


Research Report

Speech and language therapy for primary progressive aphasia across the UK: A survey of current practice

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Abstract

Background: Primary progressive aphasia (PPA) describes a heterogeneous group of language-led dementias. People with this type of dementia are increasingly being referred to speech and language therapy (SLT) services. Yet, there is a paucity of research evidence focusing on PPA interventions and little is known about SLT practice in terms of assessment and provision of intervention.

Aims: To survey the practices of SLTs in the areas of assessment and intervention for people with PPA.

Methods & Procedures: A 37-item, pilot-tested survey was distributed electronically through the Royal College of Speech and Language Therapists (RCSLT), Clinical Excellence Networks (CENs) and social media networks. Survey items included questions on care pathways, assessment and intervention approaches, and future planning. Analysis was conducted using descriptive statistics and thematic analysis.

Outcomes & Results: A total of 105 SLTs completed the survey. Respondents reported more frequently using formal assessment tools designed for stroke-related aphasia than for dementia. Informal interviews were reportedly always used during assessment by almost 80% of respondents. Respondents were significantly more likely to use communication partner training than impairment-focused interventions. Goal attainment was the most commonly used outcome measure. Respondents provided 88 goal examples, which fell into six themes: communication aid; conversation; functional communication; impairment focused; specific strategy; and communication partner. Additionally, respondents reported addressing areas such as future deterioration in communication and cognition, decision-making and mental capacity, and driving. Ten (9.4%) respondents reported the existence of a care pathway for people with PPA within their service.

Conclusions & Implications: This survey highlights the range of current PPA assessment and intervention practices in use by the respondents. Communication partner training is commonly used by the surveyed SLTs, despite the lack of research evidence examining its effectiveness for PPA. There is a need to develop evidence-based care pathways for people with PPA in order to advocate for further commissioning of clinical services.

Keywords: primary progressive aphasia, speech and language therapy, assessment, treatment, survey.

What this paper adds

What is already known on the subject

People with PPA present with communication difficulties, yet they find it difficult to access SLT services. Research literature examining the effectiveness of PPA interventions remains sparse and is dominated by impairment-based approaches to word relearning. Little is known about the nature of services delivered by SLTs to people with PPA in the UK.

What this paper adds to existing knowledge

SLT respondents report using informal assessment tools such as interviewing, or those designed for stroke-related aphasia, not for dementia. SLTs report that they were more likely to select communication partner training than

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naming interventions for people with PPA. The SLT role is wide-ranging and, in addition to enhancing participation in activities of daily living, it includes addressing future deterioration in communication and cognition, decision-making and mental capacity, and driving.

What are the potential or actual clinical implications of this work?

The study provides a benchmark for clinical practice in this emerging area of service provision, and data to support the development of care pathways for people with PPA. There is a need for the SLT profession to advocate for more consistent commissioning of evidence-based PPA services across the UK, and the development of care pathways can enable this process.

Background

Dementia has been identified as the leading cause of death in England and Wales (Office for National Statistics (ONS) 2015), and it is estimated that one-third of people born in the UK in 2015 will go on to develop it (Lewis 2015). At present frontotemporal dementia (FTD) is the most common cause of younger onset dementia with UK population prevalence estimates of approximately 11/100,000. Primary progressive aphasia (PPA) syndromes collectively account for around one-third of these cases (Coyle-Gilchrist *et al.* 2016). This conservative estimate means there are at least 2300 people currently living with PPA in the UK.

PPA describes a heterogeneous group of language-led dementias, often associated with FTD and Alzheimer's disease, which, in the initial stages, present as an insidious deterioration in language skills, on a background of intact cognitive functions (Mesulam 1982). Currently there are three internationally recognized PPA syndromes, each presenting a distinct profile of language difficulties (Gorno-Tempini *et al.* 2011, Marshall *et al.* 2018). Semantic variant PPA (svPPA, most often associated with an underlying FTD pathology, sometimes called semantic dementia) results in difficulties in understanding word meanings. People with svPPA present with fluent, often empty speech and will have difficulty naming objects, yet can use and understand grammar appropriately. Logopenic variant PPA (lvPPA, most often associated with an underlying Alzheimer's pathology) is identified by an individual's difficulties in expression. Although fluent, people with lvPPA present with difficulties accessing word forms and with phonological assembly. Non-fluent agrammatic variant PPA (navPPA, most often associated with an underlying FTD pathology) presents as a dysfluent apraxic disorder and/or an agrammatism. People with navPPA demonstrate groping, effortful speech and may use increasingly less complex grammatical structures over time.

Given the centrality of communication difficulties experienced by people with PPA and their families, a referral to speech and language therapy (SLT) seems warranted. Yet, people with PPA report being more

isolated from SLT services than from any other allied health discipline (Riedl *et al.* 2014). The authors of this German study suggest that this may be due to the rarity of the condition, resulting in relatively few people with PPA living within an SLT service's catchment area. This in turn may mean the SLTs themselves have little experience in working with people with the condition. However, in a companion paper to this one reporting different aspects of the same survey, Volkmer *et al.* (2018) highlight one-third of 105 UK SLTs working with people with PPA report an increase in referral numbers over recent years, mostly from neurologists. A total of 353 people with PPA were reported as seen over a 24-month period, averaging 3.27 per SLT respondent. In addition, more than three-quarters of the respondents reported that there were people with PPA who were *not* able to access their services, most often due to a lack of awareness amongst referrers of the SLT's role, difficulties in diagnosis and restrictive service criteria. Researchers in the United States also report an increase in referrals for both assessment and differential diagnosis of PPA variant, as well as for treatment (Henry and Grasso 2018). Taylor *et al.* (2009) hypothesize that, in Australia, neurologists are most likely to refer to SLT as a result of knowledge of the treatment SLTs provide to people with non-progressive stroke-related aphasia.

