – not suitable (steps to property) awaiting re-housing¶

Previously employed – carpenter¶ — *Comment [SB3]: Impact of diagnosis¶*

Previously independent – reduced mobility due to Berger's disease¶

Post-op mobility – wheelchair/crutches¶

Post-op rehabilitation – inpatient/local NHS Hospital/EB Mobility Centre¶

District Nurse follow-up¶

EB mobility centre¶

¶

In November 2006 the patient visited his GP because of concerns that small scratches on one of his toes were not healing. These scratches were on a toe on his good leg and how the patient had acquired them was unknown. Several courses of antibiotics were prescribed but the infection was not resolved.¶ — *Comment [SB4]: Timeframe/delay issue?¶*

¶

The patient reported that his GP made an emergency referral to XX hospital at the end of February/beginning of March 2007 due to the continued infection and extreme pain the patient was experiencing. The toe had started to show signs of gangrene but "not the wet sort".¶ — *Comment [SB5]: Avoidable delay?¶* — *Comment [SB6]: Pain issue¶*

¶

Sometime between November and March the patient had also seen a consultant at his local hospital – I am assuming for routine checks because of Berger's disease although this was not clarified with the patient. The consultant saw the infected toe and the patient reported that the plan would be for him to be admitted to XX hospital following a forthcoming angiogram. The consultant advised the patient that he would liaise with XX hospital to arrange this.¶ — *Comment [SB7]: Inter-hospital communication issue?¶* — *Comment [SB8]: Inter-hospital communication? Referral?¶*

- Partner felt that car parking was too expensive – £6.00 on average per day over 8 weeks
- Partner also felt that visiting times should be more flexible, although patient felt these were flexible enough. Visiting hours 2-8pm but he was aware that arrangements could be made for visiting outside of these hours if required.
- Patient would have liked more physiotherapy, with a greater range of exercises and preferably away from the ward. He believed however that more may have been available to him had he not had a wound infection. He liked the idea of including swimming in his rehabilitation programme. Sometimes the physiotherapists seemed to overlap in their care provision – the patient often had just finished an exercise session with one when another would attend a short while later.
- Care since discharge had been good. Felt well supported.
- Patient had been for leg fitting the week prior to our meeting. All had gone well but he was disappointed that the artificial leg was not ready for him to go home with that day. Prior to the appointment he had not received any information on what to expect, length of time, etc.
- Patient would be happy to have all his future care at XX. He is facing the possibility of a 2nd amputation and, if he could choose, he would prefer to go to XX rather than his local hospital, despite the travelling involved. Patient had felt involved with his care and the decisions taken about his care.

- Informed consent was freely given by the patient and his partner.
- Interview transcript not required.
- Patient not concerned about anonymity.
- Patient would like to receive a report of the findings/outcomes of the study.

MAIN THEMES/ISSUES – representing varied stages of patient's journey

- More and clearer information – between patients and staff, and between staff. Strong need for better and clearer communication between hospitals — patient experienced a long delay from initial GP referral to consultation at XX and then confusion over plan.
- Physical impact/pain/infection/amputation
- Delays in appointments/transfer/surgery delays – impact on patient
- Influence of staff attitude/approach – impact e.g. of humour on experience
- Workloads impact on staff and patients
- Other patients/visiting/visitors/tea trolley/urn for visitors to use/visiting times
- More imaginative physiotherapy
- Cost of car parking

Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

VASCULAR PATIENT JOURNEY
XXX HOSPITAL

'Tell us about your care. What do we do well? How could we make it better?

CONFIDENTIAL
REPORT OF PATIENT INTERVIEWS
AUGUST to NOVEMBER 2007

Sue Baron, School of Health & Social Care, Bournemouth University in affiliation with XXX Hospital NHS Foundation Trust

Introduction

Patients with peripheral vascular disease who had undergone a femoral bypass graft (MDI code I70.9: generalized and unspecified atherosclerosis) were selected by an information analyst from XXX NHS Trust in accordance with a matrix sample designed by the Vascular Patient Journey Project Team. Full ethical approval had been given for the patient interviews by the XXX Research Ethics Committee as part of the PhD project entitled '*A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery'.*

An initial list of 33 patients was supplied; out of these a number had duplicate entries, whilst some patients did not fully meet the Project team's matrix sample selection criteria. A final list of 25 eligible patients was given to the vascular nurse practitioner/local facilitator, who successfully made telephone contact with 14 potential participants. The remaining 11 patients were unable to be contacted by telephone despite repeated attempts. Details about the study were forwarded to the 14 potential participants, prior to being contacted by the researcher/patient journey facilitator to arrange an informal home interview. At this stage, out of the initial 14 selected, two male patients and one female patient declined the invitation to participate due to ill health, leaving 11 patients who consented to be interviewed.

The patients' ages ranged from 45 – 80 years. Six males aged 46, 59, 64, 67, 69 and 72 years, and five females 45, 63, 66, 72 and 80 years of age consented to take part in the study. Nine patients undertook informal recorded interviews at home which lasted, on average, for approximately one hour. Two telephone interviews were conducted at the participants' requests because of the impracticalities of a home visit and because these patients wanted the opportunity to have their views heard. Six participants were accompanied by their spouse/partner/relative. Written, informed consent was freely given by all parties, as appropriate, prior to the commencement of the informal interview. All participants were reminded of their right to withdraw from the study, at any time.

All patients recruited had a diagnosis of peripheral vascular disease (Taunton MDI diagnostic code (ICD10), I70.9 (General Surgery, Diagnostic/Operative MDI Coding Book, January 2006, pg 34)), and had undergone femoral bypass surgery between March and June 2007 (Taunton MDI Operative Procedures (OPCS4) codes L583, L592, L593, L595, L601, L603, L653, T555), with at least 1 participant representing each of the additional inclusion criteria as set by the project team, see below

VASCULAR PATIENT JOURNEY – SELECTION MATRIX		
Patients with Peripheral Vascular Disease (Total = 11)	**Elective Admission** >40 years (male/female)	**Emergency Admission** >40 years (male/female)
MDI diagnosis code I70.9	5	6
Diabetes	4	3
Hypertension	4	3
Cardiovascular disease	2	1
Discharged home	4	5
Discharged other	1	1

The above table does not include co-morbidity information for one patient as this was not revealed during the interview. A number of participants reported other co-morbidities, details of which are not included as they had not been required as part of the selection

criteria. Eight participants revealed that they had previously been smokers, 2 stated they were non-smokers; 4 male patients reported having leg ulcers which had been treated by district or practice nurses from their GP surgery; none had received care from a PCT leg ulcer clinic.

In general the patients and carers interviewed gave a positive account of their healthcare experiences at XXX Hospital, and in particular the relationships they had fostered with the healthcare professionals involved in their care. The following are examples of feedback received during the interviews:

> The care received whilst '*in hospital was fantastic'*, especially by the nurses despite '*being worked off their feet'*. The patient had enjoyed having a laugh with the nurses which they acknowledged as being very therapeutic.
> Another patient spoke highly of the care given by the '*excellent*' consultant. Continuity and consistency of care had been of great importance to their overall experience.
> '...*swiftness at admission was amazing'*. The consultant had telephoned patient's spouse on the day of operation to keep them informed, making them feel very included in their spouse's care. Continuity of care had again been greatly valued.
> *'The nursing staff worked very hard and were very busy but were in control of what they were doing and instilled confidence - super care*.'
> *I didn't like to use the call bell; I could see them rushing around with so much to do. When I did use it they were there, I didn't have to wait...'*
> One patient recalled how they had not been worried about their operation because they knew they would be well looked after *'no fear about going into hospital again because I knew I was going to be looked after…'*
> Support from nurse practitioner was excellent and much valued "*…she's a star…*"
> "*..The anaesthetist was very nice…he gave good information…even drawing a sketch of the operation*".
> "*Would go into XXX again tomorrow* if I had to…"

Following analysis of the recorded interviews a number of themes emerged for further discussion with the Vascular Patient Journey Project team. These have been categorised as follows

Each of the themes outlined above were mentioned by the majority of patients.

The informal interviews opened with the participant being invited to give an account of their healthcare experience in accordance with the questions on the Participant Information sheet, *"Please tell us about your care.   What did we do well? How could we make it better?"*

1.   TIME FROM INITIAL GP APOINTMENT TO VASCULAR CONSULTANT APPOINTMENT

Several of the patients interviewed had experienced previous hospital admissions and previous surgery.

Of those patients who were newly diagnosed with peripheral vascular disease the majority recalled making an appointment to see their GP because of increasing leg pain, which caused difficulty walking and disrupted sleep. The following includes verbatim extracts from the participants' recorded interviews:

1. Impromptu telephone conversation, not recorded – patient spoke of experience from time of emergency admission, with same day surgery. No information with regard to GP care, or previous medical history, was disclosed during the conversation. (Admission from other hospital on 8th April, 2007, surgery 8th April, discharge home 12th April)

2. (Patient) '… *November of last year* (2006) *I caught an infection in my toe, I'd scratched my toe, don't know how… and went to see the doctor because it wasn't healing…course of antibiotics …can't get it down to the toes being as the antibiotics flow in the blood, so it wasn't repairing … it just got worse, and worse till after Christmas I had an appointment to go to XXX* (March 2007)*…to have it sorted out…hopefully to have a bypass put in my leg so it could heal better…I was in a lot of pain, agony then…so I went into XXX as an emergency…'* Patient also explained ' *…saw GP again beginning of March 2007, because infection continued with extreme pain and possible gangrene in toe…GP made urgent referral to XXX … mix up in communication between consultant at (local) hospital and XXX'.* Letter received from XXX with regard to care being transferred to new consultant in May 2007*…* unable to wait, patient made contact, was seen in clinic and admitted as an emergency. (GP appointment November 2006, referral to XXX March 2007, emergency admission 4th March, by-pass graft 8th March, below knee amputation 17th March 2007; total admission nearly 6 weeks)

3. (Patient) '…*saw my doctor…had terrible pain in my legs and I said my toes feel cold …* (doctor) *wrote a letter there and then and phoned up local hospital and that same day* (6th July 2006) *I was up the general hospital and saw a consultant who said 'yes you've got problems here' …the next thing was they did an MRI on the 15th August…then saw consultant at local hospital on 24th October… then nothing.'* (Spouse) '…*waiting until the 15th of May* (2007)' (Patient)'…*at end of April saw doctor for some more pain killers … I was having to get up about every 3 hours during the night having to take a couple of pain killers … when I saw doctor he said 'what do you want more for?' …he said 'haven't you had your operation yet?' I said I've not heard from them so of course then he gave us the phone number for the reception clerk at XXX… he said I'm not going to be pig in the middle…phone them up direct… of course when we phoned up direct we found out …been missed off the list'* (GP initial appointment July 2006, admission 31st May 2007, surgery 1st June, discharged 5th June 2007, total admission 6 days)

4. (Patient) Patient consulted GP in February 2007 for advice after sustaining a small skin tear on top of their foot when falling in the shower. '*…had had ulcers before*

so thought it was prudent to go round to the local surgery to get it looked at and properly dressed…and get in the system if you like…well, weeks went by and the ulcer was treated but it was getting bigger, and bigger and bigger and bigger until we got to April time when the surgery referred me, put me on a list to go and see a surgeon…I had a letter from, I don't know where…, which said I was to report to … hospital (local) to see a surgeon early in May…had a phone-call from … hospital (local), …a day or two before we were actually due to go there cancelling this appointment, and I then had an appointment with Mr …a month later which was here, Tuesday 5th of June. He looked at my leg and done some tests with a like a blood pressure thing that you put round here that you take blood pressure with and a Doppler machine, is it?...and he concluded that there was no pulse, or very little pulse in the bottom end of my leg, foot, whatever. And he made arrangements over the phone while we were there for me to go into XXX the next day…I went in there and had the vein scan on the 6th, they couldn't fix the blood flow by putting a balloon in at that stage…I had to then have this vein operation which he carried out on the Friday morning, the 8th of June. The swiftness of the admission was amazing…the way Mr … treated us was really first class' (GP appointment February 2007. GP referral April 2007; admission 6th June, 1st operation 8th June, discharge 27th June, 2007; total admission time 3 weeks followed by a further urgent procedure in August 2007)

5. Patient had had several previous hospital admissions and focussed on their journey from the point of admission to an unfamiliar ward (Admission date 10th April, 1st operation 11th April, discharge 13th April; total admission 4 days).

6. (Patient) '…*been going to doctor* (now retired), *oh, we loved him…with these legs for years…five years … with the pain, he used to tell me to walk through the pain barrier and it was getting harder and harder, I just couldn't do it anymore … and the nurse said…because I do these dopple-op tests or something …they do them at the surgery… couldn't get any pulse in there …has he done anything about these yet?...and I says 'no'… God, she said, because he should have done … then I went to the new doctor and within a week I got a letter from the hospital and two weeks after that I went in and had the operation'* (admitted 19th March, 1st operation 20th March, 2nd operation 22nd March and intensive care stay; discharge to home, total admission time 9 days)

7. Patient recounted their journey from the point of admission so no information is available on the referral process and times. (Admission from clinic 13th June, 1st operation 26th June, discharge to home 28th June, 2007)

8. (Patient) '…*went to the GP in the February 2006 because I knew I'd got a slight problem there and I thought maybe if they put a flue brush through there I'd be alright! …I wanted to go …for a holiday so I thought I had better get it checked out…GP decided to do an ECG, that was abnormal…sent to Mr…first thing he did was another ECG and that was abnormal, he did a coronary angiograph and that was perfect…nothing wrong…I was shocked but didn't think to say why were the ECGs abnormal…still don't know…then had vascular scans on my leg…came up with a partial blockage on that leg. '…when I went in with a DVT* (8th August 2006), *that was while I was waiting for treatment for this leg, for a bypass…waiting for an angioplasty…they couldn't do it, they wouldn't do it because they discovered that not only had I got the DVT in that leg, I had an embolism and an aneurism in the graft* (other leg)…*the old graft I had had in 2001…'* (GP appointment February 2006, hospital admission August 2006 (DVT), this admission 30th April, 2007, 1st operation 1st May, emergency 2nd procedure 2nd May, discharge to other hospital 10th May, 2007, total admission time 11 days)

9. Patient recounted their experience from time of hospital admission. They had been a patient at XXX on numerous occasions. (Admission 13th March, operation 4th May, discharge 18th May) Further hospital admission since May 2007.

