ABSTRACT

Title of Dissertation:	DECISIONAL NEEDS OF AFRICAN AMERICAN SMOKERS FOR LUNG CANCER SCREENING
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The burden of lung cancer is significant for African Americans, especially African American men, who have the highest lung cancer death rates compared to all racial and ethnic groups. In 2013, the United States Preventive Services Task Force (USPSTF) provided a recommendation for annual screening using low-dose computed tomography (LDCT) due to the disease-specific mortality benefit. Given the test's limitations (e.g., false positives, radiation exposure) the USPSTF and other medical organizations endorse informed decision-making, a process by which individuals weigh the benefits and harms of the test and make a decision about usage. The recent release of the screening guidelines and promotion of informed decision-making provides a timely opportunity to examine patients' decision-making processes around lung cancer screening. The purpose of this study was to describe aspects of decision-making for lung cancer screening including knowledge and awareness about LDCT, values related to screening, uncertainty about the test, and decision-making

preferences among African American adult smokers. Additionally, this study examined the extent to which decision-making components are associated with screening intentions. The Ottawa Decision Support Framework provided the conceptual framework for this study, positing that patients' decisional needs (e.g., knowledge, personal values) impact decisional quality (e.g., being informed, low regret) which ultimately influences behavior (e.g., use of health services). First, patient and provider key informant interviews (N=9) were conducted to inform the development of a decisional values measure. Next, a survey was administered to African American (N=119) long-term smokers. Among the study sample, lung cancer screening awareness and knowledge were limited (Mean=7.1 out of 15). Individuals were experiencing uncertainty about the screening decision, but lower decisional conflict was associated with greater likelihood of talking with friends about LDCT as well as screening intention (*p's*<.05). This is one of the first studies to describe the decisional needs of an entirely African American sample of smokers for lung cancer screening using LDCT and to examine the associations between these components of decision-making and screening intentions. Findings have implications for addressing the decisional needs of African American smokers to promote informed decision-making for LDCT and to thwart further cancer inequities.

DECISIONAL NEEDS OF AFRICAN AMERICAN SMOKERS FOR LUNG CANCER SCREENING

by

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Chapter 1: Introduction

Background

The burden of lung cancer in the United States is a major public health concern. Lung cancer is the most commonly diagnosed cancer in men and women following prostate and breast cancer diagnoses respectively (American Cancer Society, 2018a). It is also the leading cause of cancer death among men and women and is expected to result in 142,670 deaths in 2019 (American Cancer Society, 2018a, 2019). Among African Americans, lung cancer is the second most commonly diagnosed cancer and it accounts for the greatest number of cancer-related deaths in this population (American Cancer Society, 2016, 2019). Disparities exist in the burden of this disease such that African American males' incidence and death rates are higher for lung cancer in comparison to whites (American Cancer Society, 2016; DeSantis, Miller, Goding Sauer, Jemal, & Siegel, 2019). Relative to their white counterparts, African American women are at a lower risk of getting the disease, but have comparable cancer death rates (American Cancer Society, 2016; DeSantis et al., 2019).

Recent results from the National Lung Screening Trial (NLST) helped inform screening recommendations for low-dose computed tomography (LDCT), a scan that detects lung cancer early and lowers the risk of dying from the disease (The National Lung Screening Trial Research Team, 2011). This randomized controlled trial of over 50,000 participants found a 20% relative reduction in lung cancer mortality in participants who received lung cancer screening using LDCT versus radiography (NLST, 2011). The findings from this trial guided the United States Preventive Services Task Force (USPSTF), an independent body of experts, release of a Grade B recommendation for annual lung cancer screening for individuals who are considered high risk

(55 to 80 years old, 30 pack-year smoking history, and who currently smoke or who have quit in the last 15 years (Humphrey et al., 2013). While there are acknowledged benefits of LDCT screening (mortality reduction), there are also limitations associated with the test (e.g., false positives). The NLST found a high rate of false positives (96.4%), estimated overdiagnosis (18.5%), and radiation exposure. Given these considerations, providers and patients must determine appropriate eligibility and engage in informed decision-making by weighing the benefits and harms of the test.

Informed decision-making (IDM) is a process that allows for gathering of relevant health information and examining possible outcomes. Endorsement of IDM is common in cancer prevention and control because there are often choices to be made regarding screening or treatment options available. The USPSTF along with many other major medical organizations promote IDM for individuals considering lung cancer screening using LDCT, because of the known benefits and risks. Individuals eligible for lung cancer screening are encouraged to consider their personal preferences as it relates to the options and to make a decision that is aligned with their own values.

Problem Statement

African Americans are disproportionately impacted by lung cancer with 15% of cases being lung cancer for African American men and 11% for African American women. While the disparity in death cancer rates has narrowed between African Americans and whites, primarily due to lower prevalence of smoking, it still accounts for the greatest number of cancer-related deaths in this population (American Cancer Society, 2016; DeSantis et al., 2019). An evidence-based screening test is now available to detect lung cancer early and reduce mortality and these results were extended to African Americans who participated in the NSLT. A secondary data

analysis revealed an overall mortality reduction among this group in the definitive trial. However, it is estimated that only 3.9% of eligible individuals across all racial and ethnic groups are screened via LDCT (Jemal & Fedewa, 2017). Reasons cited for poor adherence include the need for more information about the benefits and harms of the test (Jemal & Fedewa, 2017). Poor utilization of the test may be further exacerbated in racial/ethnic minorities based upon the eligibility requirements for the test itself. A lower proportion of African Americans achieve a 30+ pack-year smoking history compared to other groups (Kitts, 2019) which may be attributed to differences in smoking patterns by race/ethnicity such that African Americans smoke lower quantities of cigarettes (Okuyemi, Ebersole-Robinson, Nazir, & Ahluwalia, 2004; Schane, Ling, & Glantz, 2010). Other contributors to non-adherence specific to this population may include lack of medical coverage and barriers to early detection and screening.

Informed decision-making allows for a consideration of the options through a process which includes: 1) identifying personal characteristics and other determinants that influence an individuals' decision-making needs, 2) providing decision support tailored to those needs, and 3) evaluating the decision-making process and outcomes. An assessment is necessary to first identify what a population requires to make a decision about lung cancer screening using LDCT. These needs may include deficits in knowledge and awareness, connection to support and resources, and clarity of personal values. The Ottawa Decision Support Framework (O'Connor et al., 1998) posits decisional needs may be specific to the type of decision to be made as well as the characteristics of those involved in making the decision. While previous research illustrates differences in cancer screening adherence between African Americans and other racial/ethnic groups with African Americans reporting lower levels of cancer screening utilization (e.g., colorectal cancer) due to individual (e.g., fear, lack of knowledge) and systematic barriers (e.g.,

health insurance, access), there may be other factors unique to lung cancer screening (e.g., barriers related to the stigma of smoking and lung cancer). There has been initial development and evaluation of decision aids to promote informed decision-making for lung cancer screening using LDCT (Erkmen et al., 2018; Fraenkel, Peters, Tyra, & Oelberg, 2016; Lau et al., 2015; Lillie et al., 2017; Mazzone et al., 2017; McDonnell et al., 2018; Percac-Lima et al., 2018; Reuland et al., 2018; Volk, Hawk, & Bevers, 2014), however, this study proposes to first identify the specific needs of African Americans who are at high risk for lung cancer and who may benefit from lung cancer screening. This study's findings may help inform future decisional support tools targeted toward this priority population.

Theoretical Framework

This dissertation project is guided by the Ottawa Decision Support Framework which is an evidence-based model for making health decisions. It is grounded in multiple theories (Ajzen & Fishbein, 1980; Bandura, 1982; Fischhoff, Slovic, & Lichtenstein, 1980; Janis & Mann, 1977; Keeney, 1982; Norbeck, 1988; Orem, 1995; Tversky & Kahneman, 1981) and asserts that individuals' decisional needs will affect their decision quality which in turn impacts their behavior including the use of services. Needs that are unmet may negatively impact decisional quality like having gaps in knowledge, unrealistic expectations, and inadequate support to make decisions. The recent release of the lung cancer screening guidelines and the endorsement of informed decision-making calls for the examination of patients' decision-making needs around lung cancer screening.

Study Purpose

The purpose of this study was to describe the decision-making needs including knowledge and awareness about the test, values related to screening, uncertainty about the test, and decision-making preferences among African American adult men and women who may be eligible for lung cancer screening using LDCT. Additionally, this study examined the extent to which select components of decision-making are associated with intentions to be screened for lung cancer in the future among those who are screening-eligible.

Research Questions, Aims, and Hypotheses

The proposed study sought to answer the following research questions: 1) what are the decisional needs of African American adult men and women smokers who may be eligible for lung cancer screening using LDCT? and 2) among those screening-eligible to what extent are these decision-making components associated with intentions to be screened for lung cancer in the future? The research aims are:

Aim 1: To describe knowledge and awareness about LDCT screening, personal values about LDCT screening, uncertainty (decisional conflict) about the test, as well as decisional support and resources (e.g., decisional preferences, external information support) among high-risk African American adults. To achieve this aim, a survey was administered to N = 119 African American adult men and women who closely mirror the United States Preventive Services Task Force eligibility criteria for screening (55 to 80 years old, currently smoke or have quit within the last 15 years, no previous diagnosis of lung cancer).

Aim 2: To examine the extent to which knowledge, decisional preferences, decisional conflict, and external support are associated with participant intentions to undergo lung cancer screening

in the future among those eligible for LDCT screening. This study tested the associations between the selected decisional needs and screening intentions among the sample.

H1: Individuals with greater knowledge about lung cancer screening, who prefer to make a decision about lung cancer screening with their doctor, who have lower levels of uncertainty about the course of action, and who report having the information they need to make a decision about getting screened will be more likely to report intention to be screened for lung cancer in the next six months.

A convenience sample was employed utilizing multiple recruitment strategies: 1) individuals who participated in the Religion and Health in African Americans (RHIAA) study who agreed to be re-contacted for future research were invited to participate, 2) flyers were distributed at the University of Maryland Medical System and the Baltimore City Cancer Program's community outreach events, 3) flyers were posted and passed out at local health and community settings within the District of Columbia (DC) and Maryland region, and 4) the study was presented in person at smoking cessation group sessions and in five Public Housing communities. The study was powered to address the research questions and aimed to enroll N = 182 which would allow for sub-group analysis as well as reasonable missing data. The survey included questions organized by knowledge, awareness, decisional support and resources, decisional values, decisional conflict, lung cancer screening intention, and background demographics and characteristics.

Public Health Implications

Given racial disparities in lung cancer screening diagnosis and mortality, it is particularly important to assess the decision-making needs of diverse groups, such as African Americans, to help inform future interventions that may need to be targeted to promote informed decision-

making for this community. This research study assessed the needs of African American adults who are at high risk for developing lung cancer and who may be eligible for lung cancer screening using LDCT. This research has the potential to make significant and innovative contributions by: 1) describing what African Americans know about lung cancer and lung cancer screening, 2) identifying what smokers want or need regarding decision-making for lung cancer screening, 3) describing personal values and importance about the options related to screening, and 4) examining to what extent these decisional needs are associated with screening intentions. This study is also well-positioned to identify which groups may require more decisional support through sub-group analysis. Ultimately, the information gathered from this study may be used in future intervention development to specifically target the needs of this populations and to evaluate what decision support strategies may be most effective.

Definition of Terms

African American or Black: This study will refer to those individuals who self-identify as Black or African American which is defined as a person having origins in any and of the Black racial groups of Africa. The United States Census Bureau adheres to the Office of Management and Budget standard on race and ethnicity (US Census Bureau, 2018).

Benefits/Risks: The pros and cons of options in a decision. May also be expressed as reasons to choose or not to choose a particular option.

Decision-making Process: The extent to which a person is helped to: recognize that a decision needs to be made; knows about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; understand that values affect the decision; be clear

about which features of the options matter most to them; discus values with their clinician, and become involved in decision-making in ways they prefer.

Decisional Conflict: Uncertainty about course of action to take when the choice among options involves risk, loss, regret, challenge to personal life values.

Decisional Needs: What a patient population needs to make better decisions and what a population of health practitioners need to improve the support they provide to patients during decision making.

Decisional Support: Methods (e.g., counseling, tools, coaching) used to clarify the decision to be made, address any decisional needs, provide information including facts about the options, clarify values, guide in deliberation and communications, and monitor and facilitate progress.

Decisional Quality: The extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties.

False Positive Result: A test which incorrectly indicates that a particular condition or attribute is present. For cancer screening, when a test shows an abnormal test result, but cancer is actually absent.

False Negative Result: A test result which incorrectly indicates that a particular condition or attribute is absent. For cancer screening, when a test shows a normal test result, but cancer is actually present.

Informed Decision-Making: A decision that is made after all of the relevant information and possible outcomes have been examined.

Knowledge: In this study, cognizance of the health problem or situations (lung cancer, lung cancer screening).

Low-dose Computed Tomography: An X-ray scan of the body using a low dose of radiation, takes three dimensional pictures of the lungs to detect nodules which are areas of abnormal tissue

Lung Cancer: Originates when malignant cells in the lung grow abnormally forming a tumor.

Screening: Screening allows for detection of a disease in asymptomatic individuals.

Non-small Cell Lung Cancer: Group of lung cancers that behave similarly, such as squamous cell carcinoma and adenocarcinoma.

Overdiagnosis: The diagnosis of a medical condition that would never have caused any symptoms or problems.

Pack-year: A way to measure the amount a person has smoked over a long period of time. It is calculated by multiplying the number of packs of cigarettes smoked per day by the number of years the person has smoked. For example, 1 pack year is equal to smoking 1 pack per day for 1 year, or 2 packs per day for half a year, and so on.

Pulmonary Nodule: A spot on the lung when performing an imaging test.

Radiation Exposure: A measure of the ionization of air due to ionizing radiation from photons; gamma rays and X-rays.

Sensitivity: If a person has a disease, how often will the test be positive (true positive).

Shared Decision-Making: The process of a patient working together with his/her healthcare providers to make a medical decision.

Small Cell Lung Cancer: Small cell lung cancer is a disease in which malignant cells form in the tissues of the lung. There are two main types of small cell lung cancer. Smoking is the major risk factor for small cell lung cancer.

Specificity: If a person not have the disease, how often will the test be negative (true negative).

Values: Desirability or personal importance of outcomes of options.

Chapter 2: Review of the Literature

Lung Cancer Burden

Lung carcinoma, referred hereafter as lung cancer, originates when malignant cells in the lung grow abnormally forming a tumor (American Cancer Society, 2018a; National Cancer Institute, 2018a). In the United States (U.S.) lung cancer is the most commonly diagnosed cancer in men and women following prostate and breast cancer diagnoses respectively (American Cancer Society, 2019). This disease accounts for approximately 13% of all new cancer cases and it is estimated that 228,150 individuals will be diagnosed with lung cancer in 2019 (American Cancer Society, 2019). Most diagnoses (~85%) are non-small cell lung cancer (NSCLC) which includes squamous cell carcinoma, adenocarcinoma, and large cell carcinoma. These subtypes are grouped together based upon the prognosis and treatment options (American Cancer Society, 2018c). There are other types of lung cancer that are less common including small cell lung cancer which accounts for 10-15% of the cases and lung carcinoid making up less than 5% of cases (American Cancer Society, 2018c). Lung cancer is the leading cause of cancer mortality among men and women and is expected to result in 142,670 deaths in 2019 (American Cancer Society, 2018a, 2019). The disease accounts for more cancer deaths than those attributed to breast, prostate, and colon cancers combined (National Cancer Institute, 2018b). The 5-year relative survival rate for lung cancer is low (19%), but among the 16% of lung cancers diagnosed at a localized stage the 5-year survival rate is 56% (American Cancer Society, 2018a). There is a financial burden associated with lung cancer that has resulted in $13.4 billion spent in cancer care and $36.1 billion due to loss of productivity because of lung cancer mortality (American Lung Association, 2016).

