

## **ABSTRACT**

Title of dissertation: CERVIXCHECK: A SPIRITUALLY-BASED SMS TEXT MESSAGING PILOT INTERVENTION TO INCREASE CERVICAL CANCER AWARENESS AND PAP TEST SCREENING INTENTION AMONG AFRICAN AMERICAN WOMEN

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African American women account for a disproportionate burden of cervical cancer incidence and mortality rate when compared to non-Hispanic White women. Cervical cancer is one of the most preventable types of cancer, and women can be screened for it with a routine Pap test. Given that religion occupies an essential place in African American lives, framing health messages with important spiritual themes and delivering them through a popular communication delivery channel may allow for a more culturally-relevant and accessible technology-based approach to promoting cervical cancer educational content to African American women.

Using community-engaged research as a framework, the purpose of this multiple methods study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging intervention to increase cervical cancer awareness and Pap test screening intention among African American women. The study

recruited church-attending African American women ages 21-65 and was conducted in three phases. Phases 1 and 2 consisted of a series of focus group discussions (n=15), cognitive response interviews (n=8), and initial usability testing that were conducted to inform the intervention development and modifications. Phase 3 utilized a non-experimental one-group pretest-posttest design to pilot test the 16-day text messaging intervention (n=52). Of the individuals enrolled, forty-six completed the posttest (retention rate=88%).

Findings provided evidence for the early feasibility, high acceptability, and some initial efficacy of the CervixCheck intervention. There were significant pre-post increases observed for knowledge about cervical cancer and the Pap test ( $p = .001$ ) and subjective norms ( $p = .006$ ). Additionally, results post-intervention revealed that 83% of participants reported being either “satisfied” or “very satisfied” with the program and 85% found the text messages either “useful” or “very useful”. 85% of the participants also indicated that they would “likely” or “very likely” share the information they learned from the intervention with the women around them, with 39% indicating that they had already shared some of the information they received with others they knew. A spiritually-based SMS text messaging intervention could be a culturally appropriate and cost-effective method of promoting cervical cancer early detection information to African American women.

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INTERVENTION TO INCREASE CERVICAL CANCER AWARENESS AND PAP TEST  
SCREENING INTENTION AMONG AFRICAN AMERICAN WOMEN

By

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## Dedication

This dissertation is lovingly dedicated to my wonderful parents, **Xuoi Van “Franker” Le** and **Con Thi “Cathy” Phan**, and beautiful younger sister **Amy “My Linh” Le** for their incredible patience and unwavering support during this crazy journey. My family instilled in me the importance of hard work and higher education. They cultivated my thirst to learn more, to understand more, to keep growing, to strive to be a better version of myself, and to always remember to give back. They exemplify the meaning of strength, perseverance, and courage and without all that they have sacrificed on my behalf, I would not be where I am today.

In particular, the Vietnamese proverb, *“Co cong mai sat; co ngay nen kim”* which translates to ‘*a person who works hard and dedicates herself to any endeavors in life will likely succeed and accomplish her objectives*’, celebrates and legitimizes the important beliefs that my parents taught me. As with many refugee families who started their life in America, my family experienced heavy financial and cultural burdens. My parents barely spoke English and had little to no assistance accessing resources. This did not, however, discourage my parents from instilling in me the importance of strong character. Being raised in a traditional Vietnamese working class family, my parents encouraged the belief that the ethic of hard work and dedication to a job well done was more valuable than intelligence alone. Yes, education was important, but maintaining cultural ties to my community and giving back was heavily stressed. Although what my parents kept reemphasizing seemed redundant at first, I understand now that my experience growing up, with all its’ ups and mostly downs, was a blessing in disguise because it instilled in me a strong work ethic and sense of responsibility. For everything that they have done and given me, I can only hope that I will be able to do the same for those around me.

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*Gia dinh minh da thanh cong!*

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## **Chapter 1: Introduction**

### **Background of the Problem**

Cervical cancer incidence and mortality rates have drastically decreased in the United States (U.S.) over the last few decades (Siegel, Naishadham, & Jemal, 2013; SEER, 2012a; SEER, 2012b), however, some populations continue to bear a larger burden of disease (Bynum, Guillaume, Brandt, & Fletcher, 2014; DeSantis, Naishadham, & Jemal, 2013). Each year, nearly 12,000 women are diagnosed with cervical cancer and approximately 4,000 die of the disease (Bynum et al., 2014; SEER, 2012a; SEER, 2012b). Although cervical cancer occurs most often in Hispanic women, African American women tend to have lower 5-year survival rates and die more often than any other race (National Cancer Institute, 2008; American Cancer Society, 2013). In fact, African American women develop cervical cancer about 50% more often than non-Hispanic white women and have twice the cervical cancer mortality rate compared to white women (DeSantis et al., 2013; National Cancer Institute, 2008; SEER, 2012a; SEER, 2012b). Of the close to 2,000 African American women diagnosed with cervical cancer each year, over 40% will die (National Cancer Institute, 2008; Howlader et al., 2012; SEER, 2012a; SEER, 2012b; Centers for Disease Control and Prevention (CDC), 2012).

Cervical cancer is one of the most preventable types of cancer, and women can be screened for it with a routine Papanicolaou (Pap) test (Bynum et al., 2014; DeSantis et al., 2013). Screening and early detection are critical components in eliminating these disparities in health outcomes for African American women (Bynum et al., 2014; DeSantis et al., 2013). There are a number of social and cultural factors that relate to prevention and screening behaviors that impact cancer mortality rates. Religious involvement is one of these factors

(Deshpande, Sanders Thompson, Vaughn, & Kreuter, 2009; Holt et al., 2009a; King, Burgess, Akinyela, Counts-Spriggs, & Parker, 2005; Lincoln & Mamiya, 2001; Lumpkins, Coffey, Daley, & Greiner, 2013; Peterson, Atwood, & Yates, 2002). Extensive research has shown that religious involvement plays an important role in the African American community (Deshpande et al., 2009; Holt et al., 2009a; Holt, Wynn, & Darrington, 2009; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002). In particular, older African Americans women have been found to be more religiously involved than other groups (Holt et al., 2009a; Lincoln & Mamiya, 2001).

Religious involvement has been associated with cancer beliefs, screening, risk, and prevention behavior and has great potential for use in the development of cancer prevention and screening communication interventions for this group (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002). Because of the popularity of church-based cancer screening programs for African Americans and the well-established association between religious involvement and health in the literature (Deshpande et al., 2009; Holt et al., 2009a; Holt et al., 2009b; Holt et al., 2009c; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002), it is important to determine how religious involvement specifically relates to cervical cancer screening intentions and behavior. Our understanding of the impact of religious involvement on cervical cancer screening intention and behavior over time among African Americans women remains limited. If more is known about this relationship, we will be better able to inform church-based cancer-related interventions and improve their efficacy. This study aimed to address these gaps by examining determinants of Pap test screening intention and behavior and to develop, pilot test, and evaluate the feasibility, acceptability, and initial

efficacy of a spiritually-based short message service (SMS) text messaging educational intervention to increase cervical cancer awareness and Pap test screening intention among church-attending African American women ages 21 to 65 who reside in the greater Maryland, Washington, D.C., and Virginia areas.

### **Purpose of the Study**

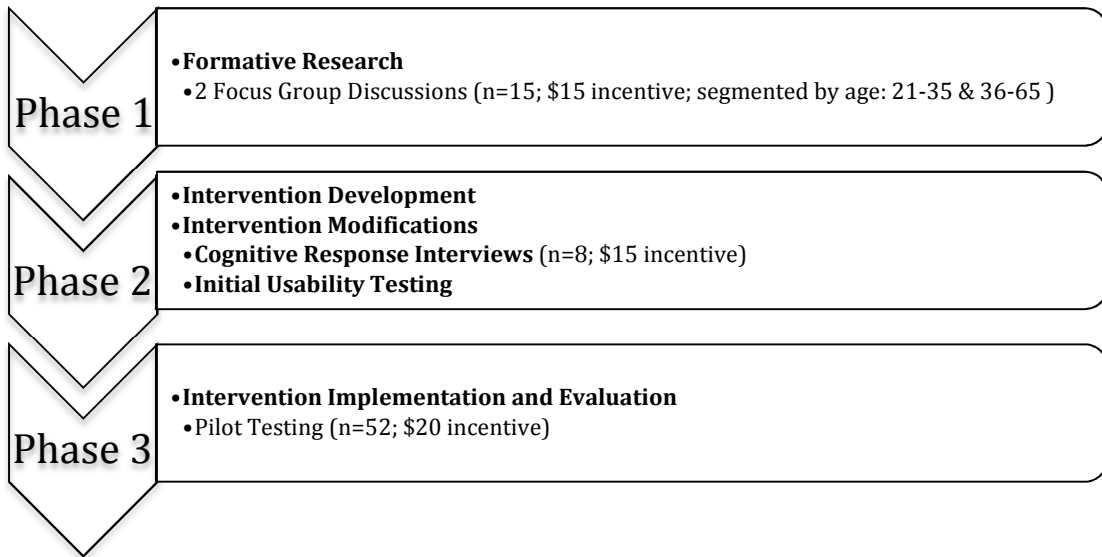
The purpose of this multiple methods pilot study was to examine Pap test screening intention among church-attending African American women ages 21-65. Using community-engaged research as a framework, this dissertation study developed, pilot tested, and evaluated the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging educational intervention in the promotion of cervical cancer early detection information. This study sought to investigate the relationships between socio-demographic factors, the text messaging pilot intervention, health-related beliefs, and health seeking intentions for Pap test screening in African American women who reside in the greater Maryland, Washington, D.C., and Virginia areas.

The study ultimately pilot tested a spiritually-based SMS text messaging educational program designed to increase intention towards Pap test screening for cervical cancer among church-attending African American women ages 21-65. This study was conducted in three phases, corresponding with the following three specific aims:

- In Phase 1 (Specific Aim #1), formative research was conducted through two semi-structured focus group discussions to inform the development of the spiritually-based SMS text messaging educational intervention in increasing cervical cancer awareness and Pap test screening intention in church-attending African American women.



- In Phase 2 (Specific Aim #2), the spiritually-based SMS text messaging cervical cancer educational intervention was developed. Cognitive response interviews were used to assess the content of the SMS text messaging library, to ensure that the content was acceptable and understandable, particularly for church-attending African American women ages 21-65. Initial usability testing of the pilot program was also completed during Phase 2.
- In Phase 3 (Specific Aim #3), the spiritually-based SM text messaging cervical cancer educational intervention was pilot tested and evaluated for its' feasibility, acceptability, and initial efficacy to increase cervical cancer awareness and Pap test screening intention among church-attending African American women ages 21-65 who reside in the greater Maryland, Washington, D.C., and Virginia areas.



### **Specific Aims, Research Questions, and Hypotheses**

Aim 1: To conduct formative research to inform the development of a spiritually-based SMS text messaging educational intervention for increasing cervical cancer awareness and Pap test screening intention in church-attending African American women ages 21-65.

**Research Question 1:** What is the role of knowledge, beliefs, attitudes, barriers, facilitators, motivators, and psychosocial predictors in cervical cancer screening in church-attending African American women who reside in the greater Maryland, Washington, D.C., and Virginia areas?

**Research Question 2:** What factors should be considered when developing a spiritually-based cervical cancer SMS text messaging educational intervention for church-attending African American women age-eligible for Pap test screening (21-65)?

Aim 2: To develop a spiritually-based SMS text messaging educational intervention to increase cervical cancer awareness and Pap test screening intention among church-attending African American women through the use of community-engaged research methods. Through a community-engaged approach involving an iterative process, this intervention will consist of a SMS text messaging program on cervical cancer early detection from a spiritual perspective.

Aim 3: To pilot test and evaluate the feasibility, acceptability, and initial efficacy of this spiritually-based SMS text messaging educational intervention to increase cervical cancer awareness and Pap test screening intention among church-attending African American women who reside in the greater Maryland, Washington, D.C., and Virginia areas. This study will use a one-group pretest-posttest design. A total of 50 church-attending African American women between the ages of 21 and 65 (who have not had a past medical history of cervical cancer or hysterectomy) will be recruited through local faith-based organizations.

**Research Question 3:** To what extent is the spiritually-based SMS text messaging educational intervention feasible and acceptable for use in increasing cervical cancer

awareness and Pap test screening intention among church-attending African American women age-eligible for Pap test screening (21-65)?

**Hypothesis 3:** Study participants will express positive intervention feasibility (e.g., participants recall receiving them) and acceptability (e.g., participants indicate satisfaction with the intervention and will report that they would recommend the program to their friends).

**Research Question 4:** Is a spiritually-based SMS text messaging educational intervention using community-engaged research methods efficacious in increasing research participants' (a) knowledge of cervical cancer, relevant guidelines for cervical cancer screening, and cervical cancer risk factors, and (b) intent to undergo Pap test screening?

**Hypothesis 4:** Cervical cancer knowledge, attitudes, subjective norms, perceived behavioral control, and intention towards Pap test screening will significantly increase from baseline to the immediate posttest.

### **Influence of Religion in the African American Community**

Religion and religious institutions strongly influence individual behavior and social norms (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002). Extensive research suggests that African Americans, on average, demonstrate a high degree of religious involvement (Taylor, Chatters, & Levin, 2004). They have the highest percent of religious affiliation of any other group in the United States with 87% of African Americans describing themselves as belonging to a religious group (Sahgal & Smith, 2009). Analyses using the National Survey of Black Americans conducted by Taylor, Chatters, and Levin (2004) show that more than

90% of African Americans report that they have attended religious services as an adult beyond weddings and funerals (Taylor et al., 2004). Of those respondents who have attended religious services as an adult beyond weddings and funerals, roughly 70% state that they attended religious services at least a few times a month, and two-third of them reported that they are church members.

It is logical to consider health promotion programs that engage faith-based institutions and that are spiritually-based to address the health needs of the African American community given the relatively high relevance and frequency that religion plays for this group of individuals (Sahgal & Smith, 2009). According to a report by the Pew Research Center, 76% of African Americans pray daily as compared to 58% of the rest of the population and 53% of African Americans attend worship services at least once a while, whereas in the rest of the population, only 39% attend as frequently (Sahgal & Smith, 2009). African American women have especially high rates of religious commitment as 84% report religion as being very important and 59% attend worship services at least once a week (Sahgal & Smith, 2009). Given the role that religion plays in the daily lives of African American women, it is important to understand how their religious beliefs and behaviors may influence how they perceive, initiate, engage, and participate in cervical cancer screening prevention.

### **Text Messaging as an Intervention Delivery Medium**

SMS text messaging was selected as the primary delivery channel for the intervention materials due to its' popularity and high use among African American women. Nationally representative data show that African American adults have the highest prevalence of smartphone ownership when compared to other racial and ethnic groups (Smith, 2013) and

are more likely to own a mobile phone (87%) when compared to non-Hispanic Whites (80%) (Lenhart, 2010). African Americans have also been shown to be more likely to use their mobile phones to send and receive SMS text messages (Duggan, 2013; Duggan & Rainie, 2012; Buis et al., 2013; Joseph et al., 2015) and to access social media websites (i.e., Twitter, Facebook) (Duggan & Brenner, 2013; Buis et al., 2013; Joseph et al., 2015).

Mobile phone technology, also known as Mobile Health or “mHealth” (Fox & Duggan, 2012), represents a nearly universal form of communication among minority populations and is a promising new medium of intervention delivery in health research. The most recent data from the Pew Internet and American Life Project indicates that use of SMS text messages has drastically increased in recent years (Duggan & Rainie, 2012), with over 80% of all adults reporting that they use mobile cell phones for sending or receiving SMS text messages (Smith, 2013). The Pew Internet and American Life Project reports that 80% of African Americans and 80% of all women use mobile cell phones for sending or receiving SMS text message (Duggan & Rainie, 2012). Estimates from the Pew Internet and American Life Project show that African Americans send and receive SMS text messages more frequently (M=70.1/day; Mdn=20/day) than non-Hispanic Whites (M=31.2/day, Mdn=10/day) (Smith, 2011). The low cost and widespread use of mobile phones and the convenience of SMS text messaging suggest potential suitability for delivering health promotion interventions to African American women.

Literature relating to SMS text messaging has revealed that SMS text messages may be an effective strategy for stimulating behavior change or supporting behavioral interventions (Cole-Lewis & Kershaw, 2010; Fjeldsoe, Marshall, & Miller, 2009; Le et al., 2015). Periodic cues through this type of communication medium have also been found to be

effective in reinforcing healthy behaviors (Cole-Lewis & Kershaw, 2010). For example, combined social media and SMS text messaging interventions have been used to successfully promote weight loss (Napolitano, Hayes, Bennett, Ives, & Foster, 2013; Herring, Cruice, Bennett, Davey, & Foster, 2014; Joseph et al., 2015) and various health behaviors (i.e., physical activity, dietary behaviors) (Valle, Tate, Mayer, Allicock, & Cai, 2013; Laranjo et al., 2014; Joseph et al., 2015) in previous research and have several benefits compared to mailed print-based or traditional face-to-face health interventions. Specifically, SMS text message reminders have established popularity with patients and have been shown to be more cost-effective than paper or telephone-based reminder strategies (Fry & Neff, 2009).

Despite the high prevalence of SMS text messaging, social media, and mobile Internet use among African American women, few interventions have used such technologies to deliver health promotion programs to African American women. Review of the literature found no studies using SMS text messaging as a means to promote cervical cancer early detection information to this population. Existing and commonly used SMS text messaging infrastructures, when combined with traditionally effective intervention approaches, may be especially advantageous for promoting routine Pap testing among African American women.

Given the high levels of technology use in the African American women population and substantial evidence suggesting that technology-based health promotion efforts are effective (Joseph, Durant, Benitez, & Pekmezi, 2013; Davies, Spence, Vandelanotte, Caperchione, & Mummery, 2012; Vandelanotte, Spathonis, Eakin, & Owen, 2007; Maher et al., 2014; Norman et al., 2007; Joseph et al., 2015), the absence of studies utilizing SMS text messaging as a means to promote cervical cancer early detection information represents a missed opportunity to reducing cervical cancer mortality rates in this population. Although

there is a growing body of literature reporting positive outcomes of SMS text message-based communication with sexually transmitted infections (STIs) and cancer prevention, there is still very little research about the integration of communication technologies with traditionally effective intervention approaches such as being spiritually-based. Framing intervention materials in this manner allows for a more culturally appropriate technology-based approach to promoting cervical cancer early detection information to African American women.

### **Community-Engaged Research**

This dissertation utilized community-engaged research as a framework to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging educational intervention in the promotion of cervical cancer early detection information. Community-engaged research is a “collaborative process between the researcher and community partner that creates and disseminates knowledge and creative expression with the goal of contributing to the discipline and strengthening the well-being of the community” (Office of the Provost and Senior Vice President for Academic Affairs: Community Engagement, Virginia Commonwealth University, 2016). Community-engaged research is not a methodology in and of itself, but is a framework or approach for conducting research.

The core of all community-engaged research is the understanding that the community will be involved in a meaningful way (MacQueen et al., 2001; McDonald, 2014).

Community engagement occurs on a continuum and varies greatly in the strength and intensity of the community-academic collaboration. Research objective, project, participants, community history and local politics, among others determine this variation. Community-

engaged research requires partnership development, collaboration and negotiation, as well as the commitment from both the communities and academic researchers to addressing local health issues. Each community-academic partnership develops its own way of working together.

A community-engaged and participatory approach involving an iterative process was used in this dissertation study to develop the SMS text messages in a way that resonated with church-attending African American women and to engage them in designing and refining SMS text messages that had appeal to them. Rudd and Comings (1994) urge the inclusion of participant involvement in the development and production of their own learning materials. This type of empowerment process allows the opportunity for learners to define the content and outcome of their own learning (Aldoory, Braun, Maring, Duggal, & Briones, 2015).

### **Public Health Implications**

From a public health standpoint, this dissertation study informs the work of researchers engaged in efforts to meet *Healthy People 2020* objectives to reduce the death rate from cancer of the uterine cervix (C-4) and to increase the proportion of women who are counseled by their providers about Pap tests (C-18.2). Furthermore, technology-based platforms can provide researchers the ability to reach a large number of people at a relatively low cost; which can ultimately lead to a greater public health impact with regards to cervical cancer early detection health promotion efforts.

### **Theoretical Framework**

The purpose of this pilot trial was to develop, implement, and evaluate a spiritually-based SMS text messaging intervention designed to increase cervical cancer awareness and Pap test screening intention among church-attending African American women ages 21 to 65



who reside in the greater Maryland, Washington, D.C., and Virginia areas. The Theory of Planned Behavior (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991) was used to guide the study. This behavioral health theory explains the relationships between behaviors and beliefs, attitudes and intentions (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986). It has three main aspects: an attitudinal factor, subjective norm, and perceived behavioral control. According to Ajzen (1991), the combination of attitudes, subjective norms, and perceived behavioral control, referred to as direct measure, can have a direct effect on behavioral intention (Ajzen, 1991). It posits that behavioral intentions are a “measure of the likelihood that a person will engage in a given behavior” (Ajzen & Fishbein, 1980, p. 42). The Theory of Planned Behavior provides a theoretical framework within which to consider a woman’s intention to obtain a Pap test.

### **Definition of Terms**

African American: The term African American will be used throughout this study to refer to “a person having origins in any of the Black racial groups of Africa” (U.S. Census Bureau, 2013), or otherwise self-identifies as Black or African American.

Cervical Cancer: This term refers to cancer that has developed in the cervix. It is also known as carcinoma of the cervix (National Cancer Institute, 2015).

Pap Test: A Pap test is a cervical cancer screening exam that detects abnormal changes in cervical cells. It is a procedure in which “a small brush or spatula is used to gently remove cells from the cervix so they can be checked under a microscope for cervical cancer or cell changes that may lead to cervical cancer. A Pap test may also help find other conditions, such as infections or inflammation. It is sometimes done at the same time as a pelvic exam and may also be done at the same time as a test for certain types of human papillomavirus

(HPV)". A Pap test can also be called a Pap smear or a Papanicolaou test (National Cancer Institute, 2015).

Human Papillomavirus (HPV): HPV, also known as the Human Papillomavirus, refers to "a type of virus that can cause abnormal tissue growth (e.g., warts) and other changes to cells. Infection for a long time with certain types of HPV can cause cervical cancer" (National Cancer Institute, 2015).

HPV Vaccine: The HPV vaccine refers to "a vaccine used to prevent genital warts, anal cancer, cervical cancer, vulvar cancer, and vaginal cancer caused by certain types of HPV. It is also used to prevent lesions that are caused by those viruses and that can lead to anal, cervical, vulvar, or vaginal cancer" (National Cancer Institute, 2015).

HPV Test: The HPV test is "a laboratory test in which cells are tested for DNA or RNA from certain types of HPV that are known to cause cervical cancer. A HPV test may be done at the same time as a Pap test for cervical cancer screening in women aged 30 to 65 years. A HPV test may also be done after certain abnormal Pap test results" (National Cancer Institute, 2015).

HPV/Pap Cotest: The HPV/Pap cotest refers to "a procedure in which a HPV test and a Pap test are done at the same time to check for cervical cancer. The HPV test looks for DNA or RNA from certain high-risk types of HPV in samples of cells taken from the cervix. The Pap test checks for cervical cancer cells and cell changes that may lead to cervical cancer. The same cell sample may be used for both the HPV test and the Pap test. Women aged 30 to 65 years may have an HPV/Pap cotest every 5 years. Cotesting is more likely to find abnormal cells or cervical cancer than a Pap test alone is" (National Cancer Institute, 2015).

Adherent/Adherence: Based on the American Cancer Society (ACS), U.S. Preventive Services Task Force (USPSTF) and/or American College of Obstetricians and Gynecologists (ACOG) guidelines that were released in 2012, a women is adherent or in adherence with the current Pap test screening recommendations if she has had her last Pap test within the last three years. The term adherent/adherence may also occasionally be referred to or used synonymously with the terms “compliant/compliance” or “maintain/maintenance”.

Religion: Religion involves all factors related to an organized system of beliefs, practices, rituals, and symbols (Thoresen, 1998).

Spirituality: Although definitions of religion and spirituality have been used inconsistently throughout the literature, they have often been defined in “overlapping ways by different investigators over the years” (Roth et al., 2012; Johnstone, Yoon, Franklin, Schopp, & Hinkebein, 2009). For this dissertation study, spirituality will be used synonymously to religion and will refer to a “highly personalized and individualized engagement with transcendence or sacred matters affecting the spirit” (Hall, Meador, & Koenig, 2008; Koenig, 2008). Within this context, spirituality will be seen as similar to, but less structured and behavioral in nature than religiosity. In addition, the concept of spirituality will not necessarily be as heavily linked with ideas of transcendence and the metaphysical as it may have traditionally defined (Holt, Clark, & Osuji, 2006).

Spiritually-Based: The term spiritually-based, as opposed to religiously-based, will be used throughout this study (except when summarizing the work of others, where their terminology will be retained) to refer to any materials that relate to or incorporate the concepts of both religiosity and/or spirituality such as the use of relevant scripture passages or religious themes. Examples of religious themes include, for example, taking care of the body, which is

a gift from God or supporting one another's health through the fellowship of the church (Winett et al., 1999; Holt et al., 2003a; Holt, Lukwago, & Kreuter, 2003; Holt et al., 2009c).

Religious Involvement: This term encompasses both religious beliefs and religious behaviors (Roth et al., 2012) and is one of the approaches of measuring spirituality (Koenig, King, & Carson, 2012). It may be expressed by “attendance at religious services, identification with a religious community, reading a sacred text (e.g., Torah, Koran, Bible), and commitment to distinctive beliefs and behaviors” (Roth et al., 2012; Levin, 2009).

Religious Beliefs: The religious beliefs dimension refers to “feelings of having a personal relationship with God or a higher power and one's personal/internal religious activities such as prayer” (Roth et al., 2012; Lukwago, Kreuter, Bucholtz, Holt, & Clark, 2001; Holt, Haire-Joshu, Lukwago, Lewellyn, & Kreuter, 2005).

Religious Behaviors: The religious behaviors dimension involves “public and/or organized activities such as service attendance, participation in other organized religious activities (e.g., choir practice, scripture study), and talking to others about faith” (Roth et al., 2012; Lukwago et al., 2001; Holt et al., 2005).

Mobile Health (mHealth): Mobile phone technology, also known as Mobile Health or “mHealth” (Fox & Duggan, 2012), refers to the “overall use of mobile devices in healthcare, which includes text messaging, cellular applications, internet applications and interfacing with electronic health records, and other types of data transmission” (Schilling et al., 2013). It is a general term that refers to the use of mobile phones and other wireless technology in medical care. The most common application of mHealth is the use of mobile phones and communication devices to educate consumers about preventive health care services. However, mHealth is also used for disease surveillance, treatment support, epidemic

outbreak tracking and chronic disease management. mHealth represents a nearly universal form of communication among minority populations and is a promising new medium of intervention delivery in health research. mHealth differs from eHealth in the sense that this term refers specifically to interventions that are delivered through mobile phones (mHealth), as opposed to the Internet (eHealth) (Schilling et al., 2013).

Short Messaging Service (SMS): This term refers to a “simple, limited character (140-160) text message format that is compatible with any type of cellular phone” (Schilling et al., 2013).

Opt-In: The option of a recipient to start participation in the SMS text messaging pilot intervention and begin receiving messages from the project team.

Opt-Out: This term refers to the “option of a recipient to end participation in the text message program and stop receiving further messages” (Schilling et al., 2013).

One-Way SMS Text Messaging: One-way SMS text messaging refers to text blasting or bulk messaging, where simple, one-way text messages are sent to a list of recipients (Schilling et al., 2013). This type of text messaging communication feature/approach requires minimal or no customizability and has been shown to be useful for public health alerts or health education campaigns.

Two-Way SMS Text Messaging: This term refers to the ability (e.g. of an intervention or SMS system) to send messages and to receive text message responses (Schilling et al., 2013).

Tailored SMS Text Messages: Tailored (or personalized) SMS text messages refer to messages that are customized in a way that make the responses more relevant and directly targeted to the intended recipient (Schilling et al., 2013). This type of text messaging

communication feature/approach requires more customizability and possibly the ability to interface with electronic health record systems and databases.

Community-Engaged Research: Community-engaged research refers to the “collaborative process between the researcher and community partner that creates and disseminates knowledge and creative expression with the goal of contributing to the discipline and strengthening the well-being of the community” (Office of the Provost and Senior Vice President for Academic Affairs: Community Engagement, Virginia Commonwealth University, 2016). The core of all community-engaged research is the understanding that the community will be involved in a meaningful way (MacQueen et al., 2001; McDonald, 2014). Community engagement occurs on a continuum and varies greatly in the strength and intensity of the community-academic collaboration.

Member Checks: Member checks are primarily used in qualitative inquiry methodology and refer to the “quality control process by which a researcher seeks to improve the accuracy, credibility and validity of what has been recorded during a research interview” (Harper & Cole; 2012; Barbour, 2001; Byrne, 2001; Coffey & Atkinson, 1996; Doyle, 2007; Lincoln & Guba, 1985). Member checking is also known as participant verification (Rager, 2005), informant feedback, respondent validation, applicability, external validity, and fittingness (Morse, Barrett, Mayan, Olson, & Spiers, 2002).

Barriers: Barriers are defined as “any state, condition, or event that makes it difficult or prevents” a woman from obtaining cervical cancer screening (Johnson et al., 2003; Heaman et al., 2014).

Motivators: The term motivators refer to the “internal or psychological factors” that stimulate a woman to seek cervical cancer prevention or screening (Heaman et al., 2014).

Facilitators: The term facilitators refer to the “external factors” that would make it easier for a woman to access cervical cancer prevention or screening (Heaman et al., 2014).

## **Chapter 2: Literature Review**

### **Background on Cervical Cancer**

Cervical cancer, also known as carcinoma of the cervix, is one of the highly preventable forms of cancer. It is the third most common cancer diagnosis and cause of death among gynecological cancers in the United States (U.S.), and the second leading cause of death in women 20-39 years old (U.S. Cancer Statistics Working Group, 2015). Cervical cancer affects the cervix, the area connecting the uterus to the vagina (U.S. Department of Health and Human Services Office on Women's Health, 2014). Human Papillomavirus (HPV), the most common sexually transmitted infection (STI), causes virtually all cases of cervical cancer worldwide (Kaiser Family Foundation, 2013). Cervical cancer develops gradually, usually over several years, beginning with subtle changes in the cells from normal to pre-cancerous to cancerous (U.S. Department of Health and Human Services Office on Women's Health, 2014).

In the United States, the incidence rate is 7.7/100,000 and the mortality rate is 2.3/100,000 (National Cancer Institute Surveillance Epidemiology and End Results Program (NCI SEER), 2015). In Maryland, the cervical cancer incidence and mortality rates are below the national rates, 7.5/100,000 and 2.1/100,000 respectively (U.S. Cancer Statistics Working Group, 2015). The Prince George's County mortality rate is the second highest in Maryland (3.0/100,000), and the incidence rate is 7.2/100,000 (State Cancer Profiles, n.d., "Death rate report"; State Cancer Profiles, n.d., "Incidence rate report").

From 2008-2012, the median age at diagnosis for cervical cancer was 48 years of age, while the median age at death for the disease was 57 years of age (NCI SEER, 2015). Rates based on cases diagnosed in 2008-2012 from the 17 Surveillance Epidemiology and End



Results (SEER) geographic areas showed that 0.1% were diagnosed under age 20; 14.0% between 20 and 34; 24.4% between 35 and 44; 24.0% between 45 and 54; 17.9% between 55 and 64; 11% between 65 and 74; 5.8% between 75 and 84; and 2.8% for those 85+ years of age (NCI SEER, 2015). The data also showed that approximately 0.0% died under age 20; 5.0% between 20 and 34; 14.0% between 35 and 44; 24.1% between 45 and 54; 23.0% between 55 and 64; 16.1% between 65 and 74; 11.4% between 75 and 84; and 6.3% for those 85+ years of age (NCI SEER, 2015). In 2012, 12,042 women in the United States were diagnosed with the disease and 4,074 women in the United States died from it (Centers for Disease Control and Prevention, 2015). The American Cancer Society's estimates for cervical cancer in the United States for 2015 are about 12,900 new cases of invasive cervical cancer that will be diagnosed and about 4,100 women who will die from the disease (CDC, 2015).

Cervical cancer negatively impacts an individual's physical, mental, and social well-being. Symptoms include bone fracture; leaking of urine or feces from the vagina; vaginal discharge and bleeding; and pelvic, back, and leg pain (Medline Plus Medical Encyclopedia, 2014). Treatments (hysterectomy, radiation therapy, and chemotherapy) can cause infertility, severe lower abdominal pain, and bowel and bladder problems (Cancer Research UK, 2015). During treatment, women often cannot fulfill their normal social and economic roles and may experience depression and anxiety (Ashing-Giwa et al., 2004). Untreated, cervical cancer can metastasize and lead to death (American Cancer Society, 2015a; American Cancer Society, 2015b). If the cancer has metastasized, a woman's relative five-year survival rate is 16.5% (NCI SEER, 2015).

Cervical cancer also has severe economic impacts on society; in 2005, the U.S. spent \$2 billion on cervical cancer treatment alone (National Cancer Institute (NCI), 2014). The annual direct medical costs associated with cervical cancer ranges between 300-400 million U.S. dollars (Insigna, Dasbach, & Elbasha, 2005). The trend incidence and survival estimates of the cost of cervical cancer in the U.S. were \$1.21 billion in 2010, and \$1.73 billion in 2020 (Mariotto, Yabroff, Shao, Feuer, & Brown, 2011).

**Cervical Cancer Incidence and Mortality Rates.** During the past 40 years, the number of incident cases and death rates of cervical cancer have decreased significantly (U.S. Cancer Statistics Working Group, 2015). This is due mostly to the fact that more women are getting screened. Incidence and death rates for cervical cancer in the United States are shown below (Surveillance, Epidemiology, and End Results (SEER) Program, 2007; Surveillance, Epidemiology, and End Results (SEER) Program, 2006 Surveillance, Epidemiology, and End Results (SEER) Program, 2006):

<b>Racial/Ethnic Group</b>	<b>Cervix</b>	
	<b><u>Incidence</u></b>	<b><u>Death</u></b>
All	8.7	2.6
African American/Black	11.4	<b>4.9</b>
Asian/Pacific Islander	8.0	2.4
Hispanic/Latino	<b>13.8</b>	3.3
American Indian/Alaska Native	6.6	4.0
White	8.5	2.3

*Statistics are for 2000-2004, age-adjusted to the 2000 U.S. standard million population, and represent the number of new cases of invasive cancer and deaths per year per 100,000 women.\**

### **African American Women & Cervical Cancer: The Disproportionate Burden.**

Although Pap testing has the ability to reduce cervical cancer incidence and mortality, some populations continue to bear a larger burden of the disease (Bynum et al., 2014; Siegel et al., 2013; DeSantis et al., 2013). Data shows that disparities in cervical cancer incidence and mortality exist between racial and ethnic groups (SEER, 2007; SEER, 2006; Miller et al., 1996; NCI SEER, 2015). On a national level, African American women experience the second highest incidence rate of cervical cancer (11.4/100,000) and the highest death rate (4.9/100,000) (SEER, 2007; SEER, 2006). When compared to White women in the general population, African American women have a 34% higher incidence of cervical cancer and are twice as likely to die of the disease in the United States (Bynum et al., 2014; Siegel et al., 2013; DeSantis et al., 2013).

In Prince George's County, where there is a large population of African Americans, the cervical cancer rate is 10-25% higher than the national rate (Fleming, Schluterman, Tracy, & Temkin, 2014). While 88% of African American women in the United States have had a Pap test, and 92% in Maryland, the disparity in their mortality rate cannot be overlooked (Kaiser Family Foundation, 2013). Despite the similarities in cancer screening habits between African American and White women, the former is still more likely to be diagnosed with advanced stage of cervical cancer (DeSantis et al., 2013; Garner, 2003; Rauh-Hain et al., 2013).

Although these racial differences are evident, several studies have indicated that race is not a predictor of cervical cancer; the effect of race diminishes as other factors, such as education and socioeconomic status, are taken into account (Garner, 2003; Brooks et al., 2000). A Massachusetts study found that these racial differences could possibly be caused by inadequate education for patients and providers, fear and mistrust of the healthcare system, cultural differences in health seeking behaviors, and challenge in diagnostic testing after an abnormal Pap test (Massachusetts Cancer Registry, 2010; Nolan et al., 2014). Another study by Schwartz and colleagues (2003) found that socioeconomic status accounts for most of the diagnosis stage disparity between African Americans and Whites for cervical cancer (Schwartz, Crossley-May, Vigneau, Brown, & Banerjee, 2003). Other studies have attributed the differences in cervical cancer mortality rates between African American and White women to the quality of screening and follow-up after abnormal screening that African American women receive (DeSantis et al., 2013), and to higher disease stage upon diagnosis (DeSantis et al., 2013; Fleming et al., 2014; Garner, 2003; Rauh-Hain et al., 2013).

Adherence to cervical cancer screening recommendation among African American women is also similar to that of White women overall; however, this utilization of Pap tests among African Americans is limited to younger women (Hoyo et al., 2005; Porterfield, Dutton, & Gizlice, 2003; Martin, Parker, Wingo, & Heath, 1996). Among African American women over 40 years of age, adherence to Pap test screening is low and corresponding invasive cervical cancer incidence and subsequent mortality are high (Porterfield, Dutton, & Gizlice, 2003). Factors for non-adherence to recommended screening for cervical cancer have been an active topic of debate. Reasons that have previously been shown to predict low adherence to Pap test screening for African American women include socioeconomic and

demographic variables such as age, race, low income, inner-city residence, lack of health insurance coverage, and low educational status (Hoyo et al., 2005; Paskett et al., 1999; Tatum, Wilson, Dignan, Paskett, & Velez, 1997; Sung, Alema-Mensah, & Blumenthal, 2002; Hewitt, Devesa, & Breen, 2002; Benard, Lee, Piper, & Richardson, 2001; Richards & Klemm, 2000; Simoes et al., 1999; Mandelblatt et al., 1999; Wells & Horm, 1998; Borum, 1997; O'Malley, Mandelblatt, Gold, Cagney, & Kerner, 1997; Pearlman, Rakowski, & Ehrich, 1996; Burnett, Steakley, & Tefft, 1994; Weiss, Kau, Sparks, & Swanson, 1994; Ackermann, Brackbill, Bewerse, Cheal, & Sanderson, 1992; Hendershot, 1981).

Of the two studies (post-2002 guidelines) that evaluated screening behaviors in African American women (Limmer, LoBiondo-Wood, & Dains, 2014), both showed that higher educational level was significantly and strongly positively associated with screening adherence (Datta et al., 2005; Hoyo et al., 2005). Both these studies also indicated that financial difficulty was a negative predictor of screening adherence. The agreement was that women with health insurance and higher income were significantly more like to receive cervical cancer screening. Particularly in the Hoyo et al. (2005) study, it was found that perceived pain (i.e. perception that the Pap test was painful) was associated with non-adherence to screening recommendations (OR = 4.78; 95%CI: 1.67–13.7). Additionally, it was also determined that difficulty to pay for the office visit coupled with perceived pain was associated with a nearly six-fold increase in risk of non-adherence (OR = 5.8; 95%CI: 2.8–15.5). However, in this study, previously recognized barriers to screening including lower education and socioeconomic status, poor access to care, knowledge of and exposure to known risk factors of invasive cervical cancer, cancer fatalism, and perceived racism were not independently associated with non-adherence.

The study by Datta et al. (2005) included a large sample of 40,009 respondents identified from the Black Women's Health Study, whereas Hoyo et al. (2005) conducted their study with a smaller sample of 144 African American women aged 45 to 65 years. Datta et al. (2005) reported a 91.7% adherence rate in their study. They also noted, however, that study included a sample of women who were more educated than most African American women. In the Hoyo et al. (2005) study, screening adherence was 83%, a prevalence lower than that reported among North Carolinian women of all races in a similar age group (Porterfield, Dutton, & Gizlice, 2003). However, this prevalence was slightly higher than the 73% reported among African American women of the same age group in a similar urban population (Rockhill, Newman, & Weinberg, 1998), and the 66% reported among African American women in the Southern United States (Coughlin, Thompson, Seeff, Richards, & Stallings, 2002).

Both studies relied on convenience sampling and differed in their definitions of adherence to cervical cancer screening. Datta et al. (2005) defined adherence as having received a Pap test within the 2 years prior to data collection, whereas Hoyo et al. (2005) defined adherence as having received a Pap test within the 3 years prior to data collection. Exact adherence to cervical cancer screening is difficult to assess, as recommendations for the timing of Pap tests has historically varied among recommending authorities. A woman may be considered adherent if she follows a cervical cancer screening schedule, based on the American Cancer Society (ACS), U.S. Preventive Services Task Force (USPSTF) and/or American College of Obstetricians and Gynecologists (ACOG) guidelines, with reasonable diligence. Knowledge of adherence to this set of guidelines is important, as these new guidelines were developed and released in March 2012.

It has been evident that there has been an increase in mass education both in rural (Earp, Altpeter, Mayne, Viadro, & O'Malley, 1995) and urban areas (Paskett et al., 1999) and reductions in financial difficulties with Pap tests covered by the majority of health insurance plans including Medicaid during the last three decades. Regardless of these reductions in educational and financial barriers, disparities in cervical cancer screening have persisted, with African American women being one of the populations that continue to bear a disproportionate burden of the disease. Although Prince George's County is the county with the most affluent population of African Americans (with more than half, 63.4%, of the country comprised of African Americans), it is not excused from cancer incidence and mortality nor is it immune to suboptimal cervical cancer screening rates or disparities. Prince George's County still ranked 15 out of 24 counties for the socioeconomic status of its population (Robert Wood Johnson Foundation & University of Wisconsin Population Health Institute, 2015). While the cervical cancer mortality rate in other counties have been falling, Prince George's County is the only county that has not met the Healthy People 2.2 objective, and for which the cervical cancer death rate has remained stable. Thus, although African American women are getting screened for cervical cancer at rates comparable to White women, the disproportionate burden of cervical cancer in African American women still exists. Identifying opportunities to improve Pap test screening utilization and adherence are critical to cervical cancer prevention and control (Bynum et al., 2014; DeSantis et al., 2013).