Given its degenerative nature, care pathways for PPA need to include different components than those for people with acute onset non-progressive aphasia. The European Pathways Association (EPA) (2018) defines a care pathway as 'an explicit statement of the goals and key elements of care based on evidence, best practice and patient expectation'. Volkmer *et al.* (2018) highlight that more than 90% of SLT respondents across the UK who were working with people with PPA reported there was no care pathway for PPA within their services. Taylor *et al.* (2009: 12) reported 'no clear single management pathway' for SLT practice for PPA in New South Wales, Australia.

Previous attempts to outline key elements of care for PPA have come from studies carried out in the United States. For example, Rogers and Alarcon (1998) describe three key principles for management of people

with PPA, including planning interventions in anticipation of continued decline, working with communication partners upon whom individuals will inevitably become dependent, and directing therapy at the level of disability since restitution is not ultimately possible given the deteriorating nature of the disease process. In contrast, a phased approach to treatment has been proposed by Hinshelwood and Henry (2016), whereby in the mild stage of the disease restorative therapies are employed, in the moderate stages Augmentative and Alternative Communication (AAC) and multimodal communication are prioritized, and in later stages there is a focus on environmental supports and communication partner training (CPT). More recently, Rogalski and colleagues have advocated an overarching person-centred approach that 'proactively informs the care plan through dynamic interactions with the clinician' (Rogalski *et al.* 2016: 286) in order to maximize participation in daily life activities and maintain independence (see also Rogalski and Khayum 2018).

While such elements inform a PPA care pathway for SLT services, there remains a paucity of research evidence to underpin specific intervention approaches, and a lack of knowledge of best practice and client expectation. A 2013 systematic review of non-pharmacological interventions for PPA identified 39 studies investigating interventions for a total of 67 people (Carthey-Goulart *et al.* 2013). A total of 21 of these described interventions targeting solely svPPA and 31 of the 39 studies were impairment-based interventions (word relearning). The effectiveness of restorative word-retrieval therapies for PPA is the focus of two more recent systematic reviews (Jokel *et al.* 2014, Cadório *et al.* 2017) and a research update (Croot 2018). A systematic review of the effects of functional communication-focused interventions for people with PPA and their caregivers is currently in preparation by the authors (Volkmer *et al.* 2019).

Despite the focus on impairment-based interventions in the research evidence, limited literature on best practice indicates that functional communication-focused interventions are considered a higher clinical priority (Volkmer 2013). Kindell *et al.* (2015) conducted a study with six SLTs in England to ascertain consensus on the focus of SLT for svPPA (referred to as semantic dementia). The top three therapeutic priorities were enabling better communication with family carers, supporting and educating the multidisciplinary team (MDT), and focusing on abilities and strengths (Kindell *et al.* 2015).

This study aims to reveal the practices of UK SLTs in the areas of assessment and management of PPA, including outcome measurement. The literature suggests that SLTs have a wide-ranging role in supporting people with PPA (Marshall *et al.* 2018, Volkmer 2013) but no one yet has a UK-wide perspective on this.

Materials and methods

This survey conforms to the CHERRIES survey reporting checklist (Eysenbach 2004) and Turket *al.*'s (2018) extension to it. The Departmental Ethics Chair in Language and Cognition at University College London waived approval as the study met the criteria for service evaluation.

Survey development

Previous SLT surveys of clinical practice provided direction on development of survey sections and questions, specifically PPA in an Australian context (Taylor *et al.* 2009), non-progressive aphasia (Beckley *et al.* 2017, Sirman *et al.* 2017) and progressive dysarthria (Collis and Bloch 2012). The literature on speech and language interventions for PPA (Carthey-Goulart *et al.* 2011, Volkmer 2013, Kindell *et al.* 2015) was consulted to guide category fields for questions related to assessment and intervention. Occupational and geographical domains were based on recognized socioeconomic classifications (ONS 2010) and statistical regions (ONS 2009) within the UK. Questions were refined by the first author (an SLT) with expert advice from co-authors to ensure relevance, until a 37-item survey was agreed for initial piloting.

Pilot phase

A convenience sample of six practising SLTs piloted the survey to assess usability. To maintain the largest possible sample for the main study, we invited SLTs based in the UK who do not work with people with PPA, and SLTs who see people with PPA but work in Australia (this was a convenience sample of SLTs known to the first author). Pilot respondents recorded the time taken to complete the survey and provided written feedback on the format, category fields and wording of questions. Modifications in the light of this feedback included introduction of a number of 'other' or 'none' categories and provision of category examples in one question. Additionally, the survey format was modified to ensure respondents had to provide an answer before moving on, and a 'back' button was inserted so respondents could review their answers. After piloting, the number of questions in the final survey was unchanged. Questions were not randomized and page numbers not displayed, but instead a progress bar was provided.

The final survey comprised five sections: (1) Clinical background; (2) Number, type and source of patients; (3) Time spent on management of people with PPA; (4) Specific assessment and intervention approaches; and (5) Outcome measures and planning for the future. There were closed questions (for speed of completion) and open questions to elicit additional information

(Schaeffer and Dykema 2011). For the complete survey, see appendix 1.

Main survey

This survey was delivered online to facilitate dissemination across the UK. It was made available to respondents for 8 weeks from 4 February to 7 April 2016, using Opinio 7.3 software. Once closed, no further responses were recorded. The initial page of the online survey provided a statement making it clear that by continuing, respondents were giving consent to participate in the survey and that their responses would be stored anonymously. No personal data were collected.

Sample selection

In order to achieve a representative cohort of UK SLTs, the Royal College of Speech and Language Therapists (RCSLT) was contacted to facilitate survey dissemination. A letter to the editor containing the survey link was published in the RCSLT practice magazine, *The Bulletin*, which is distributed to all 13,809 practising members. The survey link was also disseminated through an RCSLT electronic research newsletter and was e-mailed to 14 relevant Clinical Excellence Networks associated with the RCSLT for onward dissemination to members. E-mail and social media were also used to disseminate the link through the first and fourth authors' networks, including via Twitter and the first author's blog site. A reminder was sent via all these routes 2 weeks before closing the survey (see the supplemental data online for dissemination details). The e-mail inviting SLTs to take part mentioned the development of an intervention but did not refer to CPT.