Modifiable and non-modifiable factors contribute to individuals' risk for developing lung cancer. The most prominent and preventable risk factor for this chronic disease is cigarette smoking as 81% of lung cancer deaths are due to smoking and this risk is dependent upon an individuals' smoking history (duration and quantity) (American Cancer Society, 2018a; American Lung Association, 2016). The overall lifetime risk of developing lung cancer is 1 in 15 and 1 in 17 among men and women, respectively. Compared to individuals who are classified as 'never smokers', men who smoke are 23 times more likely to be diagnosed with lung cancer and women smokers are 13 times more likely (American Lung Association, 2016). While rates of smoking are declining, a large number of current or former smokers (~94 million) are at high risk for being diagnosed with the disease (Jemal & Fedewa, 2017). Other smoking behaviors (e.g., cigar and pipe use) as well as exposure to secondhand smoke puts individuals at an increased risk for developing lung cancer (American Cancer Society, 2018a). Annually, 7,000 or more lung cancer deaths are a result of secondhand smoke (American Cancer Society, 2018c). Other environmental risk factors include exposure to radon, asbestos, and occupational carcinogens (e.g., inhaled chemicals). Similar to other cancers, age and heredity play a role in risk. Individuals with a family history of lung cancer may be more likely to receive a lung cancer diagnosis and most lung cancer cases are in individuals 65 years or older (American Cancer Society, 2018c; American Lung Association, 2016).

Differences in Lung Cancer Burden Among African Americans

Lung cancer is the second most commonly diagnosed cancer and it accounts for the greatest number of cancer-related deaths in African Americans (American Cancer Society, 2016; DeSantis et al., 2019). In 2019, 25, 390 new lung cancer cases are expected or 12.5% of cancer diagnoses in this population (American Cancer Society, 2016). Health disparities exist across the

lung cancer continuum such that African American men are more likely to be diagnosed with lung cancer in comparison to non-Hispanic whites (85.4 versus 74.3 per 100,000) and die from it in comparison to all other racial and ethnic groups (American Lung Association, 2016; Sin, 2017). African American males' death rates are also higher for lung cancer in comparison to whites (American Cancer Society, 2018b). While the overall exposure to cigarette smoke is lower among African American males, the lung cancer incidence rate (age-adjusted) is 15% higher than the rate for white men (American Cancer Society, 2016; DeSantis et al., 2019). Relative to their white counterparts, African American women are at a lower risk of getting the disease (49.2 versus 57.4 per 100,000), but have comparable cancer death rates (American Cancer Society, 2018b). The leading cause of cancer deaths among African Americans is due to lung cancer, with 16,550 deaths estimated in 2019 (American Cancer Society, 2016). Overall 5-year survival rates are low for lung cancer and African Americans have poorer survival rates in comparison to whites (16% versus 19%, respectively) (American Lung Association, 2016). There are differences in the 5-year survival rate for lung cancers diagnosed at the localized stage for African Americans such that the survival rate is 52% versus 56% in the population overall (American Cancer Society, 2016; National Cancer Institute, 2018b).

Contributors to Health Disparities in Lung Cancer

The prevalence of cigarette smoking is similar between African Americans and whites and about 19% of African American adults report current use of tobacco (CDCTobaccoFree, 2018). Individuals with lower socioeconomic status, which is highly correlated with race in the United States, experience differential rates in lung cancer incidence and mortality rates (DeSantis et al., 2019). There are a number of factors that may explain these differences including lack of medical coverage, barriers to early detection and screening, and unequal access to improved

cancer treatments. Both African American adults and children are more likely to be exposed to secondhand smoke in comparison to other racial and ethnic groups and research has supported the deleterious effects of secondhand smoke (Homa et al., 2015). When reviewing cancer trends over time, declines in cancer incidence have been observed which are due to a decrease in the number of lung and prostate cancer diagnoses (American Cancer Society, 2016, 2018a). There have also been decreases in cancer deaths among African Americans over time, however, disparities persist with higher rates of cancer death relative to whites (American Cancer Society, 2016). These differences are largely attributed to breast and colorectal cancer in women and prostate, colorectal, and lung cancers in men (American Cancer Society, 2018b).

Lung Cancer Early Detection (Screening)

Screening allows for detection of a disease in asymptomatic individuals. The only recommended screening test for lung cancer is low-dose computed tomographic screening also referred to as low-dose helical computed tomography (CT), low-dose CT scan, or LDCT due to its high sensitivity (80% to 100%) and specificity (28% to 100%) (Toyoda, Nakayama, Kusunoki, Iso, & Suzuki, 2008; U.S. Preventive Services Task Force, 2016). The procedure, an X-ray scan of the body using a low dose of radiation, takes three dimensional pictures of the lungs to detect nodules which are areas of abnormal tissue. While the majority of nodules detected in the lungs are benign, 20% to 60% of the screens will show abnormalities which can be due to scar tissue, infection, cancer, or other conditions ("NCCN Guidelines for Patients® | Lung Cancer Screening," 2017). Nodules that are cancerous have different characteristics then benign nodules including being larger in size and having rough edges (spiculations) as well as the density of the nodule ("NCCN Guidelines for Patients® | Lung Cancer Screening," 2017). If nodules are detected, a follow-up protocol (e.g., National Comprehensive Cancer Network) is

conducted which includes subsequent scans to monitor the size, shape, and density of the nodules as well as additional tests (e.g., PET scan). Among cases where nodules are not detected, continued annual screening using LDCT is recommended.

National Lung Screening Trial

The National Cancer Institute funded the National Lung Screening Trial (NLST), a multi-center randomized study which compared low-dose helical CT with chest radiography to determine whether it would reduce lung cancer mortality among individuals at high risk (The National Lung Screening Trial Research Team, 2011). During a two-year enrollment period, NLST enrolled 53,454 participants who were between 55 and 74 years, had a 30 pack-year cigarette smoking history, and if a former smoker had quit in the past 15 years. Study participants were randomly assigned to one of two conditions: 1) undergoing three screenings using LDCT annually or 2) completing three annual screenings using a single-view posteroanterior chest radiography. Lung cancer diagnoses and deaths were collected for five years post enrollment. There was a high rate of screening adherence in this trial (more than 90%) and results indicated a relative reduction in lung cancer mortality using LDCT of 20% relative to radiography (95% CI, 6.8 to 26.7; P=0.004). There was also a 6.7% reduction in overall mortality, with 1,877 deaths in the LDCT condition versus 2,000 in the radiography group (95% CI, 1.2 to 13.6; P=0.02). There are acknowledged limitations of this study including the high rate of false positives, overdiagnosis, by detecting cancers that may never have caused symptoms, and the unknown long term effect of cancer caused by radiation exposure due to the test itself. Despite the limitations, the results from this definitive trial which was the largest to date along with other evidence guided the screening recommendations released in 2013 by the United States Preventive Services Task Force (USPSTF), an independent body of national experts in disease

prevention and evidence-based medicine who make recommendations about preventive services (Humphrey et al., 2013).

A secondary data analysis was conducted utilizing data from NLST to examine overall and lung cancer specific mortality by race (Tanner et al., 2015). African Americans in the NLST were younger, more likely to be current smokers, experience a higher number of comorbidities, and had less education. Lung cancer screening using LDCT reduced lung cancer mortality more in African Americans versus all racial groups (hazard ratio, 0.86 vs. 0.61). Among smokers, African Americans were twice as likely to die from lung cancer versus their white counterparts. African Americans also had higher overall mortality than whites. However, among the African Americans screened, there was a reduction in overall mortality.

The Dutch-Belgian Lung Cancer Screening Trial (NELSON)

In September 2018, the Dutch-Belgian Lung Cancer Screening trial (NELSON), the second largest randomized controlled trial following NLST reported their results at the International Association for the Study of Lung Cancer (IASLC) 19th World Conference on Lung Cancer. The NELSON trial enrolled 15,792 individuals who were randomized to two groups (screening with CT versus control) and followed for more than 10 years. The findings from the trial indicated a mortality benefit of LDCT among high risk smokers. Overall, LDCT reduced mortality by 26% in men and up to 61% in women over the 10-year study period.

Recommendations Around Lung Cancer Screening

The USPSTF updated the recommendations for lung cancer based upon the results from the NLST and other commissioned studies (de Koning et al., 2014; Humphrey et al., 2013). Humphrey and colleagues (2013) conducted a review of the literature including studies related to screening for lung cancer. The systematic review concluded there was strong evidence to support

the use of LDCT to significantly reduce mortality from lung cancer, but that harms were associated with screening. A comparative modeling study was conducted for the USPSTF by de Koning et al. (2014) that utilized the NLST, the Prostate, Lung, Colorectal, and Ovarian Cancer Screening Trial, the Surveillance, Epidemiology, and End Results program, and the U.S. Smoking History Generator to identify the benefits and harms of LDCT. The National Cancer Institute's Smoking History Generator serves as an input for the lung cancer models conducted which simulates individual life/smoking histories. The study found that the most effective screening strategy is annual LDCT for lung cancer for individuals 55 to 80 years old with a 30 or more pack-year smoking history. Based upon the body of evidence, the USPSTF provided a Grade B recommendation and a clinical suggestion to offer or provide lung cancer screening (Humphrey et al., 2013; U.S. Preventive Services Task Force, 2016). The grades assigned to the group's recommendations provide an indication of the quality of the evidence and recommendations for practice. The scale includes the following grades: A ("The USPSTF recommends the service. There is high certainty that the net benefit is substantial"); B ("The USPSTF recommends the service. There is high certainty that the net benefit is moderate or there is moderate certainty that the net benefit is moderate to substantial"); C ("The USPSTF recommends selectively offering or providing this service to individual patients based on professional judgment and patient preferences. There is at least moderate certainty that the net benefit is small"); D ("The USPSTF recommends against the service. There is moderate or high certainty that the service has no net benefit or that the harms outweigh the benefits"); and I ("The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of the service. Evidence is lacking, of poor quality, or conflicting, and the balance of benefits and harms cannot be determined"). The recommendation for lung cancer screening

reads, “The USPSTF recommends annual screening for lung cancer with low-dose computed tomography (LDCT) in adults aged 55 to 80 years who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years. Screening should be discontinued once a person has not smoked for 15 years or develops a health problem that substantially limits life expectancy or the ability or willingness to have curative lung surgery”.

Complementary to the recommendations released by the USPSTF, other major medical organizations (e.g., American Cancer Society, National Comprehensive Cancer Network, American Lung Association, American Thoracic Society) endorse lung cancer screening using LDCT for eligible individuals, although variations to the eligibility criteria exist. For example, the American Cancer Society recommends “that clinicians with access to high-volume, high-quality lung cancer screening and treatment centers should initiate a discussion about lung cancer screening with patients aged 55 to 74 years who have at least a 30-pack-year smoking history, currently smoke or have quit within the past 15 years, and who are in relatively good health” (American Cancer Society, 2013; Wender et al., 2013). The National Comprehensive Cancer Network criteria are defined by individuals greater than 50 years old with a smoking history of at least 20 pack years, and one additional risk factor (e.g., Chronic Obstructive Pulmonary Disease, family history of lung cancer, exposure to substances associated with lung cancer (i.e. radon, asbestos), or a past history of lymphoma, esophageal cancer, lung or head and neck cancer (“NCCN Guidelines for Patients® | Lung Cancer Screening,” 2017). In addition to the endorsement of screening using LDCT, this test is covered under Medicare and the Affordable Care Act. Based on the body of evidence, the Centers for Medicaid and Medicare Services released a memorandum indicating the organization’s decision to cover lung cancer screening with LDCT as a reimbursable expense for appropriate beneficiaries who meet eligibility criteria

and who have undergone lung cancer screening counseling and a shared decision-making visit with their clinician (Volk et al., 2014). The Affordable Care Act mandates that all marketplaces cover lung cancer screening without copayment or coinsurance for individuals 55 to 80 years who are at high risk because of their smoking status or who have quit smoking within the last 15 years (Healthcare.gov, 2018).

Potential Risks of Lung Cancer Screening

In addition to the known benefits of lung cancer screening, there are acknowledged potential harms associated with LDCT including: 1) false positives, 2) overdiagnosis, and 3) radiation exposure. This test can lead to subsequent testing (e.g., further imaging, biopsies) that may be unnecessary and can also result in psychological harms (e.g., cancer worry). Cases in which individuals who receive a positive result from the screening, but after further follow up it is determined they do not have cancer are classified as a false positive. The National Cancer Institute's Cancer Intervention and Surveillance Modeling Network (CISNET) comparative modeling study concluded that the number of false positive results increased proportionally to the number of LDCT screenings, which resulted in 1.0 to 4.0 false positive results per person screened. In the NLST, 96.4% of the positive screening results in the LDCT group were false positives (The National Lung Screening Trial Research Team, 2011). The majority of the NLST participants received follow-up imaging as a result of a positive test (>90%), had surgery (4.2%), or a biopsy (2.2%) (Pinsky, Bellinger, & Miller, 2017). In the NLST 3.8% (95% CI, 3.4 to 4.3) were true positives. Horeweg and colleagues (2014) conducted the NELSON trial, a randomized study to evaluate the effect of LDCT screening with increasing screening interval versus no screening on lung cancer-specific mortality (N =15,822) (Horeweg, 2014). Analysis in this study aimed to assess the performance of this test including sensitivity and specificity. Sensitivity was

84.6% (95% CI, 79.6 to 89.2) and specificity was 98.6% (95% CI, 98.5 to 98.8) at 2-year follow up. The positive predictive value was 40.4% (95% CI, 35.9 to 44.7). Other trials report varying positive predictive value findings ranging from 4.1% to 16.4% (Becker et al., 2012; Pastorino et al., 2012).

Overdiagnosis refers to the detection of cancer that may have never exhibited symptoms or caused harm to the patient and may lead to overtreatment. Overdiagnosis can result in unnecessary cost, psychological harms (e.g., anxiety, cancer worry), and quality of life issues due to treatment of a disease that may have never become symptomatic. The CISNET modeling study indicates that 8.7% to 13.5% of screening-detected lung cancer cases are a result of overdiagnosis (de Koning et al., 2014). Patz and others (2014) used data from the NLST to estimate overdiagnosis and found that 18.5% (95% CI, 5.4% to 30.6%) of all lung cancers detected via LDCT were an overdiagnosis (Patz et al., 2014). A retrospective estimation analysis was conducted to determine the volume-doubling time for screening-detected lung cancer using LDCT to differentiate between aggressive versus indolent cancers (Veronesi et al., 2012). A quarter (25%) of the lung cancer cases were slow-growing, suggesting overdiagnosis.

The LDCT test exposes individuals to radiation (estimated radiation exposure absorption for LDCT is 1.4 millisievert [mSv]) and radiation exposure is linked to an increased risk of developing cancer. In comparison, a person's annual exposure to radiation in the U.S. is 2.4 mSv on average (United States Nuclear Regulatory Commission, 2017). While the NLST did not directly measure the effect of radiation exposure on cancer due to the length of the follow-up period, other studies have aimed to estimate the proportion of radiation-induced caner due to LDCT screening. The CISNET modeling study found more radiation-related lung cancer deaths among individuals who began annual screening before age 50 versus those who started the

screening after age 50 which is consistent with previous studies (de Koning et al., 2014). In 2008, Berrington de Gonzalez, Kim and Berg conducted risk modeling to estimate radiation risk for three annual LDCT screens before age 55 years and to determine the mortality reduction from LDCT that would outweigh the harms of radiation-induced lung cancer deaths (González, Kim, & Berg, 2008). The results indicated before age 50 the mortality reduction would need to be substantial to outweigh the risks of radiation exposure. A similar study was conducted by Brenner (2004) to provide an estimate of radiation-related lung cancer risk associated with LDCT and to determine the mortality benefit needed to outweigh the harms. This study concluded the estimated number of radiation-associated lung cancers would be 1.8% (95% credibility interval: 0.5% to 5.5%) or 36,000 individuals if half of all U.S. current and former smokers between the age of 50-75 received annual LDCT screening (Brenner, 2004).