**Role of the Pap Test in Cervical Cancer Control.** Fortunately, cervical cancer is one of the most preventable cancers (American Cancer Society, 2015a). In the late 1930s, the Pap test was developed to detect abnormal changes in cervical cells (Kaiser Family Foundation, 2013). The Pap test is an essential part of a regular gynecologic exam and is

performed to collect cervical cells for evaluation. When a woman has a Pap test performed, she is positioned on an exam table and a speculum is gently inserted to open the vagina. The speculum allows the physician or nurse to view the cervix and upper vagina. Once the physician can see the cervix, a cervical brush and/or wooden scraper of some combination is used to collect the cells. While the technique is a little different depending on the device chosen, in general, the physician will gently rotate the device in the endocervix (the cervical canal) and the ectocervix (the portion of the cervix extending into the vagina) to collect squamous and glandular cells (National Cervical Cancer Coalition, n.d.).

There has been an evolution in cervical cancer screening guidelines over the years, the newest iteration of which was published in 2012 (The American College of Obstetricians and Gynecologists, 2012). There are three key groups that make policy recommendations: the American Cancer Society along with the American Society of Colposcopy and Cervical Pathology and the American Society of Clinical Pathology; the U.S. Preventive Services Task Force (USPSTF); and the American College of Obstetricians and Gynecologists (Centers for Disease Control and Prevention, 2012b; U.S. Preventive Services Task Force, 2014; U.S. Preventive Services Task Force & Agency for Healthcare Research and Quality, 2014). The consensus between the three groups regarding general recommendations for average risk women<sup>1</sup> include the following:

- Start screening at age 21 regardless of sexual history
- Screen ages 21 and up by cytology (Pap test) every three years
- Begin HPV co-testing with Pap test at age 30
- Screen by HPV/Pap co-test every 5 years from ages 30-65

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<sup>1</sup> Women with no history of high-grade precancerous cervical lesions or cervical cancer, no in utero exposure to diethylstilbesterol, immunocompromise, and is not HIV positive.



- Stop testing at age 65 with adequate screening history<sup>2</sup>
- Follow screening guidelines regardless of HPV vaccine status

If detected at the pre-cancer stage, a woman can be treated before the cancer develops with a 100% success rate (Medline Plus Medical Encyclopedia, 2014). If detected at the earliest cervical cancer localized stage, a woman's relative five-year survival rate is 92.4% (NCI SEER, 2015). Healthy People 2020 have prioritized increasing screening rates (U.S. Department of Health and Human Services, 2015). The long-term goal is for 93% of female patients ages 21-65 to receive a Pap test at least once every three years by the year 2020 and to increase the proportion of women who are counseled by their providers about Pap tests screening rates from the 2008 rate (age adjusted to the year 2000 standard population) of 59.8% to 65.8% in 2020 for females aged 21 to 65 years (U.S. Department of Health and Human Services, 2015).

The availability of Pap tests have greatly benefited society, both in developed and developing countries. It can prevent cervical cancer by allowing clinicians to identify and remove precancerous lesions before they develop into cancer. It can also identify cancer early in the course of the disease when treatment is more effective and the chance of recovery is high (U.S. Preventive Services Task Force, 2014; U.S. Preventive Services Task Force & Agency for Healthcare Research and Quality, 2014). Over the last 50 years, Pap tests have significantly reduced the incidence and mortality rates of cervical cancer in the United States (NCI SEER, 2015), reducing cervical cancer deaths by 75% between 1955 and 1992 (University of Southern California Norris Cancer Hospital, 2009). Cervical cancer screening via the Pap test has the best cost-benefit profile of all the forms of cancer screening from a

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<sup>2</sup> 3 consecutive negative cytology, or two negative co tests within 10 years with the most recent test performed within 5 years.

public health perspective. According to health economists, an intervention is cost-effective if it can save one year of life for less than \$50,000 (Centers for Disease Control and Prevention (CDC), 2008); Pap tests save one year of life for only \$5,392 (CDC, 2008). Largely caused by a virus, cervical cancer also has clear risk factors (sexual contact), and the natural progression of the disease is that it normally spreads slowly over a number of years therefore giving more time for the screening program to catch it early. Therefore since cervical cancer is preventable, adverse effects and treatment costs can be avoided through consistent screening.

The Pap test is an effective screening mechanism in reducing morbidity and mortality for cervical cancer. In a National Institutes of Health consensus statement on cervical cancer (National Institutes of Health, 1996), it was reported that despite recognized benefits of Pap test screening, substantial subgroups of American women have not been screened or are not screened at regular intervals. Reasons for nonparticipation in screening must be determined for populations known to be under-screened, specifically ethnic minorities, the elderly, the uninsured, and the poor (National Institutes of Health, 1996; Centers for Disease Control and Prevention, 2012a). The first step in understanding reasons for nonparticipation requires the examination of factors affecting a woman's intention to screen for cervical cancer.

**Role of the Human Papillomavirus Vaccine in Cervical Cancer Control.** Aside from the Pap test, another preventive measure that can be taken to minimize one's risk for cervical cancer is to get immunized with the HPV vaccine (Centers for Disease Control and Prevention, 2012c; CDC, 2012c). The Advisory Committee on Immunization Practices (ACIP) recommends a series of three HPV4 or HPV2 vaccines for females and males preferably between the ages of 11 and 12, or up to the age of 26 if not previously vaccinated

(Markowitz et al., 2014). The current 2012 National Cervical Cancer Screening guidelines recommend that women between the ages of 21 and 65 should have a Pap test every 3 years, or if they opt to have the test done less frequently, women between the ages of 30 and 65 should have a Pap test and a HPV DNA test every five years (U.S. Preventive Services Task Force, 2014; U.S. Preventive Services Task Force & Agency for Healthcare Research and Quality, 2014). Cervical cancer is very curable if caught early during its' onset, hence the reason why the Pap test has been extremely successful in decreasing the incidence and mortality rate in women who adhere to those screening guidelines. Because the HPV vaccine is fairly new (with Gardasil, the HPV vaccine made by Merck & Company, first licensed for use in June 2006), its' effect on reducing cervical cancer rates cannot be estimated yet (CDC, 2012c).

In terms of cervical cancer prevention, it has been suggested that African American women are less accepting of the HPV vaccine (Scarinci, Garces-Palacio, & Partridge, 2007). A study that evaluated the acceptability of the HPV vaccine among Latinas and African American women found that African American women were more skeptical about the effectiveness of the vaccine and its' possible side effect (Scarinci et al., 2007; Strohl et al., 2015; Watkins, Reitzel, Wetter, & McNeill, 2015). The women also indicated that being vaccinated could encourage risky sexual behaviors among women who perceived themselves as being immune from HPV (Scarinci et al., 2007). Another barrier to the acceptability and use of the HPV vaccine in the African American community is the lack of knowledge about the Human Papillomavirus and the HPV vaccine. A study conducted by Strohl and colleagues (2015) demonstrated that most middle-aged African American had low knowledge of HPV, cervical cancer, and the HPV vaccine (Strohl et al., 2015). In another

study, it was found that older age, lower education, no family history of cancer, and a stronger reliance on God for good health were predictors of a lack of awareness among church-going African American women (Watkins et al., 2015).

### **Religious Involvement and Churches**

One important part of African American culture is religious involvement (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002; Taylor et al., 2004). African American culture is often characterized by the enduring influence of religion and family (Berry & Blassingame, 1982). Within the African American community, the role of religion and the church have a long history and tradition of providing support and leadership (Giger, Appel, Davidhizar, & Davis, 2008; Lincoln & Mamiya, 2001). Much research has been devoted to the role of religion in African American families, politics, values, and traditions (Giger, Appel, Davidhizar, & Davis, 2008; Lincoln & Mamiya, 2001).

African Americans have the highest percent of religious affiliation of any other groups in the United States; 87% describe themselves as belonging to a religious group (Sahgal & Smith, 2009). Religious involvement, which encompasses both religious beliefs and religious behaviors (Roth et al., 2012; Lukwago et al., 2001; Holt et al., 2005), is also relatively high in the African American population. According to a report by the Pew Research Center, 76% of African Americans pray daily as compared to 58% of the rest of the population and 53% of African Americans attend worship services at least once a while, whereas in the rest of the population, only 39% attend as frequently. African American women have especially high rates of religious commitment as 84% report religion as being

very important and 59% attend worship services at least once a week (Sahgal & Smith, 2009; Taylor et al., 2004).

### **Church-Based Cancer Prevention Programs Targeting African Americans.**

Religion plays a big role in the African American community, making it an important aspect to consider and incorporate in health interventions centered on this community. According to Blocker and colleagues (2006), the African American church is a promising site for health promotion activities (Blocker et al., 2006). They are often the most visible, respected, and heavily frequented institutions in African American communities (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002; Taylor et al., 2004; Campbell et al., 2000; DeHaven et al., 2004).

Religious organizations such as churches are seen as not only a place for seeking spiritual guidance and social interactions, but also a force in political welfare and social action. The church is seen as a viable place to reach and educate African Americans as they have looked to the church for leadership in areas beyond spirituality (Holt et al., 2009a). Religion and spirituality are most often sought after for serious health conditions including cancer (Dessio et al., 2004).

Working with faith-based communities is not a new strategy; many initiatives and programs developed have shown promise in modifying parishioner's health behaviors in church settings (Duan, Fox, Derose, & Carson, 2000). For example, a study that was carried out in Los Angeles by Duan and colleagues (2000) provided promising support for using churches as a venue for health promotion messages of regular cancer screenings (Duan et al., 2000). At their year 1 follow up, significantly more baseline adherent participants had maintained the target behavior as compared to the control group not receiving phone

counseling. There was also a notable uptick of mammography screenings in participants who were non-adherent at baseline, although the increase was not statistically significant (Duan et al., 2000). Within the last decade, there has been a growing body of research on faith-based cancer control interventions (Allen et al., 2014; Holt et al., 2014a; Holt et al., 2014b; Lopez & Castro, 2006; Wasserman et al., 2006; Katz, Kauffman, Tatum, & Paskett, 2008; Matthews, Berrios, Darnell, & Calhoun, 2006), such as breast cancer (Duan et al., 2000; Darnell, Chang, & Calhoun, 2006), cervical cancer (Haynes, Escoffery, Wilkerson, Bell, & Flowers, 2014); liver cancer (Juon et al., 2008), colorectal cancer (Holt et al., 2011; Holt et al., 2012), and prostate cancer (Saunders et al., 2015; Holt et al., 2014a; Saunders et al., 2013; Holt et al., 2009b).

When it comes to reaching the African American population, the church has been a trusted and familiar setting to deliver health interventions (Paskett et al., 1999). Church members view that good health is a gift from God, and often use faith and trust in God as a way to cope with health problems and treatments (Matthews et al., 2006). An evaluation of a faith-based breast and cervical cancer screening intervention among African American women found that incorporating aspects of spirituality and religion in the health intervention enhanced participants' health (Matthews et al., 2006). Health interventions in the church have been successful because the church plays a central role in the African American community, they believe that there is a strong link between faith and health, and because bringing health education to people within their belief context increase the efficacy of the intervention (Kotecki, 2002).

There has been a host of church-based cervical cancer interventions with the Hispanic and Latino populations (Allen et al., 2014; Lopez & Castro, 2006; Wasserman et al., 2006),

but very few with African American women. Amongst them is an intervention originally proven to be successful among the Latino community, entitled *With Love We Learn* (WLWL), which was modified and adapted for African American women (Haynes et al., 2014). In this particular case study conducted by Haynes and colleagues (2014) where a cervical cancer education program was adapted and disseminated in two African American churches, evaluations during the pilot phase revealed that the program was well received by church leaders, trainers and program participants (Haynes et al., 2014). This project employed a collaborative approach in which the curriculum and education materials from a similar Latino targeted program were adapted in partnership with church leaders and parishioners for the African American faith-based community.

In another study conducted by Davis and colleagues (1994) that examined the efficacy of a church-based model of social influence in improving access and participation in cervical cancer prevention programs in minority women in Los Angeles, results yielded high rates of participation, as well as buy in from pastors and lay health leaders (Davis et al., 1994). Conclusions from this program which targeted female parishioners 21 years of age and older supported the notion that using indigenous sources of social support can increase uptake of health behaviors.

One way of strengthening cervical cancer prevention and early detection programs, suited to the culture of African American women, may be to include spiritual-based content (Winett et al., 1999; Holt, Kyles, Wiehagen, & Casey, 2003). This is especially the case when working through churches. Typology of religious orientation has previously been used to characterize church-based interventions (Winett et al., 1999). Interventions that are considered Level 1 use the church as a venue for recruitment. Level 1 interventions tend to

have program messages that are secular in nature. Level 2 interventions are when health care professionals implement secular interventions through the church. In Level 3, instead of traditional health care professionals, it is through lay individuals that these similar secular interventions through the church are delivered. Lastly, a Level 4 intervention is when interventions intentionally integrate religious or spiritual content such as the use of relevant scripture passages or religious themes. Examples of religious themes include, for example, taking care of the body, which is a gift from God or supporting one another's health through the fellowship of the church (Winett et al., 1999; Holt et al., 2003a; Holt, Lukwago, & Kreuter, 2003; Holt et al., 2009c). Spiritually-based cervical cancer prevention and early detection interventions can therefore be created by putting health in a spiritual context, ultimately using important spiritual themes to frame the cancer educational messages. It is these Level 4 interventions that are underrepresented in the church-based health promotion and intervention literature.

**Religiosity vs. Spirituality.** In this dissertation study, the term *spiritually-based*, as opposed to *religiously-based*, was used (except when summarizing the work of others, where their terminology was retained). There has been much discussion over the definitions of religiosity and spirituality (Zinnbauer et al., 1997). In one example, religion has been operationalized as “an organized system of beliefs, practices, rituals, and symbols,” while spirituality has been defined as “one’s transcendent relationship to some form of higher power” (Thoresen, 1998, p. 415). Within this context, spirituality could be seen as a broader construct than religiosity, where religiosity is a component of spirituality. In another example, religiosity involves institutionalized doctrine that inhibits people and spirituality



involves inner emotions and is characterized by freedom (Koenig, McCullough, & Larson, 2001). In this sense, religiosity is seen as distinct from spirituality.

Although it is recognized that these terms are distinct yet overlapping (Musick, Traphagan, Koenig, & Larson, 2000; Holt et al., 2006), and that the approach used in this dissertation study did involve religious concepts, this study also had the potential to involve broader concepts (e.g., balance of health body, mind, and spirit) and thus, justified the term spirituality. Previous research has shown that church-attending African Americans view spirituality as similar to, but less structured and behavioral in nature than religiosity (Holt et al., 2006). Their definitions of spirituality were also not as heavily linked with ideas of transcendence and the metaphysical as may be those of the general public. Furthermore, findings from Holt and colleagues (2006) notably reported that the church-attending African American community often uses the term spiritual rather than religious to refer to the approach they used, similar to the one that was adopted in this dissertation study (Holt et al., 2006).

### **Health Information Technology: Incorporating SMS Text Messaging**

Mobile phones are a ubiquitous part of our everyday lives. By the end of 2011, there were approximately 6 billion mobile subscriptions that accounted for nearly 87% of the world's population (Bender, Yue, To, Deacken, & Jadad, 2013). Rapid technological advances have led to the emergence of smartphones that combine the voice and SMS text messaging functions of cell phones with powerful computing technology that can support third-party applications, Internet access, and wireless connectivity with other devices (Bender et al., 2013). About 85% of adults in the United States, including the majority of African Americans, own a cell phone and 53% own a smartphone (Fox, 2012).

SMS text messaging is one of the most popular and prevalent mobile phone activities today, with over 80% of all adults sending and receiving text messages (Smith, 2013; Head, Noar, Iannarino, & Grant Harrington, 2013). “Texting” is part of everyday lives and allows for convenient access to audiences who can readily obtain messages on their own time (Aldoory, Yaros, Prado, Roberts, & Briones, 2016; Bock et al., 2012; Cole-Lewis & Kershaw, 2010; Kharbanda et al., 2011). Due to prevalence and potential effectiveness, the U.S. Department of Health and Human Services called for more SMS text message interventions that address chronic disease (Greene, 2011; Aldoory, Yaros, Prado, Roberts, & Briones, 2016). By reaching African American women through a channel that they are already using on an everyday basis, health text messages reduce the burden on these women to alter their routine to obtain health information (Fjeldsoe et al., 2009; Smith, 2011).

**Active Users of SMS Text Messaging.** With respects to SMS text messaging, there are several groups that text on a daily basis at higher-than-average levels (Smith, 2011). Based on cell phone owners who use SMS text messaging among a sample of 2,277 adults (age 18 and older) who were telephone interviewed by Princeton Survey Research Associates International from April 26 to May 22, 2011, the average number of SMS text messages sent or received on a normal day is approximately 41.5, with the median user sending or receiving 10 SMS text messages per day. Women send and receive SMS text messages more frequently (M=42.0/day; Mdn=15/day) than men (M=40.9/day, Mdn=10/ day). Besides African Americans sending and receiving SMS text messages on a more frequent basis (M=70.1/day; Mdn=20/day) than non-Hispanic Whites (M=31.2/day, Mdn=10/ day) (Smith, 2011), young adults between the ages of 18 to 29, as another example, are the most avid texters. Whereas middle-aged adults between the ages of 30 to 49 send or receive an average

of 27 SMS text messages on a normal day (Mdn=10/day), the group of young adults astoundingly send or receive an average of 87.7 SMS text messages on a normal day (Mdn=40/day). Older adults report using SMS text messaging on a less frequent basis. For adults 50 to 64 years of age, the average number of SMS text messages sent or received on a normal day is approximately 11.4 (Mdn=3/day). Seniors 65 years and older send and receive an average of 4.7 SMS text messages on a normal day (Mdn=2/day). Although the use of SMS text messaging decreases by age group, it is evident that a majority (73%) of American adults still use this mobile-based technology to communicate. The higher-than-average levels of SMS text messaging in women (M=42.0/day; Mdn=15/day) and African Americans (M=70.1/day; Mdn=20/day), as well the indication that most Americans across all age-groups still engage in some frequency of SMS text messaging (for those between the ages of 18-64:  $M \geq 11.4$ /day;  $Mdn \geq 3$ /day), suggest the potential suitability of delivering a SMS text messaging-based health intervention to African American women ages 21 to 65.

### **SMS Text Message-Based Interventions: A Strategic Communication Channel.**

In considering the use of SMS text messages as a delivery strategy in interventions supporting health behavior change, researchers must, however, also consider some of the barriers and limitations that come along with it. Technology factors have been found to have a greater impact on the intention to use SMS text messages in several interventions (Corneille, Hall-Byers, Clark, & Younge, 2015; Ceccuci, Peslak, & Sendall, 2010). Greater uptake and acceptability were observed among individuals who were already using mobile service to receive other types of information, who felt confident in their ability to use the service, and who thought that it was beneficial (Corneille et al., 2015; Ceccuci et al., 2010). The more complex the system, the less likely it was to be adopted by participants. Factors

that did not affect participants' buy-in into the SMS text messaging intervention were privacy and security concerns (Corneille et al., 2015).

The acceptability of a SMS text messaging intervention for delivery and access to cancer health information was also explored in a separate study conducted by Schoenberger and colleagues (2015). Through predominately African American churches, this study conducted focus group interviews among health ministry leaders and congregation members (Schoenberger, Phillips, & Mohiuddin, 2015). The discussions identified illiteracy, age limitation, cost (for those who did not have unlimited text messages), lack of credibility, and the need for tailored messages as potential barriers to SMS text message-based interventions.

While there are certainly some barriers and limitations to consider, there are also a handful of advantages to researchers of a SMS text message-based intervention. Due to the widespread use and low cost of this technology, it pervades all age groups and many cultures and socioeconomic backgrounds, including in developing countries (Nhavoto, Gronlund, & Chaquilla, 2015). It allows communication across geographic boundaries and reach people directly where they are located (Shaw et al., 2013). In particular, SMS text messaging is a widespread technology that has been shown to be effective at reaching minority and traditionally hard-to-reach populations, across a multitude of health topics such as STI prevention, breast and prostate cancer early detection, physical activity, and dietary behaviors and that has allowed researchers to truly reach participants "where they are" (Cole-Lewis & Kershaw, 2010; Fjeldsoe et al., 2009; Le et al., 2015; Napolitano et al., 2013; Herring et al., 2014; Joseph et al., 2015; Valle et al., 2013; Laranjo et al., 2014; Wen et al., 2014).

Further benefits to SMS text message-based interventions include convenience to the participants and the potential for the programs to be more cost-effective in the long run (Fry

& Neff, 2009). The use of SMS text messaging interventions can minimize participant burden associated with accessing and obtaining the intervention information and materials. For example, such programs could decrease participants' burden of not having to attend face-to-face intervention sessions and would allow the participants 24-hour access to intervention materials. Combined with a spiritually-based approach, mobile phone technology and SMS text message-based programs have the increased potential to serve as strategic intervention mediums to improve disparities in health outcomes for African American women.

### **Health-Related SMS Text Messaging Interventions for Minority Populations.**

Literature surrounding health information technology has shown that this mode of health intervention delivery is feasible and acceptable and that SMS text messages are a promising strategy for motivating health behavior change or supporting health behavior change interventions (Le et al., 2015, Cole-Lewis & Kershaw, 2010; Fjeldsoe et al., 2009; Napolitano et al., 2013; Herring et al., 2014; Joseph et al., 2015; Valle et al., 2013; Laranjo et al., 2014). In particular, several studies have suggested that SMS text message-based health interventions may especially be impactful for minority populations and in reaching traditionally hard-to-reach populations (Nhavoto et al., 2015; Wen et al., 2014; Shaw et al., 2013). In one study, feasibility and perception of supportive SMS text messages for postpartum depression were explored (Broom, Ladley, Rhyne, & Halloran, 2015). Low-income racial and ethnic minority women (48% African American, 8% Non-Hispanic White, 2% Mixed-Race) in this study received four SMS text messages per week for six months and it was found that using SMS text messages were feasible and well-accepted among this group. Similarly, in a postpartum smoking relapse prevention intervention (Txt2Commit) that focused on inner-city African American, White, and Hispanic women and their personal

needs, the use of SMS text messages were found feasible (Wen et al., 2014). In this smoking cessation intervention, three proactive messages per day were delivered for a month after birth and included crave and lapse user initiated message functions. The developmental process for this study suggested that the application of theory and best practices in the design of SMS text messaging cessation interventions was not only feasible, but also necessary for ensuring that similar programs are evidence-based and user-centered. In a diabetes support intervention, entitled Self-Management Support for Blood Glucose (SMS4BG), SMS text messaging provided prompts around diabetes education, management, and lifestyle factors (Dobson et al., 2015). Participants, 17 to 69 years of age in this 3-month pilot study, reported positive impacts of the intervention on their diabetes and health behaviors, and showed significant decreases in their HbA1c from baseline.

**Health-Related SMS Text Messaging Interventions in the African American Community.** A number of previous studies have used SMS text messaging to promote a variety of health-related outcomes among African Americans. Some of these SMS text messaging interventions have focused on sexual health and were able to provide findings that substantiate the high ownership of cell phones and frequent use of SMS text messaging in the African American community, as well as the benefits and effectiveness of employing such programs in support of health promotion and behavioral change interventions. In one sample of urban women recruited from a STI clinic (87% African American), cell phone use was nearly universal (Samal et al., 2010). Seventy-nine percent of the sample reported using SMS text messaging, and 60% responded favorably to receiving health information via cell phones or the Internet. Similarly, in an alternate study of 102 African American women between the ages of 18 to 25 who were recruited from the waiting room in an inner-city Health

Department STI clinic, 89% indicated that they owned their own mobile phone, with the median number of SMS text messages being 80 sent in a day (among those who reported less than 1000 sent messages per day) (Broaddus, Marsch, & Fisher, 2015). In this two-phased study designed to measure participants' perceptions of the risks and benefits of a SMS text message-based sexual communication intervention, and a traditional small-group intervention (both based on an evidence-based intervention designed for young adult African American women), both qualitative and quantitative findings suggested that mHealth interventions can be more convenient for participants and mitigate the greater risk of potential social stigma associated with face-to-face programs. However, within this sample of African American women at risk for STIs, there was not a clear preference for intervention modality used to deliver intervention content regarding sexual safety negotiation. Amongst this group, there were approximately an equal number of participants who indicated a preference for the face-to-face, group-based intervention as did the text message-based intervention. Additionally, the women did not significantly differ in terms of their willingness to participate in the two intervention types, although trends in the data did suggest the possibility of greater willingness for the text message-based intervention. Benefits of both intervention modality were further highlighted in this study. The major benefit of the group-based intervention was the ability to talk with and learn from others who may have had similar experiences and could provide real world examples for negotiating sexual safety. The benefits of the SMS text message-based intervention revolved around the convenience and ubiquity of SMS text messaging, avoidance of negative social judgments by group members, and greater privacy protections afforded by passwords and personal control of the mobile phone. These results were somewhat surprising, as the study team had expected

greater levels of concern with privacy of cell phones and security of confidentiality within this modality given the concerns raised within the research community. In a research study conducted in San Francisco, Levine and colleagues (2008) were actually able to report on the effectiveness of a SMS text message-based intervention at reaching high-risk, predominantly African American adolescents (Levine, McCright, Dobkin, Woodruff, & Klausner, 2008). This SMS text message-based intervention was used to dispense information and resources for STIs, HIV, and pregnancy prevention.

A number of other studies have suggested how SMS text message-based interventions may especially be impactful for minorities and in reaching traditionally hard-to-reach populations (Nhavoto et al., 2015; Wen et al., 2014; Shaw et al., 2013; Trent, Thompson, & Tomaszewski, 2015). In a culturally-relevant physical activity intervention that targeted African American women, messages were delivered three times per week via Facebook and through SMS text messaging (Joseph, Keller, Adams, & Ainsworth, 2015). Results from this pilot study showed an increase in light/moderate physical activity, enhanced psychosocial outcomes, participant satisfaction and a decrease in sedentary lifestyle among their participants. Promising results were also evident in another study that utilized SMS text messaging to enable ongoing communication with African American women who were participating in a weight management program within the Chicago area (Gerber, Stolley, Thompson, Sharp, & Fitzgibbon, 2009). The ninety-five African American women (30 to 65 years of age) who agreed to participate in this portion of a larger weight management study received an average of three SMS text messages per week (with over 4,500 messages sent during the first four months which included both general and personal messages). The participants were offered opportunities to control the time, frequency, and type of messages



that they received and ultimately expressed generally positive attitudes toward the incoming SMS text messages, with only one participant declining to continue after enrollment.

Feasibility and acceptability of a SMS text messaging intervention were also evident in another study that focused on acute decompensated heart failure in a largely African American population (Nundy et al., 2013). Study messages included self-care reminders, patient education on diet, symptom recognition, and health care navigation. Similar to the previous studies, this intervention also showed a high rate of satisfaction and preliminary evidence of improvement in the behavioral outcome of heart failure self-management.

Feasibility, acceptability, and short-term preliminary efficacy of using SMS text messages to improve clinic attendance for moderately long-acting reversible contraception appointments among young urban, largely African American, adolescent girls and young adult women (13 to 21 years of age) using Depo-Provera were also found in the DepoText Pilot Intervention (Trent et al., 2015).

Yet other studies have yielded results that were not statistically significant or have yet to report their findings. For example, in one study on weight control among racial and ethnic minority women, daily SMS text messages for self-monitoring tailored behavioral goals such as 10,000 steps per day were sent to the participants. Although there was a trend toward greater text messaging adherence being associated with greater percent weight loss ( $r=-.36$ ;  $p=.08$ ), it was reported that this did not reach statistical significance (Steinberg, Levine, Askew, Foley, & Bennett, 2013). In another study that focused on improving hypertension medication adherence in African Americans through a SMS text message reminder-based system, study findings were still pending (Buis et al., 2015).

### **Cancer-Specific SMS Text Messaging Interventions for Minority Populations.**

SMS text messaging interventions that focus on cancer prevention have appeared within the last few years, although these interventions do not necessarily focus or include representation from the African American community. For example, in a study conducted by Kratzke and colleagues (2014), 546 college women in New Mexico were surveyed about their breast cancer prevention information-seeking and interest in smartphone applications (Kratzke, Amatya, & Vilchis, 2014). Over half of the participants (54%) desired a breast cancer prevention mobile application. In addition, in a separate study by Kratzke and colleagues (2012) where a convenience sample of 157 women were surveyed at an imaging center in rural New Mexico, results showed that approximately 87% of the women indicated that they used a cell phone, 47% of them indicated that they used SMS text messaging, 36% were interested in receiving SMS text messages about breast cancer prevention, and 37% had an interest in receiving mammogram reminder through SMS text messages (Kratzke, Wilson, & Vilchis, 2012).

In a different study, Dang and colleagues (2013) surveyed 905 Hispanic women attending a health fair in Los Angeles about their technology use, mammography use, and breast cancer knowledge (Dang, Estrada, Bresee, & Phillips, 2013). Ninety-two percent were foreign-born, most had completed either some high school or elementary education (77%), and most (62%) were uninsured. The majority (67%) spoke and read only Spanish. 60% of the sample, aged 40 years or older, indicated that they have had a recent mammogram. About 70% of the women reported that they have a mobile phone, 65% use SMS text messaging daily, and almost half (45%) wished to receive a mammogram reminder by SMS text.

Similar to the above research, Lakkis and colleagues (2011) conducted a study that focused on the uptake of mammography screening (Lakkis et al., 2011). In their study, Lakkis and colleagues (2011) compared the effects of two different types of SMS text message reminders on increasing screening mammography among women at the American University of Beirut who belonged to a health insurance plan (Lakkis et al., 2011). The women within their study sample (n=385), who had not had a mammogram in the past two years, were randomly assigned to the two groups. Members of the first group received a general SMS text message inviting them to have a mammogram and the second group received an additional SMS text message about the benefits of mammography screening. About 31% of the first group underwent a screening mammogram during the 6-month follow-up period, compared to 32% in the second group ( $p>.05$ ). The use of SMS text messages as reminders of breast self-exams has also been studied in women in Delhi, India (Khokhar, 2009). In addition to SMS text messaging, this study also reported that peer-to-peer email and social media communications could be a promising approach to encourage routine cancer screening.

Preliminary results across some more recent studies on cancer-specific SMS text messaging interventions for minority populations have shown favorable increases in their targeted behavioral outcomes. For example, in a study of younger Korean American women, a SMS text messaging program for cervical cancer screening was created to stimulate increases in knowledge and behavior pre-post intervention (Lee et al., 2014). This study, based on the Fogg's Behavioral Model (Fogg, 2009), was a 7-day SMS-based cervical cancer screening program where messages were individually tailored to each participant. The Fogg's Behavioral Model was used to identify structural and cultural barriers that prevent Korean

women from receiving a Pap test. Preliminary results showed that 23% of participants received a Pap test after the intervention.

In a study of prospectively enrolled consecutive outpatients between the ages of 18 to 80 years of age, researchers explored the effectiveness of SMS text messages in assuring the preparation-to-colonoscopy interval before bowel preparation for colonoscopy screening (Park et al., 2015). Patients in the control and intervention groups were instructed to follow the same regimen before their colonoscopy. However, individuals in the intervention group received a SMS text message reminder 6 hours before their scheduled colonoscopy. The SMS text message reminder resulted in patients from the intervention group ingesting an appropriate amount of polyethylene glycol (PEG) fluid. Notably in this study, all 5 of the patients who did not take the PEG fluid were in the control group.

To further illustrate the possible benefits of a cancer-specific SMS text messaging intervention, one can also consider the research conducted by Spark and colleagues (Spark, Fjeldsoe, Eakin, & Reeves, 2015). In their pilot single-group, pre-post-designed study, Spark and colleagues investigated whether a 6-month extended contact intervention via highly tailored SMS text messages would support long-term weight loss, physical activity and dietary behavior change in breast cancer survivors (versus usual care). Results from this study supported the feasibility, acceptability, and provided preliminary evidence on efficacy of a SMS text message-delivered extended contact intervention to promote the maintenance of weight loss and physical activity among a predominately older female subgroup. Overall, their findings suggested that extended contact might have helped to attenuate weight regain and promote the maintenance of long-term change in physical activity.

**Cancer-Specific SMS Text Messaging Interventions in the African American Community.** The number of SMS text messaging studies that focus on cancer prevention and control among African Americans remains limited. In one study of predominately African American women, findings revealed that this group was receptive to receiving SMS text messages that focus on cancer and health information (Schoenberger, Phillips, Mohiuddin, McNees, & Scarinci, 2013). This study explored the use of communication technologies and the acceptability of using mobile technology to access and receive cancer and health information among the Deep South Network for Cancer Control trained Community Health Advisors as Research Partners.

Similarly, some feasibility and positive acceptability of using SMS text messaging in a prostate cancer research project were also found for older African American men between the ages of 40 to 69 (Le et al., 2015). In the Men's Prostate Awareness Church Training project, SMS text messages were added to a men's health intervention that aimed to increase informed decision making on prostate cancer screening. Within this project, the SMS text messages served the following purposes: (1) to remind participants of upcoming workshops; (2) to serve as post-workshop message reinforcement; (3) to provide spiritual/motivational messages; and (4) to serve as a participant retention tool. Overall, the inclusion of SMS text messages in a men's health research project, particularly as a value-added element of the intervention, was found to be feasible, acceptable, and a promising avenue to reach mature African American men.

While study findings are still pending, Yuan and colleagues' work also utilized SMS text messaging as a means to reach mature African American men. Their study targeted men between the ages of 40 and 75 and aimed to improve their adherence to prostate cancer

screening. In this study, a personalized automated messaging system using a two-way rich media mobile messaging system was developed and used to send its' participants reminder and confirmation communications for making an appointment for prostate cancer screening, keeping the appointment, and reporting the test results back to the investigators (Yuan et al., 2012). This theory-based study, which aimed to increase compliance with cancer screening through a two-way rich media mobile messaging based on personalized risk assessment, also provided health promotion materials such as videos via a secured website through the use of SMS text messages.

Although the use of SMS text messaging interventions for health promotion is growing in the general population and is emerging among minorities and the medically underserved, there does not appear to be previous research using this technology to increase cervical cancer prevention among African American women, in particular a stand-alone SMS text messaging intervention that uses a spiritually-based approach. This study will provide important insights regarding the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging educational intervention in the promotion of cervical cancer prevention information for what may be an overlooked minority population and missed opportunity in health information technology research (Joseph et al., 2015; Joseph, Durant, Benitez, & Pekmezi, 2013; Davies et al., 2012; Vandelanotte, Spathonis, Eakin, & Owen, 2007; Maher et al., 2014; Norman et al., 2007).

### **Theoretical Framework: The Theory of Planned Behavior**

Azjen and colleagues' Theory of Planned Behavior (1988) is an intrapersonal level theory that evolved from Fishbein and Ajzen's original Theory of Reasoned Action (Ajzen, 1988). Ajzen added the construct of *perceived behavioral control* to account for behaviors

that were not under volitional control (Ajzen, 1991). The Theory of Planned Behavior explains the relationships between behaviors and beliefs, attitudes and intentions (Ajzen & Madden, 1986). It is centered on beliefs about behavior, norms and control, and posits that behavioral intention is the most proximal antecedent of behavior. The Theory of Planned Behavior posits that behavior is determined by *intention* to perform that behavior. *Intention* is in turn determined by the following three main constructs: *attitude*, *subjective norms*, and *perceived behavioral control* (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986).

An individual's *attitude* towards a behavior is whether they view the behavior as beneficial or not (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986). Their attitude is determined by their behavioral beliefs (i.e., their specific knowledge or anticipatory outcomes of performing the behavior), which is weighed with the evaluation of that behavior (i.e., the valence they attach to the outcomes of that behavior, whether it is good or bad). Thus, an individual who holds strong beliefs that positively valued outcomes will result from performing the behavior will have a positive attitude towards the behavior. Alternatively, a person who holds strong beliefs that negatively valued outcomes will result from the behavior will have a negative attitude.

Another main determinant of intention is an individual's *subjective norm* (i.e., one's perception of what is acceptable for that behavior) (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986). Subjective norms are determined by one's normative beliefs (i.e., what they think key individuals such as their parents, friends and important others, think about the behavior), weighed by one's motivation to comply to what these key individuals think. Thus, a person who thinks a referent thinks he or she should

perform a behavior and is motivated to meet expectations of those referents will hold a positive subjective norm. Conversely, a person who believes these referents think he or she should not perform the behavior will have a negative subjective norm, and a person who is less motivated to comply with those referents will have a relatively neutral subjective norm.

Finally, the third factor determining behavioral intention is the individual's *perceived behavioral control* (i.e., their perception of their ability to actually perform a behavior or how much power they think they have or can exert over that behavior (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986). This is a product of their control beliefs (i.e., the various factors which they believe may help or hinder their efforts to perform a given behavior), weighed by perceived power (i.e., the extent to which those identified factors can be an influence in their ability to ultimately perform the behavior). Ajzen and colleagues added perceived behavioral control to account for factors outside an individual's control that may affect intentions and behaviors. An individual's perceived behavioral control is heightened when there is an increase in the resources and opportunities that she thinks she possesses and when there is a decrease in the amount of obstacles she anticipates. Success of the Theory of Planned Behavior in explaining behavior depends on the degree to which the behavior is under volitional control (i.e., individuals can exercise a large degree of control over the behavior).

Although the Theory of Planned Behavior is an intrapersonal level theory (i.e., it deals with beliefs, attitudes, and behaviors of the actual individual), it does still have the latitude to address other individuals and recognizes the key role of key referents in an individual's attitude to a behavior and ultimately their intention to perform a behavior. In cervical cancer prevention, it is important to consider an intrapersonal level theory such as



the Theory of Planned Behavior because the ultimate goal is to try to impact the Pap test screening behavior of the individuals themselves; however it is also important to leverage the support of a (presumably) key individual in their lives (e.g., family members, friends, fellow congregation members). Furthermore, it is important to recognize that an individual does not behave independently of the wishes, thoughts, and influences of others around them. As a whole, this theory adequately addresses the individual's several sets of beliefs and involves the consideration of others who are best in positions to influence those sets of beliefs.

With regards to cervical cancer prevention, the constructs from the Theory of Planned Behavior are being considered (as opposed to just the constructs from the Theory of Reasoned Action) because the perceived behavioral control construct is particularly salient with screening for cervical cancer in the African American community. For a group where highly traditional individuals might have an external locus of control for chronic diseases such as cervical cancer (e.g., some individuals may have the attitude that "It's meant to be", "It was heaven's plans or me", or "There is nothing I can do about it... if I'm going to get it, I'm going to get it"), it is important for us to address the level of control these women have over engaging in preventive screening to mitigate their risk of getting cervical cancer later in their lives.

Another strength of framing this dissertation with the constructs from the Theory of Planned Behavior is that the theory accounts for the possibility that individuals may not always have volitional control over their behavior and that the most important aspect of behavior is the intention to perform an action and various factors that can influence behavior. The theory posits that behavioral intentions are a "measure of the likelihood that a person will engage in a given behavior" (Ajzen & Fishbein, 1980, p. 42). The stronger a person's

intention, the more likely she is to perform a behavior. The *intention* construct has been repeatedly shown to be a good behavior predictor, particularly for short-term behavior change. Though the strengths of the Theory of Planned Behavior are that each of its' constructs are clearly described and have been successfully applied across a variety of contexts, limitations worth noting include how the theory does not directly address unanticipated barriers or environmental constraints nor does it directly account for socio-demographic factors. Ajzen (1985) maintained that distal factors, such as demographic characteristics or personality traits, have no direct effects on behaviors and that such variables may "be related to behaviors if, and only if, they influence the beliefs that underlie the behavior" (Ajzen, 1985, p. 14).

**Theory of Planned Behavior and Cervical Cancer Prevention.** The Theory of Planned Behavior has been successfully used for a wide variety of behavior and in a broad range of contexts (Sutton, 1998; Conner & Armitage, 1998; Armitage & Conner, 2001). The Theory of Planned Behavior is one of the more frequently used behavioral theories in cancer prevention research (Jennings-Dozier, 1999; Linton, Porche, & Steele-Moses, 2010; Glanz, & Bishop, 2010) and was selected as the theoretical background in the current study due to its' particular focus on how the combination of attitudes, subjective norms, and perceived behavioral control can have an effect on behavioral intention (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991; Ajzen & Madden, 1986).

A number of cervical cancer studies have utilized constructs from the Theory of Planned Behavior to carry out their intervention within the African American community (American Cancer Society, 1981; Bloom, Hayes, Saunders, & Flatt, 1987; Davis et al., 1994; Ahijevych & Bernhard, 1994; Holland, Foster, & Louria, 1993; Kottke et al., 1995;

Duelberg, 1992). Two particular research investigations have examined cervical cancer screening intention and behavior using the Theory of Reasoned Action, which is a precursor to the Theory of Planned Behavior (Ajzen, 1988). First, in a study conducted by Burnett and colleagues (1994), it was found that attitudes ( $p=.007$ ) and subjective norms ( $p=.0001$ ) were related to intention to screen for cervical cancer in a sample of 229 African American and 21 Latina women (Burnett, Steakley, & Tefft, 1994). Knowledge of cervical cancer was also found to be negatively related to intention to have a Pap test ( $p=.004$ ). This study did not find relationships between intentions and demographic variables, personal history of cancer, and family history of cervical cancer. The second Theory of Reasoned Action-based study was conducted by Barling and Moore (Barling & Moore, 1996). In this study, the relationships of cervical cancer screening behaviors, knowledge, attitudes, social norms, and intentions with respect to Pap tests among a sample of 72 women volunteers from two universities in Australia were examined. Findings from this study showed that intentions were stronger than actual behaviors, with 85% indicating that they intended to have a Pap test within the next two years. Through regression analyses, the researchers also found that more positive attitudes and strong social norms significantly predicted more likely intentions to engage in a Pap screening test within the next 2 years ( $F=7.74$ ;  $p<.001$ ;  $R^2=.36$ ). Moreover, intention and age predicated actual Pap test screening behaviors, with older women more likely to have had regular Pap tests than younger women ( $F=3.45$ ;  $p<.001$ ;  $R^2=.24$ ).

