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# A Community-Driven Approach to the Development of a Digital Decision Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African-American Men in Communities of Faith

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A COMMUNITY-DRIVEN APPROACH TO THE DEVELOPMENT OF A  
DIGITAL DECISION AID TO FACILITATE INFORMED DECISION  
MAKING FOR PROSTATE CANCER SCREENING AMONG AFRICAN-  
AMERICAN MEN IN COMMUNITIES OF FAITH

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## **DEDICATION**

To those who believed.

Thank you to my family, friends, committee, and colleagues who have supported me throughout this academic journey. I could not have done this without you.

## ACKNOWLEDGMENTS

I would like to thank Dr. Daniela Friedman, my committee chair and advisor for her tireless support of my efforts to become a leader in digital health communications. I have certainly been fortunate to have her and such a tight knit committee (Dr. Heather Brandt, Dr. Jay Bernhardt, and Dr. James Hebert) to guide my research and provide fruitful feedback on my many presentations, publications, funding applications, job decisions, and the list goes on. I would also like to thank the funders of my dissertation research: USC's Science and Health Communication Research Group, USC's Institute for African American Research, and USC's Office of the Vice President for Research. Finally, I would like to thank the 39 men who not only sacrificed their time to help me in my research endeavors, but also served as pillars of support throughout the research process.

## ABSTRACT

**Background:** African American (AA) men are significantly more likely to die of prostate cancer (PrCA) than other racial groups. Therefore, it is critical to identify effective strategies for providing information about the risks, benefits, and uncertainties of PrCA screening and the importance of informed decision making (IDM). To assess whether a computer-based IDM decision aid (DA) for PrCA screening would be appropriate for middle-age and older AA men, this formative evaluation study examined participants (1) PrCA risk and screening knowledge, 2) decision-making processes for PrCA screening, and 3) usage of, attitudes toward, and access to interactive communication technologies (ICTs). The usability and acceptability of the DA also was assessed. **Methods:** Thirty-nine AA men, ages 37-66 in South Carolina, were recruited through faith-based organizations to participate in one of six 90-minute focus groups (FGs) (Phase I) and to complete a 45-item demographic and health information seeking survey. Twenty-one of these 39 men volunteered to participate in one of seven additional FGs to provide feedback on a storyboard, script, and demonstration of a DA. They were also asked to complete a 35-item computer fluency and self-efficacy survey (Phase II). A full prototype of the DA was developed by the research team based on information gathered through Phases I and II FGs. A heuristic evaluation survey and prototype of the DA was sent to seven expert reviewers. Ten of 21 participants involved in Phase II FGs were randomly selected to participate in a 30- to 60-minute in-depth interview to assess the usability of the DA. **Results:** Participants were knowledgeable about PrCA; however,

few engaged in IDM with their doctor and few were informed about the associated risks and uncertainties of PrCA screening. Most participants used ICTs on a daily basis for various purposes, including health information seeking. They were also open to using a novel computer-based DA for PrCA IDM if the system was easy to use and characters (e.g., avatars) were culturally appropriate. With regard to the usability, both participants and expert reviewers were accepting of most aspects of the DA, but suggested minor changes to improve effectiveness (e.g., improve avatar aesthetics). **Conclusions:** Because AA men have low exposure to IDM for PrCA, but frequently use ICTs for multiple purposes including health information seeking, digital DAs may be appropriate for this population. These DAs should not only aim to increase PrCA screening knowledge (especially regarding the risks and uncertainties of screening), but also stress the importance of IDM and prepare the user to engage in IDM with a doctor. It is also important to engage the community and expert reviewers in a formative, multi-stage development process to ensure that the resulting DA is optimal for use in the specific community. Future research should explore the effectiveness of the DA on AA women. The impact of the DA should also examine the impact of the DA when expanded to other channels (e.g., mobile phones).

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## CHAPTER 1

### INTRODUCTION

While prostate cancer (PrCA) is the most commonly diagnosed non-skin cancer among all men, there is a pronounced disparity in the incidence and mortality rates between African-American (AA) and European-American (EA; i.e., White) men. More specifically, AA men have an incidence rate of PrCA that is over 50% higher than in EAs on average (American Cancer Society, 2013c; DeSantis, Naishadham, & Jemal, 2013; U.S. Cancer Statistics Working Group, 2013), and this differential is 1.5 times larger in South Carolina (SC) (Hebert, et al., 2009b). Mortality disparities are even more extreme (about 2.5 times higher in AAs) (Hebert et al., 2009b). Owing in part to these racial disparities (i.e., while ignoring cancer in EAs, where disease is much more indolent) is the fact that PrCA has very different implications in AAs, in whom disease tends to be more aggressive. This has led to considerable controversy regarding the benefits of PrCA screening (Andriole et al., 2009; Barry, 2009; Schroder, et al., 2009; Smith, Cokkinides, & Brawley, 2012; U.S. Preventive Services Task Force, 2011). Whereas some non-profit and grassroots organizations embrace the lifesaving potential of prostate-specific antigen (PSA) screening (Mitka, 2009; National Medical Association, 2011; Us TOO International, 2011), some medical and research experts disagree about the efficacy of the test (Barry, 2009). Most notably, the United States Preventive Services Task Force (USPSTF) had previously found inconclusive evidence regarding the effectiveness of PrCA screening for men less than 75 years of age, its recently released report advises

against PSA screening for healthy men of all ages (U.S. Preventive Services Task Force, 2011). However, organizations, such as the American Cancer Society (ACS) and the American Urological Association, recommend that men make an informed decision with their doctor about whether or not to be screened for the disease (American Cancer Society, 2013c; American Urological Association, 2011). In order to make an informed decision, individuals must have clear, understandable information (Informed Medical Decisions Foundation, 2012). Therefore, the Institute of Medicine continues to recommend the use of effective, plain-language, and culturally appropriate communication strategies to reach people with varying levels of health literacy (Institute of Medicine, Committee on Health Literacy, & Board of Neuroscience and Behavioral Health, 2004).

Several research studies have recognized interactive communication technologies (ICTs) (e.g., kiosks) as effective and culturally appropriate mediums for disseminating plain-language health content to diverse populations (Bernhardt, Mays, Eroğlu, & Daniel, 2009; Bernhardt, Mays, & Kreuter, 2011; Gielen et al., 2007; Porter, Cai, Gribbons, Goldmann, & Kohane, 2004; Thompson, Lozano, & Christakis, 2007) and serving as decision-making aids for the prevention and/or treatment of a number of chronic diseases, including lung, colorectal, and PrCA, diabetes, and cardiovascular disease (Allen, Mohllajee, Shelton, Drake, & Mars, 2009; Banegas et al., 2013; Cupertino, et al., 2010; Ellison, Weinrich, Lou, Xu, Powell, & Baquet, 2008; Evans et al., 2010; Jeste, Dunn, Folsom, & Zisook, 2008; Jimbo, Kelly-Blake, Sen, Hawley, & Ruffin, 2013; Kassan et al., 2012; Lindblom, Gregory, Wilson, Flight, & Zajac, 2011; Miller et al., 2011; Ozanne, Annis, Adduci, Showstack, & Esserman, 2007b; Sawka et al., 2011; Schrijvers,

Vanderhaegen, Poppel, Haustermans, & Audenhove, 2013; Schroy, Mylvaganam, & Davidson, 2014; Shaffer, Owens, & Zikmund-Fisher, 2013; Wakefield et al., 2011; Weymiller et al., 2007). **However, there have been no studies to date that have tested the feasibility of using an avatar-led, computer-based decision aid (DA) in a faith-based setting to facilitate the informed decision making (IDM) process for AA men regarding PrCA screening.** This study addressed the high saliency of PrCA in SC (ranks 4<sup>th</sup> in the nation for PrCA deaths with the highest mortality rate in AA men) (South Carolina Department of Health and Environmental Control, 2011) by leveraging faith-based partnerships (SC ranks 3<sup>rd</sup> in the nation for highest church attendance) (The Pew Forum On Religion and Public Life, 2009) and drawing on the past successes of mentors and others with employing community-based approaches to address health disparities (Braun et al., 2012; Friedman, et al., 2012a; Friedman, Thomas, Owens, & Hebert, 2012c; Friedman et al., 2012d; Thomas, Owens, Torres, Friedman, & Hebert, 2012a; Wilcox et al., 2010). **The overall goal of this study was to conduct formative research that promoted and facilitated IDM regarding PrCA screening in SC, particularly among AA men.** The study involved the development and testing of a computer-based, avatar-led, IDM DA for PrCA screening. The research was guided by a technology acceptance framework (Venkatesh, Morris, Davis, & Davis, 2003) and operationalized through a community-based approach. Some elements of this community-based approach were adopted from the community-based participatory research literature (Israel et al., 2010; Israel, Schulz, Parker, & Becker, 2001; Israel, et al., 2003; Schulz et al., 2011; Strong et al., 2009). Community-based approaches emerge as a critical strategy to engage stakeholders and identify culturally and geographically

appropriate methods to overcome health and cancer disparities (Braun et al., 2012; Friedman et al., 2012d; Hebert, Brandt, Armstead, Adams, & Steck, 2009a; Jandorf, et al., 2006; Wallerstein & Duran, 2010). The community-based approach was key to the success of this research because it provided AA men in the targeted community with an opportunity to actively collaborate with researchers in order to develop an optimal resource for enhancing their ability to make informed decisions about PrCA screening.

### **Specific Aims**

#### **Aim 1**

To determine AA men's (1) current PrCA risk and screening knowledge, (2) decision-making processes for PrCA screening, and (3) usage of, attitudes toward, and access to ICTs (e.g., computers, ATMs, kiosks).

**RQ1.** What do AA men know about the risk factors and symptoms for PrCA?

**RQ2.** What do AA men know about the types of PrCA screenings and the risks, benefits, and uncertainties of these screenings?

**RQ3.** How are AA men making decisions about PrCA (e.g., shared, individual)?

**RQ4.** In general, how often, and for what purposes are AA men using technology?

***Aim 1 methods.*** A purposive, (Patton, 1990) convenience sample of AA men ages 40-65 years from local State Baptist Young Women's Auxiliary Health Ministry (SBYWA) affiliated churches were recruited to participate in 90-minute focus groups (Phase I). A maximum of 10 men were included in each of the six focus groups (FGs). The FG guide was based on pre-existing instruments, but included some original items. A short demographic survey was also administered. Qualitative data were analyzed using

both open and axial coding techniques to identify relevant themes within and between the six FGs (Strauss & Corbin, 1998). Quantitative data from the demographic survey were analyzed using SPSS v 20 (SPSS Inc., 2012). A manuscript describing findings from Aim 1 will be submitted to the *American Journal of Men's Health* (See Chapter 4, Manuscript 1).

## **Aim 2**

To develop and assess the usability and acceptability of an interactive DA for increasing knowledge, self-efficacy, and intention to make an informed decision about PrCA screening among AA men in faith communities.

**RQ5.** What are AA men's perceptions about the user-friendliness of the DA (i.e., ease of use)?

**RQ6.** What are AA men's perceptions about whether or not people in the community will support their use of a DA for seeking PrCA information?

**RQ7.** What are AA men's perceptions about whether or not a collaboratively developed DA will increase their prostate knowledge?

**RQ8.** What are AA men's perceptions regarding whether or not a collaboratively developed DA will increase their IDM self-efficacy and intention to participate in IDM?

**RQ9.** What are AA men's perceptions regarding whether or not a collaboratively developed DA will increase their self-efficacy relating to their technology use?

**RQ10.** What are AA men's perceptions regarding whether or not they will have enough technological support to use the DA (e.g., help from someone else if they have a question about kiosk)?

**RQ11.** What are experts' perceptions about whether or not the DA meets industry standards and best practices?

**Aim 2 methods.** Men who were previously recruited to participate in Aim 1 FGs were invited to participate in one of seven additional FGs in which they provided feedback on a script, storyboard, and sample prototype of the DA that were developed based on themes identified in Aim 1 (Phase II). The most common themes were used to make changes to further develop the DA. After the final DA was developed, it underwent expert review by faculty in media arts, digital health, and health communication to determine whether the DA met industry standards and utilized best practices. Following the receipt of input from the panel of expert reviewers, 10 men who participated in Phase II FGs were randomly selected to participate in in-depth interviews to solicit their perceptions about whether the DA could lead to the targeted outcomes (e.g., IDM self-efficacy). Questions for the FGs and in-depth interviews were developed based on existing instruments. Prior to the FGs, these 21 men were provided with a 36-item survey to determine men's perceived overall health, health literacy, decisional conflict, decision self-efficacy and (5) computer, email and web fluency. All qualitative data were analyzed using both open and axial coding process to identify common themes in FGs and in-depth interviews. All quantitative data was analyzed using SPSS v 20. (SPSS Inc., 2012). A manuscript based on findings from Aim 2 will be submitted to the *Journal of Health Communication* (See Chapter 4, Manuscript 2).

This study contributed to the development of a DA to facilitate IDM in AA men regarding PrCA screening and lead to increased participation in IDM among AA men, who are at risk of the most aggressive PrCA in the world (American Cancer Society,

2011, 2013c; U.S. Cancer Statistics Working Group, 2013). In addition, the results for this study can be used to: 1) inform the greater science and health communication community about the potential efficaciousness of working collaboratively with AA men to develop a new technology to assist with their IDM and 2) provide best practices to researchers on developing potentially effective, health communication technologies through community/academic partnerships.

## CHAPTER 2

### LITERATURE REVIEW

#### **Cancer Burden**

In 2013, the ACS estimated that more than 238,590 new cases of PrCA will be diagnosed and 29,270 men will succumb to the disease (American Cancer Society, 2013c). However, the burden of premature deaths due to PrCA is not consistent across racial and ethnic groups. African American males are at a 50% higher risk than their EA counterparts of being diagnosed and suffer higher mortality from PrCA than any other racial or ethnic group (American Cancer Society, 2013b, 2013c; DeSantis et al., 2013; U.S. Cancer Statistics Working Group, 2013). These differentials are about 50% higher in SC than in the country as a whole (Drake et al., 2006). The mortality rates in AAs, especially in SC, argue strongly in favor of addressing this serious public health problem in a cogent way.

#### **Prostate Cancer Etiology**

There has been no specific cause identified for PrCA or the disparities that exists between AA and EA men. However several researchers have suggested multiple genetic, biological, and environmental factors that can lead to AA men being diagnosed with more aggressive cancers at earlier ages than their EA counterparts (Chang et al., 2011; Drake et al., 2006; Ekman, 2012; Mason et al., 2010; Nguyen et al., 2010; Post et al., 2011; Powell, Bock, Ruterbusch, & Sakr, 2010; Powell et al., 2013; Rose et al., 2010; Wallace et al., 2008). For example, some biomarkers, such as androgens, have been

linked increased PrCA risk (Kim et al., 2011). In a recent comparative study on PrCA-specific biomarkers in EA and AA men, researchers found that all six of the studied biomarker levels were expressed at significantly higher levels in AA men (Kim et al., 2011). Similarly, there have been multiple studies that have recognized specific genes that serve as inflammatory conduits to PrCA and these genes are commonly expressed disproportionately in AA men (Odedina et al., 2009; Okobia, Zmuda, Ferrell, Patrick, & Bunker, 2011). In addition, there have been several studies that have found both dietary (e.g., fatty-meat consumption) (Davies, Batehup, & Thomas, 2011; Hsing & Chokkalingam, 2006; Kristal, et al., 2010; Ma & Chapman, 2009; McCarty, 2001) and environmental (e.g., pesticides, cadmium) (Aimola et al., 2012; Hartwig, 2013; Mullins & Loeb, 2012) factors that can potentially affect PrCA risk through the increased production of serum insulin, testosterone, and other hormones. Based on these studies, AAs may be at a higher risk for PrCA than EAs because they are more likely to have high-fat, low fruit and vegetable diets (Dubowitz et al., 2008; Gary et al., 2004; Hite et al., 2010) and have a higher likelihood of residing in a neighborhood where they are more susceptible to being exposed to environmental pollutants (Ash & Fetter, 2004; Wilson, Richard, Joseph, & Williams, 2010). However, further research is needed on all of the aforementioned causal paths for PrCA and PrCA disparities.

### **Types of Prostate Cancer Screening**

There are two types of screening for PrCA, the digital rectal exam (DRE) and the prostate specific antigen (PSA) test. The DRE is performed by placing a gloved finger into the rectum to feel the prostate for any abnormalities, which can indicate that cancer may be present (American Cancer Society, 2013a). Most cancers of the prostate typically

occur on the back of the gland, which can be felt during the DRE (American Cancer Society, 2013a). The PSA is a blood test that assesses the amount of a naturally occurring protein that is produced by the prostate (American Cancer Society, 2013a). The normal level of PSA in the blood is less than 4 nanograms per milliliter (ng/mL) of blood (American Cancer Society, 2013a). The higher the PSA is above this level, the greater the chances are that a man could have PrCA. However, having a PSA level below 4ng/ml does not guarantee that a man does not have the disease, nor does having a PSA level higher than 4ng/ml mean that the disease is definitely present (American Cancer Society, 2013a). Neither the PSA nor the DRE exams are 100% accurate for detecting PrCA (American Cancer Society, 2013a).

### **Prostate Cancer Screening Controversy**

Despite the burden of PrCA in the US, especially among AAs, there is disagreement among medical and cancer research experts regarding the efficacy of PrCA screening, particularly the PSA test (Andriole et al., 2009; Barry, 2009; Schroder et al., 2009; Smith et al., 2012; U.S. Preventive Services Task Force, 2011). For example, the USPSTF released recommendations in October 2011 advising against PSA screening for healthy men of all ages (U.S. Preventive Services Task Force, 2011). The body of scientific evidence, however, on which the USPSTF recommendation was based, included a catalogue of studies that had little to no AA participation. Two of the largest and most recent PrCA screening trials have been the center of the screening controversy and also lacked adequate AA participation (Andriole et al., 2009; Schroder et al., 2009). The U.S. study, titled “Prostate, Lung, Colorectal, and Ovarian (PLCO) Cancer Screening Trial on Prostate Cancer Mortality,” was a 10-year, multi-center, randomized trial among

76,693 American men and concluded that men who received PSA and DREs did not have significantly lower PrCA mortality rates than men who did not receive any PrCA screening exams (Andriole et al., 2009). “The European Randomized Study of Screening for PrCA” was also a 10-year study conducted among 182,000 men to determine the effectiveness of the PSA exam for reducing PrCA mortality (Schroder et al., 2009). Schroder et al. (2009) found that the PSA was effective at significantly reducing the rate of PrCA mortality among study participants, but with detrimental effects resulting from overdiagnosing PrCA. Overdiagnosis is disadvantageous because it can lead men to undergo unnecessary surgeries or receive other treatments for indolent forms of PrCA that are accompanied by a range of potentially serious, lifelong side effects (Welch & Albertsen, 2009). Therefore, men who would likely not have succumbed to their cancer may be exposed to the many risks associated with biopsy and PrCA treatment. These risks include, but are not limited to infection, incontinence, and impotence (U.S. Department of Health and Human Services, 2003; Welch & Albertsen, 2009). Though ACS also took into consideration the findings from these two large studies, the organization’s current PrCA screening guidelines recommend that men make an informed decision with a doctor about whether or not to undergo screening (American Cancer Society, 2010b). ACS’s screening guidelines also suggest that AA men begin conversations with their doctor regarding PrCA screening beginning at age 45 (American Cancer Society, 2013c). It is acknowledged, however, that AA men are often members of medically underserved populations and therefore may not have access to a regular doctor to engage in IDM regarding PSA screening (Carpenter et al., 2009; Wolf et al., 2010). For men without a regular source of care, ACS suggests participating in community-

based screening programs only if high quality IDM can be ensured and follow-up care/counseling services are available for those with abnormal results (Wolf et al., 2010).

### **Benefits of Informed Decision Making (IDM) Interventions**

The Centers for Disease Control and Prevention's (CDC) Task Force on Community Preventive Services defines IDM as:

*“when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time”* (Briss et al., 2004).

Research has demonstrated that individuals involved in IDM for cancer screening have numerous benefits, such as improved knowledge, beliefs, and risk perceptions regarding cancer screening (Informed Medical Decisions Foundation; Martinez, Schwartz, Freres, Frazee, & Hornik, 2009; O'Brien, et al., 2009). These benefits also have been confirmed in studies specific to PrCA screening IDM in AA men. For example, a recent study by Drake, Shelton, Gilligan and Allen (2010) tested the efficacy of a computerized, church-based PrCA screening DA on 73 AA men. They found that a one-time, 30-minute education module (containing information about the risks, benefits, limitations of PSA and a short IDM guide which assisted users with task such as identifying information needs) led to significant increases in men's prostate knowledge and screening IDM self-efficacy (Drake et al., 2010). Wray, Vijayumar, Jupka, Zellin, & Shadid (2011) also

reported similar results following their community-based PrCA screening DA with 63 AA men. Due to the intricate nature of PrCA and the existing controversy about PrCA screening (Andriole et al., 2009; Barry, 2009; Schroder et al., 2009; Smith et al., 2012; U.S. Preventive Services Task Force, 2011; Witte, 2009), it is necessary that men, particularly AA men, have: 1) knowledge about prostate anatomy; PrCA; and the risks, benefits, and uncertainties of PrCA screening, and 2) the self-efficacy necessary to share their screening decision with a doctor. Having the opportunity to make an informed decision with a doctor could potentially lead to the early detection and treatment of PrCA (American Cancer Society, 2010a). On the assumption that virulent cancers are preferentially detected, IDM may lead to a reduction in the overall cancer burden in SC and amelioration of the cancer disparities gap between AA and EA men. As part of the process, IDM also can lead to a shared decision to forgo screening or to employ active surveillance (i.e., an observational follow-up strategy where a patient forgoes treatment, but makes routine appointments with the doctor to assess the rate at which a cancer is growing) if an indolent form of the cancer is identified (National Institutes of Health, 2011). The decision not to be screened or immediately treated can reduce overdiagnosis or overtreatment (National Institutes of Health, 2011). Technology may be a conduit for facilitating these decisions, particular because of its increasingly widespread availability (Pew Internet & American Life Project, 2012c).

### **Technology Use Among Adults**

Access to ICTs is increasingly growing each year. For example, the Pew Research Center reports that 46% of American adults had access to the internet in 2000, whereas 85% of adults have access to the internet as of May 2013 (Pew Internet & American Life Project,

2013g). Pew also reports that 91% of U.S. adults own a cell phone and over half of these phones are smartphones (Pew Internet & American Life Project, 2013g). In addition, 25% of adults have adopted tablet computers or e-readers (Pew Internet and American Life Project, 2013). As for more traditional technologies, Nielsen reports that 289 million people across the U.S. own at least one television and approximately 83% of these people have digital or satellite cable, 86% own a DVD player, 47% own a DVR, and 56% own a game console such as an Xbox 360 (Nielsen, 2012a). Last, 77% of all adults listen to broadcast radio on a daily basis with an average listening time of 109 minutes per day (Nielsen, 2009). These estimates demonstrate the potential for disseminating health information to diverse populations (e.g., AA men).

All of the aforementioned technologies are being used for a number of purposes. Of the current internet users, approximately 92% perform general searches, 91% use email, 71% participate in online shopping, 64% engage in social networking, and 61% are banking online (Pew Internet & American Life Project, 2012d). Cell phone users are engaging in similar activities including sending/receiving text messages (81%), accessing the internet (60%), sending/receiving email (52%), downloading applications (50%), getting directions (49%), and listening to music (28%) (Pew Internet & American Life Project, 2013g). Television users most often view sports-related programming, particularly National Football League (NFL) broadcasts. Six of 10 top broadcast and five of 10 cable programs receiving the highest viewership during 2011 were sponsored by the NFL (Nielsen, 2011). However, in addition to all of the aforementioned technology-use activities, adults are also frequently using various technologies for health information seeking.

**Technology use: Health information seeking among U.S. adults.** Individuals seek and receive health information from a variety sources (Bundorf, Wagner, Singer, & Baker, 2006). These sources can be interpersonal sources such as health professionals, friends, and relatives, and media sources such as television, newspapers, and magazines (Pew Internet & American Life Project, 2011; Rains, 2007; Savolainen, 2008). However, there is a considerable amount of research that indicates adults' growing dependence upon the internet and other electronics (e.g., mobile phones, social networks, email) as sources for health and wellness information (Pew Internet & American Life Project, 2012b, 2012d, 2013c, 2013g; Pew Internet and American Life Project, 2009b, 2011, 2012, 2013; Rains, 2007; Savolainen, 2008).

***Health information seeking on the internet.*** The number of people searching the internet for health information is growing considerably each year (Pew Internet & American Life Project, 2013c). As of 2013, a reported 59% of adult internet users reported searching for health information as compared with 25% in 2000 (Pew Internet & American Life Project, 2013c; Pew Internet and American Life Project, 2009a). The substantial growth in the number of internet users seeking health information can be explained partly by the exponential growth in overall internet access (Pew Internet & American Life Project, 2013c). In addition to the 77% of people who use a general search engine (e.g., Google) to find information on a specific topic (e.g., medical procedure or treatment, how to lose or control weight), some adults also use the internet to read medical commentary or news; watch health-related video; view drug, doctor, or hospital reviews; or track their, weight, diet, and/or exercise information (Pew Internet and American Life Project, 2011). A study by Weaver, Mays, Weaver, Hopkins, Eroglu, and Bernhardt (2010) reported that half of the 559 internet

users surveyed in their study spent time during a typical week looking at illness and or wellness information. However, online health information seeking was more prevalent among women (Weaver, Mays, Weaver, Hopkins, Eroglu, & Bernhardt, 2010).

***Health information seeking: social networking.*** Approximately 73% of all adult internet users visit social networking sites such as Facebook/Myspace and 15% of social network users visit these sites to seek health information (Pew Internet & American Life Project, 2013e; Pew Internet and American Life Project, 2011)

. In particular, individuals not only seek health information on these sites (e.g., CDC's Facebook page), but also use the sites to memorialize a family member or friend who has succumbed to a health condition, raise money for a health-related cause, post comments to create awareness about a particular health condition, and/ or either start or join a health-related support group (Pew Internet and American Life Project, 2011).

***Health information receipt: email.*** In addition to searching actively for health information online, adults also have relied on email for a means of receiving health information (Pew Internet and American Life Project, 2009b). For example, 14% of internet users have signed up to receive email updates or alerts about health or medical issues (Pew Internet and American Life Project, 2011). Pew also reports that more adults use email than youth (Pew Internet and American Life Project, 2011). Few recent studies have assessed the efficacy of email as a means to communicate health messages to diverse populations. However, findings from one recent study indicated email-based interventions led to improvements in self-efficacy, work attendance, physical activity, and consumption of adequate nutrition among workers ages 19-65 (Block et al., 2008). Friedman et al. (2012) also examined the feasibility of using email to send messages to AA men and women during

a PrCA and medical research education intervention. These brief email messages reiterated main points covered in education sessions (Friedman et al., 2012c). Participants expressed satisfaction with the convenience of receiving timely health information each week through email' (Friedman et al., 2012c).

***Health information seeking and receipt: mobile phones.*** Ninety-one percent of U.S. adults use cell phones and half of these users own smartphones (Pew Internet & American Life Project, 2013g). Approximately 50% of all smart phone users and 6% of traditional users receive health information through their device (Pew Internet & American Life Project, 2013c). This number has increased 21% since 2010 (Pew Internet and American Life Project, 2012). Specifically, individuals are using their cell phones to search online for health information, download health-related applications, and receive health-related text messages (Pew Internet and American Life Project, 2012). Most health-related mobile activities are being carried out by smart phone users (Pew Internet & American Life Project, 2013c). For example, while 52% of smartphone users participate in health information seeking or receipt, only 6% of non-smartphone users participate in these activities (Pew Internet & American Life Project, 2013c) In addition, while few cell phone users are participating in the receipt of health-related text messages, 9% of smartphone versus 6% of non-smart phone users receive these messages (Pew Internet and American Life Project, 2012). Furthermore, 19% of smartphone users have reported downloading a health-related application such as those for tracking personal dietary and exercise information (Pew Internet and American Life Project, 2012).

With the overall growing number of Americans with access to cell phones, public health professionals have begun to utilize mobile applications, such as text messaging, for the

purpose of health promotion. Though texting, for example, is not utilized often for health information receipt, several studies have shown the efficaciousness and feasibility of texting as a means to promote behavior change (Blackburn & Blatnik, 2013; Buhi et al., , 2013; Buis et al., 2013a, 2013b; Cole-Lewis & Kershaw, 2010; Fjeldsoe, Miller, & Marshall, 2010; Haapala, Barengo, Biggs, Surakka, & Manninen, 2009; Head, Noar, Iannarino, & Grant Harrington, 2013; Kharbanda, Stockwell, Fox, & Rickert, 2009; Krishna & Boren, 2008; Lim, Hocking, Hellard, & Aitken, 2008; Mason, Benotsch, Way, Kim, & Snipes, 2013; Patrick, 2010; Sharifi et al., 2013; Shaw et al., 2013; Weitzel, Bernhardt, Usdan, Mays, & Glanz, 2007). In a systematic review to evaluate the impact of cell phone (e.g., text messaging) interventions on diabetes management, Krishna et al (2008) found that nine of ten studies showed that individuals receiving these interventions reported significant improvements in their blood sugar level. These changes can be attributed to the participants' increase in both diabetes knowledge and self-efficacy to manage the disease (Krishna & Boren, 2008). Furthermore, results from studies on the effectiveness of using mobile applications for health promotion and disease management indicated that application users are also more actively involved in managing their health (e.g., frequency of blood glucose monitoring, dietary self-monitoring adherence) (Arsand et al, 2012; Cafazzo, Casselman, Hamming, Katzman, & Palmert, 2012; Lieffers & Hanning, 2012; Mosa, Yoo, & Sheets, 2012; Shaw et al., 2013). Mobile phone applications also provide doctors with useful information necessary to provide optimal care for patients including pertinent information about a prescription drug or a medical calculator to determine the necessary drug dosage (Mosa et al., 2012)

## **Cancer Information Seeking**

**General cancer information seeking.** According to the National Cancer Institute, almost 40% of individuals in the U.S. have searched for cancer information (National Cancer Institute, 2008a). Over half (55%) of these individuals sought information online followed by those who received information from their health care providers (24.9%) (National Cancer Institute, 2008a). Other sources were far less used, but included printed materials, family members, friends, and informational specialists (e.g., health educator) (National Cancer Institute, 2008a). Findings from a study on the cancer information seeking and scanning behaviors of the general population indicated that individuals are using a variety of sources (e.g., mass media, internet) to find screening information in addition to seeking information from their doctor (Kelly et al., 2010). Other data suggest that an individual's source for cancer information is dependent upon factors such as whether or not the information seeker has a specific chronic illness as opposed to being interested in the topic for other reasons (e.g., prevention) (Pew Internet & American Life Project, 2010). For instance, Pew reports that people who have chronic diseases such as cancer are less likely to go online for information than a healthy individual (Pew Internet & American Life Project, 2010). Individuals who have cancer will instead rely on their doctor for disease specific information (Pew Internet & American Life Project, 2010).

A few recent studies indicate that cancer patients who are seeking information about treatment may rely on their doctor as a primary source, but commonly seek out secondary sources (e.g., internet, interpersonal) (Nagler et al., 2010b; Ramsey et al., 2009; Walsh et al., 2010). These secondary source-seeking behaviors vary based on the

individual's income, age, educational background, and type of cancer. In particular, Walsh et al. (2010) found that overall, 42% of male and female patients sought secondary cancer information from a family member, followed by the internet (31%), books (30%), friends/co-workers, (25%) support groups (15%), scientific research reports (13%), and foundations (12%). However, those patients who were less than 55 years of age, with a college degree, higher incomes, and/or had suffered from PrCA were more likely to search for information on the internet than those individuals who were younger, less educated, had lower incomes, or suffered from other cancers (e.g., breast cancer). An article review on the impact of internet on cancer outcomes showed that people with cancer found the internet useful for gaining the social support of friends, family and the internet community; viewing timely medical news or information about their specific treatment; and sometimes seeking advice from online medical experts (Eysenbach, 2003). According to Eysenbach's (2003) review, some of the documented outcomes that can result from seeking health information online included reduced anxiety, improved compliance with doctor's recommendations, realistic expectations about treatment, and increased involvement in care (Fleisher, Bass, Ruzek, & McKeown-Conn, 2002; Mills & Sullivan, 1999; Mossman, Boudioni, & Slevin, 1999).

**Prostate cancer information seeking.** There are few studies that have sought to determine the PrCA information seeking behaviors and sources for individuals who do not have a history of PrCA. However, there has been some research on the information seeking behaviors of PrCA patients (Nagler et al., 2010a; Nagler et al., 2010b; Ramsey et al., 2009; Walsh et al., 2010). In a study of men and women's cancer seeking behaviors in a predominately EA sample population, Walsh et al. (2010) found that PrCA patients seeking

information for treatment IDM were more likely than those with breast, lung, or colorectal cancer patients to use the internet for finding treatment information to supplement information received from a physician. In a study of PrCA survivors, researchers found that men used multiple sources to find information about PrCA, but the doctor was the most frequently reported source prior to cancer diagnosis (47%) followed by traditional sources such as magazines (26%), newspapers (19%), and pamphlets (23%) (Cegala et al., 2008). Following their PrCA diagnosis and prior to treatment, men most often reported that the doctor (89%), internet (64%), and pamphlets (61%) were their regular sources for PrCA information (Cegala et al., 2008). Though the number of sources consulted did not necessarily lead to a man being more informed, the study did find that men who felt more informed about their treatment options were more comfortable communicating with their doctor about these options (Cegala et al., 2008). In two recent studies, Nagler and colleagues found that PrCA patients relied most often on their doctor for information, however, they also used secondary information from other interpersonal or media sources such as family members, other cancer patients, books/pamphlets, television, and internet (most often) to support their treatment IDM (Nagler et al., 2010a; Nagler et al., 2010b). These studies show that technologies such as internet are not only useful for finding general cancer information or supplementing cancer information provided by a physician, but may also aid in the IDM process regarding cancer treatment.

### **Technology use and health/cancer information seeking among AAs**

**General technology use among AAs.** African Americans have more access to television and consume more hours of live television than any other racial/ethnic group (Nielsen, 2011). While the average amount of television consumed per day across all races

and ethnicities across the U.S. is five hours and eleven minutes, AAs consume approximately seven hours and twelve minutes of television per day (Nielsen, 2011). The top 10 programs among AA broadcast channel (e.g., Fox, CBS) viewers were all NFL-related and at least half of the top ranked programs viewed on cable channels were also sports related (Nielsen, 2011). African Americans also use broadcast radio at slightly higher rates than EAs, with over 93% of AAs tuning in at an average of two hours and six minutes per day (Arbitron, 2012; Nielsen, 2009). According to Arbitron, a media research group, the most popular radio format for AAs is Adult Urban Contemporary which commonly plays rhythm and blues and jazz music (Arbitron, 2012).