There are also psychological harms associated with the screening procedure. Studies have described the psychological effects across the screening continuum including the stress a patient may experience leading up to the test as well as once the screen is complete, but before results are received (Harris et al., 2014; Wu, Raz, Brown, & Sun, 2016). Among those individuals who receive a positive screening test, their results may recommend undergoing surveillance by checking the growth of the nodule over a period of time. This waiting period can result in uncertainty and feelings of angst for the patient and their family members. Several studies have evaluated increased anxiety levels following receipt of a positive screening result (Broadstock, Michie, & Marteau, 2000; Byrne, Weissfeld, & Roberts, 2008; Cockburn, Staples, Hurley, & De Luise, 1994; Lerman et al., 1991; Ong, Austoker, & Brett, 1997; Swanson, McIntosh, Power, & Dobson, 1996). There are also psychological effects and stigma that may be associated with a disease that is closely related to smoking behavior.

Informed Decision-Making

Given the established benefits, harms, and uncertainties associated with lung cancer screening using LDCT all screening guidelines include an endorsement of informed decision-making (IDM) (Boiselle, 2013; Pinsky et al., 2017; Watson et al., 2016; Wender et al., 2013). IDM as defined by the USPSTF and the Task Force on Community Preventive Services, is "an individual's overall process of gathering relevant health information from both his or her clinician and from other clinical and non-clinical sources, with or without independent clarification of values" (U.S. Preventive Services Task Force, 2003). Shared decision-making (SDM), a strategy used to achieve informed decision-making, is defined by these groups as "a particular process of decision-making by the patient and clinician in which the patient understands the risk or seriousness of the disease or condition to be prevented, understands the preventive service, including the risks, benefits, alternatives, and uncertainties, has weighed his or her values regarding the potential benefits and harms associated with the service, and has engaged in decision-making at a level at which he or she desires and feels comfortable" (U.S. Preventive Services Task Force, 2003). Patient decision aids are tools that may be used to support the decision-making process by providing information in a balanced manner when there are multiple options and helping patients review the information in order to make a determination that is congruent with their personal values and preferences.

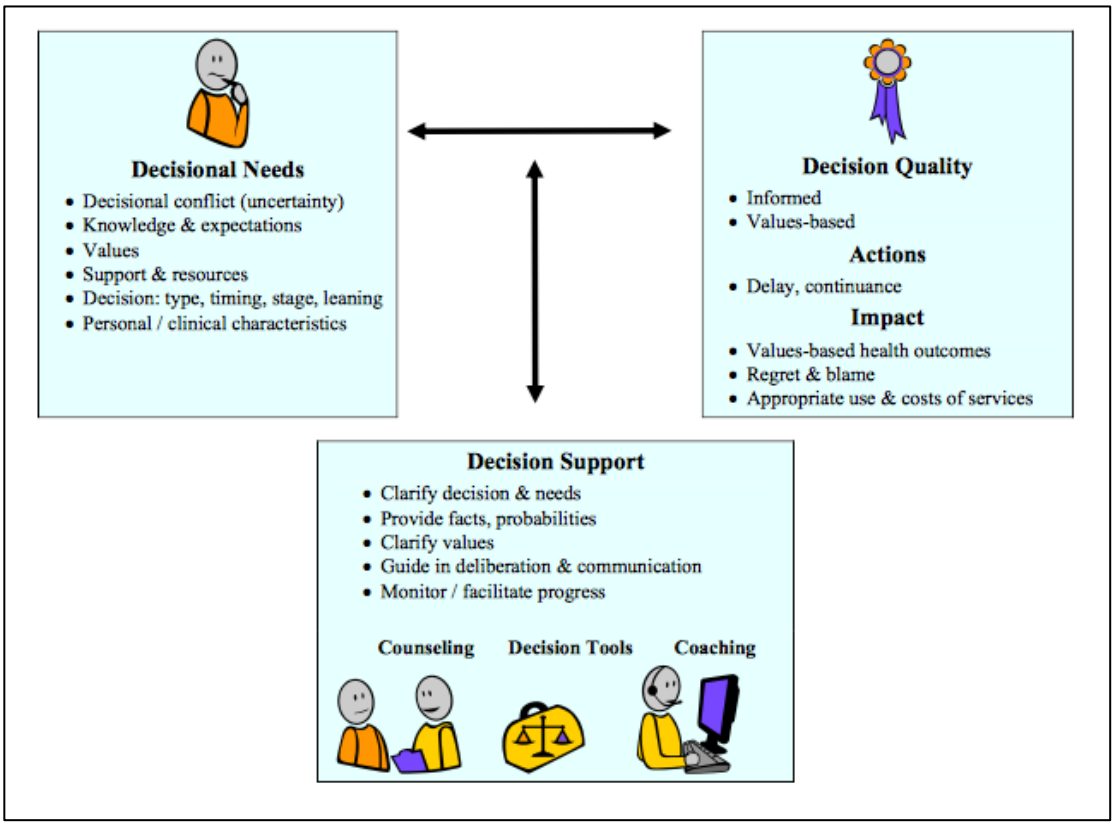
The process of IDM has been promoted widely in cancer prevention and control and has resulted in increased knowledge, improved understanding of risk, reduced decisional conflict, and increased physician-patient communication and trust (O'Connor et al., 1999; Stacey et al., 2017). While these individual- and interpersonal-level factors are affected by IDM, the impact this approach has on health behavior outcomes is mixed (Stacey et al., 2017; U.S. Preventive

Services Task Force, 2003). However, IDM should allow patients to weigh the benefits and harms and make a decision that is aligned with their own values and so the end goal may not always be directly related to a health behavior outcome. Despite the usefulness of IDM, there are differences between groups regarding their willingness to engage in the process, their interest in playing an active role in health decisions as well as their ability to understand the complex nature of decision-making (Kaplan & Frosch, 2005).

Ottawa Decisional Support Framework

The Ottawa Decisional Support Framework (**Figure 1.1**), an evidence-based model for improving quality in making health decisions, is grounded in theory across multiple disciplines (Ajzen & Fishbein, 1980; Bandura, 1982; Fischhoff et al., 1980; Janis & Mann, 1977; Keeney, 1982; Norbeck, 1988; Orem, 1995; Tversky & Kahneman, 1981). The framework posits there is a structured process in making health decisions which includes: 1) identifying personal characteristics and other determinants that influence an individuals' decision-making needs; 2) providing decision support tailored to the patient needs which may include counseling, decision tools, or decision coaching; and 3) evaluating the decision-making process and outcomes. It suggests that patients' decisional needs (e.g., knowledge, values) impact their decisional quality (e.g., being informed, feeling clear about personal values and preferences) which ultimately influences their behavior (use of health services) (O'Connor et al., 1998; The Ottawa Hospital Research Institute, 2015). Decisional support tools can help improve quality by addressing any unmet decisional needs.

Figure 1.1 Ottawa Decision Support Framework (The Ottawa Hospital Research Institute, 2015)



Decisional Needs

The initial component in the decision-making process identifies determinants that are related to decisions, which ultimately shape an individual's needs. These factors are organized by: 1) perception of decision, 2) perception of others, 3) resources to make decisions, and 4) personal and clinical characteristics. Perceptions of decisions include: *knowledge* of the health problem, the options and outcomes; *expectations* of the perceived likelihood of the outcome associated with making a decision; *values* or personal weight of the option outcomes; *decisional conflict* about the course of action to take*; stage of decision-making* from not thinking about the options to having carried out the choice; and *predisposition* to choose one option over the other

(The Ottawa Hospital Research Institute, 2015). Perceptions of others that factor into individuals' decisions include: *opinions and practices* of a spouse, family, peer, or clinician, for example, he decides or thinks is an appropriate choice; *support* of available sources (e.g., information, advice, access to services from social networks, health care providers) required to make a decision; *pressures* of persuasion, influence, or coercion from others to make a given choice; and *role in decision-making* which includes the extent of wanting to be involved in the decision-making process. Resources to make a decision include *previous experience* or exposure to the situation, the options, related outcomes and the decision-making process; *self-efficacy* or the ability to make a decision or engage in SDM; *motivation* to make a decision or share in the decision; *skills* in making a decision and then taking any needed action; and *external support* which includes information, advice, emotional, instrumental, financial, and professional resources from others. Background characteristics of the *patien*t (e.g., age, gender, education, health status) and the *practitioner* (e.g., age, gender, ethnicity, counselling style) are also factors that may influence decisions.

Decisional Needs in Lung Cancer Screening

Leading up to and following the release of the USPSTF recommendations for lung cancer screening via LDCT, studies have been conducted to understand the decision-making needs, particularly the knowledge and awareness of screening among individuals eligible for the test (Cardarelli et al., 2017; Carter-Harris, Ceppa, Hanna, & Rawl, 2017; Carter-Harris et al., 2018; Gressard et al., 2017; Mishra S, et al, 2016; Simmons, Gray, Schabath, Wilson, & Quinn, 2017). Most recently, Springer (2018) describes a lung cancer screening awareness campaign implemented in a rural area of Michigan. This campaign used a number of strategies including

radio broadcast media, gas stations and convenience stores advertisements, and marketing a website about lung cancer screening. Lung cancer screening awareness was increased through these campaign sources. A cross-sectional study was conducted to examine sociodemographics, knowledge, and lung cancer screening behavior among 438 screening-eligible individuals (Carter-Harris et al., 2018). Overall, knowledge scores were low, but knowledge was lower among African American participants (M=3.19, Range 0-9) compared to whites (M=4.02, $p<0.001$). In 2017, Carter-Harris and colleagues published themes from a qualitative study conducted to explore the knowledge and beliefs of smokers about lung cancer screening (Carter-Harris et al., 2017). Focus group participants (N = 26) had poor knowledge related to lung cancer screening. Mishra (2016) conducted semi-structured qualitative interviews with 22 patients to describe knowledge and attitudes about lung cancer screening, smoking cessation, and shared decision-making (Mishra S, et al, 2016). The interviews conducted indicated that participants lacked awareness about LDCT screening. In another qualitative study, focus groups were conducted among high-risk community members and primary care providers to examine knowledge and attitudes about LDCT screening (Simmons et al., 2017). Community members had not heard of LDCT screening and the majority reported that a healthcare provider had never recommended the test. Sin and colleagues (2016) administered interviews and focus groups to understand barriers to lung cancer screening among Korean immigrant men and found lack of knowledge about lung cancer and lung cancer screening served as a barrier to screening (Sin, Ha, & Taylor, 2016). Cardarelli (2017) enrolled 54 individuals (61% greater than 55 pack-year history) to participate in focus groups to discuss the development of a lung cancer screening program. Prior to participating in the focus group discussions, most participants were unaware of lung cancer screening (Cardarelli et al., 2017). One hundred five smokers participated in gender

specific focus groups to explore perceptions about lung cancer screening (Gressard et al., 2017). The study found that awareness about lung cancer screening was low among participants.

In addition to measuring knowledge and awareness regarding lung cancer screening, studies have also examined other factors related to individuals' decision-making needs including: personal values, perceived benefits and barriers, and uncertainty related to the test (Cataldo, 2016; Duong et al., 2017; Hall et al., 2018; Schapira et al., 2016; Sharma et al., 2018; Silvestri, Nietert, Zoller, Carter, & Bradford, 2007). Byrne and colleagues (2019) surveyed 27 patients following lung cancer screening in two community-based radiology clinics and measured decision-making factors important to the study population (Byrne, Lillie, & Studts, 2019). Results indicated that screening efficacy and salience were rates as most important in their screening decisions. Among this sample, a healthcare provider recommendation was rated as not important. Cataldo (2016) conducted a national survey of 338 older smokers (>55 years) with a >30 pack-year smoking history to identify the demographics, smoking history, health risk perceptions, knowledge and attitudes among this group (Cataldo, 2016). A binary logistic regression was conducted to determine significant predictors of agreement to obtain screening using LDCT. Perceptions of accuracy of the test, belief that early detection of lung cancer would result in better outcomes, belief that they were at high risk, and were not afraid of CT scans all significantly predicted a decision to have the screening test. A telephone survey was conducted and data were collected from current and former smokers about previous LDCT screening and reasons for undergoing or not undergoing the test (Delmerico, Hyland, Celestino, Reid, & Cummings, 2014). Among those who were not willing to get screened, lack of insurance and being afraid to find out whether they have cancer were significant predictors. The majority of current smokers (78.5%) and former smokers (81.4%) were willing to undergo the test if it were

recommended by their doctor. Silvestri and colleagues (2007) administered a telephone survey utilizing random-digit dialing to a national sample of individuals 40 years of age or older (N = 2,001) (Silvestri et al., 2007). Current smokers were less likely to believe that early detection would improve survival in comparison to never smokers ($p<0.05$). Smokers were also less likely to be willing to consider LDCT (OR=0.48, CI, 0.32 to 0.71). Never smokers reported higher beliefs that the risk of getting the disease and the accuracy of the test were important to their decision to get screened. In a cross-sectional study, patient and primary care providers were questioned about their attitudes and adherence toward lung cancer screening (Duong et al., 2017). Eighty patients referred for LDCT at an academic medical center completed the questionnaire and among adherent participants, they believed the LDCT was accurate, early detection was valuable, and they had physician trust. Asymptomatic, high-risk smokers between the ages of 55 to 74 were recruited from an academic urban hospital to collect data regarding beliefs about lung cancer and screening and their relationship to screening (N = 108) (Jonnalagadda et al., 2012). Beliefs associated with a decreased intention to screen included fatalistic beliefs, fear of radiation exposure, and anxiety related to the CT scans. This study also examined differences in beliefs by race/ethnicity and found several differences in beliefs toward lung cancer and screening by minority versus non-minority participants. Focus groups (n = 16) and in-depth interviews (n = 5) were conducted among screening-eligible individuals to obtain their response to an educational booklet designed to provide messages about the benefits, risks, and costs of lung cancer screening (Sharma et al., 2018). Themes that emerged from this qualitative study included associated cost of the exam as a potential barrier, apprehension regarding the results, needing more information about the eligibility criteria as well as details about the test itself.

Other studies have aimed to measure decisional conflict by collecting information about the level of uncertainty individuals have about lung cancer screening. Recently, Hall and others (2018) conducted a cross-sectional study of 169 current and former smokers (Hall et al., 2018). Respondents reported high clarity about why they were being referred to undergo lung cancer screening. Lower education levels, not receiving Medicare, and greater stress and anxiety were related to lower levels of clarity regarding screening. Another study examined the role of uncertainty in decision-making for lung cancer screening (Schapira et al., 2016). Twenty-two adult current or former smokers participated in structured interviews and half of the participants met the USPSTF's eligibility criteria for screening. Themes emerged from this study regarding uncertainty and how it impacts the screening decision.

Fewer studies have primarily measured the decision-making preferences of individuals considering lung cancer screening. Thirty-seven current smokers at participating Veterans Health Administration sites completed a semi-structured qualitative interview over the phone (Greene et al., 2018). The goal of this study was to explore what those at highest risk for lung cancer understood and how they made decisions about lung cancer screening. Smokers overestimated the benefits and minimized the risks of lung cancer screening. In the qualitative study conducted by Mishra and colleagues (2016), they asked participants about their shared decision-making preferences and most said they preferred one-on-one discussions with a healthcare provider (Mishra S, et al, 2016). During the focus groups conducted by Cardarelli (2017), participants suggested having information about lung cancer screening come from one's family doctor or specialty provider would be important (Cardarelli et al., 2017). A study of 28 veterans and primary care providers was conducted to explore perspectives on lung cancer screening. Through

questionnaires and focus groups both providers and patients were open to exploring modalities and tools to improve shared decision-making (Kanodra et al., 2016).