10. (Patient) '…*I found that I couldn't get comfortable in bed...I was getting quite bad stinging pains in the feet and lower legs when I was laying down...I found I could get relief from the stinging by sleeping in a easy chair with my legs more or less vertical…the result of that was that the legs started to swell…not a good way of spending the night either…sleeping in a chair…this went on for at least 2 months… I had had an ulcer on the lower leg…for about 7 months…*' (Spouse)'…*to me it was a very difficult and worrying time but for you it was horrible because you was trying to sleep in the chair and you were in a lot of pain…having your leg dressed two or three times a week by the nurse…she was getting more and more concerned…we spoke to the doctor on the phone, which is one of the things we don't really like about our surgery…didn't actually see the doctor in that two months…we spoke several times on the phone, either you or I, and you were given three lots of antibiotics over that period; and also, to help with the pain, they started …on lyrica an antidepressant, that was supposed to manage the vascular pain problem. I was getting very desperate in that time that no-one was seeing-…except the practice nurse was seeing -, but to my mind things were getting out of control, - really was very poorly…*' (Patient) '*Dr- (GP) eventually suggested I went to the hospital for an overnight stay for intravenous antibiotics* (nurse had asked GP to look at the ulcer) (Spouse) '…*as soon as he* (GP) *saw it he said oh I'm afraid we can't deal with this any more, I feel you need five nights and days of intravenous antibiotic, you'd better go up to XXX today, which is what we did…*' (Interviewer) '…*Why did you not get to see the GP?*' (Spouse) '*It's something that's come into being over the last 2 years and they've lost a lot of people, and we're not terribly happy with the situation…we have a phone consultation initially, supposedly, and then if they think they need to see you obviously they say well come in tomorrow, but you cannot ring up and say I need to see the doctor…the doctor will phone you back and discuss the situation…*' (Spouse) '*At this point, when – went into hospital, - hadn't been able to walk anywhere…even as far as the end of our road to the surgery, for nearly 18 months…because of the pain, the claudication pain or whatever they call it…getting more and more immobile…*' (1st operation in March 2007, 6 week hospital admission, followed by further emergency surgery in June for revision of reconstruction)

11. (Patient) '…*saw chiropodist for routine appointment at local hospital. Discoloured big toe with pain in same leg…chiropodist made telephone call to doctor at same hospital for immediate referral…transferred to XXX same day.*' (Admitted 20th March, 1st operation 27th March transferred to another hospital 28th March 2007)

Points for consideration

➤ Inter-hospital communication – a number of patients had experienced a breakdown of communication between hospitals.
➤ Could GP's make earlier referrals?
➤ At least one patient felt his outcome would have been more satisfactory had he been seen earlier by a consultant at XXX.
➤ Generally it appeared that once patients had received their initial consultation at XXX their healthcare experience improved. None-the-less, several patients reported a considerable delay between the time they first presented with their problem to the GP and obtaining treatment.

2. TELEPHONE CONTACT WITH XXX HOSPITAL

Of those participants who commented on their experiences of telephoning the hospital there were mixed reactions to ease of accessibility as illustrated by the following accounts;

i. '…very difficult to get hold of …secretary…because I don't know her number…um...I've got this letter which was the appointment for me to go to XXX for me scan and that…First of all I've got to find out XXX hospital number which doesn't appear on here anywhere…so I've got to go and find a phonebook to find out the hospital's phone number. When you phone that number up you get a computer answer you, ask you for the name of department, or number of the ward, but I want to speak to Mr… secretary, so I say that and the machine doesn't understand of course, so it says it doesn't understand. So I say Mr …secretary again, and the machine says it doesn't understand so how do you get from that position …why don't you use the phone and phone the number up? (Patient offered me the phone)...so it then said 'did you say willow?', and I said, No! So, it then said I'll pass you to an operator and I said 'Thanks' to a machine…I didn't just say thanks I can tell you! Then I got an operator …then it's done within 5 seconds…so that machine they got answering the telephone is an absolute pain for anyone that don't know exactly who they want to talk to… not had to use it before only ever had direct numbers … go try it… I insist! That turned out, I think to be the most annoying thing out of all of everything'

ii. '…to start with it was an automated thing and that didn't seem to know, understand what I was saying, so then I got from a plastic woman or man a human one…somebody then gave me a direct number…'

iii. '…we often go through to the direct hospital number…of course it's got one of those voice recognition systems…and it works…it says which department/ward do you want?...so I would say Mr…secretary and it would say 'calling Mr …….fine it works…'

iv. '…ask for – to be bleeped and she gets straight back to us…'

Points for consideration

> How effective is the automated voice recognition system? Does it help or hinder the patient experience?
> Should appropriate contact numbers be included on all correspondence?

3. COMMUNICATION AND INFORMATION

The majority of patients felt that communication was good between themselves and the healthcare professionals who delivered their care. For the most part the patients also reported that they had been given adequate information about their diagnosis, operation and plan of care, and if more was required felt confident that their questions would be answered satisfactorily.

i. (Patient) '…communication …second to none…'

ii. (Patient) '…the doctors…they come in and they gather around and they talk to you but sometimes they talk over you, you know what I mean? I mean there's a group of doctors...they're never on their own, nine times out of ten they're not, you know…they talk across you, you know, and if you're not medically minded and you don't know what they're on about, you could be sitting there and you're just not

with the conversation…nine times out of ten they're not ill-mannered, they do try to keep you in the conversation and stuff but sometimes you just think well what are they talking about 'cos they're using words that I didn't even know like, you know, medical terms. …if you wasn't sure you could ask the nurses and they would tell you exactly…would have liked more information… written and verbal…'

iii. (Patient) '…I got a bed blister on the back of my ankle of my remaining leg but, obviously if this one goes, if I get an infection in here, in this one, I can't have a by-pass they said they'd have to straight remove… I woke up in the morning and I had above my bed 'Nil By Mouth' and I'm thinking hold on I've had me operation me leg's been removed, everything else, but nobody's told me 'nil by mouth', and they were saying 'yeh, … you've got to go for an operation. I thought well, between the people that were on the ward we could have a bit of a joke, a bit of a banter between some of the patients, you know… so they was going… somebody's got up in the middle of the night and changed the card over… so we thought they were having a laugh, or whatever, you know? …so I was goin' come on who's changed the card?' …Until the nurse came over and said '...that's right …you've got an operation', and I'm thinking come on tell me about it, what operation? I've had me leg removed, I can't have any more done…eventually the doctor came and saw me…had to go to the other side of the hospital to have an injection in my back to open up my veins…they classed this as an operation.'

iv. (Patient) '…I'd have liked an injection like that…the one I had that went right into the small of my back and opened up my veins…I thought if, well, if they can open up the veins for an injection like that* (for antibiotics) *they could have given me an injection for the black toe … it might have heeled the toe … since met lots of people there* (XXX hospital) *suffering with the same thing as me…go back there every year…swear blind by these injections…'* The patient, and their partner, felt that an amputation might have been avoided had this injection been given earlier in their care. They wanted more information about these injections and to know if they would help to save the remaining leg. '…the hospital are so worried about that leg… me damaging it…XXX's last words to me, me main doctor that did all the operation and everything, he looked at this leg and he said '…, nothing to worry about this leg', he said 'but wrap this other one up in cotton wool, that's the one that you've got to look after 'cos, he said, if you do something to that one there's no bypass or anything for that one.'* (Partner) *'…it is scary, it **is** scary…'*

v. Patient had experienced problems with hospital records not being sent between XXX and their local hospital.

vi. (Patient) '…had the same consultant all the way through, he was marvellous, and he explained everything clearly…he didn't talk down to you and spoke in a language we could understand…'

vii. (Patient) '…the doctor, he explained he was going to take this vein out, for the blockage and that…very clearly… which of course the man has done…first rate…very good job…that part yes, but he didn't say about afterwards…'* (Patient struggled with the psychological effects of post-operative recovery.)

viii. (Spouse) '…you did have that booklet about bypass… British Heart Foundation…two booklets … actually said about what you were going to have done…'cos we'd never heard of it, every time you say somebody's had a bypass you think it's the heart…I think it's quite new, I don't know…'*

ix.   (Patient) '*…had expected to be able to walk more, do more…no written information about the possible after effects of having anaesthesia...blockage and bypass surgery explained very clearly but didn't say about afterwards…separate compartments all doing their own jobs but no connections…they've all done a good job – the surgical side, the hospital side, excellent; but the psychological side nobody tells you about the sense of isolation, the highs, the lows, the mood swings, feeling fed up, snappy, tearful, depressed, the tiredness, the possible after effects of anaesthesia and surgery. I would like to suggest that the psychological side is explained to the patient; what the effects of anaesthetic might be on the body and the mind…a small information leaflet, clear and simple language not gobbledygook, not lots of pages… which makes you aware of how you may feel after…reached a turning point when my friend gave me a copy of a booklet he had received from Bristol*. (The United Bristol Healthcare NHS Trust entitled '*A patient's guide to recovery and heart health following heart surgery*')

x.   (Patient) '*…if you like to take those log sheets away with you and read them at your leisure…what you were feeling, write it down and that sort of helps you to bring it out you know…* (Patient gave the researcher/patient journey facilitator their weekly journal which had been used to document their feelings, the tiredness, and their frustrations during the period of post-operative recovery. Writing a diary had been very therapeutic.)

xi.   (Patient) '*…if you have the knowledge, great…but, if you don't, you say what the hell's up with me?*'

xii.   (Patient) '*…dealing with early days… following the operation…I had a very sore lip…thought this tooth's very sharp and during the operation the edge had been knocked off it…and it was cutting my lip.* The patient recounted what happened after reporting the broken tooth and the conflicting advice and information that had followed. The patient never received a letter that had been promised on discharge and had since seen their own dentist and had the tooth repaired.

xiii.   (Patient) '*This was of major concern to us, wasn't it? …for the first 10 days it was a case of Mr… coming and having a look and wanting me to show some improvement in the ulcer before he would discharge me. Then he decided that he wanted to put a vac pack on my ulcer…to help it heal. '…that was done by the vascular nurse…every three days this dressing was changed.' 'The basis of the problem was that I was getting told by one team, the doctors, that this was heading for me staying in for a long time to have a skin graft; I was told by the vascular nurse that basically I would have to stay in there until the ulcer healed completely, but I was being told by Mr … that all he was interested in was seeing some major improvement in it before he was going to discharge me. So towards the end of my stay in hospital I was getting these three different stories so I asked the staff nurse to find out…what exactly was happening…disjoint information.* Information finally clarified satisfactorily with consultant. Patient recounted how the indecision about the hospital stay had also impacted on their spouse.

xiv.   (Spouse) '*Communication was very good, I was notified if anything went wrong or anything like that, even at 1 or 2 o'clock in the morning I had phone calls.*' (Patient) '*…it was always fully explained to me and to you…nice and clear…very good communication….* (Spouse)… (Patient had been taken back into theatre) '*…Mr—rang and left message on answer phone to say they were taking … back down* (to theatre)... *it was him that rung* (consultant) *…when … came out of the theatre he rung me, and then after… recovery …went to high dependency they rang me at 2 o'clock in the morning to say that … was in there…*' (Patient) '*We've*

always had good contact. Mr – always used to come in, sit down and explain everything…at times I wish he hadn't (both laugh) *especially before the first one…to say I was a bit nervous would be understating the situation…like when they did an angiogram there's this possibility of stroke, death, blah, blah, blah and afterwards you find out they've never had a case of it in XXX* (both laugh).'

xv. (Patient) '…*it's also if we get in touch with secretaries if we're not sure about something, we always get an answer back…no complaints with communication…whoever we've rung we've always ended up getting answers.*'

xvi. Patient recounted importance of being able to see the images from a scan and being given information about what was going on, this had been helpful. With regard to the surgery performed '…*they can't say how long it will last, could be a week, could be years, they don't know, but I don't know anything after that, what happens? …because without this, and without them doctors, I'd have had no legs by now, so I'm grateful to them… and they're a nice bunch.*'

xvii. (Patient) '…*I just wanted them to get in and do it…I didn't want the information…fine without* (Patient was accompanied to all appointments by a relative so that they had information. Patient had a hearing impairment) (Daughter) '…*Mr –explained it all to me, he was really nice…* (Patient) '*They gave all the information to her not me…*' (Patient) '…*knows what's going on and explains it all to me…*' (Referring to daughter).

xviii. (Patient) '…*going into XXX Hospital the last time, I was under the impression I was only going to go in for tests…and they kept me in, they kept me and kept saying I couldn't go home, in the end I was there for a week …and when I said could I go home they said no you can't because we've got to take further tests… and I had to stay in another week, which was 2 weeks… and I didn't even have an operation until the end of that two weeks…kept asking people to explain to me…I found it very difficult to talk to anybody of any help to me…I wasn't too happy about that…would have liked somebody to sit and talk to me about it..*'

xix. At the time of their interview, patient was awaiting notice of further surgery following a hospital consultation. They were concerned not to have received any communication with regard to this several weeks later. They wondered if they had been overlooked. The relative was encouraged to follow-up using contact numbers they had been given by XXX.

xx. (Patient) '…*had a pre-op assessment ….all very professional, no hitches …everything was explained except that they did say that they thought they were going to use an artificial artery or vein for my bypass when in actual fact they took a vein from my other leg. Consequently I was in hospital longer than I would have been…*'

xxi. (Patient) '…*the nurse said…'why didn't you tell us about this before?' …and I said, well I did, I've been saying something all night. 'Well', she* (the nurse) *said, 'nobody told me'… that was the actual words that were used…'I didn't feel listened to…no, I wasn't taken any notice of…*' (Patient experienced post-operative bleed for which they received six units of blood and required emergency surgery.)

xxii. (Patient) '…*Mr…had said …we won't start the warfarin yet, we'll get the angioplasty done. Then somebody else came along and said right we'll start the warfarin and they brought it that night, and I said well, I don't think I'm supposed to have it now…so they went away to ask, couldn't find anybody so they withheld it.*

Then the next day they did start it and I think when the consultant came round he wasn't very pleased that it had been started…'

xxiii. (Patient) '…*why were the ECG's abnormal? I still don't know*…'

xxiv. (Patient) '…*if I had any questions at all I would ask and I would always get a good answer*…'

xxv. (Patient) '…*one thing we did have a problem with, and we did address it…was one morning when Mr- came round and he was happy with everything the way it was, and I was quite happy and I really wanted to come home…and said you could probably go home tomorrow…not two seconds later the dietician team walked in and the boss said well, I want to put you up on this…something IV she wanted to put up, and she was talking about me being on it for quite a few days…which meant I'd have to stay in hospital a lot longer. We did say about that, about them actually meeting together before they actually came in to see me and discuss it between them*…'

xxvi. (Patient) '…*I think the more information you've got the better*…'

xxvii. (Patient) '…*lack of communication between groups…they came down to take me to put this line in my neck but I didn't know I was going for it. So, I wasn't ready, I didn't know I was going to have it anyway…two like porters came down to get me and took me up to the little operating room. They did apologise, there'd been a confusion but how that happened I don't know, then they went ahead and did it…it was just lack of communication somewhere there I think…if I'm going to go down for that sort of thing I want to know about it…the thing was it was visiting time, my mother had just turned up; obviously if I'd have known I'd have said well don't bother coming in mum*…'

xxviii. (Patient reading extract from diary) *'Time now 11 o'clock and an anaesthetist has just been to speak with me and discuss the various options. I didn't realise I had a choice.'*

xxix. (Spouse) *'We're still not sure what happened there because they said they were going to take a vein from the other leg to use to bypass that artery and – had drawings done on both legs…but they hadn't touched that leg so we don't know whether – got a bit of plastic in there, or whether they opened up and found it wasn't as bad as they'd thought, or anything, we don't know what happened, but it's better so we count our blessings…'*

xxx. (Patient) *'…it was nearly all verbal, I think, I don't remember feeling that I'm not being told; I think had I of felt that way I would have, again, asked…'*

Points for consideration

- Copies of the booklets referred to by one of the participants had since been obtained from the United Bristol Healthcare NHS Trust and were available for review by the Project team.
- Information leaflet on after effects of anaesthesia and surgery.
- How might inter-hospital communication be improved to ensure patients do not 'slip through the net'?
- Availability/accessibility of patient's notes between XXX and local hospitals.
- Consistency of patient information – how might accuracy be improved?