Aligning with some of the findings from the above-mentioned studies, Jennings-Dozier's work (1999) also focused on exploring Pap test screening intention among African American and Latina women (Jennings-Dozier, 1999). This correlational study, to determine the empirical adequacy of the Theory of Planned Behavior to explain Pap test screening

intention, was conducted amongst a sample of 108 African American and 96 Latina adult women who were recruited from urban community-based agencies located in a large mid-Atlantic metropolitan area. Results from this investigation suggested that attitude remains one of the major determinants of cervical cancer screening behavior. It was found that a direct relationship between attitude and perceived behavioral control and intention to obtain an annual Pap test did, indeed, exist in both subgroups. For the African American subgroup, findings from this study showed that attitude ( $p < .001$ ) provided the best explanation of intention for these women to obtain an annual Pap test, followed by perceived behavioral control ( $p < .001$ ). It was also found that while the subjective norms construct did not significantly predict intention, the external variables of age and income did have indirect effects on intention.

### **CervixCheck: A Call to Explore**

Health communication programs can be developed and strengthened by framing health in a spiritual context. These spiritual themes can be identified through formative research with the priority population, and then pilot tested for feasibility, acceptability, and initial efficacy (Holt et al., 2009c). Winett and colleagues (1999) view this type of Level 4 program as a necessary but not sufficient intervention approach for continued behavior change and thus, warrants the potential integration of health information technology as a delivery mechanism (Winett et al., 1999). The development, implementation, and evaluation of this CervixCheck spiritually-based SMS text messaging pilot intervention in efforts to increase cervical cancer prevention among African American women provided important findings into what may be considered an overlooked minority population and missed opportunity in health information technology research (Joseph et al., 2015; Joseph et al.,

2013; Davies et al., 2012; Vandelanotte et al., 2007; Maher et al., 2014; Norman et al., 2007).

By using important spiritual themes to frame cervical cancer educational content and by delivering these health messages through a popular communication delivery channel for this targeted group, cancer interventions can move one step closer to being more accessible and culturally appropriate for the African American women community.

## Chapter 3: Methods

### Study Overview

African American women account for a disproportionate burden of cervical cancer incidence and mortality rate when compared to non-Hispanic White women (Bynum et al., 2014; DeSantis et al., 2013; National Cancer Institute, 2008; SEER, 2012a; SEER, 2012b). The purpose of this study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging educational intervention to increase cervical cancer awareness and Pap test screening intention among church-attending African American women who reside in the greater Maryland, Washington, D.C., and Virginia areas. who reside in the greater Maryland, Washington, D.C., and Virginia areas (with preference for those from the Prince George's County, MD jurisdiction). Relationships between socio-demographic factors, the pilot SMS text messaging intervention, health-related beliefs, and health seeking intentions of African American women to participate in Pap test screening were examined. The Theory of Planned Behavior was adapted and slightly modified to frame the examination of psychosocial variables and the intent of church-attending African American women to participate in Pap test screening. This chapter provides detailed description of the methods and procedures that were used in this study.

### Research Design

**Study Setting.** This dissertation study took place in Prince George's County, Maryland, the county with the highest percent racial/ethnic minorities in the State of Maryland (U.S. Census Bureau, 2015; U.S. Centers for Disease Control and Prevention (CDC), 2010). Prince George's County has a population of 863,420, with 9.4% of individuals living below the poverty level and 64.47% African American. Prince George's County is a

very diverse area outside of Washington, D.C., that includes both affluence and extreme poverty (U.S. Census Bureau, 2015). This Mid-Atlantic region is neither Northern nor Southern.

**Study Population.** Although eligibility criteria for this dissertation project allowed church-attending African American women (ages 21 to 65) who reside in the greater Maryland, Washington, D.C., and Virginia areas to participate, it primarily targeted individuals who reside in Prince George's County, Maryland. Religion occupies an essential place in the lives of African Americans and incorporating religious and/or spiritual content to health programs has increasingly been recognized by researchers as a means for reaching and modifying parishioner's health beliefs and behaviors (Berry & Blassingame, 1982; Giger, Appel, Davidhizar, & Davis, 2008; Lincoln & Mamiya, 2001; Sahgal & Smith, 2009; Holt et al., 2005; Holt et al., 2009a; Holt et al., 2009b; Holt et al., 2009c; Holt et al., 2014; Saunders et al., 2015; Saunders et al., 2013). The targeted age range of 21 to 65 years is based on the U.S. Preventive Services Task Force's current recommendation for cervical cancer screening (CDC, 2012a). The U.S. Preventive Services Task Force recommends screening for cervical cancer in women age 21 to 65 years with cytology (Pap test) every 3 years or, for women age 30 to 65 years who want to lengthen the screening interval, screening with a combination of cytology and HPV testing every 5 years (U.S. Preventive Services Task Force, 2012).

The leading cause of death in Prince George's County, among those age 45-64, is cancer (CDC, 2010). Though Maryland is one of the more affluent states, it is not exempt from cancer incidence and mortality nor is it immune to suboptimal cervical cancer screening rates or disparities. Cervical cancer incidence among Maryland women increased at a rate of 1.2% per year from 2007 to 2011, with the increase in incidence rates for African American

women being greater than that for White women (Maryland Department of Health and Mental Hygiene (MDHMH), 2014; Medicaid Behavioral Risk Factor Surveillance System (MBRFS), 2008). According to Maryland Cancer Registry data, the age-adjusted incidence rate (per 100,000) for cervical cancer in 2011 was 6.1 for Whites and 7.4 for African Americans in Maryland (MDHMH, 2014; MBRFS, 2008). In Prince George's County, the age-adjusted incidence rate (per 100,000) for cervical cancer in African Americans was 8.3 (Maryland Department of Health and Mental Hygiene (MDHMH), 2013; MBRFS, 2008).

For age-adjusted mortality rates (per 100,000) for cervical cancer, the rate in 2011 was 1.7 for Whites and 3.2 for African Americans in Maryland (MDHMH, 2014). The number of cervical cancer deaths from 2007 to 2011 was 17 cases for Whites and 45 for African Americans in Prince George's County (MDHMH, 2014). From 2007-2011, the total number of cervical cancer cases was 41 for Whites and 110 for African Americans in Prince George's County (MDHMH, 2014). In 2012, approximately 88% of Maryland women ages 21 to 65 years reported that they have had a Pap test within the past 3 years, below the Healthy People 2020 target of 93% (MDHMH, 2014; CDC, 2012a).

**Study Design and Sampling Plan.** This dissertation used a multiple methods approach with a non-experimental one-group pretest-posttest design with a convenience sample. This design was originally proposed because it was intended as an initial feasibility study. If this pilot study could establish feasibility, acceptability, and impact on the proposed outcomes, then the approach could then be tested in a future randomized controlled trial. Given the anticipated timeline, this study design was also selected because it allowed for the maximization of the intervention's reach by permitting as many women to participate, and to utilize the information that was shared in the pilot program, as possible. This intervention



empowered women by stimulating dialogue with peers and thus, raised awareness of cervical cancer prevention.

Study participants, across all three phases, were recruited through personal communication, as well as through the distribution of print and electronic fliers. For the most part, participants were recruited through an existing network of churches, health and women's ministries, community health advisors, and through participants from a previous cancer-based research project. Fliers were posted at local faith-based organizations and, as a strategy to enhance the recruitment process, willing Pastors and community health advisors were asked to make an announcement about the study during the church service and/or at their respective ministry meeting(s), as well as to share the electronic flyer through their respective listservs. The announcements were delivered from a script prepared by the principal investigator. The script that was provided focused on the purpose of the study and the principal investigator's contact information for individuals that were interested in participating in the study. Additional recruitment efforts included: (1) electronic flyers that were distributed to a number of varying listservs (e.g. alumni listservs from nearby universities and local sorority chapters) and (2) electronic flyers that were posted and shared using popular social media outlets such as Facebook and Twitter.

Individuals who were interested in participating in the study were then asked to directly contact the principal investigator, either by phone or email. From there, the principal investigator was able to explain the purpose of the study, eligibility criteria, confidentiality, and the voluntary nature of participation in either an oral and written format to participants prior to obtaining their commitment. Through the recruitment efforts listed above, a total of 75 church-attending African American women between the ages of 21 to 65 were enrolled in

this dissertation study. A total of 15 individuals participated across the two focus group discussions (Phase 1), another 8 participated in the cognitive response interviews (Phase 2), and 52 eligible women participated in the piloting portion of the spiritually-based SMS text messaging educational intervention to increase cervical cancer awareness and Pap test screening intention (Phase 3). The final phase (Phase 3) of this dissertation study investigated the feasibility, acceptability, and impact on outcome measures over two time points: (1) baseline and (2) immediate post-intervention.

### Conceptual Model

The following conceptual model (Figure 1) illustrates the various constructs, factors, and variables that were examined in this pilot study. The solid lines, shown below, represent the relationships that were directly measured and reported in this dissertation.

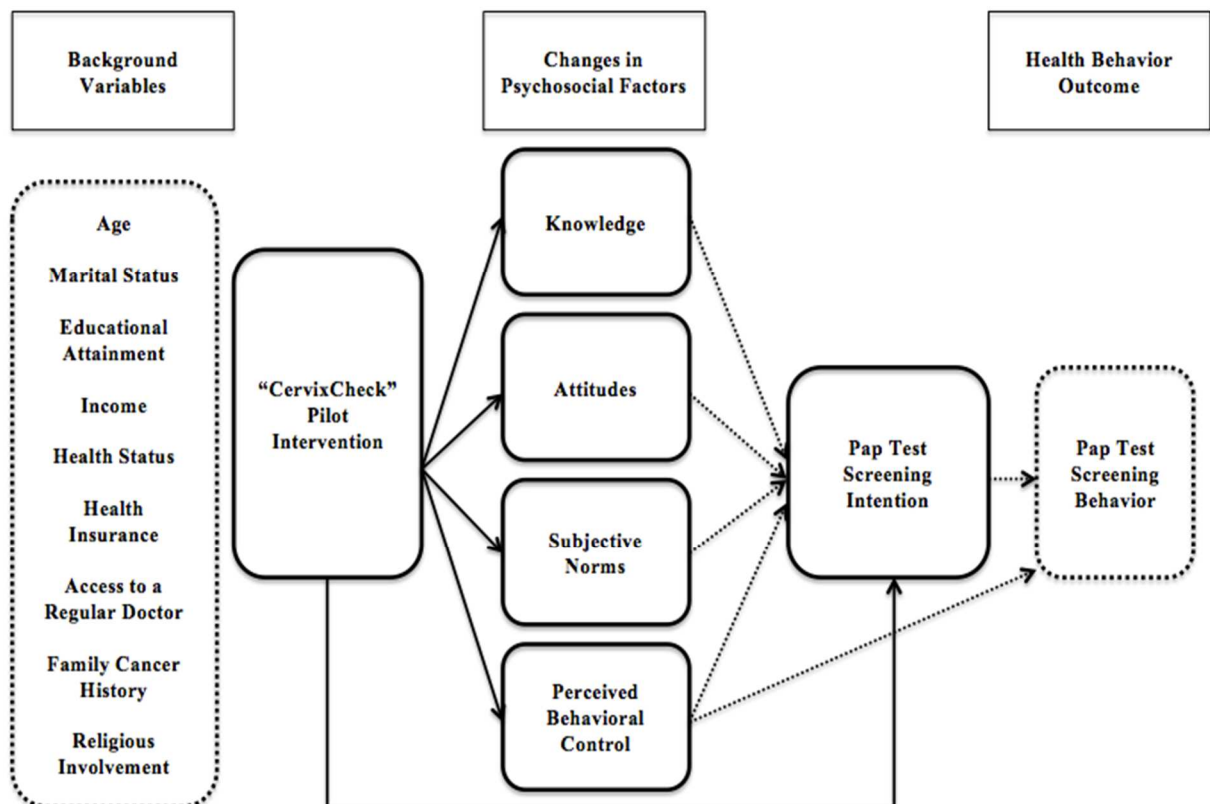


Figure 1. Conceptual Framework (Adaptation of the Theory of Planned Behavior)

## **Data Collection Procedures**

Prior to beginning the data collection process, all study personnel completed CITI training. Upon completion of CITI training, formal training sessions were held with two undergraduate research assistants for the purpose of ensuring standardization of procedures and integrity of the data. Specific practices included the review of scripts for recruitment, screening forms, seeking consent, maintaining confidentiality, and focus group, cognitive response interview, and survey administration. The semi-structured interview guides and surveys were developed based on the literature, experience of the investigators, and previous research predominately conducted with the African American population.

## **Study Activities**

**Aim 1.** Prior to intervention development, formative research was conducted through two semi-structured focus group discussions to inform the development of the spiritually-based SMS text messaging educational intervention in increasing cervical cancer awareness and Pap test screening intention in church-attending African American women. The focus groups not only qualitatively explored African American women's beliefs and attitudes about cervical cancer prevention and education, but also assisted in determining factors that needed to be considered when developing the spiritually-based SMS text messaging educational intervention aimed at increasing Pap test screening intention in church-attending African American women. Participants were asked to identify any unique factors that could serve as facilitators, motivators, and barriers in implementing a spiritually-based SMS text messaging educational intervention specifically aimed at increasing Pap test screening intention in church-attending African American women. The information from the focus group discussions helped to inform the format (e.g., frequency/timing) and content (e.g.,

messaging) for the intervention and how best to enable women to learn about, open up, and talk about a potentially sensitive topic.

The two focus group discussions were conducted with the target intervention recipients. They were limited to self-identifying church-attending African American women who were between the ages of 21 and 65 and who had indicated that they reside within Prince George's County, MD. Only individuals who had not had a past medical history of cervical cancer or hysterectomy (i.e. the surgical removal of the corpus uteri) were considered for this study. Eligible participants who were interested in participating in Phase 1 of the study had to also have been willing to discuss topics surrounding culture, technology use, and cervical cancer prevention and education.

The 15 enrolled African American women, ranging from 23 to 58 years of age, were recruited from the research team's personal networks and from current collaborations with faith-based organizations in Prince George's County. Participants were also recruited through social media (Facebook), emails sent to numerous listservs, flyers posted at churches, workplaces and campuses, and snowballing techniques during the months of February and March 2016. Those responding to the recruitment materials were screened for eligibility prior to being scheduled for one of the two focus group discussion sessions.

The two focus groups that were held were segmented by age (21-35; 36-65 years) to facilitate discussion and identify any age group differences as well as to minimize social desirability bias. The focus groups followed a semi-structured format and last approximately 90 minutes each, with time allotted for review of the study and participant informed consent; "fellowship" period that included an opportunity to socialize and partake in refreshments prior to the facilitated discussion; and wrap-up that included a summary of the focus group,

distribution of cervical cancer educational brochures, completion of a socio-demographic survey, and distribution of incentives. The principal investigator facilitated the focus group discussions and the two undergraduate research assistants served as the note-takers for the focus group sessions. Both focus group sessions were audiotaped with participants informed that they were being recorded. The facilitator explained the research aims and informed the participants that the investigators were planning to use SMS text messaging to promote cervical cancer early detection information to African American women. All participants received written information about the study and signed individual consent forms. Study participants in Phase 1 received \$15 for their involvement in the focus group discussion.

**Aim 2.** Findings from the focus group discussions informed the format (e.g. frequency/timing) and content (e.g. messaging) for the pilot SMS text messaging intervention. Methods to develop the SMS text messaging strategy also included the following: (1) review of previously published literature, (2) examination of successful SMS text message interventions presented at national and local conferences and events (e.g. 2015 Society of Behavioral Medicine Conference, NIH mHealth listserv, research forums), (3) review of existing spiritually-based SMS text messages, (4) review of health-related Biblical scripture, and (5) recommendations from a community advisory board. Frequency and timing of the SMS text messages that will be delivered were determined by the preferences and needs of the target audience. SMS text message content was determined prior to initiation of the pilot study. A total of 18 short project-specific SMS text messages that were health-related and spiritually-themed were developed by the principal investigator and initially reviewed by members on an community advisory board. Each draft message was 2-3 sentences long to make it suitable for delivery via a text message.

Once the spiritually-based cervical cancer SMS text messaging educational pilot intervention was developed, cognitive response interviews (n=8) were used to assess the content of the SMS text messaging library, to ensure that the content was acceptable and understandable, particularly for church-attending African American women ages 21-65. Inspirational, spiritual messages were also reviewed for appropriateness and contextual meaning during this phase (Phase 2) of the study. Similar to the eligibility criteria for the focus group discussions, the cognitive response interviews were limited to self-identifying church-attending African American women who were between the ages of 21 and 65 and who had indicated that they reside within Prince George's County, MD. Again, only individuals who had not had a past medical history of cervical cancer or hysterectomy were considered for this study. Focus group participants were ineligible to participate in Phase 2 of this dissertation study.

Participants for the cognitive response interviews were recruited and screened for eligibility, as in the focus groups. Participants were expected to meet in person at an agreed-upon location and time of convenience. This often meant meeting in the community during the evenings and weekends to enable those who worked during the day to participate. They made appointments with the principal investigator to read content from the SMS text messaging library and answer open-ended questions about what they read (cognitive response technique). Cognitive response procedures involve intensive one-on-one interviews in which participants may be asked to think aloud about the content they have read, paraphrase the information, and respond to other planned inquiries and probes (Forsyth & Lessler, 1991; Sudman, Bradburn, & Schwartz, 1996; Holt et al., 2009d). Recommendations were then made for the revision of difficult or offensive material. This testing occurred at

various locations throughout the community, depending on the transportation needs of the participant.

Each one-on-one cognitive response interviews lasted approximately 1 hour where in-depth discussions of each of the draft messages took place. Towards the end of each of the cognitive response interviews, participants were also asked to take a look at the SMS text messaging library as a whole. At this point, each participant was asked to rank and discuss her ordering preference of the draft messages. They also had the option to “drop” any draft messages that they did not feel appropriate or relevant and/or to “add” any additional messages that they would like to see included in the library. Based on suggestions from the participants, the research team revised the texting curriculum following findings from the cognitive response interviews. Participants in Phase 2 received \$15 for their involvement in the cognitive response interviews.

In addition to conducting the cognitive response interviews, initial usability testing of the pilot program was also completed during Phase 2 of the study. During this time, the principal investigator and the two research assistants conducted the initial usability testing of the pilot program. During the initial usability testing, the principal investigator and the two research assistants tested the revised draft system and used this time to identify and correct some of the programming issues that come up. Although the initial usability testing of the revised draft system was primarily completed by the principal investigator and the two research assistants, an invite to review and provide additional feedback and recommendations on the frequency, timing, and general appearance and content of the spiritually-based cervical cancer SMS text messaging educational pilot intervention was also extended to members on the community advisory board and to the participants who previously participated in the

focus group discussions during Phase 1. The spiritually-based cervical cancer SMS text messaging educational intervention was thus, finalized through an iterative community-engaged process.

**Aim 3.** Once the spiritually-based cervical cancer SMS text messaging educational intervention was finalized, Phase 3 aimed to have it pilot tested and evaluated for its' feasibility, acceptability, and initial efficacy to increase cervical cancer awareness and Pap test screening intention among church-attending African American women who reside in the greater Maryland, Washington, D.C., and Virginia areas (with preference for those from the Prince George's County, MD jurisdiction). This study utilized a non-experimental one-group pretest-posttest research design with a convenience sample.

***Recruitment and Sample Size.*** A total of 52 church-attending African American women between the ages of 21 and 65 were recruited for Phase 3 of this dissertation study. As previously noted, recruitment efforts included personal communication, as well as the distribution of print and electronic fliers. For the most part, participants were recruited through an existing network of churches, health and women's ministries, community health advisors, and through participants from a previous cancer-based research project. Individuals who were interested in participating in the study were then asked to directly contact the principal investigator, either by phone or email. From there, the principal investigator was able to explain the purpose of the study, eligibility criteria, confidentiality, and the voluntary nature of participation in either an oral and written format to participants prior to obtaining their commitment.

***Criteria for Sample Selection: Participant Eligibility.*** Phase 3 of this dissertation study was limited to self-identifying church-attending African American (Black) women who



are between the ages of 21 and 65 and who indicate that their residency is within the greater Maryland, Washington, D.C., and Virginia areas. There was a recruiting preference for women from the Prince George's County, MD jurisdiction. Only individuals who have not had a past medical history of cervical cancer or hysterectomy (i.e., the surgical removal of the corpus uteri) were considered for this study. Eligible participants in this particularly phase must have also indicated that they had access to a phone that was capable of receiving and sending SMS text messages.

Although the general recommendation for Pap test screening (for average risk women, ages 21 and up) is supposed to be every three years, "previous screening behavior" was not be taken into consideration as an eligibility criteria for this pilot study. Because this dissertation was an initial feasibility study and the outcomes included program feasibility, acceptability, and their impact on outcomes that do not directly affect Pap test screening behavior, it was not absolutely necessary to screen out women who may have received their last Pap test within the past 3 years. Again, if this pilot study was able to establish positive feasibility, acceptability, and impact on the proposed outcomes, then the approach could then be tested in a future randomized controlled trial where actual screening behavior can also be taken into consideration.

***SMS Text Messaging Enrollment and Implementation.*** For Phase 3, surveys administered before and after the pilot test were conducted electronically. Study participants were emailed a copy of the baseline survey at the start of the program and then, upon completion of the program, they were emailed a copy of the post-program follow-up survey. The baseline and post-program follow-up survey were expected to take participants

approximately 20 minutes, each, to complete. At the end of Phase 3, participants received \$20 in appreciation of their involvement in the pilot study.

Prior to baseline data collection, prospective participants were screened using a standardized screening form (Appendix T) to determine their eligibility for the study. If eligibility was established, consent forms were e-mailed out to the prospective participants (Appendix N). If the eligible participant was still interested in participating in the pilot project, then she was asked to begin her project enrollment process by reviewing and filling out the consent form and sending it back to the principal investigator. During this eligibility screening and enrollment phase, participants were also provided with an explanation of the study's aims and procedures, the data collection process, and the approximate time it would take to complete the surveys. Participants were then given an opportunity to ask questions about the study prior to being emailed a copy of the baseline survey.

Full participant enrollment into the pilot program required a three-step process. First, eligible participants had to have returned their signed informed consent document to the research team. Secondly, the participants had to provide the research team with their cell phone number and service provider. Lastly, the final step to fully enroll into the pilot project involved an initial SMS "welcome/opt-in" text message being sent out asking for verification from the participants that they had indeed received their very first project-related SMS text message from the research team. After fully enrolling into the pilot program, participants still had the option to opt-out in the future if they felt like the SMS text messages were becoming too burdensome for them.

To administer the spiritually-based cervical cancer SMS text messaging educational pilot intervention, the principal investigator used EZ Texting, a web-based SMS service to

send and receive the SMS text messages. EZ Texting is a 100% opt-in service and was an online resource that allowed the principal investigator to send and receive SMS text messages through a secure website. All data sent and received from the EZ Texting service is encrypted via 256 Bit SSL (HTTPS) encryption. Additionally, all data storage is inline with PCI compliance standards and is audited and certified by 403labs.com. As they have listed in their Privacy Policy, EZ Texting does not share or access any of their client's data and furthermore, their privacy practices are audited and certified by TrustE (<http://clicktoverify.truste.com/pvr.php?page=validate&url=www.eztexting.com&sealid=101> ). Using the EZ Texting web-based service eliminated privacy issues with participants having access to the researcher's personal cell phone number. It was also a fairly affordable and easy online system to navigate.

## **Measures**

The following section provides a detailed description of the measures that were used in Phase 3 of this dissertation study. The description includes an explanation of the instruments and their content, as well as their use in previous research. Where applicable, information regarding the reliability of the scales that were used to measure each of the variables in this study will also be described.

**Feasibility.** Feasibility considerations included (1) the extent to which the principal investigator was able to develop and distribute the SMS text messages to the target audience and (2) the extent to which the target audience recalled receiving them. To measure recall, participants' were asked to indicate whether they recalled "receiving any SMS text messages" from the program ("yes", "no", and "not sure"), the total number of SMS text messages that they recall receiving, and the topics that the SMS text messages covered.

**Acceptability.** A series of open- and closed-ended items were used to assess participants' satisfaction of the pilot program, as well as whether participants talked with others about the program or showed their program materials (e.g., forwarding their program-related SMS text message) to others. Acceptability, in the closed-ended manner, was assessed using the following 12 statements on participants' satisfaction with the program's text messages:

- Did you share any of the information you received from the CervixCheck project with others?
- Overall, how satisfied were you with the CervixCheck project?
- How useful were the SMS text messages that you received from the CervixCheck project?
- I enjoyed getting text messages from the CervixCheck pilot project.
- The CervixCheck text messages kept me informed about cervical cancer prevention and early detection.
- The CervixCheck text messages kept me engaged on the topic of cervical cancer prevention and early detection.
- The CervixCheck text messages made learning about cervical cancer prevention better.
- The CervixCheck project helped me to better support the health needs of the women around me.
- I would share the information I learned from the CervixCheck project with the women around me.

- I would recommend a cervical cancer SMS text messaging program, like CervixCheck, to others in my community if it was offered in the future.
- I wish to continue receiving occasional SMS text messages from the CervixCheck program.
- I would participate in a similar SMS text messaging-based project in the future.

The first question was measured with either a “yes” or “no” response. For those that indicated “yes”, they were also asked with whom they shared the study information and materials. The second and third questions were measured using five-point Likert response scales that ranged from “very satisfied” or “very useful” to “very dissatisfied” or “not at all useful”, with a sixth response option that allowed participants to indicate that the questions, for whatever reasons, were “not applicable”. The next set of nine statements were measured using five-point Likert response scales that ranged from “strongly disagree” or “very unlikely” to “strongly agree” or “very likely”, with a sixth response option that allowed participants to indicate that they “did not get” the messages.

**Initial Efficacy.** The remainder and majority of the direct measures that were used in this study were adopted from the Pap Smear Intention Questionnaire (PSIQ) developed by Linton and colleagues (Linton, Porche, & Steele-Moses, 2010). The PSIQ was developed and psychometrically tested as an instrument to determine Pap test screening intention among women in rural Southeast Louisiana (Linton et al., 2010). This instrument was guided by the Theory of Planned Behavior and the items on the PSIQ were derived from the results of semi-structured elicitation interviews conducted among a group of the target population (n=32). The psychometric properties of the PSIQ were determined through content and face validity, test-retest and internal consistency reliability. The PSIQ evidenced reliability and

validity based on internal consistency with alphas of .59 to .89, test-retest reliability, and a content validity index of 0.84.

A 5-point Likert-type scale was originally used by Jennings (1999) in her study to measure Pap test intention amongst African American and Latina women (Jennings-Dozier, 1999), and thus, a 5-point Likert scale was also adopted and used to obtain responses for the variables included in the PSIQ (Linton et al., 2010). The 5-point Likert-type scales that were used in this study comprised of a range from “strongly disagree to strongly agree” and “very hard to very easy”, with the extreme negative receiving a score of 1 and the extreme positive receiving a score of 5.

***Attitude 3-Item Subscale.*** The 3-item attitudinal subscale was measured with the following questions:

- When I think about getting a Pap smear, I believe it is beneficial.
- When I think about getting a Pap smear, I believe that it is important.
- When I think about getting a Pap smear, I believe that it is good.

This subscale (Linton et al., 2010) was scored based on the responses that were obtained on a 5-point scale, ranging from “strongly disagree” to “strongly agree”. The sum of the responses ranged from 3-15, with a high score indicating a positive attitude towards obtaining a Pap test. Harmful/beneficial are the examples of negative and positive endpoints respectively.

The test-retest correlation of this 3-item direct measure of attitude subscale was acceptable at .87, a high correlation. The internal consistency for this 3-item subscale was acceptable at a Cronbach alpha of .87.

***Subjective Norm 3-Item Subscale.*** The 3-item subjective norm subscale was measured with the following questions:

- I usually do what most people who are important to me think I should do.
- Most people who are important to me think that I should have a Pap smear every 1-3 years.
- Most people who are important to me have a Pap smear every 1-3 years.

This subscale (Linton et al., 2010) was also scored based on the responses that were obtained on a 5-point scale, ranging from “strongly disagree” to “strongly agree”. The sum of the responses ranged from 3-15, with a high score indicating that most important others have great influence towards the participant obtaining a Pap test. The test-retest coefficient correlation of this 3-item direct measure of attitude subscale was acceptable with a moderate correlation of .52. The internal consistency for this 3-item subjective norm subscale was acceptable with a Cronbach alpha of .72.

***Perceived Behavioral Control Subscale.*** The 2-item perceived behavioral control subscale was measured with the following questions:

- It is mostly up to me whether or not I get a Pap smear every 1-3 years.
- For me getting a Pap smear every 1-3 years would be...

This subscale (Linton et al., 2010) was scored based on the responses that were obtained on a 5-point scale. The first question was measured on a scale ranging from “strongly disagree” to “strongly agree”. The second question was measured on a scale ranging from “very hard” to “very easy”. The sum of the responses ranged from 2-10, with a high score indicating great control over obtaining a Pap test. The test-retest correlation of this 2-item perceived behavioral control subscale was acceptable with a moderate correlation of .75. The internal consistency for this subscale was not conducted by Linton and colleagues (2010) because

there were two items, one measuring controllability and the other measuring capability (Linton et al., 2010).

***Pap Test Screening Intention.*** The 1-item intention measure was collected using the following question: I plan to get a Pap smear in the next 1-3 years. This is a 1-item measure (Linton et al., 2010) that was scored based on the responses that were obtained on a 5-point scale, ranging from “strongly disagree” to “strongly agree”. The score for this measure ranged from 1-5, with a high score indicating high intention to obtain a Pap test. This item had an acceptable high test-retest correlation of .82. The internal consistency reliability was not calculated for intention because it was comprised of only one item.

***Pap Test Screening Behavior.*** Behavior was measured using the following question: What year did you have your most recent Pap smear? The internal consistency reliability was not calculated for behavior because it was comprised of only one item (Linton et al., 2010).

***Cervical Cancer and Pap Test Knowledge Subscale.*** Cervical cancer and Pap test knowledge items were adapted from previous studies conducted by Bynum and colleagues and used in the Behavioral Risk Factor Surveillance System (Bynum et al., 2014; Bynum, Wigfall, Brandt, Richter, Glover, & Hébert, 2013; Bynum, Wright, Brandt, Burgis, & Bacon, 2009; Bynum, Brandt, Friedman, Annang, & Tanner, 2011). The following nine items were used to assess cervical cancer and Pap test knowledge:

- A Pap smear is a test to find out if you have a sexually transmitted infection (STI) or sexually transmitted disease (STD). (*False*).
- A Pap smear is a test to find out if a woman is pregnant. (*False*).
- A Pap smear checks for changes in the cells of a woman’s uterus, also called the womb. (*False*).



- A Pap smear checks for changes in the cells of a woman’s cervix. *(True)*.
- Cervical cancer is easier to prevent if abnormal cells are found early. *(True)*.
- All women should be getting Pap smears by the time they are 21 years old. *(True)*.
- Women who are done having children do not need to keep having Pap smears. *(False)*.
- Getting regular Pap smears is the best thing a woman can do to prevent cervical cancer. *(True)*.
- If a woman has a Pap smear result that is not normal that usually means that she has cancer. *(False)*.

The response options for the knowledge items included “true”, “false”, and “don’t know”. To create a maximum 9-point cervical cancer and Pap test knowledge index score, items were summed where correct responses were given a score of 1 and incorrect and “don’t know” responses were assigned a score of 0. The sum of the responses ranged from 0-9, with a higher score indicating a greater degree of knowledge concerning cervical cancer and Pap test screening. The term Pap “smear” was used rather than Pap “test” for the knowledge items because of the familiarity of the term Pap smear in the African American population (Bynum et al., 2014).

**Socio-demographic and Health-related Factors.** The socio-demographic background variables that were collected at baseline included: age, marital status, educational attainment, employment status, income, and religious involvement. Health-related background variables that were also collected at baseline included: health status, health insurance, access to a regular doctor, and family cervical cancer history. Socio-demographic and health-related background variables were used to describe the study sample in this

dissertation study. The majority of these questions used a forced choice categorical response in order to allow for consistent information to be collected from all of the enrolled participants. Details regarding how some of the above socio-demographic and health-related background factors were assessed are listed here:

***Age.*** Age was measured through a single item asking for participants' date of birth at enrollment and then converted into a continuous item by calculating the age of the participant on the date of enrollment.

***Marital Status.*** This variable was assessed through a single categorical item with five response options: "single", "living with partner", "married", "separated or divorced", and "widowed".

***Educational Attainment.*** Educational attainment was measured using a single ordinal item ("What is the highest grade or year of school you have completed?") with five response options: "elementary", "some high school", "high school graduate", "some college or technical school", and "college graduate".

***Health Insurance Status.*** Health insurance status was assessed through four dichotomous items with "yes" and "no" as the two response options for each item and instructions for participants to mark all that apply. Participants were asked "Which, if any, types of health insurance do you have?" and the four items listed included: "Medicaid", "Medicare", "insurance through an employer/work", and "any other form of health insurance".

***Family Cervical Cancer History.*** Family history of cervical cancer was measured using two items asking participants to identify individuals in their family that have been diagnosed with cancer of cervix. The first item asked participants "has anybody in your

family (first degree relative) had cervical cancer” and had the following three categorical response options: “yes”, “no”, and “not sure”. For those that indicated yes on this question, they also had the following three categorical response options: “mother”, “sister”, and/or “daughter”. The second item asked “has any other family members had cervical cancer?” and had the same three initial categorical response options: “yes”, “no”, and “not sure”. For those that indicated yes on this specific question, they also had the following four categorical response options: “grandmother”, “aunt”, “cousin”, and/or “other” (with space to write in a description). Each response option for both items was coded 1 for a marked response and 0 for no response. The items’ responses were summed (excluding the “none” and “not sure” responses) for a single continuous item of total number of family members diagnosed with cervical cancer and then recoded to a dichotomous item with two response options: “family history of cervical cancer” (1) and “no family history” (0).

***Religious Involvement.*** Religious involvement was assessed to determine whether the pilot intervention was more effective for women with different levels of the construct. The notion that religious involvement (or religiosity) is multidimensional is well-accepted in the literature (Allport & Ross, 1967; Levin, Taylor, & Chatters, 1995; Roth et al., 2012; Holt et al., 2005). This construct was measured using an established scale that has been validated in this population (Holt et al., 2009a; Holt et al., 2009b). In this instrument, religious involvement is treated as a two-dimensional construct (Holt et al., 2003b). Five items assessed the behavioral dimension (e.g., church service attendance, involvement in other church activities) ( $\alpha=.79$ ) and four items assessed the belief dimension (e.g., feeling the presence of God in one’s life, perceiving a personal relationship with God) ( $\alpha=.85$ ). These items were assessed in a 4-point Likert-type format (ranging from “strongly disagree” to

“strongly agree”) except for service and activity attendance (“0”, “1-3” “4+” times per month). This two-dimensional religious involvement model has been used successfully among African Americans and had adequate test-retest reliability ( $r=.89$ ) (Lukwago et al., 2001).

### **Data Analysis Plan**

This dissertation was a three-phased study that used a multiple methods research approach and that required both qualitative and quantitative analyses.

**Qualitative Analyses.** Aim 1 of this dissertation study was analyzed in a qualitative manner. It was conducted by the principal investigator, alongside with two undergraduate research assistants. The focus group discussions and cognitive response interviews were be conducted by the principal investigator, alongside two research assistants. The focus group discussions and cognitive response interviews were digitally-recorded and the audiotapes were transcribed verbatim. The principal investigator reviewed each of the transcripts for transcription accuracy. Each of the focus group transcriptions was also combined with two sets of observers’ detailed field notes and summary reports.

Data from Phase 1 and Phase 2 were analyzed using standard text analysis. Themes were identified in accordance with the methods described by Owen (1984). Open coding, which involved the line-by-line analysis of each transcript (as directed by the interview guide), was conducted (Bynum et al., 2009). Data-driven content analysis was used to explore the findings with the principal investigator and two trained research assistants identifying themes independently. In an iterative analytic process, the three researchers independently read and reviewed the transcripts to generate impressions. Together with the

research questions that shaped the discussion and interview guides, these impressions then formed the basis of our initial coding framework.

The principal investigator and the two trained research assistants ultimately met to discuss codes and themes, identify representative quotes and convergent/divergent responses, and reach an agreement on what best represented the communities' perspective regarding issues concerning cervical cancer screening and what is needed to develop the spiritually-based cervical cancer SMS text messaging educational intervention. The key codes and themes were identified and interpreted using the constant comparison method and by reviewing field notes (Glaser, 1978; Morse & Field, 1995; Strauss & Corbin, 1998). In particular, findings from the focus group discussions informed the format (e.g. frequency/timing) and content (e.g. messaging) for the pilot SMS text messaging intervention. Once the spiritually-based cervical cancer SMS text messaging educational intervention was developed, cognitive response were used to assess the content of the SMS text messaging library, to ensure that the content was acceptable and understandable, particularly for church-attending African American women ages 21-65. Participants from Phases 1 and 2 were also extended an opportunity to review the findings and to confirm the main themes and specific phases that demonstrated them.

**Quantitative Analyses.** Aim 3 of this dissertation study sought to examine the relationships between socio-demographic factors, the pilot SMS text messaging intervention, health-related beliefs, and health seeking intentions of African American women to participate in Pap test screening. Statistical Package for the Social Sciences (SPSS), version 23.0 for Macintosh data file, was used for all quantitative analyses.

Prior to conducting study analyses, assumptions underlying the selected statistical methods were also assessed (e.g., normality). Decisions for the statistical significance of any findings in this study was made using an alpha level of 0.05.

***Univariate and Bivariate Analyses.*** Univariate analyses were conducted to describe the socio-demographic, health-related, and behavioral characteristics of the study participants. All items were analyzed for their distribution using descriptive statistics (e.g., means, frequencies, and standard deviations). Descriptive statistics were calculated to create a profile of study participants for demographic and Pap test screening-related characteristics. Key study variables, such as the pilot study's feasibility and acceptability, were reported using counts and sample proportions.

Differences in constructs relating to knowledge and attitudes about cervical cancer and the Pap test, subjective norms, perceived behavioral control over obtaining a Pap test, and Pap test screening intention from baseline to study completion were reported by the mean and standard deviation and tested using the paired t-test. To evaluate study participants' intent of getting a Pap test in the next 6 months and whether they already have an appointment to get a Pap test within the next 6 months, the McNemar's test was used for paired binary data to compare the percent of participants that provided each response from pre- to post- test. These two variables were dichotomized into "thought about testing within 6 months" and "no thoughts about testing within 6 months", as well as "have an appointment to test within 6 months" and "no appointment to test within 6 months." These measures at post-test were estimated using the sample proportions and 95% confidence intervals were estimated using the exact method. Given the preliminary nature of this pilot intervention and

the relatively small sample size, multivariate analyses were not conducted. Again, decisions for the statistical significance of any findings was made using an alpha level of 0.05.

**Missing Data.** Missing values exist in most survey studies. With incentives in place, previous pilot studies have shown that missing values tend to fall below 5% for most variables. This held true for the present study. The missing data for all variables was less than 5% and due to the very small number of cases for each variable with missing data ( $n < 5$ ), a determination of whether or not data was missing completely at random through statistical tests was not appropriate.

Although there are a number of options available for handling missing data of less than 5% (e.g., listwise deletion, pairwise deletion, and mean substitution) (Roth, 1994), the missing data in this dissertation study was addressed through listwise deletion. This method of handling missing data consisted of excluding cases from any calculations involving variables that may have missing data (Munro, 2001). The advantage of this method was that this process would produce true correlation matrices.

### **Data Management**

Rigorous and systematic quality control was enforced during all stages of this dissertation study. Data collection included standardized training of all individuals involved, and adherence to carefully specified procedures for interviewing and probing during the focus group discussions and cognitive response interviews. Hard copies of survey forms and copies of signed informed consent forms were stored in a locked file cabinet in the principal investigator's office. Audiotapes and transcripts from the focus group discussions and cognitive response interviews were stored without identifiers in the aforementioned file cabinet. Audiotapes were destroyed after being transcribed.

Quantitative data collected from enrolled participants were ultimately transferred into SPSS, along with the subject's unique identification number. Data checking and cleaning methods included examining the plausible ranges for responses to each of the individual variables via frequency distributions, evaluation of each missing data value for possible oversight upon entry, normality, scatterplots, frequencies, descriptives, and outliers using SPSS. Electronic databases that contain identifiers were stored as password protected files with only the principal investigator having access.

### **Human Subjects Protection**

This dissertation study was reviewed and approved by the University of Maryland Institutional Review Board's procedures for research involving human subjects (866903-1) (Appendix A). The purpose of the study, eligibility criteria, confidentiality, and the voluntary nature of study participation was explained to every participant in oral and written formats before the study began. The surveys, administered in Phase 3, required approximately 20 minutes to complete. For each survey completed, participants received \$10, for a total of \$20 for their involvement in the piloting phase (Phase 3). Along with the final incentive, each participant also received a set of educational materials on cervical cancer prevention, along with the option to receive a summary of the results. The set of educational materials included the National Cancer Institute's booklets on cervical cancer prevention and Pap test screening and a variety of fact sheets and pamphlets from the Centers for Disease Control and Prevention that focuses on explaining cervical cancer risks, symptoms, and screening recommendations, particularly for African American women. A bookmark, with information on free cancer screening in the local community, was also distributed to the study participants.



The rights of the study participants were protected using several methods. First, the participants were fully informed about the purpose of the study. Second, the participants were informed that their involvement in the study was strictly voluntary and that they had the option of withdrawing from the study at any point. Lastly, the participants were also provided with an explanation of the measures that would be taken to ensure the confidentiality of the survey data.