Decisional Needs in Lung Cancer Screening among African Americans

While many studies have aimed to describe individuals' decision-making needs and relate these factors to intentions or behavior, most studies included homogenous samples and were unable to conduct sub-group analysis among African American participants or were qualitative in nature. Studies conducted by Carter-Harris (2018) and Jonnalagadda (2012) conducted analysis stratified by race and found differences in knowledge and beliefs about screening. The studies led by Schapira (2016) and Kanodra (2016) included a majority (72% and 57%) of African American high risk individuals. One study was identified that conducted focus groups with an all African American sample of current and former smokers without a cancer diagnosis to explore their knowledge and beliefs about lung cancer (Lathan, Waldman, Browning, Gagne, & Emmons, 2015). There was an awareness among participants regarding the connection between smoking and lung cancer, symptoms of the disease, and its poor outcomes. Participants were also interested in personalized smoking-cessation information. Williams and colleagues (2019) recently reported on an ongoing intervention program to increase community awareness of lung cancer screening through education utilizing community health workers among racial/ethnic minorities and low socioeconomic individuals (L. B. Williams, McCall, Joshua, Looney, & Tingen, 2019). The study aims to impact participants' knowledge, attitudes, and beliefs about lung cancer and to increase early detection and prevention behaviors.

Decision Support

Decision support which is defined as methods (e.g., counseling, tools, coaching) used to clarify the decision to be made, address any decisional needs, provide information including facts about the options, clarify values, guide in deliberation and communications, and monitor and facilitate progress. These tools aim to help people participate in making a health choice that aligns with their person values and preferences. Decision support should also tailor its strategy based upon the decisional needs of the individual. They are not intended to replace clinical encounters, but serve to supplement those discussions. There are criteria and standards that outline the components of patient decision aids (International Patient Decision Aid Standards, 2013). Another form of decision support, decision coaching, utilizes a trained facilitator who supports individuals who are in the decision-making process through various modes of communication (e.g., telephone, face-to-face). The components of decision support include clarifying the decision to be made, addressing any decisional needs, providing information including facts about the options, clarifying values, guiding in deliberation and communications, and monitoring and facilitating progress.

Decision Support in Lung Cancer Screening

Decision aids have been developed to evaluate the impact on the decision-making process among patients eligible for lung cancer screening using LDCT. Dharod (2019) examined the feasibility of a digital health outreach strategy to identify patients eligible for lung cancer screening and to promote use of a decision aid. Of the N=99 patients eligible for lung cancer screening, n=81 made a decision to get screened following completion of the interactive website and decision aid. Erkmen and colleagues (2018) employed an enhanced shared decision-making

model into practice and 190 patients received a shared decision-making visit. Most patients (98.4%) underwent LDCT (Erkmen et al., 2018). A prospective, one-group study design was used to test a decision aid and shared decision-making strategy among 20 patient and primary care physician dyads. Both groups rated the aid as helpful and easy to use. Eighty percent of patients indicated their intent to be screened (McDonnell et al., 2018). Percac-Lima (2018) conducted a randomized trial of 1,200 smokers to evaluate the impact of a patient navigation program on lung cancer screening rates (Percac-Lima et al., 2018). Intervention participants reported higher LDCT screening rates (23.5%) versus the control group (8.6%, $p<0.001$). A single-group, pre-post-test study was conducted to test a lung cancer screening decision aid video among screening-eligible patients. Participants knowledge increased significantly (Reuland et al., 2018). Approximately one-third (28%) of participants changed their preference either to or from screening pre- to post-test. Mazzone and others (2017) evaluated the impact of a counseling and shared-decision making visit on lung cancer screening (Mazzone et al., 2017). Significant improvement in knowledge was reported ($p=.03$ to $p < .0001$). A study was conducted among patients in a Veterans Health Administration system to identify the factors important to patients making a decision to get screened for lung cancer (Lillie et al., 2017). Participants (N=1,388) were randomized to either direct lung cancer screening invitation which was mailed with a decision aid versus usual care. Personal risk of lung cancer was cited as the most important factor to making a decision to get screened. Health risk from the test itself was the least important factor. The decision aid participants rated false-positives, knowledge, screening convenience, and anxiety as important issues compared to the usual care participants. A randomized controlled trial was conducted to compare formats (descriptive versus experienced probability) on knowledge, beliefs, endorsement of lung cancer screening, and screening

intentions (Fraenkel et al., 2016). A total of N =276 patients were randomized to one of three groups: 1) numbers only, 2) numbers + icon arrays, 3) numbers + a set of slides illustrating false-positives. Participants randomized to the numbers + icon arrays had the highest knowledge in comparison to the other groups (p=0.001). Positive beliefs about lung cancer screening were reported among participants in the numbers + experienced format compared with the numbers + icon array format. Lau (2015) conducted a pre-post-test among participants who received a web-based decision aid for lung cancer screening (www.shouldiscreen.com) (Lau et al., 2015). The decision aid was perceived as useful by the study participants. Knowledge increased and decisional conflict decreased significantly pre- to post-test (p's <0.001). Additionally, concordance between participants' preference for screening and the USPSTF recommendation improved following the decision aid (p<0.001). Volk and colleagues (2014) assessed the feasibility of a patient decision aid about LDCT (Volk et al., 2014). Fifty-two participants were included in the study and the decision aid was viewed as acceptable. There was a significant increase in lung cancer screening knowledge (25.5% of questions answered correctly before and 74.8% after; P<0.01). While overall knowledge increased, an understanding of screening eligibility remained poor. Participants indicated an interest in screening following the intervention. They also reported being clear about their personal values (benefits and harms of screening that mattered most to them). A pre-post-test was administered to patients within Kaiser Permanente as a part of their lung cancer screening program to evaluate the impact of a 60-minute class on knowledge and decision-making (Sakoda et al., 2018). Knowledge increased for some items, patients reported having the information they need, and the majority (60%) felt they knew what choice was best for them.

Decision Quality

The final component in the framework is delineated by the *quality of the decision* and the *quality of the process* of decision-making. Quality of the decision is defined as "the extent to which the chosen option best matches informed clients' values for benefits, harms, and scientific uncertainties" and the quality of the process of decision-making is "the extent to which a person is helped to: recognize that a decision needs to be made; knows about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; understand that values affect the decision; be clear about which features of the options matter most to them; discuss values with their clinician, and become involved in decision-making in ways they prefer".

Decision Quality in Lung Cancer Screening

Decision quality is often measured in studies evaluating the impact of decision support tools. Few studies have assessed the quality of decision-making for lung cancer screening apart from testing an intervention. Wiener and colleagues (2018) conducted a qualitative study among patients and clinicians to describe early experiences in decision-making about lung cancer screening (Wiener et al., 2018). Among the 49 patients who received lung cancer screening in the past year, they perceived receiving little information about lung cancer screening or the benefits and limitations of the test. They also did not think significant deliberation about the decision had occurred.

The articles described above regarding the components of decision-making are summarized in **Appendix A**.

Summary

The burden of lung cancer is a public health priority and an evidence-based procedure (LDCT) exists which can detect the disease early and reduce mortality. However, since the USPSTF recommendations for lung cancer screening using LDCT were released in 2013 there has been no significant change in the percentage of eligible individuals screened (3.3% in 2010 to 3.9% in 2015). Only 262,700 of the 6.8 million smokers eligible received the test (Jemal & Fedewa, 2017). The reasons for the slow uptake of this screening test are multi-layered, but include the need for more information about the benefits and limitations of the test for both patients and providers (Jemal & Fedewa, 2017). Other major cancers (e.g., colorectal cancer screening) that have screening tests available have seen lower adherence to screening among African Americans which results in disparities. While the barriers identified among African Americans for other cancers may be similar for lung cancer screening (e.g., fatalistic beliefs, medical distrust, access to care), there may be other considerations specific to the lung cancer screening test for this population. The Ottawa Decision Support Framework suggests there are components of a decisional process that ultimately impacts behavior. While there has been initial development of decision aids to promote informed decision-making, additional formative research is needed, particularly among African Americans at high risk for being diagnosed with lung cancer to identify the informational and decisional needs of this group. Additionally, LDCT resulted in a significant reduction in lung cancer mortality among African Americans in the NLST. This provides a strong rationale for studying aspects of the decision-making process and how they may support or hinder action in an all African American sample. The dissertation research project used the Ottawa Decision Support Framework to describe aspects of informed decision-making (e.g., knowledge, personal values, uncertainty, preferences) and assessed the

relationship between these components and screening intentions of African American adult smokers who may be eligible for screening.

Chapter 3: Manuscript #1: Development of Decisional Values Statements for Lung Cancer Screening among African American Smokers

Abstract

It is estimated that 3% to 5% of smokers eligible for lung cancer screening via low-dose computed tomography (LDCT) have received the test. The reasons for slow uptake are multi-layered, but include patients' needs for more information about the benefits and limitations of LDCT and consideration of their personal values about the screening decision. Values and preferences may be specific to the type of decision to be made and the characteristics of those involved in making the decision. Thus, we developed a personal values measure for LDCT for African Americans and report its initial psychometric properties. Patient and provider key informant interviews (N=9) identified factors important to African American smokers' decisions about lung cancer screening. Based on these interviews, values statements were created for the measure. The resulting tool was administered to N=119 African American smokers in a cross-sectional study. An exploratory factor analysis revealed two components explaining 64% of the variance. *Cons of Screening* included items like '…screening will not find all lung cancers or all lung cancer early'. *Pros of Screening* measured concepts such as 'lowering your risk of dying from lung cancer' and 'getting peace of mind'. The final 12-item measure had excellent internal consistency (α=.89 overall; α=.86 and .88 for subscales, respectively). This new tool provides a promising values measure for lung cancer screening among African Americans and could inform future values clarification tools promoting informed decision-making.

Introduction

Results from the National Lung Screening Trial (NLST) helped inform screening recommendations for low-dose computed tomography (LDCT), a scan that detects lung cancer early and lowers the risk of dying from the disease (The National Lung Screening Trial Research Team, 2011). This randomized controlled trial of over 50,000 participants found a 20% relative reduction in lung cancer mortality in participants who received lung cancer screening using LDCT versus radiography (NLST, 2011). The findings from this trial guided the United States Preventive Services Task Force (USPSTF), an independent body of experts, release of a Grade B recommendation for annual lung cancer screening for individuals who are considered high risk (55 to 80 years old, 30 pack-year smoking history, and who currently smoke or who have quit in the last 15 years (Humphrey et al., 2013)). While there are acknowledged benefits of LDCT screening (e.g., mortality reduction), there are also limitations (e.g., false positives), and risks (e.g., radiation exposure) associated with the test (NLST, 2011). Given these considerations, providers and patients must determine appropriate eligibility and engage in informed decision-making (IDM) by weighing the benefits, limitations, and harms.

The USPSTF along with many other major medical organizations (e.g., American Lung Association, National Comprehensive Cancer Network) promote IDM for individuals considering lung cancer screening using LDCT, because of the known advantages and disadvantages ("NCCN Guidelines for Patients® | Lung Cancer Screening," 2017). Individuals eligible for lung cancer screening are encouraged to consider their personal preferences and to make a decision that is aligned with their own values. Values in this context refers to the "desirability or personal importance a respondent places on the benefits and risks of an option" (Available from www.ohri.ca/decisionaid.). For example, in O'Connor's validated values

measure, respondents are asked to consider factors (e.g., protection from hip fractures, risk of blood clots) that are viewed as important by people making a specific decision (e.g., making a decision about osteoporosis therapies) and then asked to indicate how important each factor is to them ('not at all important to me in this decision' to 'extremely important to me in this decision'; (The Ottawa Hospital Research Institute, 2015).

Initial development and evaluation of decision aids to promote IDM for lung cancer screening using LDCT exist (Erkmen et al., 2018; Fraenkel et al., 2016; Lau et al., 2015; Lillie et al., 2017; Lowenstein et al., 2016; Mazzone et al., 2017; McDonnell et al., 2018; Percac-Lima et al., 2018; Reuland et al., 2018; Volk et al., 2014). Some of these decision aids include values clarification exercises to help individuals determine what matters most to them. Volk and colleagues (2014) assessed the feasibility of a patient decision aid about LDCT (Volk et al., 2014). Fifty-two participants were included in the study and reported being clear about their personal values (benefits and harms of screening that mattered most to them). A study was conducted among patients in a Veterans Health Administration system to identify the factors important to patients making a decision to get screened for lung cancer (Lillie et al., 2017). Participants (N=1,388) were randomized to either direct lung cancer screening invitation which was mailed with a decision aid versus usual care. Personal risk of lung cancer was cited as the most important factor to making a decision to get screened. Health risk from the test itself was the least important factor. Thirty current and former smokers with no history of lung cancer watched a patient decision aid video to explore how these individuals valued potential benefits and harms of lung cancer screening (Hoffman et al., 2018). After viewing the decision aid, participants indicated potential regret and finding cancer early as highly important in their

decision. Concerns about false positives, overdiagnosis, and radiation exposure were reported as moderately important, but these responses varied.

While current research is addressing personal values in lung cancer screening through the inclusion of values clarification exercises in decision aids, it is acknowledged that values and preferences may be specific to the *type of decision* to be made as well as the *characteristics of those involved in making the decision* (O'Connor et al., 1998). Elucidating factors that are specific to individuals facing the lung cancer screening decision can help inform future values clarification exercise statements. Additionally, it is important to have valid measures that can assess the impact of these values clarification tools on smokers' decisions about lung cancer screening via LDCT. The role of background characteristics, including race/ethnicity, may be important to explore among those making a decision about lung cancer screening. In the case of lung cancer, the burden of the disease is significant for African Americans, especially African American men who have the highest lung cancer death rates compared to all other racial and ethnic groups (American Cancer Society, 2019; DeSantis et al., 2019). Previous research also points to lower levels of other evidence-based cancer screening (e.g., colorectal cancer) utilization between African Americans and other groups due to individual (e.g., fear, lack of knowledge) and systematic barriers (e.g., health insurance, access) (Ata A, Elzey JD, Insaf TZ, Grau AM, Stain SC, Ahmed NU, 2006; Carlos RC, Underwood W, III, Fendrick AM, Bernstein SJ, 2005; Ioannou GN, Chapko MK, Dominitz JA, 2003)). To avoid racial disparities in decision-making processes and ultimately screening rates for LDCT, it is important to uncover any considerations unique to this patient population faced with this specific decision.

The goal of the present study was: 1) to identify factors that may be important to African Americans considering lung cancer screening via LDCT and 2) to develop statements to measure

personal values about the screening test. The current paper describes findings from patient and provider key informant interviews (N=9) that informed the initial development of the values statements and describes the psychometric properties of the decisional values tool. A cross-sectional study of African Americans (N=119) was conducted and the new measure was included to describe aspects of decision-making related to the screening decision among African American adults at risk for lung cancer due to long-term tobacco use.

Methods

Key Informant Interviews

The initial phase of the research consisted of key informant interviews at the provider- and patient-level to obtain information about decisional values that may be salient to African American smokers when considering whether to be screened for lung cancer.

Providers were recruited using a purposive sampling method, which included snowball sampling. Our team had a list of providers who were part of lung cancer screening programs at their respective institutions and were sent an invitation letter via email. The following eligibility criteria were used: 1) 21 years of age or older, 2) currently works in a healthcare setting, and 3) works in the area of lung cancer and lung cancer screening. The providers were asked to email the first author (RMW) directly to schedule a convenient date and time to conduct a 20-minute interview over the phone. Among those eligible and interested, RMW obtained verbal informed consent. Incentives were not offered to the providers.

Patients were invited to participate in the study through flyers distributed during local community health promotion events and word of mouth. Interested participants were directed to contact RMW who assessed their eligibility and arranged a date, time, and location to complete a

20-minute interview in-person. The criteria for inclusion complemented the screening recommendations but did not require a minimum pack-year smoking history. Individuals who were 55 to 80 years old, identified as African American, were current or former smokers, and did not have lung cancer were invited to participate in the study. Volunteers participated in the informed consent process and following completion of the survey were provided $10 as a thank you for their time. This work was approved by the University of Maryland Institutional Review Board (#1300307-1).

The interview guide was semi-structured in nature and the items were targeted based upon the interviewee (provider vs. patient). **Table 3.1** includes items asked of the participants. All interviews were digitally recorded and transcribed verbatim using an external transcription service.