When considering access to broadband internet, AAs have considerably less access than EAs (Cohall et al., 2011). However, AAs have adopted smart phones at significantly higher rates and use more phone features (i.e., mobile applications, internet, sending email, mobile banking, and taking pictures) than EAs (Pew Internet & American Life Project, 2013b). As of 2013, 79% of AAs (compared with 80% of EAs) have access to a cell phone, but 64% of AAs and 53% of EAs own a smartphone (Pew Internet & American Life Project, 2013f). African Americans' adoption of mobile technology has led to modest narrowing of the digital divide between EAs and AAs (Pew Internet & American Life Project, 2013g). For instance, when considering broadband only access to the internet, 74% of EAs and 64% of AAs have access to a broadband internet connection (Pew Internet & American Life Project, 2013d). Conversely, 60% of AAs vs. 52% of EAs have access to the internet wirelessly (Pew Internet and American Life Project, 2013). Taking into account wireless and broadband Internet, 86% of EAs versus 85% of AAs have internet access (Pew Internet & American Life Project, 2013g).

**Health information seeking among AAs.** African Americans most often seek out health information from a doctor (primary source), but also use interpersonal, traditional, and technology-related sources to support their search (Montague & Perchonok, 2012; Rooks, Wiltshire, Elder, BeLue, & Gary, 2012). For example, a study by Owens and colleagues found that nearly 75% of the AA participants reported their primary doctor as one of their regular sources of general health and cancer information followed by television (43%) and newspaper (31%) (Owens, Thomas, Friedman, & Hebert, 2011a). In addition, respondents reported being willing to receive health/cancer information through internet, email, and text messaging (42%, 40%, and 25% respectively) (Owens et al., 2011a). Additionally, 78% of all participants reported owning mobile phones that were capable of receiving text messages and over half of those individuals reported being willing to receive health-related text messages as part of a PrCA education program (Owens et al., 2011a). Rooks et al. (2012) found that in addition to their physician, AAs most often consulted books (33%) family (32%), internet (25%), or TV/ radio (24%) for health information (Rooks et al., 2012). Pew reports that 74% of AAs seek health information online about a variety of topics, but most often search for disease-specific information (Pew Internet & American Life Project, 2013c). AAs are also significantly more likely than EAs to seek information on the internet about weight control or additional information about an advertised drug (Pew Internet & American Life Project, 2013c).

**Cancer information seeking among AAs.** There have been few recent studies that have assessed AAs' cancer-specific information sources, particularly for PrCA (Friedman et al., 2012c; Owens et al., 2011a; Ross et al., 2011). However, Ross et al. (2011) reported that men rely on their primary care provider for PrCA information (only half had ever received

any information), but also used other sources (Ross et al., 2011). While 86% of study participants reported receiving information from their physicians, 62% received PrCA information from the mass media, 61% from printed sources, 36% from peers, and 18% from the internet (Ross et al., 2011). In addition, 80% of the participants who reported seeking any PrCA information used multiple information sources (e.g., doctor and internet) (Ross et al., 2011).

### **Technology use and health/cancer information seeking among middle-age and older adults**

**General technology use among middle-age and older adults.** According to Pew, 83% of middle aged adults (i.e., 50-64) and 56% of older adults (i.e., 65+) (**middle-age and older adults will all be referred to as older adults throughout this section**) use the internet or email and the majority of both age groups (76% of 50-64, 70% of 65+) use these resources daily (Pew Internet & American Life Project, 2013g). These numbers have increased exponentially since 2002 when approximately 55% of adults 50-64 and 15% of adults 65+ used the internet (Pew Internet & American Life Project, 2012e). Older adults who go online are more likely to have higher annual incomes (i.e., incomes above that received by seniors with Medicare) and have education levels beyond a high school level (Cresci, Yarandi, & Morrell, 2010).

Older adults (60% of 50-64, 43% of 65+) are also logging onto social media, such as Facebook, to stay in touch with their families and are increasingly adopting technology resources such as cell phones, laptops, e-readers, and tablets (Pew Internet & American Life Project, 2012e, 2013a). For example, as of 2013, 87% of adults 50-64 and 76% of adults 65+ own a cell phone (39% of adults 50-64 and 18% of those 65+ own a

smartphone)(Pew Internet & American Life Project, 2013f; Pew Internet and American Life Project, 2013). In addition, a greater percentage of adults 50+ watch TV than younger adults and they also spend significantly more time watching TV (Nielsen, 2012b). Older adults also listen to radio more often than young adults (Nielsen, 2009). Older adults most often listen to radio for news, jazz, and classical broadcasts (Arbitron, 2011), but also report receiving health information (Cutilli, 2010; Owens et al., 2011a). In a study of older adults, Mitzner, et al. (2010) found that adults use various household technologies and generally have a good attitude towards the technology if they perceived it as being easy to use and useful for a specific task. Older adults in the study most commonly used technologies in their homes (e.g., cellphones, computers) and they used these resources for a variety of reasons such as seeking information online about physicians/medications and making general phone calls. Mitzner et al. (2010) also found that aspects of technology that encouraged use among older adults were those that enhanced communication, reduced the time to complete a task, and were accessible. Dislikes that were found regarding technology use for older adults included the inconveniences of technology ownership (e.g., cost of having cell phone, unwanted calls), having too many or too few programming features, poor quality of content or output (e.g., bad television shows, TV with poor sound), and lack of reliability of the technology to perform a given task. Other barriers to technology use in older adults have included lack of perceived behavior control (Heart & Kalderon, 2011; Mitzner et al., 2010), lack of perceived usefulness (Fisk, Rogers, Charness, Czaja, & Sharit, 2009; Heart & Kalderon; Mitzner et al., 2010; Morris, Goodman, & Brading, 2007), computer anxiety (Chu, Huber, Mastel-Smith, & Cesario, 2009; Czaja et al., 2006), cognitive decline (Czaja et

al., 2006), lack of self-efficacy (Chu et al., 2009; Czaja et al., 2006), lack of prior use experience (Czaja et al., 2006), physical (e.g., blindness) and mental disabilities, and poor health (Cresci et al., 2010; Czaja et al., 2006).

**Health/cancer information seeking among older adults.** Older adults are less likely to use technology such as the internet to search for health information in comparison to younger adults ages 18 to 49, but over half use the internet as a resource (Pew Internet & American Life Project, 2013c). In 2013, Pew reports that 83% of adults 50-65 and 56% of adults 65+ seek health information online (Pew Internet & American Life Project, 2013g). Older adults who look for health information online most often seek information about a specific disease/medical problem or a certain medical treatment/procedure (Pew Internet & American Life Project, 2012e). Older adults often rely on their doctor as their primary sources of care, but also consider traditional sources, such as magazines, to be a valuable source of health information and emotional support (Friedman, Corwin, Rose, & Dominick, 2009; Friedman & Hoffman-Goetz, 2003). Despite their lower participation in technology use for health than younger adults, older adults have been frequently reported to use technological interventions to improve their health (Ammann, Vandelanotte, de Vries, & Mummery, 2012; Berman, Iris, Bode, & Drengenberg, 2009; Bond, Burr, Wolf, & Feldt, 2010; Choi, Kong, & Jung, 2012; Demiris et al., 2013; Krishna & Boren, 2008; Neafsey et al., 2011; Peels et al., 2013; van Stralen, de Vries, Mudde, Bolman, & Lechner, 2011; Wijsman, et al., 2013).

### **Benefits of Computer Technologies for IDM**

**Benefits of computer technologies for IDM: general.** The Institute of Medicine recommends the use of effective, plain-language and culturally appropriate cancer

communication strategies (Institute of Medicine et al., 2004). Several research studies have recognized ICTs (e.g., DAs) as an effective and culturally appropriate medium for disseminating plain-language health content (Andersen, Andersen, Youngblood, & Colmenares, 2008; Bernhardt et al., 2009; Finkelstein J, Wood J, & Cha, 2012; Fox, 2009; Gielen et al., 2007; Lasky, Kogut, Campbell, & Risica, 2011; Pendleton et al., 2010; Porter et al., 2004; Portnoy, Scott-Sheldon, Johnson, & Carey, 2008; See et al., 2010; Teolis, 2010; Thompson et al., 2007) and serving as DAs for the prevention and/or treatment of chronic diseases in ethnically and literacy diverse populations (Allen et al., 2009; Cupertino et al., 2010; Ellison et al., 2008; Evans et al., 2010; Khan et al., 2011; Lindblom et al., 2011; Miller et al., 2011; Ozanne et al., 2007b; Sawka et al., 2011; Schroy et al., 2014; Wakefield et al., 2011). For example, in a meta-analysis of 75 studies, Portnoy et al. (2008) found that computer-delivered interventions improved knowledge about, attitudes towards, and intentions to change negative health behavior in the areas of nutrition (Baranowski et al., 2003; Irvine, Ary, Grove, & Gilfillan-Morton, 2004), tobacco/substance use (Strecher et al., 2006), binge/purging actions (Taylor et al., 2006; Zabinski, Wilfley, Calfas, Winzelberg, & Taylor, 2004), and general health maintenance such as wearing sun screen (Glazebrook, Garrud, Avery, Coupland, & Williams, 2006). In a systematic review of 25 studies, Fox (2009) found that interactive computer-based education programs had a number of benefits for users including increasing knowledge (Green et al., 2004; Keulers, Welters, Spauwen, & Houpt, 2007; Linne & Liedholm, 2006; Miller, Kimberly, Case, & Wofford, 2005; Stromberg, Dahlstrom, & Fridlund, 2006) and self-efficacy (Green et al., 2004; Miller et al., 2005); enhancing IDM about disease treatment (Meyer, Fasshauer, Nebel, & Paschke, 2004) and

decision-making satisfaction (Green et al., 2004); and reducing high-risk behaviors such as injected drug use (Marsch & Bickel, 2004). Other benefits of computer education included facilitating doctor-patient communication and improving health literacy (Lasky et al., 2011; Teolis, 2010).

**Benefits of computer technologies for IDM: cancer.** There are also several cancer specific studies that have demonstrated the feasibility and effectiveness of using online and computer-based interventions for increasing health knowledge, influencing healthy behaviors, and assisting with decisions about screening (Banegas et al., 2013; Bass, Gordon et al., 2012; Hassinger et al., 2010; Holubar et al., 2009; Menon, Szalacha, Belue, Rugen, Martin, & Kinney, 2008; Ryhänen et al., 2010; Schroy et al., 2011; Shaffer et al., 2013). In a systematic review of 14 studies on the effects of internet or interactive computer-based patient education in the field of breast cancer, Ryhänen et al. (2010) found that most interventions to date have led to an increase in user knowledge about breast cancer (Heller, Parker, Youssef, & Miller, 2008; Ozanne, Annis, Adduci, Showstack, & Esserman, 2007a; Shaw et al., 2007), but other outcomes regarding effectiveness of these interventions on breast care or doctor-patient relationship were mixed. For example, while some studies reported an increase in a patient's confidence in their doctor's ability to provide quality care (Gustafson et al., 2001) or a patient's active participation in care (Gustafson et al., 2001; Wise, Han, Shaw, McTavish, & Gustafson, 2008), other studies demonstrated no significant change in the effectiveness of the doctor-patient relationship (Ozanne et al., 2007a; Shaw et al., 2007). In another recent study, researchers used a computer-based DA as an intervention in a population with varying levels of health literacy to encourage colon cancer screening (Miller et al., 2011).

They found that their intervention led to a significant increase in screening self-efficacy and readiness. Similarly, Bass et al. (2012) found that involving the community in the development of a colorectal cancer screening, touch-screen DA for a low-literacy AA population resulted in an intervention which increased the amount of individuals receiving colorectal screening. A third study, assessed the knowledge, beliefs, attitudes, and behaviors related to colorectal screening and level of desire for participating in decision making related to colorectal screening among a diverse group of clinic and ambulatory care patients following their use of an interactive computer-based DA for colorectal screening (Schroy et al., 2014). Findings from the study indicated that 95% of patients in the intervention group (control group received no intervention) identified a preferred screening option, and scores related to satisfaction with decision making, colorectal cancer knowledge, and intention to be screened were significantly higher among the individuals in the intervention group than those in the control group (Schroy et al., 2014).

Whereas, the aforementioned studies were conducted in controlled environments where researchers were able to facilitate the DA use, other studies have employed self-guided, public DAs (e.g., kiosks) (Ashish & Trout, 2012; Thompson et al., 2007). These DAs have been used in a number of settings, such as hospitals, bars, supermarkets, restaurants, laundromats, and churches, to provide health information and produce behavior change (Ashish & Trout, 2012; Jones, 2009). In addition to measuring the change in psycho-social behaviors, some behavioral studies that use public DAs as interventions also base their success outcomes on the number of users (Kreuter et al., 2006). By measuring the number of DA users, researchers can determine how many

people are being exposed to their intervention and decide whether the benefits of maintaining the DA outweigh the cost of disseminating the intervention by this method (Jones, 2009). One of the most recent DA interventions performed in a church setting was the “Reflections of You” program which provided women with tailored breast cancer screening information (Kreuter et al., 2006). The study concluded that people in churches, as opposed to other community settings (e.g., laundromats), were more likely to complete the intervention. However, through a systematic review, Ashish & Trout (2012) concluded that Medicare, Medicaid, and the uninsured were open to using digital DAs for receiving health information, but had varying preferences for the locations for DA. Adults on Medicare most preferred that DAs containing health information be placed in the church, whereas those on Medicaid or the uninsured most often preferred to access health DA in neighborhood health centers and public libraries (Ashish & Trout, 2012).

**Benefits of computer technologies for IDM: prostate cancer.** For PrCA specifically, there have been multiple studies demonstrating the efficaciousness of using computer-based interventions to educate men about PrCA and/or help them make an informed decision about cancer screening and/or treatment (Frosch, Bhatnagar, Tally, Hamori, & Kaplan, 2008; Ilic, Egberts, McKenzie, Risbridger, & Green, 2008; Kassin et al., 2012; Krist, Woolf, Johnson, & Kerns, 2007). Diefenbach & Butz (2004) created a computer-based multi-media DA containing interactive videos of physicians and other cancer patients, PrCA information, and an “expert system” that measured the amount of information that patients received to ensure that individuals left with enough information to make an informed decision. The DA, called the Prostate Interactive Education System

(PIES), was evaluated for acceptability among men with early-stage PrCA survivors and their spouses regarding treatment decisions (Diefenbach & Butz, 2004). Findings indicated that most of the participants exhibited a high satisfaction level with the software and would prefer using the decision-aid software over printed materials to find information (Diefenbach & Butz, 2004). A similar study among men without PrCA tested the usability, use patterns, and usefulness of an interactive PrCA screening DA containing informational video clips about PrCA screening and treatment. Authors found that a DA for PrCA screening was usable by the target population (Kassan et al., 2012). Although only half of participants logged onto the DA and most users were likely to be educated and EA, users found that the resource helped them understand the pros and cons of screening and the amount of information provided was reported to be just enough. In addition, half of the men reported that the intervention made them think of new questions to ask their doctor about PrCA screening (Kassan et al., 2012). In a study by Allen et al. (2009) a computer-based DA was administered to a group of AA men to facilitate the PrCA screening IDM process. Outcome measures included knowledge, IDM self-efficacy, and decisional conflict. The researchers found that there were significant improvements in knowledge and decision-making self-efficacy among the intervention group participants (Allen et al., 2009). Researchers also observed a substantial reduction in decision-making conflict and increased participation in the IDM process (Allen et al., 2009).

### **Games for Health**

A game is defined as “*an activity engaged in for diversion or amusement.*” (Merriam-Webster, 2013). According to (Smed & Hakonen, 2003), a game consists of

three components: 1) players who are willing to participate in the game (e.g., for enjoyment, diversion or amusement), 2) rules which define the limits of the game, and 3) goals which give rise to conflicts and rivalry among the players. Gamification, on the contrary, is defined as “*using game mechanics for non-game applications*” (Renaud & Wagoner, 2011). These game mechanics could be aspects such as providing a point system or interactive feedback (Flatla, Gutwin, Nacke, Bateman, & Mandryk, 2011; McCallum, 2012). In some cases, gamified applications and interventions that address a topic that is more serious in nature (e.g., health) are referred to as “serious games” (Susi, Johannesson, & Backlund, 2007). Both games and gamified interventions have been used to provide education or therapy, promote behavior change, and manage the health of populations ranging from youth to older adults in areas such as physical activity (Biddiss & Irwin, 2010; Guderian et al., 2010; Guy, Ratzki-Leewing, & Gwadry-Sridhar, 2011; Lu, Kharrazi, Gharghabi, & Thompson, 2013; McCallum, 2012; Papastergiou, 2009; Peng, Crouse, & Lin, 2013; Studenski et al., 2010), behavioral health (Kato, Cole, Bradlyn, & Pollock, 2008), physical therapy (Bateni, 2012; Primack et al., 2012; Szturm, Betker, Moussavi, Desai, & Goodman, 2011), cancer (Fuchslocher, Gerling, Masuch, & Kramer, 2011), diabetes (DeShazo, Harris, & Pratt, 2010; Thompson et al., 2010), stroke (Burke et al., 2009a; Burke et al., 2009b; Dores et al., 2011), mental health (Hall, Chavarria, Maneeratana, Chaney, & Bernhardt, 2012; Maillot, Perrot, & Hartley, 2012; Peretz et al., 2013) and sexual health (Tortolero et al., 2010). For example, Szturm et al., 2001 tested the effects of a game-based intervention on balance impairment in a group of older adults and found that adults who received their rehabilitation program through an interactive game format had significantly higher post-balance scores than those who

received a general program. Similarly, in a recent systematic review, Hall et. al., (2012) found that most recent game-based health interventions for older adults had significant positive effects on mental, physical (e.g., balance), and social health.

### **Avatar Technology and Health**

Avatars are a virtual incarnation, embodiment, or manifestation of a person with a high level of behavior, flexible motion, realistic appearance, and the ability to react to its environment (Google, 2012; Magnenat-Thalmann & Thalmann, 2006). One of the first avatars resembling a human was William Fetter's Landing Signal Officer, which was developed for Boeing in 1959 to be used to study the instrument panel of a Boeing 747 (Magnenat-Thalmann & Thalmann, 2006). Since then "virtual humans" (i.e., avatars) have been used for a number of purposes including simulations for trainings (e.g., training for soldiers and surgery practice) characters for games, actors for movies, and presenters for TV, web programs, and virtual worlds such as SecondLife™ (Boulos, Hetherington, & Wheeler, 2007b; Magnenat-Thalmann & Thalmann, 2006).

Avatars are also beginning to appear in health-related interventions, although most studies have only measured the acceptability of these interventions. In a study about the use of conversational agents (i.e., avatars) for promoting healthy nutrition and physical activity through motivational interviewing, Schulman and Bickmore (2011)'s formative evaluation showed high satisfaction levels with an avatar-led program among men and women ranging from ages 21 to 68 (Schulman, Bickmore, & Sidner, 2011). Similarly, Lisetti & Visser (2012) found that 75% of participants felt either as comfortable or more comfortable interacting with an avatar during a motivational interviewing session about reducing alcohol consumption than they would with a real

counselor (Lisetti, Yasavur, de Leon, Amini, Rische, & Visser, 2012). Many who favored the avatar-led interview felt positive about the experience because the avatar was unbiased and could not judge or embarrass them for their alcohol consumption behavior (Lisetti et al., 2012).

In another recent study, Bickmore, Pfeiffer, and Jack (2009) tested the feasibility of a virtual nurse agent (i.e., avatar) to teach hospital patients about their post-hospital discharge self-care regimen. The bedside touch-screen system was tested among 30 non-hospitalized patients who were asked to role play as if they were a patient (Bickmore, Pfeifer, & Jack, 2009). Participants were mostly AA (77%), between the ages of 20 and 60, and had varying levels of computer use, computer literacy, and health literacy (Bickmore et al., 2009). Through individual interviews that took place following their interaction with the virtual nursing agent, Bickmore et al. (2009) found that patients were highly accepting of the module with 37% reporting that they were more comfortable receiving post-discharge information from a virtual nursing agent than a doctor. Prevalent themes regarding participants' acceptability of the intervention were the participants' appreciation of the depth of information provided and the fact that the virtual nursing agent was available for as much time as the participant needed (Bickmore et al., 2009).

Although there are many general advantages to using avatars in health interventions such as addressing low literacy by including audiovisual components, eliminating variability in intervention implementation, tailoring information based on individual patients, and implementing race concordance (Lisetti, 2012), there have been no studies to date that have documented the use of avatars to promote cancer-related awareness or IDM about cancer screening. However, the aforementioned findings

relating to the feasibility of using avatar-led interventions with age and ethnically diverse individuals, the growing access to and use of technology in AA and older populations, and the success of computer-based health interventions indicates that there may be benefits to incorporating avatars into computer-based, PrCA screening IDM interventions targeting AA men. The inclusion of avatars may further enhance the effectiveness of the computer-based, PrCA DAs by providing culturally appropriate, plain-language information through a race concordant, human-like figure capable of engaging AA men in the type of conversational exchange necessary to prepare them for IDM with their doctor as recommended by the ACS.

### **Previous Work, Studies, and Preparation of Student**

**Research Activities.** I currently serve as project coordinator for a National Cancer Institute (NCI) funded PrCA pilot education intervention (U54 CA153461; PI: Hébert; Project Leader: Friedman), “Promoting the Role of Cancer Research within an African-American Faith-based Community: A Focus on Prostate Cancer.” The specific aims of this project are to assess, among AAs in a faith-based setting: 1) current knowledge and attitudes regarding PrCA prevention and screening, and participation in PrCA research, 2) changes in knowledge and attitudes about research participation following a pilot education program, and 3) culturally appropriate strategies for promoting cancer research among AAs in a faith-based community (Friedman et al., 2012a). The project’s partners include the NCI Community Cancer Centers Program and the Community Clinical Oncology Program at Spartanburg Regional Gibbs Cancer Center & Research Institute, and UsTOO International Spartanburg and Greenville Chapters in upstate SC.

As project coordinator, I organized the recruitment and scheduling of study participants (n=109); created promotional materials; maintained communication with study participants and community partners; conducted FGs with AA men and women of various ages and literacy levels, developed codebooks for qualitative data analysis; developed and tested survey and FG instruments; collected, managed, analyzed, and interpreted data; co-developed, implemented, and evaluated educational curricula; drafted and edited abstracts, manuscripts, and conference posters; and disseminated findings at local and national conferences and community forums.

One of my most recent efforts on the pilot project included the co-development of survey items to assess whether mobile technology would be an effective channel for communicating prostate health information to complement in-person PrCA education sessions. The four education sessions included in the pilot project focused on preparing men to make an informed decision about whether to receive PrCA screening. Specifically, the sessions included topics about: 1) prostate anatomy, 2) prostate screening guidelines and technology, 3) participation in clinical trials research, and 4) the informed consent process. We found that most (68%) of the 81 participants surveyed owned mobile phones that were capable of receiving text messages and nearly half of those individuals were willing to receive PrCA-related text messages during the course of the pilot study (Owens et al., 2011a; Owens, Thomas, Friedman, & Hebert, 2011b). The final results show that that using technology for improving cancer and general health communications in community settings is feasible. The results from the survey were disseminated at the 2011 James E. Clyburn Health Disparities Lecture held at the University of South Carolina USC, and at the 2011 International Cancer Education Conference in Buffalo, NY (Owens et al., 2011a).

I also served as Co-Principal investigator on a project that was funded through USC's Science and Health Communication Research Group (SHCRG) to test the feasibility of using Photovoice, a qualitative methodology, with PrCA pilot project participants to: 1) enhance communication between participants and researchers; 2) empower AA men and women to examine their health decisions through photographs; and 3) to better understand how participants from this community make health and cancer-related decisions. There were 15 AAs who participated in the photovoice project which involved taking photographs of aspects of their community that affected how they make health-related decisions. Following the exercise, participants were asked to provide short audio and written narratives describing select photos. Four primary themes emerged in participants' photographs and narratives: 1) food choices, 2) physical activity practices, 3) community environment and access to care, and 4) influences of spirituality and nature on health. Our team also found that, although the written and audio-recorded narratives were similar in content, the audio-recorded responses were more descriptive. The results of this study not only indicated the feasibility of using new qualitative methodologies in the AA population, but it also indicated the effectiveness of using multiple technology-based techniques (i.e., photos and voice narratives) to determine how individuals are making health decisions and also to empower the community by giving them a means to recognize the many factors that are influencing their health decisions (Thomas, Owens, Friedman, Torres, & Hebert, 2013). The photos and text from the photovoice project were included in a booklet that was shared with all study participants and community and clinical partners.

I also served as Principal Investigator of a PrCA-focused grant funded through the USC's Institute for African American Research (IAAR) which helped accomplish the data collection and analysis for Aim 1 of this dissertation. In addition, I have been awarded two grants through the USC's Science and Health Communications Research Group (SHCRG) and USC's Office of the Vice President for Research. The funding helped me accomplish a portion of the development, data collection and analysis for Aim 2.

**Presentations, publications, and grant proposal development history.** I have served as an author on five NCI pilot project manuscripts (Friedman et al., 2013; Friedman et al., 2012c; Friedman et al., 2012d; Owens et al., 2013) and first or second author on 19 regional/national presentations (Friedman D.B. et al., 2013; Owens & Thomas, 2012; Owens et al., 2011a; Owens et al., 2011b; Owens, Thomas, Friedman, & Torres, 2012; Owens, Jackson, Thomas, Friedman, & Hebert, 2013; Owens, Friedman, Brandt, & Hebert, 2013a; Owens, Friedman, Brandt, Bernhardt, & Hebert, 2013b; Owens, Friedman, Brandt, & Hebert, 2013c; Owens, Friedman, Brandt, Hebert, & Bernhardt, 2013d; Owens, Friedman, Jackson, & Hebert, 2013e; Owens et al., 2012a, 2012b; Owens et al., 2013f; Owens et al., 2013g; Thomas et al., 2011a; Thomas et al., 2012; Thomas, Owens, Friedman, Torres M.E., & Hebert, 2012b). Four of the presentations listed previously received awards including (Owens et al., 2013c; Thomas et al., 2011a; Thomas et al., 2011b; Thomas et al., 2012b). I also produced six grants in amounts ranging from \$2,000 and \$65,000. I was awarded two grants from the USC's SHCRG, one from USC's IAAR, and one from USC's Office of the Vice President for Research. All of the manuscripts, presentations, and grants aforementioned provided a solid foundation and sources of funding for my dissertation research. For my research and

scholarship, I was awarded the 2013 Distinguished Graduate Scholar Award from the University's Office of Vice President for Research.

**Workgroups, consulting, and continuing education activities.** I have been involved in several professional and consulting activities, including serving as a member of the South Carolina Cancer Alliance (SCCA) Prostate Cancer Workgroup, USC's SHCRG, and Student Advisory Board for a Social Media Campaign through the South Carolina Department of Health and Environmental Control. I have also participated in conferences of the SCCA and other relevant seminars and trainings in health disparities and oncology through the USC's Cancer Prevention and Control Program (CPCP) and in the community. I have led community PrCA education in collaboration with organizations such as UsTOO (Lexington, Spartanburg, and Greenville Chapters) and Healthy Columbia. In addition, I have been hired as a consultant by multiple USC research staff and graduate students to serve as a FG facilitator and data analysis expert. My experience working with multidisciplinary research experts on professional workgroups, participating in continuing education opportunities, and serving as a consultant for various health-related research projects, has been exposed me to a cadre of new theories and frameworks that have enhanced my dissertation research.

**Didactic training.** I have received extensive didactic training through my public health research courses in measurement, evaluation, program planning, primary and secondary data management/analysis, statistics, and qualitative research design which have provided me with a foundation in research methods and theory/intervention development. I have also taken courses to strengthen my knowledge of health communication campaign design, communications theory, and game design. I have

excelled in these courses as a student, maintaining a 4.0 grade point average. I have also demonstrated my knowledge of course materials through the successful passing of a qualifying examination. Furthermore, I continue to apply what I have learned through my courses in my positions as a project coordinator on the NCI pilot project; as Principal and Co-Principal investigators on grants; and as a consultant for various projects.

**Other work experience.** Prior to my matriculation into the doctoral program at USC, I served as a community health educator and consultant for the Atlanta-based Comprehensive Men's Health Initiative (CMHI) and as a Management Analyst for the Centers for Disease Control and Prevention. Through CMHI's Barbershop Initiative, I used a socio-ecological approach to teach high-risk AA men about PrCA. On the community level, CMHI aided local medical centers in training area barbers to serve as PrCA educators in minority communities. CMHI also altered the physical environments of participating barbershops to include multimedia computer DAs that provided informational video clips, text-based materials, PodCasts, and web content to aid the barbers in their presentations. It was the organization's aim to make men aware of PrCA and the benefits, risks, and uncertainties of PrCA screening. These efforts were to ensure that men had the knowledge necessary to make an informed decision about screening. Through my service with CMHI, I learned to leverage the use of new technologies in an effort enhance cancer communications and reduce health disparities. These skills have not only been an instrumental contribution to the goals and aims of the proposed research, but have afforded me the opportunity to engage in professional activities such as serving on workgroups and advisory boards.

Lastly, as a contractor and management analyst for CDC, I was tasked with the co-management of the Preventive Medicine Residency and Fellowship Program. During my

tenure, I was exposed to a plethora of original research being conducted by state, federal, and non-profit employed physicians with expertise in public health. Through this experience, I gained a clinical perspective on public health and learned the importance of fostering interdisciplinary partnerships in an effort to effectively reduce health disparities. Developing and maintaining strong research partnerships with community leaders and academic colleagues, in particular, were essential to the success of this research study.

### **Implications of Research for Candidate**

In addition to the implications that this innovative research may have on the burden of PrCA in SC and the state of the science on PrCA screening, conducting this research has enhanced my research skills needed to participate in continued cancer-related health disparities, cancer communication, and new technology research including: 1) community relationship building and recruitment; 2) qualitative data analysis; 3) the development and application of diverse theoretical and conceptual frameworks to cancer-related disparities research; 4) fostering and maintaining interdisciplinary partnerships; 5) the development of the skills necessary to have an active role in technology intervention development (e.g., design-document writing, story-board development); and 6) the reporting and dissemination of research results. This research opportunity also allowed me to collaboratively develop a tool that will not only increase prostate knowledge, but provide an interactive exercise that can prepare men to have this discussion with a doctor

## CHAPTER 3

### METHODS

#### Overview of Research Design

To combat cancer-related health disparities, the NCI funded South Carolina Cancer Disparities Community Network-II 's (SCCDCN-II; U54/CA153461, PI: Hebert) Community Outreach Core (COC) at USC collaborates with the SBYWA Health Ministry, by focusing on faith-based initiatives that connect the health and spiritual needs of its members. The COC's partnership with the SBYWA presented an ideal opportunity for me to engage in community-driven cancer disparities research particularly because community-based programs in SBYWA congregations have been well received and are effective based on the 10 years of collaborative research and culturally appropriate educational efforts working with various investigators at USC (Campbell et al., 2007; Casey, Thiede, Call, & Klingner, 2001; Edwards, Jumper-Thurman, Plested, Oetting, & Swanson, 2000; Green et al., 2009; Hennessey et al., 2005; Mayo, Scott, & Williams, 2009; Minkler & Wallerstein, 2003; Scott & Stewart, 2009; Suarez-Balcazar, Harper, & Lewis, 2005; Viswanathan et al., 2004; Wilcox et al., 2010; Williams & Scott, 2006; Yanek, Becker, Moy, Gittelsohn, & Koffman, 2001). The SBYWA is organized into eight health ministry regions. The region of interest for this research was Region 5 (around Columbia, SC). I partnered with the COC (Core Leader: Brandt) to conduct formative research that aligned with the SCCDCN-II's goal of developing and testing interventions that are likely to reduce the burden of cancer. The research involved the development of a

computer-based DA for PrCA screening. The research was guided by a technology acceptance framework (Venkatesh et al., 2003) which was operationalized based on community-based principles (e.g., equitably involving community in the intervention development process) (Israel et al., 2001; Israel et al., 2003; Schulz et al., 2011). Community-based strategies are a promising way to address cancer disparities (Braun et al., 2012; Freeman, 2003, 2004; Freeman & Chu, 2005; Hebert et al., 2009a; Kerner, Guirguis-Blake, Hennessy et al., 2005; Minkler & Wallerstein, 2003; Viswanathan et al., 2004; Wallerstein & Duran, 2010). Through the development of authentic partnerships with the target audience and stakeholders, cultural and contextual relevance of interventions is increased (Letcher & Perlow, 2009; Wallerstein & Duran, 2010). Thus, the likelihood of improvement in knowledge and preventive behavior is maximized, resulting in better health outcomes (Kerner, 2008; Kerner et al., 2005; Wallerstein & Duran, 2010; Zerhouni, 2003, 2005).

The **specific aims** of my dissertation research were as follows:

**Aim 1:** To determine AA men's: 1) current PrCA risk and screening knowledge, 2) decision-making processes for PrCA screening, and 3) usage of, attitudes toward, and access to interactive communication technology (e.g., computers, ATMs, DAs).

**Aim 2:** To develop and assess the usability and acceptability of an interactive DA for increasing knowledge, self-efficacy, and intention to make an informed decision about PrCA screening among AA men in faith communities.

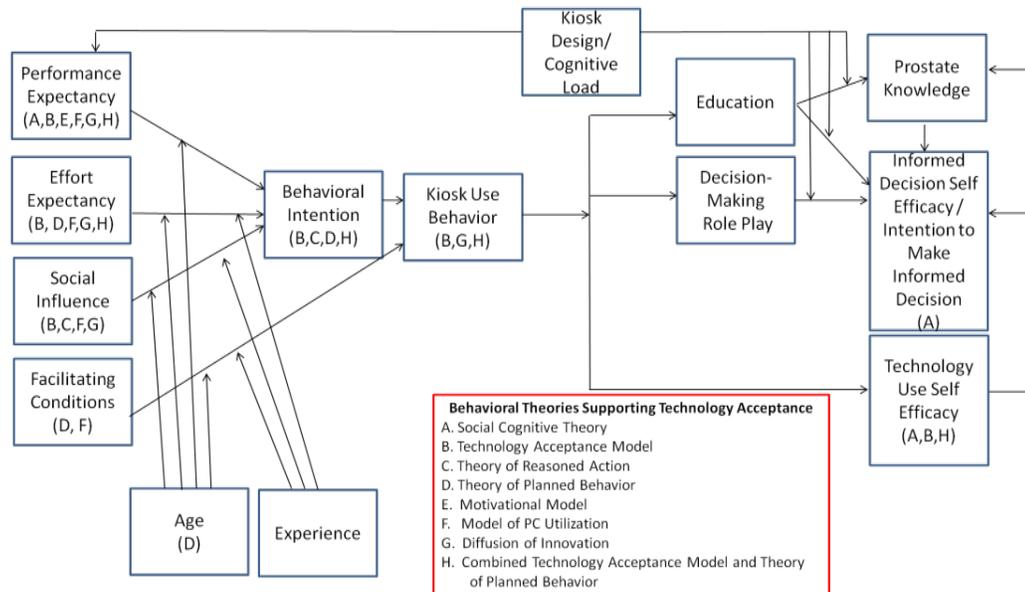
### **Conceptual Framework**

The conceptual framework in Figure 3.1 was adapted from Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh et al., 2003). The

theory suggests that four key constructs: 1) **performance expectancy** (i.e., the degree to which a person believes that performing an action such as using technology will contribute to personal gains), 2) **effort expectancy** (i.e., the degree of ease associated with technology use), 3) **social influence** (i.e., the degree to which an individual perceives the importance that his social network will place on the use of the technology) and 4) **facilitating conditions** (i.e., degree to which an individual believes that an organizational and technical infrastructure exists to support use of the system), moderated by factors such as age and experience, contribute to an individuals' intention to use and ultimate adoption of a technology (Venkatesh et al., 2003). The theory is based on the consolidation of eight validated health behavior theories: Social Cognitive Theory (Bufford, 1986), Theory of Reasoned Action (Fishbein & Ajzen, 1979), Theory of Planned Behavior (Ajzen, 1991), Technology Acceptance Model (Compeau & Higgins, 1995), Motivational Model (Davis, Bagozzi, & Warshaw, 1992), Model of PC Utilization (Thompson, Higgins, & Howell, 1991), Diffusion of Innovations (Rogers, 2003), and Combined Technology Acceptance Model and Theory of Planned Behavior (Taylor & Todd, 1995), which contain several common tenants supporting the adoption of any technology (see Appendix A to see how these constructs relate to the model).