Participant inclusion criteria comprised SLTs (1) practising in the UK (practising SLTs are employed in the UK National Health Service (NHS) from a band 5, entry level, to band 8, highly specialist, manager or consultant); and (2) who had ever worked with a person with diagnosed or possible PPA. Respondents completed questions in section 1 of the survey on qualification, years of employment and experience of working with people with PPA. If they did not meet the inclusion criteria at this point, they exited the survey. Respondents who met the study criteria continued to section 2 of the survey.

Data analysis

Following the elimination of duplicates (the last entry was used), completed surveys were extracted and analysed. Data were downloaded to IBM's Statistical Package for Social Science 23 software. Response rates were calculated in accordance with the CHERRIES definition (Eysenbach 2004). Data on referral rates and pat-

terns, and barriers to accessing SLT, are reported in Volkmer *et al.* (2018). This paper reports on care pathways, assessment and intervention practices, outcome measurement, and future planning. A chi square test of independence was performed to examine the relation between intervention type and frequency of use. Remaining data were examined using frequency counts and contingency tables (Sauerbrei and Blettner 2009). For open-ended questions or 'other' response categories, both descriptive statistics, such as coding and counting responses, and qualitative analysis were used. The latter included thematic analysis (Braun and Clarke 2006) of intervention goals supplied by respondents.

Results

Demographics of SLT respondents

There were 179 unique survey visitors, of which 106 agreed to participate by starting to complete the survey, resulting in a participation rate of 179:106. One participant exited the survey because they had insufficient experience with PPA. The remaining 105 had experience of working with people with PPA and submitted complete surveys, resulting in a completion rate of 106:105. There are no available data on numbers of UK SLTs providing services for PPA, therefore it is not possible to calculate the percentage response rate. Respondents were from a range of grade bands between 5 and 8, and worked across several professional locations, that is, primary care, acute health and mental health. Table 1 summarizes respondent characteristics. Just over one-third were employed at band 7 (37.1%, $n = 39$) and just under one-third at band 6 level (31.4%, $n = 33$). More than half had over 10 years' experience (54.3%, $n = 57$). Just under half were based in primary care (45.7%, $n = 48$), with 28 in acute health (26.7%) and 15 in mental healthcare (14.3%). There are no national data on proportions of SLTs employed in primary care, acute health and mental health, yet this sample appears representative as services to mental health are known, within the profession, to be fewer. On comparing respondent rates across UK regions (ONS 2009) the highest number of respondents were from Scotland (17.1%, $n = 18$) and fewest respondents came from the North West of England (1.9%, $n = 2$).

Care pathways

All respondents who reported having a care pathway for people with PPA (9.4%, $n = 10$) were asked to describe this pathway (see figure 1 for key components). One respondent listed an onward referral process to another SLT service. Two respondents described their service's care pathway as comprising only assessment and advice.

Table 1. Characteristics of SLT survey respondents

Years post-qualification		Current banding	
1–2	12.4% (13)	Newly qualified	5.7% (6)
3–4	6.7% (7)	Band 5	6.7% (7)
4–10	26.7% (28)	Band 6	31.4% (33)
> 10	54.3% (57)	Band 7	37.1% (39)
		Band 8	11.4% (12)
		Other	7.6% (8)
Healthcare service		Geographical region	
Acute healthcare	26.7% (28)	East	7.6% (8)
Mental healthcare	14.3% (15)	East Midlands	4.8% (5)
Primary care	45.7% (48)	Northern Ireland	9.5% (10)
Charity/third sector	3.8% (4)	London	13.3% (14)
Independent/private	0	North East	3.8% (4)
Other	9.5% (10)	North West	1.9% (2)
		Scotland	17.1% (18)
		South East	15.2% (16)
		South West	10.5% (11)
		Wales	5.7% (6)
		West Midlands	4.8% (5)
		Yorkshire and the Humber	5.7% (6)

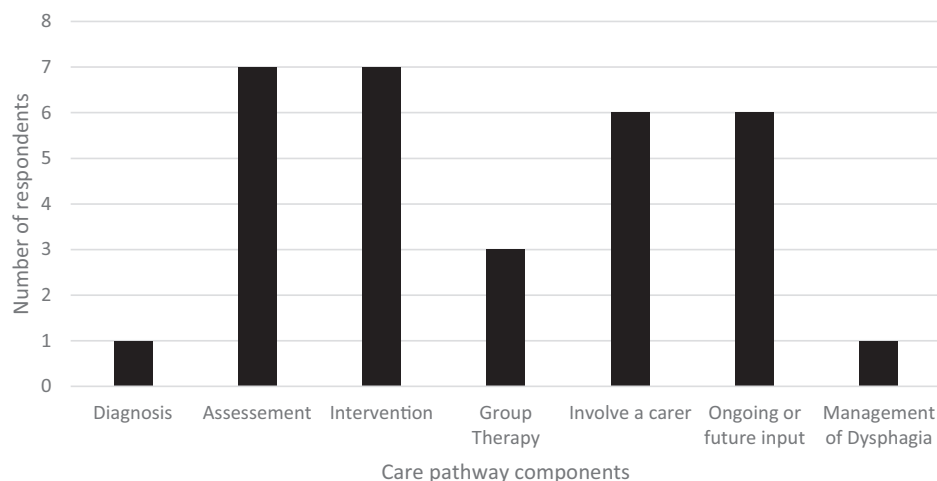
Components of 10 Care Pathways

Figure 1. Components of care pathways described by SLT respondents.

One respondent provided a detailed seven-stage care pathway delivered over six sessions, where following assessment at stage 1, the remaining stages focused on a range of interventions including: 'Rehearsal and integration of appropriate strategies into communication, through modelling, rehearsing and home tasks which incorporate significant communication partners. Provision of information regarding appropriate high-tech communication aids.' This respondent was the only one who referenced the intervention research literature. The other six respondents provided an overview of their service's care pathways by giving some examples of intervention mode (individual, dyadic and group) or activities that may be offered. Only one of the 10 respondents

reporting a local PPA care pathway described dysphagia assessment and management.