**Sources of Research Material.** Sources of research material that was collected specifically for this dissertation study included audiotapes, observational notes, and transcriptions from the focus group discussions and cognitive response interviews, as well as the surveys that were electronically administered before and after the pilot test. No other data was used for the purposes of this research.

**Recruitment and Informed Consent.** The principal investigator recruited potential participants using IRB-approved materials and scripts. Eligibility was initially determined before the principal investigator could offer the eligible women the opportunity to enroll in the study. Eligible participants were then read the informed consent information and told about the study protocol. The principal investigator also made sure that all questions were answered and that the potential participants fully understood what their participation in the study would entail. Those who were still interested were asked to provide their written consent to participate in the project.

**Potential Risks.** There were minimal risks to participants involved in this study. It was possible that thinking about cervical cancer and HPV infection may have generated stress or anxiety for some individuals. Psychological distress after reading any project-related SMS text messages that contained content about sensitive topics was also believed to pose

minimal risk. The consent document specified the option to withdraw from the study.

Persons showing any signs of anxiety or discomfort would have been offered the option to leave the pilot study. Although somewhat likely, these risks were not considered serious.

Because the study surveys assessed only minimally sensitive issues, they posed little risk. The study also did not include invasive or clinical procedures and therefore, should not have posed any harm. Other potential risks were minor and included time and inconvenience that may have come with participating in survey research and data collection.

Lastly, loss of confidentiality is always a risk with human participants; however this risk was minimal as the principal investigator adopted multiple safeguards to ensure that confidentiality was protected. Confidentiality of the subjects was maintained and consent was obtained as previously mentioned.

**Protection Against Risks.** Data collected was kept strictly confidential. Individuals were not identified in comments made during the pilot study or in its' publication.

Throughout the study, identification of individuals was solely for scheduling purposes.

Confidentiality was assured in the following way: Participants were assigned a four-digit participant identification number at the time of enrollment. Once the study database was complete, the identifiers such as name and address were removed, so that the identification number was the only identifier available. Participant identifiers were stored electronically in password-protected databases and in hard copies stored in locked file cabinets. In order to reduce the risk of loss of confidentiality, access to personal identification information were limited to the study's principal investigator. All computerized data was safeguarded by passwords known only to the principal investigator. Similar methods have been used in past research and they have been extremely effective in protecting against potential risks.

**Potential Benefits.** Although the principal investigator considers the aforementioned risks to be generally mild and unlikely, steps were definitely taken to reduce their occurrences. The principal investigator believes that there are benefits associated with learning about cervical cancer, human papillomavirus, and Pap test screening because these activities may increase the salience or awareness of the importance of this health issue to participants. An additional benefit for the participants is that they will have an opportunity to share with others issues around cancer and perhaps, to gain knowledge and information that may help them make more informed choices about their own health and that of their families. Other potential benefits of this dissertation study include its' potential ability to increase Pap test screening intention and participation rates among African American women and the opportunity that arises for subjects participating in this research study to assist in the development of cancer control activities that are appropriate for this particular ethnic group. The minimal risks described above are warranted in light of these benefits. Benefits also included information of the resources of free cervical cancer screening and referral services.

**Confidentiality.** Again, rigorous and systematic quality control was enforced during all stages of this dissertation study (see sections on “Data Management” and “Protection Against Risks”). To uphold confidentiality, a complete list of the participants' correct name and contact information was stored separately from the data. The computer that was used to deliver the SMS text messages was located in principal investigator's office and was, and still is, password protected. The pilot intervention and SMS text messages were not delivered until the signed informed consent documents were returned to the principal investigator.

When using the EZ Texting online software, confidentiality was maintained by using a new, unique login username and password created by the principal investigator, and after

sending the SMS text messages the principal investigator logged out of the account immediately. The username and password was stored in a locked cabinet in the principal investigator's locked office, along with the participants' personal cell phone numbers. Upon study completion and post-assessments, the participants' personal cell phone numbers and SMS text message were deleted from the "contacts" database in the EZ Texting account permanently, to ensure privacy

### **Limitations**

There were several limitations to this dissertation study. One potential limitation to the study was the possibility of selection bias from participants' enrollment in the study. Eligible participants were recruited through an existing network of churches, health and women's ministries, community health advisors, and through participants from a previous cancer-based research project. Due to the nature of this type of recruitment, participants may have potentially self-selected into the study. Furthermore, enrolled participants in this study were self-identified church-attending individuals and thus, the findings from this pilot program may not be generalizable to other populations.

**Qualitative Approach: Phases 1 and 2.** There were a number of limitations specific to the qualitative approach. First, the process of working with church-attending African American women on message design and refinement was fluid and often nonlinear. The principal investigator gave up her own sense of control over the project as it evolved into a partnership endeavor. Secondly, despite efforts to recruit individuals with varying socio-demographic characteristics, participants from the focus group discussions and cognitive response interviews had fairly high education with 74% having at least an undergraduate degree (n=17). Furthermore, the majority (96%; n=22) of the focus group discussion and

cognitive response interview participants indicated that they had some sort of health insurance coverage during the time that this study was conducted and that they had already been screened for cervical cancer at some point in their lives. Finally, although the principal investigator conducted quality control measures, the findings from this study may still be at risk for social acceptability bias. The sample from the formative phases of this study may still lack representativeness of the larger population of church-attending African American women, thus potentially limiting the generalizability of the findings.

**Quantitative Approach: Phase 3.** Several limitations specific to the quantitative approach employed in this study are also worth nothing. First, this research may not have been completely able to prevent non-response bias. Although the principal investigator intended to maximize her recruitment efforts to the best of her ability, there was still a possibility that the eligible and enrolled study individuals may have already been aware of the importance of cancer early detection and would have therefore had more positive attitudes and perceived behavioral control towards Pap test screening than those who ultimately elected to not participate in this study. Thus, findings from this dissertation may be biased and not generalizable to individuals that are less aware of the importance.

Additionally, the sampling design for this dissertation study was also a non-random sample of African Americans in consideration of cultural and administrative issues. As African Americans put high values on social relationships, being invited to participate in a study by people with whom they are familiar (e.g., health ministry leaders, health care professionals who work in the African American community, community health advisors, and/or organizational partners from an already existing community network) was a more reasonable approach than being contacted by a third-party telephone interviewer they do not

know. Although this study utilized a convenience sample, this culturally sensitive sampling strategy served as the initial step to create some degree of capacity building among the African American women community and could ideally create a sustainable infrastructure to support future research and cervical cancer intervention programs. To address the representativeness of the sample in this pilot study, the principal investigator examined the homogeneity between the pilot sample and census data in terms of age, gender, marital status, employment, educational attainment, etc. after the data collection. This post hoc procedure provided some additional insight into the generalizability of the findings from this pilot intervention.

Another potential limitation to this study was the relatively small sample size. Having a smaller sample size to work with may have potentially impacted the statistical analyses and conclusions for this dissertation. The smaller scope of this multiple methods pilot study allowed us to explore the study aims in-depth, but only with a smaller and select sample of church-attending African American women who were predominately from Prince George's County, Maryland. Further research is needed to validate the effectiveness of a similar intervention using a more rigorous research design, such as a randomized controlled trial with multiple follow-up time points, in a larger sample of African American women.

Lastly, this research was not able to explore the relationship between behavioral intention and actual Pap test screening behavior. While behavioral intention is a strong predictor of behaviors, this dissertation research study did not directly measure the Pap test screening behaviors for those that participated in this spiritually-based SMS text messaging educational intervention. Because our study was not designed for a long-term follow-up period, it was not possible for us to determine whether the study participants' intent to

undergo Pap test screening would significantly increase over time, potentially translating into actual behavior change. Further research should seek to explore this relationship in an attempt to fully understand the antecedents to providing an opportunity for African American women to engage in actual Pap test screening behavior.

## Chapter 4: Manuscript 1

### Development of a Spiritually-based SMS Text Messaging Program to Increase Cervical Cancer Awareness among African American Women

#### Abstract

**Background/Purpose:** African American women account for a disproportionate burden of cervical cancer incidence and mortality when compared to non-Hispanic White women. Given that religion occupies an essential place in African American lives, delivering health messages through a popular communication delivery channel and framing them with important spiritual themes may allow for a more accessible and culturally appropriate approach to promoting cervical cancer educational content to African American women. This paper aims to describe the design and development of the CervixCheck project, a spiritually-based short message service (SMS) text messaging pilot intervention to increase cervical cancer awareness and Pap test screening intention among church-attending African American women ages 21-65. **Methods/Approach:** Through focus group interviews (n=15), formative research was conducted to explore facilitators, motivators, and barriers to cervical cancer screening. The interviews were also used to identify logistical factors that should be considered when developing the CervixCheck intervention. Culturally appropriate and spiritually-grounded SMS text messages were developed based on the analysis of focus group data and the review of previous studies that incorporated technology into health behavior change interventions. After the CervixCheck intervention was developed, cognitive response interviews (n=8) were used to review the content of the text messaging library, to ensure that the content was acceptable and understandable, particularly for church-attending African American women ages 21-65. **Results/Findings:** Design and development of the SMS text messages involved consideration of the content of the messages and technological specifications. Focus group participants overwhelmingly reported cellphone use and an interest in receiving spiritually-based SMS text messages on cervical cancer prevention and early detection. Findings from the cognitive response interviews revealed that the content of the text messaging library was acceptable and understandable with the target population. The revised SMS text messaging library currently includes 22 messages for delivery over 16 days, averaging 11 texts per week, with no more than two messages delivered per day. Initial usability testing also showed early feasibility. **Conclusions/Significance:** The design and development of the CervixCheck intervention provides important insight into what may be considered an overlooked minority population and missed opportunity in health information technology research. With increased Internet penetration through the use of smart phones, it is appropriate to investigate the viability of technology as a means to reach minority communities and to reduce health disparities.

**Key words:** SMS Text Messaging; African American; Women's Health; Cervical Cancer Disparities; Pap Test Screening; Health Information Technology; Spiritually-Based Intervention; Formative Research; Community-Engaged Research



Development of a spiritually-based SMS text messaging program to increase cervical cancer awareness among African American women

## **INTRODUCTION**

Although cervical cancer incidence and mortality rates have drastically decreased in the United States over the last few decades (Siegel, Naishadham, & Jemal, 2013; SEER, 2012a; SEER, 2012), particularly due to Papanicolaou (Pap) testing, some populations still continue to bear a larger burden of the disease (Bynum et al., 2014; Siegel et al., 2013; DeSantis et al., 2013). On a national level, African American women experience the second highest incidence rate of cervical cancer (11.4/100,000) and the highest death rate (4.9/100,000) (SEER, 2007; SEER, 2006). When compared to White women in the general population, African American women have a 34% higher incidence of cervical cancer and are twice as likely to die of the disease in the United States (Bynum et al., 2014; Siegel et al., 2013; DeSantis et al., 2013).

### ***Religiosity/Spirituality and Health in the African American Community***

Screening and early detection, particularly by identifying opportunities to improve Pap test screening utilization, are critical components in eliminating the aforementioned disparities in health outcomes for African American women (Bynum et al., 2014; DeSantis et al., 2013). There are a number of social and cultural factors that relate to prevention and screening behaviors that impact cancer mortality rates. Religious involvement is one of these factors (Deshpande, Sanders Thompson, Vaughn, & Kreuter, 2009; Holt et al., 2009a; King, Burgess, Akinyela, Counts-Spriggs, & Parker, 2005; Lincoln & Mamiya, 2001; Lumpkins, Coffey, Daley, & Greiner, 2013; Peterson, Atwood, & Yates, 2002). Extensive research has

shown that religious involvement plays an important role in the African American community (Deshpande et al., 2009; Holt et al., 2009a; Holt, Wynn, & Darrington, 2009; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002). In particular, older African Americans women have been found to be more religiously involved than other groups (Holt et al., 2009a; Lincoln & Mamiya, 2001).

Religious involvement has been associated with cancer beliefs, screening, risk, and prevention behavior and has great potential for use in the development of cancer prevention and screening communication interventions for this group (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002). Because of the popularity of church-based cancer screening programs for African Americans and the well-established association between religious involvement and health in the literature (Deshpande et al., 2009; Holt et al., 2009a; Holt et al., 2009b; Holt et al., 2009c; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002), it is logical to consider health promotion programs that engage faith-based institutions and that are spiritually-based to address the health needs of the African American community. Given the relatively high relevance and frequency that religion plays in the daily lives of African American women, (Sahgal & Smith, 2009), it is important to explore how religious beliefs and behaviors may influence an individual's perception, initiation, engagement, and participation in cervical cancer screening prevention.

### ***Text Messaging as an Intervention Communication Delivery Channel***

Mobile phone technology, also known as Mobile Health or "mHealth" (Fox & Duggan, 2012), represents a nearly universal form of communication among minority populations and is a promising new medium of intervention delivery in health research. In

particular, short message service (SMS) text messaging has been identified as a successful approach to affecting health knowledge, intent, and behavior change (Aldoory, Yaros, Prado, Roberts, & Briones, 2016; Bock, Heron, Jennings, Magee, & Marrow, 2012; Cole-Lewis & Kershaw, 2010; Fjeldsoe et al., 2009; Marshall, & Miller, 2009; Le et al., 2015). Numerous studies have also reported the effectiveness of SMS text messaging interventions for sensitive health-related issues, such as sexually transmitted infection prevention. For example, combined social media and text messaging interventions have been used to successfully promote weight loss (Napolitano, Hayes, Bennett, Ives, & Foster, 2013; Herring, Cruice, Bennett, Davey, & Foster, 2014; Joseph et al., 2015) and various health behaviors (i.e., physical activity, dietary behaviors) (Valle, Tate, Mayer, Allicock, & Cai, 2013; Laranjo et al., 2014; Joseph et al., 2015) in previous research and have several benefits compared to mailed print-based or traditional face-to-face health interventions. Specifically, SMS text message reminders have established popularity with patients and have been shown to be more cost-effective than paper or telephone-based reminder strategies (Fry & Neff, 2009). Such evidence implies that SMS text messaging can be an effective medium to deliver health information and promote preventive behaviors.

### ***Active Users of SMS Text Messaging***

With respect to SMS text messaging, there are several groups that text on a daily basis at higher-than-average levels (Smith, 2011). Based on cell phone owners who use SMS text messaging among a sample of 2,277 adults (age 18 and older) who were telephone interviewed by Princeton Survey Research Associates International from April 26 to May 22, 2011, the average number of SMS text messages sent or received on a normal day is approximately 41.5, with the median user sending or receiving 10 SMS text messages per

day. While women send and receive SMS text messages more frequently (M=42.0/day; Mdn=15/day) than men (M=40.9/day, Mdn=10/ day), African Americans send and receive SMS text messages on a more frequent basis (M=70.1/day; Mdn=20/day) than their non-Hispanic White counterparts (M=31.2/day, Mdn=10/ day) (Smith, 2011). Although the use of SMS text messaging decreases by age group, it is evident that a majority (73%) of American adults use this mobile-based technology to communicate. The higher-than-average levels of SMS text messaging in women (M=42.0/day; Mdn=15/day) and African Americans (M=70.1/day; Mdn=20/day), as well the indication that most Americans across all age-groups engage in some frequency of SMS text messaging (for those between the ages of 18-64: M>11.4/day; Mdn>3/day), suggest the potential suitability of delivering a SMS text messaging-based health intervention to African American women ages 21 to 65.

SMS text messaging was selected as the primary delivery channel for the current intervention due to its popularity and high use among African American women. Nationally representative data show that African American adults are more likely to own a mobile phone (87%) when compared to non-Hispanic Whites (80%) (Lenhart, 2010). Additionally, African Americans, in general, are more likely than their non-Hispanic White counterparts to use their mobile phones to send and receive SMS text messages (Duggan, 2013; Duggan & Rainie, 2012; Buis et al., 2013; Joseph et al., 2015) and to access social media websites (i.e. Twitter, Facebook, etc.) (Duggan & Brenner, 2013; Buis et al., 2013; Joseph et al., 2015). The most recent data from the Pew Internet and American Life Project reports that 80% of African Americans and 80% of all women use mobile cell phones for sending or receiving SMS text message (Duggan & Rainie, 2012). The low cost and widespread use of mobile

phones and the convenience of SMS text messaging further suggest the potential suitability of employing this type of mobile-based

### ***Current Study***

The purpose of this three-phased multiple methods study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of “CervixCheck”, a spiritually-based SMS text messaging intervention for the promotion of cervical cancer early detection among church-attending African American women age 21-65. Given the high levels of technology use in African Americans and substantial evidence suggesting that technology-based health promotion efforts are effective for stimulating behavior change and supporting behavioral interventions (Joseph, Durant, Benitez, & Pekmezi, 2013; Davies, Spence, Vandelanotte, Caperchione, & Mummery, 2012; Vandelanotte, Spathonis, Eakin, & Owen, 2007; Maher et al., 2014; Norman et al., 2007; Joseph et al., 2015), the minimal previous research on SMS text messaging as a means to promote cervical cancer early detection represents a missed opportunity to reducing cervical cancer mortality rates in this population. Although there is a growing body of literature reporting positive outcomes of SMS text message-based communication with sexually transmitted infections and cancer prevention, none of the SMS text message interventions for health promotion use a spiritually-based approach, and few focus on cervical cancer screening in African American women, making this intervention unique. Spiritually-based SMS text messages on health allows for a more culturally appropriate technology-based approach to promoting cervical cancer early detection educational content to African American women and can potentially serve as an effective intervention strategy to reach this population.

This paper reports on the formative research (Phase 1) that was conducted to inform the development of the CervixCheck intervention. We also report on the iterative process of intervention and delivery system development (Phase 2). Phase 3 of this study, reported elsewhere, was used to determine the feasibility, acceptability, and initial efficacy of SMS text messages in the delivery of cervical cancer early detection educational content to African American women.

## **METHODS**

### ***Study Overview and Design***

The CervixCheck project was conducted in three phases. Phases 1 and 2, completed in February and March 2016 and reported in this paper, involved the development and initial usability testing of a SMS text messaging intervention and automated distribution system.

*[Insert: Figure 1. Intervention Development Process]*

First, two semi-structured focus group discussions (n=15) were conducted to explore knowledge, beliefs, attitudes, barriers, facilitators, and motivators in cervical cancer screening for church-attending African American women ages 21-65. They were also used to identify factors (e.g. message content and timing) that should be considered when developing a spiritually-based SMS text messaging intervention targeted at women like themselves. Next, culturally appropriate and spiritually-grounded SMS text messages were developed based on the analysis of the focus group data and the review of previous studies that incorporated technology into health behavior change interventions. Finally, after the CervixCheck intervention was designed and developed, cognitive response interviews (n=8) were used to assess the content of the text messaging library. The compilation of text

messages in the library database were ultimately refined and incorporated into an automated SMS distribution system and was piloted for feasibility, acceptability, and initial efficacy in Phase 3 (reported elsewhere).

### ***Community-Engaged Approach***

Community-engaged research requires partnership development, collaboration and negotiation, as well as the commitment from both the community and academic researchers to addressing local health issues. Community-engagement activities involved in this study included the following: (1) conducting formative research for intervention development; (2) setting the study in the community, at an agreed-upon location and time of convenience to the study participants; (3) securing buy-in and recruitment/retention support from Pastors and community health advisors; (4) forming a community advisory board; and (5) building in and carrying out member checks throughout the study.

### ***Participant Eligibility, Recruitment, and Sample***

African American women aged 21-65 years were recruited from the research team's professional networks and from current collaborations with faith-based organizations in Prince George's County, MD. Participants were also recruited through social media (Facebook), emails sent to numerous listservs, flyers posted at churches, workplaces and campuses, and snowballing techniques during the months of February and March 2016. Those responding to the recruitment materials were screened for eligibility prior to being scheduled for either a focus group discussion or a cognitive response interview.

Phases 1 and 2 of the CervixCheck intervention were limited to self-identifying church-attending African American women who were between the ages of 21 and 65 and who had indicated that they reside within Prince George's County, Maryland. Only

individuals who had not had a past medical history of cervical cancer or hysterectomy (i.e. the surgical removal of the corpus uteri) were considered for the study. Eligible participants who were interested in participating in Phase 1 or 2 of the intervention must have also been willing to discuss topics surrounding culture, technology use, and cervical cancer prevention and education. Participants were expected to meet in person at an agreed-upon location and time of convenience. This often meant meeting in the community during the evenings and weekends to enable those who worked during the day to participate. Individuals in the focus group discussions and cognitive response interviews received \$15 each for their involvement. Participants were only eligible to participate in either the focus group discussions or the cognitive response interviews.

### ***Focus Group Discussions***

Prior to intervention development, formative research was conducted through two semi-structured focus group discussions to inform the development of the CervixCheck intervention. The focus group discussions qualitatively explored African American women's beliefs and attitudes about cervical cancer prevention and education, and assisted in determining factors that would be needed to be considered when developing the spiritually-based SMS text messaging educational intervention aimed at increasing Pap test screening intention in church-attending African American women. Participants (n=15) were asked to identify any unique factors that could serve as facilitators, motivators, and barriers in implementing a spiritually-based SMS text messaging educational intervention specifically aimed at increasing Pap test screening intention. The information from the focus group discussions helped to inform the format (e.g. frequency/timing) and content (e.g. messaging)



for the intervention and how best to enable women to learn about, open up, and talk about a potentially sensitive topic.

The focus groups were segmented by age (21-35; 36-65 years) to facilitate more open discussion and identify any age group differences. The sessions followed a semi-structured format and lasted approximately 90 minutes with time allotted for review of the study and participant informed consent; “fellowship” period that included an opportunity to socialize and partake in refreshments prior to the facilitated discussion; and wrap-up that included a summary of the focus group, distribution of cervical cancer educational brochures, completion of socio-demographic surveys, and distribution of gift cards. The principal investigator facilitated the focus group discussions, while two undergraduate research assistants served as the note-takers. Both focus group sessions were audiotaped with participants informed that they were being recorded. The facilitator explained the research aims and informed the participants that the investigators were planning to use SMS text messaging to promote cervical cancer early detection information to African American women. All participants received written information about the study and signed individual consent forms.

### ***SMS Text Message Development***

Findings from the focus group discussions informed the format (e.g. frequency/timing) and content (e.g. messaging) for the SMS text messaging intervention. Methods to develop the SMS text messaging strategy also included the following: (1) review of previously published literature, (2) examination of successful SMS text message interventions presented at national and local conferences and events (e.g. 2015 Society of Behavioral Medicine Conference, NIH mHealth listserv, research forums), (3) review of

existing spiritually-based SMS text messages, (4) review of health-related Biblical scripture, and (5) recommendations from a community advisory board. Frequency and timing of the SMS text message delivery were determined by the preferences and needs of the target audience. SMS text message content was determined prior to initiation of the pilot study. A total of 18 short project-specific SMS text messages that were health-related and spiritually-themed were developed by the principal investigator and initially reviewed by members on the community advisory board. To ensure suitability for delivery via a SMS text message, each message was 2-3 sentences long.

### ***Community Advisory Board***

Members of the priority population were identified and approached by the principal investigator to serve on a community advisory board. The six advisory board members ranged from 22 to 61 years of age. All members were church-affiliated African American women. Two were not married and four were married or living with a partner. Four reported that they were employed full time, one was employed part time, and one was retired. Four indicated that they either were currently serving or had previously served in a leadership capacity within their local congregations (e.g., head of a health or women's ministry, previous community health advisor). This advisory board contributed to the development of the intervention materials and provided recommendation for other aspects of the project (e.g., recruitment strategies, SMS text messaging content and delivery time/format).

### ***Cognitive Response Interviews***

Once the spiritually-based cervical cancer SMS text messaging educational intervention was developed, cognitive response interviews (n=8) were used to assess the content of the SMS text messaging library, to ensure that the content was acceptable and

understandable, particularly for church-attending African American women ages 21-65. Inspirational, spiritual messages were also reviewed for appropriateness and contextual meaning during this phase of the study. These participants were recruited and screened for eligibility, as in the focus groups. They made appointments with the principal investigator to read content from the SMS text messaging library and answer open-ended questions about what they read (cognitive response technique). Cognitive response procedures involve intensive one-on-one interviews in which participants may be asked to think aloud about the content they have read, paraphrase the information, and respond to other planned inquiries and probes (Forsyth & Lessler, 1991; Sudman, Bradburn, & Schwartz, 1996). Recommendations were then made for the revision of difficult or offensive material. This testing occurred at various locations throughout the community, depending on the transportation needs of the participant.

Each one-on-one cognitive response interview lasted approximately 1 hour where in-depth discussions of each of the draft messages took place. Towards the end of each of the cognitive response interviews, participants were also asked to take a look at the SMS text messaging library as a whole. At this point, each participant was asked to rank and discuss her ordering preference of the draft messages. They also had the option to “drop” any messages that they did not feel appropriate or relevant and/or to “add” any additional messages that they would like to see included in the library. Based on suggestions from the participants, the research team revised the texting curriculum following findings from the cognitive response interviews. The final product was a programmed spiritually-based SMS text message library on cervical cancer prevention and early detection to be delivered over a 16-day period.

### ***Initial Usability Testing***

Initial usability testing of the pilot program then ensued. During this time, the principal investigator and the two research assistants conducted the initial usability testing of the CervixCheck program. During the initial usability testing, the principal investigator and the two research assistants beta tested the revised system and used this time to identify and correct some initial programming issues. Although the initial usability testing of the revised draft system was primarily completed by the principal investigator and the two research assistants, an invite to review and provide additional feedback and recommendations on the frequency, timing, and general appearance and content of the spiritually-based cervical cancer SMS text messaging educational intervention was also extended to members on the community advisory board and to the participants who previously participated in the focus group discussions during Phase 1. The spiritually-based cervical cancer SMS text messaging educational intervention was then finalized for subsequent feasibility testing (described elsewhere).

### ***Data Analysis***

The focus group discussions and cognitive response interviews were digitally-recorded and the audiotapes were transcribed verbatim. The principal investigator reviewed each of the transcripts for transcription accuracy. Each of the focus group transcriptions was also combined with two sets of observers' detailed field notes and summary reports.

Data from Phase 1 and Phase 2 of the CervixCheck intervention were qualitatively analyzed using standard text analysis. Themes were identified in accordance with the methods described by Owen (Owen, 1984). Open coding, which involved the line-by-line analysis of each transcript (as directed by the interview guide), was conducted (Bynum et al.,

2009). Data-driven content analysis was used to explore the findings with the principal investigator and two trained research assistants identifying themes independently. In an iterative analytic process, the three researchers independently read and reviewed the transcripts to generate impressions. Together with the research questions that shaped the discussion and interview guides, these impressions then formed the basis of the initial coding framework.

The principal investigator and the two trained research assistants met to discuss codes and themes, identify representative quotes and convergent/divergent responses, and reach an agreement on what best represented the communities' perspective regarding issues concerning cervical cancer screening and what is needed to develop the spiritually-based cervical cancer SMS text messaging educational intervention. The key codes and themes were identified and interpreted using the constant comparison method and by reviewing field notes (Glaser, 1978; Morse & Field, 1995; Strauss & Corbin, 1998). Participants from Phases 1 and 2 were also extended an opportunity to review the findings and to confirm the main themes and specific phases that demonstrated them.

### ***Quality Control Measures***

At the end of each focus group discussion and cognitive response interview, the principal investigator debriefed with participants, asking them for feedback on the process used to design and refine the text messages. This member check allowed the researchers to determine whether the community-engaged and participatory approach was useful. Along with the transcripts, each focus group also had two note-takers to record observations using a set of open-ended questions measuring participants' demeanor before, throughout, and at the discussions, their understanding of concepts, their level of attentiveness and involvement,

and any extenuating circumstances that might have affected the discussions. These “observers’ detailed field notes” helped determine the effectiveness of the community-engaged and participatory. Quality control was also measured by an external review procedure by members of the community advisory board. After reading the data analyses, the reviewers assessed whether the themes and subthemes aligned with quotes and answered the research questions.

### ***Ethical Approval***

This research was reviewed and approved according to the University of Maryland Institutional Review Board’s procedures for research involving human subjects (866903-1).

## **RESULTS**

### ***Focus Group Characteristics***

The 15 focus group participants ranged in age from 23 to 58, with a mean age of 39.57 years ( $SD = 14.17$ ;  $Mdn = 45.50$ ). One individual had less than a high school education, three had a high school diploma or GED (General Educational Development credential), one had attended some college, six had a bachelor’s degree, three had a master’s degree or higher, and one did not answer the question. Six were currently single, five were married or living with a partner, three were separated or divorced, and one was widowed. Nine were employed full time, one was not employed at the time, one was receiving disability, four were employed part time, and one did not answer the question. Only one individual reported being a cancer survivor and nine reported having a family history of cancer. 14 reported having been screened for cervical cancer at some point in their lives, whereas one had not. Of the 15 women who participated in the focus group discussions,

approximately half (n=8) indicated that they had undergone a Pap test within the previous 3 years, with one-third (n=5) of the women reporting that they had received their most recent Pap test within the last 12 months. All but one reported having some form of health insurance coverage.

### ***Focus Group Findings and Recommendations***

Although general access to healthcare (e.g. having coverage through health insurance or access to a regular doctor nearby) was mentioned as a reason as to why women in their communities may not get screened for cervical cancer, the participants overwhelmingly expressed how the lack of screening within their communities may actually have more to do with the lack of general knowledge, awareness, and communication around this particular type of cancer. Women across both focus groups mentioned how cervical cancer and Pap testing get minimal attention in their community, especially in comparison to other cancers such as breast cancer and prostate cancer. One women shared how “[she] kn[e]w a lot of people who don’t get diagnosed sometimes until it’s too late because a lot of people just don’t think about it. They think of all the other cancers first before they think of cervical cancer.” Another women shared how “you just don’t hear too many people talk about cervical cancer... a lot of people may not think ‘ok look, let’s go get tested’... how are we supposed to know to go get screened [cervical cancer] if we don’t even hear people around us talking about it?” When asked why the women believed this was the case in their community, one women shared:

“... well, it’s the generations too... the conversations are not there. My mom never talked to me about it. Everything that I’ve learned regarding maintaining my body as a woman... [it was] derived from or what I was exposed to in school and things of

that nature... and they didn't talk about it because she wasn't comfortable or she didn't know... I truly believe it is from education, direct communication.”

Another woman in the same focus group also shared:

“... and there's the fear of cancer... when you hear cancer, it's like 'oh no, I am not going to go in and get checked for that... no way'... I don't want [the doctors] to tell me that I have it... but a lot of them are just not aware of how important it is for you to actually go in and get tested for any cancer... breast cancer, cervical cancer, or any cancer... it's really important for us to get tested so we know what is going on with our bodies and so that we can know what our options are...”

to which the majority of her fellow focus group participants nodded in agreement.

Participants in both focus groups agreed that the lack of general knowledge, awareness, and communication about cervical cancer is a contributing factor to why many women in their communities do not often get screened or treated until it is too late.

As the focus group discussions naturally transitioned over to whether or not the participants have ever gotten Pap test screened and what their experiences were like, the following additional themes surfaced: (1) discomfort (e.g. most of the participants described getting the Pap test as being invasion, awkward, painful, cold, and uncomfortable); (2) intergenerational relationships (e.g. the older generation, the parents, are not discussing these issues with their children; there is a lack of conversations around cervical cancer and Pap testing within the family setting); (3) confusion regarding current screening recommendations (e.g. some of the women did not know when you should start getting the Pap test and how often you should get them); and (4) patient/provider relationship and communication (e.g. doctors need to actively let their patients know the importance of



getting a Pap test, the risk of not getting one, and patiently walk their patients through what the procedure is like). With regards to general knowledge around the Pap test, a little over half of the focus group participants indicated that they were unaware that it was a screening procedure for cervical cancer. One woman emphasized this concern by sharing, "... when you came into womanhood, I mean, it was my understanding that part of your normal yearly thing was, you go get a Pap smear, but I never connected it to cervical cancer... I just assumed it was part of my physical exam... now I'm wondering how often I actually got these Pap smears done." Moreover, there was a lot of confusion across both of the focus groups when the women were asked whether they knew what the screening recommendations currently were for cervical cancer. Although all of the participants reported familiarity with the Pap test, most of the women (83%) were unable to correctly identify what the current Pap test screening recommendation was for cervical cancer. These individuals were unable to identify when (i.e. at what age) a women should begin to get Pap test screened and how often these screenings should take place.

During the last portion of the focus group discussions, participants were asked to discuss how they would go about educating and encouraging individuals, like themselves, to get Pap test screened. They were initially asked about their current access, use, and preference for various technology-based programs and platforms.

*[Insert: Table 1. Technology Access, Use, & Preferences]*

All participants in the focus groups had text-capable phones with 87% indicating that they had unlimited usage plans. The participants overwhelmingly reported cellphone use and an interest in receiving spiritually-based SMS text messages on cervical cancer prevention.

The participants were also asked to share their thoughts on what they felt would be the best way to deliver information about cervical cancer and the benefits of getting Pap smear screened as recommended, and whether incorporating technology to some extent was a reasonable idea. Without hesitation, the majority (87%) of the participants across the two focus groups ecstatically agreed that utilizing text messages would be a great way to quickly get short health-related educational messages across to individuals in their community. One woman shared how

“... everyone has a [cell] phone and texts these days... not just the younger people and teenagers... doesn't matter how old you are... like my mom texts me a lot... telling me to come over dinner or to remember to do something... she doesn't text as much as my daughter, but she does text... and come on, she's 62! It took us a heck of a time to teach her, but she really got the hang of it. She still doesn't know how to use our tablet or computer though...”

while another woman voiced the following:

“... who doesn't text? I may not [send] text much... you know, I'm almost 53, but I get them often. I get [text messages] from my family, church groups... and I like the ones that they send me about the traffic... like accidents... or storms... and now my doctor, my dentist, you know... she sends me a text about my upcoming appointment with her. I like those! I also like how if I forget or need to find something, I can go back to check some of my old texts to see if the information is still there.”

Further recommendations from the focus group discussions regarding what a text-messaging based program would look like included: (1) having a catchy project name that reflects the topic at hand; (2) making sure the text messages were not going to get delivered too early in

the morning (i.e. before 8am) or too late in the evening (past 8pm); (3) incorporating testimonials from women like themselves or from famous celebrities that they can identify with; (4) balancing the health-related educational messages with other messages that were broadly more positive and motivational in nature; (5) ensuring that the faith-based messages included direct scriptures that most church-attending individuals can quickly recognize; and (6) including local resources where individuals can go get screened for cervical cancer, especially if health insurance coverage is not a possibility.

Although participants indicated the popularity of unlimited text messaging plans within their communities, they stressed that the research team should never send out more than two messages per day. There were mixed feelings regarding receiving daily messages from the project. Some individuals indicated that they would appreciate the regularity and consistency of getting the daily messages, whereas others indicated that “it would be too much for me” or that “I kind of would like a break here and there, you know...” In general, participants indicated that sending out several messages, a few days each week, would be completely acceptable, as long as it did not exceed two per day and that at least one of these two messages (within the same day) was not health-content heavy. To have some balance and to keep individuals like themselves engaged, participants stressed the importance of having at least one of the messages be a more general spiritually- or motivationally-based message.

A final recommendation that surfaced during the focus group discussions revolved around the project name. Though reasonably appealing, the originally proposed project name was ultimately replaced based on a suggestion that came from one of the focus group participants. A proposed project name, CervixCheck, was favored by the majority of the

participants across both focus groups, as well as all of the participants during the cognitive response interviews. All of the women in the first focus group enthusiastically nodded in agreement when one of their fellow participants shared the following, "... you need a sexy, like a catchy [project] name, something that gets straight to the point and tells us, you know, like something that reminds us that we need to get specifically checked for cervical cancer... it's just something we don't really ever hear or talk about... but I mean, it's really important." As opposed to having a generic project name stressing the idea of overall women's health, the appeal with the new project name was that it actually reflected the specific type of cancer that the project was trying to target.

### ***Initial Draft of the SMS Text Messaging Library***

Through the focus group discussions, messages and wording preferences and recommendations for incorporation into the text messages were recorded. Based on the information collected, the research team developed a 14-day one-way SMS text messaging pilot intervention. The recommendations of the focus groups and the advisory board were reviewed by the investigative team and used, along with a review of existing cervical cancer educational materials, to develop draft content for the SMS text messages to be used in the intervention. The originally drafted SMS text messaging library was comprised of a total of 18 messages. The 18 draft messages included the welcome and closing messages to participants, as well as 9 health-specific messages and 7 spiritually-based messages. Core content covered areas such as the definition of cervical cancer, cervical cancer's impact on the African American women population, the role of Pap testing in cervical cancer prevention and early detection, and information on where individuals can go for free/low-cost screening in their local communities. The spiritually-based messages involved themes

such as: being a good steward over the body as a gift from God; personal responsibility for the life and body, which is a gift from God; being healthy so that one can serve God and those important around her; use of faith to get through cervical cancer screening; God will take care of us, but we must do our part and get screened; and various scriptures supportive of health. Selective examples of messages from the initial draft of the SMS text messaging library is shown here:

*[Insert: Table 2. Selected Examples of Messages from the Draft SMS Text Messaging Library]*

### ***Cognitive Response Testing Participant Characteristics***

The 8 cognitive response testing participants ranged from 21 to 65, with a mean age of 41.67 years ( $SD = 18.77$ ;  $Mdn = 41.67$ ). Four had attended some college, two had a bachelor's degree, and two had a master's degree or higher. Three were currently single, two were married or living with a partner, and three were separated or divorced. Two reported that they were retired, two were employed full time, one was not employed at the time, two were employed part time, and one individual did not answer the question. None reported being a cancer survivor and only six reported having a family history of cancer. All participants reported having been screened for cervical cancer at some point in their lives and everyone, also indicated that they had some sort of health insurance coverage during the time of their individual cognitive response interviews. Of the 8 women who participated in the cognitive response interviews, 75% ( $n=6$ ) indicated that they had undergone a Pap test within the previous 3 years, with half ( $n=4$ ) of the women reporting that they had received their most recent Pap test within the last 12 months.

### ***Cognitive Response Testing Recommendations***

Participants understood and found acceptable the vast majority of the content that was tested. A consistent concern that surfaced during the cognitive response interviews was one about the first educational message (health 1) and when it should actually be presented in the program. Participants did not like the idea that the very first educational message from the project would be one that hones in on the devastating impact that cervical cancer has on women in their community. Although all of the women acknowledged the importance of including such a message, they did not feel that it was appropriate to start with a message that “invokes fear” or “is depressing”. One woman shared how “yea, you should move this [message] to later in the program... you want to start with a more uplifting message... I know you want to catch our attention about cervical cancer and how it affects people like me, but an initial message like this would totally turn me off... I know it’s important but it just sounds too scary.”

Another concern that arose during Phase 2 was how there was still some confusion as to where the cervix was and what the Pap test procedure included. To remedy these concerns, participants recommended that we include direct links to images and/or videos that would elaborate on the anatomy of the women’s reproductive area. One woman explained how “for those of us who want more information, at least you can have it right there and easily accessible... even if we don’t look at what you send us right away, at least it’ll be in our phones and we can return to it when we feel like it.”

Other recommendations from participants in Phase 2 included the need to “really bring in the personal stories” and to place an emphasis on testimonials from women like themselves. Some of the participants also provided direct edits on how to the research team could condense some of the draft messages that originally ran beyond the 160 characters

limit. Since system specifications limits text content to 160 characters and spaces, our drafted messages needed to be re-designed to be concise. Lastly, a message “sign-on” was recommended for any text that the project team was planning to send out. There was general consensus across the cognitive response interviews that some sort of project branding was necessary to let participants know which messages were directly coming from the research team. It was also noted that a message “sign-on”, as opposed to a message “sign-off”, would be ideal because “you want your participants to know right away that that incoming message is from you, your project... If you start each of these messages with your project’s name, those participating in the project can get in the habit of recognizing them as soon as they come.” Beyond the recommendations mentioned above, other materials tested during Phase 2 were found to be both understandable and acceptable, including the spiritual themes and scriptures.

In response to feedback from the participants in Phase 2, we revised the texting curriculum to include four additional messages. The 22 “final” messages include the welcome and closing messages to participants, as well as 10 health-specific messages, 4 spiritually-based messages, and 6 messages that were both health-specific and spiritually-based in nature. The messages now span across 16-days, averaging at about 11 texts per week, with no more than two messages scheduled for delivery per day.

*[Insert: Table 3. Scheduling of SMS Text Messages for the CervixCheck Pilot Intervention]*

The welcome/opt-in message is scheduled to take place on the Saturday before the first program message is sent off the next day (i.e. on a Sunday). During the weekdays and on Saturdays, messages are scheduled for delivery at 12pm (around lunch time) and/or 4pm

(before the end of a regular work day's shift). On Sundays, messages are scheduled for delivery at 2pm (after most church services) and 5pm (before dinner time). "Off days" are scheduled for every Monday and Friday, days of the week in which participants indicated that they would be "more swamped" and that it would not be ideal to receive program-related information. The closing message is also scheduled for delivery on a Sunday.

## **DISCUSSION**

This paper reports on the design and development of the CervixCheck project, a spiritually-based SMS educational pilot intervention aimed at increasing cervical cancer awareness and Pap test screening intention among church-attending African American women ages 21 to 65. This intervention situates health beliefs and behaviors in the context of culture (Airhihenbuwa, 1993; Holt et al., 2009c) and information technology. Previous research have suggested that the development and implementation of culturally appropriate interventions through a community-based or -engaged approach can be successful in addressing the underutilization of cancer screening among African Americans (Holt et al., 2009c; Chan, Haynes, O'Donnell, Bachino, & Vernon, 2003; Chavez, McMullin, Mishra, & Hubbell, 2001; Gregg & Curry, 1994). The process in developing this intervention involved substantial participation of the priority population in all stages of the intervention development. This participation is viewed as a necessary element of a culturally appropriate intervention, not only to allow for community ownership of the project but to ensure that the intervention is indeed culturally appropriate, and not based on assumptions from the research team that may or may not be accurate.