The UTAUT has been used to study the acceptance and use of a number of information systems which primarily fall into four categories: 1) **communications** (e.g., mobile banking, texting, phone, and television), 2) **general purpose systems** (e.g., internet and online banking), 3) **desktop applications**, and 4) **specialized business systems** (e.g., hospital IT) (Williams, Rana, & Dwivedi, 2012). There have been few research studies conducted on the model's utility in measuring the use and adoption of an

informational DA (Hung, Chang, & Yu, 2006; Wang & Shih, 2009); however, these studies have validated the UTAUT's use with DA-based systems.



**Figure 3.1:** Conceptual Framework based on Venkatesh et al (2003) and Mayer and Moreno (2003)

In the pictorial framework (Figure 3.1), each construct is labeled with the letter of the theory that provides support for its role in the model. For example, the Social Cognitive Theory, labeled (A), has relevance to both performance expectancy and IDM self-efficacy through similar constructs captured by the theory (i.e., expectation or anticipated outcome of their behavior; self-efficacy). Based on the proposed framework and our community-based approach (i.e., involving the community as equitable collaborators), I posited that an individual's perception that 1) the DA would lead to an increase in knowledge about PrCA, 2) the DA was be easy to use, 3) others in his social network would support the use of the DA, and 4) there would be support to facilitate use of the DA (e.g., someone available to address questions about the DA), would influence whether AA men ages 40-65 years would adopt the DA as a source of PrCA information.

The DA's adoption by individuals in our target population also would be moderated by their age and their experience using similar technologies. I also posited that the DA (which included education and a role play exercise) would lead to actual increases in prostate knowledge, decision-making self-efficacy/intention to make an informed decision, and technology use self-efficacy if the culturally appropriate content was presented in a way that reduced cognitive load. According to Mayer's Theory of Cognitive Multimedia Learning (CMLT), individuals process information through two channels that have limited capacity (i.e. cognitive load) (Mayer & Moreno, 2003). The theory also states that learning is a process of filtering, selecting, organizing, and integrating information based upon prior knowledge (Mayer & Moreno, 2003). Therefore, Mayer has several recommendations for designing multimedia that can enhance a person's capacity for processing information and enhance learning. For example, Mayer recommends that multimedia presentations include audio components as opposed to only visual words in the presentation to reduce the amount of attention that a person has to devote to processing text (Mayer & Moreno, 2003). The CMLT has been used to design several health and non-health related computer-based media for older adults (Paas & Sweller, 2012; Struve & Wandke, 2009; Van Gerven, Paas, & Tabbers, 2006; van Weert, van Noort, Bol, van Dijk, Tates, & Jansen, 2011; Wilson & Wolf, 2009; Xie, Yeh, Walsh, Watkins, & Huang, 2012). Last, I posited that the use of the DA might make men comfortable using technology in the future to find health and PrCA information. Their increased technology use self-efficacy could also result in an increased knowledge and decision-making self-efficacy beyond use of the DA. When used in conjunction, the UTAUT and CMLT not only offer a full perspective of the various ways

in which technology can affect health outcomes, but also provide the appropriate framework to guide the community-driven development of the DA and the study of its usability.

### **Aim 1: Formative Research**

**Sampling description and procedures.** Aim 1 was accomplished through a grant awarded by USC's IAAR. To accomplish Aim 1, a purposive, (Patton, 1990) convenience sample of AA men ages 40-65 years from SBYWA affiliated churches was asked participate in one of six FGs. I used purposeful recruitment strategies that have been successfully used by myself and other USC researchers in partnership with SBYWA (Braun et al., 2012; Bynum et al., 2011; Bynum, Brandt, Friedman, Annang, & Tanner, 2011; Bynum, Brandt, Sharpe, Williams, & Kerr, 2011; Bynum, Wright, Brandt, Burgis, & Bacon, 2009; Caldwell, Swan, Allen, Sullivan, & Snow, 2009; Friedman et al., 2012a; Heiney, Adams, Hebert, & Cunningham, 2005; Heiney et al., 2010; Heiney, Adams, Wells, & Johnson, 2010; Heiney et al., 2012; McFall et al., 2009; Peck, Sharpe, Burroughs, & Granner, 2008; Sharpe et al., 2010; Sharpe et al., 2011; Ureda et al., 2011; Wilcox, Sharpe, Parra-Medina, Granner, & Hutto, 2011). These methods included flyers, in-person announcements, radio promotion on stations with a large number of AA listeners, messages on AA community organization and healthcare system websites/listservs, and participation in health-related activities (e.g., health fairs) at churches. Recruitment efforts were guided by Vesey's framework on the recruitment and retention of minority groups that involves a series of strategies such as leveraging partnerships in the community to assist researchers throughout the planning and implementation process (Vesey, 2002). The specific strategies from Vesey's framework

used for this study were: 1) conceptualization, planning, and development of the recruitment plan and promotional materials in collaboration with community partners, 2) recruitment of study sample with partners, 3) developing culturally appropriate study materials (e.g., FG/interview guides), contacting and interviewing the study participants, and 4) reporting findings to the community at various stages in the research process (Friedman et al., 2012a). Eligibility criteria required that AA men ages 40+: 1) spoke and comprehended English, 2) had no personal history of PrCA, and 3) had no history of cognitive decline that will inhibit their participation. Recruitment efforts resulted in 39 participants (although the recruitment goal was 40 men).

Focus groups were selected as the method for data collection because many decisions, including those about technology use and health are either made in a “social context” or greatly influenced by a person’s social environment (Patton, 1990). In addition, Patton reports that FGs can lead to the collection of several diverse perspectives, at once, that can enhance the quality of data and help eliminate extreme views which may not be typical of the population as a whole (Patton, 1990). Also, **utilizing** a community-based approach in partnership with the AA faith community increased scientific validity and population relevance, ultimately providing all stakeholders with the most invaluable information for producing an effective IDM tool (Altman, 1995; Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2003; Rawl, Menon, Burness, & Breslau, 2012; Sanders Thompson, Lewis, & Williams, 2013; Viswanathan et al., 2004; Wallerstein, 2000). Furthermore, churches were selected as appropriate settings for this research because prior studies have concluded that AAs’ spiritual needs (in addition to their socio-cultural and psychological needs) often

influence their participation and trust in health research (Campbell et al., 1999; Campbell et al., 2004; Colon-Otero et al., 2009; Holt et al., 2009; Huang & Coker, 2010; McClelland et al., 1998; McNabb, Quinn, Kerver, Cook, & Karrison, 1997; Reid, Hatch, & Parrish, 2003; Resnicow et al., 2005; Resnicow et al., 2002; Resnicow et al., 2001; Rimer, Briss, Zeller, Chan, & Woolf, 2004; Vesey, 2002; Yanek et al., 2001).

A maximum of eight to 10 men were included in any of the first six FGs. The sampling of the FGs for this study was based on the qualitative research principles of saturation and sufficiency (Glaser & Strauss, 1967; Morse & Field, 1995; Seidman, 1998; Strauss & Corbin, 1998). Saturation is the point at which the analysis of resulting data produces no substantial new elements and sufficiency refers to the range of variability in the characteristics of participants (Seidman, 1998; Strauss & Corbin, 1998). According to Morse and Field (1995), when more in-depth and useful data is received from a group of participants, fewer participants are needed to reach saturation. Based on prior research, I predicted that saturation and sufficiency should be reached within five to six FGs (Friedman et al., 2012a; Friedman et al., 2012c).

#### **Data collection procedures.**

**Demographic survey.** Prior to the FGs conducted for Aim 1, participants were provided with a short demographic and behavior survey. The 18-item survey assessed their openness to using technologies for: 1) receiving health information, 2) non-technology-related resources of health information, 3) most common and preferred sources of health information, 4) PrCA screening behaviors, and 5) PrCA IDM practices.

**Focus groups.** The 90-minute FGs were held in the fellowship halls of churches around in Columbia, SC and at a conference room provided by USC's Cancer Prevention and

Control Program (CPCP). The locations of the FGs were determined by the number of people available from a select church. For example, if one church had five or more men willing to participate in a FG, I traveled to their church to conduct a FG and invited other interested men to attend the FG at that specific church. During the FG, participants were asked questions about: 1) their current PrCA knowledge including prostate anatomy, PrCA prevention symptoms, prostate screening and diagnosis, and risks and benefits of PrCA screening, 2) their decision-making process regarding whether or not to receive PrCA screening, and 3) types of, access to, and personal or health-related use of ICT. They were also asked about social and physical barriers/facilitators of using ICTs and suggestions for eliminating these barriers. Items for the FG guide were created based on domains from my previous work on a NCI-funded PrCA pilot project (e.g., knowledge, perceptions, communication needs) (Friedman et al., 2012b; Friedman et al., 2012c; Friedman et al., 2012d; Owens O.L. et al., 2013; Thomas et al., 2013), but expanded to include general content about their technology acceptability and use (e.g., “How often do you use email to find health information?”). I moderated and digitally recorded each FG. All data were transcribed by a professional transcription service (Alacri Tech™). Following transcription, I compared audio recording to the transcripts to ensure quality. To protect participant confidentiality, all names were removed from the transcripts by the transcription service and I verified all transcripts for any names or additional identifiers. Data were saved on a password protected computer and all audio files were deleted from recording devices.

**Measures and specification of variables.** Table 3.1 details both the theoretical constructs and FG topics and the qualitative measures that were used to answer each of the research questions for Aim 1. The theoretical constructs and FG topics describe the

specific domains of interest based on the research questions. For example, RQ1 sought information about AA men’s knowledge of PrCA risk factors and symptoms (i.e., PrCA knowledge). The qualitative measures/question topics section refers to the origin and number of items used to measure the construct/FG topic. Therefore, based on the current example, PrCA knowledge was measured using one qualitative survey item followed by two prompts. The single survey question and the two prompts were based on published instruments including those from Compeau et al. (2001), Cormier et al. (2002), and Friedman et al. (2012).

**Table 3.1:** Research Questions, Theoretical Constructs, and Measure/ Instruments

Research Question (RQ)	Theoretical Construct/ Focus Group Topic	Qualitative Measures/Question Topic
<b>RQ1:</b> What do AA men know about the risk factors and symptoms for prostate cancer?	Prostate Cancer Knowledge <sup>1</sup>	1 Qualitative Prostate Cancer Knowledge items and 2 Prompts based on Compeau et al. (2001), Cormier et al. (2002), and Friedman et al. (2012)
<b>RQ2:</b> What do AA men know about the types of prostate cancer screenings and risks benefits and uncertainties of these screenings?	Prostate Cancer Knowledge <sup>1</sup>	1 Qualitative Prostate Cancer Knowledge items and 2 Prompts based on Compeau et al. (2001), Cormier et al. (2002), and Friedman et al. (2012)
<b>RQ3:</b> How are AA men making decisions about prostate cancer (e.g., shared, individual)?	Prostate Cancer Screening Decision Making <sup>1</sup>	1 Qualitative Prostate Cancer Screening Decision Making item and 11 Prompts based on Friedman et al. (2012)
<b>RQ4:</b> In general, how often and for what purposes, are AA men using technology?	Technology Use <sup>1</sup>	4 Original Qualitative Technology Use Items with several Prompts; 7 Quantitative Items based on Owens et al. (2011)
	Technology Use <sup>1</sup> Self-efficacy	1 Original Qualitative Technology Use Self-efficacy Item

<sup>1</sup> The topic is not a construct of a theory, but has been measured through scales or items in the studies listed in the qualitative measures/question topic column.

**Data analysis/analytic approach.** Frequencies of the data on the demographic survey were calculated using SPSS 20 (SPSS Inc., 2012). Data from FG transcripts were analyzed using NVivo<sup>®</sup> 9 (QSR, 2010), a qualitative software program that aids in organizing, analyzing, and interpreting data. Prior to downloading FG transcript data into NVivo<sup>®</sup>, my dissertation committee chair and I developed a preliminary draft codebook through an open coding process (Strauss & Corbin, 1998). Open coding of analogous transcripts led to the conceptual organization of the data based on potential themes (Strauss & Corbin, 1998). After the codebook was finalized, NVivo<sup>®</sup> was used to re-code all transcripts and facilitate the axial coding process. Axial coding helped identify any thematic relationships that existed between codes (Strauss & Corbin, 1998). Inter-rater reliability was calculated by hand using a percent agreement method where the number of agreed upon codes were divided by the total number of items coded (i.e., agreements and disagreements) (Neuendorf, 2002). The initial percent agreement in coding between my dissertation committee chair and myself was 67% after each of us coded two full transcripts separately, but the coding scheme was discussed thoroughly and agreement of 100% was reached. Throughout the analysis process, emergent themes were compared and contrasted between and within FGs (Strauss & Corbin, 1998) The themes revealed through the analysis were used to develop a user-friendly DA interface containing culturally-appropriate, plain-language PrCA information.

## **Aim 2: Development and Feasibility Testing of PrCA IDM Intervention (DA)**

**Intervention development.** Based on, but not contingent upon, findings from Aim 1, I worked with an interdisciplinary team of experts in media arts (faculty member and 3D animator) and health communication and technology (dissertation committee and

other faculty) to achieve **Specific Aim 2**. Specifically, this team customized a user-friendly DA interface containing PrCA information and a role play exercise to prepare eligible AA men to make an informed decision regarding whether or not they should be screened for PrCA. When ultimately implemented, the DA will be the first to provide AA men with a PrCA screening education session through a stand-alone computer in the faith-based community. It also is the first study to use avatar technology to provide PrCA information for the purpose of enhancing IDM regarding PrCA screening. According to the Agency for Health Care Research and Quality, there is at least one other study (“Exploratory and Developmental Grant to Improve Health Care Quality through Health Information Technology”) utilizing avatars to provide education to enhance PrCA treatment decision making (Agency for Healthcare Research and Quality, 2014). An avatar model was chosen for this DA because avatars have been demonstrated by several experts to be effective in general/health education and more interactive than video and voice/text-only DAs (Baker, Wentz, & Woods, 2009; Beard, Wilson, Morra, & Keelan, 2009; Boulos, Hetherington, & Wheeler, 2007a; Satter et al., 2010). Avatars are considered effective because they mimic human interaction (van den Brekel, 2008).

The DA interface was developed using animation software called I-Clone (Reallusion, 2012). I-Clone allows the user to create a life-like avatar and animate it using Microsoft Kinect’s™ motion capture (MoCap) capabilities. When used in conjunction with I-clone, the Microsoft Kinect™ can translate both the voice and movements of a person into data which can then be used to animate a customized avatar. The animator and I designed three avatars (two doctors and a receptionist) based on data collected through Aim 1 and best practices such as those outlined in the Microsoft

Usability Guidelines and Usability.gov (Keeker, 2007; U.S. Department of Health and Human Services, 2012). The animation expert also recorded MoCap data, recorded and mixed all avatar voiceovers, and combined the avatars with MoCap and audio data into short video clips. The health communication experts on the project were vital to the creation and evaluation of the culturally appropriate, plain-language PrCA content and assisted with the production of the script for module. I provided gesturing and voiceover for the avatar. The media arts experts and I programmed the DA to operate based on a decision tree that was collaboratively developed by my mentoring team and I. The resulting interface was housed on an all-in-one, touch-screen computer which acted as a DA. The complete intervention was approximately 10 to 12 minutes in duration and was designed to be self-administered during a single session. The content for the DA was developed using information from: 1) NCI's "What You Need To Know About Prostate Cancer" booklet (National Cancer Institute, 2008b), 2) my previous work as project coordinator of the NCI-funded pilot project, "Promoting the role of cancer research within an AA faith-based community: A focus on Prostate Cancer,"(U54 CA153461; PI: Hébert; Project Leader: Friedman) (Friedman et al., 2013; Friedman et al., 2012c; Friedman et al., 2012d; Owens O.L. et al., 2013; Thomas et al., 2013), and 3) a second NCI funded study "Community interventions in non-medical settings to increase IDM for Prostate Cancer Screening" (U48 CCU409664-2B; PI: Hébert; Co-PI Ureda) (Chan, McFall, Byrd, Mullen, Volk, Ureda, Calderon-Mora, Morales, Valdes, & Kay Bartholomew, 2011; McFall et al., 2009). These resources included information about PrCA, PrCA screening guidelines, the controversy about the effectiveness of PSA screening, and the importance of IDM. The specific information presented from these

sources and the format of the DA was based on information gathered during FGs that were conducted for Aim 1 and the FGs in Aim 2. Following the development of the DA, a complete prototype of the DA was provided to multiple experts for a review. Following this expert review, I tested the usability of the DA for helping men make informed decisions about PrCA.

### **Sampling description and procedures.**

**Focus groups.** Seven additional 90-minute FGs were held with a sample of men who participated in Aim 1 FGs. Inviting the same men to participate in the FG was advantageous because these men were already familiar with the topics of interest, were invested in the development process, and were able to give more useful feedback on the preliminary development of the DA prototype that was developed partly based on ideas these men provided during FGs held in Aim 1. Similar to FGs held in Aim 1, the location of the FGs occurred in their churches and in a conference room at the CPCP.

**Expert review.** With guidance from my dissertation committee members, a panel of health technology experts across the U.S. was selected to review the DA content and usability. These experts included faculty in media arts, digital health, and health communication. Expert reviews or heuristic evaluations are ways to quickly, but effectively evaluate an intervention design for its compliance with recognized usability standards and best practices (Molich & Nielsen, 1990; Nielsen & Mack, 1994). It was imperative to have an expert review for the DA prior to usability testing (i.e., in-depth interviews) to ensure that the DA interface design and functionality was sufficient for the intended use.

**In-depth interviews.** Ten, 90-minute in-depth interviews were held with a random sample of men who participated in Aim 2 (Phase II) FGs. Each participant was assigned a

number. The number was inputted into a computerized random number generator (Urbaniak & Plous, 2011) which was calibrated to provide one random number at a time between 1 and 21. I then called to invite each of the selected individuals associated with the randomly generated numbers to participate in the usability testing of the final DA prototype. For those individuals who declined further participation, their numbers were discarded and additional random numbers were generated to replace those participants who declined. The process was repeated until 10 men were selected. All individual interviews were held at CPCP.

**Measures and specification of variables.** Table 3.2 details both the theoretical constructs/FG topics and the qualitative measures that were used to answer each of the research questions for Aim 2. Most of the theoretical constructs/FG topics listed below are tenants of the UTAUT which forms the guiding framework for this study.

Expert review refers to the process which was used to ensure that the DA met basic industry standards prior to testing its usability. All technology use questions were measured using items based on Venkatesh et al. (2003), while the expert review questions were based on a heuristic evaluation instrument developed by Nielsen (1994).

**Table 3.2:** Research Questions, Theoretical Constructs, and Measures/Instruments

Research Question (RQ)	Theoretical Construct/ Focus Group Topic	Qualitative Measures/Question Topic
<b>RQ5:</b> What are AA men’s perceptions about the user-friendliness of the DA (i.e., easy to use?).	Technology Effort Expectancy <sup>1</sup>	5 technology effort expectancy items with multiple prompts based on Venkatesh et al. (2003)
<b>RQ6:</b> What are AA men’s perceptions about whether or not people in the community will support their use of a DA for seeking health/PrCA information?	Social Acceptance of Technology <sup>1</sup>	1 social acceptance item based on Venkatesh et al. (2003)
<b>RQ7.</b> What are AA men’s perceptions about whether or	Performance Expectancy <sup>1</sup>	1 item based on Venkatesh et al. (2003) to

not a collaboratively developed DA will increase their prostate knowledge?		measure performance expectancy for increasing PrCA screening knowledge
<b>RQ8:</b> What are AA men's perceptions regarding whether or not a collaboratively developed DA will increase their IDM self-efficacy and intention to participate in IDM?	Performance Expectancy <sup>1</sup> Self-efficacy	1 item based on Venkatesh et al. (2003) to measure Performance Expectancy for increasing decision-making self-efficacy
	Performance Expectancy <sup>1</sup> Self-efficacy	1 item based on Venkatesh et al. (2003) to measure performance expectancy for decision-making self-efficacy and intention to make informed decision.
RQ9. What are AA men's perceptions regarding whether or not a collaboratively developed DA will increase their self-efficacy relating to their technology use?	Performance Expectancy <sup>1</sup> Self-efficacy	1 item based on Venkatesh et al. (2003) to measure performance expectancy for increasing technology use self-efficacy
<b>RQ10:</b> What are AA men's perceptions regarding whether or not they will have the enough support to use the DA?	Facilitating Conditions <sup>1</sup>	2 facilitating conditions items based on Venkatesh et al. (2003)
<b>RQ11:</b> What are the perceptions about whether or not the DA meets industry standards and best practices?	Expert Review <sup>2</sup>	10 item scale based on Nielsen (1994)

<sup>1</sup> The theoretical construct is a tenant of Venkatesh et al. (2003) Unified Theory of Technology Use and Acceptance. <sup>2</sup> Expert review is a process by which the proposed DA will be critically analyzed to ensure that it meets industry standards and best practices.

### **Data collection procedures.**

**Focus groups.** Prior to the FGs, participants were provided with a 36-item survey (developed based on existing instruments) to determine their: 1) perceived overall health (DeSalvo et al., 2006), 2) health literacy (Morris, MacLean, Chew, & Littenberg, 2006), 3) decisional conflict (O' Connor, 1995b), 4) decision self-efficacy (O' Connor, 1995a), and 5) computer, email and web fluency (Bunz, Curry, & Voon, 2007). Survey items were selected to provide more insight on the appropriateness of a digital DA tool for providing PrCA education to the target population.

During each FG, participants were provided with a storyboard (containing a script) and a short physical demonstration of the DA. The FG protocol was conceptualized based on the theoretical framework (i.e., UTAUT and CMLT). Specifically, domains of both theories were used to craft questions to determine men's: 1) perception of the cultural appropriateness and literacy level of the PrCA screening information (e.g., cognitive load, CMLT), 2) perceptions of the general usability of the DA including their thoughts about the format in which the information is presented or quality of content (e.g., performance expectancy, UTAUT), and 3) recommendations for improving the interface to reduce navigation effort and enhance information accessibility (e.g., effort expectancy, UTAUT). The FG guide was also based on domains from guides produced by Usability.gov, a resource published by the U.S. Department of Health and Human Services for developing and testing, easy-to-use web-based products for all populations (U.S. Department of Health and Human Services, 2012). Furthermore, we relied on the Microsoft™ Usability Guidelines to assess other dimensions of the DA that could affect its usability including the perceived challenge of the question and answer activities or the avatar's character strength (Agarwal & Venkatesh, 2002; Keecker, 2007). Minor updates were made to the DA following these FGs such as increasing text size. (See Chapter 4, Manuscript 2, Table 4.3).

**Expert reviews.** Each of the six experts, from academic and industry institutions, was invited to be a part of the panel through an email that provided details of the study and the evaluation process. After agreeing to be a member of the review panel, each expert was asked to sign and return a confidentiality agreement form which restricted the sharing of the DA with anyone without permission. The confidentiality agreement (which

was crafted by legal counsel at USC) could be returned either by email or post-mail. Upon the receipt of the signed confidentiality agreement, each member of the panel was mailed a copy of the DA on a DVD with basic instructions regarding how to access the start-up file contained on the DVD. In addition, each member was sent an electronic copy of the heuristic evaluation instrument and asked that their evaluation be returned to me electronically within two weeks. The 13-item, open ended heuristic evaluation instrument (based on Nielsen's 10 Heuristics) was created to evaluate the usability of electronic interface designs. The 10 Heuristics covered a number of aspects such as the ability for the system to provide the user with timely feedback about what is going on in a module (e.g., letting user know that they are about to participate in an activity and providing them with feedback throughout the activity) (Nielsen & Mack, 1994). Although the instrument focused on specific questions to guide the review process, the reviewers were encouraged to provide additional thoughts or concerns that could improve the DA. Though some suggestions were made by expert reviewers, no actual changes were made to the DA prior to in-depth interviews. (See Chapter 4, Manuscript 2, Table 4.4 for expert suggestions).

***In-depth interviews.*** In-depth interviews were used in Aim 2 to test the usability of the final DA prototype because these interviews provided the research team with a personal perspective of their DA use that could not be captured in a group setting. In particular, I was able to better assess specific usability issues by observing participant's use of the DA and interview them privately about these issues. According to Marshall and Rossman (2011), an in-depth interview is the "primary strategy for capturing the deep meaning of an experience in participants own words" (Catherine Marshall &

Rossmann, 2011). The interviews were guided by the theoretical framework and community-based principles to determine the DA's: 1) usability (Bangor, Kortum, & Miller, 2008; Sawka et al., 2011) (i.e., effort and performance expectancy, UTAUT), 2) accessibility (i.e., facilitating conditions, UTAUT), 3) potential(s) for improving both technology-use self-efficacy (Compeau & Higgins, 1995; Shih, 2006), and 4) likelihood of increasing AA men's intention to participate in the IDM process (Kim, Knight, Tomori, Colella, Schoor, Shih, Kuzel, Nadler, & Bennett, 2001). I also assessed men's perceived impact on cognitive load and PrCA knowledge (Mayer & Moreno, 2003). These constructs were measured by including modified questions from pre-existing scales (referenced above) and those from Usability.gov in the interview guide (U.S. Department of Health and Human Services, 2012). These metrics can be used to collect both performance data (what actually happened) and preference data (what participants thought) (U.S. Department of Health and Human Services, 2012). Taking a qualitative approach to this work was effective because it provided deeper context into how AA men's knowledge, self-efficacy, and intention to make an informed decision was being affected by various aspects of the DA, as opposed to solely measuring whether or not the DA works (Patton, 1990). For example, I was interested in finding out if and how the design of the DA enhanced usability of the DA and what further changes could be made to improve the usability. Specifically, men were allowed to interact with the DA immediately prior to the in-depth interview where I asked them to "think aloud" (i.e., talk through each movement) while I observed their interaction with the DA and collected performance data (i.e., how well they were navigating through the material). The think-aloud and observation methods have been effective with the development and usability

testing of interface designs because they allow the researcher to better understand those aspects of the design which help or hinder the user from retrieving information (Fleisher, Buzaglo et al., 2008; Jaspers, Steen, van den Bos, & Geenen, 2004; Meropol et al., 2013; Wen, Miller, Stanton, Fleisher, Morra, Jorge, Diefenbach, Ropka, & Marcus, 2012). For example, through their use of think aloud methods and staff observations during the usability testing of a web-based aid to improve doctor patient communication, Fleisher et al. (2008) were able to identify changes to their computer-based DA that enhanced the functionality of their intervention. These changes included aspects such as re-writing instructions, adding “next” arrows to the aid, and removing shading from various pages. Gathering such specific information about the usability of the DA could not be accomplished through the use of quantitative methods alone. Data for Aim 2 FGs and in-depth interviews were recorded, professionally transcribed, and protected as was performed in Aim 1.

**Data analysis and approach.** Analysis of the data on the demographic survey was conducted using SPSS 20.0 (SPSS Inc., 2012). Data from Aim 2 FGs and in-depth interview transcripts were analyzed using NVivo<sup>®</sup> 9 (QSR, 2010) and coded as described in the Data Analysis and approach for Aim 1. Data from expert reviews were also managed using NVivo<sup>®</sup> 9, but did not undergo a formal coding process. Expert reviewer comments were organized into a matrix using Microsoft Excel.<sup>™</sup> Comments from each reviewer were placed into parallel columns accompanied by the specific survey question. Common themes were then identified among the six of seven reviewers who completed the evaluation.

The themes/findings revealed through the analysis of the FGs and expert reviews were used to make some updates to the DA prior to the in-depth interviews (i.e., usability testing). Other updates were simply reported for future modification. Following the feasibility testing, the findings were used to recommend best practices for: 1) creating culturally appropriate, technology interventions, and 2) working with academic and community partners to produce these low-cost, technology-focused interventions

## CHAPTER 4

### RESULTS

#### 4.1 Manuscript 1

Digital Solutions for Informed Decision Making: An Academic-Community Partnership  
for the Development of a Prostate Cancer Decision Aid for African-American Men<sup>1</sup>

Owens OL, Friedman DB, Brandt HM, Bernhardt JM, & Hébert JR. Article status -  
To be submitted to American Journal of Men's Health

## Abstract

**Background:** African American (AA) men are significantly more likely to die of prostate cancer (PrCA) than other racial groups and there is a critical need to identify effective strategies for providing information about the risks, benefits, and uncertainties of PrCA screening and the importance of informed decision making (IDM). To assess whether a computer-based IDM intervention for PrCA screening would be appropriate for middle-age and older AA men, this formative evaluation study examined their: (1) PrCA risk and screening knowledge, (2) decision-making processes for PrCA screening, (3) usage of, attitudes toward, and access to interactive communication technologies (ICTs), and (4) perceptions and preferences regarding a novel computer-based intervention. **Methods:** A convenience/purposive sample of 39 AA men ages 37-66 in the Southeastern United States were recruited through faith-based organizations to participate in one of six 90-minute focus groups (FGs) and complete a 45-item demographic survey. **Results:** Participants were generally knowledgeable about PrCA, however, few engaged in IDM with their doctor and few were informed about the associated risks and uncertainties of PrCA screening. Most participants used ICTs on a daily basis for various purposes including health information seeking. Most participants also were open to a novel computer-based intervention if the system was easy to use and its animated characters were culturally appropriate. **Conclusions:** Because our study participants had low exposure to IDM for PrCA, but frequently use ICTs, IDM interventions using ICTs may be appropriate for AA men and should be explored for feasibility and effectiveness. These interventions should aim to increase PrCA screening knowledge and stress the importance of participating in IDM with their doctor.

**Keywords:** Interactive Communication Technology, Cancer Communication, Prostate Cancer Screening, Informed Decision Making, Health Disparities

### **Background**

Prostate cancer (PrCA) is the most commonly diagnosed non-skin cancer and the second leading cause of cancer death among all men in the US, with 238,590 expected to be diagnosed and 29,720 predicted to succumb to the disease in 2013 (American Cancer Society, 2013b). However, there is a pronounced disparity in the incidence and mortality rates between African-American (AA) and European-American (EA) (i.e., White) men (Siegel, Naishadham, & Jemal, 2012; U.S. Cancer Statistics Working Group, 2013). More specifically, AA men have an incidence rate of PrCA that is over 50% higher than in EAs on average, (American Cancer Society, 2011, 2013b). Owing in part to these racial disparities is the fact that PrCA has very different implications in AAs, in whom disease tends to be more aggressive. The disparities between AAs in comparison to other races and recent longitudinal research has led to considerable controversy regarding the benefits of PrCA screening (Andriole et al., 2009; Barry, 2009; Schroder et al., 2009; Smith, Cokkinides, & Brawley, 2012; U.S. Preventive Services Task Force, 2011). Whereas some non-profit and grassroots organizations embrace the lifesaving potential of prostate-specific antigen (PSA) screening (a blood test) (Mitka, 2009; National Medical Association, 2011; Us TOO International, 2011), some medical and research experts disagree about the efficacy of the exam (Barry, 2009). The American Cancer Society (ACS), however, recommends that men make an informed decision with their doctor about whether or not to be screened for the disease (American Cancer Society, 2013b). The Centers for Disease Control and Prevention's (CDC) Task Force on Community

Preventive Services defines informed decision making (IDM) as: “when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time” (Briss et al., 2004).

In order to make an informed decision, individuals must have clear, understandable information (Informed Medical Decisions Foundation, 2012). Therefore, the Institute of Medicine recommends the use of effective, plain-language, and culturally appropriate communication strategies to reach people with varying levels of health literacy (Institute of Medicine, Committee on Health Literacy, & Board of Neuroscience and Behavioral Health, 2004). Several research studies have recognized interactive communication technologies (ICTs) (e.g., computers) as effective and culturally appropriate mediums for disseminating plain-language health content to diverse populations (Bernhardt, Mays, Eroğlu, & Daniel, 2009; Bernhardt, Mays, & Kreuter, 2011; Gielen et al., 2007; Porter, Cai, Gribbons, Goldmann, & Kohane, 2004; Thompson, Lozano, & Christakis, 2007) and serving as decision aids (DAs) for the prevention and/or treatment of a number of chronic diseases including lung, colorectal, and prostate cancers, diabetes, and cardiovascular disease (Allen, Mohllajee, Shelton, Drake, & Mars, 2009; Cupertino et al., 2010; Evans et al., 2010; Kassan et al., 2012; Lindblom, Gregory, Wilson, Flight, & Zajac, 2011; Miller et al., 2011; Schroy, Mylvaganam, & Davidson, 2011; Wakefield et al., 2011; Khan et al., 2011; Stromberg et al., 2006; Weymiller et al.,

2007). Some outcomes that have been demonstrated through the use of ICTs for cancer in general include increasing health knowledge, influencing healthy behaviors, and assisting with decisions about screening (Bass et al., 2012; Hassinger et al., 2010; Ryhänen, Siekkinen, Rankinen, Korvenranta, & Leino-Kilpi, 2010; Schroy et al., 2011). For PrCA specifically, there have been studies demonstrating the efficaciousness of using computer-based interventions to increase men's knowledge about PrCA, enhance their IDM self-efficacy, and reduce decisional conflict regarding cancer screening and/or treatment (Frosch, Bhatnagar, Tally, Hamori, & Kaplan, 2008; Ilic, Egberts, McKenzie, Risbridger, & Green, 2008; Kassan et al., 2012; Krist, Woolf, Johnson, & Kerns, 2007).

### **Technology Use and Health & Cancer Information Seeking among African Americans**

When considering access to interactive communication technologies such as computers, over half of AAs own a desktop (45%) or laptop (51%) computer (Pew Internet & American Life Project, 2012b). As for broadband internet, AAs have less access than EAs (74% versus 64%) (Cohall, Nye, Moon-Howard, Kukafka, Dye, Vaughan, & Northridge, 2011) (Pew Internet & American Life Project, 2013b). However, AAs' adoption of mobile (93% of AAs versus 90% of EAs) and smart phones (64% of AAs versus 43% of EAs) has led to a modest narrowing of the digital divide (Pew Internet and American Life Project, 2013).

AAs most often seek out health information from a doctor (primary source), but also use other sources such as interactive communication technology to support their search. Pew reports that 74% of AAs seek health information online about a variety of topics, but most often search for disease-specific information (Pew Internet & American Life Project, 2013a).