Of the 10, only one respondent described being involved in the diagnosis of PPA, although seven respondents stated that assessment was part of the care pathway. When describing the assessment stage of the care pathway, one respondent provided detailed information including tools used:

Assessment of impairment and activity/participation. This will include an aphasia and communication strengths and weaknesses profile, with specific consideration of spontaneous strategy use by the client. It will also include identification of the client's significant communication partners and their roles.

(Assessments: dynamic testing with Boston Naming Test (BNT); PALPA subtests; CAT subtests).

Seven of the 10 respondents with a care pathway stated that intervention was a part of it, with two explaining that this was based on the 'individual's profile'. Three respondents mentioned impairment-focused interventions, with one of the three describing the provision of:

Impairment based neuro-protective therapy drilling of functional words (written and/or spoken as appropriate) through modelling in session and in home tasks. Control items to be used to aid evaluation of this input.

Another respondent added the caveat that:

A package of impairment-based therapy may be offered and provided if the client is keen, has support and responds well.

Education and 'explanation of the condition' were mentioned by three respondents as part of the intervention stage of their service's care pathway. Three respondents described provision of group therapy (one of whom specified a couples group), and six respondents described involvement of a carer.

Functional communication-focused intervention options were described by four respondents, with one commenting:

Training in supportive conversational partner strategies offered (not formal training package, but tailored to individual). Low-tech AAC & communication passports/life story work.

Finally, six of the 10 respondents with a care pathway described ongoing or future input such as onward referral to other services, signposting to support groups, and review or maintenance sessions within the SLT service.

All respondents were asked how many sessions they devoted to assessment and management activities. Respondents were given the following definitions:

- Assessment includes assessment of language and communication, contributing to the diagnosis of PPA, and assessment of dysphagia and mental capacity assessment.
- Management includes case/care review meetings, joint sessions with other disciplines, education for the person with PPA, family education, staff education, impairment-focused language intervention, functional communication-focused interventions, combined language/communication-focused intervention, group therapy with people with PPA, and management of dysphagia.

Figure 2 summarizes the average number of SLT sessions respondents reportedly spent on assessment and management activities. On average, respondents spent

2.2 sessions on communication assessment, but only 1.2 sessions on diagnosis, 0.8 sessions on dysphagia assessment and 0.5 sessions on mental capacity assessment. The results show that respondents spent more time on functional communication-focused interventions than on any other activity, with an average of 4.9 sessions. This contrasts with 2.8 sessions for impairment-focused intervention, 2.8 sessions for combined language and communication intervention, 2.0 sessions on family education, 2.0 sessions on education for the person with PPA, and 1.5 sessions on group therapy. The smallest amount of time was spent on joint sessions with other disciplines, on average 0.5 sessions.

Assessment tools

Respondents were asked to rate on a five-point scale (never, occasionally, sometimes, often, always) the frequency with which they used a selection of 10 listed assessment tools over the last 24 months. Figure 3 presents the reported frequency of use of assessment tools. The least used tool, Mini Mental State Exam (MMSE; Creavin *et al.* 2016), was rated as never used by 83% ($n = 87$) of respondents and always used by 1.9% ($n = 2$) of respondents. Comparatively the most used tool, informal interview, was rated as never used by 4.7% ($n = 5$) respondents and always used by 78.1% ($n = 82$) of respondents. The second most commonly used tool, informal functional assessment, was rated as never used by 6.67% ($n = 7$) of respondents and always used by 65.7% ($n = 69$) of respondents. The third most commonly used tool, informal impairment-based communication screen, was rated as never used by 15.2% ($n = 16$) and always used by 38.1% ($n = 40$). The most commonly used formal published assessment was identified as the Comprehensive Aphasia Test (CAT; Swinburn *et al.* 2004), always or often used by 44% of ($n = 46$) respondents and never used by 30.5% ($n = 32$) of respondents. When asked to state other assessments they used, respondents identified 28 further formal tools. The most commonly named were the Mount Wilga High Level Language Test (Christie *et al.* 1986) (mentioned by six respondents), the Montreal Cognitive Assessment (MOCA; Freitas *et al.* 2012) (five respondents), the Butt Non Verbal Reasoning Test (Butt and Bucks 2017) (three respondents) and the Controlled Oral Word Association Test (COWAT; Patterson 2011) (three respondents). Of the remaining 24 stated tools, four were suggested by two respondents each, and the remainder by one respondent each.

Intervention approaches

Respondents were asked to rate on a five-point scale the frequency (never, occasionally, sometimes, often, always)