- ➢ It was evident that good, clear, relevant and timely information is of paramount importance to patients.
- ➢ Impact of communication, either good or poor, on spouse/partner/relative.
- ➢ Establishing trusted, reliable, and effective communication links with healthcare professionals appeared to strongly influence the participants' and their spouses/partners/relatives' perceptions of their overall healthcare experiences.

4. SHORT NOTICE/EMERGENCY ADMISSION

Although six of the eleven participants had experienced emergency admissions only two patients briefly spoke about this part of their journey. However, one patient specifically requested that their experience of being informed about a short-notice admission be recorded because of the anguish it had caused.

i. (Patient) *'…so I went in as an emergency but had a wait of about 3 or 4 days before anything was done..'* Patient was admitted on 4th March and had surgery on 8th March. Was made nil by mouth on a number of occasions before finally having their operation which took 8½ hours.

ii. Patient was particularly keen for their experience of being given short notice of an urgent, short notice admission to be reported. The patient had been to an outpatient appointment at XXX a week prior to the researcher's visit. During the appointment they had had a duplex scan '*…the technician who did it said the vein was underperforming, a restriction… that something would have to be done…contacted consultant by phone…told me that if I had any pain over weekend to seek medical help…when we arrived home…fair old drive (*approx 1 hour 30 minutes)*…someone had already phoned but there wasn't a number we could ring back and eventually, about 5pm or something…another lady phoned to say that provision had been made for me to be in XXX first thing in the morning (*a Friday)*…couldn't make it for two or three reasons…made to feel guilty…message coming through about how urgent this had to be done… basically we was told that this could cost me my leg if I didn't take up this opportunity which made things pretty awful…weekend feeling extremely worried…been ill all weekend…* (Spouse) *…the person admitted herself that she wasn't a medical person, and I think that it if had been that desperate a medical person would have come on…* (patient) *But, even then, how would we have played it…? …*(Spouse) *…hadn't had a phone call from anyone at XXX yesterday (*Monday) *so at 2 o'clock phoned …secretary…in view of franticness of calls on Friday…nothing on screen…then had call from…who told me what was going to happen…pre-assessment on…* (10 days time)*…booked in for that balloon procedure (*15 days time)*…so it wasn't that urgent…'*

iii. (Patient) '*…it seemed like I went one day (*to GP) *and I was in the next, 'cos I was saying to my daughter I don't know whether to have this, it's all too soon, it's a bit frightening, but, you know, I went and had it done…and it was good'.*

iv. (Spouse) '*…we spent most of the day in -…waiting for a bed, but that's understandable, that wasn't a problem we were being dealt with…'*

Points for consideration

- ➢ The possible adverse effects of giving a short-notice/urgent admission to patients.
- ➢ Would it be more appropriate for patients to be notified of short-notice/urgent admission by medical staff or nurse practitioner?

> ➤ The potential impact on the patient of being nil by mouth and cancelled for theatre, more than once, following an emergency admission.

5. RELATIONSHIPS WITH HEALTHCARE PROFESIONALS

All the patients interviewed had reported developing, on the whole, excellent relationships with the health professionals delivering their care which they had greatly valued. The opportunity to 'have a laugh' with their healthcare providers was important to many of the patients interviewed.

It was evident that feeling supported, with enough information was implicit

i. The patient referred to a young female doctor as a '*waste of time'* because she had attempted but not been able to take a blood sample.

ii. (Patient) "*…the nurses were absolutely fantastic…I didn't want for anything…they were absolutely run off their feet…you could see that they were struggling…there was just so much …I used to have a good laugh with the nurses…the nurses, and the doctors, do a fantastic job…some of them could be grumpy but when you saw what they got to put up with…you'd be surprised that people want to do the job* (nursing)*…but to me they're worth their weight in gold."*

iii. (Patient) "*…even though …hospital is nearer to me I would rather go back to XXX for my care because they know me. I know… is across the road from me…but XXX was very good and I never wanted for anything…"*

iv. (Patient) "*…I had a social worker there…anything you needed she got it for you, she was very good…'"*

v. (Patient) "*…a very quiet voice in my ear said 'how are you going …I woke up and there's our lad, Mr…, the surgeon, kneeling down, he said 'How's it going?' I said oh fine, he said 'How's the leg?' I said marvellous, you know, I said it's great, no pain in my leg, you know I couldn't get away from it I said, and the foot's lovely…so he said 'How do you feel about going home this afternoon?'…and I said do you want me to start singing Hallelujah? 'Alright I'll have a word with sister and you can go out this afternoon' he said."*

vi. (Patient) "*…I thought I was treated respectfully by all staff… I didn't know how to address staff nurses, I didn't feel it was right for me to say hello whoever…I would sooner say 'staff' or something like that…*(spouse) '*…it's the generation you were brought up in".* Patient was referring to respect for hierarchy and ranking and believed that using first names for certain 'ranks' of staff might be disrespectful.

vii. (Patient) "*The way Mr … treated us was really first class"* (spouse) "*On the day of the operation I was told to ring at 3pm and …wasn't back. I rang at 5pm and couldn't get anyone…I got through at 5.30 pm and I was told that … had been taken back in which obviously I was very worried about…was told somebody from surgical team would ring me and actually Mr … himself phoned me about 7pm…and I thought that was really very, very nice…when we go to the clinic he's always very good to me as well, I don't feel like I'm in the way or anything, he's always inclusive, isn't he?"* (Patient) "*Oh yes…he's a super man.*"

viii. (Patient) '*…I personally feel it's a misunderstanding, I didn't realise they were still in the handover…I spilled some water…so I called…all of a sudden this one comes flying in…we're still handing over, wha, wha, wha and out…I thought she*

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didn't even ask what the problem was…I could have been… dying for all she knew. Another occasion I asked if I could have a bit of help just getting my feet into bed, sounded daft, but because of the operation it hurt to lift my feet from the floor and get them in the bed…you'll have to get your own feet into bed at home…right, I said, but at least I wouldn't be trying to get in that flippin' bed…'cos I'll bite back…'

ix.   (Patient) *'…the only one…who didn't seem so friendly …was the one who did the scan on my legs…* (Patient still had open wounds) *'She said, get these off…'* - referring to wound dressings – *'I says they're open wounds, and they were, and she scanned all the way down them, and that was agony…I've got finger marks on the ceiling…that was agony.'*

x.   (Patient) *'…at night I couldn't get hold of the nurse…I rang the bell three times and nobody came…and I thought where are all the nurses at night? I had to get up to go to the toilet on my own, I didn't have anybody help me and I was very unhappy about it* (normally uses a three wheeled support at home)… *most of the nurses may I add were lovely, I'm not complaining about all nurses, but this one particular nurse, I've tried to speak to her quite reasonably …she was very impatient with me…then she said…'don't forget you're in an NHS hospital…this isn't a private ward…and I looked at her and said I didn't ask you that I just asked where the …so she said 'well, I've only got one pair of hands'…she was very bad tempered that night and that was upsetting for me…'*

xi.   (Patient) '…*I wasn't afraid to ask for anything, you know, because I felt the nurses would do anything they could to help me, but, I had to ask if I wanted any help. I felt sick one day, really sick, don't know what upset me that day, but I said to a nurse, oh I'm going to be sick, and…she got a paper thing, a proper thing for being sick in and she gave to me and said 'here you are', and I was sick in this thing and the next thing I knew she'd gone. She didn't give me a glass of water or anything, and I had to get down to the toilets to get some water to rinse my mouth out…that annoyed me. It was only that once, but just that once annoyed me. I didn't get the help I should have done.'*

xii.   (Patient) '…*Dr .., very good…he spoke to me and said certain things about what they're going to do…but then he'd turn to these other young doctors and discuss things and then off he'd go…he didn't stay very long, that's for sure.'* The anaesthetist was very nice…he came round and had quite a chat with me…he even did a little sketch for me…'*

xiii.   (Patient) *'…apart from that one nurse that just wouldn't listen to me…when I came back* (from theatres) *the first time, my care in ward …really I wouldn't fault it, I think they were really very good…I've been in there before … I wouldn't hear anything against ward-…'*

xiv.   (Patient) *"I wasn't complaining about being put in a side room…it was the fact that you got total lack of contact – not total but very limited contact with anybody sort of thing – and of course the more well you are…on your own…yes, because at the start they come in doing blood pressures and everything else and as you get to know 'yeh, you're fine' you see them less, and less and less (laughs), and because she (his wife -added) had to catch a bus to get over from here to XX, she could only spend a limited amount of time with me per day so it got very, very boring."*

xv.   (Patient) *'…she's wonderful, if there's anything not done…she's a star. The last operation I went in for, I went in on a Sunday and she came in and did all my*

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paperwork, to make sure it was all done, and done correctly. In fact, on occasions when I was down in the dumps after certain ops…she came in one evening to take me for a walk around the grounds, rather than me just sitting or being next to the hospital bed…she is a star, she's wonderful…'

xvi. (Patient) '…*I've been that happy with all of those nurses and anybody that works on ward - that I actually went out and I bought them all presents…34 of them…but, you know, if it wasn't for their care, etc, I wouldn't be here anyway…The good thing about ward - is I know where I am going, I know the people on there…and they're all wonderful…'*

xvii. Patient reported that the care by the consultant had been very good and that they had been given enough information. Patient felt that their overall care at XXX was good.

Points for consideration
➢ The above remarks illustrate the importance of building therapeutic relationships with patients.
➢ Being and feeling listened to and included in care decisions, with enough information, was important to both patients and their spouses/partners/relatives.
➢ Time and attention were greatly appreciated but sometimes lacking, particularly in relation to care on the ward.
➢ Being able to laugh with a healthcare provider was greatly valued.

6. NURSE WORKLOADS

All participants made reference to nurses' workloads and a number seemed genuinely concerned about the pressures under which nurses were expected to cope and still deliver an acceptable level of healthcare. The workloads had inevitably on occasions had a detrimental effect on the patients' experience of healthcare.

i. (Interviewer) '…*what about the care that you actually had during that time*?' (Patient) *'Fantastic, fantastic – I couldn't ask for any more. The nurses were absolutely brilliant you know, and you didn't want for anything and you could see that they were run off their feet, could see that, you know, they were struggling to keep with you like because there was just so much there…the nurses do a fantastic job…they were very good…when you see what some of them have to put up with…nobody deserves that, you know, you'd be surprised that people want to do the job…to me they're worth their weight in gold.'*

ii. Patient reported that they had "*felt out of it*" and at times '*stranded*' because of the needs of other patients and the time their care demanded of the nursing staff.

iii. (Patient) '…*this is quite incredible - the ward sister came from Fiji, the ward staff from the Philippines…'*

iv. (Spouse) '…*we thought the staff worked very hard, you know ...worked really, really hard…they were very busy…having worked in a care home I know the pressures…'* (Patient) '…*all the staff nurses gave the impression that they were in command of all situations that appeared to be in front of them…'* (Spouse) '*But you could tell how pushed they were…I kept saying I don't know how they remember to do it all…because they were like from one end to the other, weren't they, all the time…'* (Interviewer) '…*could have done with more staff?'* (Spouse) *'I think they could have done with more staff, yeh, but they did very well…'*

v. (Patient) '…*I've never had a complaint about the level of actual nursing care I've received… got on well with most of the nurses there was only one I didn't…I called* (call bell), *all of a sudden this one comes flying in – 'We're still handing over, wah wah wah wah', bang and out – I thought, she didn't even ask me what the problem was. I could have been ruddy dying for all she knew.'*

vi. (Patient) '…*every time I've been in, err, them poor nurses was run off their feet but they never moaned if you wanted them, they was there. That's what I felt with me, they was there…from the time I was in until I come out it was great. When I had my big operation…it seemed as though they was by my side 24 hours a day, they was always there, um, really nice…I wouldn't call them anyway unless it was an emergency* (use of call bell) *…I could see them rushing about, they'd got that much to do…when I did use it they was there right away…'*

vii. (Patient) '…*I really feel sorry for these nurses, from the time I opened my eyes at six o'clock they have been non-stop…the little one there has done a double shift, flat out and is still coping…'*

viii. (Patient) '…*I rang the bell three times and nobody came, and I thought where are all the nurses at night?'*

ix. (Patient) '…*I had to look after myself a bit…there was other people needing far more attention than me…I didn't get much individual attention…I didn't really feel looked after enough…I wasn't afraid to ask for anything, you know, because I felt the nurses would do anything they could to help me, but I had to ask if I wanted any help…I didn't get the help I should have done…anyway, it was hardly worth mentioning'* (Interviewer) '*No, it is worth mentioning and that's what I'm here for…'*

x. (Patient) '…*my bed was soaked in blood…got drains everywhere…'* (Interviewer) '*How long before you had your sheets changed then?'* (Patient) '*Oh, it wasn't that long…they were pretty good actually because they had to be changed two or three times…'* (Interviewer) '*Could that have been improved do you think?'* (Patient) '*Um, well, yes once it seemed to be quite a long time before they came to change all the dressings and sort it out, but then it's such a busy ward and they haven't got too many staff on there. Um, I think they were doing, you know, what they could but, yes it could have been a bit sooner…'* (Interviewer) '*Do you know how long roughly?'* (Patient) '…*from when I sort of said well, this looks a bit mucky …I'm very wet here…I think it was over an hour…'*

xi. (Patient) '…*the care itself has been wonderful, all round really…there's been the odd occasion where I've had to wait longer than I would have wanted for oramorph when needed but, usually, I think the reason for that is the usual, they're short staffed, or shortness of staff at the time. As I say the overall care has been brilliant…'*

xii. (Patient) '…*I was also appalled at some of the nurses' behaviour on nights on ward -. It could be put down to, again, shortage of staff…'*

xiii. (Spouse)'…*but it was very busy in – ward, they were rushed off their feet…'*

7. HEALTHCARE DELIVERY

The following verbatim extracts relate to in-patient care on a number of wards, including the medical assessment unit, at XXX hospital. Specific wards and areas have not been

identified. On the whole, the participants gave a positive account of their healthcare delivery.

i. (Patient) - With regard to in-patient care the participant reported that they "… *had been looked after very, very well*". However, the patient commented that they had felt slightly '*isolated*' on the ward, despite reporting that the overall care had been good. They expanded on this by stating how their bed had been between two ill patients – one patient receiving an IV infusion from what looked like '*sand-bags*'. They had been aware that this patient was unable to go to the toilet and seemed very unwell. The patient on the other side couldn't move and needed full care. The participant reported that they had "*felt out of it*" and at times '*stranded*' because of the needs of these patients and the time their care demanded of the nursing staff.