However, there have been few recent studies that have assessed AAs' cancer-specific information sources, particularly for PrCA (Friedman, Thomas, Owens, & Hebert, 2012b; Ross, Dark, Orom, Underwood, Anderson-Lewis, Johnson, & Erwin, 2011). Ross et al. (2011) found that men rely on their primary care provider for PrCA information (only half had ever received any information), but they also used other sources which included the internet (Ross et al., 2011).

**Benefits of computer technologies for prostate cancer screening IDM.** For PrCA specifically, there have been multiple studies demonstrating the efficacy of using computer-based interventions to educate men about PrCA and/or help them make an informed decision about cancer screening and/or treatment (Frosch et al., 2008; Ilic et al., 2008; Kassan et al., 2012; Krist et al., 2007). In a study by Allen et al. (2009). for example, a computer-based DA was administered to a group of AA men to facilitate the PrCA screening IDM process. Outcome measures included knowledge, IDM self-efficacy, and decisional conflict. The researchers found that there were significant improvements in knowledge and decision-making self-efficacy among the intervention group participants (Allen et al., 2009). Researchers also observed a substantial reduction in decision-making conflict and increased participation in the IDM process (Allen et al., 2009). Similar positive outcomes have been demonstrated through computer-based interventions that include avatars (Lisetti, 2012).

**Avatar technology in computer-based interventions.** Avatars are animated human-like depictions appearing in an electronic format, often on a website or computer screen. They represent a virtual incarnation, embodiment, or manifestation of a person with a high level of behavior, flexible motion, realistic appearance, and the ability to react

to its environment (Google, 2012; Magnenat-Thalmann & Thalmann, 2006). Avatars also have recently been used in health-related interventions (Lisetti, 2012; Lisetti, Yasavur, de Leon, Amini, Rishe, & Visser, 2012; Schulman, Bickmore, & Sidner, 2011) as a means of addressing low literacy, eliminating variability in intervention implementation, tailoring information based on individual patients, and implementing race concordance by matching avatar appearance to participants (Lisetti, 2012). There have been no studies to date that have examined the use of avatars to promote cancer-related awareness or IDM about cancer screening. However, because of the feasibility and potential effectiveness of using avatar-led interventions with age and ethnically diverse populations, further research on the use of avatars in computer-based PrCA IDM interventions is warranted.

In order to create the most effective future IDM intervention for AA men in SC faith communities, we conducted formative research to determine AA men's: 1) current PrCA risk and screening knowledge, 2) decision-making processes for PrCA screening, (3) usage of, attitudes toward, and access to ICTs (e.g., computers, ATMs, kiosks), and (4) preferences toward a novel ICT intervention using avatars. The results from this formative research are intended to determine the appropriate PrCA content, interface (e.g., inclusion of an avatar), and functionality of a collaboratively developed, computer-based tool.

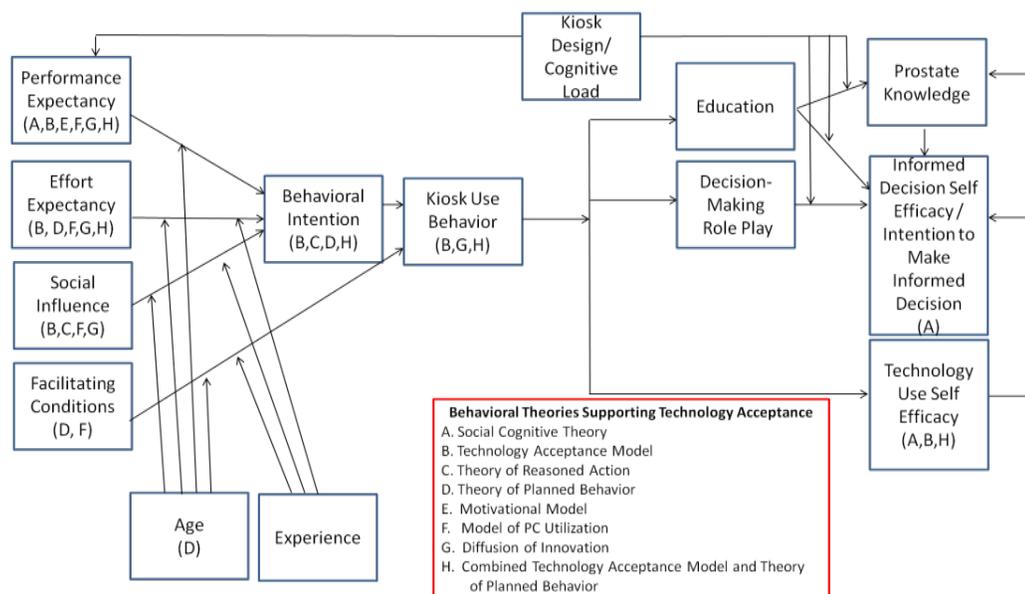
### **Conceptual Framework.**

The conceptual framework guiding this study (Figure 4.1) has been adapted from Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, Morris, Davis, & Davis, 2003). The theory posits that four key constructs:

(1) **performance expectancy** (i.e., the degree to which a man believes that a computer-based IDM intervention (i.e. DA) that delivers education and a decision making role play will lead to personal gains such as prostate knowledge), (2) **effort expectancy** (i.e., the degree of ease associated with using the DA to retrieve information), (3) **social influence** (i.e., the degree to which an individual perceives the importance that his social network (e.g., friends and family) will place on the use of the DA and (4) **facilitating conditions** (i.e., degree to which an individual believes that an organizational and technical infrastructure exists to support use of a DA for IDM), moderated by factors such as age and experience, contribute to an individual's behavior intention (i.e., intention to use) and DA use behavior (i.e., adoption of the DA as a regular source of information) (Venkatesh et al., 2003). The theory is based on the consolidation of eight validated health behavior theories (e.g., Social Cognitive Theory) which contain several common tenants supporting the adoption of any technology (Ajzen, 1991; Bufford, 1986; Compeau & Higgins, 1995; Davis, Bagozzi, & Warshaw, 1992; Fishbein & Ajzen, 1979; Rogers, 2003; Taylor & Todd, 1995; Thompson, Higgins, & Howell, 1991).

Also, to develop a computer-based DA that will lead to my long-term targeted outcomes (i.e., improved prostate knowledge, greater informed self-efficacy/intention to make an informed decision, and increased technology use self-efficacy), researchers also must be cognizant of principles relevant to interface design and their impact on an individual's ability to process information disseminated by computer-based interventions. According to Mayer's Theory of Cognitive Multimedia Learning (CMLT) (represented by the DA design/cognitive load in Figure 4.1), individuals process information through two channels that have limited capacity (i.e. cognitive load) (Mayer & Moreno, 2003).

Therefore, Mayer & Moreno have several recommendations for designing multimedia that can enhance a person's capacity for processing information and enhance learning. For example, multimedia presentations should include auditory as opposed to visual words in the presentation to reduce the amount of attention that a person has to devote to processing text (Mayer & Moreno, 2003). The CMLT has been used to design several health and non-health related computer-based media for adults (Paas & Sweller, 2012; Struve & Wandke, 2009; Van Gerven, Paas, & Tabbers, 2006; van Weert, van Noort, Bol, van Dijk, Tates, & Jansen, 2011; Wilson & Wolf, 2009; Xie, Yeh, Walsh, Watkins, & Huang, 2012). When used in conjunction, the UTAUT and CMLT not only offer a full perspective of the various ways in which technology can affect health outcomes, but also provide the appropriate framework to guide the formative research, development, and feasibility testing of the ICT.



**Figure 4.1:** Conceptual Framework based on Venkatesh et al (2003) and Mayer and Moreno (2003)

## Methods

### Sampling Description and Procedures

A purposive, (Patton, 1990) convenience sample of AA men, ages 40+ years from churches were asked to participate in one of six FGs. Recruitment efforts were guided by Vesey's framework on recruitment and retention of minority groups that involves a series of strategies such as leveraging partnerships in the community to assist researchers throughout the planning and implementation process (Vesey, 2002). Purposeful recruitment strategies including the distribution of flyers to churches, barbershops, and community organizations; in-person announcements at churches; one-on-one meetings with pastors and community leaders; radio promotion on stations with a large number of AA listeners; messages on AA community organization, academic, and healthcare system websites/listservs; and participation in health-related activities (e.g., health fairs) at churches. Eligibility criteria required that AA men, 40+: (1) speak and comprehend English, (2) have no personal history of PrCA, and (3) have no history of cognitive decline that would inhibit their participation.

Churches were selected as appropriate settings for this research because prior studies have concluded that AAs' spiritual needs (in addition to their socio-cultural and psychological needs) often influence their participation and trust in health research (Campbell et al., 2004; Holt et al., 2009; Huang & Coker, 2010; Resnicow et al., 2005; Rimer, Briss, Zeller, Chan, & Woolf, 2004; Vesey, 2002). A maximum of eight to ten men were included each of six FGs. The sampling for the FGs in this study was based on the qualitative research principles of saturation and sufficiency (Glaser & Strauss, 1967; Morse & Field, 1995; Seidman, 1998; Strauss & Corbin, 1998). Based on prior research,

it was predicted that saturation and sufficiency should be reached within five to six FGs (Friedman et al., 2012).

### **Data Collection Procedures**

**Demographic surveys.** Prior to the FGs, 39 men were provided with a short demographic and behavior survey. The 18-item survey assessed men's: (1) use of technologies for receiving health and cancer information, (2) non-technology related resources for health and cancer information, (3) most common and preferred sources of health and cancer information, (4) PrCA screening behaviors, and (5) PrCA IDM practices.

**Focus groups.** The 90-minute FGs were held in the fellowship halls of churches around the city and at a conference room on the campus of the University of South Carolina. During the FG, participants were asked questions about: (1) their current PrCA knowledge including prostate anatomy, PrCA prevention symptoms, prostate screening and diagnosis, and risks and benefits of PrCA screening, (2) their decision-making process regarding whether or not to receive PrCA screening, and (3) types of, access to, and personal or health-related use of interactive communication technology. They were also asked about social and physical barriers/facilitators of using ICTs and suggestions alleviating these barriers. In addition, men were asked about recommendations for a culturally appropriate computer-based DA for promotion IDM regarding PrCA screening. Items for the FG guide were created based on domains from our team's previous work on research (Friedman et al., 2012), but expanded to include general content about their technology acceptability and use (e.g., "How often do you use email to find health information?") which are consistent with constructs in our conceptual framework. The FGs were moderated and digitally recorded. All data were transcribed by

a professional transcription service. Following transcription, the audio recording was compared to transcripts to ensure quality.

**Data analysis/analytic approach.** Analyses of the data on the demographic survey were calculated using SPSS 20.0 (SPSS Inc., 2012). Data from FG transcripts was managed using NVivo<sup>®</sup> 9 (QSR, 2010), a qualitative software program. Prior to downloading FG transcript data into NVivo<sup>®</sup>, a preliminary draft codebook was developed through a using a grounded theory approach where the open coding of analogous transcripts by two researchers led to the conceptual organization of the data based on potential themes (Glaser & Strauss, 1967; Strauss & Corbin, 1998). After the codebook was finalized, NVivo<sup>®</sup> was used to facilitate the axial coding process of all transcripts. Axial coding helped us identify any thematic relationships that existed between codes (Strauss & Corbin, 1998). Inter-rater reliability was calculated by hand using a percent agreement method where the number of agreed upon codes are divided by the total number of items coded (i.e. agreements and disagreements) (Neuendorf, 2002). Throughout the analysis process, emergent themes were compared and contrasted between and within FGs (Glaser & Strauss, 1967). The study was approved by the IRB.

## Results

### Demographic Survey

**Descriptive Characteristics of Participants.** The sample (Table 4.1) included 39 AA men with a mean age of 53.6 (SD =7.2). Most participants either had some college (33%) or completed a college or higher degree (47.9%). Many of the participants were married (61.5%), employed full-time (53.8), and had some form (e.g., private, Medicare)

of health insurance (92%). Household incomes were variable but a quarter (26%) of participants reported earning between \$20,000-\$39,000.

### **Findings: Focus Groups**

Qualitative findings below have been divided into two main categories based on both our original research questions and the pattern of the results. These categories are as follows: PrCA knowledge and decision making, and technology use and barriers (Table 4.2).

#### **Prostate cancer knowledge and decision making.**

*Prostate cancer knowledge: symptoms, risks, and screening.* Overall, most participants had at least some knowledge about PrCA including the symptoms, risks and screening for PrCA. However, participant's knowledge about each of these areas varied. They knew the least about PrCA symptoms. The most commonly mentioned symptoms were those related to difficulty urinating or frequent urination. The most common misperception was that PrCA caused rectal bleeding. Most participants were also particularly familiar with the most common risk factors for PrCA and most often reported race (e.g., AAs being at the highest risk), heredity, age, and diet as risks for the disease. The most common reasons why participants reported that AAs are at the highest risk included that AAs have unhealthy diets, lack visits to a doctor's office, have inadequate health insurance, and/or lack of awareness about PrCA. In addition, most participants were knowledgeable about the two types of PrCA screening (i.e., PSA and DRE) and the recommended age at which conversations about PrCA screening should take place (i.e., as early as 40 to 45 for high risk groups). However, there were also some misperceptions

about PrCA screening such as confusion of the PrCA screening (particularly the DRE) with a colon cancer screening (i.e., or colonoscopy).

***Prostate screening decision making.*** The majority of participants reported receiving either one or both screenings (i.e., digital rectal exam or PSA) for PrCA and received their first screening at or near the age of 40. These screenings were most often performed at a doctor's offices by recommendation of the participant's doctor, as a requirement of a job, or as a personal decision. In many cases, participants reported receiving PrCA screenings on an annual basis. In addition, some participants sensed that doctors didn't provide patients with a role in the decision making process, but rather swayed participants towards screening. Those who had no prior information about PrCA screening simply relied on the information provided by their doctor. However, even those who did have prior information about PrCA screening (whether from their doctor or other sources) were not informed about the risks and uncertainties of the PrCA screening.

#### **Technology Use and Barriers.**

***Technology use: definitions, access, and purposes.*** When asked about what types of items come to mind when they hear the word technology, most participants associated the term with electronic items such as cell phones, computers, tablets, television, radio, and internet. All participants reported having access to at least one of these technologies, but most had access to more than one. Almost all participants reported using technology (particularly computers, mobile phones, and television), on a daily basis and for various purposes including those related to business, leisure, and receiving/seeking health and cancer information. For example, when asked where he receives health and cancer information, one participant responded "A lot of information I've been able to gather, just

not about cancer but just about any kind of different medical issue, has been on the internet.” Although mentioned slightly less often, a few participants also reported receiving health and cancer information through radio and mobile phones.

***Technology usability/barriers.*** Although most of the participants reported being comfortable using technology, they were typically not able to communicate what elements of the actual interface or features/functions of technologies made them easy to use. They simply referred to the accessibility of the technology. When asked what would make it hard for others to use the various technologies aforementioned, many participants reported that the lack of prior experience, lack of technology education, and age may affect a person’s ability to use a technology, but overall they suggested that the technologies they use are effortless.

#### **Recommendations for a computer-based intervention.**

***Content.*** When asked about the content that should be included in a computer-based DA to help a man make an informed decision with his doctor, all participants reported that the intervention should focus on a number of topics including prostate location, disease prevalence, signs and symptoms, age at which participants should begin discussions about screening, PrCA prevention, and treatment options. Participants also stressed that this information should be simple enough for any lay person to use, especially those who are older or have lower literacy levels.

***Intervention Features/User Interest.*** There were several features that were recommended for the DA to make it easy to use by AA participants with varying levels of computer literacy and also attract the interest of a person to use the intervention. General features recommended by participants included having large text and buttons, an audio

option for individuals who did not prefer reading, an index for navigating to specific information without having to sit for the entire presentation, a touch-screen, interactive-interface, a question and answer exercise, and having African American presenters. Some participants also stressed that the DA should not exceed five to ten minutes in duration, be as simple as possible to use, and their privacy (i.e., information provided and received) should be protected.

Participants were also asked to give their thoughts on an avatar being featured in the DA and while most were open to the idea, three to four participants expressed concerns. Those participants who were open to the avatar most frequently reported four main features that the avatar should exhibit including the avatar should be: (1) male gendered, (2) AA, (3) aged similar to the target population, and (4) as human-like as possible. The key concern voiced by the few participants who were slightly skeptical about the inclusion of an avatar was the age-appropriateness of using an avatar. Because avatars are commonly associated with games and play, some participants wondered whether older men would use the intervention if it included an avatar. For example, one participant reported “Because I’m in my 50’s right now, ...I would watch it. But you may have some that are older, that will say, I don’t have time for this.”

In addition to general features of the computer intervention, participants were asked what specific features should be included to promote user interest. The most commonly mentioned features were video of sports or images of the opposite sex. In a discussion about what is going to attract a man to use the DA, a participant suggested “you need something that is going to draw them over; fishing, football....or something like that just to catch the eye.” Another participant stated “For some folks, an attractive

female would be right on.” Other commonly mentioned features to promote interest included moving graphics or text that can catch an individual’s attention and offering an incentive such as a coupon or promotional item for using the intervention.

### **Discussion**

This research provided insight regarding AA men’s PrCA screening knowledge and decision making. It also provided the authors with a deeper understanding of the selected AA men’s use of, attitudes toward, and access to technologies. In addition, we were able to gain insight on AA men’s perceptions and preferences regarding a novel computer-based DA for PrCA education. These findings have multiple implications for using technology as a vehicle to promote informed decision making for PrCA screening.

#### **Prostate Knowledge**

Overall, participants were knowledgeable about PrCA including the symptoms, screenings, and risk factors. Participants knew the least about the types of symptoms for PrCA. Though they most commonly referred to urinary issues (e.g., frequent urination), there are also several other common symptoms such as pain in the back or pelvis, blood in the semen, painful ejaculation, and swelling in the legs, which were never mentioned (American Cancer Society, 2013d). In addition, there were few participants that reported that PrCA can also produce no symptoms. Furthermore, it is noteworthy that the most common misperception regarding PrCA screening was rectal bleeding. Although the prostate is located in front of the bladder and below the rectum and blood has been known to be found in the urine or semen of men with PrCA, blood from the rectum is not typically associated with PrCA. Bleeding in the rectum has however, been found to be periodically associated with prostate biopsies and treatment (American Cancer Society,

2013a). There also have been few studies showing that AA men have less general PrCA knowledge than men of other races, including PrCA symptoms (Barber, Shaw, Folts, Taylor, Ryan, Hughes, Scott, & Abbott, 1998).

Most participants were familiar with both the DRE and PSA and seldom confused it with other exams such as the colonoscopy. Men commonly confuse PrCA screening, DRE in particular, with screenings for colon cancer because both exams involve a rectal examination (Bastani, Gallardo, & Maxwell, 2001; Beeker, Kraft, Southwell, & Jorgensen, 2000; Kilbridge et al., 2009; Palmer, Midgette, & Dankwa, 2008). In addition to the anatomical similarities of the two exams, both exams are sometimes administered on a routine basis (although routine screening is not recommended for PrCA) (American Cancer Society, 2013a). For example, according to the many of the participants, PrCA screening is being recommended on an annual basis beginning at ages ranging from 40 to 50 by their doctors. It is also recommended by ACS that men and women receive a flexible sigmoidoscopy every 5 years and a colonoscopy every 10 years beginning at age 50 (American Cancer Society, 2013a). Therefore, it is not uncommon to find men who confuse the PrCA and colon cancer screenings include the age and time frame at which each should take place (Carter, Tippet, Anderson, & Tameru, 2010; Friedman, Corwin, Rose, & Dominick, 2009).

Participants also were considerably knowledgeable about the main risk factors for PrCA. They most commonly reported race, heredity, and diet as factors for PrCA. Age was mentioned less often; however, age is the most significant factor for PrCA because a man's chances of developing PrCA increase substantially as he gets older (American Cancer Society, 2013a). According to the ACS, over two-thirds of men who develop

PrCA are over the age of 65 (American Cancer Society, 2013a). Race and heredity are also common risk factors for PrCA (American Cancer Society, 2013a). AA men are twice as likely as White men to develop and die from PrCA (Siegel et al., 2012). Men who have a father or other male family member with a history of PrCA are also at a greater risk for PrCA (American Cancer Society, 2013a). In addition, as mentioned by participants, one of the solutions recommended for reducing the likelihood of PrCA is the adoption of a healthy lifestyle (e.g., reducing the intake of fatty-foods) (American Cancer Society, 2013a).

### **Prostate Screening Decision Making**

Based on their knowledge of PrCA risk factors, symptoms, and screening, participants seemed informed; however, they were not making sharing decisions about screening with their doctors as recommended by the ACS. In fact, many participants reported not being informed about the risks of screening prior to receiving PrCA screening. Instead, many of these participants were told about the risks of not receiving the screening and recommended to receive screening. It is important however, that men know about the risks of PrCA screening which are the chances that the PSA can result in a false negative, false -positives, and over-diagnosis (American Cancer Society, 2013c) A false negative can lead to a man feeling secure about not having PrCA when in fact the cancer is present. A false positive can take place when the PSA is elevated by something other than cancer (e.g., rigorous physical activity) (American Cancer Society, 2013c). A PSA score can also be falsely lowered by these factors (e.g., medications) when cancer is actually present (American Cancer Society, 2013c). The over diagnosing of cancers is disadvantageous because it can lead men to undergo unnecessary surgeries or receive

other treatments for indolent forms of PrCA (Welch & Albertsen, 2009). Therefore, men who would have likely not succumbed to their cancer may be exposed to the many risks associated with PrCA treatment. These risks include, but are not limited to incontinence and impotence (American Cancer Society, 2013c; Welch & Albertsen, 2009). It is because of these uncertainties about the effectiveness of PrCA screening, that men need to be well informed and share the decision with their doctor.

### **Technology Use**

Consistent with prior research with middle-age and older adults, participants used various technologies (particularly internet and cell phones) on a frequent basis for a number of purposes (e.g., health information seeking) (Bundorf, Wagner, Singer, & Baker, 2006; Pew Internet & American Life Project, 2012a, 2013b; Pew Internet and American Life Project, 2009a, 2009b; Rains, 2007). Most participants reported that the technologies they used were effortless and reported high levels of fluency with completing computer, email, and web related tasks (e.g., sending an email). Some participants suggested that these technologies would be easy for any individual with prior experience using similar technologies (e.g., men who used internet on their job expressed being more comfortable using the internet outside the job). In addition, participants felt that a man's age could contribute to his technology use and perception of how difficult it is to use a particular technology. Based on the conceptual framework, age and experience can both potentially moderate other factors (e.g., effort expectancy) to affect technology use. However, according to our formative research, solely age-related disabilities (e.g., poor eye sight) were rarely perceived by participants as making technologies more difficult to use for older AA men. Technology use was often perceived by participants as

easy or difficult based on their prior experience with using similar technologies. For example, because older men might be less likely to use technology for the purposes of a job, they may be less inclined to use similar technologies outside the job. Therefore, when older, inexperienced men are required to use a new technology, it is exceedingly more difficult. To overcome the perceived difficulty, some participants suggested that some older men may need instructions or education to use new technologies.

### **Intervention Features/User Interest**

The recommendations for a computer-based DA to facilitate IDM regarding PrCA screening were consistent with technologies used by many individuals on a daily basis. For example, many mobile (i.e. cellphones, tablets) and service kiosks (Redbox, ATM, Self-checkout) have many of the features (e.g., touch-screen, interactive, audio, index) mentioned. By creating a DA that is congruent with existing, commonly used technologies, but customizing it to accommodate older users, the intervention can be easy to use for people with varying ages and computer literacy levels. Participants also recommended a question and answer exercise to be included. The exercise could be helpful to increase knowledge of the participant because it will allow the participant to have recall the information learned, respond, and potentially hear the information repeated. In regards to the participant's concerns about privacy, many studies have concluded that AA men have a mistrust of the medical system and this wariness stems from prior unethical practices of the medical and research communities (Hammond, 2010; Hammond, Matthews, & Corbie-Smith, 2010; Moore, Hamilton et al., 2012; Moore et al., 2013). Last, though most participants were open to using the avatar if it was realistic and race-concordant, and avatars have been effective in many studies, some of

them were skeptical about the use of an avatar in the computer-based DA. With the paucity of educational tools that use avatars outside the context of a game, it is not surprising that some participants associated the avatar solely with games.

### **Study Limitations**

The convenience sample was well educated with no participants completing less than high school and a great majority that had at least completed some college. Therefore, the results from this study may not be generalized to populations with lower education levels. In addition, the results cannot be generalized to other racial and ethnic groups. Despite these limitations, this study provided valuable information that can be used to contribute to the future development of culturally appropriate, plain-language tools for helping AA men make informed decisions about their prostate health.

### **Conclusion and Implications**

The research presented shows that participants were knowledgeable about PrCA, in general, although knowledge on some topics (e.g., symptoms) was limited. Therefore, it would be advantageous for future interventions to provide AA men with basic information about PrCA prevalence, anatomy, risks, symptoms, and screening and emphasize the role of healthy lifestyle, and knowing the risks, benefits, and uncertainties of PrCA screening. Also, given the recommendations by the ACS for men to participate in IDM regarding PrCA screening, the information included in an educational intervention not only needs to provide information about the risks, benefits, and uncertainties of PrCA screenings, but also stress the significance of sharing this decision with their health care provider. In addition, because of the growing access and acceptability of various technologies within diverse AA communities, these devices

should be considered for use in the widespread dissemination of PrCA information and preparing men for making informed PrCA screening decisions. Furthermore, establishing community partnerships that contribute to the formative research process can be exceedingly beneficial when assessing the cultural appropriateness of a computer-based intervention and the best design that will lead to optimal impact.

These findings also have important implications for future research. Our study included a small, non-generalizable sample of AA men. It is documented in the literature that AA men rely on relatives/friends (particularly AA women) to find health information and in some cases will involve these individuals in their healthcare decisions (Friedman et al., 2012c; Levinson et al., 2005), but women were not included in my study.

Therefore, future studies should focus on assessing AA women's PrCA knowledge, technology use, and role in men of faith communities' PrCA screening decisions. In addition, most of the men in this study also reported being screened for PrCA which may have affected their knowledge of PrCA and perception of how the DA should be designed. Future studies should also include men who have not been screened for PrCA as they may have a different perspective on the DA design. Furthermore, since men report that their most common and preferred source for health information is their doctor, more research is warranted on the role of the doctor in men's informed decision making processes.

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**Table 4.1:** Descriptive Statistics (Mean (SE) or % of Study Participants, n=39)

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<b>Age</b>	53.6 (7.2)
<b>Education</b>	
High School	27.0
Some College or Vocational School	33.0
Completed College or Vocational School	18.0
Post Graduate School	22.0
<b>Marital Status</b>	
Single/Never Married	18.0
Married	61.0
Separated	10.0
Divorced	8.0
Other	3.0
<b>Income</b>	
>19,999	18.0
20,000-39,999	26.0
40,000-59,999	5.0
60,000-79,999	18.0
80,000- 99,999	10.0
<100,000	15.0
Not Reported	8.0
<b>Employment</b>	
Full time	54.0
Part time	8.0
Retired	10.0
Unemployed	15.0
Not Reported	13.0
<b>Health Insurance Type (All that apply)</b>	
Employer	49.0
Private	51.0
Medicare	15.0
Medicaid	5.0
Military Healthcare	28.0
Prescription Drug Coverage	13.0
Other	3.0
No Coverage	8.0

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**Table 4.2:** Focus Group Themes

<b>FOCUS GROUP THEMES AND SUBTHEMES</b>	<b>Summary</b>	<b>Explanatory/ Representative Quotes</b>
<b>1. Prostate Cancer Knowledge</b>		
Prostate Cancer Risks	Most participants were knowledgeable about cancer risks including links to race, age, heredity, and diet.	“As a black man..., we are more susceptible to get it [PrCA] than Caucasians or any other race.”
Prostate Cancer Screening	Most participants were knowledgeable about two types of PrCA screening with few misperceptions that were most often linked to confusion with a colonoscopy	“They do a blood test, or do a rectal inspection to see....if the prostate is swollen...”
Prostate Cancer Symptoms	Participants had some but varied knowledge about the symptoms of PrCA with some misperceptions.	“I think having polyps over a long period of time that aren’t removed. It turns into cancer.” (misperception)
<b>2. Prostate Screening Decision Making</b>		
Participant’s healthcare provider makes final decision	Many participants received screening as advised by a healthcare provider	“The first thing she does is say it’s that time a year again...She puts on the plastic glove. Drop your pants, and turn around.”
Participant’s job requires screening	Some participants (e.g., military) were required to receive annual screening exams.	“In the military it was forced upon you...”
<b>3. Technology Use</b>		
Definitions, access, and purposes	Technology was defined by electronic items such as cell phones, computers, tablets, television, radio, and internet. These items were used on a daily basis for a variety of professional and leisurely purposes.	“Every day at work I’m on the internet emailing.”

Health and cancer information	Participants report frequently using TV and internet as frequent sources for health and PrCA information.	“A lot of information I’ve been able to gather, just not about cancer but just about any kind of different medical issue, has been on the internet.”
Technology usability/barriers	The lack of prior experience or education, and age may affect a person’s ability to use a technology, but most participants suggested that technologies are effortless.	“It’s not a matter of what we can do to make it easier, other than education... Basically you have to have the willingness to learn”

## 4.2 Manuscript 2

An Iterative Process for Developing and Evaluating a Digital Prostate Cancer Decision

Aid for African-American Men<sup>2</sup>

<sup>2</sup>Owens OL, Friedman DB, Brandt HM, Bernhardt JM, & Hébert JR. Article status -  
To be submitted to Journal of Health Communication

## Abstract

**Background:** The burden of prostate cancer (PrCA), particularly among African American (AA) men, amplifies the need for men to make informed decisions about PrCA screening. To create the most effective digital decision aid (DA) for increasing prostate knowledge, decision self-efficacy, and intention to make an informed decision, this study implemented an iterative approach to developing a culturally appropriate DA. **Methods:** A short DA prototype containing PrCA information and interactive activities was developed by the research team. A sample of 21 AA men, ages 37-66 in the Southeastern United States then participated in one of seven 90-minute focus groups (FGs) and completed a 36-item survey. Updates were made to prototype based on participant feedback. Following these updates, the DA and heuristic evaluation surveys were distributed to seven expert reviewers. Ten men were also randomly selected to participate in interviews regarding usability of the DA. **Results:** Participants and expert reviewers agreed with many aspects of the DA, but some suggested changes to the format, content, and graphics to enhance the DA's effectiveness. Development and evaluation processes and implications are discussed. **Conclusions:** Using digital DAs for informed decision making may be appropriate for AA men. It is important to engage the community and experts in an iterative development process to ensure that a DA is optimal for use and relevant for the target population.

Keywords: Digital Health, Technology, Cancer Communication, Prostate Cancer Screening, Informed Decision Making, Health Disparities

## Background

African American (AA) men's prostate cancer (PrCA) incidence is 50% higher than in European American (EA; i.e., White) men on average and are also twice as likely to die from the disease (American Cancer Society, 2013; Siegel, Naishadham, & Jemal, 2014). Owing in part to these racial disparities is the fact that PrCA has very different implications in AAs, in whom disease tends to be more aggressive (Drake, 2006, Hebert, 2009). Whereas clear screening recommendations have been provided to reduce the burden of other cancers (e.g., colorectal), recent longitudinal research has led to considerable controversy regarding the benefits of PrCA screening (Andriole et al., 2009; Barry, 2009; Schroder et al., 2009; Smith, Cokkinides, & Brawley, 2012; U.S. Preventive Services Task Force, 2011), particularly the prostate specific antigen (PSA) screening. Whereas some non-profit and grassroots organizations support PSA screening (Mitka, 2009; National Medical Association, 2011; UsTOO International, 2011), some medical and research experts disagree about the efficacy of the exam (Barry, 2009, Roobol, 2011). The American Cancer Society (ACS), however, recommends that men make an informed decision with their doctor about whether or not to be screened for the disease (American Cancer Society, 2013). An informed decision is defined as: When the individual understands key aspects of a disease including the risk, benefits, and uncertainties of the screening or treatment, and make involve themselves in the decision making process at the level they desire (Briss et al., 2004).

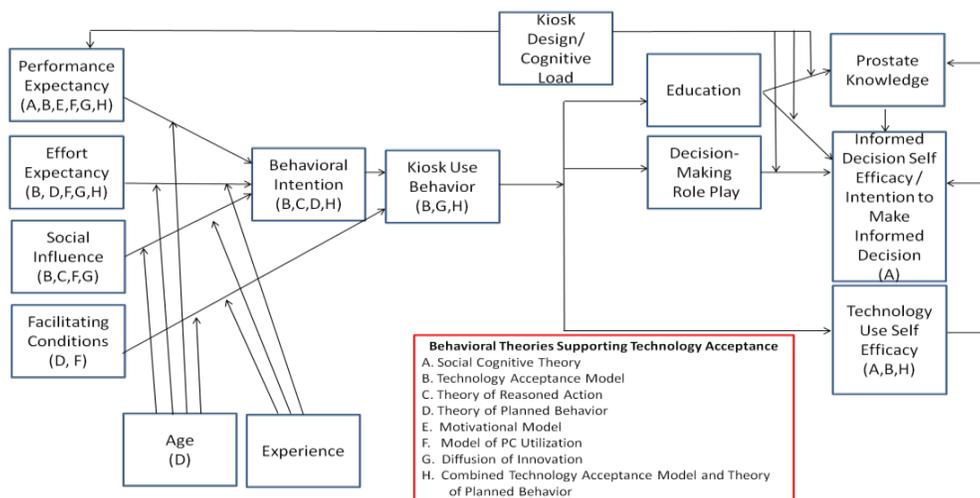
In order to make an informed decision individuals need effective, plain-language, and culturally relevant information appropriate for their diverse literacy levels (Informed Medical Decisions Foundation, 2012; Institute of Medicine, Committee on Health

Literacy, & Board of Neuroscience and Behavioral Health, 2004). Multiple research studies have recognized interactive communication technologies (ICTs; e.g., computers) as effective and culturally appropriate mediums for disseminating plain-language health content to diverse populations (Bernhardt, Mays, Eroğlu, & Daniel, 2009; Bernhardt, Mays, & Kreuter, 2011; Gielen, McKenzie et al., 2007; Lisetti, 2012; Lisetti, Yasavur, de Leon, Amini, Rische, & Visser, 2012; Schulman, Bickmore, & Sidner, 2011) and serving as decision aids (DAs) for the prevention and/or treatment of a number of chronic diseases including PrCA (Allen, Mohllajee, Shelton, Drake, & Mars, 2009; Evans et al., 2010; Kassan et al., 2012; Stronmberg et al., 2006; Wakefield et al., 2011; Weymiller et al., 2007). Outcomes demonstrated through the use of DAs for PrCA include increased knowledge, enhanced IDM self-efficacy, and reduced decisional conflict regarding cancer screening and/or treatment (Frosch, Bhatnagar, Tally, Hamori, & Kaplan, 2008; Ilic, Egberts, McKenzie, Risbridger, & Green, 2008; Kassan et al., 2012; Krist, Woolf, Johnson, & Kerns, 2007). There have been no computer-based DAs to date that have used an avatar to facilitate AA men's IDM process regarding PrCA screening.