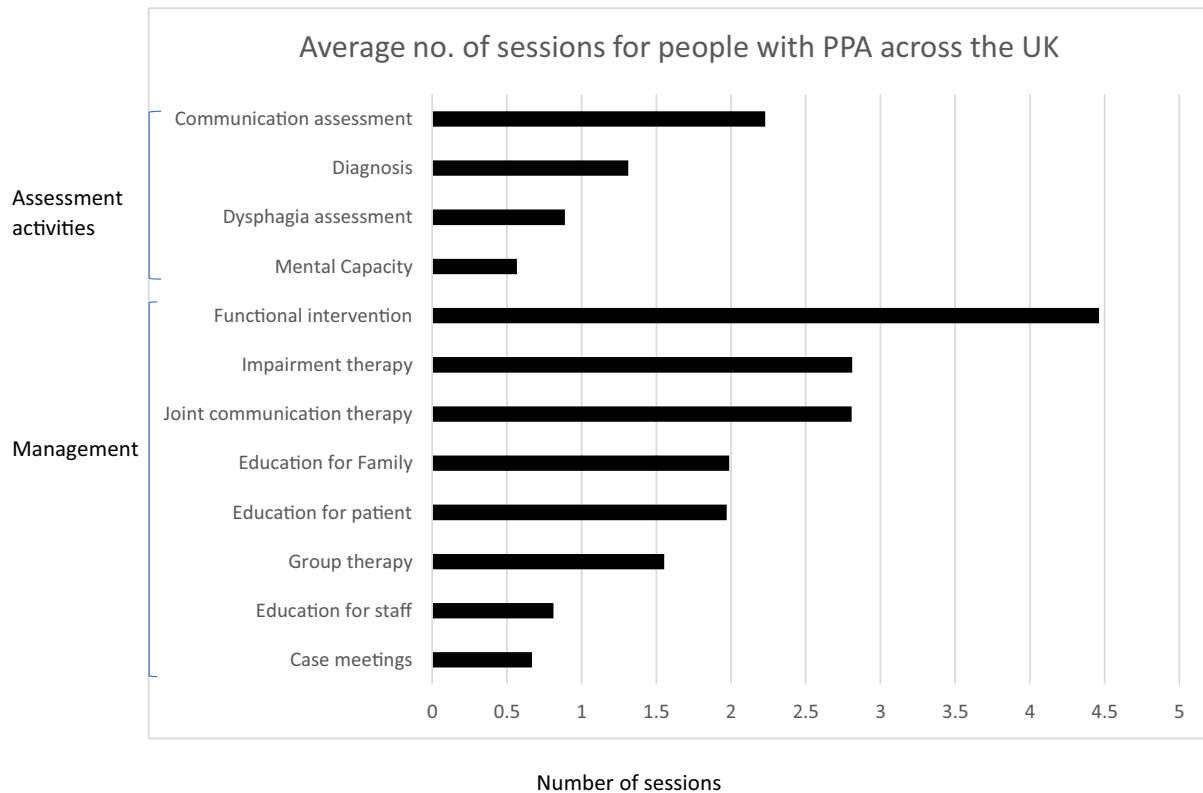


Figure 2. Average number of sessions spent on assessment and management activities by SLT respondents working with people with PPA across the UK. Assessment activities were defined as: assessment of language and communication, contributing to diagnosis of PPA, dysphagia assessment and mental capacity assessment. Management activities were defined as: functional communication-focused interventions, impairment-focused language intervention, combined language/communication-focused intervention, family education, education for a person with PPA, group therapy with people with PPA, staff education, and case/care review meetings. [Colour figure can be viewed at wileyonlinelibrary.com]

with which they had used seven listed intervention approaches over the last 24 months. Figure 4 presents the reported frequency of use of intervention approaches. The least used intervention approach, impairment directed interventions for speech production, was rated as never used by 69.5% ($n = 73$) of respondents. No respondents indicated they always used this approach, but it was often used by 8.6% ($n = 9$) of respondents. Comparatively the most used intervention, communication training for families and carers, was rated as never used by 1.9% ($n = 2$) and always or often used by 84.8% ($n = 81$) of respondents. The second most commonly used intervention, functional communication-focused interventions, was rated as never used by 17.1% ($n = 18$) and always or often used by 42.9% ($n = 45$) of respondents and sometimes used by 28.6% ($n = 30$) of respondents. Communication training for staff was rated as never used by 37.1% ($n = 39$) respondents, always used by 20% ($n = 21$), and sometimes used by 29.5% ($n = 31$). Impairment directed interventions were rated as never used by 30.5% ($n = 32$), always or often used by 20% ($n = 21$), and sometimes used by 31.4% ($n = 33$). A chi square test of indepen-

dence was performed to examine the relation between intervention type (communication training/impairment focused) and frequency of use (always/never). The relation between these variables was significant, $\chi^2(2, N = 215) = 71.6442, p = 0.00$, demonstrating that communication training is significantly more likely to be rated as always used than impairment-focused intervention. When asked to state other intervention approaches they used, respondents reported 12 options. The most commonly identified were communication books and wallet cards, mentioned by 14 respondents, whilst life story work and total communication strategies were each suggested by three respondents.

Measuring outcomes

When asked which outcome measures they used to document progress in therapy, respondents were able to choose multiple options from a list of six options. Goal setting was reported as the most commonly used measure (53.8%, $n = 57$), followed by self-rating scales completed by the person with PPA or their communication partner (50%, $n = 53$), language assessment (48.1%,