Provider and Patient Characteristics

Of the eight providers contacted, five (62.5%) agreed to participate and four of the five (80%) patients who expressed interest completed the in-person interview. Overall, nine key informant interviews were conducted (n=5 providers; n=4 patients). Providers included a primary care physician, oncologist, thoracic surgeon, pulmonologist, and radiologist representing four different healthcare institutions. Patients included n=2 males and n=2 females with a mean age of 69 years, smoked an average of 11.5 cigarettes per day, n=2 currently smoked, and n=2 had previously quit smoking.

Survey Item Generation

The instructions and phrasing of the items were adapted from a validated decisional values scale and other values items used in the literature (O'Connor et al., 1999; Taylor et al.,

2013). The goal of the key informant interviews was to identify values relevant to lung cancer screening and important to the population that could be used as items included in the cross-sectional study. The first author (RMW) reviewed the transcripts for accuracy comparing them to the recording and minor adjustments were made. Next, a content analysis of the data was conducted to identify themes and categories (Neuendorf, 2017). RMW reviewed the transcripts providing labels (positive factors, negative factors) to the relevant text. Next, these statements were grouped into categories (e.g., mortality benefit, fear/fatalism) that informed the development of the decisional values for lung cancer screening items. The senior author (CLK) reviewed the labels, categories, and draft items and made recommendations for refinement. The process was iterative in nature and items were revised until consensus was reached.

The 17-item self-administered measure includes statements framed in the context of pros of getting screened for lung cancer and the cons of getting screened which can be found in **Table 3.2**. Sample pros of screening items include: "How important is lowering your risk of dying from lung cancer?"; "How important is getting peace of mind to find out you do not have lung cancer?". Example items highlighting possible cons of screening include: "How important is the idea lung cancer screening may lead to more testing if there is an abnormal result?"; "How important is the idea that getting screened for lung cancer would make you feel badly about your smoking history?". Individuals responded to the statements using a 5-point Likert-type scale (1=Not at all important to 5=Extremely important).

Cross- Sectional Study Survey Method

A multi-pronged approach was utilized for recruitment. These strategies included placing advertisements in a local newspaper, posting flyers in health clinics, distributing flyers in other community-based settings (e.g., libraries, recreational centers), and speaking at local health

department's smoking cessation clinics and in five District of Columbia Housing Authority public housing communities. Additionally, participants from a previous study who agreed to be contacted in the future about similar research and who were potentially eligible were re-contacted by a mailed invitation letter (Holt et al., 2015).

The eligibility criteria for the study included: 1) self-identify as African American, 2) be 55-80 years old, 3) currently smoke or have quit within the past 15 years, and 4) have not been diagnosed with lung cancer. Each person who completed the survey received $10, as a token of appreciation and the American Lung Association's "Is Lung Cancer Screening Right for Me?" Q&A leaflet. The survey was administered online using Qualtrics, over the phone, and in-person. The overall survey took approximately 20 minutes to complete and included the 17-item decisional values measure as well as items capturing participants' knowledge and awareness of lung cancer screening, preferences regarding their level of involvement in the screening decision, decisional uncertainty, lung cancer risk factors, other cancer screening behaviors, and background characteristics.

Data Analysis

Data analysis was conducted with SPSS 23.0. Descriptive statistics were computed to examine the distribution of the variables of interest including background characteristics and the decisional values measure. The factorability of the data was verified using the Kaiser-Meyer Olkin Measure of Sampling Adequacy & Bartlett's Test of Sphericity. An exploratory factor analysis was conducted to identify potential subscales, internal consistency reliability (Cronbach's alpha) was computed for the overall scale and identified subscales, and predictive validity was assessed by analyzing associations between the decisional values items and lung cancer screening intention variable.

Results

Participant Characteristics

Table 3.3 provides the characteristics of the 119 participants who completed the survey. They were a mean age of 62.7 (SD=6.3), 37.1% had some college or more, 38.5% had never been married, 26.7% were retired, most (74.8%) had an annual income of $20,000 or less, and 85% went to their primary care physician for routine medical care. Regarding smoking status, 79% of participants currently smoked, the average pack-year was 23.7 (SD=19.9), median=20, and a little more than half the sample (53.8%) had a 20 or greater pack-year smoking history.

Item Characteristics

Prior to testing the 17-item measure for factorability the Kaiser-Meyer Olkin & Bartlett's Test of Sphericity were conducted to determine how well suited the measure was for a factor analysis and whether it would be useful (Dziuban & Shirkey, 1974). The Kaiser-Meyer Olkin value was .864 and with a value close to 1.0 the results indicate that a factor analysis would be suitable and the significance level for the Bartlett's Test of Sphericity was $p < .001$ suggesting that a factor analysis may be useful with the present data. Next, an exploratory factor analysis using the Principal Component Analysis extraction method was conducted to determine the proportion of variance in the variables that might be accounted for by underlying factors. Eigenvalues greater than 1.0 and the scree plot was used to determine factor retention. Oblique rotation (nonorthogonal) method was utilized and among the factors included in the pattern matrix, only those with a correlation coefficient greater than .40 and without cross-loading above .40 were included in the final model.

The initial model included three factors which we operationalized as the pros of screening, the cons of screening, and emotions related to the decision (e.g., the feeling that if you had lung cancer you would feel like it was your fault, getting screened for lung cancer would make you feel badly about your smoking history). However, this initial model was not retained, because two of the three items in the third factor cross-loaded. In subsequent models, items were cross-loaded and removed (i.e., "How important is the idea that you would prefer to focus on other things in your life than thinking about screening for lung cancer?"). After removal of ambiguous items, the final two-factor model explained 64% of the variance (Factor 1: 49%, Factor 2: 15% proportion explained). The 2-factor model included: 1) *Cons of Lung Cancer Screening* (7-item) like lung cancer screening will not find all lung cancers or all lung cancers early and 2) *Pros of Lung Cancer Screening* (5-item) which measured concepts such as lowering your risk of dying from lung cancer and getting peace of mind. The 12-item instrument had excellent internal consistency reliability (α =.89) and acceptable subscale reliability (α =.86 and .88 respectively). **Table 3.4** presents the factor loading for the final 12-item decisional values for lung cancer screening measure.

The mean score for the *Cons of Screening* was 28.4 (SD=6.1) out of 35 and the *Pros of Screening* mean score was 22.1 (SD=3.8) out of 25. To determine whether the decisional values items predicted intention to be screened for lung cancer via LDCT in the next six months, adjusted linear regression analyses were conducted with the sub-scales and then with the total values measure. The *Pros of Screening* sub-scale significantly predicted screening intentions such that higher reported pros was associated with greater likelihood of screening intention (*B*=.10, *SE*=.04, *β*=.36, *p*<.05). The *Cons of Screening* sub-scale was not significantly associated with likelihood of screening. Higher ratings on the overall decisional values measure was

marginally associated with greater likelihood of getting screened in the next six months (*B*=.30, *SE*=.08, β=.23, *p*=.09).

Discussion

This study aimed to first identify the specific values of African Americans smokers who may benefit from lung cancer screening and use the data generated to inform a decisional values tool validated in this priority population. To our knowledge this the first decisional values measure created for African Americans who may be eligible for lung cancer screening due to their smoking history. The process for developing this measure was iterative and included the perspectives of potentially eligible patients and providers involved in lung cancer screening delivery. The cross-sectional study that followed the development of this tool allowed for an initial psychometric evaluation administered to a sample of lower socioeconomic level African American smokers who are currently eligible or who may become eligible for lung cancer screening via LDCT.

The accumulating evidence for the benefits of lung cancer screening to reduce lung cancer-specific mortality are mounting with the recent release of the NELSON trial results (International Association for the Study of Lung Cancer 19th World Conference on Lung Cancer, 2018). However, due to the limitations and possible harms associated with LDCT, most medical organizations including the Center for Medicaid and Medicare Services are endorsing the process of informed and shared decision-making. To promote informed decision-making in this context, individuals' decisional needs must be met and this includes addressing any gaps in knowledge about the health problem, considering personal values related to the health behavior, and the role the patient wants to play in the decision-making process (O'Connor et al., 2003; Sepucha et al.,

2013; The Ottawa Hospital Research Institute, 2015). Additionally, research suggests that for a patient population to make better, quality health choices individuals must understand any associated benefits and risks of the procedure and place importance on those factors that is consistent with their own personal values (Sepucha et al., 2013). Values may be specific to the decision to be made as well as the personal characteristics of those involved in making that decision (O'Connor et al., 1998). The present study addresses an important need in this field by first exploring possible factors that may be of importance to African Americans faced with the decision to be screened for lung cancer using LDCT, followed by the development of a tool specific to this screening decision, and then administering it in the priority population. A brief tool now exists that can be used to inform future values clarification exercises aimed at helping African Americans eligible for lung cancer consider their decision and can also capture the impact of this type of intervention on their behavior (values-based decision) and perceived quality (e.g., feeling informed, not having regret).

As a result of our discussion with key informants, statements were included in the decisional values measure that veered away from the benefits and risks of the procedure itself. They captured psychological factors (e.g., How important is the idea that getting screened for lung cancer would make you feel badly about your smoking history?) and two of these items resulted in a third factor in the initial model. While the 3-factor model was not retained, it warrants further examination. It is possible there are other factors of importance to this population that should be considered in their decision-making process. If values statements are not inclusive and culturally appropriate, they may miss factors important to certain groups and will result in people making decisions that are not aligned with their own values. For certain groups, it may be appropriate to focus solely on the benefits and limitations of the test itself, but

for other populations it may be important to consider the emotional components associated with getting screened.

Limitations of the current study need to be considered when considering the results. The overall goal of this work was to determine factors that could be included in the statements to capture values specific to lung cancer screening, but it did not include methods used in other measurement development projects (e.g., cognitive testing of the items, pilot testing). However, the structure of the items followed previously validated tools and adapted them to make them specific to the topic of lung cancer screening. On average, participants highly rated both the pros and cons of screening suggesting that both negative and positive factors would be important to their decision. This study is not able to assess the degree to which these personal values discriminate between the actual behavior (decision to screen versus not to screen), but we did evaluate associations between intentions to screen. Our newly developed scale includes items that delineate decisional balance (pros versus cons) and offers promising psychometrics that can be used in future work to determine additional criterion-related validity and reliability. Additionally, the responsiveness of this scale to measure the impact of interventions will be important to establish in additional research. The aim of this work was not to create a tool for the general population, but rather to address a need by determining factors that may be particularly important to African Americans and to create a tool that may resonate with this group. The validation sample included individuals from a lower socioeconomic group which aligns with national data that points to higher smoking prevalence among people with lower socioeconomic status, particularly lower levels of education (Centers for Disease Control and Prevention, 2010). However, future studies should assess the reliability of this tool in sub-groups.

Utilization of existing evidence-based cancer screenings have been lower among certain groups, including African Americans. While the reasons for lower use differ, particular attention must be paid to this priority population as healthcare institutions seek to identify patients and engage them in an informed process of making a decision to get screened for lung cancer using LDCT. If diverse groups of individuals' needs are not addressed including tapping into the things that are most important to them, racial disparities will be extended to this latest evidence-based modality. This new decisional values tool for lung cancer screening can be used to ascertain what is important to African American smokers at high risk for lung cancer and to develop new interventions that can help overcome any gaps in understanding of the benefits and limitations of the test, address other factors important to them, and support patients in making a high-quality decision.

Table 3.1 Items for Key Informant Interview

Provider Items	*Patient Items*
• Tell me where you work. • Please describe your role within the organization. • Please describe the primary audience/individuals you serve. • Describe how lung cancer screening is done within your organization. • What are some of the successes you have seen related to providing lung cancer screening? (Probe: Tell me about one or two of those successes; What factors contributed to that success?) • What are the challenges of providing lung cancer screening? (Probe: Provide one or two examples of those challenges; How have the challenges been handled?) • I would like you to think about why patients may get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why. • I would like you to think about why patients may NOT get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why. • What information/resources do you think patients need to make a decision about lung cancer screening using low-dose computed tomography? • What information/resources do you need to help patients make a decision about lung cancer screening using low-dose computed tomography? • Is there anything else you would like to add?	• Low-dose computed tomography screening is used to detect lung cancer. Have you read or heard about this type of lung cancer screening before talking with me today? If yes, Tell me about what you read and/or heard. If no, What would you like to know about lung cancer screening? • Has a doctor ever recommended lung cancer screening for you in the past? If yes, When was that? What happened? • Did you get tested for lung cancer following your doctor's recommendation? If yes, Why? If no, Why not? • I would like you to think about why you might get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why. (Probe: Tell me more.) • I would like you to think about why you might NOT get tested for lung cancer using low-dose computed tomography. Please tell me all the possible reasons you can think of and explain why. (Probes: Tell me more; Why do you think that?) • Is there anything else you would like to add?

Table 3.2 17-item Decisional Values for Lung Cancer Screening Measure

Below are listed some things people consider when making a decision about lung cancer screening using low-dose computed tomography. Please indicate how important these are to you by selecting extremely important to me to not at all important to me.
…lowering your risk of dying from lung cancer?
…getting a lung cancer screening test that may help you live longer?
…getting peace of mind to find out you do not have lung cancer?
…making you feel like you are doing everything you can for your health?
…following your doctor's opinion about lung cancer screening?
…thinking about family or friends who have dealt with lung cancer?
…knowing the test has little risk?
…the out of pocket cost of the screening?
…where you have to go (testing location) to get lung cancer screening?
…the idea that lung cancer screening may lead to more testing if there is an abnormal result?
…the idea that you would prefer to focus on other things in your life than thinking about screening for lung cancer?
…the idea that lung cancer screening will make you worry about lung cancer?
…the idea that lung cancer screening will not find all lung cancers or all lung cancers early?
…the idea that not all patients who have lung cancer diagnosed by screening will avoid death from lung cancer?
…the idea that the lung cancer screening test might show something wrong that turns out not to be cancer?
…the idea that getting screened for lung cancer would make you feel badly about your smoking history?
…the feeling that if you had lung cancer you would feel like it was your fault?

Note. Bolded items are the 12 retained following the factor analysis, comprising the final instrument.

Table 3.3 Characteristics of Cross-Sectional Study Participants (N = 119)

Characteristic	
Age (mean, sd)	62.7 (6.3)
Gender, N (%)	
Male	54 (46.2%)
Female	63 (53.8%)
Education, N (%)	
Grade 8 or less	6 (5.2%)
Grades 9 through 11	23 (19.8%)
Grade 12 or GED	44 (37.9%)
College 1 year to 3 years	34 (29.3%)
College 4 years or more	9 (7.8%)
Marital Status, N (%)	
Never been married	42 (38.5%)
Currently married	15 (13.8%)
Living with partner	13 (11.9%)
Separated or divorced	23 (21.1%)
Widowed	16 (14.7%)
Employment, N (%)	
Full-time employed	11 (9.5%)
Part-time employed	12 (10.3%)
Not currently employed	20 (17.2%)
Retired	31 (26.7%)
Receiving disability	42 (36.2%)
Income, N (%)	
< $5, 000	25 (23.4%)
$5,001 - $10,000	32 (29.9%)
$10,001 - $20,000	23 (21.5%)
$20,001 - $30,000	8 (7.5%)
$30,001 - $40,000	5 (4.7%)
$40,001 - $50,000	4 (3.7%)
> $50,000	10 (9.3%)
Typically go to receive medical care, N (%)	
Primary care physician's office	91 (85.0%)
Urgent care	2 (1.9%)
Emergency room at the hospital	8 (7.5%)
Other	6 (5.6%)
Current smoker (% yes)	94 (79.0%)
20+ pack-year (% yes)	64 (53.8%)
Years smoked (mean, sd, median)	33.7 (15.4), 35
Average cigarettes smoked per day (mean, sd, median)	13.4 (8.4), 10
Pack-year history (mean, sd, median)	23.7 (19.9), 20

Note. All variables are missing less than 10% of data.