The findings showed that a culturally appropriate SMS text messaging intervention



should be developed based on the target population's perspectives and input. The intervention development required collecting data from the participants regarding both the content and delivery formats of the culturally relevant health messages. In general, the participants felt that a cervical cancer educational program, framed within a spiritual context, was a good and innovative idea. The spiritual concepts generated by this group of participants were quite similar to those generated in previous cancer screening educational interventions, especially in qualitative projects examining spirituality and health beliefs (Holt et al., 2009c; Holt, Lewellyn, et al., 2005; Holt & McClure, 2006). In order to be additionally effective with the target population, the SMS text message content also needed to be encouraging, empowering, and thought-provoking, all while being short, informative, and direct. The focus group discussions suggest that the messages should focus on raising awareness and increasing general knowledge and acceptance of the Pap test to change attitudes, possibly prior to any specific behavior change (Mattson & Basu, 2010; Pollard et al., 2016). There was also a general preference for the inclusion of culturally appropriate visual and motivational messages that emphasizes one's role in relation to God, family, community, and women like themselves. Overall, these findings are consistent with the Centers for Disease Control and Prevention's suggestions that in order to quickly engage the reader, messages need to be clear, give important information first, be action-based and easy to understand (Centers for Disease Control and Prevention. 2012; Pollard et al., 2016). As mobile technology become more popular and advanced, a culturally appropriate SMS text messaging intervention could be an effective medium to deliver sensitive health information and eventually promote positive health behavior in underserved population.

Studies investigating SMS-based interventions in minority populations have recommended more extensive research to better understand the most effective content of text messages to increase the benefits derived from mobile health applications (Raifman, Lanthorn, Rokicki, & Fink, 2014; Thirumurthy & Lester, 2012; Githinji et al., 2015). This paper reports on formative research conducted to inform the development of an automated one-way text messaging intervention to disseminate cervical cancer prevention and early detection education. The development of the SMS text messages not only involved consideration related to the content of the messages, but also with technological specifications. The findings from Phase 1 and Phase 2 of this study show the importance of obtaining feedback about the content of text messages and of pre-testing the text messaging distribution system before further implementation should take place.

Text message interventions should be carefully developed, tested and refined before implementation to ensure they are written in the most appropriate way for their target population. Although some may be tempted to rely on common sense and skip a formative stage prior to implementation of interventions, the process of iterative formative research to develop the content and logistics for developing this program was indispensable to identify challenges to be addressed prior to the implementation of the piloting phase (Phase 3). This research provides insights into the appropriate number of messages to consider, the timing of when they should ideally be sent, and the educational content for consideration in a SMS text message-based intervention to promote cervical cancer prevention and early detection information for African American women. Message development research is important for effective interventions and public health practitioners need to pay close attention to how the messages will be received by the recipients.

The development, and ultimately the implementation and evaluation, of this CervixCheck spiritually-based SMS intervention will provide important findings into what may be considered an overlooked minority population and missed opportunity in health information technology research (Joseph et al., 2015; Joseph, Durant, Benitez, & Pekmezi, 2013; Davies et al., 2012; Vandelanotte, Spathonis, Eakin, & Owen, 2007; Maher et al., 2014; Norman et al., 2007). Although there is a growing body of literature reporting positive outcomes of SMS-based communication with sexually transmitted infections and cancer prevention, there is still very little research about the integration of communication technologies with previously reported effective intervention approaches such as being spiritually-based. By using important spiritual themes to frame cervical cancer educational content and by delivering these health messages through a popular communication delivery channel for this targeted group, cancer interventions can move one step closer to being more accessible and culturally appropriate for the African American women community.

There are, however, some limitations to the approach used during the formative phases of this study. These limitations include the use of convenience samples and referrals for selection of participants in the intervention development. First, members of the advisory board were recruited to the project by members on the investigative team. Most of these individuals had already worked with the research team on previous cancer-related research projects and had a vested interest in the community. Although there were attempts to include individuals from a variety of backgrounds, they may not have been representative of the priority population.

Secondly, another potential limitation to the study is the possibility of selection bias from participants' enrollment in the focus groups or cognitive response interviews. Although

an attempt was made to provide a balanced perspective by recruiting from a wide variety of networks, eligible participants were predominantly recruited by the principal investigator through an existing network of churches, health and women's ministries, community health advisors, and participants from a previous cancer-based research project. Due to the nature of this type of recruitment, participants may potentially self-select into the study. Furthermore, eligible participants in this study are self-identified church-attending individuals and thus, the findings from this pilot program may not be representative of the larger African American women community.

Third, although the authors acknowledge the important role that the Human Papillomavirus (HPV) vaccine holds in cervical cancer prevention, this study did not heavily focus on this approach. Even women who were vaccinated when they were younger need regular Pap test screening because the vaccines do not protect against all cervical cancers. Additionally, previous studies have suggested that African American women are less accepting of the HPV vaccine (Scarinci, Garces-Palacio, & Partridge, 2007; Strohl et al., 2015; Watkins, Reitzel, Wetter, & McNeill, 2015). Future studies should evaluate the acceptability of the HPV vaccine among the African American community and explore the feasibility of promoting Human Papillomavirus and HPV vaccine educational content through mobile-based technology.

Lastly, this research may not have been able to fully prevent non-response bias. Although the principal investigator intended to maximize her recruitment efforts to the best of her ability, it is still possible that the eligible and enrolled study individuals may have already been aware of the importance of cancer early detection and would therefore have had more positive attitudes and perceived behavioral control towards Pap test screening than

those who elected to not participate in this study. Thus, findings from this study may be biased and, ultimately, not generalizable to individuals who are less aware of the importance.

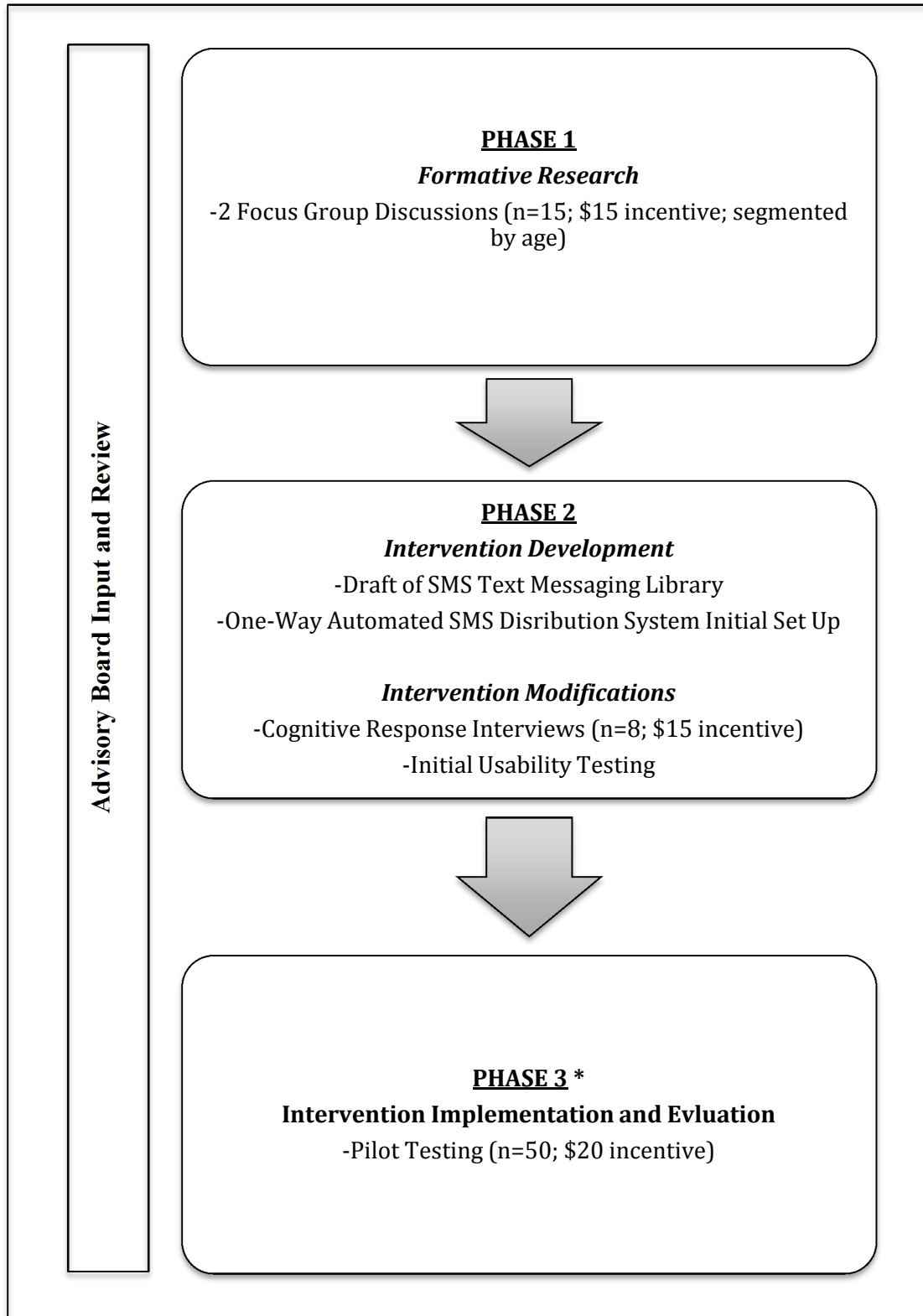
Albeit the limitations presented here, it is important to note that the non-random sampling design for this study was also purposefully selected in consideration of cultural issues. As African Americans put high values on social relationships, being invited to participate in a study by people with whom they are familiar (e.g. health ministry leaders, health care professionals who work in the African American community, community health advisors, and/or organizational partners from the already existing community network) was proposed as a more of a reasonable recruitment approach than being contacted by a third-party telephone interviewer they do not know. Although this study utilizes a convenience sample, this culturally sensitive sampling strategy serves as the initial step to create some degree of capacity building among the African American women community and will ideally create a sustainable infrastructure to support future research and cervical cancer intervention programs similar to this one.

In the next phase of this project, we will pilot test the CervixCheck program and will use baseline and follow-up surveys to assess the program feasibility, acceptability, and initial efficacy. The findings from this intervention will inform future research and practice in developing culturally appropriate health communication approaches for church-attending African American women. If this pilot intervention shows feasibility, acceptability, and initial efficacy for increasing cervical cancer awareness and Pap test screening intention, such a program can be adapted or further expanded and evaluated for its' effectiveness in its' contribution to the elimination of cancer disparities that negatively impact African American communities. Future studies using a more rigorous research design (e.g., a randomized

controlled trial with multiple follow-up time points) with a larger sample of African American women is therefore needed to validate the effectiveness of interventions such as the CervixCheck program.

From a public health standpoint, this study also informs the work of researchers engaged in efforts to meet *Healthy People 2020* objectives to reduce the death rate from cancer of the uterine cervix (C-4) and to increase the proportion of women who are counseled by their providers about Pap tests (C-18.2). Furthermore, technology-based platforms can provide researchers the ability to reach a large number of people at a relatively low cost; which can ultimately lead to a greater public health impact with regards to cervical cancer early detection health promotion efforts.

Figure 1. Intervention development process



\* Phase 3 of this study is reported elsewhere.

Table 1. Technology access, use, & preferences for participants in the focus group discussions and cognitive response interviews (n=23)

	N (%)
Contact Preference	
Cellphone	22 (95.7)
Home	1 (4.3)
Use a cellphone	
Yes	23 (100)
Is your phone a “smart phone”	
Yes	17 (73.9)
No	6 (26.1)
Use a cellphone for text messaging	
Yes	23 (100)
How often do you use text messaging to communicate	
More than once a day	18 (78.2)
Once a day	2 (8.7)
2-3 times a week	2 (8.7)
Once a week	0 (0)
Less than once a week	1 (4.4)
Computer at home with internet	
Yes	19 (82.6)
No	4 (17.4)
Do you have a Facebook account	
Yes	15 (65.2)
No	8 (34.8)
Do you have a Twitter account	
Yes	10 (43.5)
No	13 (56.5)



Table 2. Selected examples of Messages from the draft SMS text messaging library

<u>Text Order/#</u>	<u>Message Type</u>	<u>Construct</u>	<u>Key Message</u>	<u>Message Text</u>	<u>Character # (w/ Spaces)</u>
1	start	welcome	thank you for enrolling	[CervixCheck] Hi, [first name of participant]. Thank you for being part of the "CervixCheck" Women's Health Project. If you are still interested in receiving text messages over the next two weeks from the "CervixCheck" project about cervical cancer, please reply to xxxxx with the response "YES".	276
2	health 1	knowledge	impact; rates/statistics	African American women are at higher risk of dying from cervical cancer than other women. This is because too often the cancer is found later, after it has spread.	163
3	spiritual 1	knowledge	taking care of health	"My People are destroyed from lack of knowledge." -Hosea 4:6	60
9	spiritual 4	subjective norms	responsibilities	When it comes to our health, doing "our part" means that we take care of our bodies in general, and get the routine exams that we need. This includes getting a Pap test -- the part we do so that God can do His part.	215
13	spiritual 6	per. beh. control	self-motivation to take action	"I can do all things through Christ which strengtheneth me." - Philippians 4:14	78
15	health 8	cues to action	resources: link to more information/free services	When are you due for your routine Pap test? Talk to your doctor to find out. No insurance? No problem. For more information and to see if you are eligible for free screening, go here: [short url].	195
16	health 9	social network	spread the word; intergenerational communication	Spread the word and pass the wisdom down from one generation to the next. Share this information with the next generation like a good family recipe.	148

Table 3. Scheduling of SMS text messages for the CervixCheck pilot intervention

<u>Message #</u>	<u>Day</u>	<u>Day of Week</u>	<u>Time</u>	<u>Interactive Activity?</u>
1	1	Saturday	12:00pm	request for response 2 opt in
2	1	Saturday	8:30pm	
3	2	Sunday	2pm	
4	2	Sunday	5pm	
5	4	Tuesday	12pm	link to supplemental website
6	4	Tuesday	4pm	link to image
7	5	Wednesday	12pm	“true/false” question posed (prompt for a close-ended response); website link
8	6	Thursday	12pm	
9	6	Thursday	4pm	link to supplemental website
10	8	Saturday	12pm	
11	8	Saturday	4pm	
12	9	Sunday	2pm	“thoughts?” (prompt for an open-ended response)
13	9	Sunday	5pm	“agree/disagree” question posed; (prompt for an open-ended response)
14	11	Tuesday	12pm	
15	11	Tuesday	4pm	link to testimonial
16	12	Wednesday	12pm	link to testimonial
17	13	Thursday	12pm	
18	13	Thursday	4pm	
19	15	Saturday	12pm	link to resources
20	15	Saturday	4pm	
21	16	Sunday	2pm	
22	16	Sunday	5pm	(prompt for further questions)

## Chapter 5: Manuscript 2

### **CervixCheck: A spiritually-based text messaging intervention to promote cervical cancer awareness and Pap test screening intention among African American women**

#### **Abstract**

**Background/Purpose:** On a national level, African American women have a 34% higher incidence of cervical cancer and are twice as likely to die of the disease when compared to White women. In response to the need to improve cervical cancer prevention and Pap test screening knowledge and utilization, we developed and pilot tested a 16-day SMS text message-based intervention. The CervixCheck study was designed to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging intervention aimed at increasing cervical cancer awareness and Pap test screening intention in church-attending African American women ages 21-65. **Methods/Approach:** The Theory of Planned Behavior guided the development of the CervixCheck intervention. Phases 1 and 2 consisted of a series of focus group discussions, cognitive response interviews, and initial usability testing that were conducted to inform the intervention development and modifications. Phase 3 utilized a non-experimental one-group pretest-posttest design to pilot test the intervention. Findings presented here report on Phase 3. Of the 52 participants at baseline, 46 completed the post-program survey. **Results/Findings:** The current study provides evidence for the early feasibility, high acceptability, and some initial efficacy of the CervixCheck intervention. There was a significant pre-post increase observed for knowledge about cervical cancer and the Pap test ( $p = .001$ ) and subjective norms ( $p = .006$ ). Findings post-intervention also revealed that 83% of participants reported being either “satisfied” or “very satisfied” with the CervixCheck intervention and 85% found the SMS text messages either “useful” or “very useful”. **Conclusions/Significance:** A spiritually-based SMS text messaging intervention could be a culturally appropriate and cost-effective method of promoting cervical cancer early detection information to church-attending African American women.

**Key words:** SMS Text Messaging; African American Women; Cervical Cancer Disparities; Pap Test Screening; Health Information Technology; Mobile Phone; Spiritually-Based Intervention; Community-Engaged Research

CervixCheck: A spiritually-based text messaging intervention to promote cervical cancer awareness and Pap test screening intention among African American women

## **INTRODUCTION**

Cervical cancer is the third most common cancer diagnosis and cause of death among gynecological cancers in the United States (U.S.), and the second leading cause of death in women 20-39 years old (U.S. Cancer Statistics Working Group, 2015). Although cervical cancer occurs most often in Hispanic women, African American women tend to have lower 5-year survival rates and die more often than any other race (National Cancer Institute, 2008; American Cancer Society, 2013). In fact, African American women develop cervical cancer about 50% more often than non-Hispanic white women and have twice the cervical cancer mortality rate compared to white women (DeSantis et al., 2013; National Cancer Institute, 2008; Surveillance, Epidemiology, and End Results (SEER) Program, 2012a; SEER, 2012b). Of the close to 2,000 African American women diagnosed with cervical cancer each year, over 40% will die (National Cancer Institute, 2008; Howlader et al., 2012; SEER, 2012a; SEER, 2012b; Centers for Disease Control and Prevention (CDC), 2012a). Fortunately, cervical cancer is one of the most preventable types of cancer, and women can get screened for it with a routine Papanicolaou (Pap) test (Bynum et al., 2014; DeSantis et al., 2013). The Pap test is an extremely effective tool for reducing cervical cancer and increasing Pap testing rates could significantly reduce the cancer burden in African American women (Bynum et al., 2014; DeSantis et al., 2013).

Well-established research have shown that there are a number of social and cultural factors that can serve as both barriers and facilitators to screening for African American

women. Religious involvement, which encompasses both religious beliefs and religious behaviors (Roth et al., 2012; Lukwago et al., 2001; Holt et al., 2005), is one of these factors (Deshpande, Sanders Thompson, Vaughn, & Kreuter, 2009; Holt et al., 2009a; King, Burgess, Akinyela, Counts-Spriggs, & Parker, 2005; Lincoln & Mamiya, 2001; Lumpkins, Coffey, Daley, & Greiner, 2013; Peterson, Atwood, & Yates, 2002, Taylor et al., 2004). Within the African American community, the roles of religion and the church have a long history and tradition of providing support and leadership (Giger, Appel, Davidhizar, & Davis, 2008; Lincoln & Mamiya, 2001). Much research has been devoted to the role of religion in African American families, politics, values, and traditions (Giger, Appel, Davidhizar, & Davis, 2008; Lincoln & Mamiya, 2001). African American women have especially high rates of religious commitment as 84% report religion as being very important and 59% attend worship services at least once a week (Sahgal & Smith, 2009; Taylor et al., 2004).

Within the last decade, there have been a growing body of research on faith-based cancer control interventions (Allen et al., 2014; Holt et al., 2014a; Holt et al., 2014b; Lopez & Castro, 2006; Wasserman et al., 2006; Katz, Kauffman, Tatum, & Paskett, 2008; Matthews, Berrios, Darnell, & Calhoun, 2006), such as breast cancer (Duan et al., 2000; Darnell, Chang, & Calhoun, 2006), cervical cancer (Haynes, Escoffery, Wilkerson, Bell, & Flowers, 2014); liver cancer (Juon et al., 2008), colorectal cancer (Holt et al., 2011; Holt et al., 2012), and prostate cancer (Saunders et al., 2015; Holt et al., 2014a; Saunders et al., 2013; Holt et al., 2009b). A host of church-based cervical cancer interventions have focused on the Hispanic and Latino populations (Allen et al., 2014; Lopez & Castro, 2006; Wasserman et al., 2006); however, there have been very few targeting African American women (Haynes et al., 2014; Davis et al., 1994). An evaluation of a faith-based breast and

cervical cancer screening intervention among African American women found that incorporating aspects of spirituality and religion in the health intervention enhanced participants' health (Matthews et al., 2006). Church members view that good health is a gift from God, and often use faith and trust in God as a way to cope with health problems and treatments (Matthews et al., 2006).

One way of strengthening cervical cancer communication programs suited to the culture of African American women may be to include spiritual-based content (Winett et al., 1999; Holt, Kyles, Wiehagen, & Casey, 2003). This is especially the case when working through churches. Typology of religious orientation has previously been used to characterize church-based interventions (Winett et al., 1999). Interventions that are considered Level 1 use the church as a venue for recruitment. Level 1 interventions tend to have program messages that are secular in nature. Level 2 interventions are when health care professionals implement secular interventions through the church. In Level 3, instead of traditional health care professionals, it is through lay individuals that these similar secular interventions through the church are delivered. Lastly, a Level 4 intervention is when interventions intentionally integrate religious or spiritual content such as the use of relevant scripture passages or religious themes. Examples of religious themes include, for example, taking care of the body, which is a gift from God or supporting one another's health through the fellowship of the church (Winett et al., 1999; Holt et al., 2003a; Holt, Lukwago, & Kreuter, 2003; Holt et al., 2009c). Spiritually-based cervical cancer communication interventions can therefore be created by putting health in a spiritual context, ultimately using important spiritual themes to frame the cancer educational message. It is these Level 4 interventions that are underrepresented in the church-based health promotion and intervention literature.

Short message service (SMS) text messaging as a promising strategy for stimulating behavior change or supporting behavioral interventions (Cole-Lewis & Kershaw, 2010; Fjeldsoe, Marshall, & Miller, 2009; Le et al., 2015) has also emerged in a number of research initiatives. With mobile phones playing a ubiquitous part of our everyday lives, it is not surprising that some researchers are beginning to adopt and incorporate mobile technology research into their health behavior interventions. There are a handful of advantages to researchers of a SMS text message-based intervention. Due to the widespread use and low cost of this technology, it pervades all age groups and many cultures and socioeconomic backgrounds, including in developing countries (Nhavoto, Gronlund, & Chaquilla, 2015). It allows communication across geographic boundaries and reach people directly where they are located (Shaw et al., 2013). In particular, SMS text messaging is a widespread technology that has been shown to be effective at reaching minority and traditionally hard-to-reach populations, across a multitude of health topics such as sexually transmitted infection (STI) prevention, breast and prostate cancer early detection, physical activity, and dietary behaviors and that has allowed researchers to truly reach participants “where they are” (Cole-Lewis & Kershaw, 2010; Fjeldsoe et al., 2009; Le et al., 2015; Napolitano et al., 2013; Herring et al., 2014; Joseph et al., 2015; Valle et al., 2013; Laranjo et al., 2014; Wen et al., 2014).

Further benefits to SMS text message-based interventions include convenience to the participants and the potential for the programs to be more cost-effective in the long run (Fry & Neff, 2009). The use of SMS text messaging interventions can minimize participant burden associated with accessing and obtaining the intervention information and materials. For example, such programs could decrease participants’ burden of not having to attend face-to-face intervention sessions and would allow the participants 24-hour access to intervention

materials. Combined with a spiritually-based approach, mobile phone technology and SMS text message-based programs have the increased potential to serve as strategic intervention mediums to improve disparities in health outcomes for African American women.

Despite the high prevalence of SMS text message, social media, and mobile Internet use among African American women, few interventions have used such technologies to deliver health promotion programs to African American women. Review of the literature found no studies using text messaging as a means to promote cervical cancer early detection information to this population. Existing and commonly used text messaging infrastructures, when combined with traditionally effective intervention approaches, may be especially advantageous for promoting routine Pap testing among African American women. Given the high levels of technology use among African American women and substantial evidence suggesting that technology-based health promotion efforts are effective (Joseph, Durant, Benitez, & Pekmezi, 2013; Davies, Spence, Vandelanotte, Caperchione, & Mummery, 2012; Vandelanotte, Spathonis, Eakin, & Owen, 2007; Maher et al., 2014; Norman et al., 2007; Joseph et al., 2015), the absence of studies utilizing SMS text messaging as a means to promote cervical cancer early detection information represents a missed opportunity to reducing cervical cancer mortality rates in this population. Although there is a growing body of literature reporting positive outcomes of SMS text message-based communication with STIs and cancer prevention, there is still very little research about the integration of communication technologies with traditionally effective intervention approaches such as being spiritually-based. Framing intervention materials in this manner allows for a more culturally appropriate technology-based approach to promoting cervical cancer early detection information to African American women.



Literature surrounding health information technology has shown that this mode of health intervention delivery is feasible and acceptable and that SMS text messages are a promising strategy for motivating health behavior change or supporting health behavior change interventions (Le et al., 2015, Cole-Lewis & Kershaw, 2010; Fjeldsoe et al., 2009; Napolitano et al., 2013; Herring et al., 2014; Joseph et al., 2015; Valle et al., 2013; Laranjo et al., 2014; Lee, Koopmeiners, Rhee, Raveis, & Ahluwalia, 2014; Lee, Koopmeiners, McHugh, Raveis, & Ahluwalia, 2016). Although there has been a growing body of research that have used SMS text messaging to promote a variety of health-related outcomes among African Americans (Samal et al., 2010; Levine, McCright, Dobkin, Woodruff, & Klausner, 2008; Nhavoto et al., 2015; Wen et al., 2014; Shaw et al., 2013; Joseph, Keller, Adams, & Ainsworth, 2015; Nundy et al., 2013; Steinberg, Levine, Askew, Foley, & Bennett, 2013; Buis et al., 2015), the number of SMS text messaging studies that focus on cancer prevention and control among this population remains limited (Schoenberger, Phillips, Mohiuddin, McNees, & Scarinci, 2013; Le et al., 2015; Yuan et al., 2012). Review of SMS text messaging interventions in the African American community have yielded some mixed results. While most of the interventions were able to report promising results (Samal et al., 2010; Levine et al., 2008; Nhavoto et al., 2015; Wen et al., 2014; Shaw et al., 2013; Joseph et al., 2015; Nundy et al., 2013; Schoenberger et al., 2013; Le et al., 2015) such as program feasibility, increased impact in reaching the priority population, high rates of program satisfaction and favorability, and preliminary evidence of improvement in their targeted outcome measures, some have produced results that were not statistically significant or have yet to report their findings (Steinberg, Levine, Askew, Foley, & Bennett, 2013; Buis et al., 2015; Yuan et al., 2012).

Although the use of SMS text messaging interventions for health promotion is growing in the general population and is emerging among minorities and the medically underserved, there does not appear to be previous research using this technology to increase cervical cancer prevention among African American women, in particular a stand-alone SMS text messaging intervention that uses a spiritually-based approach. These spiritual themes can be identified through formative research with the priority population, and then pilot tested for feasibility, acceptability, and initial efficacy (Holt et al., 2009c). Winett and colleagues (1999) view this type of Level 4 program as a necessary but not sufficient intervention approach for continued behavior change and thus, warrants the potential integration of health information technology as a delivery mechanism (Winett et al., 1999). By using important spiritual themes to frame cervical cancer educational content and by delivering these health messages through a popular communication delivery channel for this targeted group, cancer interventions can move one step closer to being more culturally appropriate and accessible for the African American women community. The purpose of the CervixCheck study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging intervention aimed at increasing cervical cancer awareness and Pap test screening intention in church-attending African American women ages 21-65.

## **METHODS**

### ***Research Design and Data Collection***

Findings presented here report on the pilot testing phase, Phase 3. Results from the formative phases, Phases 1 and 2, have been published elsewhere [CITE]. This study utilized

a non-experimental one-group pretest-posttest research design with a convenience sample. The eligibility criteria for study participants were: (1) being a self-identifying church-attending African American (Black) women aged 21 to 65; (2) living in the greater Maryland, Washington, D.C., and Virginia areas (with preference for those from the Prince George's County, MD jurisdiction); (3) having no prior medical history of cervical cancer or hysterectomy (i.e. the surgical removal of the corpus uteri); and (4) having access to a phone that is capable of receiving and sending SMS text messages. There was specifically a recruiting preference for women from Prince George's County, MD because this county's cervical cancer mortality rate is the second highest in Maryland (3.0/100,000), with an incidence rate of 7.2/100,000 (State Cancer Profiles, n.d., "Death rate report"; State Cancer Profiles, n.d., "Incidence rate report"). While the cervical cancer mortality rate in other counties have been falling, Prince George's County is the only county that has not met the Healthy People 2.2 objective, and for which the cervical cancer death rate has remained stable.

Recruitment efforts included personal communication, as well as the distribution of print and electronic fliers. For the most part, participants were recruited through an existing network of churches, health and women's ministries, community health advisors, and through participants from a previous cancer-based research project. Fliers were posted at local faith-based organizations and, as a strategy to enhance the recruitment process, willing Pastors and community health advisors were asked to make an announcement about the study during the church service and/or at their respective ministry meeting(s), as well as to share the electronic flyer through their respective listservs. The announcements were delivered from a script prepared by the principal investigator. Additional recruitment efforts included:

(1) electronic flyers that were distributed to a number of varying listservs (e.g. alumni listservs from nearby universities and local sorority chapters) and (2) electronic flyers that were posted and shared using popular social media outlets such as Facebook and Twitter. Interested individuals who expressed interest in participating in the study were then asked to directly contact the principal investigator, either by phone or email. From there, the principal investigator was able to explain the purpose of the study, eligibility criteria, confidentiality, and the voluntary nature of participation in either an oral and written format to participants prior to obtaining their commitment.

Full participant enrollment into the program required a three-step process. First, eligible participants had to have returned their signed informed consent document to the research team. Second, the participants had to provide the research team with their cell phone number and service provider. The final step to fully enroll involved an initial SMS “welcome/opt-in” text message being sent out asking for verification from the participants that they had received their first project-related SMS text message from the research team. After fully enrolling into the pilot program, participants still had the option to opt-out in the future if they felt like the SMS text messages were becoming too burdensome for them. At the end of the study, participants received \$20 in appreciation of their involvement in the pilot study.

### ***Intervention Development***

We developed the contents of this spiritually-based SMS text messaging communication intervention using community-engaged research methods. Through a series of focus groups and cognitive response interviews with our targeted population, and with input and review from an advisory board, we determined that the CervixCheck program

would be a 16-day intervention consisting of a total of 22 text messages that would include both health-specific and spiritually-based content. Details regarding the design and development of the CervixCheck program have been reported elsewhere [CITE].

### ***Theoretical Framework***

Guided by the Theory of Planned Behavior (Ajzen & Fishbein, 1980; Ajzen, 1985; Ajzen, 1988; Ajzen, 1991), the CervixCheck program aimed to develop and deliver messages that would 1) improve participants' knowledge and attitudes about cervical and 2) positively increase their Pap test screening intention (see Figure 1 for conceptual framework).

*[Insert: Figure 1. Conceptual Framework (Adaptation of the Theory of Planned Behavior)]*

According to Ajzen (1991), the combination of attitudes, subjective norms, and perceived behavioral control, referred to as direct measure, can have a direct effect on behavioral intention (Ajzen, 1991). It posits that behavioral intentions are a “measure of the likelihood that a person will engage in a given behavior” (Ajzen & Fishbein, 1980, p. 42). The Theory of Planned Behavior provides a theoretical framework within which to consider a woman's intention to obtain a Pap test.

The Theory of Planned Behavior has been successfully used for a wide variety of behavior and in a broad range of contexts (Sutton, 1998; Conner & Armitage, 1998; Armitage & Conner, 2001). It is one of the more frequently used behavioral theories in cancer prevention research (Jennings-Dozier, 1999; Linton, Porche, & Steele-Moses, 2010; Glanz, & Bishop, 2010) and a number of cervical cancer studies have specifically utilized constructs from the Theory of Planned Behavior to carry out their intervention within the African American community (American Cancer Society, 1981; Bloom, Hayes, Saunders, &

Flatt, 1987; Davis et al., 1994; Ahijevych & Bernhard, 1994; Holland, Foster, & Louria, 1993; Kottke et al., 1995; Duelberg, 1992). As a whole, this theory adequately addresses the individual's several sets of beliefs and involves the consideration of others who are best in positions to influence those sets of beliefs. This is particularly important to keep in mind when working with the African American community, where the culture is often characterized by the enduring influence of religion and family.

The informational/educational content of the CervixCheck intervention covered areas such as basic health information about the cervix and cervical cancer, cervical cancer's impact on the African American women population, the role of Pap testing in cervical cancer prevention and early detection, information on where individuals can go for free/low-cost screening in their local communities, and testimonials from cervical cancer survivor. Some of the themes covered in the spiritually-based messages included: personal responsibility for the life and body, which is a gift from God; use of faith to get through cervical cancer screening; being healthy so that one can serve God and those important around her; and God will take care of us, but we must do our part and get screened. Although the CervixCheck program was intended as an automated one-way text messaging intervention to disseminate cervical cancer prevention and early detection education, a handful of questions and links to supplemental websites and videos were also incorporated into the program in order to keep the enrolled participants further engaged (e.g., (CervixCheck) TRUE/FALSE (resp. opt): Having routine Pap tests gives u a good chance 2 find problems earlier when they r easier 2 treat. <http://go.umd.edu/gri>; (CervixCheck) God has given the doctors knowledge & technology. This is a true blessing that comes from God. Do you agree/disagree & why?

Response is optional; (CervixCheck) "I had no symptoms at all... nothing. If I hadn't gone in 4 my cervical screening test when I did, I may not be here 2day." <http://go.umd.edu/srv>).

### ***Measures***

Study participants were emailed a copy of the baseline survey at the start of the program and then, upon completion of the program, they were emailed a copy of the post-program follow-up survey.

***Outcome measures.*** The primary outcomes of interest for this study were the feasibility and acceptability of the CervixCheck intervention in the promotion of cervical cancer prevention and early detection education. Secondary outcomes of interest included changes in knowledge and attitudes about cervical cancer and the Pap test, subjective norms, perceived behavioral control over obtaining a Pap test, and Pap test screening intention.

***Baseline measures.*** We collected participants' socio-demographic information (age, marital status, educational attainment, employment status, income, and religious involvement) and health-related information (health status, health insurance, access to a regular doctor, and family cervical cancer history). We also collected information about knowledge related to cervical cancer and the Pap test, attitude towards obtaining a Pap test, influence that important others may have towards a participant's Pap test screening behavior, control over obtaining a Pap test, and Pap test screening intention.

We used subscales from Linton and colleagues' (2010) Pap Smear Intention Questionnaire (PSIQ) to measure attitude towards obtaining a Pap test, influence that important others may have towards a participant's Pap test screening behavior, control over obtaining a Pap test, and Pap test screening intention (Linton, Porche, & Steele-Moses, 2010). The test-retest reliabilities reported in this section are from Linton and colleagues'

previous work with women in rural Southeast Louisiana. For the attitude subscale, the test-retest reliability of this 3-item measure was acceptable at .87, a high correlation. The internal consistency for this 3-item subscale was acceptable at  $\alpha = .87$ . For the subjective norm subscale, the test-retest reliability of this 3-item measure was modest at .52. The internal consistency for this 3-item subjective norm subscale was acceptable with at  $\alpha = .72$ . For the perceived behavioral control subscale, the test-retest reliability of this 2-item measure was acceptable at .75. The internal consistency for this subscale was not conducted by Linton and colleagues (2010) because there were two only items. The 1-item intention item (“I plan to get a Pap smear in the next 1-3 years”) (Linton et al., 2010) was scored using a 5-point scale, ranging from “strongly disagree” to “strongly agree”, with a high score indicating high intention to obtain a Pap test. This item had an acceptable test-retest reliability of .82. Finally, cervical cancer and Pap test knowledge was measured with 9 items adopted from previous studies conducted by Bynum and colleagues and used in the Behavioral Risk Factor Surveillance System (Bynum et al., 2014; Bynum, Wigfall, Brandt, Richter, Glover, & Hébert, 2013; Bynum, Wright, Brandt, Burgis, & Bacon, 2009; Bynum, Brandt, Friedman, Annang, & Tanner, 2011). The response options for the knowledge items (e.g., a Pap smear is a test to find out if a woman is pregnant; a Pap smear checks for changes in the cells of a woman’s cervix; cervical cancer is easier to prevent if abnormal cells are found early) included “true”, “false”, and “don’t know”. To create a maximum 9-point cervical cancer and Pap test knowledge index score, items were summed where correct responses were given a score of 1 and incorrect and “don’t know” responses were assigned a score of 0. The sum of the responses ranged from 0-9, with a higher score indicating a greater degree of knowledge concerning cervical cancer and Pap test screening. The term Pap “smear” was used rather



than Pap “test” for the knowledge items because of the familiarity of the term Pap smear in the African American population (Bynum et al., 2014).

*Posttest measures.* Immediately post-intervention, we administered a follow-up survey of the same items collected at baseline. In addition to assessing intervention feasibility and participants’ recall of the SMS text messages post-intervention, we also assessed participants’ satisfaction with the intervention and the extent to which participants may have talked with others about the program and/or shared their program materials (e.g., forwarding their program-related SMS text message to others).

### ***Data Analysis***

Differences in knowledge and attitudes about cervical cancer and the Pap test, subjective norms, perceived behavioral control over obtaining a Pap test, and Pap test screening intention from baseline to immediate posttest were reported by the mean and standard deviation and tested using the paired t-test. To evaluate study participants’ intent of getting a Pap test in the next 6 month, we used McNemar’s test for paired binary data to compare the percent of participants that provided each response from pre- to posttest. These two dichotomous variables included “intent to test within 6 months” and “no intent to test within 6 months”, as well as “have an appointment to test within 6 months” and “no appointment to test within 6 months.” We estimated these measures at posttest using the sample proportions and 95% confidence intervals were estimated using the exact method. We report on the measures of feasibility and acceptability by using counts and sample proportions. Decisions for the statistical significance of any findings in this report was made using an alpha level of 0.05.

### ***Ethical Approval***

This research was reviewed and approved according to the University of Maryland Institutional Review Board's procedures for research involving human subjects (866903-1).

## **RESULTS**

### ***Demographic Characteristics of the Sample***

Fifty-two participants who met the inclusion criteria were enrolled and completed the intervention and data collection protocol. Of those enrolled, forty-six individuals completed the posttest, making for a 88% retention rate. Study participants' baseline demographic information (n=52) is presented in Table 1.

*[Insert: Table 1. Socio-demographic characteristic of participants at baseline (n= 52)]*

The majority (76.9%) of our participants were residents from Prince George's County, MD. Participants' ages ranged from 23 to 58, with a mean age of 37.71 years ( $SD = 10.25$ ;  $Mdn = 37$ ). One (7.7%) individual had a high school diploma, six (11.5%) had attended some college, and the remainder (80.8%) of the participants were college graduates. Almost all (98.1%) participants reported being employed, either part-time or full-time. Our sample was evenly split between those who have had at least one child (50%) and those who reported having no children (50%). At baseline, all participants reported having some sort of health insurance coverage and 88.5% reported having a regular doctor. More than two-thirds (69.2%) considered their current health status as either "very good" or "excellent".

### ***Pap Test Screening***

Overall, 98.1% (n=51) of the study participants reported that they had received a Pap test at one point or another in their lives. Of the 52 enrolled participants at baseline, 82.7%

(n=43) of the women in the present analysis indicated that they had undergone a Pap test within the previous 3 years (recent screening). 53.8% (n=28) reported receiving their most recent Pap test within the last 12 months.

### ***Cell Phone Access and SMS Text Messaging Interest***

All (100%) of the participants indicated that they had a cell phone and that they use their cellular device for SMS text messaging. Of the 52 enrolled participants, an overwhelming majority reported having a smartphone (92.3%) and using SMS text messaging to communicate “more than once a day” (90.4%). With regards to how often the participants indicated that they would like to receive SMS text messages from a program like CervixCheck, the three largest categories were on an “as needed for news/announcements”, “a few times a week (3/week)”, or “daily” basis (19.2%, 17.3%, and 19.2%, respectively).

### ***Changes in Knowledge, Attitudes, Subjective Norms, and Perceived Behavioral Control***

Table 2 reports on the pre- to post-intervention changes in measures of knowledge and attitudes about cervical cancer and the Pap test, subjective norms, perceived behavioral control over obtaining a Pap test, and perceived barriers to cervical cancer prevention and screening.

*[Insert: Table 2. Pre- to post-intervention changes in knowledge, attitudes, subjective norms, and perceived behavioral control (n=46)]*

There was a significant increase in knowledge about cervical cancer and the Pap test ( $p = .001$ ). On average, participants’ knowledge about cervical cancer and the Pap test was higher during the posttest ( $M = 8.17, SE = .16$ ), than at pretest ( $M = 7.55, SE = .19$ ). This difference,  $-.62$ , BCa 95% CI  $[-0.96, -0.28]$ , was significant  $t(41) = -3.64, p = .001$ . There was also a significant increase in subjective norms ( $p = .006$ ). On average, participants’

subjective norms were higher during the posttest ( $M = 11.33$ ,  $SE = .29$ ), than at pretest ( $M = 10.64$ ,  $SE = .29$ ). This difference,  $-.69$ , BCa 95% CI  $[-1.17, -0.21]$ , was significant  $t(44) = -2.90$ ,  $p = .006$ . No significant differences were observed for attitudes about cervical cancer and the Pap test, perceived behavioral control over obtaining a Pap test, perceived barriers to cervical cancer prevention and screening, or Pap test screening intention.

### ***Pap Test Screening Intention***

Table 3 reports on study participants' intent of getting a Pap test, before and after the pilot intervention.

*[Insert: Table 3. Table 3. Study participants' intent of getting a Pap test pre- and post-intervention (n=46)]*

We did not observe a statistically significant difference in study participants' intent of getting a Pap test in the next 6 months.

### ***Feasibility and Acceptability of the Intervention***

Table 4 reports on feasibility and acceptability of the CervixCheck spiritually-based SMS text messaging intervention.