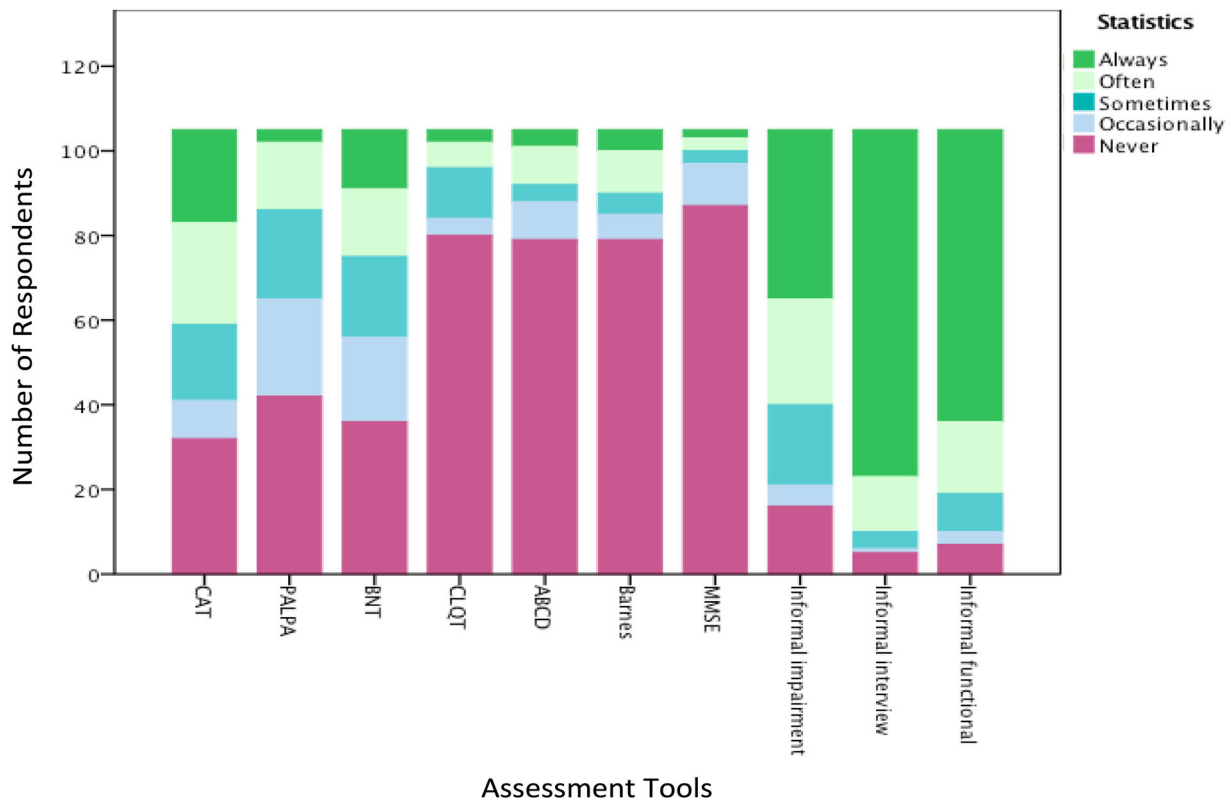


Figure 3. Frequency of reported use of assessment tools with people with PPA over the last 24 months. [Colour figure can be viewed at wileyonlinelibrary.com]

$n = 51$), Therapy Outcome Measures (TOMS; Enderby *et al.* 2013) (34.9%, $n = 37$), rating scales completed by the SLT (19.8%, $n = 21$), and video-recording of conversation (7.6%, $n = 8$) (the exact aspect of the recording that provided an outcome measure is not known since we did not ask respondents to provide further information). Respondents were asked for examples of other outcome measures they used and provided nine further tools. Audio recording, and the East Kent Outcome Measure (EKOS; Murphy and Logan 2009) were each identified by two respondents, whilst the remaining seven measures: Aphasia Impact Questionnaire—21 (Swinburn 2013), client feedback, carer feedback, informal naming assessment, Communication Outcomes after Stroke (Long *et al.* 2008), Cognitive Linguistic Quick Test (Helm-Estabrooks 2001) and Visual Analogue Self-Esteem Scale (Brumfitt and Sheeran 1999), were identified by only one respondent each. Respondents were asked to provide examples of the types of goals set and provided 88 in total. Six separate main themes arose from analysis of these goals: communication aid; conversation; functional communication; impairment focused; practising a strategy; and communication partner. Figure 5 provides examples of the goals listed by respondents. Each goal was assigned to one theme. Of the 88 goals, 50% ($n = 44$) fell into the second and

third themes: conversation; and functional communication. Conversation goals centred around using specific strategies, such as gesture or drawing, in conversations. A total of 14 of the functional communication goals related to completing specific functional communication activities with family and friends, such as ordering a meal or coffee. A total of 30% ($n = 29$) of goals focused on using a communication aid (first theme), such as tablet devices and wallet cards or communication books in a specific situation only 10% ($n = 9$) of goals fell into the fourth theme impairment focused, which comprised those associated with word relearning and naming, such as learning a certain number of words in a certain time frame. A total of 16% ($n = 14$) of goals fell into the fifth theme, practising a strategy, such as learning to use circumlocution effectively when experiencing a word finding difficulty. Finally, 9% ($n = 8$) of goals targeted a communication partner and focused on using a specific strategy to support or enable their partner with PPA in conversations.

Future planning and onward referral

Respondents were asked whether they addressed cognitive changes and deterioration in communication, legal issues including assessment of capacity, driving, family