Table 3.4 Retained Factors for the Decisional Values Measure

Item	*Cons of Screening Factor Loading*	*Pros of Screening Factor Loading*
…lung cancer screening may lead to more testing if there is an abnormal result?	.923	.147
…not all patients who have lung cancer diagnosed by screening will avoid death from lung cancer?	.810	.041
…lung cancer screening will not find all lung cancers or all lung cancers early?	.786	-.118
…the lung cancer screening test might show something wrong that turns out not to be cancer?	.753	-.138
… the out of pocket cost of the screening?	.652	.077
…getting screened for lung cancer would make you feel badly about your smoking history?	.621	-.142
…if you had lung cancer you would feel like it was your fault?	.496	-.261
…making you feel like you are doing everything you can for your health?	-.061	-.918
…following your doctor's opinion about lung cancer screening?	-.135	-.911
…knowing the test has little risk?	.113	-.829
…lowering your risk of dying from cancer?	.226	-.719
…thinking about family or friends who have dealt with lung cancer?	.087	-.676

Chapter 4: Manuscript #2: Decisional Needs for Lung Cancer Screening among African American Smokers

Abstract

Adherence to most evidence-based cancer screenings is lower among African Americans, contributing to persistent disparities. With the release of lung cancer screening guidelines for low-dose computed tomography (LDCT), it is important to understand the decision-making processes for this priority population to achieve equitable utilization. The purpose of this study is to describe aspects of decision-making for LDCT among African Americans and to examine associations between select components of decision-making and screening behavior intentions. N=119 African Americans with a long-term smoking history (current or former smokers [quit <15 years]), aged 55 to 80 years, and without lung cancer were recruited to participate in a cross-sectional survey administered online, by phone, or in-person. We measured knowledge, awareness, decisional conflict, preferences, and values related to lung cancer screening. Participants were a mean age of 62.7 (SD=6.3), 46.2% were male, and the median pack-year smoking history was 20. Most participants (65.8%) had not heard of LDCT and the total knowledge score was M=7.1/15 (SD=1.8). Individuals were experiencing uncertainty about the screening decision, but lower decisional conflict was associated with greater likelihood of talking with friends (*B*=.24, SE=.10, β=.23, p <.05) about LDCT. Among high risk individuals, low decisional conflict predicted greater likelihood of intention to be screened in the next six months (*B*=.32, SE=.15, β=.30, p<.05). Findings have implications for addressing the decisional needs of African American smokers to promote informed decision-making for LDCT and to thwart further health inequities.

Introduction

An evidence-based screening test (low-dose computed tomography or LDCT) is now available to detect lung cancer early and reduce lung cancer-specific mortality (The National Lung Screening Trial Research Team, 2011). The results from the National Lung Screening Trial were extended to African Americans in which a secondary data analysis revealed lung cancer screening using LDCT reduced lung cancer mortality more in African Americans compared with all racial groups (Tanner et al., 2015). Despite the small number of African Americans who participated in the trial (4.4%), they had a higher incidence of lung cancer and were diagnosed at a younger age (Tanner et al., 2015). The burden of this disease is significant for African Americans, especially African American men who have the highest lung cancer death rates compared to all other racial and ethnic groups (American Cancer Society, 2019; DeSantis et al., 2019). Despite the potential for benefit, especially among those at highest risk, it is estimated that only 3.9% of eligible individuals across all racial and ethnic groups are screened via LDCT (Jemal & Fedewa, 2017). Reasons cited for poor adherence are multi-faceted and include the need for more information about the test, issues concerning access to care, and low physician awareness of the current screening recommendations and reimbursement policies (Jemal & Fedewa, 2017).

These initial reported reasons for underuse of LDCT are consistent with factors (e.g., lack of medical coverage, barriers to early detection and screening) that have traditionally contributed to cancer disparities in African Americans (e.g., lack of medical coverage, barriers to early detection and screening) (Artiga & Hinton, 2018; Fiscella & Sanders, 2016). This screening modality requires informed and shared decision-making, because of the test's established benefits, harms, and uncertainties which might present an additional layer of complexity for

engaging diverse patient populations (Richmond et al., 2018). Despite its usefulness, there are differences between groups regarding willingness to engage in the process of informed decision-making, interest in playing an active role in health decisions, and ability to understand the complex nature of decision-making (Kaplan & Frosch, 2005). Poor utilization of the test may be further exacerbated in racial/ethnic minorities based upon the eligibility requirements for the test itself (Kitts, 2019). A lower proportion of African Americans achieve a 30 plus pack-year smoking history compared to other groups. This may be attributed to differences in smoking patterns by race/ethnicity, such that African Americans smoke a lower number of cigarettes per day and are more likely to be non-daily smokers compared to white smokers (Okuyemi et al., 2004; Schane et al., 2010)

To thwart racial disparities in screening rates for LDCT, which are likely to have the downstream consequence of an increase in racial disparities in early detection and mortality rates, we must rapidly identify the decisional needs of this group which includes uncovering gaps in knowledge and awareness, understanding personal values that are important, determining any uncertainty about the course of action to take, and supporting the role individuals want to play in the process (O'Connor et al., 1998; The Ottawa Hospital Research Institute, 2015). While studies have aimed to describe individuals' decision-making needs and to relate these factors to screening intentions or behavior, to date, most studies included homogenous samples and were unable to conduct sub-group analysis among African American participants or the studies were qualitative in nature (Kanodra et al., 2016; Lathan et al., 2015; Schapira et al., 2016). Fewer studies have focused on the knowledge, values, and preferences for lung cancer screening among African American high-risk individuals (Carter-Harris et al., 2018; Jonnalagadda et al., 2012; L. B. Williams et al., 2019).

To identify the decisional needs of African Americans who may be eligible for LDCT, we conducted a cross-sectional study among N=119 long-term smokers. The research aims were: 1) to describe knowledge and awareness about LDCT screening, personal values about LDCT screening, uncertainty (decisional conflict) about the test, as well as decisional support and resources among high-risk African American adults and 2) to examine the extent to which knowledge, decisional preferences, decisional conflict, and informational support are associated with participant intentions to discuss screening with others and, among those at higher risk, to undergo lung cancer screening in the future. We hypothesized that individuals with greater knowledge about lung cancer screening, who prefer to make a decision about lung cancer screening with their doctor, who have lower levels of uncertainty about the course of action to take, and who report having the information they need to make a decision about getting screened, would report greater intention to be screened for lung cancer in the next six months.

Method

Recruitment was multi-pronged and occurred between October 2018 and February 2019. Individuals were recruited through advertisements in a local newspaper, flyers in University of Maryland Medical System health clinics and other community-based settings (e.g., libraries, recreational centers), and speaking engagements at local health departments' smoking cessation clinics, and in public housing communities. Additionally, we mailed an invitation letter to participants from a previous study (N=583; Holt et al., 2015) who agreed to be re-contacted about similar research and who were potentially eligible for this project due to their smoking history. Participants were recruited from five District of Columbia Housing Authority public housing communities in Washington, DC (65%), from newspaper advertisements (18%), from

community-based settings (8%), were previous study participants (6%), and the remaining were from smoking cessation and health clinics (3%).

The eligibility criteria for the current study included: 1) self-identifying as African American, 2) being 55-80 years old, 3) currently smoking or having had quit within the past 15 years, and 4) not having a diagnosis of lung cancer. These criteria mirrored the United States Preventive Services Task Force criteria for screening via LDCT, but did not include the 30 pack-year minimum. Although number of pack-years was not an exclusion criterion this variable was documented for use in analyses. Each person who completed the survey received $10 as a token of appreciation and the American Lung Association's "Is Lung Cancer Screening Right for Me?" Q&A leaflet. The survey took an average of 20 minutes and was administered online using Qualtrics, over the phone, or in-person. The study was approved by University of Maryland's Institutional Review Board (#1300307-1).

Measures

Decisional Needs

Decisional needs are operationalized as "what a patient population requires to make better health decisions" and includes addressing any gaps in knowledge about the health problem, considering personal values related to the health behavior, any uncertainty (decisional conflict) about the screening, and the role the patient wants to play in the decision-making process (Available from www.ohri.ca/decisionaid.). The specific measures for each of these concepts are described below.

Knowledge & Awareness

To assess participants' general awareness about the screening test, the following item was asked, 'Low-dose computed tomography (CT) screening is used to detect lung cancer. Have you read or heard about this type of lung cancer screening before taking this survey?'(Lau et al., 2014). The response options include: Yes, No, Don't Know/Not Sure. A 15-item knowledge measure was used to assess participants' understanding of concepts to make an informed decision about lung cancer screening using LDCT (e.g., 'Factors that increase chances of developing lung cancer include: smoking, family history of lung cancer, getting the flu, COPD, age, drinking alcohol, smoking marijuana'; Lau et al., 2014). Participants were asked to indicate whether the statements were true, false, or unsure. These items included several domains: risk factors for developing lung cancer, screening benefits, screening risks, age eligibility, and false positives. Correct items were summed (unsure was coded as incorrect) with higher scores indicating greater knowledge. Psychometrics were not conducted in previous research (Lau et al., 2014), but for the current sample, the internal consistency reliability was .55.

Decisional Values

A 12-item measure that includes statements framed in the context of pros and cons of getting screened for lung cancer was developed for the present study which will be presented in detail in a separate manuscript. Individuals were asked to respond to the statements using a 5-point Likert-type scale (5=Extremely important to 1=Not at all important). Sample pros of screening items include: "How important is lowering your risk of dying from lung cancer?"; "How important is knowing the test has little risk?". Example items highlighting possible cons of screening include: "How important is the idea lung cancer screening may lead to more testing if there is an abnormal result?"; "How important is the idea that getting screened for lung cancer

would make you feel badly about your smoking history?". The 7-item cons scale was out of 35 and the 5-item pros scale was out of 25 with higher scores suggesting higher importance of the statement. The measure had good internal consistency reliability in the present sample (α=.89 overall; α=.86 and .88 for pros and cons subscales, respectively).

Decisional Conflict

The SURE (Sure of myself; Understand information; Risk-benefit ratio; Encouragement) tool assessed uncertainty about the choice to get screened versus not getting screened (Ferron Parayre, Labrecque, Rousseau, Turcotte, & Légaré, 2014; Légaré et al., 2010). The 4-item measure asks: 'Do you feel sure about the best choice for you?'; 'Do you know the benefits and risks of each option?'; 'Are you clear about which benefits and risks matter most to you?'; and 'Do you have enough support and advice to make a choice?'. The response option for each item is yes or no. A total score less than 4 suggests that a patient experiences clinically significant decisional conflict (Ferron Parayre, Labrecque, Rousseau, Turcotte, & Légaré, 2014; Légaré et al., 2010). The SURE has adequate internal consistency (KR-20 coefficient of .70). In the present sample, the KR-20 was slightly lower at .62.

Decisional Support & Resources

Decisional support was operationalized as participants' preferences regarding the amount of control they want in making a decision about lung cancer screening using the Control Preferences Scale (Degner, Sloan, & Venkatesh, 1997). This is a widely-used measure with evidence of reliability and validity. A single item asks, 'Please select the statement that sounds like you': 1) I prefer to make the decision about lung cancer screening; 2) I prefer to make the final decision about lung cancer screening after seriously considering my doctor's opinion; 3) I

prefer that my doctor and I share responsibility for deciding whether to get screened for lung cancer; 4) I prefer that my doctor makes the final decision about lung cancer screening, but seriously considers my opinion; and 5) I prefer to leave all decisions regarding lung screening to my doctor. To assess decisional resources, respondents were asked if they have the information they need to make and implement a decision. The following item was asked: 1) 'Do you feel you have all of the information that you need to make an informed decision about whether or not to be screened for lung cancer using CT?' The response options include: Yes, No, Don't Know/Not Sure.

Lung Cancer Screening Intentions

Participants reported intentions to talk with their doctor, family, or friends about lung cancer screening. Among those participants with a 20 or more pack-year smoking history, a single item was included to measure intention to be screened in the future, 'How likely is that you will get tested for lung cancer using low-dose computed tomography (CT) in the next six months?' (Duong et al., 2017). Response options for all intention-related items were: 5=Extremely likely, 4=Somewhat likely, 3=Neither likely nor unlikely, 2=Somewhat unlikely, 1=Extremely unlikely with higher scores indicating greater intention to engage in talking with others or getting tested for lung cancer.

Covariates

Standard measures collected key sociodemographic variables including age, gender, education, employment, marital status, income, and health insurance status. Other risk factors for lung cancer were assessed (family history, exposure to secondhand smoke, exposure to radon).

Items related to individuals' previous cancer screening behaviors were also collected (lung, breast, cervical, prostate, and colorectal).

Data Analysis

We conducted descriptive statistics to characterize knowledge about LDCT, personal values, decisional preferences, decisional conflict, information resources, and participant characteristics. Due to gender disparities in lung cancer mortality rates, we presented the variables of interest stratified by gender. Bivariate analyses examined associations between the decisional needs variables, the covariates, and the screening intention items. To determine whether select decisional needs variables predicted participant screening intentions, linear regressions were conducted. These models were conducted to evaluate the unique contribution of each predictor on the outcome variables of interest (e.g., likelihood to discuss screening with doctor, family members, or friends). Among participants with a 20 or more pack-year smoking history, these regression models were conducted to examine predictors of screening intention. SPSS Version 23.0 was used for all analyses.

Results

Among the N=204 individuals assessed for eligibility, n=79 were excluded (not meeting inclusion criteria), n=5 were administratively withdrawn, and n=1 declined participation. The participation rate was 95% with N=119 individuals completing the survey.

Participant Characteristics

Participants were a mean age of 62.7 (SD=6.3), 37.1% had some college or more, 38.5% had never been married, 26.7% were retired, and most (74.8%) had an annual income of $20,000 or less (**Table 4.1**). This was largely a Medicaid and Medicare recipient group with 85%

reporting going to their primary care physician for routine medical care. Regarding smoking status, 79% of participants currently smoked, and the average number of pack-years was 23.7 (SD=19.9), median=20, and a little more than half the sample had a 20 or greater pack-year (53.8%) smoking history.

Descriptive Analysis

Table 4.2 presents the decisional needs items stratified by gender. Most (65.8%) had not heard of LDCT and the total knowledge score was M=7.1 (SD=1.8) out of a possible 15. Participants were asked the level of importance of pros (e.g., mortality reduction) and cons of screening (e.g., false positives). Individuals rated the pros of screening as high (M=22.1, SD=3.8 out of 25) and the mean cons score was M=28.4, SD=6.1 out of 35. For decisional conflict, the mean score for the sample was 2.8 (SD=1.3) out of 4, suggesting participants were experiencing uncertainty regarding their decision to be screened. Approximately one-third (34.8%) preferred to share the LDCT screening decision with their doctor. Less than half (40%) of the participants felt they had all the information they needed to make an informed decision about getting screened for lung cancer.

Table 4.3 presents the screening intention variables by gender. Participants reported higher levels of intentions to talk with their doctor about screening in the next 6 months (M=4.3 out of 5, SD=1.1), whereas intentions to talk with family (M=3.9, SD=1.2) or friends (M=3.6, SD=1.3) about the test were lower on average. Among those individuals with a 20 or more pack-year smoking history, M=4.0, SD=1.2 reported intentions to get tested for lung cancer via LDCT in the next 6 months.

Bivariate Analyses

Associations between Background Characteristics and Screening Intentions

Correlations and one-way analysis of variance tests were conducted to look at associations between the background characteristics and the outcomes of interest in the current sample (**Table 4.4**). A marginal association was detected such that women (M=4.4, SD=.90) reported higher likelihood of intentions to talk with their doctor about LDCT in comparison to men (M=4.1, SD=1.2; F (1, 112) = 3.1, p=.08). There was a marginal association between marital status and intention to be screened for lung cancer in the next six months (F (4, 53) = 2.2, p=.08), however, the posthoc analysis did not reveal any patterns in the differences between marital status and screening intentions. Income was significantly associated with the screening intention item (F (6, 49) = 2.9, p<.05). Posthoc analyses revealed individuals with an income level of $10,000-$20,000 reported significantly higher levels of intentions to get tested for lung cancer in comparison to individuals with an income of at least $50,000. Although multiple recruitment strategies were used, 65% of the sample was recruited from public housing communities in DC. To determine whether nonindependence was present in the current sample, we created a recruitment source variable (1=public housing vs. 0=other recruitment source) and conducted a test of within-group agreement (r_{wg}) for the outcome variables of interest. The threshold to determine whether interdependence both within each group and across the overall sample exists is .70 (Grawitch & Munz, 2004; James, Demaree, & Wolf, 1993). Within each group coefficients ranged from .52 to .75 and the overall coefficients were .58 to .71. Based upon this evaluation, we controlled for 'recruitment source' in the multi-variable models.