### **Conceptual Framework**

The conceptual framework guiding this study (See Figure 4.2) has been adapted from Venkatesh's Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, Morris, Davis, & Davis, 2003). The theory posits that four key constructs: (1) **performance expectancy** (i.e., the degree to which an individual believes that a computer-based DA will lead to personal gains such as prostate knowledge), (2) **effort expectancy** (i.e., the degree of ease associated with using the DA to retrieve information), (3) **social influence** (i.e., the degree to which an individual perceives the

importance that his social network will place on the use of the DA), and (4) **facilitating conditions** (i.e., degree to which an individual believes that infrastructure exists to support use of a DA for IDM), moderated by factors such as age and experience, contribute to an individual's intention to use the DA (Venkatesh et al., 2003). The theory is derived from eight validated health behavior theories (Ajzen, 1991; Bufford, 1986; Compeau & Higgins, 1995; Davis, Bagozzi, & Warshaw, 1992; Fishbein & Ajzen, 1979; Rogers, 2003; Taylor & Todd, 1995; Thompson, Higgins, & Howell, 1991). The conceptual framework is also based on Mayer's theory of cognitive multimedia learning (CMLT) (represented by the kiosk design/cognitive load in Figure 4.2), which recognizes that individuals process information through two channels that have limited capacity (i.e., cognitive load) (Mayer & Moreno, 2003). Therefore, in order to reach our targeted outcomes (e.g., increased PrCA knowledge), researchers must not only be cognizant of aspects relevant to participants' acceptance of the DA, but also design the DA to deliver content in a way that is non-taxing on the participant's short term memory.



**Figure 4.2:** Conceptual Framework based on Venkatesh et al (2003) and Mayer and Moreno (2003)

## Methods

### Intervention Development

In an earlier study phase, 39 AA men were recruited from a local faith community in the Southeastern United States to participate in six FGs. Through these FGs, we assessed participants' prostate knowledge, screening decision making practices, technology use patterns, and their ideas regarding a digital DA. Based on findings from these FGs, an interdisciplinary team of experts in computer science and health communication customized a user-friendly digital interface containing PrCA information and a role play exercise to prepare AA men to make an informed decision regarding whether or not they should be screened. Prior to the development, the research team created a storyboard in Microsoft Powerpoint™ and a script that could provide details to the development team regarding each element of the proposed DA including aesthetics and functionality. The 45-slide storyboard also provided a way for the team and community to think through the many decisions that could potentially be made within the DA and the multiple accompanying interactive responses. Following the draft of the storyboard and script, members of the research team reviewed all materials prior to beginning the development process. The DA's digital interface was designed using I-Clone™, an animation software that allows the user to create a life-like avatar and animate it using Microsoft Kinect's™ motion capture (MoCap) capabilities (Reallusion, 2012). Voiceover was recorded separately then added to the avatar following the MoCap process. Design of the initial avatar was based on data collected through the prior FGs (e.g., avatar should be AA) and best practices such those outlined in the Microsoft™ Usability Guidelines (e.g., character strengths) and Usability.gov (Keeker, 2007; U.S.

Department of Health and Human Services, 2012). It was intended during initial stages of conception that the DA would contain three avatars (i.e., receptionist, doctor 1, and doctor 2) with distinct roles in the education program (e.g., welcome, presenter, role play). The script for the DA was developed using information from: (1) NCI's "What You Need To Know About Prostate Cancer" booklet (National Cancer Institute, 2008), and (2) previous PrCA education programs (Chan et al., 2011; Friedman et al., 2012). These resources include information about prostate anatomy, PrCA screening guidelines, the PrCA screening controversy, and the importance of IDM for screening. The resulting intervention was a 10-minute, two part education module (i.e., DA) with a question and answer exercise and a role play section to prepare men to speak with a physician about PrCA screening.

### **Data Collection Procedures**

Thirty-nine AA men ages 37-66 who were recruited during an earlier study phase (to determine AA men's PrCA knowledge, screening behaviors, and decision making and their technology use behavior) were invited to take part in a second FG aimed to provide feedback on materials related to the DA. Twenty-one of these men were available to participate in one of seven, 90-minute FGs. Men who were unavailable either had other commitments or did not respond to follow-up.

**Demographic surveys.** Prior to the FGs, these 21 men were provided with a 36-item survey (developed based on existing instruments) to determine their: (1) perceived overall health (DeSalvo, et al, 2006), (2) health literacy (Morris, MacLean, Chew, & Littenberg, 2006), (3) decisional conflict (O'Connor, 1995b), (4) decision self-efficacy (O'Connor, 1995a), and (5) computer, email and web fluency (Bunz, Curry, & Voon,

2007). Survey items were selected to provide more insight on the appropriateness of a digital DA tool for providing PrCA education to the target population.

**Focus groups.** Focus groups were held in the fellowship halls of churches around the city and at a conference room on the campus of the University of South Carolina. During each FG, participants were provided with a copy of the storyboard and script for the DA and shown a short demonstration of the prototyped DA. The FG protocol was conceptualized based on the theoretical framework (i.e., UTAUT and CMLT). Specifically, domains of both theories were used to craft questions to determine men's: (1) perception of the cultural appropriateness of the PrCA screening information (e.g., cognitive load, CMLT), (2) perceptions of the general usability of the DA including their thoughts about the format in which the information is presented or quality of content (e.g., performance expectancy, UTAUT), and (3) recommendations for improving the DA's digital interface to reduce navigation effort and enhance information accessibility (e.g., effort expectancy, UTAUT). The FG guide also was based on domains from Usability.gov, a resource published by the U.S. Department of Health and Human Services for developing and testing, easy-to-use web-based products for all populations (U.S. Department of Health and Human Services, 2012). Furthermore, we relied on the Microsoft™ Usability Guidelines to assess other dimensions of the DA that could affect its perceived usability including men's opinions regarding the challenge level of the question and answer activity or the avatar's character strength (Agarwal & Venkatesh, 2002; Keefer, 2007). The FGs were moderated and digitally recorded. All data were transcribed by a professional transcription service. Following transcription, the audio recordings were compared to transcripts to ensure quality.

**Expert Review.** Prior to the expert review, modifications were made to the DA based on feedback received during FGs with 39 AA men. These changes are reflected in Table 1. A seven member panel of experts in health communication, media arts, and digital health were recruited through email to participate in the review process. These experts were selected based on the recommendation of members of the research team based on their significant scholarly contributions to their respective fields. After accepting our invitation and signing a confidentiality agreement, copies of the DA were burned onto DVDs and sent to each member along with a heuristic evaluation instrument based on Nielson's 10 Heuristics (Nielson & Mack, 1994). The 10 Heuristics are open-ended, qualitative questions that cover a number of aspects such as the ability for a system to provide the user with timely feedback (Nielson & Mack, 1994). Each reviewer was asked to write a thorough response to each question and return both the evaluation and any additional feedback electronically within three weeks. Six of seven reviewers returned their evaluations.

**In-Depth Interview.** Ten participants were randomly selected from the 21 Aim 2 (Phase II) FG participants for in-depth interviews to test the feasibility of the DA. The interviews were guided by the theoretical framework to determine the DA's: (1) usability (Bangor, Kortum, & Miller, 2008) (Sawka et al., 2011), (2) acceptability (Davis, 1989; Kwasi, 2007) (i.e., behavior intention, UTAUT), (3) potential for improving technology-use self-efficacy (Compeau & Higgins, 1995; Shih, 2006), and (4) AA men's perception of the DA for preparing men to participate in IDM regarding screening (Kim et al., 2001). We also assessed participants' perceived impact on cognitive load (CMLT) and PrCA knowledge (Mayer & Moreno, 2003). These constructs were measured by including modified questions from pre-existing scales (referenced above) and those from Usability.gov in the interview guide (U.S.

Department of Health and Human Services, 2012). Specifically, men were invited to interact with the DA immediately prior to the in-depth interviews. During their interaction, participants were asked to “think aloud” (i.e., talk through each movement) as we observed their interaction with the DA and one researcher collected notes in MicrosoftWord™ regarding each participant’s performance (e.g., areas where they may have been unsure how to proceed) (Fleisher et al., 2008; Wen et al., 2012).

**Data analysis/analytic approach.** Analyses of the data on the behavioral survey were calculated using SPSS 20.0 (SPSS Inc., 2012). Data from FG transcripts and in-depth interviews was organized using NVivo® 9 (QSR, 2010), a qualitative software program. Prior to downloading FG transcript or interview data into NVivo®, two separate preliminary draft codebooks (one for FGs and one for interviews) were developed using a grounded theory approach where the open coding of analogous transcripts by two researchers led to the conceptual organization of the data based on potential themes (Glaser & Strauss, 1967; Strauss & Corbin, 1998). After both codebooks were finalized, NVivo® was used to re-code all FG and interview transcripts and facilitate the axial coding process. Axial coding helped us identify any thematic relationships that existed between codes (Strauss & Corbin, 1998). Inter-rater reliability was calculated for all the FG and in-depth interview data a by hand using a percent agreement method where the number of agreed upon codes are divided by the total number of items coded (i.e. agreements and disagreements) (Neuendorf, 2002). Throughout the analysis process, emergent themes were compared and contrasted between and within FGs (Glaser & Strauss, 1967). A similar analysis and theme comparison scheme was used for in-depth interview data. Expert reviewer comments were organized into a matrix using Microsoft

Excel™. Comments from each reviewer were placed into parallel columns accompanied by the specific survey question. Common themes were then identified among the six of seven reviewers who completed the evaluation.

## **Results**

### **Survey Findings**

#### **Demographic Characteristics**

The sample included 21 AA men with a mean age of 52.4 (SD =7.4). Most men either had some college (47.6%) or completed a college or higher degree (38.0%). Many of the participants were married (57.1%), employed full-time (52.4), and had some form (e.g. private, Medicare) of health insurance (100%). Household incomes were variable but over a quarter (28.6%) of participants reported earning between \$20,000-\$39,000.

#### **Other Survey Results**

**Current Health, Literacy, Decisional Conflict & Decision Self-Efficacy.** In general, most participants reported their health as excellent (83%), never needing help reading/understanding written material from their doctor or pharmacy (55%). Most (75%) also reported having low decisional conflict including knowing what PrCA options were available to them, having enough support from others to make a screening decision (95%), making a screening decision without pressure from others (91%), knowing the benefits of making an informed decision about whether or not to receive screening (80%), and having enough advice to make an informed PrCA screening decision (81%). Men also had a high level of PrCA screening decision self-efficacy with the majority reporting being very confident or confident about their ability to: find PrCA screening facts (91%), understand PrCA screening (90%), asking their doctor questions without feeling dumb

(90%), telling the doctor why PrCA screening is or is not right for them (81%), and/or delaying the decision about whether or not to receive PrCA screening if more time is needed (81%).

**Technology Use, Computer/Email/Web Fluency, Health Information Seeking, and Screening Decision Making.** Most participants were avid users of technology and used these tools to engage in general and/or PrCA health information (HI) seeking or receipt including television (72%), internet (64%), email (49%), cell phone applications (33%), texting (18%), and/or kiosks (5%). In addition, participants had high mean scores in computer (M=1.56), email (M=1.56), and web fluency (M=1.56) which ranged from 1 (very confident) to 5 (not at all confident). Participants most commonly preferred and reported a doctor as a source for HI (95%), but also reported being open to technologies such as email (72%), internet (67%) and cell phone applications (54%), as sources of HI. In addition, almost all participants had either received a PSA (89%) or DRE (95%) over the past 3-5 years but only 54% reported having a discussion and making an informed decision with their doctor prior to undergoing screening.

#### **Findings: Focus Groups with AA Men**

Most participants had positive opinions about the following aspects of the DA: performance expectancy/user engagement, facilitating conditions, effort expectancy, social influence, content effectiveness, character strength, and format. Overall, most participants reported that elements of the DA were appropriate, easy-to-use, and engaging for AA men of varying levels of computer literacy. There were, however, some suggestions for improving the DA. These suggestions included adding testimonials and

animations to cue the users when it is time to make the next decision (e.g., press next to hear more). All participants also suggested that a football screensaver (which was originally proposed by researcher to be included in the DA) be altered to include a variety of actual sports clips (as opposed to animated clips) and that we consider adding an incentive component to increase the number of users. See Table 4.3 for representative quotes and suggested/actual changes to the DA prior to the expert review.

### **Findings: Expert Reviews**

Overall, most experts reported that the DA met the principles of interaction design recommended by Nielsen & Mack, 1994 (e.g., error prevention), however, there were a few changes suggested to improve the usability of the DA. These changes included making aesthetic and animation changes to the avatars to make them look more realistic and enhance the avatar's character strength (e.g., movement, believability), changing orientation of navigation buttons, adding prompts to inform user when to make a selection and what selection options are available, and identifying how to reduce the transition time in between screens after a selection is made. Additional suggestions related to adding more detailed content to the DA. Refer to Table 4.4 for more detail on findings and suggested changes to the DA that were incorporated prior to the follow-up in-depth interviews with AA men.

### **Findings: In-Depth Interviews with AA Men**

Almost all participants reported that the DA was well designed, easy to use, and the content was easy to remember. A few small changes were recommended to improve the DA's usability. The most commonly recommended change to the DA was the addition of user cues that prompt a user when to proceed to the next screen of the DA.

For example, when most users approached the DA, they were unsure when to press the start button because a screen saver clip was playing in the background. They instead sat and watched the sports clip in its entirety and asked the researcher if they should move forward. However, almost all participants moved almost seamlessly through the DA after viewing the instructions clip which is provided following the screensaver. Cues or an automatic transition also were suggested for the question and answer section of the DA which requires the user to answer a question and press next to proceed to the next question. Additional observations gathered through the “think-aloud” exercise (but not mentioned by the participants during the in-depth interviews) indicated that: (1) some participants were not sure whether they should touch the text of the answer or the accompanying answer bubble to provide an response to questions, (2) a few participants had trouble using the onscreen answer bubbles because of their size, and (3) many participants were unsure at certain points during the role play activity whether to choose an option on the screen to proceed or to press next.

With regard to their perceptions about whether the DA would lead to our targeted outcomes (i.e., increased prostate knowledge, IDM self-efficacy, and technology use self-efficacy), participants reported that they expected the DA to perform well. In particular, they thought their IDM self-efficacy (i.e., comfort with making a screening decision with a doctor) would increase because of improved PrCA knowledge and practice with a simulated conversational exchange gained through the DA. When asked whether the DA would lead to a higher likelihood of men making appointments to speak with their doctors following use of the DA, many participants thought it would. Others stated that it may not directly prompt a user to speak with a doctor but it would make them likely to

speaking with a relative about the information they received. In turn, it would be possible that the relative would be the one to encourage AA men to visit their doctor. In addition, almost all participants perceived that a person with little computer experience may be more likely to use technology in the future (particularly for finding health information) if the technology functioned similarly to the DA (e.g., touch-screen, no searching, easy to use). See Table 4.5 for representative quotes.

### **Discussion**

The study exemplifies the iterative community/academic engaged process of developing and evaluating a digital DA to facilitate informed decisions among AA men regarding PrCA screening. The findings show that AA men and expert reviewers agreed with most of the DA's design of elements, however, they suggested minor changes to the format and graphics to make the tool more effective. Findings show that expert reviewer and participant concerns were somewhat similar with regard to the needed addition of cues to prompt the user when to proceed and they also agreed on some aspects of the avatar (e.g., making avatar older). Other concerns were not shared by both expert reviewers and participants (e.g., making buttons sleeker and closer in proximity and altering the transition in between screens). None of the participants provided comments or suggestions for the design or orientation of the buttons and most participants were comfortable with the transition style of the DA because it served as a cue when the user should proceed to the next screen. When asked if cues were added to the DA whether they would change the transition style, only one participant asked if the background with the avatar would remain visible for at least a short period following the conclusion of the avatar's presentation on any given screen. In addition to the comments provided by

participants and reviewers, the researcher's observation of the participants' use of the DA also provided additional insight on areas where the DA could be improved. In some cases, when the researcher asked the participant about areas of concern, participants still reported a positive use experience. Therefore, the think-aloud exercise was useful in determining potentially problematic areas of the DA that may have otherwise been undiscovered.

Based on our overall findings and our conceptual framework (i.e., effort expectance, performance expectancy), there is a high likelihood that AA men of diverse ages and levels of computer literacy will use the DA if slight modifications are made to the DA (e.g., adding cues) and the DA is made physically accessible. In addition, because of the simple design (e.g., lack large amounts of text, simple language), it is likely that the DA will lead to our targeted outcomes (Mayer & Moreno, 2003). Though the DA may have required minimal changes in our study to solidify its appropriateness for facilitating the informed PrCA screening decisions of AA men, engaging the community in a multi-staged process was pivotal to the development of the DA.

Many researchers are increasingly including formative phases in their research to inform the development, implementation, and evaluation of community-based health-related programming (DeJoy, Padilla, Wilson, Vandenberg, & Davis, 2013; Dy et al., 2011; Haerens et al., 2010; Strolla, Gans, & Risica, 2006; Wells et al., 2012; Wray et al., 2009). There are several benefits of formative research including providing contextual information about the community (e.g., behaviors, barriers, etc.), identifying resources that already exist in the community, and gathering insight directly from the community regarding how to intervene (Ahmed et al., 2010; DeJoy et al., 2013; Strolla et al., 2006).

In addition, having several methods (i.e., FGs, expert reviews, interviews) for and iterations of collecting feedback during the development of an intervention can lead to a deeper understanding about potential inhibitors and facilitators of the intervention and provide ideas about how the intervention can best be implemented to influence outcomes (Patton, 2002; Srivastava & Hopwood, 2009). Furthermore, these triangulated methods can serve as a means to validate study findings through data comparison (e.g., focus group vs. in-depth interview data vs. expert reviews) (Guion, Diehl, & McDonald, 2011). Future researchers who seek to develop digital interventions should use a similar iterative approach. It also may be beneficial to include other family members such as caregivers, relatives, and significant others in the design process because they may be involved in the gathering of health information and decision making for these potential users. For example, in AA populations it has been found that AA women are influential in the seeking and communication of PrCA information to AA men (Davison, Degner, & Morgan, 1995; Friedman, Corwin, Dominick, & Rose, 2009; Friedman, Corwin, Rose, & Dominick, 2009; Friedman, Thomas, Owens, & Hebert, 2012; McFall, Ureda, Byrd, Valdes, Morales, Scott, Williams, Calderon-Mora, Casillas, & Chan, 2009).

### **Study Limitations**

The study was a pilot and therefore the sample consisted of a small number of AA men from one mid-sized city in a southern state. The sample was well educated with no men completing less than high school and a great majority that had at least completed some college. In addition, all men reported having low decisional conflict, high levels of screening decision self-efficacy, and high levels of computer literacy. Therefore, the results from this study may not be generalizable to men who have lower education,

computer fluency, or decision self-efficacy levels or to other AA men in the same city, state, or other regions of the U.S. Despite these limitations, the study's design provided sufficient methodologic rigor to validate the findings and the findings provide valuable information that can be used to contribute to the future development of culturally appropriate, plain-language tools for helping AA men make informed decisions about their prostate health.

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**Table 4.3:** Overview of Focus Group Findings\*

<b>Construct**</b>	<b>Summary of Responses</b>	<b>Participant Comments</b>	<b>Participant Recommendations</b>	<b>Modifications to DA Prior to Expert Review</b>
<b>Performance Expectancy/User Engagement</b>	Because the DA is computerized, specific to PrCA, and doesn't require participants to read large quantities of text, most participants reported that the DA will allow information about PrCA to be found more quickly than by other means such as searching the internet. They also reported the content and avatar to be engaging. There were some suggestions for including a testimonial.	<i>"You have all the information right there, so just by touching a button it pulls the information up, which is going to help your older group instead of having to go to internet explorer, and type in the web address, [or] going to Google."</i>	<i>"Well, I would say add some experience [testimonial] with somebody that already had it [PrCA] or got it"</i>	None
<b>Facilitating Conditions</b>	All participants reported being comfortable with using the index, which would facilitate their use of the DA. Depending on the location of the	<i>"Once a person maybe starts the computer, and get it to the program then I feel that it's very simple. Once they pull up the index</i>	-	None

	DA some participants felt that a family member may be available if additional assistance was needed.	<i>and everything”</i>		
<b>Effort Expectancy</b>	Ease of system use was reported by most participants as simple and appropriate for people of all computer literacy levels. Some suggestions were provided for improving system use (e.g., ques to inform people when they need to make a selection, larger buttons and text).	<i>“I’m not very computer literate, but I can do this [DA] from the things I do on the computer at work”</i>	<i>“When it [avatar] finishes [speaking on a topic] maybe you can put a thing that says, press next.”</i>	<ul style="list-style-type: none"> <li>• Increased text and button size</li> </ul>
<b>Social Influence</b>	Most participants agreed that men in their age group would support their use of the DA.	<i>“If it’s simple enough for men our age to use it, I’m pretty sure they will...tell other people about it. ‘ If you want to know anything about prostate you have to go over to the kiosk [DA].’ ”</i>	-	None

<b>Content Effectiveness</b>	Most participants reported that the depth and amount of content was appropriate and easy to comprehend.	<i>"I think this is good...I wouldn't cut anything out, because my thing is, I understood this at glance."</i>	-	None
<b>Character Strength</b>	Most participants reported that the avatar was engaging, helpful, appropriate for the older men. Most suggestions related the young age of the sample avatar.	<i>"I think it will be easier for people to understand being engaged with [the avatar] because a lot of people can read and still don't understand what they are reading."</i>	<i>"He's a little too young really. I think maybe age him a little bit."</i>	<ul style="list-style-type: none"> <li>Created two new avatars for the DA in addition to sample avatar.</li> </ul>
<b>Format</b>	Overall, the format of the DA including name, introduction, Q&A, education, and role play sections were reported as appropriate with some suggestions (e.g., using varied real sports clips for screensaver).	<i>"I think the way it is, it's well presented, and it's a great idea. I was going to say good, but it's better than good as far as my opinion."</i>	<i>"You might want to [add] a little basketball or something like that...I wouldn't just stick with football."</i>	<ul style="list-style-type: none"> <li>Added diverse, real sports clips to DA as opposed to animated football clip.</li> </ul>
<b>Other</b>	Participants reported that incentives should be considered for attracting users to		<i>"I think that would be great [to have] some coupons at the end saying go through this, and get this."</i>	None

	the kiosk.			
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\*n=7 groups

\*\*Constructs adopted from Unified Theory of Acceptance and Use of Technology (Venkatesh et. al, 2003) and the Microsoft™ Usability Guide (Keeker, 2007)

Table 4.4: Overview of Expert Review Findings\*

Design Principle**	Definition	Summary of Expert Evaluation	Future Modifications to Intervention
<b>Visibility of system status</b>	The system should always keep users informed about what is going on, through appropriate feedback within reasonable time	The majority of reviewers reported that the DA adequately kept them informed, but two reviewers recommended adding changes including improving visibility and adding prompts in specific places in the module that can clarify selection options, and reducing delay between screen response.	<ul style="list-style-type: none"> <li>• Will add audio instructions that activate during idol time to prompt user that it is time to make a selection and what selections are available</li> <li>• Will render all assets in a DVD software that transitions more smoothly</li> </ul>
<b>Match between system and the real world</b>	The system should speak the users' language, with words, phrases and concepts familiar to the user, rather than system-oriented terms.	Most reviewers reported that the system was fairly intuitive and matched real-world convention based to an extent, but some reviewers recommended changes to avatar to make more realistic, seamless transitions, and more advanced prompts and buttons.	<ul style="list-style-type: none"> <li>• Will add audio prompts</li> <li>• Will render all assets in a DVD software that transitions smoothly and has athletically appealing buttons</li> <li>• Will make further modifications to avatars and revise animation</li> </ul>
<b>User control and freedom</b>	Users often choose system functions by mistake and will need a clearly marked "emergency exit" to leave the unwanted state without having to go	Most reviewers felt that the DA functions worked well.	None

	through an extended dialogue.		
<b>Consistency and standards</b>	Users should not have to wonder whether different words, situations, or actions mean the same thing. Follow platform conventions.	Reviewers agreed that the DA followed platform conventions.	None
<b>Error prevention</b>	Systems should design to prevent a problem from occurring in the first place. Either eliminate error-prone conditions or check for them and present users with a confirmation option before they commit to the action.	Reviewers all agreed that system is designed to avoid common errors.	None
<b>Recognition rather than recall</b>	Minimize the user's memory load by making objects, actions, and options visible.	Reviewers reported that the system well designed, but had minor suggestions for improvement such as placing buttons closer together to avoid the users having to touch different sides of the screen in order to process multiple steps (back then forward).	<ul style="list-style-type: none"> <li>Will render all assets in DVD software that has a more consolidated button menu</li> </ul>
<b>Aesthetic and minimalist design</b>	Dialogues should not contain information which is irrelevant or rarely needed.	Reviewers agreed that no additional buttons or information was included that was irrelevant. One reviewer however, suggested adding minimal detail to one portion of the role play exercise.	None

<b>Help users recognize, diagnose, and recover from errors</b>	Error should be expressed in plain language, precisely indicate the problem, and constructively suggest a solution.	All reviewers reported that the system helps the user easily recover from errors.	None
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\*n=7 reviewers

\*\*Design principles are components of Nielsen's 10 Heuristics (Nielsen & Mack, 1994) and constructs (i.e., perceptions) were adopted from Unified Theory of Acceptance and Use of Technology (Venkatesh et. al, 2003)

Table 4.5: Overview of In-Depth Interview Findings\*

Design Principles and Constructs**	Summary of Participant Evaluation	Participant Responses	Future Modifications to Intervention
<b>Visibility of system status</b>	All participants reported that the DA kept them informed throughout the program and they received feedback within a reasonable time.	<i>"I didn't think there was any noticeable pause or delays in the information that was given once you pressed the button."</i>	None
<b>Match between system and the real world</b>	All participants reported that the kiosk functioned similarly to technologies that they currently use including computers, phones, tablets, and atms.	<i>"It handles pretty simple, just like my computer."</i>	None
<b>Recognition rather than recall</b>	All participants reported that the system was well designed including the placement of buttons, available selections, and the inclusion of an index to allow direct access to various sections of the DA.	<i>"You always had the next button and the avatar clearly told you what to do and you had the navigation buttons over there for your choices."</i>	None
<b>User control and freedom</b> <b>Help users recognize, diagnose, and recover from errors</b> <b>Error prevention</b>	All participants reported that the system was design to help the user easily recover from errors and included clearly marked buttons to help them navigate to desired information within the program.	<i>"If I wanted to know about some of the signs of prostate, and I went down there and pushed another button and saw that I was not getting the information I wanted, I could always go back and make my choice over again."</i>	None
<b>Overall Ease of Use</b>	All participants reported that the system was easy to use and that the system was appropriate for both older adults as well as those with lower levels of computer	<i>"I think it would easy for anyone to operate...It has everything right there in your face that you</i>	<ul style="list-style-type: none"> <li>Will add an indicator that activates during idol time to alert user that it is time to make a selection.</li> </ul>

	literacy. There were minimal suggestions for improvement provided such as adding cues to alert user when to proceed.	<i>need to know or inform you on what you want to know. I think my little grandbaby could probably do it because it's so simple to me."</i>	
<b>Perceptions of DA's effect on prostate knowledge</b>	All participants reported that they expect the DA to increase prostate knowledge of users.	<i>"If you can do it [educate] for me, I know somebody who don't know nothing, after five minutes of listening to that [DA], they have to know it [about PrCA] now."</i>	None
<b>Perceptions of DA's effect on IDM self efficacy</b>	All participants reported that the DA will make users more comfortable participating in IDM with a doctor. Most participants also reported that a user will be more likely to speak with a doctor after using the DA.	<i>"I think the information that they are gaining gives them some conversation pieces, you know, now me and the doctor got something to talk about"</i>	None
<b>Perceptions of DA's effect on technology use self efficacy</b>	Most participants reported that the DA will make users more comfortable using technology for finding/receiving health information, but under the condition that the technology functions similarly to the DA (i.e., touch screen, no complex searches, etc.)	<i>"I think if this is really user friendly and if they have a positive experience here, then it could definitely lead to them going, 'Okay, I might be able to handle something like this.' "</i>	None

\*n=10 participants

\*\*Design principles are components of Nielsen's 10 Heuristics (Nielsen & Mack, 1994). Constructs based on the Unified Theory of Acceptance and Use of Technology (Venkatesh et. al, 2003).

## CHAPTER 5

### DISCUSSION

The goal of this dissertation was to conduct formative research that promotes and facilitates IDM regarding PrCA screening in SC, particularly among AA men. I addressed the goal by examining what AA men know about the risk factors and symptoms for PrCA (RQ1) and their knowledge about the types of PrCA screening and associated risks, benefits and certainties of these screenings (RQ2). I also assessed how AA men make decisions about PrCA screening (RQ3) and how often and for what general purposes AA men are using technology (RQ4). I developed and assessed the usability of an interactive DA for increasing knowledge, self-efficacy, and intention to make an informed decision about PrCA screening among AA men in faith communities (RQs 5-11). In addition to providing the results in this chapter, I also discuss how the study's conceptual framework and the authors' research processes can serve as a guide for those interested in academic/community collaborations for developing health technologies. Finally, I address study limitations; provide further implications for research and practice, and present final conclusions.

**Research Question 1:** What do AA men know about the risk factors and symptoms for PrCA?

During the FGs, participants commonly reported having some knowledge about PrCA including the symptoms, risks, and types of screening for PrCA. However, AA men's knowledge varied for each of these topical areas. Other than the disease's effect on

urination, AA men knew little about symptoms for PrCA. They also had some, misperceptions about symptoms for PrCA (e.g., rectal bleeding). In addition, participants were more knowledgeable about common risk factors for PrCA than AA men who were involved in previous research in the region (Friedman, Thomas, Owens, & Hebert, 2012b). They most often reported race, heredity, age, and diet as risks for the disease, which is consistent with those risk factors reported by ACS (American Cancer Society, 2013a). AAs in my study also were aware that they are at the highest risk for PrCA and reported that this disparity exists because AAs have unhealthy diets, are less likely to visit a doctor's office, have inadequate health insurance, lack awareness about PrCA, or some combination of these factors. These barriers to health, which stem from social and environmental stimuli (e.g., cultural dietary practices), have been demonstrated in other health disparities research (Freeman & Chu, 2005; Reynolds, 2008; Smith, Cokkinides, & Brawley, 2012).

**Research Question 2:** What do AA men know about the types of PrCA screenings and risks benefits and uncertainties of these screenings?

Most participants were knowledgeable about the two types of PrCA screenings (i.e., PSA and DRE) and the recommended ages at which AAs should begin conversations with their doctors about PrCA screening. There were a few misperceptions about PrCA screening such as confusion of the PrCA screening (i.e., DRE) with a colon cancer screening (i.e., or colonoscopy). These misperceptions have been documented by other researchers (Kilbridge et al., 2009; Palmer, Midgette, & Dankwa, 2008) and occur primarily because the colonoscopy and DRE are performed in the same anatomical area of the body (i.e., rectum). Also, few men knew about risks and uncertainties of the PSA

test (i.e., results can be falsely elevated or lowered by things such as medications). In addition, none of the participants reported that their doctors spoke with them about the controversy regarding risks and uncertainties of the PSA screening, but rather focused on either the benefits of having a PrCA screening or the risks of not having the exam.

**Research Question 3:** How are AA men making decisions about PrCA (e.g., shared, individual)?

The majority of participants reported receiving either one or both screenings for PrCA and some participants received these screenings on an annual basis. Typically, these screenings were recommended by the participant's doctor as a requirement of a job or as a personal decision based on information gathered through media or social circles. However, few men were knowledgeable about the risks and uncertainties of PrCA screening (i.e., PSA) and typically did not share the decision with their doctor about whether or not to receive screening as recommended by ACS (American Cancer Society, 2013a). These findings are consistent with prior research which demonstrates that AA men have limited knowledge regarding the PrCA screening controversy, rarely participate in a shared decision making process regarding screening, and most often rely on their doctor's recommendation for whether or not they will be screened (Allen, et al., 2011; Bowen, Hannon, Harris, & Martin, 2011; Hoffman, Couper et al., 2009; Hoffman, et al., 2010; Jones, Steeves, & Williams, 2009).

**Research Question 4:** In general, how often, and for what purposes are AA men using technology?

Participants across all FGs most often identified technology as being associated with electronic items such as cell phones, computers, tablets, television, radio, and

internet and often reported having access to multiple technologies. Men frequently reported using technology (particularly computers) on a daily basis and for various purposes including those related to business, leisure, and sources for health information. These findings are consistent with other research on technology use among middle-age and older adults (Bundorf et al., 2006; Pew Internet & American Life Project, 2012a, 2012c, 2012d, 2012e, 2013c; Rains, 2007).

When asked what would make it hard for others to use the various technologies aforementioned, participants reported that the lack of prior computer or technology experience, lack of technology education, and being an older/retired adult may affect a person's ability to use a technology, but overall they felt as if the technologies they use are effortless. In addition, there were some comments that place the responsibility of learning how to use technology on the consumer and most participants stated that it would not be difficult to use current technology for someone who is willing to learn. There have, however, been some reported barriers for technology use among aging and older adults noted in past research such as perceived usefulness (Fisk et al., 2009; Heart & Kalderon; Mitzner et al., 2010; Morris et al., 2007), computer anxiety (Chu et al., 2009; Czaja et al., 2006), lack of self-efficacy (Chu et al., 2009; Czaja et al., 2006), and lack of prior use experience (Czaja et al., 2006). Through our iterative, community-driven design process, we have attempted to eliminate these barriers by creating a simple, plain-language DA that has been deemed usable by our study population.

**Research Question 5:** What are AA men's perceptions about the user-friendliness of the DA (i.e., easy to use)?

Ease of system use was reported by most participants as being simple and appropriate for people of varying computer literacy levels and ages. Minimal suggestions were provided for improving system use such as providing visual or audio cues to inform the users when to press buttons to proceed through the program. Aspects that worked well for participants included having an index to allow navigation to any section of the program, large labeled buttons that also facilitated navigation throughout the program, the short instructional regarding how to use the DA, the inclusion of an avatar that provides audio education and minimal text, and having a touch-screen as opposed to a mouse/keyboard. Participants also reported that the DA was similar to technologies that they use on a daily basis including phones and tablets. Prior research has demonstrated that a well-designed health-related DA can lead to benefits such as lower computer anxiety, decreased decisional conflict, and higher IDM self-efficacy (Allen et al., 2009; Chu et al., 2009). These findings indicate that technology may not only be acceptable among AA men, but effective for facilitating PrCA IDM.

**Research Question 6:** What are AA men’s perceptions about whether or not people in the community will support their use of a DA for seeking health information?

Most participants agreed that men in their age group (40+) and others (e.g., family members) would support their use of the DA, especially if it is both simple and provides lifesaving information. Most participants also stated that if the DA provided value to the user, they would likely tell others about the DA and encourage them to use it. Men also reported that the actual use of the DA would probably depend upon the location of the DA, which was only addressed briefly in the FGs or follow-up interviews. Some suggested locations for the DA were churches, doctors’ offices, malls, and stadiums.