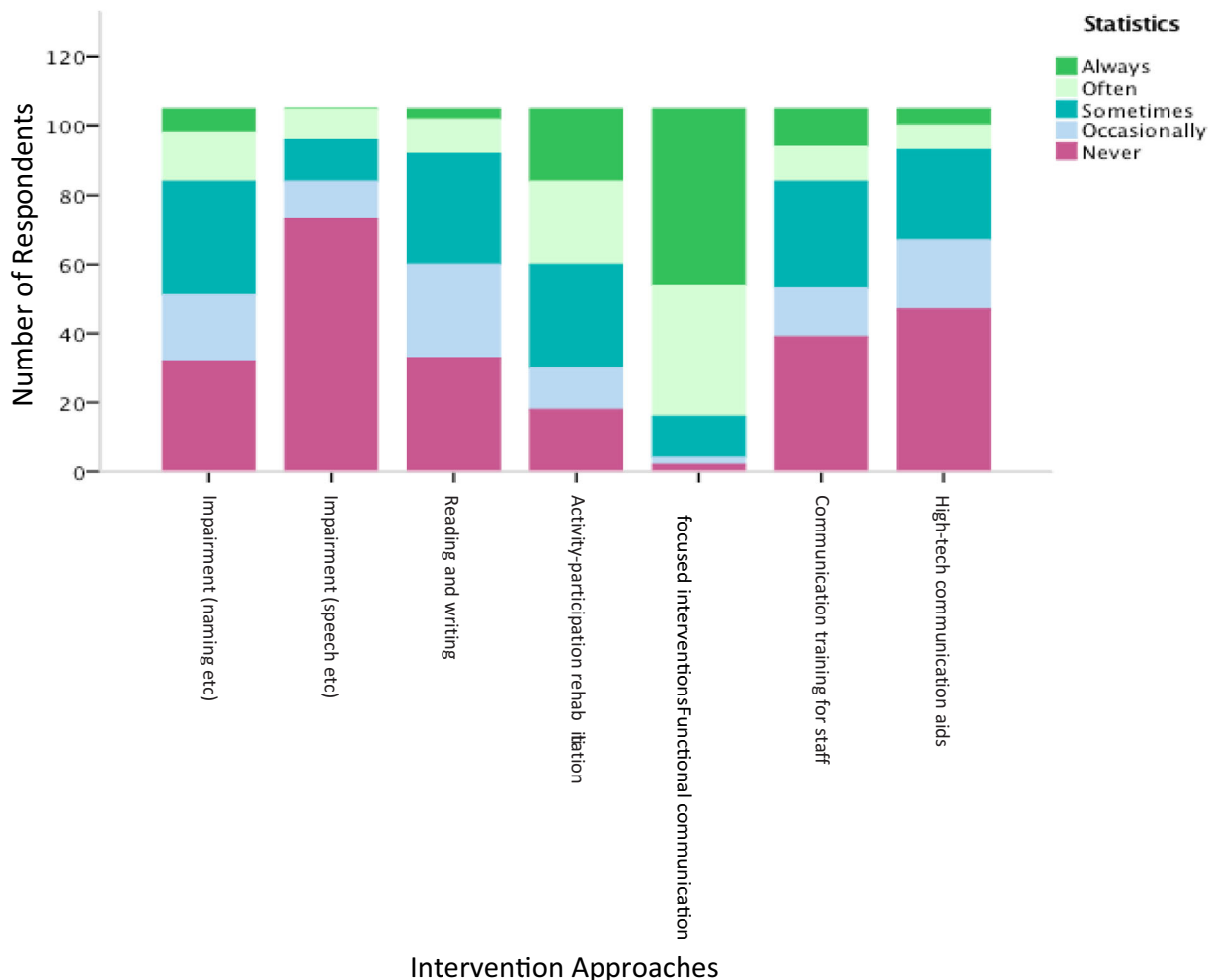


Figure 4. Frequency of reported use of intervention approaches with people with PPA over the last 24 months. [Colour figure can be viewed at wileyonlinelibrary.com]

care supports, or family finance supports in planning for the future with people with PPA (table 2). Almost all respondents (85.9%, $n = 91$) reported that they explicitly addressed both cognitive changes and deterioration in communication. When asked to give other examples of what they addressed when planning for the future, respondents identified the following additional issues: educating children; supporting other staff; housing; signposting carers to organizations for social and emotional support; and advance care planning. Respondents reported the most commonly used third-sector organizations for onward referral to be the Alzheimer’s Society and the Rare Dementia PPA Support Group. Local aphasia and memory groups, dementia cafes, and other dementia groups were listed, as well as a variety of organizations such as Befriending, Age UK, Age Northern Ireland, Alzheimer’s Scotland, Motor Neurone Disease Scotland, Young People with Dementia Groups, and Admiral Nursing.

Discussion

The role of SLTs in PPA is an emerging area of practice across the UK. This survey highlights the range of current assessment and intervention practices of SLT respondents working with people with PPA. Importantly these results demonstrate that the range of interventions used by respondent SLTs extend beyond those with a developed evidence base for PPA. The surveyed SLTs report that they prioritize communication training for families, suggesting that the needs of people living with PPA and their families are not being met by a focus on impairment alone.

Care pathways have a positive impact on the way care is organized (Seys *et al.* 2017). At present, there are no national care pathways for people with PPA or FTD, and only a small number of respondents reported having PPA care pathways within their services. A defining characteristic of a care pathway is

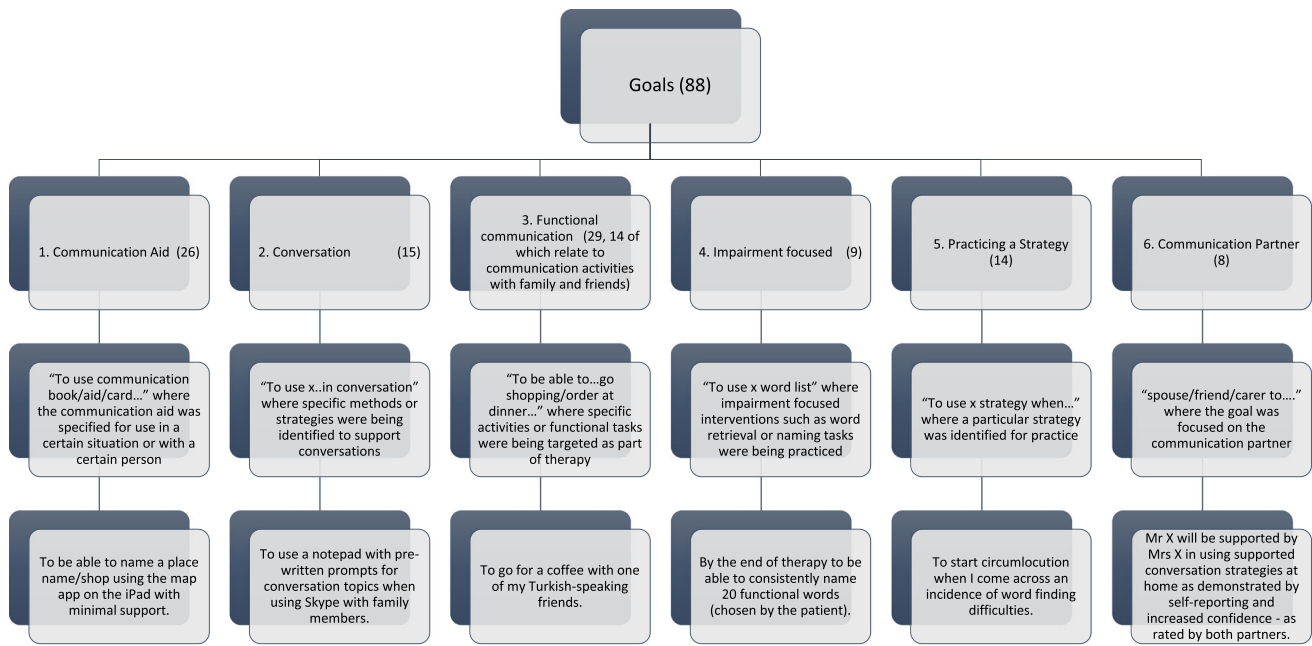


Figure 5. Example goals given by respondents organized by theme. [Colour figure can be viewed at wileyonlinelibrary.com]

Table 2. Future planning and onward referral (% response; multiple responses allowed)