Multi-variable Models

Intention to Discuss Screening with Doctor, Family, Friends

Table 4.5 presents the regression models adjusting for gender and recruitment source. The linear regression analysis indicated that lower decisional conflict was associated with greater likelihood of talking with friends (B=.24, SE=.10, β=.23, p <.05) about LDCT in the next six months. Lower conflict was also marginally associated with greater likelihood of talking with family members (B=.16, SE=.09, β=.17, p =.07) about the test. Knowledge scores, decision-making preferences, and feeling informed did not significantly predict intentions to discuss screening with doctor, family, or friends.

Intention to Screen

Among individuals in the sample at higher risk for lung cancer (≥ 20 plus pack-year), knowledge scores, decisional preferences, and feeling informed did not significantly predict screening intentions. Lower decisional conflict was associated with greater likelihood of getting screened in the next six months (B=.32, SE=.15, β=.30, p<.05). Income, gender, and recruitment source were included as covariates in the intention to screen models.

Discussion

Current patterns in racial disparities in cancer screening between African Americans and other racial and ethnic groups may shed light on what could become realized for lung cancer screening via LDCT. Above and beyond the known reasons for underutilization among the medically underserved including African Americans, this modality presents its own set of unique challenges including but not limited to the limitations and potential harms of the test itself, the complex criteria for eligibility, and the context (primary care) in which a shared decision about screening must occur. Given these reasons, it is critical to identify the needs of this group and to

assist them in making an informed decision about lung cancer screening. The present study identified a priority population consisting of lower socioeconomic status long-term current and former smokers and surveyed them on their needs, values, and preferences for lung cancer screening via LDCT. National data indicate higher smoking prevalence among lower education and income groups and the demographic makeup of our sample aligns with these data (Centers for Disease Control and Prevention, 2018). Despite a quarter of the sample being eligible for screening, most had not heard of LDCT and their knowledge about lung cancer and screening was limited which is consistent with the reported literature (Carter-Harris et al., 2018). Although lung cancer screening awareness and knowledge were limited, participants were able to identify their personal values (pros and cons) related to screening. Future research can explore how these values discriminate between the decision to get screened or not to get screened. Regarding decisional conflict, individuals in this sample were not certain about their decision to be screened which may be related to their lack of knowledge and awareness about the test itself. There was a willingness to share this decision with their doctors (35%) which is slightly lower than previous research conducted about shared decision-making preferences in African Americans (Williams et al., 2008). This finding is particularly important given the endorsement of shared decision-making in the context of lung cancer screening via LDCT. Not surprisingly, almost two-thirds stated they were either unsure or did not feel they had all the information they needed to make an informed decision. Given the gaps in knowledge, this finding suggests individuals require additional information about the test in order to feel informed.

African American men are disproportionately impacted by lung cancer having the highest lung cancer death rates in comparison to all other racial ethnic/groups (American Cancer Society, 2019). Because of this disparity, we presented the variables of interest stratified by gender, but

found few statistically significant differences between men and women in this sample. Future research should continue to examine sub-groups and determine how they may impact decisional support offered to these individuals.

Our hypotheses were focused on the outcome variable of intention to be screened for lung cancer, and despite one significant association with decisional conflict, the present findings did not fully substantiate our investigation. However, we did include measures surrounding intentions to discuss lung cancer screening with three distinct groups: provider, family members, and friends. These findings were exploratory in nature but point to predictors of likelihood of engaging in discussions with others about a health behavior. Specifically, the amount of decisional conflict was significantly associated with likelihood of talking with family members (marginal) and friends about LDCT. This suggests reducing uncertainty about the course of action to take may promote discussion about screening which may in turn influence behavior.

There were limitations in this study. Initially, this study sought to include individuals who met the United States Preventive Services Task Force's eligibility for LDCT screening. However, it was determined early in the recruitment period that several long-term smokers were being excluded due to the 30 pack-year criterion (N=34). Given the lower quantities of cigarettes smoked by African Americans (Centers for Disease Control and Prevention, 2018), it was decided to remove the pack-year smoking history as an eligibility criterion. Comparing individuals who met the United States Preventive Services Task Force guidelines (n=30) versus the other study participants (n=89), no significant demographic differences were detected on the demographic data. Although a multi-pronged approach was used to recruit individuals, this was a convenience sample and thus the findings may not be generalizable. The study design was cross-sectional in nature, providing only a snapshot, and was not able to capture actual behaviors.

Future studies that can follow participants longitudinally will be important to understand how aspects of decision-making impact screening behaviors.

To our knowledge, this is one of the first studies conducted to describe the decisional needs of an entirely African American sample of smokers for lung cancer screening using LDCT and to examine the associations between these components of decision-making and screening intentions. This study contributes to our understanding of what this population may require to gain more information about the test, what factors may be important when considering testing, and preferences for involvement in the screening decision. Importantly, the findings suggest reducing decisional conflict is important and further study is needed to determine how to address uncertainty among this group. The implications of these findings highlight a call to address the decisional needs of African American smokers in order to promote informed decision-making for LDCT. It also outlines possible targets for future decision aids or decision support interventions to enhance high quality decisions and to prevent racial disparities in screening for lung cancer.

Table 4.1. Characteristics of Cross-Sectional Study Participants (N = 119)

Characteristic	
Age (mean, sd)	62.7 (6.3)
Gender, N (%)	
Male	54 (46.2%)
Female	63 (53.8%)
Education, N (%)	
Grade 8 or less	6 (5.2%)
Grades 9 through 11	23 (19.8%)
Grade 12 or GED	44 (37.9%)
College 1 year to 3 years	34 (29.3%)
College 4 years or more	9 (7.8%)
Marital Status, N (%)	
Never been married	42 (38.5%)
Currently married	15 (13.8%)
Living with partner	13 (11.9%)
Separated or divorced	23 (21.1%)
Widowed	16 (14.7%)
Employment, N (%)	
Full-time employed	11 (9.5%)
Part-time employed	12 (10.3%)
Not currently employed	20 (17.2%)
Retired	31 (26.7%)
Receiving disability	42 (36.2%)
Income, N (%)	
< $5, 000	25 (23.4%)
$5,001 - $10,000	32 (29.9%)
$10,001 - $20,000	23 (21.5%)
$20,001 - $30,000	8 (7.5%)
$30,001 - $40,000	5 (4.7%)
$40,001 - $50,000	4 (3.7%)
> $50,000	10 (9.3%)
Insurance, N (%) (selected all that applied)	
Medicaid	80 (67.2%)
Medicare	57 (47.9%)
Insurance through an employer	12 (10.1%)
Any other form of insurance	7 (5.9%)
None	3 (2.5%)
Typically go to receive medical care, N (%)	
Primary care physician's office	91 (85.0%)
Urgent care	2 (1.9%)
Emergency room at the hospital	8 (7.5%)
Other	6 (5.6%)
Current smoker (% yes)	94 (79.0%)
Years smoked, mean (sd), median	33.7 (15.4), 35
Average cigarettes smoked per day, mean (sd), median	13.4 (8.4), 10

Table 4.2. Decisional Needs Stratified by Gender (N = 119)

Decisional Needs Variable	*Male*	*Female*	*Total*	*p-value*
Knowledge, out of 15 (mean, sd)	6.9 (2.2)	7.3 (1.4)	7.1 (1.8)	.30
Decisional Conflict, out of 4 (mean, sd)	2.6 (1.3)	2.9 (1.2)	2.8 (1.3)	.26
Decisional Values, (mean, sd)				
Pros of Screening, out of 25	21.5 (4.7)	22.6 (2.8)	22.1 (3.8)	.14
Cons of Screening, out of 35	27.7 (6.1)	29.1 (6.0)	28.4 (6.1)	.24
Control Preference, N (%)				.87
Make the decision alone	13 (25.5%)	12 (19.7%)	25 (22.3%)	
Make final decision	13 (25.5%)	15 (24.6%)	28 (25.0%)	
Share the decision	16 (31.4%)	23 (37.7%)	39 (34.8%)	
Doctor make final decision	2 (3.9%)	4 (6.6%)	6 (5.4%)	
Doctor alone	7 (13.7%)	7 (11.5%)	14 (12.5%)	
Do you feel you have all of the information you need to make an informed decision, N (%)				.72
Yes	18 (36.0%)	26 (43.3%)	44 (40.0%)	
No	16 (32.0%)	16 (26.7%)	32 (29.1%)	
Don’t know/Not sure	16 (32.0%)	18 (30.0%)	34 (30.9%)	

Table 4.3. Screening Intention Variables Stratified by Gender (N = 119)

Screening Intention Variable	*Male*	*Female*	*Total*
How likely is that you will talk with your doctor about LDCT in the next 6 months, N (%)			
Extremely Likely	26 (50.0%)	37 (59.7%)	63 (55.3%)
Somewhat Likely	14 (26.9%)	18 (29.0%)	32 (28.1%)
Neither Likely nor Unlikely	3 (5.8%)	2 (3.2%)	5 (4.4%)
Somewhat Unlikely	7 (13.5%)	5 (8.1%)	12 (10.5%)
Extremely Unlikely	2 (3.8%)	0 (0.0%)	2 (1.8%)
Mean (SD)	4.1 (1.2)	4.4 (.90)	4.3 (1.1)
How likely is that you will talk with your family about LDCT in the next 6 months, N (%)			
Extremely Likely	22 (40.7%)	25 (40.3%)	47 (40.5%)
Somewhat Likely	17 (31.5%)	21 (33.9%)	38 (32.8%)
Neither Likely nor Unlikely	5 (9.3%)	9 (14.5%)	14 (12.1%)
Somewhat Unlikely	3 (5.6%)	6 (9.7%)	9 (7.8%)
Extremely Unlikely	7 (13.0%)	1 (1.6%)	8 (6.9%)
Mean (SD)	3.8 (1.4)	4.0 (1.0)	3.9 (1.2)
How likely is that you will talk with your friends about LDCT in the next 6 months, N (%)			
Extremely Likely	13 (26.5%)	16 (26.7%)	29 (26.6%)
Somewhat Likely	15 (30.6%)	24 (40.0%)	39 (35.8%)
Neither Likely nor Unlikely	5 (10.2%)	11 (18.3%)	16 (14.7%)
Somewhat Unlikely	9 (18.4%)	5 (8.3%)	14 (12.8%)
Extremely Unlikely	7 (14.3%)	4 (6.7%)	11 (10.1%)
Mean (SD)	3.4 (1.4)	3.7 (1.2)	3.6 (1.3)
How likely is that you will get tested via LDCT in the next 6 months, N (%)[1]			
Extremely Likely	15 (42.9%)	11 (42.3%)	26 (42.6%)
Somewhat Likely	9 (25.7%)	11 (42.3%)	20 (32.8%)
Neither Likely nor Unlikely	4 (11.4%)	0 (0.0%)	4 (6.6%)
Somewhat Unlikely	5 (14.3%)	3 (11.5%)	8 (13.1%)
Extremely Unlikely	2 (5.7%)	1 (3.8%)	3 (4.9%)
Mean (SD)	3.9 (1.3)	4.1 (1.1)	4.0 (1.2)

[1]Among participants with 20+ pack year (N=64)

Table 4.4 Associations between Background Characteristics and Screening Intentions (N=119)

	Doctor		*Family*		*Friends*		*Screening*[1]	
Characteristic	*Mean (SD)*	*p-value*	*Mean (SD)*	*p-value*	*Mean (SD)*	*p-value*	*Mean (SD)*	*p-value*
Gender		.08[+]		.37		.16		.49
Male	4.1 (1.2)		3.8 (1.4)		3.4 (1.4)		3.9 (1.3)	
Female	4.4 (.90)		4.0 (1.0)		3.7 (1.2)		4.1 (1.1)	
Education		.60		.62		.48		.25
Grade 8 or less	4.2 (1.3)		4.0 (.89)		3.8 (1.3)		4.5 (.71)	
Grades 9 through 11	4.4 (.91)		4.2 (1.3)		3.8 (1.4)		4.2 (.97)	
Grade 12 or GED	4.4 (1.1)		4.0 (1.2)		3.6 (1.2)		4.0 (1.0)	
College 1 year to 3 years	4.2 (1.0)		3.9 (1.3)		3.5 (1.4)		4.0 (1.2)	
College 4 years or more	3.8 (1.2)		3.4 (1.3)		2.9 (1.2)		2.8 (2.0)	
Marital Status		.69		.38		.73		.08[+]
Never been married	4.1 (1.2)		4.0 (1.2)		3.7 (1.3)		4.1 (1.0)	
Currently married	4.1 (1.2)		3.8 (1.3)		3.1 (1.4)		3.0 (1.7)	
Living with partner	4.4 (.65)		4.3 (.75)		3.7 (1.2)		4.3 (.52)	
Separated or divorced	4.5 (.85)		3.5 (1.3)		3.6 (1.4)		4.1 (.99)	
Widowed	4.2 (1.2)		4.0 (1.4)		3.6 (1.0)		3.3 (1.5)	
Employment		.10		.28		.20		.42
Full-time employed	3.8 (1.1)		3.6 (1.4)		3.2 (1.1)		3.3 (1.5)	
Part-time employed	4.7 (.65)		4.6 (.67)		4.0 (1.0)		4.6 (.79)	
Not currently employed	3.8 (1.2)		3.8 (.97)		3.5 (1.2)		3.7 (1.3)	
Retired	4.2 (1.2)		3.9 (1.4)		3.2 (1.5)		3.9 (1.3)	
Receiving disability	4.4 (.95)		4.0 (1.2)		3.8 (1.2)		4.1 (1.2)	
Income		.29		.51		.94		.02*
< $5, 000	4.3 (.90)		4.1 (.91)		3.6 (1.1)		3.6 (.97)	
$5,001 - $10,000	4.2 (1.1)		3.6 (1.4)		3.6 (1.3)		4.1 (1.1)	
$10,001 - $20,000	4.6 (.79)		4.2 (1.3)		3.7 (1.5)		4.6 (.67)	

$20,001 - $30,000	4.1 (1.4)		3.9 (1.1)		3.3 (1.5)		3.6 (1.5)	
$30,001 - $40,000	4.2 (1.3)		4.4 (.89)		3.0 (1.2)		4.7 (.58)	
$40,001 - $50,000	4.0 (1.4)		3.8 (1.3)		3.3 (.96)		4.0 (1.7)	
> $50,000	3.5 (1.3)		3.6 (1.3)		3.5 (1.2)		2.5 (1.4)	
Typically go to receive medical care		.45		.56		.28		.77
Primary care physician's office	4.3 (1.0)		4.0 (1.20		3.7 (1.2)		4.0 (1.3)	
Urgent care/Emergency room at the hospital/Other	4.5 (.89)		3.8 (1.1)		3.3 (1.5)		4.1 (.93)	
Current smoker		.28		.70		.94		.15
Yes	4.3 (.99)		4.0 (1.2)		3.6 (1.2)		4.0 (1.2)	
No	4.0 (1.3)		3.8 (1.3)		3.5 (1.4)		3.4 (1.4)	
Age, *r*	.01	.90	.01	.95	-.08	.42	-.12	.37
Years smoked, *r*	-.09	.36	-.13	.18	-.10	.28	-.09	.49
Average cigarettes smoked per day, *r*	-.09	.33	-.05	.58	-.05	.62	-.08	.53

[1]Among participants with 20+ pack year (N=64)

[+]p<.10, *p< .05

Table 4.5. Linear Regression Analyses for Decisional Needs Variables Predicting Intention to talk with Doctor, Family, Friends about LDCT (N=119)

	Doctor				*Family*				*Friends*		
Decisional Needs Variable	R^2	*B*	*SE*	*β*	R^2	*B*	*SE*	*β*	R^2	*B*	*SE*	*β*
Lung Cancer Knowledge	.02	-.06	.06	-.11	.01	-.05	.07	-.08	.02	-.06	.08	-.07
Decisional Conflict	.04	.11	.08	.14	.09	.16^{+}	.09	.17	.11	.24*	.10	.23
Control Preference[1]	.07				.05				.06			
Make the decision alone		-.05	.27	-.02		-.50	.31	-.17		-.61^{+}	.34	-.20
Make the final decision		-.28	.26	-.12		-.18	.30	-.07		-.37	.32	-.13
Doctor make final decision		.23	.46	.05		.34	.53	.06		-.25	.56	-.05
Doctor alone		-.60^{+}	.33	-.18		-.60	.39	-.16		-.60	.42	-.15
Information needed to make an informed decision[2]	.06				.03				.05			
No		-.36	.25	-.15		-.42	.29	-.15		-.44	.31	-.15
Don’t know/Not sure		-.26	.24	-.12		-.34	.28	-.13		-.23	.29	-.08

Note: All models adjust for gender and recruitment source.