*[Insert: Table 4. Participant SMS text message recall and program acceptability ratings]*

All but three participant (93.5%) indicated at the posttest that they did indeed receive SMS text messages on their phone from the CervixCheck intervention. However, the majority (82.6%) could not recall how many total SMS text messages they actually received from the program. Only 17.4% of the women could correctly recall that a total of 22 SMS text messages were sent from the research team. Half (50%) of the participants felt that they received less SMS text messages than what the intervention had actually transmitted, while a

little under a quarter (21.7%) of the participants reported the opposite – that they felt as if they had received more SMS text messages than what our program actually delivered. The women had greatest recall for messages about cervical cancer (95.7%) and religion/spirituality (91.3%), followed by messages about Pap testing (84.8%) and women’s health (80.4%). Almost half of our sample (47.8%) recalled receiving SMS text messages that contained links to additional resources. 84.8% of the participants indicated that they would “likely” or “very likely” share the information they learned from the intervention with the women around them, with 39.1% indicating that they had already shared some of the information they received from the CervixCheck intervention with others they knew.

At posttest, 82.6% of participants reported being either “satisfied” or “very satisfied” with the CervixCheck intervention and 84.8% of them found the SMS text messages either “useful” or “very useful”. Throughout the rest of the acceptability-based posttest questions, approximately two-thirds or more of our participants reported positively (either “agree” or “strongly agree”) towards the intervention’s ability to keep them satisfied, informed, and engaged on the topic of cervical cancer prevention and early detection. Additionally, 54.4% of the participants indicated that the program helped them to better support the health needs of the women around them. Even though only a little over half (56.5%) of our sample indicated that they would “likely” or “very likely” wish to continue to receive occasional SMS text messages from the program, 82.6% of them indicated that they would participate in a similar SMS text-messaging based program in the future and would recommend a cervical cancer SMS text message program, like CervixCheck to other women in their community if it was offered. Finally, the majority of our participants found that the length of the program

(87%) and the total number of SMS text messages that we sent out (76.1%) were “about right”.

## **DISCUSSION**

The aim of the CervixCheck study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging intervention designed to increase cervical cancer awareness and Pap test screening intention in church-attending African American women ages 21-65. Preliminary results from this study suggests that a spiritually-based SMS text messaging intervention can be a culturally appropriate and effective tool for psychosocial and behavior-related changes around cervical cancer prevention for underserved populations, such as African American women. The present study revealed significant improvement in knowledge about cervical cancer and the Pap test and subjective norms, following the CervixCheck spiritually-based SMS text messaging pilot intervention. The study also showed early feasibility and received positive acceptance among our project participants. Feasibility was evidenced by the development of the SMS text messaging library, identification of a easy-to-use and secure web-based messaging system and service, successful delivery of the SMS text messages to participants, as evidenced by the 93.5% of women who reported receiving the text messages. Overall, the majority of the participants expressed a high degree of acceptability and satisfaction with the CervixCheck intervention, with no one opting out after enrollment.

Results from the baseline data allowed us to determine the preferred frequency of SMS text messages for future interventions like CervixCheck, on an “as needed for news/announcements”, “a few times a week (3/week) or “daily” basis. The high variability in

these responses suggests that there may be additional needs and benefits for a tailored program. It is possible that there are different segments of women technology users, with some individuals who may prefer more frequent messaging, while others' preference may be to receive messages on a less frequent basis. Without the original intent and ability to tailor the intervention to our study participants' preferences for message frequency, keeping everyone truly satisfied and engaged was a challenge. Our current research also suggests that similar interventions should keep in mind not to over-saturate their population with messages on a too-frequent basis.

Data collected from the post-program follow survey allowed us to assess acceptability of the SMS text messages in this population. Although recall of the 22 total SMS text messages received was low, information recall was high and accurate as few women endorsed the “foil” options of “diet and exercise”, “diabetes”, and “upcoming/local community events” messages, which were not included in the message content. Additionally, while it was encouraging to yield results that showed a high percentage of participants reporting satisfaction with the program and who indicated that they found the SMS text messages useful, there were still roughly one-third of the participants who were indifferent about whether they enjoyed getting the SMS text messages from the CervixCheck intervention. While it may seem as though our satisfaction data is not inflated with social desirability bias, this finding further suggests that there is still room for improvement with future messaging.

Nonetheless, overall findings from this study align with several others that have reported favorable results regarding program feasibility, increased impact in reaching the priority population, high rates of program satisfaction, and preliminary evidence of

improvement in intended outcome measures for SMS text message-based interventions (Samal et al., 2010; Levine et al., 2008; Nhavoto et al., 2015; Wen et al., 2014; Shaw et al., 2013; Schoenberger et al., 2013; Le et al., 2015; Lee et al., 2014; Lee et al., 2016). For example, in a culturally relevant physical activity intervention that targeted African American women, messages were delivered three times per week via Facebook and through SMS text messaging (Joseph et al., 2015). Results from this study showed an increase in light/moderate physical activity, enhanced psychosocial outcomes, participant satisfaction and a decrease in sedentary lifestyle among their participants. Similarly, feasibility of a SMS text messaging intervention was also evident in another study that focused on acute decompensated heart failure in a largely African American population (Nundy et al., 2013). Study messages included self-care reminders, patient education on diet, symptom recognition, and health care navigation. This intervention also showed a high rate of satisfaction and preliminary evidence of improvement in the behavioral outcome of heart failure self-management. Findings from the current study are also in line with previous studies of predominately African American men and women where findings revealed that this group was receptive to receiving SMS text messages that focus on cancer and health information (Schoenberger et al., 2013; Le et al., 2015; Yuan et al., 2012).

The spiritually-based nature of the present CervixCheck intervention might partly explain the high acceptance rate of the intervention in our investigation. Extensive research have suggested that African Americans, on average, demonstrate a high degree of religious involvement (Taylor, Chatters, & Levin, 2004). Religion and religious institutions strongly influence individual behavior and social norms (Deshpande et al., 2009; Holt et al., 2009a; King et al., 2005; Lincoln & Mamiya, 2001; Lumpkins et al., 2013; Peterson et al., 2002).



Furthermore, numerous studies have determined that interventions using culturally appropriate public health messages have greater success in achieving behavior change (Lustria et al., 2013; Lee et al., 2016; Lee et al., 2014; Le et al., 2015; Holt et al., 2003a; Matthews et al., 2006; Allen et al., 2014; Lopez & Castro, 2006; Wasserman et al., 2006; Haynes et al., 2014; Davis et al., 1994). Thus, it was naturally logical for us to consider the development and implementation of a spiritually-based intervention in an attempt to address the health needs of the African American community in a culturally appropriate way. Given the role that religion plays in the daily lives of African American women, it is important to understand how their religious beliefs and behaviors may influence how they perceive, initiate, engage, and participate in cervical cancer screening prevention.

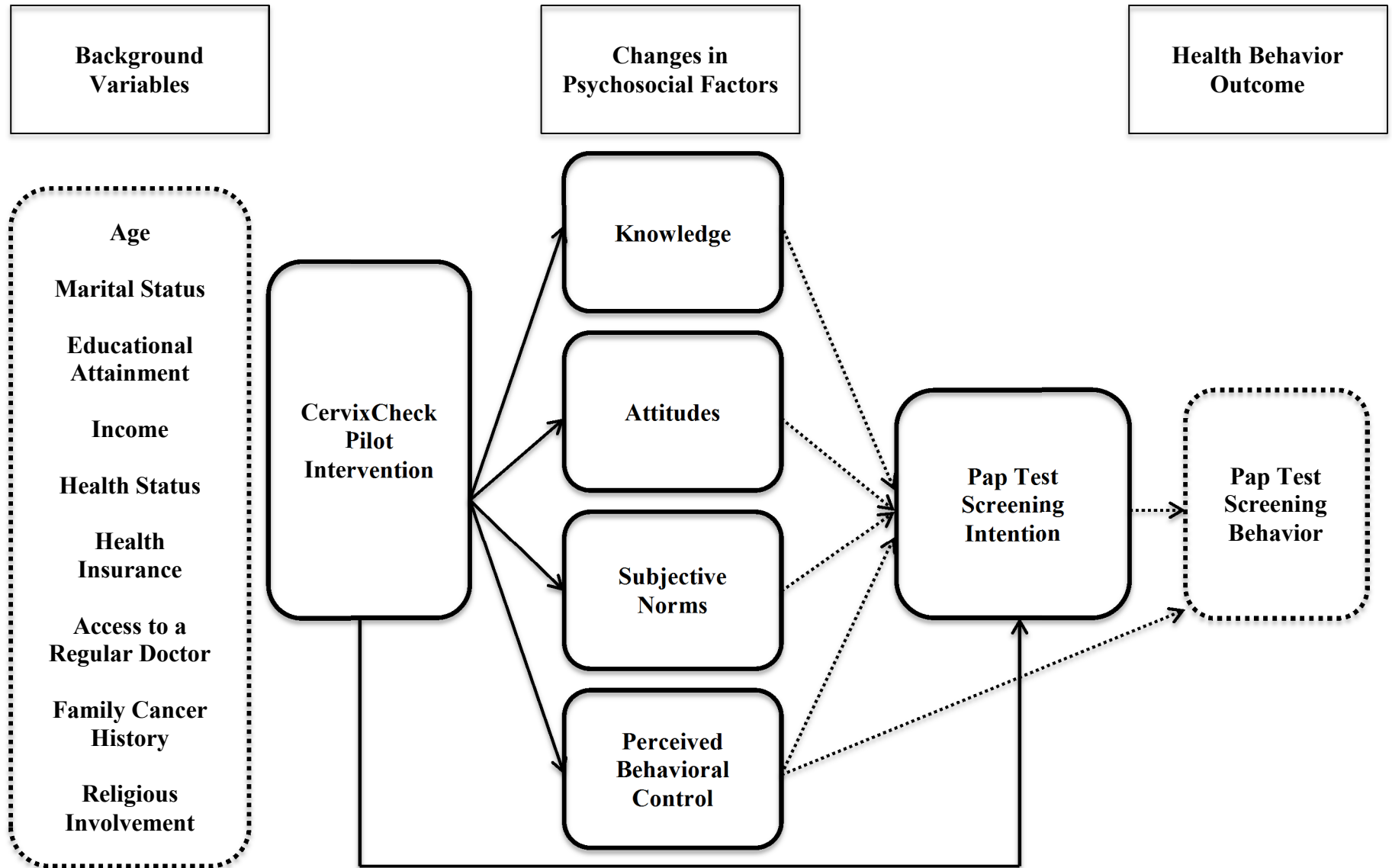
While there are certainly some promising results, there are also inherently some limitations to consider. First, we used a non-experimental one-group pretest-posttest research design with a convenience sample and had a relatively small sample size. Given that the posttest was immediately administered after the intervention ended (approximately two weeks after the study participants had completed their baseline surveys), the significant pre-post increase observed for knowledge about cervical cancer and the Pap test may have been due to a testing effect. Additionally, because our study was not designed for a long-term follow-up period, it was not possible for us to determine if participants retained the information over time, or whether their intent to undergo Pap test screening significantly increased over time, potentially translating into actual behavior change. Further research is needed to validate the effectiveness of the CervixCheck intervention using a rigorous research design, such as a randomized controlled trial with multiple follow-up time points, with a larger sample of African American women. Second, CervixCheck was originally

developed as an automated one-way SMS text messaging intervention to disseminate cervical cancer prevention and early detection education. Feedback on the post-program follow-up survey suggested that some of the study participants had an interest in and may have further gain benefit from a two-way communications intervention that is able to deliver tailored messages, in addition to the standard program messages. These tailored messages would be delivered based on the information collected at baseline and in response to any questions that participants may pose along the way. Investigation is needed to determine if it would be beneficial to individually tailor the content and if doing so would result in greater changes in some of the intended outcome measures. Finally, the ideal intervention medium is not yet known. Further research is needed to determine if a different mobile-based medium, such as an interactive smartphone mobile application, would more effective in disseminating cervical cancer prevention and early detection education and if it would result in greater changes in some of the study outcomes of interest. It is possible that an interactive smartphone mobile application may also allow participants some personal ownership and control over the type of information they receive, as well as when and how often they would like to receive it. Additional research should compare the delivery of cervical cancer prevention and early detection educational intervention through a SMS text message-based program (such as CervixCheck) to one that is delivered through a mobile application. Efforts to address some of the limitations mentioned above can lead to the development of an intervention that is even more effective and efficient in promoting cervical cancer prevention, all while ensuring participants' engagement and satisfaction.

Despite these limitations, our investigation adds important information to the field of health information technology. It provides important findings into what may be considered

an overlooked minority population and missed opportunity in mobile health communication research (Joseph et al., 2015; Joseph et al., 2013; Davies et al., 2012; Vandelanotte et al., 2007; Maher et al., 2014; Norman et al., 2007). Our findings revealed that a spiritually-based SMS text messaging intervention is a promising tool to promote cervical cancer prevention and early detection information for African American women. The current study provides evidence for the initial feasibility, high acceptability and some initial efficacy of the CervixCheck intervention. Given that mobile phone technology represents a nearly universal form of communication among minority populations (Fox & Duggan, 2012), with African Americans sending and receiving SMS text messages more frequently (M=70.1/day; Mdn=20/day) than non-Hispanic Whites (M=31.2/day, Mdn=10/ day) (Smith, 2011), a spiritually-based SMS text messaging intervention could be a cost-effective and culturally appropriate method of reaching and promoting cervical cancer early detection information to church-attending African American women. As one of the first studies to test the acceptability, feasibility, and initially efficacy of a spiritually-based SMS text messaging intervention for cervical cancer prevention, this study provides compelling evidence of the increased potential for a more culturally appropriate technology-based strategy to improve disparities in health outcomes for African American women.

Figure 1. Conceptual Framework (Adaptation of the Theory of Planned Behavior)



**NOTE:** The solid lines, shown above, represent the relationships that were directly measured and reported in this paper.

Table 1. Socio-demographic characteristic of participants at baseline (n= 52)

	<b>Frequency</b>	<b>%</b>
<b>Age</b>		
21-35	23	44.2
36-50	23	44.2
51-65	6	11.5
<b>Marital status</b>		
Single	22	42.3
Living with partner	2	3.8
Married	24	46.2
Separated/divorced	3	5.8
Widowed	1	1.9
<b>Children</b>		
0	26	50
1	7	13.5
2	11	21.2
3	7	13.5
4	1	1.9
<b>Education</b>		
Elementary	-	-
Some High School	-	-
High School Graduate	4	7.7
Some College	6	11.5
College Graduate	42	80.8
<b>Employment *</b>		
Full Time	42	80.8
Part-time	9	17.3
Not currently	2	3.8
I'm disabled	-	-
I'm retired	-	-
<b>Income</b>		
Less than \$5,000	-	-
\$5,001-\$10,000	-	-
\$10,001-\$20,000	1	1.9
\$20,001-\$30,000	3	5.8
\$30,001-\$40,000	4	7.7
\$40,001-\$50,000	7	13.5
\$50,001-\$60,000	4	7.7
\$60,001-\$70,000	4	7.7
\$70,001-\$80,000	2	3.8
\$80,001-\$90,000	5	9.6
\$90,001-\$100,000	6	11.5
More than \$100,000	15	28.8
<i>Missing</i>	<i>1</i>	<i>1.9</i>

<b>Insurance *</b>		
Medicaid	3	5.8
Medicare	-	-
Through Work	45	86.5
Other	4	7.7
<b>Current Health Status</b>		
Excellent	9	17.3
Very Good	27	51.9
Good	12	23.1
Fair	3	5.8
<i>Missing</i>	<i>1</i>	<i>1.9</i>
<b>Longstanding Illness, Disability, or Infirmary</b>		
Yes	46	88.5
No	6	11.5
<b>Regular Doctor</b>		
Yes	9	17.3
No	43	82.7
<b>Current Smoker</b>		
Yes	1	1.9
No	51	98.1
<b>Smoking History</b>		
Never smoked	48	92.3
Smoked occasionally, quit	2	3.8
Smoked regularly, quit	2	3.8
Smoke occasionally	-	-
Smoke regularly	-	-
<b>Religion</b>		
Christian	52	100
Muslim	-	-
Jehovah's Witness	-	-
Other	-	-
<b>Prince George's County Resident</b>		
Yes	40	76.9
No	12	23.1

*\* Participants were able to choose multiple responses.*

Table 2. Pre- to post-intervention changes in knowledge, attitudes, subjective norms, and perceived behavioral control (n=46)

<b>Construct</b>	<b>Baseline Pretest</b>		<b>Posttest</b>		<b>Mean Difference</b>	<b>p value</b>
	N	Mean (SD)	N	Mean (SD)		
Knowledge about cervical cancer and the Pap test	42	7.55 (1.214)	42	8.167 (1.010)	.619	0.001
Attitudes about cervical cancer and the Pap test	45	14.04 (1.882)	45	13.87 (2.018)	-.178	0.338
Subjective norms	45	10.64 (1.956)	45	11.33 (1.966)	.689	0.006
Perceived behavioral control over obtaining a Pap test	45	9.20 (1.120)	45	9.16 (0.928)	-.044	0.750
Perceived barriers to cervical cancer prevention and screening	44	.23 (.711)	44	.23 (.476)	.000	1.000
Pap test screening intention	45	4.67 (.640)	45	4.60 (.720)	-.067	0.596

Table 3. Study participants' intent of getting a Pap test pre- and post-intervention (n=46)

Intent of getting a Pap test						
		Baseline		Pap test due...		
		No intent to test within 6 months	Intent to test within 6 months	Within next 6 months	Within next 12 months	Within 13-36 months
		N (%)	N (%)	N (%)	N (%)	N (%)
Post-test	No intent to test within 6 months	15 (33.3)	6 (13.3)	-	8 (57.1)	12 (26.1)
	Intent to test within 6 months	8 (17.8)	16 (35.6)	15 (100.0)	6 (42.9)	-
	No intent to test within next 12 months	10 (22.7)	10 (22.7)	10 (66.7)	2 (14.3)	14 (31.1)
	Intent to test within next 12 months	13 (29.5)	11 (25.0)	5 (33.3)	12 (85.7)	19 (42.2)
	No intent to test within 13-36 months	8 (19.0)	8 (19.0)	6 (46.2)	7 (50.0)	-
	Intent to test within 13-36 months	15 (35.7)	11 (26.2)	7 (53.8)	7 (50.0)	12 (27.9)



Table 4. Participant SMS text message recall and program acceptability ratings

Question / Statement	Response Options	N (%)	Age		
			21-35 yrs.	36-50 yrs.	51-65 yrs.
			N (%)	N (%)	N (%)
Did you receive any SMS text messages on your phone from the CervixCheck project?	Yes	43 (93.5)	16 (88.9)	23 (100)	4 (80.0)
	No	1 (2.2)	-	-	1 (20.0)
	Not sure	2 (4.3)	2 (11.1)	-	-
How many total SMS text messages do you remember getting?	1-2	1 (2.2)	-	1 (4.3)	-
	3-5	1 (2.2)	-	1 (4.3)	-
	6-10	10 (21.7)	2 (11.1)	7 (30.4)	1 (20.0)
	11-15	11 (23.9)	6 (33.3)	4 (17.4)	1 (20.0)
	16-25	8 (17.4)	4 (22.2)	4 (17.4)	-
	26 or more	10 (21.7)	4 (22.2)	5 (21.7)	1 (20.0)
	Don't remember	2 (4.3)	1 (5.6)	-	1 (20.0)
	Does not apply	3 (6.5)	1 (5.6)	1 (4.3)	1 (20.0)
I remember receiving CervixCheck SMS text messages about... <i>(for those that indicated 'yes')</i> *	Women's health	37 (80.4)	13 (72.2)	20 (87.0)	4 (80.0)
	Cervical cancer	44 (95.7)	17 (94.4)	23 (100.0)	4 (80.0)
	Diet and exercise <sup>a</sup>	8 (17.4)	2 (11.1)	4 (17.4)	2 (40.0)
	Pap testing	39 (84.8)	15 (83.3)	20 (87.0)	4 (80.0)
	Diabetes <sup>a</sup>	-	-	-	-
	Religion/spirituality	42 (91.3)	18 (100)	20 (87.00)	4 (80.0)
	Upcoming/local community events <sup>a</sup>	1 (2.2)	1 (5.6)	-	-
	Links to additional resources	22 (47.8)	8 (44.4)	12 (52.2)	2 (40.0)
	None of the above	-	-	-	-
	Does not apply	1 (2.2)	-	-	1 (20.0)
Did you share any of the information from the CervixCheck Project with others?	No	28 (60.9)	14 (77.8)	12 (52.2)	2 (40.0)
	Yes	18 (39.1)	4 (22.2)	11 (47.8)	3 (60.0)

Overall, how satisfied were you with CervixCheck project?	Very dissatisfied	-	-	-	-
	Dissatisfied	-	-	-	-
	Neutral, no opinion	7 (15.2)	6 (33.3)	1 (4.3)	-
	Satisfied	20 (43.5)	10 (55.6)	8 (34.8)	2 (40.0)
	Very satisfied	18 (39.1)	2 (11.1)	14 (60.9)	2 (40.0)
	Not applicable	1 (2.2)	-	-	1 (20.0)
How useful were the SMS text messages that you received from CervixCheck?	Not at all useful	-	-	-	-
	Somewhat useful	1 (2.2)	1 (5.6)	-	-
	Neutral, no opinion	5 (10.9)	5 (27.8)	-	-
	Useful	27 (58.7)	11 (61.1)	14 (60.9)	2 (40.0)
	Very useful	12 (26.1)	1 (5.6)	9 (39.1)	2 (40.0)
	Not applicable	1 (2.2)	-	-	1 (20.0)
I enjoyed getting text messages from the CervixCheck pilot project.	Strongly disagree	-	-	-	-
	Disagree	1 (2.2)	-	1 (4.3)	-
	Neither disagree nor agree	14 (30.4)	9 (50.0)	3 (13.0)	2 (40.0)
	Agree	22 (47.8)	8 (44.4)	13 (56.5)	1 (20.0)
	Strongly agree	8 (17.4)	1 (5.6)	6 (26.1)	1 (20.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
The CervixCheck text messages kept me informed about cervical cancer prevention & early detection.	Strongly disagree	1 (2.2)	1 (5.6)	-	-
	Disagree	-	-	-	-
	Neither disagree no agree	4 (8.7)	4 (22.2)	-	-
	Agree	27 (58.7)	12 (66.7)	12 (52.2.)	3 (60.0)
	Strongly agree	13 (28.3)	1 (5.6)	11 (47.8)	1 (20.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
The CervixCheck text messages kept me engaged on the topic of cervical cancer prevention & early detection.	Strongly disagree	-	-	-	-
	Disagree	2 (4.3)	1 (5.6)	1 (4.3)	-
	Neither disagree no agree	5 (10.9)	4 (22.2)	-	1 (20.0)
	Agree	21 (45.7)	11 (61.1)	9 (39.1)	1 (20.0)
	Strongly agree	17 (37.0)	2 (11.1)	13 (56.5)	2 (40.0)
	Did not get	1 (2.2)	-	-	1 (20.0)

The CervixCheck text messages made learning about cervical cancer prevention better.	Strongly disagree	-	-	-	-
	Disagree	-	-	-	-
	Neither disagree no agree	11 (23.9)	9 (50.0)	2 (8.7)	-
	Agree	22 (47.8)	7 (38.9)	13 (56.5)	2 (40.0)
	Strongly agree	12 (47.8)	2 (11.1)	8 (34.8)	2 (40.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
The CervixCheck project helped me to better support the health needs of the women around me.	Strongly disagree	1 (2.2)	1 (5.6)	-	-
	Disagree	2 (4.3)	2 (11.1)	-	-
	Neither disagree no agree	17 (37.0)	9 (50.0)	8 (34.8)	-
	Agree	17 (37.0)	6 (33.3)	8 (34.8)	3 (60.0)
	Strongly agree	8 (17.4)	-	7 (30.4)	1 (20.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
I would share the information I learned from the CervixCheck project with the women around me.	Very unlikely	1 (2.2)	1 (5.6)	-	-
	Unlikely	-	-	-	-
	Neither unlikely nor likely	5 (10.9)	3 (16.7)	1 (4.3)	1 (20.0)
	Likely	24 (52.2)	12 (66.7)	12 (52.2)	-
	Very likely	15 (32.6)	2 (11.1)	10 (43.5)	3 (60.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
I would recommend a cervical cancer SMS text messaging program, like CervixCheck, to others in my community if it was offered in the future.	Very unlikely	-	-	-	-
	Unlikely	4 (8.7)	3 (16.7)	1 (4.3)	-
	Neither unlikely nor likely	4 (8.7)	1 (5.6)	2 (8.7)	1 (20.0)
	Likely	25 (54.3)	12 (66.7)	12 (52.2)	1 (20.0)
	Very likely	12 (26.1)	8 (34.8)	8 (34.8)	2 (40.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
I wish to continue receiving occasional SMS text messages from the CervixCheck program.	Very unlikely	6 (13.0)	4 (22.2)	1 (4.3)	1 (20.0)
	Unlikely	6 (13.0)	3 (16.7)	2 (8.7)	1 (20.0)
	Neither unlikely nor likely	7 (15.2)	5 (27.8)	2 (8.7)	-
	Likely	18 (39.1)	6 (33.3)	12 (52.2)	-
	Very likely	8 (17.4)	-	6 (26.1)	2 (40.0)
	Did not get	1 (2.2)	-	-	1 (20.0)

I would participate in a similar SMS text messaging-based project in the future.	Very unlikely	1 (2.2)	1 (5.6)	-	-
	Unlikely	2 (4.3)	-	2 (8.7)	-
	Neither unlikely nor likely	4 (8.7)	2 (11.1)	1 (4.3)	1 (20.0)
	Likely	23 (50.0)	12 (66.7)	10 (43.5)	1 (20.0)
	Very likely	15 (32.6)	3 (16.7)	10 (43.5)	2 (40.0)
	Did not get	1 (2.2)	-	-	1 (20.0)
The length (which was ~2 weeks) of the CervixCheck pilot program was...	Too long	1 (2.2)	-	1 (4.3)	-
	About right	40 (87.0)	14 (77.8)	21 (91.3)	5 (100.0)
	Too short	3 (6.5)	2 (11.1)	1 (4.3)	-
	Undecided/not sure	2 (4.3)	2 (11.1)	-	-
The total number of SMS text messages that the CervixCheck pilot program sent out was...	Too much	8 (17.4)	5 (27.8)	3 (13.0)	-
	About right	35 (76.1)	11 (61.1)	20 (87.0)	4 (80.0)
	Not enough	1 (2.2)	1 (5.6)	-	1 (20.0)
	Undecided/not sure	2 (4.3)	1 (5.6)	-	-

*\* Participants were able to choose multiple responses for this variable.*

*a No SMS text messages on these topics were sent*

## Chapter 6: Summary

Few interventions have used SMS text messages in cancer prevention and education, particularly targeting the African American community. Previous research illustrates the need to build upon and strengthen technology-based communication programs in order to better address the health needs of minority and traditionally hard-to-reach populations. Given the prominent role that religion plays in the day-to-day lives of African American women, it is not only important to understand how their religious beliefs and behaviors may influence how they perceive, initiate, engage, and participate in cervical cancer screening prevention, but to begin to incorporate what we do understand about this relationship into future health behavior change interventions, in particular those that use technology-based platforms.

Utilizing both qualitative and quantitative methods, the purpose of this dissertation study was to develop, pilot test, and evaluate the feasibility, acceptability, and initial efficacy of a spiritually-based SMS text messaging intervention to increase cervical cancer awareness and Pap test screening intention among African American women ages 21-65. Each phase conducted as part of this dissertation provided findings that can be (1) expanded upon to develop health initiatives and faith-centered interventions, to underserved minority groups that may face similar barriers to cervical cancer prevention and early detection education, on a larger scale or (2) adopted, and modified appropriately, to influence other harder-to-reach ethnic groups with high levels of cervical cancer and cervical cancer-related mortality where religion and spirituality may also play a central role in their daily lives.

The findings and lessons learned from this dissertation can be summarized as follows:

- Although general access to healthcare (e.g. having coverage through health insurance or access to a regular doctor nearby) was mentioned as a reason why women in their

communities may not go in to get screened for cervical cancer, the participants in this study discussed how the lack of general knowledge, awareness, and communication around this particular type of cancer may be the stronger influential factors. This may be partially influenced by the fact that all of the participants in this study had access to health insurance. However, this may also continue to hold true for others in this priority population given the fact that everyone is supposed to be (if they are not already) insured under the Affordable Care Act.

- Study participants overwhelmingly shared how cervical cancer and Pap testing get minimal attention in their community, especially in comparison to other cancers such as breast cancer and prostate cancer. Other themes that surfaced around the topic of Pap test screening included: (1) discomfort (e.g. most of the participants described getting the Pap test as being invasive, awkward, painful, cold, and uncomfortable); (2) intergenerational relationships (e.g. the older generation, the parents, are not discussing these issues with their children; there is a lack of conversations around cervical cancer and Pap testing within the family setting); (3) confusion regarding current (and recently changed since 2012) screening recommendations (e.g. some of the women did not know when you should start getting the Pap test and how often you should get them; others found the screening guidelines hard to remember); and (4) patient/provider relationship and communication (e.g. doctors need to actively let their patients know the importance of getting a Pap test, the risk of not getting one, and patiently walk their patients through what the procedure is like). With regards to general knowledge around the Pap test, a little over half of the focus group participants indicated that they were unaware that it was a screening procedure for

cervical cancer. Moreover, there was a lot of confusion across both of the focus groups when the women were asked whether they knew what the screening recommendations currently were for cervical cancer. Although all of the participants reported familiarity with the Pap test, most of the women (83%) were unable to correctly identify what the current Pap test screening recommendation was for cervical cancer. These individuals were unable to identify when (i.e. at what age) a women should begin to get Pap test screened and how often these screenings should take place. Future interventions should focus on targeting some of the aforementioned barriers in order to improve upon and to create even more effective cervical cancer prevention programs that target the African American community.

- Cervical cancer, getting Pap test screened, and just sex in general, are not frequently (if at all) talked about in certain segments of the African American community, especially outside of a doctor's visit or an introductory sex education course. A testament to this finding is that upon completion of the focus group sessions, some of the women spoke about how great it was to speak to other women about these topics, and to not only share their opinions, but to hear from others' as well. They agreed that there was a need for discussions like these to take place earlier and more often, especially within the family setting. Moreover, some of the focus group participants felt it was insightful to hear how and why some women were able to prioritize cervical cancer screening in their own lives and how others were able to initiate conversations about sexual and reproductive health within their own families. This type of interaction and communication among the women, post focus group,

reinforces the need for future interventions to incorporate modeled conversations for this targeted population.

- The burden of cervical cancer among African American women is a multifaceted issue that relates to several social, structural, cultural, and behavioral factors. The multitude of factors ranges from lack of knowledge about the topic to self-efficacy in keeping up with routine screening and misconceptions around the human papillomavirus. As a result, there needs to be an increased understanding of all the influential factors that impact African American women's decision-making in screening practices. This would help us build upon and strengthen current research in the area and to develop effective cervical cancer prevention programs that can translate the increase in knowledge to actual behavior change.
- Health outreach and campaign efforts need to be framed within a social, structural, and cultural context for African American women, with more emphasis on self-efficacy in keeping up with routine screening, cultural issues that are pertinent to their daily lives, and education, communication, and power dynamics within their family. There is a need for future interventions that can speak to their day-to-day struggles, personalize their risks, adapt to them culturally, and that can emanate a collective (family and/or community-oriented), realistic, and emotion-provoking tone. Programs that speak to these women one-on-one (as "one of their own"), or hit close to home via the discussion of personal cervical cancer-related tragedies, would serve well in the development of a successful intervention. Acknowledging and addressing the concepts of religion, spirituality, and family dynamics can also strengthen such programs. Religion and spirituality often provide African American families with



unifying beliefs, principles, and practices and therefore, should be considered and incorporated in future health prevention and outreach efforts.

- Since technology advances have made SMS text messaging more accessible among minorities, incorporating this platform in health interventions is a promising avenue to reach the African American community. SMS text messaging is supported by most mobile phones, is inexpensive, and can be accessed at a time that is convenient for the recipient. This approach can be an important asset in empowering African American women to make informed decision about cervical cancer screening, and their health in general. A major benefit of this SMS text message-based pilot intervention was the convenience to our participants. This program decreased participants' burden of not having to attend face-to-face intervention sessions and allowed them 24-hour access to our intervention materials, to which they were also able to share with others around them.
- Mobile-based interventions, such as this SMS text messaging program, should be carefully developed, tested, and refined before implementation to ensure that 1) the content is framed in the most appropriate way for their target population and that 2) the intended information is delivered and received as it is supposed to. Although some may be tempted to rely on common sense and skip a formative stage prior to implementation of such interventions, the process of iterative formative research to develop the content and logistics for similar programs, such as the one presented in this dissertation, is essential in helping to identify challenges to be addressed prior to the implementation of any piloting phase.

- The development and implementation of culturally appropriate interventions through a community-based or -engaged approach can be successful in addressing the underutilization of cancer screening among African Americans. The process of developing this pilot intervention involved substantial participation of the priority population in all stages of the intervention development. This participation was viewed as a necessary element of a culturally appropriate intervention, not only to allow for community ownership of the project but also to ensure that the intervention is indeed culturally appropriate, and not based on assumptions from the research team that may or may not be accurate. Ultimately, the intervention was finalized through an iterative community-engaged process that required a substantial amount of time and commitment from everyone involved. It is important to note that the use of a multi-pronged recruitment strategy also played a critical role in the successful implementation of this pilot program.
- Initial usability testing allowed the research team the ability to test the revised draft system and to use this time to identify and correct some of the programming issues that came up. This may have contributed to the minimal programming issues that we encountered during the piloting phase.
- Short factual health- and spiritually-based SMS text messages were well received with this targeted audience. Post-program evaluations indicated that this group may also be open to receiving interactive messages with polls and true/false quizzes with feedback reporting the aggregate responses. Allowing participants to submit keywords to receive specific information may also be well received and can also be explored in forthcoming studies.

Given the low cost, widespread use, and continuously growing field of and for mobile technology, these findings could be used to inform researchers and policy makers in designing technology-based interventions and campaigns that are culturally appropriate to better reach individuals and communities that are drawn to religion and spirituality in order to reduce cervical cancer incidence and mortality rates. Combined with a spiritually-based approach, mobile phone technology and SMS text message-based programs have the increased potential to serve as strategic intervention mediums to improve disparities in health outcomes for the African American community. Non-significant findings from this dissertation study can also serve as areas or constructs that can be targeted and improved upon in future plans for theory-based intervention development.

### ***Implications for Future Research***

By using important spiritual themes to frame cervical cancer educational content and by delivering these health messages through a popular communication delivery channel for African American women, this pilot intervention attempted to situate health beliefs and behaviors in the context of culture in hopes of moving cancer interventions one step closer to being more accessible and culturally appropriate for this targeted group. The findings of this dissertation study speak to the need for larger scaled interventions to validate the effectiveness of culturally appropriate technology-based strategies to improve disparities in cervical cancer health outcomes for underserved populations, such as African American women. For example, future studies can use a randomized controlled trial research design, with multiple follow-up time points and with a larger sample size, to determine if participants are able to retain knowledge over time and whether their intent to undergo Pap test screening will significantly increase over time, potentially translating into actual behavior change.

Results from this study also suggest that further investigation is needed to determine if it would be beneficial to individually tailor the content for a similar program and if doing so would result in greater changes in some of the intended outcome measures. Study participants may have an interest in and gain further benefits from a two-way communications intervention that is able to deliver tailored messages, in addition to the standard program messages. These tailored messages would be delivered based on the information collected at baseline and in response to any questions that participants may pose along the way. Findings around preferences for message frequency from this study also suggest that there may be additional needs and benefits for a tailored program. It is possible that there are different segments of women technology users, with some individuals who may prefer more frequent messaging, while others' preference may be to receive messages on a less frequent basis.

Finally, future research may also want to explore the impact of alternative forms of technology, such as mobile phone applications and social media, in the promotion of cervical cancer prevention information to the African American community. It is possible that an interactive smartphone mobile application may allow participants some personal ownership and control over the type of information they receive, as well as when and how often they would like to receive it. Further studies are needed to determine if this different mobile-based medium would more effective in disseminating cervical cancer prevention and early detection education and if it would result in greater changes in some of the study outcomes of interest.

In taking these steps, we could move one step closer to the development of interventions that are even more effective and efficient in promoting cervical cancer

prevention, all while ensuring participants' engagement and satisfaction. As one of the first studies to test the acceptability, feasibility, and initially efficacy of a spiritually-based SMS text messaging intervention for cervical cancer prevention, this study provides compelling evidence of the increased potential for a more culturally appropriate technology-based strategy to improve disparities in health outcomes for African American women.

## Appendices

### Appendix A: Institutional Review Board Approval Letter



1204 Marie Mount Hall  
College Park, MD 20742-5125  
TEL. 301.405.4212  
FAX 301.314.1475  
irb@umd.edu  
www.umresearch.umd.edu/IRB

DATE: February 22, 2016

TO: Daisy Le, MPH/MA  
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [868903-1] Cervical Cancer Awareness and Pap Test Screening Intention among African American Women

REFERENCE #:  
SUBMISSION TYPE: New Project

ACTION: APPROVED  
APPROVAL DATE: February 22, 2016  
EXPIRATION DATE: February 21, 2017  
REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 7

Thank you for your submission of New Project materials for this project. The University of Maryland College Park (UMCP) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Prior to submission to the IRB Office, this project received scientific review from the departmental IRB Liaison.

This submission has received Expedited Review based on the applicable federal regulations.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of February 21, 2017.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Unless a consent waiver or alteration has been approved, Federal regulations require that each participant receives a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this committee prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others (UPIRSOs) and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

Please note that all research records must be retained for a minimum of seven years after the completion of the project.

If you have any questions, please contact the IRB Office at 301-405-4212 or [irb@umd.edu](mailto:irb@umd.edu). Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Maryland College Park (UMCP) IRB's records.

Appendix B: Phase 1's Recruitment Flyer

**Cervical Cancer**  
Access & Behavior

We want to hear from you on...  
**Pap Test Screening  
Access & Behavior**

*The first focus group is currently  
scheduled to take place on Friday,  
February 26<sup>th</sup>, 2016 at 4pm.*

**UNIVERSITY OF MARYLAND SCHOOL of PUBLIC HEALTH**  
Advancing a Better State of Health

**JOIN US IN A  
ONE-HOUR  
FOCUS GROUP  
DISCUSSION  
EXPLORING AFRICAN  
AMERICAN WOMEN'S  
BELIEFS & ATTITUDES  
ABOUT CERVICAL  
CANCER PREVENTION  
& EDUCATION!**

**To participate you  
must:\***

- Be a self-identifying church-attending African American women
- Be between the ages of 21 to 65
- Reside in Prince George's County
- Be willing to discuss topics surrounding women's health

**You will be compensated  
\$15  
for your time.**

\*Note: Women who have a history of cervical cancer or hysterectomy may not participate.