<i>Areas that SLTs explicitly address in future planning</i>	
Cognitive changes and deterioration in communication	85.9% (n = 91)
Planning for legal, financial, health and social care issues including assessments of capacity	44.3% (n = 47)
Family care supports such as respite	38.7% (n = 41)
Driving	18.9% (n = 20)
Family, financial supports such as benefits	15.1% (n = 16)
<i>Most commonly used third sector organizations for onward referral</i>	
Alzheimer’s Disease Society	51.9% (n = 55)
Rare Dementia PPA support group	28.4% (n = 30)
Stroke Association	15.1% (n = 16)
Connect	13.2% (n = 14)
Dyscover	3.8% (n = 4)

identification of the required healthcare resources (The European Pathways Association 2018). Of the pathways described by respondents, only seven of the 10 included both assessment and intervention, and only one respondent outlined a detailed care pathway linked to the current research evidence. Without this kind of care pathway in place, SLTs may find it difficult to commission and thus deliver best practice care for people with PPA.

Despite there being a number of dementia-specific formal assessment tools available, the most popular assessments that respondents reported on were informal interviews, functional observation and a stroke aphasia language battery (CAT; Swinburn *et al.* 2004). Henry

and Grasso (2018) observe that standard aphasia batteries developed for use with stroke-related aphasia are better able to characterize the language profile of an individual with PPA, and to distinguish between PPA variants, in order to plan interventions, whilst assessments of dementia are generally designed to assess changes in cognition rather than language. Notably, Henry and Grasso (2018) point out that a number of tools to assess language in PPA and support intervention planning are only available in journal articles or by contacting university departments in the United States and Australia. SLTs working in clinical settings in the UK are often unable to access peer-reviewed articles, unless their employer subscribes to the relevant journal, which may account for these respondents’ overwhelming preference for informal assessment tools. This may indicate that SLTs are unsure of what formal assessment are best to use with this client group. Alternatively, this may illustrate the need for more available assessment tools designed for people with PPA that support both diagnostic profiling and intervention planning.

The average number of sessions available for impairment-focused interventions (2.8) reported by respondents is significantly less than the number of sessions reported to be effective in a recent review of impairment-based interventions for PPA (Cadório *et al.* 2017). This review examined evidence from studies delivering interventions over a range of between five and 96 therapy sessions. Despite there being little indication of the ‘optimal’ dose, longer interventions did result in better outcomes in people with svPPA (Cadório *et al.* 2017). It is possible that these SLT respondents

deprioritize impairment-based interventions knowing they are unable to deliver them at the intensity reported in the research literature. Indeed, 80% of SLT respondents identified that they would never or only occasionally use impairment-focused interventions for speech production, and 48.6% would never or only occasionally use impairment-focused interventions for naming. The disparity between recommended and clinically delivered dosages is also a known issue in stroke aphasia interventions (Doogan *et al.* 2018).

Clinical commissioning of healthcare in England is based on evidence produced in scientific research as well as local data, expertise and experiences (Swan *et al.* 2017). This approach to commissioning may account for some of the diversity in the amount of therapy that is reportedly available from SLT respondents to this survey; some services may be commissioned on expertise to which other commissioning groups do not have access. If occupational therapy or social care services for PPA are not commissioned, then an SLT may be the only health professional involved in a person's care. Consequently, these SLT respondents may prioritize broader issues such as future planning, thus reducing the time available for speech and language interventions.

When selecting intervention approaches for people with PPA, 84.8% of survey respondents reported that they always or often choose CPT for family and carers. Similarly, 37 of 88 goals listed by survey respondents focused either on conversation or on communication with family and friends, or on engaging in functional activities with family and friends. This emphasis on enabling better communication between the person with PPA and their family carer aligns with the consensus results of Kindell *et al.* (2015), which the authors describe as 'carer-focused person centred' dementia care. Rogalski and Khayum (2018) explain that the core elements of a person-centred approach to PPA include working with a client in order to facilitate their participation in everyday activities. Communicating with family and friends is a crucial everyday activity. As yet, there is no research demonstrating the effectiveness of this approach for people with PPA and their families (Taylor-Rubin *et al.* 2017).

Implications

This survey suggests that as a profession we need to investigate the potential to develop a care pathway for PPA in our services, then to shape this pathway to bring together scientific research, best practice and service user priorities in order to influence health commissioning. This study presents national data that SLTs can use in support of this aim. Given how many SLTs in this survey report using communication training for people with PPA and their families, demonstrating its effectiveness

is also of high priority for the speech and language research community. This evidence will in turn support future endeavours to influence a national care pathway for PPA, which will require rigorous evidence to inform recommendations.

Limitations

It is difficult to assess how many SLTs across the UK received this survey. The RCSLT estimates that 2000 of its registered members work with adults, but there are no data on client groups, which could include, amongst others, head and neck cancer, voice, stroke, and mental health. This figure also excludes SLTs not registered with RCSLT (this is not obligatory for employment in the NHS), who may be working in private or third-sector organizations. Yet, with a sample size of 105, representing all geographical regions of the UK, the number of respondents to this survey compares favourably with other surveys of SLT practice, with respondent numbers ranging between 13 and 147 (Taylor *et al.* 2009, Collis and Bloch 2012, Beckley *et al.* 2017, Miller and Bloch 2017, Sirman *et al.* 2017). A further limitation includes access to the survey software, with some SLT respondents reporting that this was blocked by local information technology services. This may have prevented some SLTs from responding.

Conclusions

This survey has highlighted a range of assessment tools and intervention practices used by SLT respondents working with people with PPA. SLT respondents in this study preference the use of CPT over other interventions, despite the lack of research evidence examining its effectiveness for PPA. This approach appears to complement other aspects of a potential care pathway for PPA, such as managing cognitive and communication deterioration, and issues related to future decision-making. Importantly this study has highlighted the need for evidence-based care pathways to guide SLTs working in this emerging area of practice. Care pathways can enable SLTs to advocate for commissioning of appropriately resourced services.

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Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

Supplementary Material 1 Appendix 1: Survey Questions

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