ii. (Patient) '…*the doctors made it quite clear to me…they would come up to me and say…we will try to fit you in* (emergency admission but theatre delays). *On the day the bypass did pack up the doctor came up and said we'll give you a couple of days to think about it …and I said I understand everything that's going on and I don't want a couple of days to think about it, the sooner it's done the better I will feel* (patient was still pleased to have been given option of extra time had they wanted it). *'…I'll give them their due; they actually came in on a Saturday to do it* (the amputation).

iii. (Patient) '…*I was sat in the bed thinking do I look, or don't I look?...lucky enough a doctor came along, well I say lucky enough… and the first thing he did was pull back the sheets and I got to see it anyway without thinking about it…that initial shock wasn't really that bad to be honest…I got on very well with the doctor…explained everything and that everything had gone alright…'* (Patient talking about their fear of looking at amputated limb for the first time)

iv. (Patient) '…*would like to have done more exercise, or even… something better than the exercises I had…the physios would come round your bed…the nurses called them physioterrorists!* (laughs)*…you'd get one of them come round and say ….fancy having a walk on the Zimmer frame, so you'd have a walk so far…enough…then no sooner than you've sat down and they'd gone off and said goodbye and everything…another physio would turn up and say 'Right … are you ready for your…', …you're having' a laugh aren't you?...you just been sitting behind that curtain waiting for me…? I'd like to have gone somewhere off the ward to do something, swimming or something like that…'*

v. (Patient) '…*the nurses were absolutely fantastic…I used to have a good laugh with the nurses…'*

vi. (Patient) '*She was very good, she understood…* (Physiotherapist)'.

vii. (Patient) '…*if my leg is to go wrong now…no reason for me to go back to XXX, I'd have to go to …(local hospital) now…I'm quite disappointed with that…I'd sooner go back to XXX because they know me…I know – is nearer to me…easier for visiting…but XXX were very good…I never wanted for anything…'*

viii. (Patient) '…*everybody is in their own compartment…they're all doing their own things…they've all done good jobs…but, there was no connection…the surgical side, the hospital side, excellent…but nobody tells you about the psychological side…the highs and the lows, the mood swings…getting irritable, snappy, getting fed up…the lack of communication after the operation…'*

ix. (Patient) '…*about 22 beds on the ward, a long ward, very good though…they were all very helpful on the ward…*'

x. (Patient) '…*the medical and nursing care was excellent…*'

xi. (Patient) '…*the worst thing that came out of the care that I had was the fact that when…the staff nurse got me up* (1st day post-op) *…I don't attach any blame for this …as I got up I started to feel giddy…I must have blacked out because I woke up and I was flat on the bed…and then because I had to stay in bed I developed a big sore on my heel, which is still being dealt with.* (Interviewer) '*Do you think they could have done something else to prevent that?*' (Patient) '*Well, I would have probably expected normal patient care to have been looking for signs or to prevent maybe…I don't know…putting a pillow under your leg or something*'. (Spouse) '*I will say that the allocation of pressure mattresses was, um, there should have been more because when they did realise and …was given one, within a few days it was taken away and given to someone more urgent … lack of resources.*' (Patient) '*…That was done at night time…no spare ones…the only other one they had was broke…*'

xii. (Patient) '…*the pump* (VAC machine) *…it made a hell of a difference…but there's a question over the politics of that pump because it made such a difference and I said well, am I allowed to have this thing out of here?…because the only reason, really, that I was in there for the last fortnight was to have this pump on me, there was no other treatment that I was getting…*' (Spouse) '*…to us it seemed a waste of a hospital bed'.* Patient described the disappointment at not being able to continue with VAC therapy following discharge home and how this had affected the healing of the ulcer for which nursing input was still required several months later.

xiii. (Patient) "…*we were in the annexe of that ward…the first thing that struck me about it was how poor the planning was, not by the people who now run it but by the people who originally built it, because it's one of those places where the only bit of daylight comes in – comes in from what I call factory type windows right up at the top…it's well lit. I couldn't fault the staff and the carers, as far as that goes, it's just that it's an old building and frankly it's a great shame but originally they were going to scrap all that and build new vascular units and everything apparently. Hopefully in the future that'll happen…*"

xiv. (Patient) "…*after a very short while, I was moved into a side room…I was told I'd be better there…the only thing I will say is that, although I'd had an operation, I wasn't ill…the hard bit of being in a side room, you might think it's going to be much more comfortable and luxurious, which in some ways it is, but there's another side of it which isn't so good and that is, unless a member of staff comes in to actually do something…check you over…supply meals…that sort of thing…you don't see a soul…you lose the human contact…*"

xv. (Patient) '*As far as the clinical care was concerned; no complaints, I can honestly say that and I've been in that hospital on quite a few occasions now. I can only remember once having a disagreement with anybody…never had a complaint about the level of nursing care I've received. When I got the bed sores, people were saying you should sue him…I said how can I sue him? The man's just saved my flaming life!*'

xvi. (Patient) '…*every time I went in they borrowed it on trial…a special thing they put on the operating table, acts like an airbed sort of thing…she* (nurse practitioner) *sees my name on the operating list and she phones them up to have it on trial…*'

xvii.   (Patient) '…*the beds, why oh why…do they all have those metal bar headboards...which means that when you try and sit up with the pillows against them, the pillows invariably go through the bars and leave you leaning on the metal? Why oh why…can't they just be a nice solid board that they can wipe over with their cloths…?*'

xviii. (Patient) '…*they'd got my bed but it wasn't ready for me to get in, or the other patient hadn't gone…and we had to sit in a waiting room…with a TV…they offered me a cup of tea while I was waiting…that's the only time I've ever had to wait…but I think there was an emergency happening…*'

xix.   (Patient) '…*I really feel sorry for these nurses…every time I've been in those poor nurses have been run off their feet, but they never moaned if you wanted anything done, they was there. From the time I was in till I came out it was great, when I had my big operation, the last one I had, it seemed as though they were by my side 24 hours a day, they were always there, really nice. They even washed my hair when I was flat on my back. I didn't like to use the call bell; I could see them rushing around with so much to do. When I did use it they were there, I didn't have to wait...no fear about going into hospital again because I knew I was going to be looked after…*'

xx.   (Patient) '…*pain was really well controlled.*'

xxi.   (Patient) '…*after I came out with this I had to go back for a scan…I was still taking the warfarin…apparently I should have had three days without it before I come in…then they got all my tablets mixed up…the doctor done that* (the GP)…*I was taking the wrong tablets for my diabetes…some I should definitely take I wasn't and they put all that right for me.*' (Interviewer) '*The hospital?*' (Patient) '*Yeh...*' The hospital rang the GP same day to rectify issue with medication '…*I don't know what her name is…, is absolutely brilliant…love her…someone that does the pre-op and is Scottish or something…she is absolutely wonderful and she is really at the point and what I want to say I'll say…I love going to her…*'

xxii.   Patient had been moved three times since admission. The following refers to their care on the last ward '…*on the whole, things were quite good…most of the nurses were very nice but, as I was a different patient, I wasn't getting treatment, I didn't have anybody much to talk to in there. Everybody else was getting attention all round me and I was lying there hour after hour with nobody to talk to and I kept saying to my son oh, I want to come home, I don't like it in here…*' (Patient was being treated with antibiotics prior to surgery).

xxiii. (Patient) '…*I waited two weeks and, even then, I waited all day …all day long Tuesday. Do you know they took me in, what time was it …late wasn't it, ever so late in the evening, and they came and fetched me and I had this operation done…I came back about 9 o'clock didn't I?*'

xxiv.   (Patient) '…*I found I had to wash myself…I felt I didn't get much individual attention, here's a bowl, here's the soap, here's a towel, get on with it, you know. I didn't really feel looked after enough...I didn't get the help I should have done…it was the fact I had to ask…*'

xxv.   (Patient) '…*you just do what you're told when you're in there…you don't tell the doctor what you want, do you? You can complain how you feel, I know…*'

xxvi.   (Patient) '…*would like to have gone privately…I don't like sharing great wards…don't mind being in a ward of about 6 but when it's about 20, you know, long, oh I hate that …people snoring, coughing, I couldn't stand it…*'

xxvii.   (Patient) '…*ward ... in XXX is fantastic, on the whole, waiting for the op was no problem…didn't go down until 5 o'clock time, quite late in the day, came back to the ward at quarter past 9, but I mean I wasn't worried about it…I thought I was going in the morning…quite a long time without anything* (patient referring to nil by mouth all day) *…got back in the ward… started to feel a bit queasy and my leg was uncomfortable … I knew it wasn't right, but I didn't know why or what…and when I asked I was just told, well you've had major surgery it's bound to hurt, what do you expect, goodnight, thank you very much. I asked the time and it was 11 o'clock…all through the night the time seemed to go very slowly and I was getting more and more woozy, sleepy, not knowing quite where I was or what was happening…I was feeling sick…was sick…remember bowl tipping over, I got wet from it…don't know what time in the morning it was…6, 7 o'clock it seemed to get a bit busy around me, people seemed to be a bit worried about something…I remember hearing them checking numbers…being wrapped up in this foil stuff…whipped back to theatre again…a tie had come off one of the little tributaries from the donor vein…*'

xxviii.   (Patient) '…*the nurse said…'why didn't you tell us about this before?' …and I said, well I did, I've been saying something all night. 'Well', she* (the nurse) *said, 'nobody told me'… that was the actual words that were used…I didn't feel listened to…no, I wasn't taken any notice of…*' (Patient experienced post-operative bleed for which they stated they had received six units of blood and required emergency surgery.)

xxix.   (Patient) '…*my leg from the knee down was absolutely, completely dead, I just couldn't feel anything…I got foot drop, so I was then given a boot and some exercises to do…I did get my foot working again but, from the knee to the ankle is still pretty naff* (4 months post-op)*…it hurts, it's like toothache there all the time…that just never goes away…I can feel that there's something touching my leg but it's completely different to this side* (patient referring to other leg) *…*'

xxx.   (Patient) '…*they were pretty good actually, they* (bed sheets) *had to be changed two or three times … it's such a busy ward and they haven't got too many staff on there, I think they were doing what they could but it could have been a bit sooner…*'

xxxi.   (Patient) '…*they did sort of strip me and help me to wash…I think just the first day…I would have appreciated a bit more help…maybe that's just me being lazy or something but I just felt so drained…I think if they'd said… I'll stay here and I'll help you, I wouldn't have said no.*'

xxxii.   (Patient) '…*the care itself has been wonderful, all round really…there's been the odd occasion where I've had to wait longer than I would have wanted for oramorph when needed but, usually, I think the reason for that is the usual, they're short staffed, or shortness of staff at the time. As I say the overall care has been brilliant…*'

xxxiii.   (Patient) '…*I think it was the day after I'd had it* (operation) *I was obviously very fragile, I didn't feel like doing, couldn't do anything…I wanted a wash. So I asked the nurse…so what she did, I managed to get out of bed onto a chair, and sat with the trolley over the top of me with a bowl and a towel, etc. What she did was, she undressed me, totally, and then she went off to do something else but, when she went off, she left the curtains ajar… there was a big gap in the curtains and I couldn't do anything. She didn't give me my bell, there were people walking up and down and I felt terrible…*' (Interviewer) '…*when that nurse came back to you did she make any*

apologies, or did she not return to you, did somebody else return to you?' (Patient) *'She did…I don't even think she spoke, she wasn't very clear anyway… (nurse was a different nationality)…I felt terrified…I couldn't do anything…it was outrageous, I was appalled.'*

xxxiv. (Patient) *'…my syringe driver, I had morphine, it broke and I was in immense pain and the nurse that was walking around…wouldn't come and see to it…because I wasn't one of his patients…that did make my blood boil…if you're not in their group of patients, you can see quite clearly they won't come and see to you…'*

xxxv. (Patient) *'…I was also appalled at some of the nurses' behaviour on nights, on ward -. It could be put down to, again, shortage of staff but the way a couple of the patients were spoken to was appalling…particularly when one happened to be a dear lady…she obviously wasn't with it…but she made it quite clear that she wanted the toilet and was told to 'Shut up'…it was at night time and she obviously couldn't get herself out…because she was making a noise, calling, they went and drew her curtains round her and left her…obviously there were some very nice nurses on ward – as well, it was just the occasional one.'*

xxxvi. (Patient) *'…there was one morning…I really wanted to come home and I asked him (the Consultant) and he was very happy with it all and said, you know, you could probably go home tomorrow, and then, not two seconds later the dietician's team walked in and they, the boss, said 'Well I want to put you up on this um, it was a particular type of something she wanted to do IV' …and she was talking about me being on it, you know, for quite a few days to see how it goes before they decide what they were going to do, which meant I would have to stay in hospital a lot longer…so we did say about that, you know, about them maybe meeting together before they actually came into see me, and discuss it between them..'*

xxxvii. (Patient) *'…there was one time…I'd had a central line put through my neck and it got infected…it sent me unconscious and when I came round… and I was feeling that much better they were on about putting another one in, and I voiced my opinion quite strongly that I didn't want another one put in…I found them very uncomfortable apart from anything else, but I didn't want the thought of having another one when it may get re-infected, so I did say I didn't want another one, and I didn't have another one so I was quite happy with that…'*

xxxviii. (Patient) *'…felt I was pushed out the hospital far too quick…but there was a lot of shuffling going on with the beds, there was a lot of shortages of beds um, they've closed down…but they hadn't stopped the admittances, you know, the admissions…so there was going to be a shortage of beds…I went to stay with my mum…I had a thrombosis near the top of my leg here, it was nasty, it used to pour blood…'*

xxxix. (Spouse) *'…there was a bit of a hiccough over the lyrica, because we were trying to wean - off the lyrica onto something else because it was upsetting the blood sugar. I had a chart with all the drugs - was taking just to keep track because it was getting so difficult …actually while we were in – ward, although people saw -, nobody was recognising the fact that - was on antibiotics and pain killers so many hourly and I had those still in my possession so, in desperation, after we'd been there sort of six hours, I did say to somebody… can I give – the drugs as long as I keep a record of exactly when I give them?…and that seemed fine, until – was actually admitted to a ward and then I handed everything over…about half past nine that night…but it was very busy in – ward, they were rushed off their feet…'*

xl.   (Spouse) '…*and you were quite happy there, except of course you were expected to sleep in the bed which you hadn't done for two months, and you were in a lot of pain at night. In fact the* (other patients*), when I went visiting the next day, said to me your – is really having a lot of trouble at night …we heard – crying and we were concerned…*'

xli.   (Spouse) '…*while you were in there you had two nasty bleeds from your ankle, didn't you?*' (Patient) '*Yes, two spontaneous…oh look you're standing in a puddle of blood…it was absolutely pumping out …they had to get buckets…fortunately neither of us are fazed by lots of blood and we knew what to do, just shove your thumb over it, press, and holler for help…*' (Spouse) '*I don't think anybody knew what they were dealing with the first time, the second time it happened they were a bit more on the ball.*'