These locations (with exception to stadium) have been the sites for the placement of DAs in previous successful health-related campaigns (Jones, 2009; Kreuter et al., 2006; Thompson et al., 2007).

**Research Question 7:** What are AA men's perceptions about whether or not a collaboratively developed DA will increase their prostate knowledge?

Participants were confident that because of the format and clarity of the content included in the DA and the system's ease of use, most users would be more knowledgeable about PrCA after the completion of the education program. Those participants (including those who felt they had a thorough knowledge of PrCA) reported learning at least one or more new facts about PrCA while reviewing the content (note: factual knowledge was not measured). These previously unknown facts typically related to the risks and uncertainties of PrCA screening and symptoms not occurring in all men. For example, many participants reported not knowing that some men who have PrCA do not experience any common symptoms such as frequent urination (American Cancer Society, 2013d). There have been few prior studies that have identified a disparity between AA men's PrCA knowledge as compared to men of other races (Barber, Shaw, Folts, Taylor, Ryan, Hughes, Scott, & Abbott, 1998). There is, however, an opportunity to further improve the knowledge of AA men through DAs because similar studies have demonstrated positive increases in overall PrCA knowledge among AA men who used digital PrCA-related DAs (Allen et al., 2009; Jimbo et al., 2013; Kassan et al., 2012).

**Research Question 8:** What are AA men's perceptions regarding whether or not a collaboratively developed DA will increase their IDM self-efficacy and intention to participate in IDM?

Most participants reported that they perceived the DA would make individuals more comfortable speaking with a doctor about PrCA screening because they would not only be more knowledgeable about PrCA (including knowing the risks, benefits, and uncertainties of screening), but they also would know which questions to ask when they engage in a discussion about screening (particularly because of their involvement in the role play portion of the DA). Many participants also reported that men might be more likely to visit the doctor after completing the education program specifically to talk about PrCA. Some men reported that the DA may not directly prompt men to go to the doctor, but would instead inspire them to have conversations with relatives/significant others. These relatives would then be the ones who may encourage men to visit their doctor. Prior research has documented the pivotal role of family members in the healthcare decisions of AA men (Friedman et al., 2012c; Jones, Taylor, Bourguignon, Steeves, Fraser, Lippert, Theodorescu, Mathews, & Kilbridge, 2008; Levinson, Kao, Kuby, & Thisted, 2005). Our findings also are consistent with researchers who have found success with increasing IDM self-efficacy through the use of a computerized DA (Allen et al., 2009; Andersen et al., 2008; Ashish & Trout, 2012).

**Research Question 9:** What are AA men’s perceptions regarding whether or not a collaboratively developed DA will increase a user’s self-efficacy relating to their technology use?

Overall, participants reported that the DA would make a person who has less computer experience more comfortable using other technologies in general if those technologies were designed similarly to the DA. More specifically, participants reported that users would be comfortable using technologies that are intuitive and have touch-

screen capabilities (e.g., smartphones or tablets). In addition, most participants reported that inexperienced users would also utilize the aforementioned technologies for finding health information if they were provided with a direct web address or the technology functioned similar to the DA. On the contrary, experienced computer users reported that the DA would prompt them to actively search for more detailed information on PrCA only if needed. Therefore, it may not only be advantageous to make the DA content accessible on multiple platforms (e.g., cellphone, computer/web), but also provide direct links that can provide men of varying computer literacy levels with additional PrCA information.

For diseases other than PrCA, it is uncertain whether the DA will directly prompt users with varying levels of experience to search for health information using technology-related resources unless the DA is expanded to include a suite of information about other health topics (e.g., colon cancer) as recommended by one participant. There are several health-related resources that house information on multiple topics such as the Interactive Health Tutorials sponsored by Medline Plus, a service of the National Library of Medicine (U.S. National Library of Medicine, 2013). However, these education programs do not have 3D animations (which is novel and has been demonstrated to enhance the educational experience (Schulman et al., 2011)), nor are they designed using principles to reduce the burden on a users' short term memory as recommended by Mayer & Moreno, 2003 (e.g., programs should not use text and audio simultaneously).

**Research Question 10:** What are AA men's perceptions regarding whether or not they will have enough support to use the DA?

Participants reported that the design of the DA would largely eliminate the need for human support related to their use of the DA (e.g., assistance with how to use the DA). In cases where a less experienced or older user has trouble with starting the PrCA education program, many men reported that these individuals would likely be accompanied by a younger or more experienced computer user that could provide them with general directions. Participants were confident that once a user was directed to the instructions page where avatar provides overview of the program (third scene of the DA), then the user would have more than enough knowledge to navigate through the entire program, particularly with the program being avatar led. In a previous research study, Bickmore et al, 2009 found that an avatar-led, post-hospital discharge education program was effective and acceptable for a predominately AA population with varying computer literacy levels because it provided clear instructions. Consistent with prior research, the use of avatars within programs can also be particularly advantageous with lower literacy populations because they are not as likely to read large amounts of text such as instructions (Lisetti, 2012; Lisetti et al., 2012). To further enhance the usability for the targeted population, two participants suggested adding an animation (e.g., blinking button on the screen saver page) that will cue a user that he should press start. Currently, the start button is visible, but some participants were unsure when to press it. Otherwise, it was suggested that the user may either not recognize when he should press next or ignore the next button and leave the DA once the clips of the various sports plays ended. Future iterations of the DA should contain cues and better labeling so that when a man is attracted to the DA, he leaves having received PrCA education and not simply

entertainment from the screensaver. There is no DA to date that has utilized a rolling, sports-related screensaver to attract men to a health-related DA.

**Research Question 11:** What are the perceptions about whether or not the DA meets industry standards and best practices?

Overall, expert reviewers reported that the DA met the majority of industry standards and best practices, but there were a few changes suggested to improve the usability of the DA. The specific reviewer recommendations included changes to the avatars to make them look more realistic, altering the positioning of the navigation buttons so they will be closer in proximity to one another, adding prompts to inform user when to make a selection and what selection options are available, and identifying how to reduce the transition time in between screens after a selection is made. The reviewers' recommendations were somewhat consistent with the participants' suggestions, particularly the avatar and addition of prompts. For example, the participants commented in FGs that the avatars should be made to look older and that some of the glitches in the animation be fixed. As mentioned in the prior discussion for RQ10, participants also thought it would be useful to provide some type of cuing system to tell the users when to proceed with the next page. However, the participants (as opposed to some of the reviewers) positively commented on the placement of buttons and were fine with the transition time in between DA screens.

### **Implications for Practice**

These findings have important implications for practice: 1) content and interface design for effective PrCA IDM DAs, 2) Fostering academic/community partnerships to

develop and evaluate a non-costly, culturally appropriate DAs, 3) and using an iterative research and development process for designing education programs and interventions.

**DA Design: Content.** Specifically, because our study participants' knowledge varied regarding PrCA symptoms and the risks/uncertainties of screening, it would be advantageous for public health researchers planning to design and implement effective PrCA DAs to provide a basic overview of PrCA including prevalence, anatomy, risks for PrCA, symptoms, and screening. Additionally, I think it is important to highlight that not all individuals experience the same symptoms. Sometimes symptoms people with PrCA have no disease-specific symptoms (which often appear at the later stages of PrCA). The DA content should stress the importance of understanding the risks, benefits, and uncertainties of PrCA screening and the controversy regarding the PSA test. Finally, the content included in the DA needs to emphasize the significance of sharing the IDM process with their doctor and should prepare users to engage in a conversation with their doctor through a role play exercise (i.e., demonstrating what questions should be asked during the course of a doctor/patient conversation). All of the information included in the DA should be in plain language to accommodate individuals with varying levels of literacy and also should be reviewed by the community and communication experts who have experience working with similar populations.

**DA Design: Interface.** Researchers should adopt a set of principles when designing any interface, but should refine the interface depending upon the specific needs of the population. For example, I used principles from both the Cognitive Media Learning Theory (e.g., using less text and more audio) and the Microsoft™ Usability Guide (e.g., appropriate feedback should be provided to a user within a reasonable time)

to guide my DA interface design (Keeker, 2007; Mayer & Moreno, 2003). However, working with the community, I was provided with additional suggestions for improving the design such as increasing the size of buttons, including an index to allow users to navigate quickly to specific information (e.g. PrCA symptoms), using actual sports clips as opposed to animations to attract users in public spaces, and providing users who need more detailed information with links to trusted websites and a contact number for a PrCA expert. Both content and interface design of a DA are equally important because if the DA is not easy to use then the community will be less likely to adopt it for regular use (Venkatesh et al., 2003). Similarly, if the content is not simple and does not include all the information needed to make an informed decision, then the DA will be less likely to increase men's prostate knowledge, decision-making/technology-use self-efficacy, or their intention to speak with a doctor regarding PrCA (Mayer & Moreno, 2003; Venkatesh et al., 2003). Therefore, it is important to receive input from the community and relevant experts during the design process.

**Fostering Academic/Community Collaborations.** Establishing academic/community partnerships can have several benefits: 1) researchers having a higher likelihood of developing an effective DA, 2) both researchers and the community having access to resources (e.g., equipment, experts) within the university to develop interventions (i.e., developing interventions in-house is much less expensive than contracting with an outside entity), and 3) researchers having opportunities to continue implementing research in the given communities that could not only advance the state of science and eliminate health disparities, but also potentially meet some immediate health-related needs of the community (e.g., access to healthful foods). In prior research, my

colleagues and I found that partnerships with academic/clinical/community organizations (e.g., churches, hospitals, non-profits) can also lead to relevant benefits including the enhancement of marketing and recruitment efforts for the study (Friedman et al., 2012b). For example, in this study, the nurse navigator and members of the community were willing to leverage existing relationships with organizations (e.g., churches) to recruit participants by word of mouth and flyer distribution (Friedman et al., 2012b).

**Implementing an Iterative Research and Development Process.** Developing a DA with the community through several iterations of formative research can be advantageous because it can increase the probability that the development team thoroughly addresses the barriers/constructs (e.g., effort expectancy) necessary for the target population to adopt the technology (Hong et al., 2013; Venkatesh et al., 2003). In addition, it provides an opportunity to refine design elements and so that technology will be more likely to lead to given outcomes (i.e., making sure the content is easy to understand so they are more likely to adhere to a given behavior such as speaking with a doctor about PrCA screening) (Hong et al., 2013; Mackert, Kahlor, Tyler, & Gustafson, 2009; Pfaeffli et al., 2012; Wells et al., 2012). It is acknowledged that a DA alone may not be able to address some of the physical barriers that hinder individuals from participating in IDM (e.g., no health insurance), but through the academic/community partnership and a formative research process, strategies can be formulated in attempt to ameliorate these barriers. For example, researchers can leverage their existing relationships and resources to provide either direct access to or information about free or low cost opportunities for community members to speak with a doctor following their use of the DA. Therefore, researchers should consider fostering community/academic

partnerships during the conceptualization stages of a study and conduct an iterative, formative research process prior to a full intervention pilot (Friedman et al., 2012b).

### **Implications for Future Research**

These findings also have important implications for future research (particularly for expanding this research to other populations and platforms). My study included a small, non-generalizable sample of AA men. It is documented in the literature that AA men rely on relatives/friends (particularly AA women) to find health information and in some cases will involve these individuals in their healthcare decisions (Friedman et al., 2012c; Levinson et al., 2005), but women were not included in my study. Therefore, future studies should focus on assessing AA women's and AA men's perceptions regarding the DA. Also, future studies should focus on evaluating the impact of the DA on AA men and women (e.g., IDM). The evaluation should include a comparison of the DA's impact on men when receiving: 1) PrCA information through the DA alone versus 2) the information with an AA woman present, or 3) PrCA information indirectly from a woman who has used the DA. Based on the information gathered through the aforementioned evaluation, it could be determined if and under what scenarios the DA will be most likely to increase the number of AA men who are engaging in IDM with their health care providers.

In addition, the intervention in this study was tested using only one platform (i.e., touchscreen-computer). Future research also should explore the feasibility and effectiveness of deploying the DA on platforms such as tablets and cellphones. The DA in this study was solely developed for a large touch-screen computer because it provided the simplest means to create and test the DA. However, because of the growing access to

mobile devices (especially among AAs) (Pew Internet & American Life Project, 2013g), and the success of recent studies that have used mobile interventions among aging adults (King et al., 2013; Silveira et al., 2013), it may be advantageous to expand the DA for use on these devices and perform usability tests. Some questions that should be considered are: 1) which platform is used more often overall and does platform use vary by demographic characteristics (e.g., age)?, 2) how are AA men using the DA (e.g., are they beginning the DA on a public kiosk, but completing the DA on a mobile device in the privacy of their home)?, and 3) which platform is leading to the best outcomes (e.g., IDM with a doctor) and why? It is also important to note (as mentioned in the implications for practice section) that researchers seeking to carry out studies with the DA should consider, partnering with communities/community organizations that can facilitate your entry into the community and potentially enhance recruitment (Friedman et al., 2012b). In addition, employing multiple methods (e.g., FGs, interviews) and phases (i.e., formative) of data collection also can add to the validity of the study and provide the researcher with an opportunity to identify barriers and facilitators of research implementation (DeJoy, Padilla, Wilson, Vandenberg, & Davis, 2013; Guion, Diehl, & McDonald, 2011; Mackintosh, Knowles, Ridgers, & Fairclough, 2011).

Because men in our study and others report that they most often rely on their doctor's recommendation for whether or not they will be screened, more research is warranted on the role of the doctor in men's screening decisions (Hoffman et al., 2009; Hoffman et al., 2010). In particular, future studies should focus on if, which, and how PrCA screening recommendations are influencing their advice to patients; how and when (i.e., what age) these conversations about screening are taking place; and the outcomes of

these conversations (e.g., shared decision to be screened). By researching the role of the doctor, we can determine if future interventions should also be implemented among doctors to promote shared decisions regarding PrCA screening.

Finally, it is noteworthy that participants did not mention treatment during their discussions about their PrCA knowledge or screening decision making. Though it was not our intent to assess their specific knowledge regarding treatment, it is necessary to have some knowledge of treatment when deciding to undergo screening. Discussing treatment, including its risks and side effects, is especially important to the IDM process because of the uncertainties of the PSA screening which can lead to unnecessary treatment (National Institutes of Health, 2011; Welch & Albertsen, 2009). However, knowing about treatment options can also be advantageous because it can prepare a man for future informed decisions that may need to occur regarding treatment “if” cancer is found. These treatment decisions can include whether or not to be treated (includes active surveillance and repeat PSA) and what type of treatment will be received. Currently, prostate cancer decision aids produced by leading health organizations such as the ACS and CDC information at least some information about treatment (e.g., side effects of treatment), but the details included vary (American Cancer Society, 2014; Centers for Disease Control and Prevention, 2008). For example, while the CDC’s DA gives information about the different types of treatment, the ACS’s PrCA screening DA only mentions the fact that treatment can have negative consequences (American Cancer Society, 2014; Centers for Disease Control and Prevention, 2008).

## **Study Strengths**

One key strength of this study was its iterative, community-driven design. The participants had the opportunity to be involved in several aspects of the DA development including what content was included in the DA, how the DA would function, and how the DA would look aesthetically. The researchers in this case served as the liaisons between community and the academy. The role of the researcher was to present a potential problem based on the literature, assist the community with the conceptualization of a solution based on how the problem presented itself in their specific communities, and leverage the resources available within the university (e.g., experts and students) and the community to develop a potentially viable solution through a multi-step process. The formative, multi-step process was pivotal because it facilitated the evolution of several ideas from community members into a product that was usable and for which the community could be proud. Another strength was the use of triangulated methods. Using FGs, in-depth interviews, expert reviews, and think aloud observations provided me with a means to compare data to identify similarities and discrepancies between sets of data and it also served for a means to validate overall findings (Guion et al., 2011).

## **Limitations**

The sample was well educated with no men completing less than high school and a large majority completed at least some college. In addition, all men reported having low decisional conflict, high levels of screening decision self-efficacy, and had high levels of computer literacy. Therefore, the results from this study may not be generalizable to men who have lower education levels and lower computer literacy skills. In addition, these characteristics could have been indicative of the acceptability of a digital DA as a potential intervention. Furthermore, because all 39 men were not involved in all three of

the formative phases, there can be differences of opinion between those involved in a specific phase, but not included in another. For example, an individual who participated in Phase I FGs and provided their ideas about how the DA should function, but wasn't involved in any other phases, may have had a different perspective on the actual usability (i.e., Phase III's in-depth interviews). Lastly, the sample did not include both men who had been screened for PrCA and those who had not. Those men who had previously been screened may have different knowledge and perceptions of the screening process which could have influenced the design in a way that would not be characteristic if the DA was designed by those who had not been screened (e.g., men who have been screened may need less descriptive text regarding PSA test). Despite these limitations, the study's iterative design process provided sufficient methodological rigor (e.g., triangulation) to validate the findings and these findings provide valuable information that can be used to contribute to the future development of culturally appropriate, plain-language tools for helping AA men make informed decisions about their prostate health (Guion et al., 2011).

## **Conclusions**

The research findings stress the importance of developing and implementing innovative strategies for providing PrCA education and IDM preparation to AA men. The DA that was developed may be more effective than general DAs for preparing men to speak with a physician because it not only includes information such as the risks, benefits, and uncertainties of screening, but also includes a role play exercise that can prepare men to engage in a meaningful discussion with their doctor. In addition, the iterative process (which included two rounds of FGs, an expert review, and in-depth interviews) helped guide the interface and content design and re-design of the DA to

ensure its cultural appropriateness and optimal impact. Through conducting this comprehensive formative evaluation, the DA will be more likely to lead to increased PrCA knowledge, greater IDM self-efficacy, and higher technology use self-efficacy among AA men of varying levels of computer literacy. Furthermore, because of the growing access and acceptability of various technologies within diverse AA communities, technology should be considered for use in the widespread dissemination of PrCA information and preparing men for making informed PrCA screening decisions. The dissemination of PrCA through DAs and similar technologies (e.g., internet, phones) could lead to greater access to the information necessary to participate in IDM with a physician as recommended by the ACS. Increasing AAs' ability to make an informed decision regarding whether or not to receive PrCA screening can ultimately lead to a narrowing of the disparities gap between AAs and EAs who died from PrCA. Similarly, I believe that adopting a similar process for designing technologies to educate populations and facilitate IDM regarding other health topics (e.g., colon cancer among AAs) also could lead to the amelioration of health disparities.

### **Additional Commentary**

#### **Recruitment and Intervention Development: A Learning Experience**

Based on my prior experience with implementing research in AA communities, I recognized that recruiting AA men would not be an easy task. Also, I knew that developing an innovative intervention as a doctoral candidate would be an ambitious undertaking. However, it was not until I implemented my research that I realized just how difficult it would be to recruit 39 AA men and work with them and others to develop a cutting-edge, digital intervention to promote informed prostate screening decisions.

Below I provide some advice for any student or researcher planning to conduct pilot research in the AA faith community and/or develop an original, digital intervention. I also provide some general advice for approaching the doctoral dissertation process.

***Knowing someone who knows someone:*** My recruitment strategy began by simply reaching out to people who I already knew (such as the researchers at the University who already had established partnerships with churches). Reaching out to your academic colleagues or professors can be effective for recruiting your target population, but do not expect to gain an easy entry into their communities. For example, churches connected to your academic colleagues have a higher likelihood of being “occupied” with other studies or may be “burned-out” from a recent study so they may not want to take on your study too. This is not to say, however, that you should not exhaust each and every contact.

Leave no stone unturned, because it will be the contact that you do not use that can lead to a quarter or more of your desired sample. In the case of my dissertation research, one of my academic colleagues provided me with the name of her personal church. This particular church worked well because the pastor understood the importance of my proposed research and the church’s members had previously been involved in a University-sponsored initiative for women’s health. They not only helped me recruit their members for my research, but they also set a time and date (after their midweek bible study) when I could conduct my first focus group. From this church, I was able to gain one-third of the participants I needed to meet my recruitment goal of 40. A second colleague connected me to a local pastor who was a doctoral graduate of the University of South Carolina and a former instructor. The local pastor was extremely helpful.

Although he only had three members of his church who would be eligible, he offered the

names of pastors in the city and allowed me to use his name when I contacted these individuals. One of the pastors whom he recommended was also employed at the University of South Carolina. This particular pastor offered to call other pastors around the city to ask if they would allow me to conduct research with their members. He felt as if this was the best way to obtain buy-in since many pastors are preoccupied with multiple church-related priorities. He also sent an email with information about my study to other colleagues. Even this pastor's effort to call other pastors on my behalf did not culminate into any participants. However, his email to his non-pastoral colleagues did result in three to four new participants. A third colleague was able to identify and connect me with the head of the men's ministry at a massive church whom I had attempted to contact on multiple occasions. It was only then that I was invited to their Saturday morning prayer service to conduct an interview with 10 additional men. Finally, I leveraged the resources in my own church to help with my recruitment. I not only asked my own pastor if I could make an announcement in front of the church, but I also asked at least one other "opinion/community leader" in my church to connect me to other men in the faith community. It was still not an easy task. Several men were "too busy" or "not available." Others avoided me so I would not ask them to participate. It took me multiple weeks to recruit the remaining men that I needed to meet my recruitment goal, but despite these challenges, I recruited 39 of the 40 men that I needed for my study. All of the men recruited were the result of knowing someone, who knew someone else. Unfortunately, (and of salience to aspiring doctoral students), none of my participants were a result of my other original recruitment strategies which included posting/emailing flyers, cold calls/approaching people, bulletin/newsletter announcements, or appearing on the radio.

***Other important things to know when approaching churches with your research: (1)***

Just because your research is timely and relevant, it does not mean that it will be a priority for churches to participate in your research. For example, one church that I emailed with general information about my study had both a pastor and associate minister with PhDs who questioned the usefulness of my research and asked for more information. Even after sending the pastor and associate minister more information and following up, they did not respond. Other churches to which I reached out had calendars that were packed with events so it was necessary to find someone in the church who was connected to my target population (AA men) and had a close relationship with the pastor. Please note that even when you find this person, you should be patient because it takes more time than expected to get approval. Be prepared to work around the church's schedule (e.g., they may invite you to implement your research prior to or at the beginning of an event and you may be asked to shorten your intended implementation time). (2) Some churches are already conscious about health and feel that they are already capable of providing their members with optimal health information. Also, depending on the size of the church, they may already have well-developed health ministries that include doctors, nurses, and health educators. Therefore, they may underestimate the benefit of your research to enhance their current education goals. In this scenario you must make the decision whether to sell the importance of your research and how it can further enhance their efforts or just move on to your contact at another church. Do not spend too much time selling your research if you have many other individuals or churches who may want to participate in your research. (3) Churches would rather you conduct your research at their institutions as opposed to coming to your location, so make sure your

materials/intervention are portable. I did initially plan on conducting my research at each church if they had a space where I could implement my focus groups since I knew participants would be far more likely to come to their church as opposed to driving to the university. Participants who were members of churches with fewer men unfortunately had to drive to the University because I needed a minimum number of men in each focus group. In order to help his members avoid traveling to the University, one pastor reached out to other small churches in the area to see if men at their churches would be willing to participate in a focus group to be held at his church. He never received a response. Therefore, if you include churches in your research with smaller numbers be sure it is either close in distance to the University or another facility that has rooms (e.g., library, community center) so that travel for participants will not be difficult.

***Development: Do Not Be Afraid to Learn New Skills:*** It was quite difficult to find someone who would help with the development of my digital DA with limited funds, so I decided to enroll in a game design course where I could gain the help of other talented students, and in return, they could earn both a grade and great experience. This sounded like a perfect plan, but most students wanted to develop fun games, not a prostate cancer screening DA. Only one student (a computer science major) had a slight interest in developing a PrCA DA, but he was extremely hesitant because he wasn't sure if he could produce the level of product that I desired. After all, this was just a 3- credit course and my product was daunting. Fortunately, the computer science student and a media arts graduate student agreed to help develop the DA. I was excited, but only momentarily. I had selected software that looked cool and easy to use by the looks of the software's advertisement and reviews, but it was tedious to use and required additional software to

accomplish the product that I wanted. At the end of the semester, I had only a couple clips for my DA and much work remained. However, I found funding to pay the graduate student to continue working with me. To say the least, his life went haywire, communication became terrible, and I was left with pieces of a project which I had no idea how to compile. Even with some direction that he left on a slip of paper, it was going to be an adventure because I had always sat on the sidelines and gave verbal/written input to the project, no hands on practice. Having no developer on the team forced me to read user manuals and watch YouTube tutorials until I was able to pull the pieces together in a way that made sense to show a proof of concept. Today, the DA is not as aesthetically attractive and professional as some commercial products, but the DA functions how it was intended. With more practice, I am sure that I could improve in the areas of design and development, but for now I have a proof of concept and scheduled to graduate on my timeline. Through this experience, I learned that researchers (at least one with limited grant funds) should learn as much as possible about the software being used to develop a product and keep possession of all project files. In the event that a developer or other team member is unable to meet your project deadlines, “you” can move your own development forward.

***Think Beyond Dissertation, This is your Career:*** Choosing a dissertation topic is an exciting but intricate process. There are also many ways to think about this process: Do I choose a project that is convenient, such as using data from a graduate assistantship, or should I collect original pilot data? Do I use an intervention that is in existence or build my own? In any case, it is important to use the dissertation as an opportunity to lay a foundation for a future career. Depending on how you approach your dissertation, it can

be a launch pad that can propel you into an exciting field/position or it can simply be a long research project that will be shelved as soon as you are finished. I chose to launch. Also, the dissertation can be a means to create a bridge into an area of interest that may have been previously difficult to access. In my case, I was always interested in health and technology, but I did not have any prior technology experience. Without this experience, which is typically gained through additional education, it is difficult (even with a PhD) to be hired by health technology companies or into an academic position where technology is the main focus. Therefore, I used the dissertation as an opportunity to gain skills that would make me marketable to these types of health technology organizations. To say the least, it worked. Lastly, don't be afraid to "dream big" along your academic journey and take risks. My motto is: Onward, Upward, and Beyond. When I started my dissertation, I desired to have a commercial product that would be available to the general public. People told me that developing my proposed intervention would be ambitious for a dissertation project and some even said "don't bother." I took the risk and moved forward with the development of my own DA anyway and it paid off. Though my DA is not commercial grade, I have secured a position in health technology and caught the attention of people who can help me develop my dissertation intervention into a commercial product.

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## APPENDIX A: THEORIES AND CONSTRUCTS GUIDING RESEARCH

**Table A.1:** Theories and Constructs\*Guiding Research

<b>Models and Theories</b>	<b>Constructs</b>
Theory of Reasoned Action (TRA) by Fishbein and Ajzen (1975) derives from psychology to measure behavioral intention and performance.	Attitude Subjective norm
Technology Acceptance Model (TAM) by Davis (1989) develops new scale with two specific variables to determine user acceptance of technology.	Perceived Usefulness Perceived Ease of Use Subjective Norm* Experience* Voluntariness*
Technology Acceptance Model 2 (TAM2) by Venkatesh and Davis (2000) is adapted from TAM and includes more variables.	Image* Job Relevance* Output Quality* Result Demonstrability*
Motivational Model (MM) also stems from psychology to explain behavior. Davis et al. (1992) applies this model to the technology adoption and use.	Extrinsic Motivation Intrinsic Motivation
Theory of Planned Behavior (TPB) by Ajzen (1991) extends TRA by including one more variable to determine intention and behavior.	Attitude Subjective norm Perceived Behavioral Control
Combined TAM and TPB (C-TAM-TPB) by Taylor and Todd (1995).	Perceived Usefulness Perceived Ease of Use Attitude Subjective norm Perceived Behavioral Control
Model of PC Utilization (MPCU) by Thompson et al. (1991) is adjusted from the theory of attitudes and behavior by Triandis (1980) to predict PC usage behavior.	Social Factors Affect Perceived Consequences (Complexity, Job-Fit, Long-Term Consequences of Use) Facilitating Conditions Habits

<p>Innovation Diffusion Theory (IDT) by Rogers (1962) is adapted to information systems innovations by Moore and Benbasat (1991). Five attributes from Rogers' model and two additional constructs are identified.</p>	<p>Relative Advantage*  Compatibility*  Complexity*  Observability*  Triability*  Image  Voluntariness of Use  * indicates Roger's constructs.</p>
<p>Social Cognitive Theory (SCT) by Bandura (1986) is applied to information systems by Compeau and Higgins (1995) to determine the usage.</p>	<p>Encouragement by Others  Others' Use  Support  Self-efficacy  Performance Outcome Expectations  Personal Outcome Expectations  Affect  Anxiety</p>
<p>Unified Theory of Acceptance and Use of Technology Model (UTAUT) by Venkatesh et al. (2003) integrates above theories and models to measure user intention and usage on technology</p>	<p>Performance Expectancy  Effort Expectancy  Attitude toward Using Technology  Social Influence  Facilitating Conditions  Self-efficacy  Anxiety</p>

Table from (Sundaravej, 2010)

\* Indicates that these constructs were not included in TAM 1 model, but were apart of TAM2 only. However, all constructs listed in this section of the chart were tenants of TAM2.

## APPENDIX B: IRB APPROVED CONSENT FORM



UNIVERSITY OF  
SOUTH CAROLINA

### Informed Consent Form

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

#### **Introduction and Purpose**

You are invited to take part in a research study being conducted by Shaun Owens, a doctoral candidate in the Arnold School of Public Health at the University of South Carolina. You are being asked to participate in this research study because you are an African American male between the ages of 40-65 without a history of prostate cancer, English is your first language, and you have no history of cognitive decline such as dementia. Shaun is conducting this research study to find out (1) about your current prostate cancer knowledge and technology use and (2) how technology such as computers and DA can be best used to improve your prostate knowledge and discussions with your doctor (or health care provider) about prostate cancer screening. This study is funded by the Institute of African American Research at the University of South Carolina. This form explains what you will be asked to do if you decide to take part in this study. Please read it carefully and feel free to ask any questions before you make a choice about taking part in this study.

#### **Description of Study Procedures**

If you decide to take part in this study, you will be asked to take part in one 90-minute discussion group. This discussion will be audio-recorded. You will also be asked to fill out a brief survey before taking part in this discussion group. During the first discussion group you will be asked (1) what you know about prostate cancer and prostate cancer screening (2) your current technology use and (3) how you think we can use technology to tell people about prostate cancer screening and prepare them to speak with their doctors. All study activities will take place at a mutually agreed upon time and place.

#### **Risks of Participation**

There are no known risks associated with taking part in this research. However, there is a small chance that you may be embarrassed sharing your thoughts with other men in the group. You may

feel also uncomfortable discussing prostate cancer, prostate cancer screening, or technology, but you do not have to ask or answer any questions that you do not wish to. In addition, there is a small risk that the other men in the group will know you, but we will ask every group member to keep what happens in the group and who took part in the group private. Lastly, there is a minimal risk that confidentiality can be breached through study records or audio-recordings, but we will do everything possible to keep your information protected. Please see confidentiality of records section below.

### **Benefits of Participation**

You may benefit directly from taking part in this study by learning more about prostate cancer, prostate cancer screening options, informed decision making, and the use of technology. You may also benefit others by helping to develop an educational tool that can help others make an informed decision about prostate cancer screening.

### **Costs**

There will be no costs to you for taking part in this study (other than for any parking/gas expenses you may have and your time).

### **Payments**

You will receive **\$10 in cash** for taking part in this study and completing a brief survey.

### **Confidentiality of Records**

The information that you provide us with during this study will be kept private as much as possible. A number (code) will be assigned to each participant at the beginning of the study. This number will be used on study records rather than your name, and no one other than the researchers will be able to link your information with your name. Study records/data will be stored in locked filing cabinets and protected computer files at the University of South Carolina. Audio-recordings will be temporarily stored in a locked cabinet until they are professionally transcribed into written text (transcript). All names and other identifying information **will not** be included in the transcript and the audio-recordings will be destroyed following transcription. The results of the study may be published or presented at professional meetings, but your identity will not be shared.

The study funding agency will have access to identifiable information. In rare cases, a research study may be evaluated by an oversight agency, such as the USC Institutional Review Board or the U.S. Office for Human Research Protections. If this occurs, records that identify you and the consent form signed by you may be looked at so that they may decide whether the study was properly carried out and your rights of participants were protected.

### **Contact Persons**

For more information about this research please contact Shaun Owens (student researcher) at (803) 777-9933 or [owenso@email.sc.edu](mailto:owenso@email.sc.edu) or Dr. Daniela Friedman (faculty supervisor) at (803) 777-9933 or [dfriedma@mailbox.sc.edu](mailto:dfriedma@mailbox.sc.edu). If you have any questions about your rights as a research subject contact, Lisa Marie Johnson, Manager, Institutional Review Board, University of South Carolina, Columbia, SC 29208 at (803) 777-6670 or [lisaj@mailbox.sc.edu](mailto:lisaj@mailbox.sc.edu).

### **Voluntary Participation**

The choice to take part in this study **or not** is yours. You are free not to take part or to quit taking part in this study at any time, for whatever reason, without negative results. In the event that you quit this study, the information you have already given to us will be kept private.

**Signatures /Dates**

I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to take part in this study, although I have been told that I may quit at any time without negative consequences. I have been given (or will be given) a copy of this form for my records and future reference.

**Consent to be contacted in the future: Is it ok to contact you in the future regarding other studies?**

Yes it is ok to call me       No, I do not want to be called

Participant Name (please print): \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Date:

\_\_\_\_\_

## APPENDIX C: HUMAN SUBJECTS PROTECTION

### **A. Risk to Subjects**

No project activity involving human subjects research will begin until the research has been approved by the Institutional Review Board at the University of South Carolina (USC). Based on guidance for preparing the Human Subjects Research Section in the SF424 instructions, this project fits the description of non-exempt, non-clinical research as we will collect and maintain identifiers for focus group participants for the purposes of conducting follow up feedback sessions and post-education surveys.

A1. Human subject's involvement and characteristics: Participation in this study is voluntary. Eligible participants for the proposed project will be African-American men 40-65 years of age with 1) no prior personal history of prostate cancer; and (2) no history of cognitive decline; *and be proficient in English*. Data will be collected from a possible total of 40 men (Phases I and II) Interested and eligible participants who do not meet the eligibility criteria above will be excluded from the study.

A2. Sources of materials: All attitudinal and behavioral data will be obtained through focus group sessions. The main materials will be digital recordings, written notes, and paper transcripts of the recorded sessions.

A3. Potential risks: The proposed research poses no more than minimal risk; however, this will be determined by the USC Institutional Review Board. The proposed study could lead to minimal psychological or social risks, including stress or anxiety related to the use of the DA-based DA or responding to focus group or interview questions about prostate cancer. Another inherent risk in research participation is loss of confidentiality and anonymity. Participants will be informed that all information discussed during focus groups and collected through the pilot study will remain confidential and they will not be identified in any oral or written research reports. Participants in focus groups and interviews must also agree on written consent forms to keep confidential all opinions and information voiced by other group participants. Participant data for focus groups and interviews will be identified only with a study ID. Study ID numbers and participant lists will be kept separately. All data will be kept in a locked filing cabinet in the Cancer Prevention and Control Program building with access only by the Mr. Owens and his mentors (i.e. sponsor and co-sponsors).