**For more information or to RSVP, please contact Daisy Le at [daisyle@umd.edu](mailto:daisyle@umd.edu) or at...**

- WMN4HLTH Study  
(415) 385-7330
- WMN4HLTH Study  
(415) 385-7330
- WMN4HLTH Study  
(415) 385-7330
- WMN4HLTH Study  
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(415) 385-7330



**Appendix C: Phase 1's Participant Eligibility Screener**

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Staff's Version]***

**Participant Eligibility Screening**

- African American woman
- attends church
- resides in Prince George's County, Maryland)
- no history of cervical cancer or hysterectomy
- born between 1951 and 1995: \_\_\_\_\_ (*year*)
- has access to a phone that is capable of receiving & sending SMS text messages)

---

*Last Name & First Initial or ID #*

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Community's Version]***

**Participant Eligibility Screening**

- Are you an African American (Black) woman?    YES    /    NO
- Do you attend church?    YES    /    NO
- Do you reside in Prince George's County, Maryland?    YES    /    NO    ]
- Have you ever had cervical cancer or a hysterectomy?    YES    /    NO
- What is your birthday? \_\_\_\_\_
- Do you have access to a phone that is capable of receiving & sending SMS text messages?    YES    /    NO    ]

---

*Last Name & First Initial or ID #*

## Appendix D: Phase 1's Preparation Sheet

### Cervical Cancer Screening & SMS Text Messaging Pilot Intervention

#### Focus Group Discussion

ITEM	QUANTITY	HAVE	DON'T HAVE
Informed Consent Form	30		
Black Ink Pens	15		
Name Tags	15		
Demographic Survey	15		
Legal Pads	2		
Tape Recorder	2 (1 as backup)		
Tapes / SD Memory Cards	3 (90 minutes)		
Incentive Log	1		
Cash Incentives	15 x \$15 = \$225		
Sign-In Sheet	1		
Rechargeable Batteries	1 set		
Map w/ Directions to FG Site Location: TBA	15		
Room Sign	3 sets		

## Appendix E: Phase 1's Agenda

### Cervical Cancer Screening & SMS Text Messaging Pilot Intervention

#### Focus Group Discussion

Location: \_\_\_\_\_

Date: \_\_\_\_\_

Time: \_\_\_\_\_

#### AGENDA

- |             |  |
|-------------|--|
| 1:00 - 1:05 | Welcome & Introduction                                   |
| 1:05 - 1:15 | Informed Consent Forms                                   |
| 1:15 - 2:15 | Focus Group Discussion                                   |
| 2:15 - 2:25 | Socio-demographic Surveys                                |
| 2:25 - 2:30 | Distribute Cervical Cancer Educational Materials / Q & A |
| 2:30        | Incentives Distribution                                  |

## Appendix F: Phase 1's Consent Form

<b>Project Title</b>	A Spiritually-Based SMS Text Messaging Pilot Intervention to Increase Cervical Cancer Awareness and Pap Test Screening Intention Among African American Women: Focus Group (Phase 1)
<b>Purpose of the Study</b>	This research is being conducted by Ms. Daisy Le, PhD(c), MPH/MA at the University of Maryland, College Park. We are inviting you to participate in this research project because you are a church-attending African American woman between the ages of 21 to 65. The purpose of this research project is to increase awareness about cervical cancer among African American women.
<b>Procedures</b>	<p>The procedures involve a one-time 1-1.5 hour focus group discussion exploring African American women's beliefs and attitudes about cervical cancer prevention and education. We will create a SMS text messaging educational program and see how well it works for this purpose. Your specific part involves serving on a focus group of African American women who will advise us on the best way to create this educational program. Your participation in this focus group discussion will specifically assist us in determining factors that we will need consider when developing a spiritually-based SMS text messaging communication intervention aimed at increasing Pap test screening intention in church-attending African American women.</p> <p>There will be two focus group discussions held, with a maximum of 10 individuals per session. Thus, you will be one of 20 women chosen to participate in this phase of the project. You will be expected to come to a meeting in the community or at an agreed-upon location of convenience to you. You will be expected to share your opinions on materials to be used in the SMS text messaging educational program. The discussion will be recorded and transcribed. We will provide you with a token of appreciation valued at \$15 for participating.</p>
<b>Potential Risks and Discomforts</b>	<p>Because the focus group guide asks only minimally sensitive issues, it poses little risk. You may feel some stress or anxiety from thinking about cervical cancer. However, this risk is not considered serious.</p> <p>Groups will be audio recorded and information gathered may be used in scientific presentations and publications relating to this project. The recordings will remain the property of the study staff and will not be used for any other purpose beyond those stated above. Loss of confidentiality is always a risk with human participants; however we consider this risk minimal and have put in place safeguards to ensure that confidentiality is protected (see below).</p>

<b>Potential Benefits</b>	This phase of the research is not designed to help you personally, but the results may help us learn more about how best to raise awareness about cervical cancer in the African American community.
<b>Confidentiality</b>	<p>We will do our best to keep your personal information confidential. To help protect your confidentiality, your name will not appear on any of the notes from our meetings. Information from your participation will be used for the purposes of instruction and scientific publication only. Your identity as a participant will not be revealed in any way by the investigator or her research team. Information will be made public only in the form of summaries, which make it impossible to tell who the participants were. If you like, you can receive a copy of the results of this investigation and/or discuss the study with a staff person. Just call one of the numbers at the end of this form and we will be happy to answer all of your questions and furnish you with a copy of the results.</p> <p>Any potential loss of confidentiality will be minimized by storing any data with identifying information in a locked file cabinet, and password protecting any electronic files that contain identifying information. Your name will not be included on any of the collected data. Instead, a unique number will be assigned. Through the use of an identification key, we will be able to link the collected data to your identity. Only the principal investigator, Ms. Daisy Le will have access to the identification key. All project data that contains names or identifiers will remain in secured storage such as a locked filing cabinet. We will record the focus group discussion and the tape will be destroyed after it is transcribed.</p> <p>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law. For some forms, we will use a unique numeric code for the data we have collected instead of your name. Your name will not be included on any of the data collected for this research study.</p>
<b>Medical Treatment</b>	The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.
<b>Right to Withdraw and Questions</b>	Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

	<p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Daisy Le, PhD(c), MPH/MA  University of Maryland, School of Public Health  1101H School of Public Health Building (255)  College Park, MD 20742  301-405-7875  daisyle@umd.edu</p>	
<b>Participant Rights</b>	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park  Institutional Review Board Office  1204 Marie Mount Hall  College Park, Maryland, 20742  E-mail: irb@umd.edu  Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>	
<b>Statement of Consent</b>	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
<b>Signature and Date</b>	<b>NAME OF PARTICIPANT</b> [Please Print]	
	<b>SIGNATURE OF PARTICIPANT</b>	
	<b>DATE</b>	

## Appendix G: Phase 1's Moderator's Discussion Guide

### Focus Group Moderator's Discussion Guide *Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

**TOTAL PARTICIPANT TIME REQUIRED: 1.5 HOURS / 90 MINUTES**

#### **INTRODUCTION, EXPLANATION, GROUP PROCESS (10 minutes)**

*Greet participants as they arrive. Ask them to take a seat and make themselves comfortable. Have them sign a sign-in sheet as well as fill out the participant demographic information sheet and the informed consent form. Have them settle in.*

#### **INTRODUCTION (10 minutes)**

##### **1. Introduction of facilitator and note-taker**

Welcome and thank you for coming today. My name is Daisy Le and I am the principal investigator for the “Cervical Cancer Awareness and Pap Test Screening Intention among African American Women” study. I am a doctoral candidate with the School of Public Health here at the University of Maryland, College Park and I have come to talk with you and to ask you some questions about cervical cancer screening and your sources of information for this knowledge. I will be leading today’s discussion. My role, for the most part, is to make sure that we get through our interview, keep to the time frame, and make sure that you all have a chance to talk. We will also be taking notes along the way.

In addition, I will also be audiotaping the session, but that is just to help me remember what we talked about and to ensure that I record the discussion accurately. The discussion session today will take approximately 90 minutes and of course, everything we discuss here today will strictly remain confidential. From our discussion as a group today, I will summarize what you tell me in a report for my dissertation project, but your names will not be included in the report. Phase 1 of my proposed dissertation project will utilize focus group interviews as a qualitative means to explore and examine culture & issues of access in cervical cancer prevention among African Americans. In particular, this focus group interview is being conducted to help me develop the conceptual basis for designing effective educational messages and materials surrounding the development of a spiritually-based SMS text messaging pilot intervention designed to increase cervical cancer awareness and Pap test screening intention among church-attending African American women who reside in Prince George’s County, Maryland.

##### **2. Participant introductions**

Now, let’s go around the room and have each of you introduce yourselves; give your first name and any other information about yourself you want to share with the group.

### 3. Purpose of the focus group session

A focus group is a method for collecting data similar to surveys, except that rather than asking questions on a one-on-one basis, questions are posed to the whole group and everyone is asked to respond and talk to each other. I am interested in your own opinions, in other words, what you think and feel. Today's topic is on cervical cancer and Pap test screening.

I have asked you here because you are part of the population I aim to reach, thus I consider you all to be the experts. I am interested in *your* experiences, *your* opinions, *your* concerns, and *your* thoughts related to this topic. I am interested in knowing how to encourage women, such as yourselves, to get Pap smears on a regular basis. Today I would like to hear your thoughts about anything that you would find helpful or insightful in reaching women such as yourselves. Remember – you do not have to tell me anything personal or embarrassing about yourself. Though I do want your ideas about these issues, I only want them to the extent that you feel comfortable in sharing.

#### Ground Rules

Several guidelines that I would like everyone to follow during this session are:

- RESPECT the opinions of others in this session by not judging any comments made. I want all of you to express your opinions as I am very interested in hearing multiple points of view about the issues and points that are going to be brought up. There are no right or wrong answers, only different ideas. So please be honest and share what you think.
- DO NOT HOLD SIDE CONVERSATIONS. I want to make sure that we hear what everyone says. Avoid talking over someone else so that everyone has an opportunity to comment. Because I am also recording the session, it would really help me if you could speak up so that everyone can hear you.
- Finally, please be aware that TIME IS LIMITED during this session so while I will try to address all questions and comments during this session, as the moderator, I may have to from time to time, move on from a topic. If this situation arises, please write down your additional questions or comments and I will try to respond at the end of the session. I'll now pass out paper and pencils for you to do this.

Are there any more questions before we begin?

Great! Well, let's jump right in, shall we?

---



## **I. CERVICAL CANCER** (10 minutes)

### **DEFINITION**

- When you think of cervical cancer, what comes to mind?
- Who do you feel is at risk for cervical cancer?
- What do you think makes people at increased risk for developing cervical cancer?

### **ATTITUDE**

- What can you do to prevent cervical cancer?
- If cervical cancer is detected early, can it be cured? Why or why not?
- Do you feel that people in your community are at an increased risk for cervical cancer?
- Has cervical cancer ever affected you personally?
  - PROBE: Do you know anyone who has/had cervical cancer?
- Would you say that cervical cancer prevention is currently a priority in your life?

## **II. CERVICAL PAP TEST EXAMINATIONS** (30 minutes)

Now I would like to ask you some questions specific to the cervical Pap test examinations. A Pap test or Pap smear is a routine test in which the doctor examines a woman's womb and gently wipes the opening of the womb with a flat wooden stick and/or clean cotton Q-tip to check the health of the surface skin of the opening of the womb. [*SHOW PICTURE*].

### **DEFINITION**

- Have you ever heard of a Pap smear exam or a Pap test?
- When you think of a Pap smear exam or a Pap test, what comes to mind?

### **KNOWLEDGE**

- At what age do *you* think that a woman should begin getting a Pap smear?
- At what age is it *recommended* that women begin having regular Pap smears?
- How often do *you* think a woman *your age* should get a Pap smear?

### **ATTITUDE**

- How important is it to *you* to go in to get a Pap smear done? Done annually?
- Do you believe that regular physical exams, medical screening tests, and knowledge of changes in your body may help detect early signs of cervical cancer? Why or why not?

### **GENERAL HABITS:**

Now I'd like to learn more about your general screening history and habits.

- Have you ever had a Pap smear?
  - PROBE (*if necessary*): If not, what is the most likely reason that keeps you from having one done?
- How often do you get a Pap smear?
  - PROBE: Do you go annually?

- PROMPT: *once or more a year, twice a year, once every two years, less frequent than once every four years, when there is pain, when there is a smelly discharge, etc.*
- What was the ONE main reason why you had this Pap smear test?
  - PROBE: Did you have this Pap smear test completed...
  - PROMPT: *as part of a routine physical exam, because of a specific gynecological problem, as a follow-up to a previously identified gynecological problem, etc.*
- What is ONE statement that BEST reflects your intent about getting a Pap smear?
  - PROMPT: *I have not even thought about getting a Pap smear, I have had one in the past, but am not thinking about getting another one, I know I need to think about getting one someday, but probably not in the next year, I have never had a Pap smear, but I am planning to make the appointment to get one in the next year, I plan to make an appointment to get one done within the next three months, I plan on continuing to get them yearly, no idea, etc.*
- Do you take a conscious effort to schedule your cervical cancer screening as recommended (i.e. every three years)? Why or why not?

## **MOTIVATIONS**

Many factors have been shown to influence why women go in to see a gynecologist and/or go in to get their Pap smear completed as recommended such as family members, television ads, and friends.

- What or who motivates you to go in for a Pap smear?
  - PROBE:
    - Do you think anyone influences your decision to go see a gynecologist to get your Pap smear completed as recommended? If so, who?
    - How do you think those factors or people have an effect on your screening behavior?
    - Are you motivated to get screened as recommended because of health benefits?
    - Are there any negative factors that discourage you from getting screened as recommended?

## **ACCESS & HINDERING FACTORS - OBSTACLES/FACILITATORS**

In addition to factors that may encourage you to go see a gynecologist and to get screened as recommended, there are also factors that may discourage you from doing so.

- Do you feel that Pap smear screening is readily available to you?
  - PROBE: Do you believe that screening can be inexpensive and quick? Why or why not?
  - PROMPT: *price, access, availability, etc.*
- How do you decide whether or not you should go get screened?

### III. MEDIA INFLUENTIAL FACTORS (5 minutes)

#### CERVICAL CANCER

- Within the last two years, have you seen anything about cervical cancer in the media, at workshops/presentations, and/or in a brochure?
  - PROBE: How much information did you learn from it? Who sponsored it, where was it held, and how long ago was it?

### IV. CHANNELS (10 minutes)

To further understand what influences you to go in and get your Pap smear screening done, I would like to know about advertisements and social media messages that work for you.

- What are the most memorable advertisements or social media messages that you have ever seen? This does not have to be an advertisement about going in and getting Pap smear screened.
- What stands out about those ads?

Now I am going to ask you some questions that will help me plan how to get our message out.

- Do you think a spiritually-based SMS text messaging program would appeal to other women like yourselves? Why or why not?
- What factors should be considered when developing this type of program (e.g. would you prefer messages that are intense/in-your-face messages or subliminal/low-key)?
- What would this spiritually-based SMS text messaging program look like (e.g. how often should message be sent out, what types of messages should be incorporated, etc.)?

### V. SOLUTIONS - OUTREACH & PREVENTION PROGRAMS (10 minutes)

As previously mentioned, I want to create a spiritually-based SMS text messaging program to increase cervical cancer awareness and Pap test screening intention for women, like yourselves.

- What other ways do you feel is best to receive information about cervical cancer and the benefits of getting Pap smear screened as recommended?
- Suppose you were developing a program to encourage people like yourself to go in and get screened on an annual basis. What would you do?
  - PROBE: What are some things that would encourage people to go get screened?
  - PROMPT: *Incentives? Easily accessible referrals to the closest clinics? Low-cost/free services?*
- Can you think of 3 words or a phrase that captures an important point or idea that ties in the benefits of getting Pap smear screened and cervical cancer prevention for church-attending African American women?

**ACKNOWLEDGEMENTS AND CLOSING**      *(5 minutes)*

Well, thank you for participating in this focus group and for sharing your wisdom and experience. At this point, I have asked you all of my questions. Is there any you would like to ask me? Have any of you written down a question that you would now like to bring up?

Once again, thank you so much for talking with me. The information you have provided has been very helpful. As I've mentioned earlier, everything that happened here is confidential. Your name won't be included in any materials that result from this discussion. However, if there was anything that you said today that you wish to be deleted from the tape, please let me know. Thank you again for your help.

## Appendix H: Phase 1's Participant Socio-demographic Survey

### Cervical Cancer Screening & SMS Text Messaging Pilot Intervention

#### *Focus Group: Tell Us About Yourself*

#### **INTRODUCTION**

Thanks for your interest in this study!

By filling out this 5 minute survey, YOU can help us gain a better understanding of Pap test screening among African American in the mid-Atlantic region. This information will help inform our current research and aid in the development of a pilot intervention geared toward African-American women.

YOUR CONFIDENTIALITY WILL BE PROTECTED.

#### **A1. BASIC INFORMATION**

1. What is your name? \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. What is your mailing address?  
\_\_\_\_\_
4. What is your preferred contact number? \_\_\_\_\_ Home / Office / Cell / Other (*circle*)
5. What is your cell phone number? \_\_\_\_\_
6. What is your cell phone carrier (e.g. Verizon, AT&T)? \_\_\_\_\_
7. Are you able to receive text messages? Please circle one. **YES** or **NO**
8. What is your e-mail address? \_\_\_\_\_
9. What church do you attend? \_\_\_\_\_
10. If you qualify for a future study based on your responses to this survey, can a member of the research team contact you? Please circle one. **YES** or **NO**

## A2. DEMOGRAPHICS

The purpose of this short survey is to help us get to know you better.  
All information will be kept confidential.

**1. Who are the top 3 people you go to for health advice? (Put a (X) beside your choices)**

- |                                |                            |
|--------------------------------|----------------------------|
| _____ Spouse/Significant Other | _____ Other Relatives      |
| _____ Parent(s)                | _____ Friend(s)            |
| _____ Grandparent(s)           | _____ Neighbor             |
| _____ Sibling(s)               | _____ Co-worker/Supervisor |

**2. What are the top 3 reasons why you decided to take part in this project? (Put a (X) beside your choices)**

- \_\_\_\_\_ To help people
- \_\_\_\_\_ To help my community
- \_\_\_\_\_ To get involved in health issues
- \_\_\_\_\_ To learn more about cervical cancer
- \_\_\_\_\_ To help my friend(s) who have cancer
- \_\_\_\_\_ Family member(s) have/had cancer
- \_\_\_\_\_ I have/had cervical cancer
- \_\_\_\_\_ I have/had another type of cancer (which type?) \_\_\_\_\_
- \_\_\_\_\_ I want to promote cancer awareness
- \_\_\_\_\_ Other reason \_\_\_\_\_

**3. Do you have a computer with E-mail/Internet access in your home?**  No  Yes

**4. If you work outside the home, do you have a computer with E-mail/Internet access at work?**  
 No  Yes

**5. Please tell us the top 3 places you look for health information (Put a (X) beside your choices)**

- \_\_\_\_\_ Magazine. Which one(s) \_\_\_\_\_
- \_\_\_\_\_ TV. What show \_\_\_\_\_
- \_\_\_\_\_ Spouse/Significant Other/Partner
- \_\_\_\_\_ Radio. What station(s) \_\_\_\_\_
- \_\_\_\_\_ Library
- \_\_\_\_\_ Doctor's Office
- \_\_\_\_\_ Pamphlet/Brochure. If so what kind \_\_\_\_\_
- \_\_\_\_\_ Internet. What website(s) \_\_\_\_\_
- \_\_\_\_\_ Church

**6. Date of Birth** \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

**7. Education**

- Less than High School Education
- High School Graduate or GED
- Some College
- Community College Graduate/Vocational College Graduate
- Bachelor's Degree
- Master's Degree or higher

**8. Relationship Status**

- Never Married
- Currently Single
- Currently Married or Living with Partner
- Separated or Divorced
- Widowed

**9. Current Employment**

- Full-time
- Part-time
- Receiving Disability
- Retired
- Not Currently Employed

**B. HEALTH INSURANCE AND HISTORY**

**We have varied experiences and attitudes about health, sex, and sexual health. The following section asks about where you learned about sex, as well as your beliefs and attitudes about sex and sexual communication. Please answer the following questions as fully as possible. All your responses are confidential and we appreciate your willingness to answer.**

1. What type of health insurance do you have **currently**?
  - a. Medicaid / Medicare
  - b. Private (e.g. HMO, Kaiser, Blue Shield, etc)
  - c. Not sure
  - d. No health insurance
  - e. Other \_\_\_\_\_
2. Are you a cancer survivor? **YES** or **NO**
3. If YES, please specify what type of cancer: \_\_\_\_\_
4. Do you have a family history of cancer? **YES** or **NO**
5. If YES, please specify what type of cancer: \_\_\_\_\_
6. Have you ever had a close friend or relative who has/had cancer? **YES** or **NO**
7. If YES, please specify what type of cancer. \_\_\_\_\_
8. Have you ever had vaginal sexual intercourse? **YES** or **NO**
9. If YES, at what age did you first have vaginal sexual intercourse? \_\_\_\_\_

### C. PAP KNOWLEDGE (SECTION 1)

The following section asks you about your knowledge of a Pap test. Please answer the questions to the best of your knowledge.

1. Have you ever **heard** of a Pap test?
  - a. Yes
  - b. No
  - c. Not sure/Don't know
2. A Pap test is a test for...
  - a. Cervical cancer
  - b. Breast cancer
  - c. Chlamydia
  - d. Gonorrhea
  - e. I don't know
3. A Pap test is a pelvic exam where the doctor takes a scraping of cells from the cervix to check for precancerous changes. According to medical professionals on the guidelines of cervical cancer screening, a **non-sexually active** woman should have her **first** Pap test by what age?
  - a. 16
  - b. 18
  - c. 21
  - d. 25
  - e. 30

### D. BARRIERS

There may be different reasons why women have **never** gotten a Pap test. Below are some reasons that influence women's decisions about getting a Pap test. Select the number that best describes how much the following factors **prevented** you from **EVER** getting a Pap test.

1. What are the reasons that prevented you from **EVER** getting a Pap test in your life?

	Did not prevent at all	Slightly Prevented	Moderately Prevented	Strongly Prevented
a. <b>Comfort</b> level with doctor(s)				
b. <b>Convenience</b> of hours and location of healthcare provider				
c. <b>Cost</b> of service(s)				
d. <b>Embarrassed</b> to go				
e. I am <b>healthy</b>				
f. <b>Not a priority</b>				
g. <b>Not sexually active</b>				



h. <b>Cultural beliefs</b> about cancer and Pap testing				
i. <b>Lack of communication</b> with mother/female guardian about Pap testing				

**E. ACTUAL PAP EXPERIENCE**

**The following questions are about your actual PAP test experience, particularly about your MOST RECENT PAP test. Please answer the following questions based on your experience. Your answers are entirely CONFIDENTIAL. You may skip any questions that you do not feel comfortable answering.**

1. Have you **ever** had a Pap test?
  - a. Yes
  - b. No
  - c. Not sure/Don't know
  
2. What **YEAR** was your **MOST RECENT** Pap test? \_\_\_\_\_
  
3. At what age was your **MOST RECENT** Pap test? Please write "N/A" if you have never had a Pap test. \_\_\_\_\_
  
4. What factor influenced you to have your **MOST RECENT** Pap test?
  - a. Recommendation from a friend
  - b. Recommendation from mother/female guardian
  - c. Recommendation from doctor
  - d. Concern about your own health
  - e. Concern about a sexually transmitted infection
  - f. Need to get contraception (birth control)
  - g. Other (please specify):
  - h. I have never received a Pap test
  
5. At what age did you have your **FIRST** Pap test? Please write "N/A" if you have never had a Pap test. \_\_\_\_\_
  
6. Have you gotten a Pap test **AS RECOMMENDED** since your **FIRST** Pap test (i.e. every three years)?
  - a. Yes
  - b. No
  - c. Don't know
  - d. Don't remember
  - e. Not applicable

## **F. TECHNOLOGY AND SOCIAL MEDIA USE**

**Technology and social media are increasingly ubiquitous in society, and especially among the young and college educated. These questions will inquire about the technology you access and use on a daily basis.**

1. Do you use a cell phone? **YES** or **NO**
  
2. Do you use your cellular phone for text messaging?
  - a. Yes
  - b. No
  - c. I do not use a cellular phone
  
3. How often do you use text messaging to communicate?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not use text messaging
  
4. Do you have a Facebook account? **YES** or **NO**
  
5. How often do you visit or check your Facebook account?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not visit or check Facebook
  
6. Do you have a Twitter account? **YES** or **NO**
  
7. How often do you visit or check your Twitter account?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not visit or check Twitter
  
8. Is your phone a “smart phone” (e.g. iPhone)?
  - a. Yes
  - b. No
  - c. I do not use a cellular phone

9. Which of the following actions do you use your smart phone for? Check all that apply.
- a. Send/receive text messages
  - b. Send/receive emails
  - c. Check or post on Facebook
  - d. Check or use Twitter
  - e. I do not have a smart phone

## **CONCLUSION**

**You've finished the survey! Your responses will be very helpful in helping this women's health project understand the needs of the African American female community and develop tools and programs that can eliminate the health disparities that exist for African American women. If you qualify for a future study based on your responses to this survey, a member of the research team may be in contact with you.**

**To learn more about the project, or if you have any further questions about the study, please contact:**

**Daisy Le, PhD(c), MPH/MA at [daisyle@umd.edu](mailto:daisyle@umd.edu) or at (415) 385-7330**



Appendix J: Phase 2's Recruitment Flyer



Cervical Cancer Awareness

We want to hear from you on...

# Pap Test Screening Access & Behavior



\*Note: Women who have a history of cervical cancer or hysterectomy may not participate.



Next Focus Group: Th., 3/3/2016 at 7:30pm (UMD)  
 1-on-1 Interviews: Sun., 3/6/2016-Tues., 3/8/2016

UNIVERSITY OF MARYLAND SCHOOL of PUBLIC HEALTH  
Advancing a better state of health

**JOIN US IN A ONE-HOUR FOCUS GROUP OR 1-ON-1 DISCUSSION EXPLORING AFRICAN AMERICAN WOMEN'S BELIEFS & ATTITUDES ABOUT CERVICAL CANCER PREVENTION & EDUCATION!**

**To participate you must:\***

- Be a self-identifying church-attending African American women
- Be between the ages of 21 to 65
- Reside in Prince George's County
- Be willing to discuss topics surrounding women's health

You will be compensated

# \$15

for your time.

**For more information or to RSVP, please contact Daisy Le at [daisyle@umd.edu](mailto:daisyle@umd.edu) or at...**

WMN4HLTH Study  
(415) 385-7330

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**Appendix K: Phase 2's Participant Eligibility Screener**

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Staff's Version]***

**Participant Eligibility Screening**

- African American woman
- attends church
- resides in Prince George's County, Maryland)
- no history of cervical cancer or hysterectomy
- born between 1951 and 1995: \_\_\_\_\_ (year)
- has access to a phone that is capable of receiving & sending SMS text messages)

---

*Last Name & First Initial or ID #*

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Community's Version]***

**Participant Eligibility Screening**

- Are you an African American (Black) woman?    YES    /    NO
- Do you attend church?    YES    /    NO
- Do you reside in Prince George's County, Maryland?    YES    /    NO    ]
- Have you ever had cervical cancer or a hysterectomy?    YES    /    NO
- What is your birthday? \_\_\_\_\_
- Do you have access to a phone that is capable of receiving & sending SMS text messages?    YES    /    NO    ]

---

*Last Name & First Initial or ID #*

## Appendix L: Phase 2's Eligibility Telephone Screening Script

### **Cognitive Response Interviews: Eligibility Telephone Screening Script** ***Cervical Cancer Screening & SMS Text Messaging Pilot Intervention***

*[After a potential participant has seen the recruitment flyer and calls for more information, the project staff will use the Eligibility Telephone Screening Script to discuss more information with her.]*

We are looking for church-attending African American women ages 21-65 to read and give their opinions on cervical cancer and Pap test screening health messages. This information will be used with a new spiritually-based SMS text messaging cancer educational program. You will be one of 10 African American women who have agreed to participate in an individual interview. You will receive a \$15.00 incentive for your participation.

Do you think you might be interested?

*[If yes... (screen for eligibility using the eligibility screener)].*

*[If no] Thank you for your time, have a nice day.*

#### **Eligibility Screener**

Please answer these questions to see if you can be a part of the project.

What is your race? \_\_\_\_\_

What is your date of birth? \_\_\_\_\_

Do you attend church? \_\_\_\_\_

Do you reside in Prince George's County, Maryland? \_\_\_\_\_

*[Not eligible]* I am sorry, but you would not be eligible to participate in this project. We are looking for church-attending African American women, between the ages of 21-65, who reside in Prince George's County, Maryland.

*[Eligible]* Great, you are eligible to participate. At the interview, you will be giving us your thoughts on cervical cancer and Pap test screening health messages. The interview will last an hour. For your participation, you will receive a \$15.00 incentive at the interview session. We will meet on [date] from [time] at [location]. I would like to provide you a reminder as the date nears. Can I please have your contact information (name, address and contact number)? *[Use CRT Recruitment Log]* We look forward to meeting you on [date] from [time]. If you any reason you need to contact me, you may call XXX-XXX-XXXX. Thank you very much.

**Appendix M: Phase 2's Recruitment Log**

**Cognitive Response Interviews: Recruitment Log**  
*Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

<b>ID#</b>	<b>Name</b>	<b>Address</b>	<b>Contact #</b>	<b>Best Days</b>	<b>Best Times</b>
1					
2					
3					
4					
5					
6					
7					
8					
9					
10					



## Appendix N: Phase 2's Consent Form

<b>Project Title</b>	A Spiritually-Based SMS Text Messaging Pilot Intervention to Increase Cervical Cancer Awareness and Pap Test Screening Intention Among African American Women: Individual Interviews (Phase 2)
<b>Purpose of the Study</b>	This research is being conducted by Ms. Daisy Le, PhD(c), MPH/MA at the University of Maryland, College Park. We are inviting you to participate in this research project because you are a church-attending African American woman between the ages of 21 to 65. The purpose of this research project is to increase awareness about cervical cancer among African American women.
<b>Procedures</b>	<p>The procedures involve a one-time 1-hour individual discussion about your thoughts and opinions on educational materials (i.e. SMS text messages) to be used in a cervical cancer prevention and education program for African American women. Your specific part involves participating in a one-on-one interview where you will advise us on the best way to educate people on cervical cancer screening. The interviewer will ask you to read parts of the educational materials and then ask you questions about what you read. We want your opinions about the materials, to be able to make them the best that they can be. The information you give us today will help us improve our collection of SMS text messages and make them easier to read. Your participation in this one-on-one discussion will specifically assist us in determining what other factors we will need consider as we continue to create and improve our spiritually-based SMS text messaging communication intervention aimed at increasing Pap test screening intention in church-attending African American women.</p> <p>You will be one of 10 women chosen to participate in this phase of the project. You will be expected to come to a meeting in the community or at an agreed-upon location of convenience to you. You will be expected to share your opinions on materials to be used in the SMS text messaging educational program. The discussion will be recorded and transcribed. We will provide you with a token of appreciation valued at \$15 for participating.</p>
<b>Potential Risks and Discomforts</b>	<p>Because the discussion guide asks only minimally sensitive issues, it poses little risk. You may feel some stress or anxiety from thinking about cervical cancer. However, this risk is not considered serious.</p> <p>This one-on-one discussion session will be audio recorded and information gathered may be used in scientific presentations and publications relating to this project. The recordings will remain the property of the study staff and will not be used for any other purpose beyond those stated above. Loss of confidentiality is always a risk with human participants; however we consider this risk minimal and have put in place safeguards to ensure that confidentiality is protected (see below).</p>

<b>Potential Benefits</b>	This phase of the research is not designed to help you personally, but the results may help us learn more about how best to raise awareness about cervical cancer in the African American community.
<b>Confidentiality</b>	<p>We will do our best to keep your personal information confidential. To help protect your confidentiality, your name will not appear on any of the notes from our meetings. Information from your participation will be used for the purposes of instruction and scientific publication only. Your identity as a participant will not be revealed in any way by the investigator or her research team. Information will be made public only in the form of summaries, which make it impossible to tell who the participants were. If you like, you can receive a copy of the results of this investigation and/or discuss the study with a staff person. Just call one of the numbers at the end of this form and we will be happy to answer all of your questions and furnish you with a copy of the results.</p> <p>Any potential loss of confidentiality will be minimized by storing any data with identifying information in a locked file cabinet, and password protecting any electronic files that contain identifying information. Your name will not be included on any of the collected data. Instead, a unique number will be assigned. Through the use of an identification key, we will be able to link the collected data to your identity. Only the principal investigator, Ms. Daisy Le will have access to the identification key. All project data that contains names or identifiers will remain in secured storage such as a locked filing cabinet. We will record this one-on-one discussion and the tape will be destroyed after it is transcribed.</p> <p>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law. For some forms, we will use a unique numeric code for the data we have collected instead of your name. Your name will not be included on any of the data collected for this research study.</p>
<b>Medical Treatment</b>	The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.
<b>Right to Withdraw and Questions</b>	Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

	<p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Daisy Le, PhD(c), MPH/MA  University of Maryland, School of Public Health  1101H School of Public Health Building (255)  College Park, MD 20742  301-405-7875  daisyle@umd.edu</p>	
<b>Participant Rights</b>	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park  Institutional Review Board Office  1204 Marie Mount Hall  College Park, Maryland, 20742  E-mail: irb@umd.edu  Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>	
<b>Statement of Consent</b>	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
<b>Signature and Date</b>	<b>NAME OF PARTICIPANT</b> [Please Print]	
	<b>SIGNATURE OF PARTICIPANT</b>	
	<b>DATE</b>	

## Appendix O: Phase 2's Facilitator's Script

### CRT Script *Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

Thank you for agreeing to help us by giving us your thoughts about a women's health SMS text messaging pilot program on cervical cancer screening. This information will be used with a new technology-based women's health project. These messages will be delivered through SMS text messages to African American women who take part in the project.

What I will do today is ask you to read some information and then ask you questions about what you read. The information you give me today will help us improve our collection of SMS text messages and make them easier to read.

I will tape record the interview session to make sure we are able to hear all that you have to say. There are no right or wrong answers. We want to hear what you think and feel about the material. You are free to express any concerns you have.

Your comments are confidential. Your name will not appear on anything that you have said in this interview.

First, I need you to look at the form that says Informed Consent Form. This form is for your protection. It tells you all you need to know about what we're going to do here today so that you make an informed decision that this is something you want to be a part of, or not.

We will spend about one hour talking about your opinions on the collection of short messages that we have come up with to use in the upcoming women's health SMS text messaging pilot program on cervical cancer screening. At the end of the session, you will receive \$15 cash in appreciation of your time and participation. There is minimal risk to you for participating. We will keep your name and anything you say confidential. You can stop participating at any time without penalty. When you are ready, you can place your initials at the top of each page and sign your name on the last page where it says "signature of participant" and write in the date. Do you have any questions for me?

*[Participant reads and signs the Informed Consent Form. Interviewer will also sign it and give an unsigned copy to the participant to keep.]*

I'd like to explain what I will ask you to do today and the types of questions I will be asking.

1. First, I will show you a sentence or a set of sentences, ask you to read some or all of it; and then ask you some questions about what you read.
2. I might ask you to "paraphrase" a sentence or part of it. In other words, tell me what the sentence means to you in your own words.

Let me give you an example of what I am talking about. I might ask you to do the following:  
1.

Please read the following sentence:

*Smoking can lead to many health diseases like cancer and bronchitis.*

Then, I would ask you: In your own words, please tell me what this sentence is saying?

And you might respond with:

*Smoking is the cause of several diseases today.*

OR

*Smoking can cause bronchitis.*

I may also ask you to tell me any thoughts that come to your mind as you are reading a sentence, statement or set of sentences.

Let me show you what I mean. Please read the following paragraph:

*If all adult American smokers had quit five years ago, there would have been an estimated 15% fewer overall deaths in the U.S. since then, according to a study by researchers at Rutgers University, published in the American Journal of Public Health in April.*

Then I would ask you: In your own words, please tell me what came into your mind when you read that paragraph?

And you might respond with:

*Quit smoking. We can control our health.*

OR

*I didn't know we could decrease deaths by 15% by quitting smoking.*

At times, I might ask you to tell me what a phrase or word means to you or just give me your opinion. After each sentence or set of sentences, I will let you know what I want you to do. The interview should take an hour. Do you have questions before we start?

1. Please read the following sentences:

**African American women are at higher risk of dying from cervical cancer than other women. This is because too often the cancer is found later, after it has spread.**

**In your own words**, can you please tell me what these two sentences are saying?

Please tell me what came into your mind when you read the sentences above.

2. Please read the following scripture:

**"My People are destroyed from lack of knowledge." - Hosea 4:6**

Please tell me what came into your mind when you read the sentence above.

3. Please read the following sentences:

**Cervical cancer is a cancer that begins in the cervix, the part of the womb (or uterus) that opens to the vagina. It is one of the most preventable types of cancer. [short url to image].**

In your own words, can you tell me what these two sentences are saying?

4. Please read this paragraph:

**One way of preventing cervical cancer is to have a Pap test. The Pap test looks for changes in the cervix that might lead to cancer. Your doctor can tell you how often you should have a Pap test. Finding cervical cancer early is the most powerful tool we can use to fight this disease. By having regular Pap tests, we have a good chance of finding problems earlier when they are most easy to treat.**

In your own words, please tell me what this paragraph is saying?

Please tell me what came into your mind when you read this paragraph.

5. Please read the following scripture:

**"I have come that they may have life, and that they may have it more abundantly." - John 10:10b**

Please tell me what came into your mind when you read the scripture above. Does it relate back to the paragraph you just read previously? If so, how?

6. Please read this paragraph:

**When it comes to our health, doing "our part" means that we take care of our bodies in general, and get the routine exams that we need. This includes getting a Pap test -- the part we do so that God can do His part. We know God will take care of us. But you have to help yourself, too. God has given the doctors knowledge and technology. This is a true blessing that comes from God.**

In your own words, please tell me what this paragraph is saying?

Please tell me what came into your mind when you read this paragraph.

7. Please read the following scripture:

**"Do you not know that your body is a temple of the Holy Spirit... So use every part of your body to give glory back to God." -1 Corinthians 6:19-20**

Please tell me what came into your mind when you read the scripture above. Does it relate back to the paragraph you just read previously? If so, how?

8. Please read the following sentences:

**Support the women in your life and set a good example by doing the things you need to do for you own reproductive health. Take care of your health today to take care of your family tomorrow.**

In your own words, please tell me what these two sentences are saying?

Please tell me what came into your mind when you read the sentences above.

9. Please read the following scripture:

**"I can do all things through Christ which strengtheneth me." -Philippians 4:14**

Please tell me what came into your mind when you read the scripture above.

10. Please read this paragraph:

**If your sister or friend needed help to be healthy, you would help her. Give yourself the same gift. Take charge of your health and talk to your doctor about getting checked for cervical cancer.**

In your own words, please tell me what this paragraph is saying?

Please tell me what came into your mind when you read this paragraph.

11. Please read the following sentences:

**Spread the word and pass the wisdom down from one generation to the next. Share this information with the next generation like a good family recipe.**

In your own words, please tell me what these two sentences are saying?

Please tell me what came into your mind when you read the sentences above.



12. Please read the following scripture:

**"Two are better than one, because they have a good return for their work: If one falls down, his friend can help him up." -Ecclesiastes 4:9**

Please tell me what came into your mind when you read the scripture above.

13. Now please take a look at the table below and tell me about what you think of **the order the messages are in:**

Hi, [first name of participant]. Thank you for being part of the "CervixCheck" Women's Health Project. If you are interested in receiving text messages over the next two weeks from the "CervixCheck" project about cervical cancer, please reply to xxxxx with the response "YES".
African American women are at higher risk of dying from cervical cancer than other women. This is because too often the cancer is found later, after it has spread.
"My People are destroyed from lack of knowledge." -Hosea 4:6
Cervical cancer is a cancer that begins in the cervix, the part of the womb (or uterus) that opens to the vagina. It is one of the most preventable types of cancer. <i>[short url to image]</i> .
One way of preventing cervical cancer is to have a Pap test. The Pap test looks for changes in the cervix that might lead to cancer. Your doctor can tell you how often you should have a Pap test.
"I have come that they may have life, and that they may have it more abundantly." -John 10:10b
Finding cervical cancer early is the most powerful tool we can use to fight this disease. By having regular Pap tests, we have a good chance of finding problems earlier when they are most easy to treat.
"Do you not know that your body is a temple of the Holy Spirit... So use every part of your body to give glory back to God." -1 Corinthians 6:19-20
When it comes to our health, doing "our part" means that we take care of our bodies in general, and get the routine exams that we need. This includes getting a Pap test -- the part we do so that God can do His part.
Support the women in your life and set a good example by doing the things you need to do for you own reproductive health. Take care of your health today to take care of your family tomorrow.
We know God will take care of us. But you have to help yourself, too. God has given the doctors knowledge and technology. This is a true blessing that comes from God.
<i>[Insert Testimonial]</i>
"I can do all things through Christ which strengtheneth me." -Philippians 4:14
If your sister or friend needed help to be healthy, you would help her. Give yourself the same gift. Take charge of your health and talk to your doctor about getting checked for cervical cancer.
When are you due for your routine Pap test? Talk to your doctor to find out. No insurance? No problem. For more information and to see if you are eligible for free screening, go here: <i>[short url]</i> .
Spread the word and pass the wisdom down from one generation to the next. Share this information with the next generation like a good family recipe.
"Two are better than one, because they have a good return for their work: If one falls down, his friend can help him up." -Ecclesiastes 4:9
Dear [first name of participant], thank you for participating in the "CervixCheck" project. We hope you found some of the information we shared with you beneficial! Be sure to contact us with any questions.

The table that was shown to you above showed a list of all the text messages that we hope to send out to the African American women who are eligible and who decide to take part in the upcoming women's health project. Do you think anything else should be included, changed, moved around, and/or removed?

When and how often do you think these text messages should be sent out to our participants (e.g. time of day; how often during the day/week; overall program length)?

Is there anything else you think we should consider as we continue to put together this cervical cancer screening & SMS text messaging women's health program?

Ok the last thing we would like you to do is to fill out this short survey. It has questions that will help us to describe the participants as a whole. Please be assured that we are not interested in any one person's information, but we will put it all together to describe the participants as a group.

We also would like to give you \$15 cash as a small token of our appreciation for your time today. *[Distribute cash incentive and get signature, etc.]*

Thank you again for your time and help with the project. If you need to speak with me, I will be around for a few minutes or you may contact me on my cell phone at (415) 385-7330. Also, my office number is also on the Informed Consent Form that you have a copy of.

## Appendix P: Phase 2's Participant's Copy

### [PARTICIPANT'S COPY]

1. Please read the following sentences:

**African American women are at higher risk of dying from cervical cancer than other women. This is because too often the cancer is found later, after it has spread.**

2. Please read the following scripture:

**"My People are destroyed from lack of knowledge." - Hosea 4:6**

3. Please read the following sentences:

**Cervical cancer is a cancer that begins in the cervix, the part of the womb (or uterus) that opens to the vagina. It is one of the most preventable types of cancer. *[short url to image]*.**

4. Please read this paragraph:

**One way of preventing cervical cancer is to have a Pap test. The Pap test looks for changes in the cervix that might lead to cancer. Your doctor can tell you how often you should have a Pap test. Finding cervical cancer early is the most powerful tool we can use to fight this disease. By having regular Pap tests, we have a good chance of finding problems earlier when they are most easy to treat.**

5. Please read the following scripture:

**"I have come that they may have life, and that they may have it more abundantly." -  
John 10:10b**

6. Please read this paragraph:

**When it comes to our health, doing "our part" means that we take care of our bodies in general, and get the routine exams that we need. This includes getting a Pap test -- the part we do so that God can do His part. We know God will take care of us. But you have to help yourself, too. God has given the doctors knowledge and technology. This is a true blessing that comes from God.**

7. Please read the following scripture:

**"Do you not know that your body is a temple of the Holy Spirit... So use every part of your body to give glory back to God." -1 Corinthians 6:19-20**

8. Please read the following sentences:

**Support the women in your life and set a good example by doing the things you need to do for you own reproductive health. Take care of your health today to take care of your family tomorrow.**

9. Please read the following scripture:

**"I can do all things through Christ which strengtheneth me." -Philippians 4:14**

10. Please read this paragraph:

**If your sister or friend needed help to be healthy, you would help her. Give yourself the same gift. Take charge of your health and talk to your doctor about getting checked for cervical cancer.**

11. Please read the following sentences:

**Spread the word and pass the wisdom down from one generation to the next. Share this information with the next generation like a good family recipe.**

12. Please read the following scripture:

**"Two are better than one, because they have a good return for their work: If one falls down, his friend can help him up." -Ecclesiastes 4:9**

13. Now please take a look at the table below and tell me about what you think of **the order the messages are in:**

Hi, [first name of participant]. Thank you for being part of the "CervixCheck" Women's Health Project. If you are interested in receiving text messages over the next two weeks from the "CervixCheck" project about cervical cancer, please reply to xxxxx with the response "YES".
African American women are at higher risk of dying from cervical cancer than other women. This is because too often the cancer is found later, after it has spread.
"My People are destroyed from lack of knowledge." -Hosea 4:6
Cervical cancer is a cancer that begins in the cervix, the part of the womb (or uterus) that opens to the vagina. It is one of the most preventable types of cancer. <i>[short url to image]</i> .
One way of preventing cervical cancer is to have a Pap test. The Pap test looks for changes in the cervix that might lead to cancer. Your doctor can tell you how often you should have a Pap test.
"I have come that they may have life, and that they may have it more abundantly." -John 10:10b
Finding cervical cancer early is the most powerful tool we can use to fight this disease. By having regular Pap tests, we have a good chance of finding problems earlier when they are most easy to treat.
"Do you not know that your body is a temple of the Holy Spirit... So use every part of your body to give glory back to God." -1 Corinthians 6:19-20
When it comes to our health, doing "our part" means that we take care of our bodies in general, and get the routine exams that we need. This includes getting a Pap test -- the part we do so that God can do His part.
Support the women in your life and set a good example by doing the things you need to do for you own reproductive health. Take care of your health today to take care of your family tomorrow.
We know God will take care of us. But you have to help yourself, too. God has given the doctors knowledge and technology. This is a true blessing that comes from God.
<i>[Insert Testimonial]</i>
"I can do all things through Christ which strengtheneth me." -Philippians 4:14
If your sister or friend needed help to be healthy, you would help her. Give yourself the same gift. Take charge of your health and talk to your doctor about getting checked for cervical cancer.
When are you due for your routine Pap test? Talk to your doctor to find out. No insurance? No problem. For more information and to see if you are eligible for free screening, go here: <i>[short url]</i> .
Spread the word and pass the wisdom down from one generation to the next. Share this information with the next generation like a good family recipe.
"Two are better than one, because they have a good return for their work: If one falls down, his friend can help him up." -Ecclesiastes 4:9
Dear [first name of participant], thank you for participating in the "CervixCheck" project. We hope you found some of the information we shared with you beneficial! Be sure to contact us with any questions.