xlii.   (Spouse) '…*it's very long, very old…built…for the American army during the war…working under extremely difficult situation, for instance there are poles up the middle of the wards that the flippin' beds have got to go round, you know, I don't know how the porters manage…initially at the top end, very close… to the nurses' station…but, in fact, it wasn't a very restful place…telephones continually ringing…always somebody going passed your bed…- was prepared for surgery at 9 o'clock in the morning and - actually went for surgery at 6 in the evening. That was hard…-was on a drip, naturally, because of - insulin dependency, but…so fed up just sitting there waiting…*'

xliii. (Patient) '…*the banger, the man who banged on the partition all night…the poor chap who wasn't right in the head who was spending the nights thumping on the partition…*'

xliv.   (Patient) '*The thing that really sticks in my mind, immediately after the op, in the recovery room, was the dear lady who stayed with me, and listened to me blubbing and said to me there, there. She was a great comfort and I'm very grateful to have had her there. I haven't a clue who she was except that that was maybe her job to look after people who had just had an operation, but I do remember being very confused and saying the classic line 'where am I'…*' (Spouse) '*They did ring me from the recovery room and asked me to speak to - because - was so disorientated…*'

xlv.   (Patient) '…*I like to have my hand held…it is something I get great comfort from…*' '…*subsequently, in the ward when I was recovering, I had a blubbing fit and a nurse came and held my hand, again it was of great comfort…*'

xlvi.   (Spouse, talking about post-operative period) '…*was at this rather noisy end…I think you were complaining a bit about it being very busy, people going passed the bed that you didn't know who they were or what they were and where they were going…eventually you were moved…I think you settled better then, I think you began to make better progress from then on…probably because it was that much longer from the operation, but I think you also felt…it was a more serene end of the ward.*'

xlvii. (Spouse) '- *kept a diary…while – was in hospital, quite and long, involved one…*' (Patient) '…*it's a day by day account…I keep a diary anyway…I have done for many years…it was good for me because it gave me something to do, and there isn't a lot of that going on in a hospital.* (Patient was asked how it made them feel to be reading their diary and recounting their experience) '*I read it for interest sake, um, it makes me realise how, lucky is not the right word, but lucky will do, how lucky I am to be out of that and now going about my own affairs…I suppose, for me, the worst aspect of being in hospital is that of grinding boredom. I'm not a great reader of fiction and but for the fact I was able to stroll about and chat with other inmates, other patients, I think I would have gone potty.*'

xlviii.   (Spouse) '…*We were lucky that we had a spell of nice weather at that time and you were able to just sit outside the door, but it would have been nice to have had a sort of little patio to sit in rather than just the road…*'

xlix.   (Patient) '*It was a great blessing to me that I was encouraged to be up and on my feet within a short time…so I was able to stroll about…Had I not been able to get up and stroll about, I feel my recovery could have been longer, I think.*' (Spouse) '*Not only physically but mentally…they do it for physical reasons but it has a good effect mentally*'

l.   (Patient) '*…just to get off the ward, just walking up and down the corridor outside was better than being in the ward…*'

li.   (Patient) '*Now here's a complaint…I'm certain I could have done better … I had a sort of artificial skin dressing put over the wound and the wound had continued to bleed and formed a large blister between my skin and the skin of the dressing. I feel only a little bit of thought would have been necessary to cope with this but somebody came along and pulled the dressing off and everybody got a share of the blood, me, she, the bed, the floor. The blood was in lots of places we didn't want blood to be, and I feel only a tiny amount of forethought could have avoided that. I mentioned it to I think it was a staff nurse. I said I didn't want to make a proper complaint from it…but I mentioned it. …On the same day a visiting doctor knocked my walking stick down which fell across my shin. It did make me squeak; still anybody can knock down a walking stick…she apologised…*' (Patient reading an abstract from their diary)

lii.   (Spouse) '*…you did have visits from the diabetic nurses because they'd got worried about your increasing sugar level…it had gone out of control…*' (Patient) '*…think it was the lyrica…amitriptyline …it made the sugar go berserk…the only remedy they had for this was for me to increase the intake of insulin and I'm still on a quantity which has been commented on by people in the medical business, they say gosh, this is a big dose, and it has been that way since I was on these two painkillers…*' (Patient was asked if they regularly saw a diabetic nurse, to which they answered '*no*', although they have blood samples taken and checked every six months through their practice nurse. Patient and spouse recounted their experience with a diabetic nurse from their GP practice which had not been satisfactory. She had not instilled confidence in them.)

liii.   (Spouse) '*You did… have to go on an intravenous drip though…because there was a question mark about whether you were allergic to clips because the wound wasn't closing…and you also got an infection…*' (Patient) '*You've no idea…what a nuisance being on a drip is, it has to go everywhere, and I do mean everywhere, with you. It's not too bad if the stand it's on has a good set of castors but, if you've got one which has a sticking castor so that every time you move it, it goes in a circle, that can be very frustrating…but it was good for the other patients because they laughed.*'

liv.   (Spouse) '*the thing was you'd been encouraged to think you might be home for the Easter weekend and then you got the infection, and then you had to stay…little bit disappointing…*'

lv.   (Spouse) '*…was 6 weeks almost exactly, in the end, in there…you were 10 days in before they did the operation…*' … *well, we were still worried about that when you came home because you couldn't move that leg, that they'd operated on, independently at all, could you?* (Patient) '*…I couldn't lift my leg; it was almost as if a tendon had been damaged. It is still not as good as the left leg, it was about 3*

months…it was about 3 months before I could even sit on it …I couldn't bend the knee sufficiently to sit on the bike…'

lvi.   (Patient) '…*early stages I was given a boot thing which strapped onto my lower leg and foot to help my mobility, and it did help* (prior to operation), …*towards the end of my stay, when I still only had one good leg, I got carted off in a wheelchair, two physios came and collected me…and took me to a flight of steps, and this still irritates me, because I have sufficient cleverness to be able to work out for myself that I go up the steps one at a time on the good leg. I don't need two professionals to teach me to go up a flight of steps…However; it did fill in an hour of an otherwise boring day…'* (Spouse) '*I wasn't pleased…when you went in you were walking with a stick…somebody saw that and said it was the wrong height…never after that…were you given anything else other than the stick…it wasn't followed up…'*

lvii.   (Patient) '*…on the whole I believe they provide a good standard of care…'*

lviii.   Patient recounted how the care by the nurses had generally been good apart from two incidents: i) a nurse had disagreed with the patient when they told her an intravenous infusion was painful – she had responded by saying "no, it isn't". The result of this was that the patient experienced pain and swelling at the site of the infusion. ii) The patient also recounted how when they had a low blood sugar, BM 2, during the night, the nurse had walked away. Fortunately, they had their own glucose tablets which they took. Another nurse came to check on the patient some time later.

Points for consideration

The extracts clearly demonstrate the diversity of patients' experiences whilst highlighting a range of issues for consideration in the quest for high quality, patient-centred healthcare.

   ➢ Nurse workloads
   ➢ Communication skills, including attentive and effective listening.
   ➢ Consistency and accuracy of information
   ➢ Value of therapeutic relationships for patients and their families.
   ➢ All day theatre waits
   ➢ Patient washes; early post-operative period
   ➢ Availability of pressure mattresses
   ➢ Patient medication
   ➢ Off ward physiotherapy
   ➢ Side rooms – isolation or luxury?
   ➢ Metal bar headboards
   ➢ Drip stands
   ➢ Location of patient on ward
   ➢ Releasing Time to Care - The Productive Ward, national initiative by the NHS Institute for Innovation and Improvement 2007.

8. PRIVACY AND DIGNITY

On the whole privacy and dignity appeared to have been maintained for the majority of patients. Of the 5 patients who commented; 3 had not encountered any problems; 2 reflected on their uncomfortable experiences, as illustrated in the following extracts.

   i.   Patient reported that privacy and dignity had been maintained throughout their admission.

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ii.   (Patient) '…*no problems there…very good care…the facilities were there, I was close to the toilets and stuff like that…*'

iii. (Patient) '…*I don't know whether he was a doctor or a nurse…like I said I took my own books and I'd got Jordan books…and he kept saying to me 'oh, she's got big boobs' and things like this and he came the one day to wash me…the book was on the bed and he says why does anyone want big boobs like that? Would you like big boobs? And I thought no way are you washing me, I'm sorry, and I says to him…I can manage…he was doing his job but I didn't like him saying that, that to me was stay clear, I didn't like it so I removed the Jordan book.*'

iv.   (Patient) '…*I was lucky, I was in a corner bed…I had a solid partition on one side of me…*'

v.   (Patient) '…*she undressed me, totally, and then she went off to do something else …she left the curtains ajar… there was a big gap in the curtains and I couldn't do anything. She didn't give me my bell, there were people walking up and down and I felt terrible…*'

Points for consideration

➢ The effect on the individual of not maintaining privacy and dignity

9. CLEANLINESS/INFECTION CONTROL

There were no major concerns highlighted during the patient interviews. The following accounts provide both positive and negative reports on cleanliness. In light of recent media coverage with regard to hospital cleanliness and hospital acquired infections it was encouraging that participants had not placed greater emphasis on this topic.

i.   (Patient) - (previously MRSA+)'…*I also noticed last time we looked, compared to quite a few of the hospitals in the west, south west, whatever you like to call it they've got a lower incidence* (MRSA) *than many of the others…*(Spouse) *'Not only that, the thing is where they are, those old buildings – they're old…and it is very hard for them to be kept clean…I've seen them going round with cloths on their hands, going round the screens and all that –* (Interviewer) *The cleaning is good then?* (Patient) *'Well, they come through, and you've got the divisions like, you know, like wide open doors in some wards and then you see them come with a cloth and go - to see if there's any dust on it, if there's any dust on it somebody's in trouble. I used to watch them every day…they'd be doing everything they could, they couldn't do more…in my honest opinion…The biggest problem I personally feel is the visitors coming in*'

ii.   (Patient) '…*educate, educate, educate…*' Patient felt that better education of the public was essential in the fight against infections such as MRSA and Clostridium Difficile. (Patient) '…*on the cleaning side of it, I'm not going to use names, they had two…cleaners for want of a better term* (housekeepers) *…and whenever a bed was empty you would see them come in and they'd look, there's this bed empty, and it might just be the patient just out the bed to go to the toilet and immediately they'd have the brakes off, wheel it out and wipe it all round…there's a bed there with nobody in it so they'd clean it* (laughs)*...they would clean all the frame down…things they can't get to when the patient's in it, they would also clean the wall behind the bed…*'

iii. (Patient) '…at the end of the ward there's a ledge…daughter put her arm on the ledge and it was covered with thick dust…her coat, it was terrible, really bad. I was a cleaning supervisor…the cleaning was not so good…I never seen one under my bed, they'd go around it…it could have been better…'

iv. Patient's relative reported how they continually found the alcohol gel containers empty when visiting the ward.

v. (Relative) '…what about that nurse that time that sneezed? …she didn't even bother to wipe her hands…and a student nurse, she sneezed on the back of her hand and she didn't bother to go and wipe her hands…. I mean every time I went into the ward, they've got them all over the place (alcohol gel)…you just wipe your hands…' (Interviewer) '…did you notice them hand washing; the nurses?' (Patient) 'Yes, they were very good I noticed…she said she had hay fever, didn't she? …but she was going in every bloomin' cubicle sneezing on people. I didn't think that was a good idea…'

vi. Patient referred to overall cleanliness of ward as '…very good…'

vii. Patient commented that the ward was clean.

Points for consideration

- Alcohol gel dispensers
- Hand washing
- Education of visitors
- Consistency of thorough cleaning across all environments

10. HOSPITAL CATERING

The majority of participants, or their relatives, commented about the food. There were varying opinions but on the whole the catering was reported to be satisfactory and, on occasions, good.

i. (Patient) '…food was ok, it weren't fantastic but then…it was edible put it that way…'

ii. (Patient) '…the meals there were very good…'

iii. (Patient) '…there were people complaining all day long about food, but I didn't find it that bad…some days it really wasn't good at all…I would avoid the pork casserole. One of the major problems with this food thing was, they give you the menu to tick what you wanted…and when the trolley came round they'd run out of what you'd ordered…that happened several times…I really don't see how if you have ordered a meal, you don't get that meal…same menu every week for each day…'

iv. (Patient) 'Lousy…when I went in, in 2000 …they had their own kitchens and were cooking their own food…recognisable and tasty…now, as I understand it, it's done on the hot baking system… and they bring it in and obviously it's heated up in the hospital to a required standard, enough to kill anything that's in it, including the patient. The main trouble is, it is often unrecognisable and very often slop…for example one day they'll offer you…they'll give you a choice…obviously working to a low budget. …on the telly the other night…they'd been to the Royal Cornwall hospital. They're allowed £2.60 per day, per patient for food, that's it. But they're

dishing up new potatoes and god knows what and they're sourcing it all locally…it's not coming in from some….contractor. …an alternative, perhaps you could pay the hospital an extra £1.00 per day and get something better...'

v. (Patient) *'…XXX used to have their own chef…let's be honest, you lose money straight away because you've not only got to pay for their chef's time, but they've got to have a profit out of it as well…* (Patient referring to contracted out catering service).

vi. (Patient) *'I'm not a big eater, the food I had was good enough for me…if I didn't like what was there I would have a sandwich…there was a choice…I said to my daughter I've had a very strange meal today but I've enjoyed it…don't know what it was. Only thing I could complain about was the tea…it came in a tiny cup and I have a bit of sugar usually but they wouldn't let me in there.'*

vii. (Patient) *'…the food was excellent…I said compliments to the cook once or twice because they were so nice…I really enjoyed the food…'*

viii. (Patient) *'I didn't feel hungry, I didn't want anything to eat… what food there was, I think was adequate and you did have a choice…didn't seem much wrong with the food as hospital food goes…'*

ix. (Patient) *'…the food was pretty good…my problem was that I couldn't eat a lot of the things I usually eat, and that's not their fault…I love salads…'*

x. (Patient) *'…even the oft criticised meals only occasionally were um, generally speaking the grub was ok bearing in mind the difficulties of moving large quantities of ready made meals, and there was a fair choice. Something which did irritate and cause concern was the fact that my diabetes advisors tell me I should inject myself about 20 minutes before a meal. In hospital, one never knew when it was 20 minutes before, and oft times I was using a needle only a couple of minutes before…as soon as the trolley appeared I would shove the needle in and that would only be about three minutes before eating…'*

xi. (Patient) *'…my favourite beverage is tea…at an early stage in my diabetes it was suggested that I should drink skimmed milk…this has now become a preference…Skimmed milk was never available in hospital…even Marvel would have been preferable…or little sachets…'*

xii. Patient commented that the food was good.