### **B. Adequacy Of Protection Against Risks**

B1. Recruitment and Informed Consent: Voluntary, informed, written consent will be obtained from all participants prior to their enrollment in the study. The study and

informed consent process will be explained verbally and in writing. (Mr. Owens and potentially one or more mentors will participate in all focus group sessions) These individuals will explain: 1) the purpose of the study, 2) participants will receive incentives for participating in focus groups, 3) researchers will request participants' names and addresses, solely for research purposes; 4) all information provided by participants will be kept confidential and will not be available to any federal, state, or local officials; and 5) participation in this study is completely voluntary. Interested participants will be given informed consent forms to complete in writing and will be provided with a copy for their records. Participant data will be identified with a study ID. Study ID numbers and participant lists will be kept separately. The use of names, addresses, and telephone numbers from consent forms and incentive receipt logs will only be used to contact participants for necessary follow up. Contact information will be kept on file in Mr. Owens' locked research office. This information will be secured with access only by the Mr. Owens and mentors. All participants will be informed they may terminate their study participation at any time.

**B2. Protection Against Risk:** To minimize risk of loss of confidentiality, only Mr. Owens and the mentors listed within this application will have access to research data. Furthermore, focus groups and interviews will be conducted by trained researchers. We will use culturally sensitive and appropriate language to describe the research process and obtain informed consent. All key personnel have completed cultural competence training and human subjects training, provided by the University's Office of Research Compliance.

### ***C. Potential Benefits of the Proposed Research to the Subjects and Others***

The study subjects may not obtain personal benefit; however, future benefit to individuals is likely. Each participant will receive \$20 in compensation for participating in focus groups and 10 randomly selected individuals will receive \$40 for participating in the in-depth interviews. Potential benefits to individual participants include improved knowledge and awareness about prostate cancer risk, prevention, and screening options. Each participant will also receive information on accessing additional information on prostate cancer screening. In addition, though it is not a direct focus of this project, participants who desire screening and do not have access to a primary care physician will be provided with contact information for institutions that provide free or low cost screening services. Benefits for others in the future could include increased self-efficacy in the ability to make an informed decision, improved self efficacy regarding the ability to use technology, and increased likelihood of participation in shared decision making regarding prostate cancer screening. These benefits outweigh any minimal risks of personal or social anxiety or stress related to responding to focus group questions.

### ***D. Importance of Knowledge to be Gained***

Improved cancer research communication has the potential to reduce disparities in information and knowledge. Given the uncertainties surrounding prostate cancer screening, shared decision making between health care providers and patients is encouraged regarding potential benefits and harms of screening. This formative research will identify best practice recruitment strategies and communication principles to

encourage high-risk, minority populations' increased knowledge, informed decision making, and participation in cancer prevention research.

***E. Collaborating Sites***

The research will be conducted within the SCCDN/COC State Baptist YWA affiliated churches with USC serving as lead center for all research activities. The African-American faith-based community will be the actual performance site.

***F. Data Safety and Monitoring Plan.***

*Data and safety monitoring plan:* As this is not a clinical trial and involves no more than minimal risk to participants, a data and safety monitoring board is not required; however, as previously described, procedures will be enacted to ensure safety of data to preserve confidentiality and safeguarding of data. Consent forms and incentive receipt logs containing participant contact information for follow up purposes will be stored separately from study data (demographic surveys and transcripts). The research team, including Mr. Owens and his Mentors, will be responsible for maintaining a safe research environment and for preventing adverse study events from occurring. At bi-weekly meetings Mr. Owens and his mentoring team will identify and discuss actual and/or potential threats to the integrity of the data and safety of study participants, and develop strategies for addressing such threats and maintaining a safe research environment. The procedures to be used in this study pose minimal risk to study participants. Nevertheless, the research team will be prepared to address all levels of adverse events should they occur. For example, in the event of physical injury, participants will be encouraged to see a health care provider. If a participant experiences any emotional distress from discussing issues related to comprehension of cancer information or cancer screening, project staff will pause research activities and take measures to assist the participant. All monitoring information will be included in the application to the Institutional Review Board at the USC Office of Research Compliance. In addition, Mr. Owens will record detailed narrative notes describing the adverse event. Mr. Thomas Coggins (Director, USC Office of Research Compliance) is also available to establish oversight of data.

**APPENDIX D: IRB APPROVED DEMOGRAPHIC SURVEY**



A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

**Questions About You: Information About Participants**

The following questions will tell us about who takes part in the discussion groups. Please place a check mark (☑) in the box next to your response. This information will be kept private.

1. What year were you born? \_\_\_\_\_
  
2. Which of the following best describes your race?
  - White or Caucasian
  - Black or African American
  - Native American/ Aleutian/ Eskimo
  - Asian
  - Hawaiian/ Pacific Islander
  - Other (Please specify) \_\_\_\_\_
  
3. Are you Hispanic or Latino?
  - Yes
  - No

4. What is your current marital status?
- Single / Never married
  - Married
  - Separated
  - Divorced
  - Widowed
  - Other: \_\_\_\_\_
5. What is your current employment status?
- Employed full time for wages
  - Self-employed
  - Retired
  - Unable to work/Disabled
  - Not employed
6. What was your household income in 2011?
- Less than \$20,000
  - \$20,000 to \$39,999
  - \$40,000 to \$59,999
  - \$60,000 to \$79,999
  - \$80,000 to \$99,999
  - Over \$100,000
7. How many people, including you, are usually supported on this income?
- Number of people (including you) \_\_\_\_\_
8. What is the highest level of education you have completed? (**Please check only one answer**)
- Less than high school
  - High school graduate or GED
  - Some college, technical or vocational training
  - Bachelor's degree
  - Advanced/graduate degree
9. Which type of health insurance do you have? (**Please check all that apply**)
- Employer provided health insurance
  - Private health insurance
  - Medicare
  - Medicaid
  - Military health care (TRICARE/VA/CHAMP-VA)
  - Prescription drug coverage (as part of your insurance or as a separate plan)
  - Other (Please specify: \_\_\_\_\_)
  - No coverage of any type
10. A Prostate-Specific Antigen test, also called a PSA test, is a blood test used to check men for prostate cancer. How long has it been since you had your last PSA test?  
(**Please check only one answer**)

- Within the past year (anytime less than 12 months ago)
- Within the past 2 years (1 year but less than 2 years)
- Within the past 3 years (2 years but less than 3 years)
- Within the past 5 years (3 years but less than 5 years)
- 5 or more years ago
- I have NEVER had a PSA test

11. A digital rectal exam is an exam in which a doctor, nurse, or other health professional places a gloved finger into the rectum to feel the size, shape, and hardness of the prostate gland. How long has it been since your last digital rectal exam? **(Please check only one answer)**

- Within the past year (anytime less than 12 months ago)
- More than 1 year but less than 2 years ago
- More than 2 years but less than 3 years ago
- More than 3 years but less than 5 years ago
- 5 or more years ago
- I have NEVER had a digital rectal exam

12. Did you ever discuss with a health care provider being screened for prostate cancer and then decide **whether or not** to be screened?

- Yes
- No

13. Which of the following technologies have you used? (Please check all that apply)

- Television
- ATM
- DA
- Cell Phone
- Computer
- Touch-screen Tablet Computer (e.g., IPAD)

14. Which of the following technology features have you used? **(Please check all that apply)**

- Cell Phone Application
- Texting
- Email
- Internet

15. Which of the following technologies have you used to receive health information? **(Please check all that apply)**

- Television
- DA
- Cell Phone Application
- Texting
- Email
- Internet
- I have not used any of these

16. Which of the following technologies would you be **open to receiving** health information? **(Please check all that apply)**
- Television
  - DA
  - Cell Phone Application
  - Texting
  - Email
  - Internet
  - I have not used any of these
17. What are **other sources** that you have used to receive health information? **(Please check all that apply)**
- Regular doctor
  - Health educator
  - Newspaper
  - Radio
  - Magazine
  - Other \_\_\_\_\_
18. What are source do you use **most often** to receive information? **(Please check only one answer)**
- Regular doctor
  - Health educator
  - Newspaper
  - Radio
  - Magazine
  - Television
  - DA
  - Cell Phone Application
  - Texting
  - Email
  - Internet
  - Other (Please Specify) \_\_\_\_\_
19. What is your **preferred source** for health information? **(Please check only one answer)**
- Regular doctor
  - Health educator
  - Newspaper
  - Radio
  - Magazine
  - Television
  - DA
  - Cell Phone Application
  - Texting

- Email
- Internet
- Other (Please Specify) \_\_\_\_\_

## APPENDIX E: FOCUS GROUP GUIDE (AIM 1)



UNIVERSITY OF  
SOUTH CAROLINA

### IRB Approved Focus Group Guide

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

**DIRECTIONS:** All sections will be read to participants including all prompts. Probes will be read only if needed.

#### MATERIALS AND EQUIPMENT

2 digital audio recorders  
10 pen or pencils  
10 sociodemographic questionnaires  
10 informed consent forms

**PURPOSE:** You have been invited to take part in a group discussion about prostate cancer, prostate cancer screening, your use of technology such as cell phones, internet, and DAs for health and cancer information, and the development of a computer program to help men learn more about prostate cancer screening. We invite you to share your personal thoughts and opinions as they will help us better understand how to develop a computer program that can ultimately help men make informed decisions about their prostate health. The discussion group today will last approximately an hour and a half and you will receive your incentive immediately following the discussion.

We will be audio recording the session. We do not want to miss any of your comments. Only members of the research team will have access to the audio recordings. If anyone is uncomfortable with being audio recorded, please say so, and of course, you are free to leave. The audio recordings will be kept in a locked file cabinet. They will be transcribed without any names or other identifying information. Once the audio files have been transcribed, they will be destroyed. In any reports or presentations of the findings, names

will not be used. Again, this is why all information that we take from you has a code that will be placed on the survey you filled out today and we will try not to use names when we turn on the recorder today. We also ask that each of you keep confidential the information shared in this group and the names of participants. Furthermore, we ask that you be respectful of each other during the course of this focus group. Does anyone have any questions before we begin?

**ICEBREAKER:** Let's begin with introductions. We can go around the room and say our name and where we're from. I will not turn on the recorder until after we introduce ourselves.

**SECTION I:** We will begin today's discussion by talking about what we know about prostate cancer and what you want to learn about prostate cancer for a computer program we are developing. The topics I will ask questions about include prostate cancer risk factors, signs and symptoms, and screening. It does not matter if you are familiar or unfamiliar with these topics – this will be more of a discussion. It is ok to say, "I don't know." Everyone will have the opportunity to take part. If you choose not to participate in parts of the discussion, that is alright too. Following your participation in this study, I will provide you with information about prostate cancer and prostate cancer screening.

1. What have you heard or what do you know about prostate cancer, in general?

PROMPT: What are the risk factors for prostate cancer?

PROMPT: What are some of the signs and symptoms of prostate cancer?

PROMPT: How do people get screened for prostate cancer?

PROMPT: Who should be screened for prostate cancer?

PROMPT: Where have you learned or heard about prostate cancer?

PROBE: For example, what have you learned about prostate cancer from family or friends?

PROBE: What about from television programs or news articles?

PROBE: What about from internet or text messaging?

2. Tell me about your participation in prostate cancer screening.

PROMPT: Who has been screened for prostate cancer?

PROMPT: Where did you go for screening?

PROMPT: Who, if anyone, helped you decide to go for screening?

PROMPT: What type of information about prostate cancer screening did you have prior to being screened?

PROBE: Pamphlet? Email? Internet? Television?

PROMPT: Where did you receive this information?

PROMPT: What was the content of the information that you received?

PROBE: What did it tell you about the benefits and risks of screening?

PROMPT: Did you speak with your doctor before being screened for prostate cancer?

PROMPT: If so, tell me about the conversation with you and your doctor

PROBE: What did he tell you about the risks and benefits of screening?

PROMPT: Who made the final decision about whether to be screened?

PROBE: You, Your doctor, You and Your doctor?

PROMPT: For those who have not been screened and have not spoke to a doctor about screening, tell me why.

PROMPT: For those who have not been screened and have spoke to a doctor, tell me about the conversation

Probe: For example, did your doctor tell you about the risks and benefits of screening?

PROMPT: Who do you think is at highest risk for prostate cancer?

PROMPT: Why do you think that this is?

3. The American Cancer Society (ACS) recommends that men have a chance to make an informed decision with their health care provider about whether to be screened for prostate cancer. An informed decision is defined as when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time. A decision about prostate cancer screening should be made after getting information about the uncertainties, risks, and potential benefits of screening.

PROMPT: What would be the best way that we can encourage you or other men in your community to learn more about prostate cancer and prostate cancer screening?

Probe: Television public services announcement (PSA)?

PROMPT: How can we encourage you or other men in your community to talk with the doctor about prostate cancer screening?

Probe: Provide them with pamphlets on prostate cancer rates?

PROMPT: What would be the best ways to provide information about prostate cancer screening to men in your community?

Probe: Pamphlet? Television? Text message?

PROMPT: How would these ways differ based on age?

PROMPT: What are some of the ways that you currently receive health information?

PROMPT: When you need health information, where do you go to look for it?

PROMPT: What is your preferred source of heath information?

**SECTION II:** An important part of this project is to better understand your use of technology for finding or receiving information. For example, have **you** searched for and found health or cancer information using technology? Have you received health or cancer information from others through technology? The next few questions focus on this type of technology use.

1. When you hear the word “technology,” what comes to mind?  
PROMPT: What types of items do you consider technology?  
PROBE: TV? ATM? IPAD?
2. Of the items that you named, which do you use most often?  
PROMPT: How often do you use this technology?  
PROBE: Everyday? Twice a week?  
PROMPT: For what purposes do you use these resources?  
PROBE: When you watch TV, is it to watch the news?  
PROMPT: What these technologies easy to use?  
PROMPT: What features of these technologies would you would change?  
Why?  
PROBE: For example, making buttons on cell phone larger to make them easier to press.  
PROMPT: What technologies do you not feel comfortable using? Why?  
PROMPT: What can be changed about these technologies that would make you more comfortable using them?  
PROBE: For example, if a computer company was to create less steps to accessing your email box.
3. If you use technology to find or receive health information, what specific technologies do you use?  
PROBE: Do you watch shows on television that provide health information? If so, what type of information do they provide?  
PROBE: Have you signed up to receive health information through your email or phone? If so, where do you receive this information and what specific information do you receive?  
PROBE: Do you use the internet to actively search for health information and what sites do you browse?
4. For those of you who have not used technology for this, can you share why you haven't?
5. How comfortable do you think you would feel receiving or finding health information through a touch screen computer or DA?  
PROBE: For example, the self check out at the grocery store or the screen at the gas station?

**SECTION III:** Another important part of this project is to ask for your input about how a touch-screen computer can be used for delivering prostate cancer information, education

about the risks, benefits, and uncertainties of screening, and suggestions on how to speak to the doctor.

1. If you were in charge of developing a touch screen computer program to educate men so they can make an informed decision about prostate cancer screening, what would this resource look like?

PROMPT: How long would the program be?

PROMPT: What information would you include?

PROMPT: How would this information be presented?

PROBE: For example, tell me whether the program should be animated or include real people and describe the people that you would include.

PROBE: Also, would the program have both sound and text and describe what this would look and sound like.

PROBE: What types of fonts and colors would be used (e.g., large black letters on a yellow background?)

PROMPT: How interactive do you think the computer program should be and what specific features should be included?

PROBE: For example, should men only have to touch the screen to move the program forward or should a question and answer session included?

2. What would you do to make sure the touch-screen program is easy for all men to use?

PROMPT: What features would you be sure to include or exclude to make men comfortable using the computer program?

PROBE: For example, should it include large buttons? large text? certain colors?

3. What features would you add to the computer program that will keep men interested in completing the entire program?

PROBE: For example, should it include specific pictures? Sound? Certain colors? Animation?

4. What features would you add to the program or the actual computer itself that would make men interested in using it find out more about prostate cancer?

PROBE: What would make men approach the computer?

PROBE: What would make men use the computer?

5. How do you feel about this touch screen being used in a faith-based organization such as in churches?

Thanks to everyone for your participation in today's discussion. We have just a couple things left to do today:

- (1) complete a short demographics survey.
- (2) we will distribute the participation incentives.

## APPENDIX F: FOCUS GROUP GUIDE 2 (AIM 2)



### Focus Group Guide (Phase II)

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

**DIRECTIONS:** All sections will be read to participants including all prompts. Probes will be read only if needed.

#### **MATERIALS AND EQUIPMENT**

- 2 digital audio recorders
- 10 Storyboard/Script Handouts
- 1 Laptop computer/projector

**PURPOSE:** You have been invited to take part in a group discussion about a DA prototype that is being developed to help men make informed decisions about whether or not to get screened from prostate cancer. This prototype was developed based on the focus groups that you were invited to participate in back in October of 2012. There were four main findings from the groups: (1) you are knowledgeable about some of the risks, symptoms, and screenings for prostate with some misconceptions (2) Many of you report being screened for prostate cancer, but few of you reported making a shared decision with your doctor about screening (3) almost none of you were informed about the risks and uncertainties of screening and (4) Most of you were open to receiving information from a touch-screen DA with an avatar led module as long as the module had language appropriate for people of varying literacy levels and the avatar was also African American. Therefore, me and colleagues at USC have developed some materials and we invite you to share your personal thoughts and opinions as they will help us better improve the DA. The discussion group today will last approximately an hour and a half and you will receive your incentive immediately following the discussion.

We will be audio recording the session. We do not want to miss any of your comments. Only members of the research team will have access to the audio recordings. If anyone is uncomfortable with being audio recorded, please say so, and of course, you are free to leave. The audio recordings will be kept in a locked file cabinet. They will be transcribed without any names or other identifying information. Once the audio files have been transcribed, they will be destroyed. In any reports or presentations of the findings, names will not be used. As in the last focus group in which you participated with me, we will try not to use names when we turn on the recorder today. We also ask that each of you keep confidential the information shared in this group and the names of participants. Furthermore, we ask that you be respectful of each other during the course of this focus group. Everyone should have been provided with some documents containing framed pictures and text. We will use this document along with some visual demonstrations on the computer throughout this discussion. Has everyone received this handout? Does anyone have any questions before we begin?

**ICEBREAKER:** Let's begin with introductions. Please go around the room and say our names again and where we're from. I will not turn on the recorder until after we introduce ourselves.

**SECTION I:** We will begin today's discussion walking through the document which I will refer to as a storyboard. Afterwards I will ask you to provide thoughts on the content, (which is the text on each of these pages, the graphics (this can include things like the avatar or buttons), or the format (order in which information is presented). The DA to which I will refer today is the computer on which the learning activities will take place. A DA is similar to a Redbox or an atm. In addition, the avatar is the animated character that will provide you with the information during your use of the DA. When I ask you questions today, It is ok to say, "I don't know." Everyone will have the opportunity to take part. If you choose not to participate in parts of the discussion, that is alright too.

Ok lets take a look at the storyboard (*Proceed through storyboard and explain how DA will work*)

1. Please provide me with your thoughts on the name of the DA?

PROMPT: Why do you or do you not feel that the name is appropriate for a DA about IDM about prostate cancer screening?

PROMPT: What name could work better?

PROMPT: Please provide me with your thoughts on why you think the DA name will be remembered or not remembered by users?

2. What things do you like about the introduction?

PROMPT: Why or why do you not think that the introduction will draw people towards the DA?

PROBE: In our last set of focus groups back in October, many of you said that a sports theme should be included to attract me to the DA.

What are your thoughts how we used a sports theme at the beginning?

PROBE: What are your thoughts on including the walnut which has been included to make a connection to the size of the prostate?

PROMPT: How can we improve the introduction?

3. (*Show welcome and introduction to index clips*) At the beginning of the DA session, instructions will be provided to the user. Based on the storyboard and the sample that I just showed you, why or why do you not feel that the participant will have enough information at the beginning to know how to use the DA? (Facilitating Conditions)
4. The instructions page also includes an index which we just saw in the clip and is also included in your storyboard document; please provide your thoughts on whether the index will be easy to use for the intended audience, which are African American men ages 40-65? (Ease of Use)
  - PROMPT: How do you think the index will or will not make it easy for me to navigate through the DA module?
  - PROMPT: What changes would you make to ensure the index is easy to use?
5. What added value do you feel that the avatar has for the DA? (Character strength)
  - PROBE: For example, what are your thoughts on whether or not the avatar will keep people engaged while they are using the DA?
6. Why or why do you not feel that the avatar to is appropriate for African-American men? What would you change to make him more appropriate? (Character strength)
  - PROBE: For example, should he have a different voice, skin-tone, or clothes?
7. How similarly does the DA function like the types of technology that you currently use? (Facilitating Conditions, Experience)
  - PROBE: For example, does it function like your cell phone or an atm?
8. Why or why do you not feel that the content will be effective for African American men seeking information to help them participate in informed decision making with their doctor regarding about prostate cancer screening? (MUG, Content)
  - PROMPT: What changes would you make to the depth of the content?
  - PROMPT: What changes would you make to the amount of content?
9. Based on the current format and graphics, how difficult do you think it would be for a person to use the DA? (Ease of Use)
  - PROMPT: What things can be improved about the DA to make it easier for any person to use it?

PROMPT: Why or why do you not you feel that the DA is appropriate for a person with little to no computer experience? (Ease of Use, Experience)

PROMPT: Why do you or why do you not feel that the DA would be easy to use by men your age and older?

PROBE: For example, are the buttons on the screen large enough for an older man to see and touch?

10. Currently the question and answer sections of the DA requires the user to read the question and answer responses, and then pick the correct response. What are your thoughts on the appropriateness of this format for men your age and older? (Ease of Use)

PROMPT: What can we do to the language to make these questions easier to understand?

PROMPT: What could we do to the format in which the questions and responses are presented to make the question and answer activity easier to use?

11. How much do you feel that the questions will challenge the intended user (African-American men 40-65)? (MUG, Challenge).

PROBE: E.g., Too difficult, too easy, just right?

PROMPT: What could we change about the questions make them challenging enough for the user, but not too challenging for the average user?

12. There is a role play activity at the end of the DA session where men will be engaged in a doctor patient role play exercise to prepare them to speak with their doctor about prostate cancer screening. What things about the graphics or format of this section to will make it easy for men to use? What could be changed? (Ease of Use)

PROBE: For example, is the text size or buttons? (Ease of Use)

13. How do you think of the language of the content in the role play section will make it easier for the intended user to understand? What would you change the language to make it easier to understand? (Ease of Use)

14. How do you think the current content will better prepare of a man who is going to speak with a doctor? What would you change to about the content to make sure every man was prepared to speak with their doctor? (Ease of Use)

The next questions will ask about your overall thoughts regarding the DA.

15. Why do you or why do you not feel that the **content** included in this DA will be effective for preparing men to speak with a physician about prostate cancer? If you think it will not, how would you change the content to be more effective? (MUG, Content)

PROBE: For example, is there a way we could make the language simpler?

16. How do you feel that using this DA could enable you to find out information about prostate cancer and prostate cancer screening more quickly than using other means? (Performance Expectancy)

PROBE: For example, how would using the DA provide you with a quicker way to get information about prostate cancer than finding a credible site online or seeking out a pamphlet?

PROMPT: How can we improve the DA's format, graphics, or content so that you can get the information you need quickly.

17. How do you feel that using the DA could improve a person's ability to find the information about prostate cancer that could help them make an informed decision with their doctor about screening? (Performance Expectancy)

PROMPT: How can we improve the DA, particularly the graphics and format, so that a person efficiently receives enough information to make an informed decision with their doctor about prostate cancer screening?

PROMPT: How can we improve the DA's graphics (such as including the avatar in the role play) so that a person feels comfortable speaking with their doctor about prostate cancer screening?

18. Why do you or do you not feel that people in your age group will support men's use of the DA? (Social Acceptance)

19. Why or why do you not feel that the current format, graphics, and content will keep the user engaged in the use of the DA?

Thanks to everyone for your participation in today's discussion. We have just a couple things left to do today:

- (3) Please make sure that everyone signed in.
- (4) We will distribute the participation incentives.
- (5) Please contact me if you have any further questions, my contact information is included on your consent form.

## APPENDIX G: IN-DEPTH INTERVIEW GUIDE (AIM 2)



UNIVERSITY OF  
**SOUTH CAROLINA**  
Arnold School of Public Health

### Focus Group Guide (Phase III)

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

**DIRECTIONS:** All sections will be read to participants including all prompts. Probes will be read only if needed.

#### **MATERIALS AND EQUIPMENT**

2 digital audio recorders

1 touch-screen computer containing prostate cancer education program

**PURPOSE:** You have been invited to take part in a discussion about a DA prototype that has been developed to help men make informed decisions about whether or not to get screened from prostate cancer. This prototype was developed based on the discussion groups that you were invited to participate in back in October of 2012 and April 2013. Today I invite you to share your personal thoughts and opinions as they will help us improve the DA even more. Please note that all of the specific changes that you personally recommended may not have been made to the module at this time, but may be implemented in later versions of the DA. This is not the final version but a continuing improvement process. The findings from the last discussion group indicated that most men reported positive perceptions regarding the program including: the use of the avatar for the program, your perception about whether people would support your use of the DA, the format of the sections (e.g., question and answers), the prostate cancer content, and the ease of use for older populations and populations with lower literacy. There were, however, some suggestions for improving the program including adding testimonials and animations to cue the users when it is time to

make the next decision (e.g., press next to hear more). Participants also commonly suggested that the proposed football screensaver be altered to include a variety of actual sports clips (as opposed to animated clips) and that we consider adding an incentive component to increase the number of users. The discussion today will last approximately an hour to an hour and a half and you will receive your incentive immediately following the discussion.

I will be audio recording the session. I do not want to miss any of your comments. Only members of the research team will have access to the audio recording. If you are uncomfortable with being audio recorded, please say so, and of course, you are free to leave. The audio recording will be kept in a locked file cabinet. The recording will be transcribed without your name or other identifying information. Once the audio file has been transcribed, it will be destroyed. In any reports or presentations of the findings, your name will not be used.

The first step in this interview will involve you using the DA. I would like for you to go through each page of the education program as I observe. I ask that you speak out loud as you use the DA. For example, I am pressing the start button” “now I am pressing the next button.” By speaking out loud while you use the DA, I will have a better idea about your thought process and things that may seem confusing to you. After you complete the education program, I will ask you a few questions about how well you think the program functions and whether it will be useful for men in your community.

Do you have any questions before we begin?

**SECTION I:** In today’s discussion, I will ask you to provide thoughts on the content, (which is the text on each of these pages, the graphics (this can include things like the avatar or buttons), or the format (order in which information is presented). The DA to which I will refer today is the computer on which the learning activities will take place. A DA is similar to a Redbox or an ATM. In addition, the avatar is the animated character that will provide you with the information during your use of the DA. When I ask you questions today, it is ok to say, “I don’t know.”

1. Why or why do you not feel that you had enough information to use the DA when you first approached it? (Facilitating Conditions)  
PROMPT: How can we further improve the DA so that a person will have enough information to use it?
2. How well does the DA keep you informed about how to move forward or what selections options are available while you are using the program? (Nielsen)
3. After pressing any button on the DA, why or why do you not feel that you received feedback within a reasonable time? (Nielsen)

4. Does the DA use language (i.e., words and phrases) that is familiar to the intended user (African American men ages 40+)? Why or why not? Please provide examples. (Nielsen)
5. How well do the tabs included throughout the education program allow you to navigate directly to where you wanted to go? Please provide examples. (Nielsen)
6. How does the DA function like other types of technology that you currently use? (Facilitating Conditions, Experience, Nielsen)  
 PROBE: For example, does it function like your cell phone or an atm?
7. How easily do you think it will be for a user to navigate back to the desired page if they press a button by mistake (Nielsen). Can you please describe why or why it would not be easy.
8. What are your thoughts on whether or not the buttons (such as home, back, repeat, and the index) are visible or easily retrievable? (Nielsen)
9. To what extent is the education program designed to be easily used by both people with little computer experience and those who are regular computer users? (Nielsen)
10. What are your thoughts about how well easy or difficult it was to use the first section of the program? (i.e., where avatar presents prostate information) (Ease of Use)  
 PROMPT: What could we change to make this section easier to use?
11. What are your thoughts about how easy or difficult it was to use the role play section of the program? (Ease of Use)  
 PROMPT: What could we change to make this section easier to use?  
 PROMPT: What are your thoughts on how this section will or will not prepare you to speak with a doctor about screening?

The next questions will ask about your overall thoughts regarding the DA.

12. Why or why do you not feel that the DA will make people more comfortable using technology in general or for finding health information?
13. Why or why do you not feel that the DA will make people more comfortable speaking to a doctor about prostate cancer screening?

PROMPT: What are your thoughts about whether the DA will make a person more likely to speak with a doctor about prostate cancer screening?

PROMPT: How can we improve the DA to make people more comfortable speaking with a doctor?

14. Why or why do you not feel that the DA will increase a person's knowledge about prostate cancer and prostate cancer screening?

PROMPT: How can we improve the DA, particularly the graphics and format, so that a person efficiently receives enough information to make an informed decision with their doctor about prostate cancer screening?

Thank you for your participation in today's discussion. We have just a couple things left to do today:

(6) I will provide you with your incentive

(7) Please contact me if you have any further questions, my contact information is included on your consent form.

## APPENDIX H: DA SCRIPT

### I DECIDE Script

**Frame 1:** Screen Saver Video

Sound: Crowd Roaring

**Frame 2:** Screen Saver Video

Sound: Football being kicked

**Frame 3:** Screen Saver Video

Sound: Ball flying through the air

**Frames 4 and 5:** Screen Saver Video

Sound: Nut hitting ground

Description: Man walks onto screen from the right, picks up and studies the walnut, then places it atop the “I” in the I-Decide screen logo, and exits screen on left.

**Frame 6:** Start Page

No Sound

**Frame 7:** Loading Screen

Description: Walnut spins as page loads.

**Frame 8:** Prostate University Hospital Check-In Desk

Description: Camera zooms in slowly toward desk.

Front Desk Attendant: **Welcome to prostate university hospital. The doctor will be with you momentarily.**

**Frame 9:** Welcome

Description: Avatar (Doctor 1), dressed in scrubs, stands in waiting room (left of screen)

Doctor1: **Welcome again to the Prostate University Hospital. Today, I am going to provide you with some brief information about prostate cancer and prostate cancer screening, but first let's take a look at some of the functions of this module.**

#### **Frame 10: Index Instructions**

Description: Doctor1 (left of screen) extends arms to show and explain index tabs, squats to show navigation bar, then walks to right of screen to highlight the go home button.

Doctor1: **Welcome to the homepage where I will explain how this module works. On the left of your screen is the index. By clicking on one of these buttons, you can get to specific information about a topic without having to complete the entire module. For example, if you click here on the Prostate Cancer Signs and Symptoms tab, the module will proceed to this topic and skip the information provided about What is the Prostate and What is Prostate Cancer. On the bottom of your screen is your navigation bar. The navigation bar will be located on each page. By pressing Repeat, I will repeat the information that you receive on any page. The Next button, located here, will take you to the next page. You will need to press the Next button on each page to proceed forward. The Back button will take you to the previous page. By pressing the red button labeled, "Go home" at any point during this module will bring you will back to this page where you can access the index and choose specific topics of interest.**

#### **Frame 11: Prostate Anatomy**

Description: Doctor1 (left of screen) discusses prostate anatomy while referring to an animated prostate graphic (graphic will appear on right of screen)

Doctor1: **The prostate is a male reproductive organ that is located in front of the rectum and below the bladder. The purpose of the prostate is to produce a fluid that is a part of the semen.**

#### **Frame 12: Prostate Cancer**

Description: Doctor1 (left of screen) discusses prostate cancer while referring to a pictorial prostate cancer animation (graphic will appear on right of screen)

Doctor 1: **Prostate Cancer occurs when the cells began to divide at an abnormal rate forming a tumor on the prostate. In some cases the cancer can spread to the surrounding tissue.**

#### **Frames 13-16: Infographic with voiceover**

Description: Infographic of silhouetted men (center screen) are displayed while voiceover plays. Key words (e.g., 240,000) will flash on the screen and the number of silhouetted men will change when these words are displayed. In addition, when prostate cancer

among African American men is discussed as being more prevalent, 1 of the silhouetted men will be highlighted.

**Doctor 1: Prostate Cancer is the number one non-skin cancer among men of all races, affecting over 240,000 men in 2012. According to the American Cancer Society 40,000 men are expected to die from the disease. However, African Americans are twice as likely to develop and die from prostate cancer as White men.**

**Frame 17:** Question and answer intro

Description: Doctor1 (left of screen) gives introduction to question and answer section.

**Doctor 1: On the next two pages you will be asked to answer questions about this module. Please answer the questions to the best of your ability and most importantly, this is not a test.**

**Frame 18:** Question 1\_Prostate Location

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear to acknowledge their correct answer (e.g.,

**Frame 19).** If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again (e.g., **Frame 20).**

**If A. Doctor1: The scrotum is a part of the male reproductive system that holds the testicles. It is not, however, the location of the prostate. Please try again.**

**If B. Doctor1: The rectum is a part of the digestive system. Please try again.**

**If C. Doctor1 (only check-mark animation is displayed): This is correct. The prostate is located below the bladder and in front of the rectum.**

**Frame 21:** Question 1\_Prostate Purpose

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1 (only check-mark animation is displayed): This is correct, the purpose of the prostate is to produce a fluid that is a part of the semen.**

**If B. Doctor1: Semen is produced by the testicles, not by the prostate. Please try again.**

**If C. Doctor1: This is incorrect. Please try again.**

**Frame 22:** Introducing Risk Factors

Description: Doctor1 (middle of screen) gives an introduction to section on prostate cancer risks.