## Appendix Q: Phase 2's Participant Socio-demographic Survey

### Cervical Cancer Screening & SMS Text Messaging Pilot Intervention

#### *Cognitive Response Interview: Tell Us About Yourself*

#### **INTRODUCTION**

Thanks for your interest in this study!

By filling out this 5 minute survey, YOU can help us gain a better understanding of Pap test screening among African American in the mid-Atlantic region. This information will help inform our current research and aid in the development of a pilot intervention geared toward African-American women.

YOUR CONFIDENTIALITY WILL BE PROTECTED.

#### **A1. BASIC INFORMATION**

1. What is your name? \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. What is your mailing address?  
\_\_\_\_\_
4. What is your preferred contact number? \_\_\_\_\_ Home / Office / Cell / Other (*circle*)
5. What is your cell phone number? \_\_\_\_\_
6. What is your cell phone carrier (e.g. Verizon, AT&T)? \_\_\_\_\_
7. Are you able to receive text messages? Please circle one. **YES** or **NO**
8. What is your e-mail address? \_\_\_\_\_
9. What church do you attend? \_\_\_\_\_
10. If you qualify for a future study based on your responses to this survey, can a member of the research team contact you? Please circle one. **YES** or **NO**



## A2. DEMOGRAPHICS

The purpose of this short survey is to help us get to know you better.  
All information will be kept confidential.

**1. Who are the top 3 people you go to for health advice? (Put a (X) beside your choices)**

- |                                |                            |
|--------------------------------|----------------------------|
| _____ Spouse/Significant Other | _____ Other Relatives      |
| _____ Parent(s)                | _____ Friend(s)            |
| _____ Grandparent(s)           | _____ Neighbor             |
| _____ Sibling(s)               | _____ Co-worker/Supervisor |

**2. What are the top 3 reasons why you decided to take part in this project? (Put a (X) beside your choices)**

- \_\_\_\_\_ To help people
- \_\_\_\_\_ To help my community
- \_\_\_\_\_ To get involved in health issues
- \_\_\_\_\_ To learn more about cervical cancer
- \_\_\_\_\_ To help my friend(s) who have cancer
- \_\_\_\_\_ Family member(s) have/had cancer
- \_\_\_\_\_ I have/had cervical cancer
- \_\_\_\_\_ I have/had another type of cancer (which type?) \_\_\_\_\_
- \_\_\_\_\_ I want to promote cancer awareness
- \_\_\_\_\_ Other reason \_\_\_\_\_

**3. Do you have a computer with E-mail/Internet access in your home?**  No  Yes

**4. If you work outside the home, do you have a computer with E-mail/Internet access at work?**  
 No  Yes

**5. Please tell us the top 3 places you look for health information (Put a (X) beside your choices)**

- \_\_\_\_\_ Magazine. Which one(s) \_\_\_\_\_
- \_\_\_\_\_ TV. What show \_\_\_\_\_
- \_\_\_\_\_ Spouse/Significant Other/Partner
- \_\_\_\_\_ Radio. What station(s) \_\_\_\_\_
- \_\_\_\_\_ Library
- \_\_\_\_\_ Doctor's Office
- \_\_\_\_\_ Pamphlet/Brochure. If so what kind \_\_\_\_\_
- \_\_\_\_\_ Internet. What website(s) \_\_\_\_\_
- \_\_\_\_\_ Church

**6. Date of Birth** \_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_

**7. Education**

- Less than High School Education
- High School Graduate or GED
- Some College
- Community College Graduate/Vocational College Graduate
- Bachelor's Degree
- Master's Degree or higher

**8. Relationship Status**

- Never Married
- Currently Single
- Currently Married or Living with Partner
- Separated or Divorced
- Widowed

**9. Current Employment**

- Full-time
- Part-time
- Receiving Disability
- Retired
- Not Currently Employed

**B. HEALTH INSURANCE AND HISTORY**

**We have varied experiences and attitudes about health, sex, and sexual health. The following section asks about where you learned about sex, as well as your beliefs and attitudes about sex and sexual communication. Please answer the following questions as fully as possible. All your responses are confidential and we appreciate your willingness to answer.**

1. What type of health insurance do you have **currently**?
  - a. Medicaid / Medicare
  - b. Private (e.g. HMO, Kaiser, Blue Shield, etc)
  - c. Not sure
  - d. No health insurance
  - e. Other \_\_\_\_\_
2. Are you a cancer survivor? **YES** or **NO**
3. If YES, please specify what type of cancer: \_\_\_\_\_
4. Do you have a family history of cancer? **YES** or **NO**
5. If YES, please specify what type of cancer: \_\_\_\_\_
6. Have you ever had a close friend or relative who has/had cancer? **YES** or **NO**
7. If YES, please specify what type of cancer. \_\_\_\_\_
8. Have you ever had vaginal sexual intercourse? **YES** or **NO**
9. If YES, at what age did you first have vaginal sexual intercourse? \_\_\_\_\_

**C. PAP KNOWLEDGE (SECTION 1)**

The following section asks you about your knowledge of a Pap test. Please answer the questions to the best of your knowledge.

1. Have you ever **heard** of a Pap test?
  - a. Yes
  - b. No
  - c. Not sure/Don't know
  
2. A Pap test is a test for...
  - a. Cervical cancer
  - b. Breast cancer
  - c. Chlamydia
  - d. Gonorrhea
  - e. I don't know
  
3. **A Pap test is a pelvic exam where the doctor takes a scraping of cells from the cervix to check for precancerous changes.** According to medical professionals on the guidelines of cervical cancer screening, a **non-sexually active** woman should have her **first** Pap test by what age?
  - f. 16
  - g. 18
  - h. 21
  - i. 25
  - j. 30

**D. BARRIERS**

There may be different reasons why women have **never** gotten a Pap test. Below are some reasons that influence women's decisions about getting a Pap test. Select the number that best describes how much the following factors **prevented** you from **EVER** getting a Pap test.

1. What are the reasons that prevented you from **EVER** getting a Pap test in your life?

	<b>Did not prevent at all</b>	<b>Slightly Prevented</b>	<b>Moderately Prevented</b>	<b>Strongly Prevented</b>
a. <b>Comfort</b> level with doctor(s)				
b. <b>Convenience</b> of hours and location of healthcare provider				
c. <b>Cost</b> of service(s)				
d. <b>Embarrassed</b> to go				
e. I am <b>healthy</b>				
f. <b>Not a priority</b>				
g. <b>Not sexually active</b>				

h. <b>Cultural beliefs</b> about cancer and Pap testing				
i. <b>Lack of communication</b> with mother/female guardian about Pap testing				

**E. ACTUAL PAP EXPERIENCE**

**The following questions are about your actual PAP test experience, particularly about your MOST RECENT PAP test. Please answer the following questions based on your experience. Your answers are entirely CONFIDENTIAL. You may skip any questions that you do not feel comfortable answering.**

1. Have you **ever** had a Pap test?
  - a. Yes
  - b. No
  - c. Not sure/Don't know
  
2. What **YEAR** was your **MOST RECENT** Pap test? \_\_\_\_\_
  
3. At what age was your **MOST RECENT** Pap test? Please write "N/A" if you have never had a Pap test. \_\_\_\_\_
  
4. What factor influenced you to have your **MOST RECENT** Pap test?
  - a. Recommendation from a friend
  - b. Recommendation from mother/female guardian
  - c. Recommendation from doctor
  - d. Concern about your own health
  - e. Concern about a sexually transmitted infection
  - f. Need to get contraception (birth control)
  - g. Other (please specify):
  - h. I have never received a Pap test
  
5. At what age did you have your **FIRST** Pap test? Please write "N/A" if you have never had a Pap test. \_\_\_\_\_
  
6. Have you gotten a Pap test **AS RECOMMENDED** since your **FIRST** Pap test (i.e. every three years)?
  - a. Yes
  - b. No
  - c. Don't know
  - d. Don't remember
  - e. Not applicable

## **F. TECHNOLOGY AND SOCIAL MEDIA USE**

**Technology and social media are increasingly ubiquitous in society, and especially among the young and college educated. These questions will inquire about the technology you access and use on a daily basis.**

1. Do you use a cell phone? **YES** or **NO**
  
2. Do you use your cellular phone for text messaging?
  - a. Yes
  - b. No
  - c. I do not use a cellular phone
  
3. How often do you use text messaging to communicate?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not use text messaging
  
4. Do you have a Facebook account? **YES** or **NO**
  
5. How often do you visit or check your Facebook account?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not visit or check Facebook
  
6. Do you have a Twitter account? **YES** or **NO**
  
7. How often do you visit or check your Twitter account?
  - a. More than once a day
  - b. Once a day
  - c. 2-3 times a week
  - d. Once a week
  - e. Less than once a week
  - f. I do not visit or check Twitter
  
8. Is your phone a “smart phone” (e.g. iPhone)?
  - a. Yes
  - b. No
  - c. I do not use a cellular phone

9. Which of the following actions do you use your smart phone for? Check all that apply.
- a. Send/receive text messages
  - b. Send/receive emails
  - c. Check or post on Facebook
  - d. Check or use Twitter
  - e. I do not have a smart phone

## **CONCLUSION**

**You've finished the survey! Your responses will be very helpful in helping this women's health project understand the needs of the African American female community and develop tools and programs that can eliminate the health disparities that exist for African American women. If you qualify for a future study based on your responses to this survey, a member of the research team may be in contact with you.**

**To learn more about the project, or if you have any further questions about the study, please contact:**

**Daisy Le, PhD(c), MPH/MA at [daisyle@umd.edu](mailto:daisyle@umd.edu) or at (415) 385-7330**

**Appendix R: Phase 2's Incentive Log**

**Cognitive Response Interviews: Incentive Log**  
*Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

	<b>Full Name (Last, First)</b>	<b>Mailing Address</b>	<b>Contact # &amp; Provider /Email Address</b>	<b>Signature</b>	<b>Amount Received</b>
<b>1</b>					
<b>2</b>					
<b>3</b>					
<b>4</b>					
<b>5</b>					
<b>6</b>					
<b>7</b>					
<b>8</b>					
<b>9</b>					
<b>10</b>					

Appendix S: Phase 3's Recruitment Flyer

UMD IRB Approval: 84963-1



Join us for a study on...

# Pap Test Screening Access & Behavior



\*Note: Women who have a history of cervical cancer or hysterectomy may not participate.



**HELP US LEARN MORE ABOUT THE RELATIONSHIPS BETWEEN CULTURE, TECHNOLOGY USE, AND CERVICAL CANCER PREVENTION & EDUCATION AMONG AFRICAN AMERICAN WOMEN**



**To be eligible, you must:\***

- Be a church-attending African American women
- Be between the ages of 21 to 65
- Reside in the DC/MD/VA area
- Have access to a phone that is capable of receiving and sending SMS text messages
- Be willing to receive multiple SMS text messages from the project team (~3-6 messages/day over two weeks)
- Be willing to complete two surveys on topics surrounding women's health

You will be compensated  
**\$20**  
 for your time.

**For more information or to participate in this research study, please contact Daisy Le at [cervixcheck100@gmail.com](mailto:cervixcheck100@gmail.com) or at...**

- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330
- CervixCheck Study (415) 385-7330



**Appendix T: Phase 3's Participant Eligibility Screener**

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Staff's Version]***

**Participant Eligibility Screening**

- African American woman
- attends church
- resides in Prince George's County, Maryland)
- no history of cervical cancer or hysterectomy
- born between 1951 and 1995: \_\_\_\_\_ (*year*)
- has access to a phone that is capable of receiving & sending SMS text messages

---

*Last Name & First Initial or ID #*

**Cervical Cancer Screening  
& SMS Text Messaging Pilot Intervention  
*[Community's Version]***

**Participant Eligibility Screening**

- Are you an African American (Black) woman?    YES    /    NO
- Do you attend church?    YES    /    NO
- Do you reside in Prince George's County, Maryland?    YES    /    NO    ]
- Have you ever had cervical cancer or a hysterectomy?    YES    /    NO
- What is your birthday? \_\_\_\_\_
- Do you have access to a phone that is capable of receiving & sending SMS text messages?    YES    /    NO

---

*Last Name & First Initial or ID #*

**Appendix U: Phase 3's Recruitment Log**

**Phase 3: Participant Recruitment**  
*Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

	<b>Full Name (Last, First)</b>	<b>Mailing Address</b>	<b>Contact # &amp; Provider</b>	<b>Email Address</b>	<b>Eligible?</b>
<b>1</b>					
<b>2</b>					
<b>3</b>					
<b>4</b>					
<b>5</b>					
<b>6</b>					
<b>7</b>					
<b>8</b>					
<b>9</b>					
<b>10</b>					

## Appendix N: Phase 3's Consent Form

<b>Project Title</b>	A Spiritually-Based SMS Text Messaging Pilot Intervention to Increase Cervical Cancer Awareness and Pap Test Screening Intention Among African American Women: Pilot Educational Program (Phase 3)
<b>Purpose of the Study</b>	This research is being conducted by Ms. Daisy Le, PhD(c), MPH/MA at the University of Maryland, College Park. We are inviting you to participate in this research project because you are a church-attending African American woman between the ages of 21 to 65. The purpose of this research project is to increase awareness about cervical cancer among African American women.
<b>Procedures</b>	<p>We created a SMS text messaging educational program and would like to see how well it works for increasing cervical cancer awareness and Pap test screening intention in church-attending African American women. If eligible, you will complete an initial questionnaire and participate in an educational program where you will receive multiple SMS text messages from the project team over the span of approximately 3 weeks. When the program is over, you will be asked to complete a final questionnaire.</p> <p>You will be one of 50 women chosen to participate in this phase of the project. You will be expected to have access to a phone that is capable of receiving and sending SMS text messages. At the end of the SMS text messaging educational program, we will provide you with a token of appreciation valued at \$20 for participating (i.e. \$5 for the initial questionnaire and \$15 for the final questionnaire).</p>
<b>Potential Risks and Discomforts</b>	<p>Because the questionnaires ask only minimally sensitive issues, it poses little risk. You may feel some stress or anxiety from thinking about cervical cancer. However, this risk is not considered serious.</p> <p>Information gathered from the questionnaires may be used in scientific presentations and publications relating to this project. The information collected will remain the property of the study staff and will not be used for any other purpose beyond those stated above. Loss of confidentiality is always a risk with human participants; however we consider this risk minimal and have put in place safeguards to ensure that confidentiality is protected (see below).</p>
<b>Potential Benefits</b>	You may benefit from learning more about cervical cancer early detection, through the SMS text messaging educational program. In addition, your participation may provide valuable information on the best way to raise awareness about cervical cancer in the African American community.
<b>Confidentiality</b>	We will do our best to keep your personal information confidential. Information from your participation will be used for the purposes of instruction and scientific publication only. Your identity as a participant will not be revealed in any way by the investigator or her research team.

	<p>Information will be made public only in the form of summaries, which make it impossible to tell who the participants were. If you like, you can receive a copy of the results of this investigation and/or discuss the study with a staff person. Just call one of the numbers at the end of this form and we will be happy to answer all of your questions and furnish you with a copy of the results.</p> <p>Any potential loss of confidentiality will be minimized by storing any data with identifying information in a locked file cabinet, and password protecting any electronic files that contain identifying information. Your name will not be included on any of the collected data. Instead, a unique number will be assigned. Through the use of an identification key, we will be able to link the collected data to your identity. Only the principal investigator, Ms. Daisy Le will have access to the identification key. Again, all project data that contains names or identifiers will remain in secured storage such as a locked filing cabinet.</p> <p>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law. For some forms, we will use a unique numeric code for the data we have collected instead of your name. Your name will not be included on any of the data collected for this research study.</p>
<b>Medical Treatment</b>	<p>The University of Maryland does not provide any medical, hospitalization or other insurance for participants in this research study, nor will the University of Maryland provide any medical treatment or compensation for any injury sustained as a result of participation in this research study, except as required by law.</p>
<b>Right to Withdraw and Questions</b>	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p style="text-align: center;">Daisy Le, PhD(c), MPH/MA  University of Maryland, School of Public Health  1101H School of Public Health Building (255)  College Park, MD 20742  301-405-7875  daisyle@umd.edu</p>

<b>Participant Rights</b>	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p style="text-align: center;">University of Maryland College Park  Institutional Review Board Office  1204 Marie Mount Hall  College Park, Maryland, 20742  E-mail: irb@umd.edu  Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>	
<b>Statement of Consent</b>	<p>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</p> <p>If you agree to participate, please sign your name below.</p>	
<b>Signature and Date</b>	<b>NAME OF PARTICIPANT [Please Print]</b>	
	<b>SIGNATURE OF PARTICIPANT</b>	
	<b>DATE</b>	

## Appendix V: Phase 3's Participant Baseline Survey

Baseline Survey (U:4/6/16)

ID \_\_\_\_\_

### **CervixCheck: Cervical Cancer Education and Prevention**

Thank you for your interest in this project. By filling out this survey, YOU can help us better understand Pap test screening among African-American women in the mid-Atlantic region. Your responses will be very helpful in helping this women's health project understand the needs of the African American female community. They will help us continue to create tools and programs that can improve the health status for African American women.

#### **YOUR CONFIDENTIALITY WILL BE PROTECTED.**

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_

Zip: \_\_\_\_\_

Home Phone: \_\_\_\_\_

Office Phone: \_\_\_\_\_

Cell Phone: \_\_\_\_\_

Cell Phone Carrier/Provider: \_\_\_\_\_

Email Address: \_\_\_\_\_

Name of Church: \_\_\_\_\_

**If you would prefer to complete this survey over the phone, or if you have any further questions about this project, please contact: Daisy Le, PhD(c), MPH/MA at [cervixcheck100@gmail.com](mailto:cervixcheck100@gmail.com) or at (415) 385-7330.**

**These first questions are about church, religion, and spirituality.**

Other than weddings, funerals, or other special services, have you attended a place of worship in the **past 12 months**?

- yes     no

About how many times **a month** do you usually attend religious services?

- 0     1-3     4 or more

Besides attending services, about how many times **a month** do you take part in other religious activities like scripture study, choir practice or committee meetings?

- 0     1-3     4 or more

Which, if any, of the religions do you belong to?

- Christian (ex., AME Zion, Baptist, Methodist, Episcopal, Catholic, Lutheran)  
 Muslim  
 Jehovah's Witness  
 Other

*Please circle/highlight whether you strongly disagree, disagree, neither (neutral), agree, or strongly agree.*

	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
I talk openly about my faith with others.	1	2	3	4	5
I often read religious books, magazines, or pamphlets.	1	2	3	4	5
I often watch or listen to religious programs on TV or radio.	1	2	3	4	5
My spiritual beliefs are the foundation of my whole approach to life.	1	2	3	4	5
I am often aware of the presence of God in my life.	1	2	3	4	5
I have a personal relationship with God.	1	2	3	4	5
When I am ill, I pray for healing.	1	2	3	4	5
I pray often.	1	2	3	4	5

**These next sets of questions are about the Pap smear and cervical cancer.**Have you **ever heard** of a Pap smear?

- Yes                       No                       Not Sure / Don't Know

A Pap smear is a test for... **(mark all that apply)**

- Cervical Cancer       Breast Cancer       Chlamydia  
 Gonorrhea               Not Sure / Don't Know

According to the current guidelines for cervical cancer screening, when (i.e. at what age) should a **non-sexually active** woman have her **first** Pap test?

- 16       18       21       25       30

How at **risk** do you think you are for getting cervical cancer?

- No Risk               Slight Risk               Medium Risk               High Risk

Please tell us how much <b>YOU THINK</b> each of the following factors <b>CAUSE</b> cervical cancer.	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
<b>Fate</b> or bad luck	1	2	3	4	5
Having an <b>abortion</b>	1	2	3	4	5
Having a <b>sexually transmitted disease</b>	1	2	3	4	5
Lack of physical cleanliness or <b>poor hygiene</b>	1	2	3	4	5
Having <b>many sexual partners</b>	1	2	3	4	5
<b>Not getting regular Pap tests</b>	1	2	3	4	5
<b>Smoking</b>	1	2	3	4	5
<b>Sexual activity</b> at an <b>early age</b>	1	2	3	4	5
<b>Sexual activity</b> during <b>menstruation</b>	1	2	3	4	5
<b>Trauma</b> to the vagina or cervix	1	2	3	4	5



*Please check whether you think the following statements are true, false, or don't know.*

<b>Please tell us what you think about cervical cancer and the Pap smear.</b>	<b>True</b>	<b>False</b>	<b>Don't Know</b>
A Pap smear is a test to find out if you have a sexually transmitted infection (STI) or sexually transmitted disease (STD).			
A Pap smear is a test to find out if a woman is pregnant.			
A Pap smear checks for changes in the cells of a woman's uterus, also called the womb.			
A Pap smear checks for changes in the cells of a woman's cervix.			
Cervical cancer is easier to prevent if abnormal cells are found early.			
All women should be getting Pap smears by the time they are 21 years old.			
Women who are done having children do not need to keep having Pap smears.			
Getting regular Pap smears is the best thing a woman can do to prevent cervical cancer.			
If a woman has a Pap smear result that is not normal that usually means that she has cancer.			
A woman who has not had sex but has had a Pap smear is still a virgin.			

*Please check yes, no, or not sure for each of the following statements.*

<b>There are a lot of things that make it hard to get screened – please tell us if any of these apply to you:</b>	<b>Yes</b>	<b>No</b>	<b>Not Sure</b>
I am too busy to have a test for cervical cancer.			
Having a test for cervical cancer would be too uncomfortable for me, physically.			
I don't have a way to get to the place where they do the test for cervical cancer.			
Having a test for cervical cancer can actually cause cervical cancer.			
I am too embarrassed to have a test for cervical cancer.			
The place to go for the cervical cancer test isn't open when I have time to go.			
The cost of going to the doctor for these tests would be a problem for me now.			
Having a test for cervical cancer would make me worry about having cervical cancer.			

Please circle/highlight whether you strongly disagree, disagree, neither (neutral), agree, or strongly agree.

	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
I usually do what most people who are important to me think I should do.	1	2	3	4	5
It is mostly up to me whether or not I get a Pap smear every 1-3 years	1	2	3	4	5
Most people who are important to me think that I should have a Pap smear every 1-3 years.	1	2	3	4	5
When I think about getting a Pap smear, I believe it is beneficial.	1	2	3	4	5
When I think about getting a Pap smear, I believe that it is important	1	2	3	4	5
Most people who are important to me have a Pap smear every 1-3 years.	1	2	3	4	5
When I think about getting a Pap smear, I believe that it is good.	1	2	3	4	5
I plan to get a Pap smear in the next 1-3 years.	1	2	3	4	5
A woman who loses her virginity is negatively viewed in <b>society</b> .	1	2	3	4	5
A woman who loses her virginity is negatively viewed in <b>my family</b> .	1	2	3	4	5

	Very Hard	Hard	Neither Hard nor Easy	Easy	Very Easy
For me getting a Pap smear every 1-3 years would be...	1	2	3	4	5

**A Pap smear (also called a Pap test) is a pelvic exam where the doctor takes a scraping of cells from the cervix to check for precancerous changes.**

Have you **ever had** a Pap smear?

- Yes                       No

*[If yes:]* Did you have a Pap smear:     Within the past 12 months     More than 12 months ago

*[If yes:]* What year did you have your **MOST RECENT** Pap smear? \_\_\_\_\_

*[If yes:]* What reason(s) influenced you to have your **MOST RECENT** Pap smear? (**mark all that apply**)

- Recommendation from a friend
- Recommendation from mother/female guardian
- Recommendation from doctor
- Concern about your own health
- Concern about a sexually transmitted infection
- Need to get contraception (birth control)
- Other (please specify): \_\_\_\_\_

*[If yes:]* At what age did you have your **FIRST** Pap smear? \_\_\_\_\_

*[If yes:]* Have you gotten a Pap smear **AS RECOMMENDED** since your **FIRST** Pap smear?

- Yes                       No                       I do not remember
- I do not know the current recommendation for cervical cancer screening

Have you **thought about** getting a Pap smear in the next 6 months?

- Yes                       No

Do you have an **appointment** to get a Pap smear within the next 6 months?

- Yes                       No

**Lastly, please tell us a little about yourself:**

Do you use a cellular phone?  yes  no

If yes, do you use your cellular phone for text messaging?  yes  no  not sure

If yes, is your phone a "smart phone"?  yes  no  not sure

How often do you use text messages to communicate? (**choose ONE only**)

more than once a day  once a day  2-3 times a week

once a week  less than once a week  never

How often would you like to receive text messages from a project like CervixCheck? (**choose ONE only**)

more than 2 times a day  twice a day  daily (1/day)

every other day  a few times a week (3/week)  weekly

every 2 weeks  monthly  as needed for news/announcements

never

When is your birthday (mm/dd/yyyy)? \_\_\_\_\_

What is your age? \_\_\_\_\_

Are you...

Single  Living with partner  Married

Separated or divorced  Widowed

Do you have any children?

No  Yes, I have 1  Yes, I have 2

Yes, I have 3  Yes, 4 or more

Do you currently smoke cigarettes?  yes  no

With regards to cigarette smoking, which is true for you?

- I have never smoked
- I used to smoke occasionally, but I quit
- I used to smoke regularly, but I quit
- I currently smoke occasionally
- I currently smoke regularly

Which, if any, types of health insurance do you have? (mark all that apply)

	Yes	No
Medicaid	<input type="checkbox"/>	<input type="checkbox"/>
Medicare	<input type="checkbox"/>	<input type="checkbox"/>
Insurance through an employer/work (ex. Blue Cross or HMO)	<input type="checkbox"/>	<input type="checkbox"/>
Any other form of health insurance	<input type="checkbox"/>	<input type="checkbox"/>

What is the highest grade or year of school have you completed?

- Grades 1 through 8 (Elementary)
- Grades 9 through 11 (Some High School)
- Grade 12 or GED (High School Graduate)
- College 1 year to 3 years (Some College or Technical School)
- College 4 years or more (College Graduate)

Do you currently work for pay outside of the home? (mark all that apply)

- Full time                       Part-time                       Not currently
- I'm disabled                       I'm retired

What is the total income of everyone in your household per year, before taxes? (**choose ONE only**)

- |  |   |
|--|---|
| <input type="checkbox"/> less than \$5, 000  | <input type="checkbox"/> \$50,001 - \$60,000  |
| <input type="checkbox"/> \$5,001 - \$10,000  | <input type="checkbox"/> \$60,001 - \$70,000  |
| <input type="checkbox"/> \$10,001 - \$20,000 | <input type="checkbox"/> \$70,001 - \$80,000  |
| <input type="checkbox"/> \$20,001 - \$30,000 | <input type="checkbox"/> \$80,001 - \$90,000  |
| <input type="checkbox"/> \$30,001 - \$40,000 | <input type="checkbox"/> \$90,001 - \$100,000 |
| <input type="checkbox"/> \$40,001 - \$50,000 | <input type="checkbox"/> more than \$100,000  |

Has anybody in your family (first degree relative) had cervical cancer?

- Yes     No     Not Sure
- Mother
  - Sister
  - Daughter

Has any other family members had cervical cancer?

- Yes     No     Not Sure
- Grandmother
  - Aunt
  - Cousin
  - Other: \_\_\_\_\_

Have you had any family and/or friends who have had screening (been checked) for cervical cancer?

- Yes     No     Not Sure

Have you ever had vaginal sexual intercourse?     Yes     No

*[If yes:]*    At what age did you first have vaginal sexual intercourse? \_\_\_\_\_

How do you consider your current health status?

Excellent         Very Good         Good         Fair         Poor

Do you have any longstanding illness, disability, or infirmity?

Yes     No

Do you have a regular doctor you see for your health problems?

Yes     No

Is there anytime during the past 12 months that you were without health insurance?

Yes     No         Don't Know/Don't Remember

For a doctor's visit to get my Pap smear, I would prefer to have a \_\_\_\_\_ doctor.

Male     Female     Do Not Care

For a doctor's visit to get my Pap smear, I would prefer my doctor to be of the \_\_\_\_\_.

Same Ethnicity         Different Ethnicity         Do Not Care

**You have finished the survey! Thank you very much for your participation!  
Regarding "next steps", a member of the project team will be in contact with you shortly.**

**If you have any comments or suggestions, please write them below:**

## Appendix W: Phase 3's Participant Post-Program Follow Up Survey

Follow-Up Survey (U:5/17/16)

ID \_\_\_\_\_

### CervixCheck: Cervical Cancer Education and Prevention

Thank you for your recent participation in the "CervixCheck" pilot project! To ensure that this pilot project met the needs of our participants, we are conducting this follow-up survey to gather information about your general reactions to the pilot project and the extent to which the goals and objectives were met. We would like to get your feedback so that we can get a full picture of how useful the project was to you and to find out ways to do more in the future. By filling out this survey, YOU can help us better understand Pap test screening among African-American women in the mid-Atlantic region. Again, your responses will be very helpful in helping this women's health project understand the needs of the African American female community. They will help us continue to create tools and programs that can improve the health status for African American women. We sincerely appreciate your interest and look forward to receiving your input on this important survey over the next three days.

### YOUR CONFIDENTIALITY WILL BE PROTECTED.

Name: \_\_\_\_\_

Date: \_\_\_\_\_

How did you hear about the CervixCheck project: \_\_\_\_\_

What is the best way for us to get you your incentive?

CASH

What is a good time and location to meet up with you in person? \_\_\_\_\_

TARGET GIFT CARD

What is the mailing address you would like us to send it to: \_\_\_\_\_

ELECTRONIC TRANSFER (e.g. bank account, VENMO, Paypal, etc.)

What is your bank's name and account # or the account name/# for your VENMO/Paypal Account: \_\_\_\_\_

Can we contact you in the future:     YES     NO

If you would prefer to complete this survey over the phone, or if you have any further questions about this project, please contact: Daisy Le, PhD(c), MPH/MA at cervixcheck100@gmail.com or at (415) 385-7330.



**This first set of questions is about the Pap smear and cervical cancer.**

Have you **ever heard** of a Pap smear?

- Yes                       No                       Not Sure / Don't Know

A Pap smear is a test for... (mark all that apply)

- Cervical Cancer       Breast Cancer       Chlamydia  
 Gonorrhea               Not Sure / Don't Know

According to the current guidelines for cervical cancer screening, when (i.e. at what age) should a **non-sexually active** woman have her **first** Pap test?

- 16       18       21       25       30

How at **risk** do you think you are for getting cervical cancer?

- No Risk               Slight Risk               Medium Risk               High Risk

Please tell us how much <b>YOU THINK</b> each of the following factors <b>CAUSE</b> cervical cancer.	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
<b>Fate</b> or bad luck	1	2	3	4	5
Having an <b>abortion</b>	1	2	3	4	5
Having a <b>sexually transmitted disease</b>	1	2	3	4	5
Lack of physical cleanliness or <b>poor hygiene</b>	1	2	3	4	5
Having <b>many sexual partners</b>	1	2	3	4	5
<b>Not getting regular Pap tests</b>	1	2	3	4	5
<b>Smoking</b>	1	2	3	4	5
<b>Sexual activity at an early age</b>	1	2	3	4	5
<b>Sexual activity during menstruation</b>	1	2	3	4	5
<b>Trauma to the vagina or cervix</b>	1	2	3	4	5

*Please check whether you think the following statements are true, false, or don't know.*

<b>Please tell us what you think about cervical cancer and the Pap smear.</b>	<b>True</b>	<b>False</b>	<b>Don't Know</b>
A Pap smear is a test to find out if you have a sexually transmitted infection (STI) or sexually transmitted disease (STD).			
A Pap smear is a test to find out if a woman is pregnant.			
A Pap smear checks for changes in the cells of a woman's uterus, also called the womb.			
A Pap smear checks for changes in the cells of a woman's cervix.			
Cervical cancer is easier to prevent if abnormal cells are found early.			
All women should be getting Pap smears by the time they are 21 years old.			
Women who are done having children do not need to keep having Pap smears.			
Getting regular Pap smears is the best thing a woman can do to prevent cervical cancer.			
If a woman has a Pap smear result that is not normal that usually means that she has cancer.			
A woman who has not had sex but has had a Pap smear is still a virgin.			

*Please check yes, no, or not sure for each of the following statements.*

<b>There are a lot of things that make it hard to get screened – please tell us if any of these apply to you:</b>	<b>Yes</b>	<b>No</b>	<b>Not Sure</b>
I am too busy to have a test for cervical cancer.			
Having a test for cervical cancer would be too uncomfortable for me, physically.			
I don't have a way to get to the place where they do the test for cervical cancer.			
Having a test for cervical cancer can actually cause cervical cancer.			
I am too embarrassed to have a test for cervical cancer.			
The place to go for the cervical cancer test isn't open when I have time to go.			
The cost of going to the doctor for these tests would be a problem for me now.			
Having a test for cervical cancer would make me worry about having cervical cancer.			

Please circle/highlight whether you strongly disagree, disagree, neither (neutral), agree, or strongly agree.

	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree
I usually do what most people who are important to me think I should do.	1	2	3	4	5
It is mostly up to me whether or not I get a Pap smear every 1-3 years	1	2	3	4	5
Most people who are important to me think that I should have a Pap smear every 1-3 years.	1	2	3	4	5
When I think about getting a Pap smear, I believe it is beneficial.	1	2	3	4	5
When I think about getting a Pap smear, I believe that it is important	1	2	3	4	5
Most people who are important to me have a Pap smear every 1-3 years.	1	2	3	4	5
When I think about getting a Pap smear, I believe that it is good.	1	2	3	4	5
I plan to get a Pap smear in the next 1-3 years.	1	2	3	4	5
A woman who loses her virginity is negatively viewed in <b>society</b> .	1	2	3	4	5
A woman who loses her virginity is negatively viewed in <b>my family</b> .	1	2	3	4	5

	Very Hard	Hard	Neither Hard nor Easy	Easy	Very Easy
For me getting a Pap smear every 1-3 years would be...	1	2	3	4	5

**A Pap smear (also called a Pap test) is a pelvic exam where the doctor takes a scraping of cells from the cervix to check for precancerous changes.**

Have you **ever had** a Pap smear?

- Yes                       No

*[If yes:]* Approximately when did you have your **MOST RECENT** Pap smear (**xx/yyyy**)? \_\_\_\_\_

When are you **due** for your next Pap smear (**xx/yyyy**)? \_\_\_\_\_

- within the next 6 months  
 within the next 7-12 months  
 within the next 13-24 months (~1-2 years from now)  
 25+ months from now (~2+ years from now)  
 I do not know when I am due for my next Pap smear.

Have you **thought about** getting a Pap smear within the next **6 months**?

- Yes                       No

Do you have an **appointment** to get a Pap smear within the next **6 months**?

- Yes                       No

Have you **thought about** getting a Pap smear within the next **7-12 months**?

- Yes                       No

Do you have an **appointment** to get a Pap smear within the next **7-12 months**?

- Yes                       No

Have you **thought about** getting a Pap smear in the next **13-24 months** (~1-2 years from now)?

- Yes                       No

Have you **thought about** getting a Pap smear in the next **25-36 months** (~2-3 years from now)?

- Yes                       No

*[If you answered yes to any of the 6 questions above:]* What reason(s) influence(s) you to have your **NEXT** Pap smear? (mark all that apply)

- Recommendation from the CervixCheck project  
 Recommendation from a friend  
 Recommendation from mother/female guardian  
 Recommendation from doctor  
 Concern about your own health  
 Concern about a sexually transmitted infection  
 Need to get contraception (birth control)  
 Other (please specify): \_\_\_\_\_

Has anybody in your family had cervical cancer?

- Yes     No     Not Sure
- Mother                       Grandmother                       Other: \_\_\_\_\_  
 Sister                       Aunt  
 Daughter                       Cousin

How do you consider your current health status?

- Excellent                       Very Good                       Good                       Fair                       Poor

**This last set of questions are about the CervixCheck text messages that you may have received:**

Did you receive any SMS text messages on your phone from the CervixCheck project?

- Yes
- No
- Not sure

How many **total** SMS text messages do you remember getting?

- 1-2
- 3-5
- 6-10
- 11-15
- 16-20
- 21-25
- 26 or more
- Don't remember
- Does not apply

I remember receiving CervixCheck SMS text messages about... (please mark all that apply)

- Women's health
- Cervical cancer
- Diet and exercise
- Pap testing
- Diabetes
- Religion/spirituality
- Upcoming/local community events
- Links to additional resources
- None of the above
- Does not apply

Did you share any of the information you received from the CervixCheck project with others?

- Yes

[If yes:] Who did you share it with? \_\_\_\_\_

- No

Overall, how **satisfied** were you with CervixCheck project?

- Very satisfied  
 Satisfied  
 Neutral, no opinion  
 Dissatisfied  
 Very dissatisfied  
 Not applicable

How **useful** were the SMS text messages that you received from CervixCheck project?

- Very useful  
 Useful  
 Neutral, no opinion  
 Somewhat useful  
 Not at all useful  
 Not applicable

*Please circle/highlight whether you strongly disagree, disagree, neither (neutral), agree, strongly agree, or did not get.*

How much do you agree or disagree with the following statements? [Please circle <u>one</u> ]	Strongly Disagree	Disagree	Neither Disagree nor Agree	Agree	Strongly Agree	Did Not Get
I <b>enjoyed</b> getting text messages from the CervixCheck pilot project.	1	2	3	4	5	0
The CervixCheck text messages kept me <b>informed</b> about cervical cancer prevention & early detection.	1	2	3	4	5	0
The CervixCheck text messages kept me <b>engaged</b> on the topic of cervical cancer prevention & early detection.	1	2	3	4	5	0
The CervixCheck text messages made learning about cervical cancer prevention <b>better</b> .	1	2	3	4	5	0
The CervixCheck project helped me to better <b>support</b> the health needs of the women around me.	1	2	3	4	5	0

Please circle/highlight whether you strongly disagree, disagree, neither (neutral), agree, strongly agree, or did not get.

How much do you agree or disagree with the following statements? [Please circle <u>one</u> ]	Very Unlikely	Unlikely	Neither Unlikely nor Likely	Likely	Very Likely	Did Not Get
I would <b>share</b> the information I learned from the CervixCheck project with the women around me.	1	2	3	4	5	0
I would <b>recommend</b> a cervical cancer SMS text messaging program, like CervixCheck, to others in my community if it was offered in the future.	1	2	3	4	5	0
I wish to <b>continue receiving</b> occasional SMS text messages from the CervixCheck program.	1	2	3	4	5	0
I would <b>participate</b> in a similar SMS text messaging-based project in the future.	1	2	3	4	5	0

The length (which was ~2 weeks) of the CervixCheck pilot program was...

- Too long
- About right
- Too short
- Undecided / Not sure

The total number of SMS text messages that the CervixCheck pilot program sent out was...

- Too much
- About right
- Not enough
- Undecided / Not sure

The total amount of time required to participate in the CervixCheck pilot program was...

- Too much
- About right
- Decently minimal
- Too little
- Undecided / Not sure



What did you like least about the CervixCheck project?

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What did you like most about the CervixCheck project?

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If you could change one thing to make the CervixCheck project better, what would it be?

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What else would you like to see incorporated in future projects that are similar to the CervixCheck project?

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Please provide any additional information that would assist us in future planning:

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**You have finished the survey! Thank you very much for your participation!  
The information you provided will be of great help to us as we evaluate the CervixCheck project  
and plan for future events on health and cancer prevention.**

**Regarding your incentive, a member of the project team will be in contact with you shortly.**

**If you have any additional questions, comments or suggestions, please write them below:**

**Appendix X: Phase 3's Incentive Log**

**Phase 3: Incentive Log**  
*Cervical Cancer Screening & SMS Text Messaging Pilot Intervention*

	<b>Full Name (Last, First)</b>	<b>Mailing Address</b>	<b>Contact # or Email</b>	<b>Signature</b>	<b>Amount Received</b>	<b>Giftcard/ E-Transfer/ Cash?</b>
<b>1</b>						
<b>2</b>						
<b>3</b>						
<b>4</b>						
<b>5</b>						
<b>6</b>						
<b>7</b>						
<b>8</b>						
<b>9</b>						
<b>10</b>						

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