Points for consideration

➢ Availability of skimmed milk
➢ Patient information stating approximate meal times
➢ Royal Cornwall catering

11. PATIENT-LINE

Patient-line or more specifically the ability to make and receive calls at the bedside was appreciated but generally considered too expensive.

i. (Patient) *'…this telephone/television system that's in the hospital, what's it called? Patient-line. It's dear… certainly… to phone in.* (Spouse) *'It was nice to have the chance to phone personally…but, it was very expensive… about 50p a minute'.*

(Patient) *'if you are actually an inpatient you can buy a card for £3.50 which gives you a day's television and 90p credit for the telephone, I believe…, so when I had a lot to say and I'd run out of credit… a five minute call from here* (home) *would cost £2.50 to £5.00* (takes approx 1-2 minutes to connect to patient number) *… it wouldn't be half so bad, I don't think, if you knew the money was going into the NHS perhaps…you can't have the telephone unless you buy a television ticket'. It's nice to have it there but, when you see some old people who haven't got their tellies on, is it because they can't afford it, perhaps?'*

ii. (Patient) *'…there was a common room attached to that ward and in there's a payphone but it's surrounded by hoists and all manner of medical equipment…you'd have a job to get to it if you wanted to…'*

iii. (Patient) *'…you've got that Patient-line system. The only trouble is it can be rather expensive…I have used it…mostly to make contact with home…I'm not one to listen to piped music…I took my own MP3 player with me…'*

iv. (Patient) *'…took books to read…'*

v. (Patient) *'…when it wasn't breaking down…it wasn't very satisfactory'* (Relative) *'…the most annoying thing was, the button for the on and off television was right next to the button for the telephone and answering phone, so I had to block the answer phone off with a bit of tape so that - wouldn't press the wrong button because, if - pressed that button, I couldn't phone – if - left on the answer, and I rang, I just couldn't speak to – and that was very important. Lots of other people said, don't know who designed them…you know to put the one button next to another so you can't communicate with people…'*

vi. (Patient) *'…I think Patient-line is an absolute rip off'*

vii. (Patient) *'…nobody told me that I could get that free…none of that is actually written… you have to find it out for yourself…'*

viii. (Patient) *'…the only radio that was available was rubbish…music, I like to listen to radio three…I could never find it…there was always pop music…I quite, on occasions, wanted to listen to a radio four play but I couldn't find that either…'* (Interviewer) *'…did you try ringing Patient-line to say that you'd had problems?'* (Patient) *'I don't remember doing that…'* (Interviewer) *'…but it was better to have that facility there than not, would you say?'* (Patient) *'Oh yes, if nothing else it makes one feel that one has a choice.'*

Points for consideration

- ➢ Cost
- ➢ Information leaflet which includes criteria for free services
- ➢ Maintenance of patient-line equipment
- ➢ Accessibility of payphone/use of mobile telephone

12. VISITING

Visiting was often the highlight of a patient's day. Generally the visiting times were acceptable and most patients were confident that if they had not felt well enough for visitors the ward staff would intervene. Where visiting was limited participants often

recounted feelings of isolation, loneliness and boredom. The majority of patients' relatives had at least half an hour to travel which impacted on the frequency and duration of visits.

i. Patient had no visitors apart from spouse and son on the first day after their operation because of the distance they lived from the hospital. Spouse was unable to drive, public transport was '*impossible*' and their son lived 200 miles away. The couple did not like to ask friends for help as one friend was disabled and another was in poor health.

ii. (Spouse) '…*took about an hour each way …I can understand their policy where visiting's concern … 2 to 8 pm …I found that hard only for the fact that I've got a disabled daughter, so I have to get somebody to sit with her for those times to allow me to go down to see…whereas I felt it could be a bit more flexible but then, especially with hospital infections I know why they do it.*' (Patient felt staff would be flexible with visiting when necessary)

iii. (Spouse) '*There's no direct bus from the train station to the hospital…you have to go from the station to the town and change buses to get to the hospital*…' When the patient's spouse travelled by train this had to be on their day off in order to allow enough time. When they drove, travelling by car would take about 2 hours for the round trip.

iv. (Spouse) '*I did think for me, as a visitor, the space between beds was horrendous*' (Patient) '*Especially in the far end of the ward*' (Spouse) '*I had to sit in front…you know? You couldn't get to the side…*' (Patient) '*…in some places the visitors had to sit out in the middle of the ward... very difficult for the staff…*'

v. (Spouse) '*…from a visitor's point of view I had to walk to the café to get a drink …I would quite happily have paid for a coffee. They come round with a trolley for patients…long walk to the café…especially for older visitors*'

vi. (Patient) '*…it's not only limited visiting, it's limited visibility as well…it can be very interesting sometimes with things going on in the ward that you watch, you know? It's like a spectator sport...and I guarantee you that any patient, that's at all reasonably well, does it.*' Patient was referring to their experience of being in a side room.

vii. (Patient) '*…it's six hours…to be honest when I was feeling really rough it was a bit too much…The good thing about it…with people's work times and what have you…there's more time to fit in*'

viii. (Patient) '*…it's a round trip of fifty miles, at least forty minutes, sometimes an hour…*'

ix. Patient recalled visiting problems for spouse who has mobility difficulties because of Parkinson's disease.

Points for consideration

- ➢ Impact on patient of having few or no visitors.
- ➢ On ward facility for relatives to obtain drinks

13. CAR PARKING

The main issue in relation to car parking appeared to be the cost;

i.   (Patient) '…*the price of the parking…. £6.00 a day for 8 weeks…*'

ii. (Patient) '…*apart from the rip off car park…personally I don't think you should have to pay at hospitals…if the money was ploughed back into the hospital I wouldn't mind, but I don't think it was…if you were over four hours it was £6.50, I mean that's a lot of money, you know. What is good at XXX is that they've got this multi-storey…for outpatients…that helps…*'

iii. (Patient) '…*the cost is so expensive to park your car there…you never know how long you are going to be in there…*'

iv. (Patient) ' …*the only issue with the parking is the cost…but, it was a long way to walk, I must admit, although on some occasions you've got the French doors from the day rooms that open right out onto a car park…*'

v.   (Spouse) '…*I ended up using the Park and Ride as often as I could, although it's not available on Sundays, principally because I generally speaking was there for well over four hours, which was going to cost me £6.50, and Park and Ride was £1.50, so that worked quite well. I liked the Park and Ride, although it was a bit of a nuisance when you were carting stuff around…the parking…was very, very difficult, there just weren't enough spaces…now they've built a multi-storey it's not an issue but there's a parking fee at all times…concessionary parking…doesn't occur now…*'

Points for consideration

➢ Cost; availability of concessions?
➢ Sunday Park and Ride

14. DISCHARGE

It would appear that most patients experienced an uneventful discharge apart from the following exceptions

i.   (Patient) - With regard to discharge, the patient had managed to get a friend to collect them. Unfortunately the only wheelchair available was broken and the patient had to walk from the ward to the car park which had left them exhausted.

ii. (Patient) '…*no problems with discharge… just had to arrange for district nurse…came out in a wheelchair straight up to the car, no problem…so I came out in slippers, pyjamas and a dressing gown…*

iii. Patient recounted how dressings had been taken off their wounds on the day of discharge which had been extremely uncomfortable and had caused considerable discomfort during the journey home. Patient required nursing input post-discharge for dressings for infected wounds for several months.

iv. (Patient) '…*I was transferred to ZZZ the first time, which was after the by-pass…when I went back in the second time…I refused to go back to ZZZ Hospital…there was no way I would go there, sorry, so I was then sent to WWW…a lovely little hospital…the care there was brilliant. For years…I collected hundreds and hundreds of pounds for it and it was a really super little hospital, but now, because they're talking about building a new hospital for ZZZ, nothing is being done in there from what I can make out, the morale is lower than it is at*

XXX…8 beds, practically all geriatrics and there were two of us transferred from XXX that first time …we were there an hour before anybody came to us… 8 patients here, 4 waiting for god, 2 I'm not sure about and us 2…they were definitely all over 80…'

v. (Patient) *'pushed out of the hospital far too quick…it was only a week, I think, I was in, but there was a lot of shuffling going on with the beds, a lot of shortages of beds, I think they'd closed down ward- but they hadn't stopped…the admissions that were coming in…'*

vi. Patient had been discharged to another hospital which they recounted as a very negative experience. The patient reported how this had, unfortunately, strongly influenced how they now feel about being an inpatient. During the discussion, the participant recounted how they had '…hated the experience … had felt very lonely … the telephone and television had cost a fortune (£75) … how their family had been unable to visit because of the distance …the food had been awful' … and no follow up referral had been organised for a district nurse visit after discharge, which they had to arrange themselves. They also mentioned that more support, both emotionally and psychologically would have been very welcome during this time.

15. TRANSPORT

i. Patient's spouse relied on their son, who lived 200 miles away, for transport to the hospital. At 76 years of age bus travel was "*impossible*".

ii. (Patient) *'…an ambulance brought me home…took me backwards and forwards to XXX every two weeks…transport was very good, no problem'*

iii. (Spouse) *'There's no direct bus from the train station to the hospital…you have to go from the station to the town and change buses to get to the hospital…'*

iv. (Spouse) *'The only downside we've got is transport.'* (Patient) *'Yes, transport has got diabolical…it don't turn up…the system has been changed…it's now done from a call centre. For example, they said I could come home…that was 12 o'clock…we arrived here at quarter to half past nine in the evening…and that was in a regular taxi'.* (Spouse) *'Well, the last time … was going in, it was arranged that … had transport…the hospital rang at 11 o'clock in the morning…can you be in hospital by 2 o'clock we are operating on you today…transport booked…half past one they hadn't arrived…I rang them up, it's on the way…half past two it hadn't arrived…had to ring hospital to tell them …wouldn't be there for the operation so they had to re-alter all their lists again…*

v. (Patient) *'…my son or daughter has to lose time from work to take me…then they have to spend on petrol … appointments on all different days…I'd rather have my son or daughter take me because they can come in with me…what little bits I didn't understand or didn't quite hear, because I am deaf in the one ear...they listen and they know everything that's going on. If I'd have had public or hospital transport, which a lady was telling me about…, I wouldn't have had my daughters with me.'*

Points for consideration

➢ Reliability of hospital transport
➢ Hospital transport for patient and one relative

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16. OUTPATIENT APPOINTMENTS/FOLLOW-UP CARE

A number of patients reported on their healthcare experiences since discharge

i. Daily district nurse visits for redressing and checks on open wound. Weekly physiotherapy follow-up, at home, from local hospital, increased in frequency after wound had healed. Fortnightly visits to XXX for check-ups.

ii. (Patient) '…*we had to have a nurse in every day to dress it* (the wound)…*keep an eye on it…still going backwards and forwards to XXX every other week just to check…*'

iii. (Patient) '…*the hospital are so worried about that leg… me damaging it…XXX's last words to me, me main doctor that did all the operation and everything, he looked at this leg and he said '…, nothing to worry about this leg', he said 'but wrap this other one up in cotton wool, that's the one that you've got to look after 'cos, he said, if you do something to that one there's no bypass or anything for that one.'* (Partner) '…*it is scary, it **is** scary…*' (Patient was still coming to terms with unexpected loss of the good leg and was keen to obtain further information about spinal injection which might prevent them from losing the remaining leg)

iv. (Patient) '…*I've gone back to the same scenario which I had before the leg was removed, even now…when I'm at –* (local) *hospital…I put my leg on and I walk so far then I've got to sit down…this foot will absolutely go white, it will only let me do so much…it's definitely a problem…'* '…*I'd like to go back to work if I could but I can't see it because the job…me damaging it* (because of type of job too much risk of injury to remaining leg).

v. (Patient) '…*even now you get that sort of emotional thing, nobody had told me any of the effects…this is the annoying thing…the surgical side, great; psychological, nil. There was no follow-up at all on that. It was only by the grace of God he'd had actually the same operation as me…that I knew then that all the things I had been experiencing, again the sense of isolation…all the jobs that I used to do* (and couldn't do post-operatively, friend gave booklets and patient started to keep a diary which helped) *…you feel cut off, awful because everybody else is running round behind you…doctors 3 times a week for dressings…you feel so helpless.'*

vi. (Patient) ' …*I was sent home with an infection…- rang me and said that they'd had the results of a swab that they'd taken while I was in…it turned out that I had an infection…so I went on two doses of antibiotics at the same time…'*

vii. (Spouse) '…*arranged for a walker from the Red Cross…but you didn't use it…in the hospital you were using one…I know you can hire all sorts of things there* (the Red Cross) (Patient) '…*used my father-in-law's walking stick…alright with that…'*

viii. (Patient) '…*the pump* (VAC machine) …*it made a hell of a difference…but there's a question over the politics of that pump because it made such a difference and I said well, am I allowed to have this thing out of here?…because the only reason, really, that I was in there for the last fortnight was to have this pump on me, there was no other treatment that I was getting…'* (Spouse) '…*to us it seemed a waste of a hospital bed'.* Patient described the disappointment at not being able to continue with VAC therapy following discharge home and how this had affected

the healing of the ulcer for which nursing input was still ongoing several months later.

ix. (Patient) '…*when I went down with the MRSA our own GP came in and prescribed antibiotics…the leader of the district nurses at that surgery…she rang the vascular team up…the ambulance will be there by 5 o'clock…*patient re-admitted to hospital for wound debridement and insertion of drains.

x. (Patient) '…*every time we've gone…got to have a scan or something…we've got in there and been seen…we haven't had a long wait… which at this one* (local hospital) *…your appointments say at 10 o'clock, you might get seen about half past eleven....*'

xi. (Patient) '…*loads of visits back…they're keeping a regular check…but they're losing time from work to do it…*(Daughter) '*I have to lose a day from work because I'm not allowed to take a day's holiday…have to take a week at a time…lose a day's pay…*'

xii. (Patient) '…*missing appointments all over because I can't afford it…*' Patient reported how they are missing appointments for warfarin, diabetic and wound checks, particularly at the GP surgery, because it is too far for the patient to walk and there are too many appointments for the patient to take a taxi each time,

xiii. Patient still experiencing considerable pain post-operatively which affects mobility. Patient described how the wounds restrict movements such as bending but how, overall, they felt mobility had improved '…*I can walk to the supermarket, well nearly get there, just got to cross the road…I'm scared of crossing roads so I wait till there's a crowd there, then the pain's eased so I can dash along with them…It is a bit embarrassing when you wont cross the road and you've got your grandchildren and they say 'come on … it's clear now' and I have to say 'hang on'…*'

xiv. Patient had district nurse follow-up for 3 weeks, until removal of staples.

xv. (Patient) '…*I'm better with one leg…but I'm still waiting for treatment for the right, the right leg is getting worse all the time, in fact it's a lot worse now than when I went in hospital ages ago…I can hardly walk now…it's so painful…I don't like being so helpless and this leg is the only thing that's stopping me walking about.*'

xvi. (Spouse) '… *well, we were still worried about that when you came home because you couldn't move that leg that they'd operated on independently at all, could you?* (Patient) '…*I couldn't lift my leg; it was almost as if a tendon had been damaged. It is still not as good as the left leg, it was about 3 months…it was about 3 months before I could even sit on it* (patient has a motorbike) *…I couldn't bend the knee sufficiently to sit on the bike.*' (Spouse) '*The worrying thing was, after – came out of hospital, apart from going to the surgery again because the ulcer, although smaller, the ulcer was still there and still had to be dressed…at least twice a week…couldn't get this leg up at all, it had to be lifted, so, after another 3 weeks at home, I got concerned a bit about this. I just felt that we needed a follow-up that told us 'yes, this is normal; no, it isn't'. So I actually rang, I by-passed our doctor, rightly as it proved, rang Mr – secretary told her that I was concerned and would like my – to see somebody about this situation, and give them their due, we had an appointment within a week, I think…*'

xvii. (Patient) '*…the only remedy they had for this was for me to increase the intake of insulin and I'm still on a quantity which has been commented on by people in the medical business, they say gosh, this is a big dose, and it has been that way since I was on these two painkillers…*' (Patient was asked if they regularly saw a diabetic nurse, to which they answered '*no',* although they have blood samples taken and checked every six months through their practice nurse. Patient and spouse recounted their experience with a diabetic nurse from their GP practice which had not been satisfactory. She had not instilled confidence in them.)

xviii. (Spouse) '*…we went up and saw one of the team…he said, have you had your post-operative scan...we'll organise that and then I'll see you again…should get notification of the scan within 2 weeks. Well, we got notification but the scan wasn't going to be done for another month, or more…I rang the scan people this time and said…I am certain that my – would be having a scan within 2 weeks…checked the letter and came back to me saying, yes, you are quite right come up next week…went for the scan…part of it had occluded, it had narrowed anyway in a dangerous way…back in* (hospital for further surgery) *within the week…What worries me…if we hadn't actually made the move to say can this be checked, it would not have been found and, I afraid it would have been an emergency, so that's a little bit concerning, especially as after this second op, although everything appears to have gone absolutely smoothly…nobody's seen - ,neither our GP nor anybody at the hospital and that's since May, and I don't know if there is supposed to be any follow-up.*' (Interviewed in October 2007)

xix. Patient was transferred to another hospital from XXX. No district nurse follow up was arranged following their discharge from that hospital. Patient arranged their own.

xx. Patient had been back to XXX for a follow-up appointment and scan since their operation in March 2007.