Doctor 1: **You did an excellent job answering the questions on the last two pages. Now let me provide you with some information about the things that can put you at a higher risk for prostate cancer. We call these risk factors.**

#### **Frame 23: Risk Factors for Prostate Cancer**

Description: Doctor1 (walks to right of screen) provides information on the most prominent risk factors for prostate cancer. Animated words will appear on the left of the screen (i.e., family history, age, race)

Doctor 1: **There are multiple risks for prostate cancer, but the most common are family history, age, and race. A man who has a family member such as a father who has been diagnosed with prostate cancer is at a greater risk for having the disease. As you get older, your risk for prostate cancer also increases. In addition, African American men are twice as likely to develop and die from prostate cancer as White men.**

#### **Frame 24: Symptoms**

Description: Doctor1 (walks to middle of screen) provides information on prostate cancer symptoms

Doctor 1: **There are multiple symptoms for prostate cancer. These can include things such as blood in the urine or semen, frequent urination, trouble urinating, pain in the back, hips or thighs, the starting and stopping of your urine flow, or painful ejaculation. However, not all men with prostate cancer will experience symptoms.**

#### **Frame 25: Question \_Prostate Cancer Symptoms**

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1: This is correct, some men with prostate cancer do not experience any symptoms**

**If B. Doctor1: This is incorrect. Please try again.**

#### **Frame 26: Question \_Prostate Cancer Risk**

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1: This is correct, having a family member such as a father with prostate cancer will increase your chances of developing the disease**

**If B. Doctor1: This is incorrect. Please try again.**

**Frame 27: Prostate Cancer Screening**

Description: Doctor1 (middle of screen) provides information on prostate cancer screening

Doctor 1: **There are two screenings used to detect prostate cancer, the digital rectal exam or (DRE) and the prostate specific antigen test or (PSA). During a DRE, a doctor places a gloved finger into the rectum to feel the texture and shape of the prostate.**

**The PSA test is a blood test to measure the amount of PSA in the bloodstream. PSA is a protein that is naturally produced by the prostate, but higher levels of PSA in the bloodstream can mean that you are at a higher risk for prostate cancer.**

**However, it is important to note that neither the PSA nor the DRE are 100% accurate. The PSA test, in particular, can be falsely elevated or lowered by things other than prostate cancer such as certain medications, supplements, or vigorous physical activity. Therefore, it is important to speak with your doctor about all of your medications, vitamins, and physical activity routines prior to receiving prostate screening.**

**Frame 28: Biopsy**

Description: Doctor1 (middle of screen) provides information on prostate cancer screening

Doctor 1: **If your DRE or PSA test is abnormal, your doctor may recommend that you have a biopsy. A biopsy is a procedure where a small needle is used to take small tissue samples from the prostate. The tissue samples are then looked at under a microscope to determine if cancer cells are present. The biopsy is the only way to diagnose prostate cancer. The process takes about 10 minutes and can be performed in your doctor's office. The biopsy may cause some discomfort, but your doctor will likely numb the area prior to the procedure. Following the procedure you may also experience soreness and/or also notice light bleeding in rectum or in the semen.**

**Frame 29: Question \_ PSA**

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1: This is incorrect. Please try again.**

**If B. Doctor1: This is incorrect. Please try again.**

**If C. Doctor1: This is correct. The PSA test measures the level of (PSA) a protein naturally produced by the prostate.**

### **Frame 30: Question\_ Screening**

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1: This is correct. Neither the DRE nor the PSA tests are 100% accurate.**

**If B. Doctor1: This is incorrect. Please try again.**

### **Frame 31: Question\_ Biopsy**

Description: Screen contains questions only. If a participant answers the question correctly, then an animation will appear. If a person answers a question incorrectly then Doctor1 will appear in the left bottom corner of the screen and encourage the participant to try again.

**If A. Doctor1: This is incorrect. The DRE is when the doctor places his finger into the rectum to feel the prostate. Please try again.**

**If B. Doctor1: This is correct. A biopsy is when a needle is used to take small tissue samples from the prostate.**

**If C. Doctor1: This is in correct. The PSA is a blood test is used to examine a protein in the blood.**

### **Frame 32: Controversy/Informed Decision Making**

Description: Doctor1 (middle of screen) talks about controversy to and stress the importance of making informed decisions.

**Doctor 1: There is some controversy associated with prostate cancer screening. The United States Preventive Services Task Force recommends that healthy men do not receive routine screening for prostate cancer. However, this recommendation was based on a body of research that included few to no African American men. The American Cancer Society on the other hand, recommends that men have an opportunity to make an informed decision with their doctor about whether or not screening is right for them. Making an informed decision means knowing the risks, benefits, and uncertainties of prostate cancer screening, talking to your doctor, participating in the final decision at the level that you desire, and making this decision at the time of the conversation or electing to make the decision at a later date.**

### **Frame 33: Congratulations**

Description: Doctor1 (middle of screen) congratulates the user and invites him to participate in a roll play activity.

**Doctor 1: Congratulations, you have participated in a module to prepare you to make an informed decision about whether or not to receive prostate cancer screening. If you would like to proceed with a short exercise that can prepare you to speak with your doctor about prostate cancer screening, please press next. If you would like to exit the module at this time, please press the red button labeled no (exit).**

**IF yes: Doctor exits and module proceeds to doctor's office.**

**IF no: Doctor 1: Thank you for visiting the Prostate University Hospital. Have a great day.**

### **Frames 34&35: Introduction to the Doctor (Informed Decision Making Role Play)**

Description: Doctor 2 enters room and sits down. User is prompted to interact with doctor by pressing button labeled "Hi doctor"

**Doctor 1: Hi my name is Dr. Livingston and I want to welcome to the Prostate University Hospital. It is a pleasure meeting new patients. So what brings you in today?**

### **Frame 36: What Brings You In?**

Description: Participant must respond to doctor's question about the reason for their visit. If user chooses the most appropriate prompt, then the conversation proceeds. If the use chooses a selection that is less favorable for the purposes of the conversation then Doctor 1 will appear, provide them with advice, and they will have an opportunity to try again.

**If A. Doctor2: It is great that you are concerned about your prostate health and I can certainly answer any questions that you may have. Do you have any specific questions?**

**If B. Doctor1 (enters to left of screen) (e.g., Frame 37): This is a great question, but you should be more specific. Since prostate cancer screening is not recommended to be done on an annual basis by some organizations, some doctors may not speak with you about prostate cancer screening during a conversation about a regular check up. Please choose another option.**

### **Frame 38: What Questions do you have?**

Description: Participant must respond to doctor's question about the reason for their visit.

**If A. Doctor1 (enters to left of screen): You should not ask a doctor for prostate screening until you have been informed about the risks, benefits, and uncertainties of screening and made a shared decision with your doctor about whether or not you should receive prostate cancer screening. Please select one of the other options.**

**If B. Doctor2: This is an excellent question, but before we talk specifically about your chances for developing the disease, I want to ask you some additional questions.**

**If C. Doctor2: This is a great question, but before we talk specifically about screening I would like to ask you some questions to determine if you are at a higher risk for the disease.**

**Frame 39:** What is your age

Description: Participant must respond to doctor's question via multiple response options.

Doctor2: **How old are you?**

**Frame 40:** Family History

Description: Participant must respond to doctor's question via multiple response options.

Doctor2: **Do you have a family history of prostate cancer?**

**Frame 41:** Race?

Description: Participant must respond to doctor's question about their race.

Doctor2: **Are you African American?**

**Frames 42:**

Doctor2: **Based on one or more of your selections, you are at a higher risk for prostate cancer. Let's talk further.**

Description: Participant must respond to doctor by choosing a response.

**If A. Doctor2: There are two types of screenings for prostate cancer, the prostate specific antigen exam or (PSA) which is a blood test. There is also a digital rectal exam or (DRE) where a gloved finger is used to feel the texture and shape of the prostate.**

**If B. Doctor1 (enters to left of screen): Even if you are not currently at a high risk for prostate cancer it is good to find out more about prostate cancer and prostate cancer screening for other family members or friends who may be at risk. If you**

would like to discontinue the module at this time please press “Go Home,” if not, please choose another option.

**Frame 43:**

Doctor2: **Do you have additional questions?**

Description: Participant must respond to doctor by selecting a response option.

**If A. Doctor2: Neither the DRE or PSA is 100% accurate. The PSA test, in particular, can be falsely elevated or lowered by things other than prostate cancer such as certain medications, supplements, or vigorous physical activity. Therefore, it is important to let me know about all of your medications, vitamins, and physical activity routines prior to receiving prostate screening.**

**If B. Doctor1 (enters to left of screen): It is important to know the risks, benefits, and uncertainties of a screening to make a fully informed decision about whether or not screening is right for you. Please choose the alternate option.**

**Frame 44: Ready to make decision?**

Doctor2: **Are you ready to make a decision about whether or not to receive prostate cancer screening?**

Description: Participant must respond to doctor by selecting a response option.

**If A. The user is presented with options on Frame 45.**

**If B. Doctor1 (enters to left of screen): It is important that you have as much information as possible prior to making an informed decision with your doctor. If you would like to repeat parts of this module, please press “Go home” and select specific topics on the index. Or press the contact button to be taken to a page with a phone number where you can call to receive additional information.**

**Frame 45: Let’s make a decision**

Description: Participant must select a response option.

**If A. Doctor2: Great, you have decided that you want to be screened after learning about your risk for prostate cancer, and the risks, benefits, and uncertainties of screening. If you are considering screening, please use the exercise that you have completed today to speak with your doctor about prostate cancer screening.**

**If B. Doctor2: Great. You have decided not to be screened at this time. This is ok because you have made an informed decision after learning about your risk for prostate cancer, and the risks, benefits, and uncertainties of screening.**

**If C. Doctor2: Great. You have decided not to wait and speak to a family member. This is ok because you have made an informed decision after learning about your risk for prostate cancer, and the risks, benefits, and uncertainties of screening. It is important to involve family members in your health decision making and to be sure that you are comfortable before undergoing any medical screening or treatment.**

**Frame 46: Congratulations Again**

Description: Doctor 2 congratulates the user

Doctor2: Congratulations, you have made an informed decision about whether or not to receive prostate cancer screening. We hope that you use what you have learned from this module to have a conversation with your doctor to make a shared decision about prostate cancer screening. For more information please press the button labeled “Get contact information” below.

**Frame 47: Exit**

Description: Front Desk-Check out

Front Desk Attendant: **Have a great day and thank you for visiting the Prostate University Hospital.**

## APPENDIX I: BUDGET AND JUSTIFICATION\*

**Table I.1: Budget**

	Explanation	Cost	Quantity	Total
<b>SUPPLIES</b>				
<b>Audio-Recorder</b>	<b>Focus Groups/Interviews</b>	<b>\$ 100.00</b>	<b>1</b>	<b>\$ 100.00</b>
<b>Postage</b>	<b>Focus Groups/Interviews</b>	<b>\$ .45/stamp</b>	<b>176</b>	<b>\$ 80.00</b>
<b>Software</b>	<b>Data Analysis</b>	<b>\$ 300.00</b>		<b>\$ 300.00</b>
<b>Touch-Screen All-in-One Computer</b>	<b>DA</b>	<b>\$ 1000.00</b>	<b>1</b>	<b>\$ 1,000.00</b>
<b>SERVICES</b>				
<b>Transcription</b>	<b>Focus Groups/Interviews</b>	<b>\$ 1.25/min</b>	<b>1292/min</b>	<b>\$ 1,200.00</b>
<b>Media-Arts Development</b>	<b>DA</b>			<b>\$ 1,200.00</b>
<b>Computer Programming</b>	<b>DA</b>			<b>\$ 1,200.00</b>
<b>Color Printing</b>	<b>Recruitment</b>	<b>\$ .50/page</b>	<b>200</b>	<b>\$ 100.00</b>
<b>Conference Poster Printing</b>	<b>Dissemination</b>			<b>\$ 150.00</b>
<b>Aim 1 Focus Group</b>	<b>Completion of Focus Group</b>	<b>\$ 10.00</b>	<b>39</b>	<b>\$ 390.00</b>
<b>Aim 2 Focus Group</b>	<b>Completion of Focus Group</b>	<b>\$ 20.00</b>	<b>39</b>	<b>\$ 780.00</b>
<b>In-depth interviews</b>	<b>Completion of In-depth Interview</b>	<b>\$ 40.00</b>	<b>10</b>	<b>\$ 400.00</b>
<b>TRAVEL</b>				<b>\$ 2400.00</b>
<b>TOTAL</b>				<b>\$ 9,300.00</b>

1. **Audio-Recorder** –A digital audio recorder will be needed to record and seamlessly transfer audio files to a local computer where the files will be securely stored (\$100)

2. **Postage-** Stamps will be needed to mail reminder and thank you letters to all participants (\$80).
3. **Software-** NVIVO9 (\$200) and SPSS (\$100) software will be needed to analyze qualitative and quantitative data.
4. **Touch-Screen All in One-Computer-** A Dell 23' All in One, touch-screen computer will be purchased at a cost of (\$1,000) to house the proposed module and act as a DA.
5. **Transcription-** will be required for all focus groups and in-depth interviews at a rate of \$1.25/minute x 1292 minutes= (\$1200).
6. **Media Arts Development-** A 3-D visual animator will be required to assist with the development of the proposed DA intervention. The developer will be essential to the motion capture, voice recording/mixing, and animating the avatar that will be included in the DA intervention. The animator will be hired at a rate of \$25/hr x 50hrs= (\$1200).
7. **Computer Programming -** The candidate will also hire a graduate student in the School of Computer Science and Engineering to program all elements of the DA. The computer programmer will be hired at a rate of \$25/hr x 50hrs= (\$1200).
8. **Color Printing-**200 color flyers will be printed for recruitment at a cost of \$.50/page (\$100).
9. **Conference Poster Printing-**2 color posters will be printed for presentation of study results at conferences \$75/poster (\$150).
10. **Participant Incentives-**39 focus group participants will receive an incentive of \$10 for participation in 90 minute focus groups to occur during Aim 1 and \$20 for completing an additional focus group for Aim 2. Ten of 39 who are randomly selected to participate in the in-depth interviews will receive an additional \$40 following their participation. Aim 1 (39x\$10=\$390; 39 x \$20=\$780; 10 x \$40=\$400) = \$1570
11. **Travel-** (\$2400) is requested to cover the expenses (i.e., flight, hotel, per diem) to attend two national conferences. An average cost for conference attendance is \$1200.

\*Student has received or will receive funding from the following sources: IAAR (\$1500), SHCRG (\$3000), and USC Provost (\$1000)=\$5500. Additional grants have also been submitted (See Budget paragraph under Logistics section of proposal).

## APPENDIX J: EXPERT REVIEW/HEURIST EVALUATION (AIM 2)



UNIVERSITY OF  
**SOUTH CAROLINA**  
Arnold School of Public Health

### Heuristic Evaluation\*

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

Student Researcher: Otis (Shaun) Owens, MPH, PhD(c)  
Faculty Supervisor: Daniela B. Friedman, MSc, PhD  
Department of Health Promotion, Education and Behavior

\* All questions were adapted from Nielsen's Heuristics. See references below.

**PURPOSE:** You have been invited to take part in an expert review of a prostate cancer education program (i.e., prototype) that is being developed to help men make informed decisions about whether or not to get screened for prostate cancer. This prototype was developed based on two waves of focus groups with African American men ages 37-65. These 13 focus groups took place in October 2012 (n=6) and March 2013 (n=7). Four key findings emerged from these focus groups: (1) men are knowledgeable about some of the risks, symptoms, and screenings for prostate with some misconceptions (2) Many men report being screened for prostate cancer, but few reported making a shared decision with their doctor about screening (3) almost none of the men were informed about the risks and uncertainties of screening and (4) Most of the men were open to receiving information from a touch-screen DA with an avatar led education program as long as the program had language appropriate for people of varying literacy levels and the avatar was also African American. Based on these findings, my colleagues at USC and I have developed a prototype and we invite you to share your expert feedback using this heuristic evaluation instrument as it will help us improve the usability of the final product (i.e. touch-screen DA). The evaluation instrument was developed to guide your comments, but please feel free to include additional comments as you feel appropriate. Also for each question below, please provide your suggestions for improvement. It is suggested that you skim through the entire instrument prior to reviewing the prototype. The prototype will take approximately 15 to 20 minutes

. The questions below should be completed after reviewing the prototype.

1. How effectively does the prostate cancer education program keep the user informed about how to use the program?

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2. Does the user receive feedback on their selection decisions within a reasonable time? Why or why not? Please provide examples.

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3. Does the education program use language (i.e., words and phrases) that are familiar to the intended user (African American men ages 40+)? Why or why not? Please provide examples.





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8. Is the interface of the education program designed to prevent common errors? Why or why not? Please provide examples.

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9. Does the education program effectively minimize the things that the user needs to remember by making objects, actions, and options visible or easily retrievable? Why or why not? Please provide examples.

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13. Please provide any other specific suggestions that can make this program more usable and accessible to the user.

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### References

Molich, R. and Nielsen, J., Improving a human- computer dialogue, Communications of the ACM, 33(3), 338-348, (1990).

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## APPENDIX K: DEMOGRAPHIC SURVEY 2



UNIVERSITY OF  
**SOUTH CAROLINA**  
Arnold School of Public Health

A Community Based Participatory Approach to the Development of a Computer-based Aid to Facilitate Informed Decision Making for Prostate Cancer Screening among African American Men in Faith-based Communities: An Exploratory Qualitative Study

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Survey 2

### Questions About You: Information About Participants

The following questions will tell us about who is taking part in the discussion groups. Please place a check mark (☑) in the box next to your response. This information will be kept private.

1. In general, how would you rate your current health? (General Health and Wellbeing)
  - Excellent
  - Very Good
  - Good
  - Fair
  - Poor
2. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy? (Health Literacy –single item screener)
  - Never
  - Rarely
  - Sometimes

- Often
- Always

3. Do you know what prostate cancer screening options are available to you?

(Decisional Conflict)

- Yes
- Unsure
- No

4. Do you know about the benefits of making a decision about whether or not to receive prostate cancer screening? (Decisional Conflict)

- Yes
- Unsure
- No

5. Do you have enough support from others to make a decision about whether or not to receive prostate cancer screening? (Decisional Conflict)

- Yes
- Unsure
- No

6. Are you choosing whether or not to receive prostate cancer screening with pressure from others? (Decisional Conflict)

- Yes
- Unsure
- No

7. Do you have enough advice to make a choice about whether or not to receive prostate cancer screening? (Decisional Conflict)

- Yes
- Unsure
- No

**The next questions will ask you about your confidence, comfort, or satisfaction with performing a specific health-related task.**

8. I can find the facts necessary to help me make a decision about whether or not to receive prostate cancer screening? (Decision Self-Efficacy)

- Very Confident
- Confident
- Neutral
- Not Very Confident
- Not At ALL Confident

9. I can find the facts necessary to help me make a decision about whether or not to receive prostate cancer screening? (Decision Self-Efficacy)
- Very Confident
  - Confident
  - Neutral
  - Not Very Confident
  - Not At ALL Confident
10. I understand prostate cancer screening enough to make a decision about whether or not to receive prostate cancer screening? (Decision Self-Efficacy)
- Very Confident
  - Confident
  - Neutral
  - Not Very Confident
  - Not At ALL Confident
11. I can ask my doctor questions about prostate cancer screening without feeling dumb? (Decision Self -Efficacy)
- Very Confident
  - Confident
  - Neutral
  - Not Very Confident
  - Not At ALL Confident
12. I can tell the doctor why or why I do not feel that prostate cancer screening is right for me (Decision Self- Efficacy)
- Very Confident
  - Confident
  - Neutral
  - Not Very Confident
  - Not At ALL Confident
13. I can delay my decision about whether or not to receive prostate cancer screening if I feel that I need more time (Decision Self-Efficacy)
- Very Confident
  - Confident
  - Neutral
  - Not Very Confident
  - Not At ALL Confident
14. How comfortable do you feel using the internet (Computer fluency)
- Very comfortable
  - Somewhat comfortable
  - Neither comfortable or uncomfortable
  - Somewhat uncomfortable
  - Very uncomfortable

15. How satisfied are you with your current skills for using the internet (Computer fluency)

- Very satisfied - I can do everything that I want to do
- Somewhat satisfied- I can do most things that I want to do
- Neither satisfied nor unsatisfied
- Somewhat unsatisfied- I can't do so many things I would like to do
- Very unsatisfied- I cant' do most thins that I would like to do

16. How satisfied are you with your current skills for using the internet (Computer fluency)

- Very satisfied - I can do everything that I want to do
- Somewhat satisfied- I can do most things that I want to do
- Neither satisfied nor unsatisfied
- Somewhat unsatisfied- I can't do so many things I would like to do
- Very unsatisfied- I cant' do most thins that I would like to do

**For the following questions, please circle the appropriate number according to the scale below: (Computer fluency)**

	<b>Very Well</b>	<b>Well</b>	<b>OK</b>	<b>Not so Well</b>	<b>Not At All</b>
17. I can switch computer on.	5	4	3	2	1
18. I can restart a computer.	5	4	3	2	1
19. I can begin a new document.	5	4	3	2	1
20. I can save a document.	5	4	3	2	1
21. I can open a previously saved file from any drive/directory.	5	4	3	2	1
22. I can print a document.	5	4	3	2	1
23. I can open an email program.	5	4	3	2	1
24. I can check new email messages.	5	4	3	2	1

25.	I can open a file attached to an email.	5	4	3	2	1
26.	I can delete email that I have read.	5	4	3	2	1
27.	I can send an email message.	5	4	3	2	1
28.	I can use the reply feature of email.	5	4	3	2	1
29.	I can forward email to someone other than the original email sender.	5	4	3	2	1
30.	I can use a web browser such as internet explorer.	5	4	3	2	1
31.	I can find an internet page by typing in a web address.	5	4	3	2	1
32.	I can use “back” and “forward” to move between web pages.	5	4	3	2	1
33.	I can use a search engine such as Google.	5	4	3	2	1
34.	I can save text contents from webpages.	5	4	3	2	1
35.	I can save images form webpages.	5	4	3	2	1
36.	I can create a website.	5	4	3	2	1

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## APPENDIX L: RECRUITMENT FLYER

**SEEKING AFRICAN-AMERICAN MEN TO PARTICIPATE  
IN A DISCUSSION ABOUT A NEW TOOL FOR  
PROSTATE CANCER EDUCATION**

**We are looking for:**  
African-American men  
between the ages of **40 and  
65** with **NO HISTORY** of  
Prostate Cancer.



**What you'll do:** (1) Attend 1  
discussion group that will last 90 minutes or  
less. (2) Complete 1 short survey.

**When the sessions will be held:** During the  
months of September and October.

**Where the session will be held:** On the campus  
of the University of South Carolina.

**What you'll receive:** Information about prostate  
cancer and **\$10 in cash**.

**How to sign up:** Call Shaun Owens, MPH, PhD  
candidate and student researcher at (803) 777-9933

*This study has been approved by the Institutional Review Board at the  
University of South Carolina (USC). The study is funded by the Institute of  
African American Research at USC.*



**Figure L.1:** Study Flyer

**APPENDIX M: CODE BOOK FOR PHASE I FOCUS GROUPS**

**Owens Dissertation: Phase 1: Focus Group Codebook**

**Prostate Cancer Symptoms**

PrCASymptom/Uncertainty  
PrCASymptom/Rectal Bleeding  
PrCASymptom/Troubled Urination

**Prostate Cancer Risks**

PrCARisk/Age  
PrCARisk/Race  
PrCARisk/Hereditiy

**Prostate Cancer Screening**

PrCAscreening/DRE  
PrCAscreening/location/doctor  
PrCAscreening/Frequency  
PrCAscreening /decision/job  
PrCAscreening/decision/military

**Prostate Cancer Information Source**

PrCA Information Source/Internet  
PrCA Information Source/Church  
PrCA Information Source/Radio  
PrCA Information Source/TV  
PrCA Prior Information/None

**Prostate Cancer Highest Risk**

PrCA highest risk/AA  
PrCA highest risk/AA/Diet  
PrCA highest risk/AA/Fear of Screening  
PrCA highest risk/AA/Lack of Health Insurance  
PrCA highest risk/AA/Lack of Doctor Visit  
PrCA highest risk/AA/Lack of Education

**Encouraging Learning About PrCA**

Encourage Learning/Advertise  
Encourage Learning/Heathfairs  
Encourage Learning/WOM  
Encourage Learning/WOM/Pressure

### **Encourage Doctor Conversation**

Encourage DocSpeak/WOM/Early Life  
Encourage DocSpeak/Awareness

### **Educating Others**

Educating Others/Strategies/WOM  
Educating Others/Location/Barbershop  
Educating Others/Location/ Hangouts  
Educating Others/Locations/Sports Channels  
Educating Others/Location/Social Media  
Educating Others/Location/Cell Phone  
Educating Others/No Reading  
Educating Others/Barrier

### **Barriers to IDM**

PrCA /IDM/Barrier

### **Health information Sources**

Health Information Source/Advertising  
Health Information Source/Doctor  
Health Information Source/Internet  
Health Information Source/Family  
Health Information Source/Co-Workers  
Health Information Source/Family  
Health Information Source/Cell Phone  
Health Information Source/Email  
Health Information Source/Newsletter  
Health Information Source/No Internet Use

### **Kiosk Features**

Kiosk/Comfort/Yes  
Kiosk/Feature  
Kiosk/Feature/Race Concordant  
Kiosk/Feature/Celebrity  
Kiosk/Feature/PrCA survivor  
Kiosk Features/Length  
Kiosk/Features/Research needed  
Kiosk/Feature/Avatar/No  
Kiosk/Feature/Avatar/Real  
Kiosk/Feature/Avatar/No Added Value  
Kiosk/Feature/Attention Grabber  
Kiosk/Feature/Avatar/Age appropriate  
Kiosk/Feature/touchscreen  
Kiosk/Features/Index  
Kiosk/Features/Short  
Kiosk/Features/Simple  
Kiosk/Feature/Free

Kiosk/Feature/Contact  
Kiosk/Feature/User Interest/Celebrity  
Kiosk/Feature/User Interest/topics  
Kiosk/Feature/Sex  
Kiosk/Feature/Sports  
Kiosk/Location  
**Kiosk Content**  
Kiosk/Info/Risk Factors  
Kiosk/Info/Effects  
Kiosk/Info/Prevalence  
Kiosk/Info/Screening Age  
Kiosk/Info/Prevalence/ Among AAs  
Kiosk/Info/Symptoms  
Kiosk/Info/Prostate Location

### **Technology Ease of Use**

Ease/Level of Effort  
Ease/health status  
Ease/Level of Experience  
Ease/ Experience/Opportunity/On Job  
Ease/Level of Familiarity  
Ease/Level of Familiarity/Techniques  
Ease/Level of Familiarly/Functionality  
Ease/simplicity  
Ease/education  
Lack of Ease/Lived experience  
Lack of Ease/Age  
Lack of Ease/Age/Over 60  
Lack of Ease/Age/75-80  
Lack of Ease/patience  
Lack of Ease/Frustration  
Lack of Ease/new technology  
Companies /control product

### **Technology Use**

Technology Use/ Frequency  
Technology Use/Purpose

## Appendix N: Code Book for Phase II Focus Groups

**Table N.1:** Codes for Phase II Focus Groups

Constructs	Sections	Section Codes	Suggestion Codes
Performance Expectancy	General	1A. FindInfoEasier_Yes 1B. FindInfoEasier_Computerized 1C. FindInfoEasier_IndexFindInfoEasier_Accessible 1D. Find InfoEasier_Why_Specific to prostate cancer 1E. FindInfoEasier_Conditional	1F. FindInfoEasier_Keep As Is 1G. FindInfoEasier_Burn DVD
Facilitating Conditions	Introduction/Index	2A. Intro/Index_Easy 2B. Intro/Index_Provides flexibility 2C. Intro/Index_Ease_Conditional	2D. Index_Suggestions 2E. Index_Suggestions_Closed Caption
Effort Expectancy/ Ease of Use	General	3A. Ease of Use_Simple 3B. Ease of Use_Comp Exp Level_Simple 3C. Ease of Use Comp Exp Level_Usability 3D. Ease of Use_Screen Size	3E. Ease of Use_Suggestion_Usability 3F. Ease of Use_Suggestion_Keep as Is 3G. Ease of Use_Suggestions_Text 3H. Ease of Use_Suggestions_Closed Caption
Social Influence	General	3A. SocialSupport_Yes 3B. SocialSupport_Who_Family 3C. SocialSupport_Who_Co-Workers 3D. SocialSupport_Why_Long life 3E. SocialSupport_Barriers_Fear 3F. SocialSupport_Barriers_Age	
Content Effectiveness	General	4A. ContentEffect_Reduces Fear 4B. ContentEffect_Avatar 4C. ContentEffect_Simple 4D. ContentEffect_Reiteration 4E. ContentEffect_Better Prepared	4F. Content_Effect_Sugg_Testimonial 4G. Content_Effect_Depth_Keep As Is 4H. Content_Effect_Depth_Keep Short 4I. Content_Effect_Depth_Sugg_Add total time to beginning 4J. Content_Effect_Amount_Keep As Is

			<p>4K. Content_Effect_Sugg_Animated Graphic (e.g., walnut)</p> <p>4L. ContentEffect_Sugg_Add general information about prostate health</p> <p>4M. Content_Effect_Sugg_Target Young men too</p> <p>4N. Content_Effect_Add positive ending</p> <p>4O. Content_Effect_Add option for more information</p>
	Role Play	<p>5A. ContentEffect_RP_Doc Visit</p> <p>5B. ContentEffect_RP_Ques to ask doc</p> <p>5C. ContentEffect_RP_Statistics</p> <p>5D. ContentEffect_RP_Lang_Simple</p>	<p>5E. RP Doc Speak_Suggestion_Provide positive information</p> <p>5F. RP Doc Speak_Suggestion_Informed vs. Uninformed (Scenerio)</p> <p>5G. RP Lang_Suggestion_Keep Simple</p> <p>5H. RP Lang_Suggestion_Response options</p>
Effectiveness/ Speak_Seek	Encourage Speak	<p>6A. EncourageSpeakOthers_Yes_Family</p> <p>6B. EncourageSpeakOthers_Yes_Why_Now Informed</p> <p>6C. EncourageSpeakOthers_If positive ending added</p> <p>6D. EncourageSpeakOthers_Lack of trust_large orgs</p> <p>6E. EncourageSpeakOthers_Depends on Marketing</p> <p>6F. EncourageSpeakOthers_Unsure</p>	6G. EncourageInfoSeek_Suggestion_Include Links
	Encourage Seek	<p>7A. EncourageInfoSeek_Informed Decision</p> <p>7B. EncourageInfoSeek_Yes</p> <p>7C. EncourageInfoSeek_Why_Fear</p> <p>7D. EncourageInfoSeek_If No_Stubborn</p>	
Character Strength	Avatar	<p>9A. Avatar_Value Add_Helpful</p> <p>9B. Avatar_Value Add_Calming</p> <p>9C. Avatar_Value Add_No rushing</p> <p>9D. Avatar_Value Add_Repeats Info</p> <p>9E. Avatar_ValueAdd_Engaged/Attention</p> <p>9F. Avatar_Value Add_No Reading (Instruction)</p>	<p>9K. Avatar_Suggestions_Clothes</p> <p>9L. Avatar_Suggestions_Age</p> <p>9M. Avatar_Suggestions_Celebrity</p>

		9G. Avatar_Value Add_Promote Thinking 9H. Avatar_AAs_Appropriate 9I. Avatar_Value Add_Avatar AA 9J. Avatar_ValueAdd_Privacy	9N. Avatar_Suggesti ons_Keep As Is 9O. Human Instead of Avatar 9P. Make User an Avatar
Format	Name	10A. Kiosk Name Appropriate 10B. Kiosk Name_Memorable 10C. Kiosk Name_Catchy	10D. Kiosk Name_Change 10E. Kiosk Name_Change_ More specific to PrCA
	Introducti on	11A. Introduction_Attention_Grabbing 11B. Introduction_Walnut_Good 11C. Introduction_Walnut_Confusion	11D. Introduction_Su gg_Action 11E. Introduction_Su gg_Variability 11F. Introduction_Su gg_Plan B 11G. Introduction_Su gg_Walnut_Rep lace 11H. Introduction_Su gg_Opposite Sex 11I. Introduction_Su gg_Make Fem Friendly 11J. Introduction_Su gg_Add Background 11K. Introduction_Su gg_Use Real Sports Clips
	Q&A	12A. Q&A_Simple	12B. Q&A_Sugg_Qu es Format_Questio n (No Statements) 12C. Q&A_Sugg_Qu estion Format_No Wrong Answers 12D. Q&A_Sugg_Ad d Question Narration 12E. Q&A_Sugg_Ke ep Simple 12F. Q&A Sugg_Add total number of quest 12G. Q&A_Sugg_No Repeating Correct Response Info 12H. Q&A Sugg_Highlight

			Reponses 12I. Q&A Sugg_Dont Include
	Role Play		13A. RP Format_Sugg_S care Tactic 13B. Format_Sugg_S horten Script 13C. RP Format_Sugg_K eep As Is 13D. RP Format_Sugg_S creening graphic 13E. RP Format_Suggest _Screening content 13F. RP Format_Make user an avatar 13G. RP Format_Sugg_A dd different conversation scenerios 13H. RP Format_Sugg_K eep Content Specific to PrCA (not basic checkup) 13I. RP Format Sugg_Stress PSA content
User Engagement	User Engaged	14A. User Engaged_Yes_Nature of topic User 14B. User Engaged_Yes_Graphic 14C. User Engaged_Yes 14D. User Engaged_Yes_Avatar Use 14E. User Engaged_IfNo_Why_Don't Care	
Other	Overall	15A. Kiosk Function Similar_Computer 15B. Kiosk Function Similar_Accessible	15C. Make information accessible online 15D. Have seating available at kiosk 15E. Option to share info with others 15F. Add empowering message 15G. Add evaluation 15H. No Headphones

			<p>15I. Make kiosk portable</p> <p>15J. Raised letters on buttons</p> <p>15K. Make Kiosk portable</p> <p>15L. Add incentives</p> <p>15M. Get sponsorship from credible organization</p> <p>15N. Separate screening info into another section</p> <p>15O. Background colors</p> <p>15P. Ask for contact information</p>
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**APPENDIX O: CODE BOOK FOR PHASE III IN-DEPTH INTERVIEWS**

**Table O.1:** Codes for Phase III In-Depth Interviews

<b>Design Principle</b>	<b>Corresponding Questions</b>	<b>Codes</b>
Overall Ease of Use	1,4,9,10,11	1A. EofU_Approach_Attention 1B. EofU_Approach_Simple 1C. EofU_Approach_Simple_Buttons/Index 1D. EofU_Approach_Suggestion_Additional Instructions 1E. EofU_Language_Simple 1F. EofU_Language_Difficult_Acronyms 1G. EofU_Suggestion_Change Quiz Order 1H. EofU_Language_Suggestion_Connect Definition to Acronym 1I. EofU_General_Simple 1J. EofU_First Section_Simple 1K. EofU_Second Section_Simple 1L. EofU_Second Section_Suggestion_Eliminate button 1M. EofU_Second Section_Suggestion_Add commonly asked questions 1N. EofU_Approach_Unsure how to use
Recognition rather than recall	2	2A. RecRecall_Simple/Self Explanatory
Visibility of system status	3, 8	3A. VisSysStat_Response_Quick/No Delay 3B. VisSystStat_Buttons Visible 3C. VisSystStat_Suggestion_No home button
User control and freedom/Error prevention	5, 7	4A. UserCont_Good/Simple 4B. Errorprev_Easy_Buttons
Match between system and the real world	6	5A. TechfuncOther_Audio 5B. TechfuncOther_Cell phone 5C. TechfuncOther_Games 5D. TechfuncOther_Options (Back/Forward) 5E. TechfuncOther_Snack machine
Perceptions of DA effect on Technology Use Self Efficacy	12	6A. TechSelfEff_Comfortable_General 6B. TechSelfEff_Comfortable_Searching internet

Perceptions of DA effect on IDM Self Efficacy	13	7A. IDMSelfEff_Doc 7B. Speak_Comfortable_Prepared_Knowledge 7C. Speak_Comfortable_Prepared_Ques to ask 7D. IDMSelfEff_Doc Vist_More likely 7E. IDMSelfEff_Doc Vist_More likely education
Perceptions of DA effect on Prostate Knowledge	14	8A. PrCA Know_Improve_Yes
Other		9A. Screensaver_Suggestion_Use Current sports events 9B. Screensaver_Consider including other sports 9C. Screensaver_Consider celebrity survivor 9D. General_Large Letters for Title 9E. User Behavior_Take Notes 9F. Animation_Suggestion_Reduce Arm Movement 9G. Kiosk_Suggestion_Add Printer 9H. Concern_Privacy