Points for consideration

> ➤ Some patients did not appear to be receiving follow-up appointments
> ➤ Discharge information
> ➤ Provision of VAC therapy in primary care
> ➤ Same day appointments

Conclusion

Overall, the patients were happy with the healthcare they had received from XXX hospital and were keen to express their gratitude to the healthcare professionals who had enabled this
.
None-the-less it is evident from the verbatim extracts that a number of points require further consideration by the Vascular Patient Journey Project Team. As such the main issues have been extracted from the patient interviews and collated with the findings from the Vascular Patient Journey mapping exercise and presented in a separate *Issues and Solutions* document to facilitate further discussion.

USE OF REPORT DATA

The information contained in this report was collected as part of a research project exploring the Patient Journey Approach to Patient-Centred Healthcare Delivery. Ethical

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approval was granted for the data collected to be used only by the researcher and the Vascular Patient Journey Project Team as part of the Patient Journey model of healthcare delivery, as previously agreed with Bournemouth University, XXX NHS Trust and XXX NHS Research Ethics Committee.

The contents which are to be treated as confidential reflect the views of the participants and the researcher and as such should not be copied or used for any other purpose without prior authority from the researcher, Sue Baron, School of Health & Social Care, Bournemouth University, xxx House, Christchurch Road, Bournemouth, Dorset, BXX 0XX. This document is subject to copyright ©.
Email xxx@xxx.uk

VASCULAR PATIENT JOURNEY

ISSUES AND SOLUTIONS - VERSION 5

Issues	Primary Evidence	Solution
1. Some patients report lengthy delays between initial visits to GP to consultant referral at XX Hospital.	Patient interviews	**Ongoing:** To avoid delays GPs need to make specific referrals to consultants. Delays also occur during administrative process – **PCTs** aware and dealing. **Ongoing:** Also being reviewed through Trust No Delays targets – **IPM**
2. Some patients appear to 'fall through the net' when being referred from YY to XX Hospital	Patient interviews Mapping	Vascular Consultant clinics are now being held at YY. **Ongoing: VSC and Consultant** colleagues liaising with administrator for YY hospital access codes to computer information systems such as PACS. Each site holds separate sets of notes for patients. In future 2 copies of each piece of patient information to be made and stored in both sets of notes. Consultant secretary currently dealing. Electronic Patient Record should improve this in future.

Issues	Primary Evidence	Solution
3. Duplication of clinical assessment of patient by Community Clinical Nurse Specialist and nurse team at XX prior to consultant appointment.	Mapping	**Issue resolved:** Patients who have been assessed by the Clinical Nurse Specialist in the Community Leg Ulcer Clinic, and for whom assessment forms have been completed, may now be referred direct to consultant clinic. Patients who have not been assessed by the Community CS will continue to be referred to XX as at present. **VSN/CNS**
4. Several patients had a considerable distance to travel to XX and would appreciate same day appointments e.g. consultant appointment, pre-op assessment, duplex scanning.	Patient interviews	**Ongoing:** Same day, drop-in, pre-op assessment commenced 5/12/07 but has not proved successful for patients with PVD. Several patients declined opportunity due to time factor. **Ongoing:** Same day appointments for 4 key diagnostic tests under review through **No Delay/18 week** project **VCS/IPM**
5. Imaging demand for 3-8 Duplex scans per OP clinic, imaging capacity for 1-2 Duplex scans per OP clinic. 2 week wait for urgent scans, 6 weeks wait for elective scans.	Mapping	**Issue resolved** Portable head for duplex scanner ordered, **VCS/BM**. **Ongoing:** **VCS/BM** also to explore possibility of purchasing additional portable Duplex scanner **Ongoing:** **VCS/BM** to look at possibility of recruiting trainee/junior grade sonographer and/or increasing medical staff input to provide one-stop scanning for patients in clinic.

Issues	Primary Evidence	Solution
6. No access to full range of diagnostics in peripheral clinics.	Mapping	**Ongoing:** No immediate solution. Difficulty in co-ordinating appointments between departments for 4 key diagnostic tests. Portable scanner would reduce delays for Duplex scans. **VCS/BM** **Ongoing:** Under review through **No Delay/18 week,** proposal for RADAR desk where diagnostic tests could be centrally booked **IPM**
7. Waiting List Cards (forms) not always available in clinic	Mapping	**Issue resolved** by Admissions/Outpatients Matron/TST
8. Capacity: 2 Angioplasties per list, 5 lists per week 09.30-12.30.	Mapping	**Ongoing**: Currently under review – capacity to be increased – **SR**
9. Sequence of theatre booking and pre-op assessment – requires a lot of phoning to arrange.	Mapping	**Ongoing:** Under review through **Theatre Strategy Group/No Delay/18 week (VCS/VNP/BM)** Further solution would be centralised /up-to-date information showing theatre lists/day surgery lists/ clinics and changes. **VNP** to contact xx manager regarding Electronic Trauma Board and its suitability for the Vascular Team.

Issues	Primary Evidence	Solution
10. Sometimes patients not pre-op assessed due to insufficient clinic spaces and CNP time.	Mapping	**Issue resolved:** with appointment of additional Nurse Practitioner, double POAC sessions held when required.
11. Patient notes not always available.	Mapping	**Ongoing:** New computer system currently being implemented with case note tracking module which should improve tracking and availability of patient records. **Admin Processes Review**
12. Delayed access to Cardiologist opinion.	Mapping	**Issue resolved:** Consultant Cardiologist has agreed to provide 2 additional review sessions per month **(VNP)** **Ongoing:** Possibility that Care of Elderly Consultant will provide time for patient reviews – yet to be agreed **(VNP)**
13. Patient reported great anxiety at not being able to attend for urgent, next morning, hospital admission for surgery, following phone call from XX.	Patient interview	**Issue resolved:** Patients to be contacted only by medical staff or nurse practitioner in the event of a short notice admission **(VCS/VNP)**

Issues	Primary Evidence	Solution
14. Automated hospital telephone answering system had caused frustration to a few of the participants –voice recognition was reported to be the main problem. Direct contact numbers were important.	Patient interviews	**Issue resolved:** Provision of direct contact numbers. Patient correspondence now includes contact numbers. **Ongoing: VCS** reported there was possibility for contact via an on-call mobile phone if necessary in future. **Ongoing: VCS** also considering including email address on future patient correspondence. **Ongoing: VNP** look at possibility of dedicated phone line for patient access to Vascular NP
15. Patients identified for surgical admissions lounge (SAL) are sometimes admitted to the ward (some patients reported lengthy admission wait)	Mapping Patient interviews	**Ongoing:** currently under review by **Theatre Strategy Group/Surgical Directorate.**
16. No shower available on the ward	Mapping	**Issue resolved:** Shower available.
17. Lack of side rooms for isolation	Mapping	**Issue resolved:** New surgical build will have 100% single rooms.

Issues	Primary Evidence	Solution
18. Bulk of emergency/urgent angioplasty requests made during Thursday ward round, leaving Friday morning to carry out the requests.	Mapping	**Issue resolved:** Mr Chester has stopped 5pm ward rounds.
19. All patients for angioplasty admitted as inpatients (50-60% could be treated as day cases)	Mapping	**Issue resolved/review:** 1st day case booked for 11/1/08 **SR/VNP**
20. Shortage of X-ray porters to transfer patients for angioplasty.	Mapping	**Ongoing:** Issue under review by **Facilities Department**
21. Shortage of theatre porters	Mapping	**Ongoing:** Issue under review by **Facilities Department and Theatre Strategy Group**
22. Sometimes difficult to find the patient (ward of admission)	Mapping	**Ongoing:** Patient admission details need to be centralised and readily accessible. **VNP** to liaise with admissions manager re orthopaedic board.

Issues	Primary Evidence	Solution
23. Order of theatre list confirmed from 4pm day before surgery	Mapping	**Issue resolved:** Theatre lists now confirmed by 11am day prior to list. Secretaries to prompt Consultants to ensure this will continue. **Secretaries/Consultants**
24. Wards not aware of theatre list sequencing on day of surgery	Mapping	**Ongoing:** Notification via electronic white board could alleviate problem in future. Not generally a problem in SAL (surgical admissions lounge). **Issue resolved:** Ward staff not to feed patients until 1st theatre case has gone ahead and theatre list confirmed – to include in Safety Briefing **VCS/VNP**
25. Some patients reported confusion over medication (on admission and following discharge)	Patient interviews	**Issue resolved:** Perioperative Management of Medicines - Trust protocol published by Anaesthetic Department
26. Some GPs tell patients not to bring own drugs	Mapping	**Issue resolved:** Letters now advise patients to bring current medications in pharmacy labelled boxes/containers.
27. Some patients bring drugs in blister packs	Mapping	**Issue resolved:** All XX patients are being asked to bring medication in labelled boxes rather than blister packs.

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Issues	Primary Evidence	Solution
28. OT referrals generally at pre-op assessment	Mapping	**Issue resolved**. OT referrals now being undertaken at pre-op assessment. **VNP/OT**
29. Friday theatre lists: 2 days when patient is not reviewed due to the weekend (see their doctor)	Mapping Patient interview	**Issue resolved**. All patients will now be reviewed at least once during a weekend by a junior doctor. Vascular consultants on-call 4/6 weekends **VCS**
30. Patients who had side rooms reported feelings of isolation at times	Patient interviews	**Issue resolved/review:** New surgical build contains single rooms with internal windows giving visibility of ward area so that feelings of isolation may be reduced. The windows will be provided with blinds to enable privacy when required. **VNP/WS**
31. A couple of participants recounted feelings of discomfort or anxiety brought on by 'awkward' or 'nasty' patients, or feeling isolated because of where they were located in relation to other patients (e.g. unwell patients on either side).	Patient interviews	**Ongoing/awareness raising:** Difficult to guarantee solution as dependant on bed space availability, ward staff workload, amongst other factors. **VNP/WS**

Issues	Primary Evidence	Solution
32. One patient recounted her discomfort at being surrounded by male patients on a mixed ward and opposite a '…man opposite who snored all night.'	Patient interviews	**Ongoing/awareness raising:** Difficult to guarantee solution. Surgical rebuild will reduce patient noise disturbance. **VNP/WS**
33. A number of patients reported delays in the timing of their operation – this ranged from surgery at the end of a day after being NBM all day to several days delay.	Patient interviews	**Ongoing/awareness raising:** Improved communication between medical and ward staff would help to alleviate this issue. **Medical/ward staff**.
34. Difficult to access ITU/HDU beds	Mapping	**Ongoing**. Difficulties currently under review by waiting list co-ordinator. Propose that ITU/HDU ward round times to be held at start of day, or during evening, so that potential discharges might be identified earlier.
35. A few patients would have liked more information about their plan of care, future prognosis, adverse effects of anaesthesia (including possible psychological effects) the do's and don'ts of post-operative recovery.	Patient interview	**Ongoing:** plan for Vascular Team to re-write patient information leaflets and provide a Vascular information website. **VCS/Vascular Team**.

Issues	Primary Evidence	Solution
36. Overall communication was good, but at the bedside, patients sometimes felt doctors talked over them, in a language they often did not understand, to other members of their team.	Patient interviews	**Ongoing:** Proposed solution – ward round to be reviewed. Doctors' discussion to take place away from patient bedside, if practical. **VCS and medical team**
37. One male patient felt that psychological and physical care should be of equal importance. He gave details of a booklet, supplied by another NHS Trust, that had provided the 'turning point' for his post-op recovery	Patient interviews	**Ongoing:** Currently being reviewed by nurse practitioner, physiotherapist, occupational therapist – **VNP/P/OT.** **Ongoing:** Patient Information Leaflet **VCS/Vascular Team**
38. Limited clinical psychology input (principally for amputees)	Mapping Patient interview	**Issue resolved/review:** VNP has negotiated with Psychologist additional input primarily for amputees, as required.
39. Several patients reported that they would have liked more help with washing/personal hygiene, especially in the early post-operative days.	Patient interviews	**Ongoing/awareness raising: BM/VNP** reported that a plan/pathway had been introduced for orthopaedic patients which might assist in resolving this issue. **VNP/BM/WS** to follow up.

Issues	Primary Evidence	Solution
40. More recognition of impact of previous negative care experience, the fear and anxiety of patient (e.g. central line had been associated with life-threatening infection on a previous admission)	Patient interview	**Ongoing/awareness raising:** It was felt that little could be done unless patient's notified medical/nursing staff of their anxiety/fear. Good communication and rapport with patients would facilitate disclosure. **WS/Nursing/Medical staff**
41. Inconsistencies in information - a couple of patients recounted variations in information received, and the feelings of frustration or anxiety this had caused them, and in some instances, their relatives.	Patient interviews	**Ongoing:** Suggested solution was for nurse representation at daily Vascular Meeting from 10-10.30 am **WS/VCS**.
42. Inter-professional communication –fragmentation of teams/care – some patients felt that the different health professionals did not communicate with each other	Patient interviews	**Ongoing:** Possible solution might be to provide patients with written information about the roles of health professionals who might be involved in their care during hospital admission **VSC/Vascular Team**
43. Some diabetic patients are admitted to hospital earlier than necessary prior to surgery.	Mapping/Team discussion	**Ongoing: VNP** reported that guidelines for admission/care of diabetic patients are currently under review. Trust wide initiative.
44. Pressure area care/availability of pressure mattresses	Patient interviews	**Issue resolved:** Situation improved. Air mattresses and a range of alternative devices were now readily available for use in patient pressure area care**. WS/BM/VCS**

Issues	Primary Evidence	Solution
44. Patient would have appreciated greater variety of physiotherapy, with off ward activities such as use of gym or swimming following amputation	Patient interview	**Ongoing: OT** would look at possibility of providing alternative activities for amputees/patients with longer admission times
45. Space between beds was described as 'horrendous' – not enough room for patient/nursing staff or visitors	Patient interviews	**Closed but noted:** No solution to this problem other than ensuring minimum bed space criteria is met in accordance with infection control/health and safety regulations. New build has single rooms. **WS/VNP**
46. Metal bar headboards	Patient interviews	**Closed but noted:** No immediate solution.
47. A diabetic patient felt it would have been useful to know when meals would arrive so that he could have his injection as usual 20 minutes before he ate.	Patient interviews	**Ongoing/awareness raising:** Meals arrive at approximately same time each day on the wards. Possible solution – increase patient awareness during admission and in **patient information leaflet VNP/WS**
48. Several participants felt that the hospital food could have been better. They also reported that they did not always get the food they had ordered. Suggested looking at Royal Cornwall Hospital 'in house' catering.	Patient interviews	**Closed but noted:** No immediate solution but it was generally believed that catering had improved since the time of patient interviews.

Issues	Primary Evidence	Solution
49. Tea trolley/urn for visitors to use was suggested, or option of buying a drink on the ward. Larger mugs were also requested.	Patient interviews	**Ongoing:** Larger mugs are available on some wards. **WS** to liaise with **Matron/PALS/Housekeepers** with regard to provision of drinks for visitors.
50. Availability of skimmed milk for patients.	Patient interviews	**Issue resolved/awareness raising:** Housekeepers can obtain this for patients. **Ongoing: WS** to liaise with h/keepers and check Admission to Hospital leaflet with regard to information giving to patients who require special dietary requirements. **WS/VNP**
51. Patient-line – complaints about cost, in particular calls into hospital. Patients would be more accepting if charges were benefiting hospital.	Patient interviews	**Closed but noted:** Until contract with Patient-line providers expires - no solution could be offered.
52. Cleanliness – some patients had reported observing inadequate cleaning	Patient interviews	**Issue resolved**: Improved during last 6-8 months with introduction of Rapid Response team
53. Availability of alcohol gel	Patient interviews	**Issue resolved**: No issue over availability. Responsibility of **ALL** to ensure that empty dispensers are replaced or reported.

Issues	Primary Evidence	Solution
54. Wheelchair provision	Mapping	**Ongoing:** Looking at long term wheelchair provision with EM Centre **(OT).** **Issue resolved**: Short-term loan for inpatients has improved **(OT)**
55. Delayed orthotic assessment and supply	Mapping	**Ongoing: BM/VCS** reported this as on-going problem with no immediate solution due to lack of resources/funding. Patients currently experience 6-9 month wait via hospital service; **VCS** reported quicker when consultants refer patients back to GP – Possible future solution for service to be provided in primary care.
56. Orthotists need to document input/provision of footwear in patient's notes	Mapping	**Ongoing: BM** reported that new orthotic referral form being trialled. **OT** to contact Associate General Manager (Orthopaedics) for further information.
57. Community hospital admission criteria limit access to amputees	Mapping	**OT** discrepancy over definition of *rehabilitation* for patients continues – no immediate solution. Problem generally arises because of patient social issues

Issues	Primary Evidence	Solution
58. Community hospital bed availability (delays discharge or transfer)	Mapping	**Ongoing:** Community hospital bed availability is an ongoing problem which is likely to remain unresolved because of probable future cuts in the number of beds by SHA/PCTs. Historic issues between Social Services and hospital regarding provision/funding/availability of longer term care also continue.
59. Unpredictable length of hospital stay (amputees)	Mapping	**VCS** reported that of SS Housing is currently looking into assistance for patients who have no fixed abode. **Ongoing/awareness raising: VCS** recommended that, whenever, possible details of patients who are likely to experience social problems on discharge be flagged up to **Discharge Liaison,** including prior to admission if possible
60. Delayed discharges	Mapping	**Ongoing:** ongoing review on a Trust-wide basis through rolling Audit reviews. **Discharge Chaser/XX Trust Management/Matron, Surgical Directorate/Matron, Orthopaedics/Trauma**
61. Secretarial support for production of MDI discharge summaries	Mapping	**Ongoing:** no immediate solution. **BM** reported MDI contract expires June 08.

Issues	Primary Evidence	Solution
62. Discharge summaries not being received at PCT Community Leg Ulcer clinic	Mapping	**Issue resolved: VNP** reported that **CSN** primary care now has access to electronic record and can view discharge summaries.
63. One patient felt that he should have been able to continue with VAC therapy following discharge, or been discharged earlier with VAC therapy.	Patient interviews Mapping	**Issue partially resolved: VCS** reported that patients may now be discharged with portable VAC if PCT accepts.
64. Access to VAC therapy in PCT's	Mapping	**Ongoing: VSN** reported that Service Improvement Manager is currently looking at provision of VAC therapy following discharge with Trust commissioners/ procurement
65. Some patients reported delays in their out-patient follow up, or no follow up appointments.	Patient interviews	**Ongoing:** Possible solution – **VNP** to liaise with **BM** with regard to possibility of dedicated Vascular Nurse Practitioner phone line for patient access. **Ongoing: VNP** currently looking at improving follow-up for diabetic patients.

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Issues	Primary Evidence	Solution
66. Delays in Vascular Nurse reviews	Mapping	**Ongoing: VSN** – from 3.3.08 clinic day changing to Tuesday in attempt to address problem. **BM/VSN** to confirm correct coding for non-consultant led clinics.
67. Nurse-led clinics in community hospitals	Mapping	**Issue closed but noted**: No immediate solution because of funding/resources but included in vision for future service improvement
68. Hospital transport not turning up when booked through central booking system – missed theatre slot; missed appointments.	Patient interviews Project Team	**Ongoing: BM** to liaise with **CEM** for possible solutions. **CVS** felt it would be useful if electronic records could have an indicator to identify those patients who rely on hospital transport
69. A number of patients recalled the long distance from the car park/entrance to the ward (admission and discharge)	Patient interviews	**Ongoing: BM** to liaise with **PALS.** One possible solution might be provision of a volunteer driven electric buggy service between car park/hospital/clinic/ward
70. Wheelchairs for patient use not always available.	Patient interviews	**Ongoing: BM** to liaise with **PALS.**

Issues	Primary Evidence	Solution
71. No direct bus to hospital from train station.	Patient interview	**Issue closed but noted:** Unable to resolve as responsibility lies with local Council.
72. A number of patients reported receiving poor care following transfer to other hospitals.	Patient interviews	**Issue closed/awareness raising:** Unable to resolve - other than to ensure patients are fully aware of reason for transfer and what to expect.
73. Patients and visitors felt the parking was expensive. Would be more accepting of the charge if some of the money was being utilised by the hospital.	Patient interviews	It is believed that some money does get paid back to the Trust by Q Park – **BM** to obtain further information
74. Increasing number of complex surgical cases seen at XX due to easier cases being treated at the SS treatment centre, placing increased demand on resources at XX.	Team discussion	**Ongoing:** it was accepted that the team at XX were the best suited to provide care for patients with complex surgical needs. **Trust Management** is aware of the need for increased resources to meet the extra demands **(BM).**
75. Nurse staffing/workloads	Patient interviews Team discussion	**Ongoing: BM** reported that nurse staffing levels within the surgical directorate are currently under review. **Ongoing: VNP** felt that additional training should also be provided to enable nurses to care effectively and safely for patients with increasingly complex nursing requirements.

Abbreviations

BM = Business manager; CEM = Communications and Electronics Manager; CSN = Clinical Specialist Nurse, Primary Care; IPM = Improvement Project Manager; OT = Occupational Therapist; P = Physiotherapist; SR = Superintendent Radiographer; VSN = Vascular Specialist Nurse, VCS – Vascular Consultant Surgeon, VNP, Vascular Nurse Practitioner; WS = Ward Sister

PALS – Patient Advice and Liaison Service
XX – participating NHS acute hospital Trust
SS, BB, YY, EM Centre – affiliated hospitals or treatment centres

The information contained in this document was collected as part of a research project exploring the Patient Journey Approach to Patient-Centred Healthcare Delivery. Ethical approval was granted for the data collected to be used only by the researcher and the Vascular Patient Journey Project Team as part of the Patient Journey patient-centred, service improvement model, as previously agreed with Bournemouth University, XX Trust and local NHS Research Ethics Committee.

Participant Identification Number   REC Ref No 06/Q2202/89

……………………………………

Title of Project: A study to explore the Patient Journey Approach to Patient-centred Healthcare Delivery

Principal Researcher: Sue Baron

PARTICIPANT FEEDBACK ON EFFECTIVENESS OF THE PATIENT JOURNEY

CONSENT FORM

As a member of the Vascular Patient Journey Project Team your honest and frank opinion of the Patient Journey approach to patient-centred healthcare would be greatly appreciated in order to facilitate an effective and reliable evaluation of the Patient Journey.

Please read each statement and initial the box

4. I have participated in the above research project and hereby give consent to have my views on the Patient Journey process recorded and used, anonymously, as part of the study evaluation. ☐

5. I understand that the information collected is for the purpose of the above research project and remains confidential. ☐

6. I understand that my continued participation in the study is voluntary and that I may withdraw at any time without explanation.

☐

Name ………………………………… Designation ……………………………...

Telephone …………………………...Email …………………………………

Signed (Participant)……………………….. Date …………….……………………

Signed (Researcher) …………………….. Date ………………………………..

REC Ref No 06/Q2202/89

A study to explore the Patient Journey Approach to Patient-Centred Healthcare Delivery

PARTICIPANT FEEDBACK ON EFFECTIVENESS OF THE PATIENT JOURNEY

As a member of the Vascular Patient Journey Project Team your honest and frank opinion of the Patient Journey approach to patient-centred healthcare would be greatly appreciated in order to facilitate an effective and reliable evaluation of the Patient Journey.

I would be most grateful if you could spare a few moments of your time to consider and respond to the following questions. If you feel the questions do not enable you to express your views clearly, please add any additional comments as appropriate.

If you wish to add your name to your response, this is optional but would be useful should any further clarification or information be required.

1. What do you understand by the term patient journey?

The time from first symptoms and seeking help from GP to final resolution of the problem after surgery and full healing has occurred

2. How actively involved in the PJ project would you say you were? Please explain the extent of your role.

Minor and irregular advisory/consultative role in steering group meetings only

3. What do you consider were the good aspects of the PJ Process? Please list

Clarity about the process; clear progress notes after each meeting and objectives for future actions at each stage; adequate level of consultation involving many stakeholders; researcher listening and responding to concerns whenever they arose; clinician-led development. The defined patient group.

4. What do you consider were the not so good aspects of the process? Please list

Difficulty getting stakeholders together especially during the mapping phase. Time-intensive method for the researcher. No immediate access to researcher.

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5. How do you think we could improve things for the future?
Share the methodology and the outcomes locally to enable all staff to understand the value of the approach – an article in the weekly staff bulletin or the Acute Angle news letter as well as presenting in more formal settings.

6. Any other comments?

Name (optional) XX XX…………Designation Lead Nurse Practice Development
Date ……13 May 08.

If you would be happy to discuss your involvement and views of the Patient Journey during an informal recorded interview, please tick here √

Thank you for taking the time to complete this evaluation form. Your views and opinions are greatly appreciated.

Exploring the Patient Journey: An Approach to Patient-Centred Healthcare improvement: a doctoral study
Dissemination

Conferences

November 2011: Transforming the Patient Experience, The King's Fund annual conference, London, UK. Delegate (complimentary place).

Sept 2011: 22nd International Networking for Education in Healthcare NET conference, Cambridge, UK. Theme paper PowerPoint presentation entitled *"Humanising Healthcare Education: Making it personal: Recognising the value of personal accounts towards the delivery of patient-centred, humanised care"*

June 2010: Inaugural Conference on Compassionate Care: Uncovering Compassionate Care - the why, what and how of values based care, Edinburgh, UK. Round table presentation/discussion entitled "*Making it personal: understanding the nature of compassionate care through lived experience and action research"*

October 2009: Improving Patients' Experiences in Hospital: Yes we can! – King's Fund Conference, London. Session co-leader

Oct 2008: Bournemouth University 1st Post Graduate Conference, Bournemouth, UK. PowerPoint presentation entitled *"The Patient Journey: a multi-disciplinary approach to patient-centred, compassionate healthcare"*

Sept 2008: The Bournemouth University 7th International Qualitative Research Conference 2008, Bournemouth, UK. PowerPoint presentation entitled *"The Patient Journey: a multi-disciplinary approach to patient-centred, compassionate healthcare"*

Sept 2008: SE NHS Hospital Trust – presentation to Bournemouth University 1st Post Graduate Conference, Bournemouth, UK. PowerPoint presentation entitled *"A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery"*

Sept 2007: EDCNS, Vienna, Austria: PowerPoint presentation entitled *"A Study to Explore the Patient Journey Approach to Patient-Centred Healthcare Delivery"*

Sept 2006: European Doctoral Conference for Nurse Scientists (EDCNS), Berlin. Poster presentation entitled *"Patient-Centred Healthcare: The Patient Journey"*

Seminars

February 2014: Post-graduate research workshop on Action Research, Bournemouth

University

April 2013: The Higher Education Academy and Bournemouth University Workshop and Seminar Series 2013. The power of narrative and stories in enabling learning for professional practice. *Service improvement through service user and practitioner narratives.*

March 2012: Bournemouth University research seminar: "*Exploring the Patient Journey: a multi-disciplinary, collaborative approach to person-centred health care and service improvement"*

By invitation events

4 October 2011. *The Patient Journey: A multi-disciplinary, collaborative approach to patient (person)-centred healthcare.* Dorset: Presentation to Nursing and Midwifery Expert Group and Divisional Directors at local NHS Hospital Trust.

23 June 2011: King's Fund summit – Supporting independent living – engaging health and social care in new technologies participant

3 Feb 2010: Take it to the limit workshop – How do good people find themselves offering bad care? The Kings Fund/Simply Health – participant

13 Oct 2009: Discussion session co-leader (with Dr James Munro, Director of Informatics and Research. Patient Opinion) – The King's Fund, Point of Care Programme – Improving patients' experiences in hospital: yes we can! Conference

14 Sep 2009: Meeting of 25 invited guests with Robin Youngson – Promoting Compassion in Healthcare – The King's Fund, London

October 2008. Complimentary place at launch event: Releasing Time to Care: The Productive Ward. Basingstoke and North Hampshire NHS Foundation Trust.

Baron, S., 2008. *The Patient Journey: A multi-disciplinary, collaborative approach to patient (person)-centred healthcare,* 12 September 2008, Somerset. Presentation to Patient Experience Committee, SE NHS Hospital Trust

Publications

Harding, A., Sanders, F., Medina Lara, A., van Teijlingen, E., Wood, C., Galpin, D. Baron, S., Crowe, S., Sharma, S. 2014. Patient choice for older people in primary care: theory & practice. ISRN Family Medicine (accepted)

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