[1]Reference Category: Prefer to share the decision

[2]Reference Category: Feel they have all the information they need to make an informed decision

$^{+}$p<.10, *p< .05

Chapter 5: Summary

Overview and Summary

An evidence-based screening test (low-dose computed tomography or LDCT) is now available for individuals who are at high-risk for lung cancer. This screening procedure is recommended annually for those eligible to detect lung cancer early and to reduce cancer-specific mortality (The National Lung Screening Trial Research Team, 2011). While there is an established benefit of screening via LDCT, there are known limitations (e.g., false positives) and harms (e.g., radiation exposure) supporting the need for patients to make an informed decision about getting screened for lung cancer. Although informed decision-making is endorsed in the context of lung cancer screening, little information exists on the decisional needs, or what a patient population requires to make improved decisions about their health, particularly among high-risk African American adults. This population is important, because the burden of lung cancer and the factors (e.g., lack of medical coverage, barriers to early detection and screening) that have historically contributed to cancer disparities. This dissertation aimed to: 1) describe knowledge and awareness about LDCT, personal values about LDCT screening, uncertainty (decisional conflict) about the test, and decisional support and resources (e.g., decisional preferences) among African American adults at risk for lung cancer and 2) examine the extent to which knowledge, decisional preferences, decisional conflict, and external support are associated with participant intentions to discuss screening with others and, among those at higher risk, to undergo lung cancer screening in the future. The present study identified a priority population consisting of lower socioeconomic status long-term

current and former smokers and surveyed them on their needs to make a decision about lung cancer screening using LDCT.

Prior to administering the cross-sectional survey, key informant interviews were conducted with patients and providers (N=9) to identify factors that may be important to African Americans considering lung cancer screening and to develop a tool to measure personal values about the screening test. A cross-sectional study of African American adults at risk for lung cancer due to long-term tobacco use (N=119) was conducted to describe aspects of decision-making including knowledge and awareness about LDCT, uncertainty about screening, decision-making preferences, and values related to the screening decision. This study also presented an opportunity to provide initial validation of the decisional values measure. Findings from this dissertation research highlighted gaps in lung cancer screening awareness and knowledge among the current sample. Individuals were also uncertain about the screening decision and this factor predicted intentions to talk with family members (marginal association) and friends about LDCT as well as screening intention. Specifically, lower decisional conflict was associated with greater likelihood of talking with family members and friends about lung cancer screening. Additionally, among those at higher risk, low decisional conflict predicted greater likelihood of intention to be screened in the next six months. This is one of the first studies conducted to describe the decisional needs of an entirely African American sample of smokers for lung cancer screening using LDCT and to examine the associations between these components of decision-making and screening intention. Additionally,

a promising 12-item measure of values for lung cancer screening among African Americans was developed and had good internal consistency reliability.

Implications

While this study provides an important contribution to information on the decisional needs of African American smokers at risk for lung cancer, additional research is required to add to our understanding of this area. A decisional values measure was created and initial validation indicates this may be a good tool to use in future studies that want to measure this area among African Americans or to develop values clarification tools for this group. The cross-sectional study findings are aligned with other studies that point to gaps in knowledge and awareness of LDCT (Carter-Harris et al., 2018). This research could be replicated in a larger sample which would allow for sub-group analysis and if within-group differences were found, education efforts could be targeted for those groups in most need. This study does offer important information about a priority population that could be used to address the decisional needs of this group. Interventions can be developed that aim to not only provide information about the test itself, but also target decisional conflict, values, and preferences for lung cancer screening. The significant associations detected between decisional conflict and intention to discuss screening as well as intention to screen indicate uncertainty can lower the likelihood of individuals being willing to talk to others about getting tested for lung cancer and, further, planning to get the test itself.

Strengths and Limitations

There are strengths of this dissertation research. The conceptual framework guiding the research, the selection of variables, and the planned analysis was grounded in theory which is a key strength. To our best knowledge, this is one of the first studies to describe the decisional needs of an entire sample of African Americans who may be at risk for lung cancer due to their smoking history and to relate aspects of decision-making to screening intention. Few studies have included a diverse sample of participants (Carter-Harris et al., 2018; Lathan et al., 2015), thus this study adds to the literature by providing information about the characteristics, decisional needs, and screening intentions of a priority population. This study also had an opportunity to develop and validate a new tool to measure decisional values for LDCT. This measure was specifically created to identify values that may be of importance to African Americans considering lung cancer screening. The ability to offer a new tool that may be used in the future contributes to this field of study. Given the burden of lung cancer in the African American population, especially African American men, a main strength of this project was enrollment of a relatively equal distribution of men and women. Although, we detected few gender differences, it allowed for subgroup analysis which is important in appreciating the heterogeneity that may exist within groups.

There are limitations that must be acknowledged in the interpretation of these findings. Although multiple methods were used to recruit individuals, most participants were enrolled from public housing communities in Washington, DC. The findings from this study may not be generalizable to African American long-term

smokers in other cities or settings. Although, the background characteristics of the sample did mirror national data on the socioeconomic status of smokers (Centers for Disease Control and Prevention, 2018). Initially the study intended to enroll individuals who met the United States Preventive Services Task Force's eligibility for LDCT screening, but due to feasibility, the pack-year smoking history was removed as an eligibility criteria. We did compare individuals who met the United States Preventive Services Task Force guidelines (n=30) to the other study participants (n=89) and no significant differences were detected on demographics. Future studies should aim to identify those at highest risk for lung cancer, but it must be acknowledged that smoking patterns among African Americans differ and it may be harder to identify individuals who meet a 30 pack-year smoking criteria. Further research is needed in a real-world setting to determine if this eligibility criteria will appropriately identify African American patients who are at risk for lung cancer (Kitts, 2019; Richmond et al., 2018). The cross-sectional design of the study limits the ability to make any causal inferences and only provides a snapshot of the variables of interest. The project was not able to capture actual screening behavior which would be a logical next step for future research. Data were collected via self-report which relies on honest, accurate answers. The power analysis indicated a sample size of 91 would be sufficient to detect statistically significant findings, however, marginal findings emerged from the analysis which may be due to limited statistical power. The study provided an opportunity to create values statements which were included in the cross-sectional survey and validated. Since this was not the primary focus of the dissertation, the values statements may not be all inclusive

and further validation of this measure is needed. Finally, to focus the analysis on the study's aims and to limit participant burden, other factors that may be important to the decision framework were not captured. Some variables that were collected were not analyzed for the current report. Additionally, only select variables were hypothesized to be associated with the outcomes of interest. Further analysis could be conducted on this dataset including exploring the associations between the decisional values items and the screening intention variables.

Future Research Directions

The findings from this research highlight limited awareness about LDCT, gaps in knowledge regarding lung cancer screening, and uncertainty about the screening decision among a group at high risk for the disease. There was a willingness among the study population to share the screening decision with their doctor (35%), however, this should be replicated in further studies. It should be noted that just under one-quarter (22%) wanted to make the decision on their own. Given the endorsement of shared decision-making in the context of lung cancer screening via LDCT, it will be important to learn why individuals may not want to engage in shared decision-making and to determine how to respect the preferences of this group while ensuring they make a high quality, informed decision. Efforts to support the capacity of providers to involve different patient populations in a shared decision are also needed.

Further, the study results suggested that those who reported lower decisional conflict had a greater likelihood of talking with family and friends about LDCT. Among those at highest risk, lower conflict was also significantly associated with

greater likelihood to be screened in the next six months. These results point to several future research directions. First, raising awareness and increasing knowledge about LDCT among the patient population can be prioritized. Community-based health education and information dissemination efforts that engage diverse groups could help introduce lung cancer screening via LDCT among eligible individuals. While this study did not address physician knowledge and awareness, existing research suggests education it is needed among the referring physician population as well (Jemal & Fedewa, 2017). The individuals in this study experienced uncertainty about making a lung cancer screening decision. This uncertainty was associated with plans to discuss screening and to be screened in the next six months. People who have more decisional conflict may be an important group to study to determine how to prompt them to discuss their uncertainty with others. Interventions could aim to reduce uncertainty and provide opportunities for participants to engage in discussion with trusted sources.

The majority (79%) of the sample were current smokers having smoked a median of 35 years and a median of 10 cigarettes per day. While efforts are needed to increase the utilization of LDCT and to provide decisional support, to fully address the burden of lung cancer, tobacco cessation efforts are required. The current study did not capture participants' readiness to quit, but a next step would be to explore interest in engaging in evidence-based smoking cessation programs. If formative research suggests this is an acceptable and feasible concept, a future community-based intervention could be developed to provide education on the topics of smoking

cessation and screening, offer cessation resources, and identify individuals eligible for LDCT to navigate them to screening programs.

The present study addressed an important need in this area by first exploring possible factors that may be of importance to African Americans faced with the decision to be screened for lung cancer using LDCT, followed by the development of a tool specific to this screening decision, and then administering it in the priority population. A validated, brief tool now exists that can be used to inform new values clarification exercises aimed at helping African Americans eligible for lung cancer consider their decision and can also capture the impact of this type of intervention on their perceived quality (e.g., feeling informed, not having regret) and their behavior (values-based decision). This study was not in a position to assess the degree to which these personal values are able to discriminate between the actual behavior (decision to screen versus not to screen). Studies can include this scale to determine its ability to distinguish between behavior and its responsiveness to measure the impact of interventions.

The goal of decision support interventions promoting informed decision-making is to address any unmet needs of a patient population. This dissertation research identified the needs of an all African American sample that could be used to inform the development of support tools and programs for LDCT. The concern for future racial disparities in lung cancer screening (Richmond et al., 2018) underscore the importance in determining the needs of diverse groups and to address these needs by creating decision support tools and intervention programs to promote an informed

decision, improve the quality of the decision made, and to ultimately impact lung cancer screening behavior.

Appendices

Appendix A. Review of the Informed Decision-Making Literature

Appendix B. Methods

Appendix C. IRB Application

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Appendix H. Study Survey

Appendix I. Study Flyer

Appendix A. Review of the Informed Decision-Making Literature

First Author	Title	Publication Year	Study Purpose	Decisional Needs, Support, Quality	Study Design	Study Design Description	Intervention	Findings
Byrne	Lung Cancer Screening in a community setting: characteristics, motivations, and attitudes of individuals being screened	2019	To describe the characteristics of individuals being screened in community settings including factors influencing screening decisions and level of information sought prior to screening.	Needs	Non-experimental	Participants were adults who had previously received at least on LDCT.		Screening efficacy and salience were the most important factors in screening decisions, whereas health provider recommendations were rated not important.
Cardarelli	Identifying Community Perspectives for a Lung Cancer Screening Awareness Campaign in Appalachia Kentucky: The Terminate Lung Cancer (TLC) Study.	2017	An awareness campaign promoting LDCT screenings is an opportunity to elicit patient engagement with health providers about the risks and benefits.	Needs	Formative	Focus groups representing three regions of Appalachian Kentucky known for high lung cancer rates discussed development of a lung cancer screening campaign.		A total of 54 individuals (100% white) (61.1 % female; >55 pack year history) participated. Prior to discussion, most participants had not heard of lung cancer screening. Cited needs for content of a campaign included benefits of early detection

								and payment information. Having information come from one's family doctor or specialty provider was considered important to message communication.
Carter-Harris	Lung cancer screening: what do long-term smokers know and believe?	2017	To explore knowledge and beliefs of long-term smokers about lung cancer, associated risk factors and lung cancer screening.	Needs	Formative	Qualitative study theoretically framed by the expanded Health Belief Model based on four focus group discussions.		Knowledge related to lung cancer screening and how it is performed was low; awareness of long-term smoking's association with lung cancer risk remains suboptimal.
Carter-Harris	Understanding lung cancer screening behavior: Racial, gender, and geographic differences among Indiana long-term smokers.	2018	To determine the association of sociodemographic (including key disparity-related variables) and knowledge with lung cancer screening behavior.	Needs	Non-experimental	Cross-sectional, descriptive study used survey methodology to collect data from 438 screening-eligible individuals in the state of Indiana between January and February 2017		Key differences were noted by race and geographic area of residence with total knowledge scores as well as screening behavior, respectively.

						and measured sociodemographic variables and knowledge about lung cancer and screening.		
Cataldo	High-risk older smokers' perceptions, attitudes, and beliefs about lung cancer screening.	2016	To identify demographics, smoking history, health risk perceptions, knowledge, and attitudes factors of older smokers (≥55 years) related to LDCT agreement.	Needs	Non-experimental	This is a cross-sectional, national, online survey of 338 older smokers (≥55 years) with a ≥30 pack-year smoking history.		Four of the independent variables made a unique statistically significant contribution to the model: perceives accuracy of the LDCT as an important factor in the decision to have a LDCT scan; believes that early detection of LC will result in a good prognosis; believes that they are at high risk for lung cancer; and is not afraid of CT scans.

Delmerico	Patient willingness and barriers to receiving a CT scan for lung cancer screening.	2014	Survey of adult current and former smokers that queried about past use of CT scanning and reasons for having or not having the screening done.	Needs	Non-experimental	A random-digit dialed telephone survey was administered to a representative sample of 1290 US adults.		A total of 13.4% (n = 45) of the sample had ever had a CT scan to detect lung cancer. 78.5% of current smokers and 81.4% of former smokers indicated willingness to get the test if advised to do so by their doctor. Among those who said they were not willing to get screened, lack of insurance coverage was cited by 33% of current smokers and 25% of former smokers. Additionally, 33% of current smokers were afraid to find out whether they had cancer.
Duong	Patient and primary care provider attitudes and adherence	2017	To elucidate factors associated with utilization	Needs	Non-experimental	Patients referred for LDCT at an academic medical center were questioned		Adherent respondents believed that CT technology is accurate and early

	towards lung cancer screening at an academic medical center.					about their attitudes, knowledge, and beliefs on lung cancer screening.		detection is useful, and they trusted their providers. A majority of non-adherent patients (79%) self-reported an intention to obtain a LDCT in the future.
Greene	Challenges to Educating Smokers About Lung Cancer Screening: a Qualitative Study of Decision Making Experiences in Primary Care	2018	Sought to qualitatively explore how those at highest risk for lung cancer, current smokers, experienced, understood, and made decisions about participation in lung cancer screening	Needs	Non-experimental	Thirty-seven current smokers were identified within 4 weeks of being offered LCS at seven sites participating in the Veterans Health Administration Clinical Demonstration Project and interviewed via telephone using semi-structured qualitative interviews		Biased understanding of risks and benefits was complicated by emotion-driven, uninformed decision-making. Emotional and cognitive biases may interfere with educating and supporting smokers' decision-making and may require interventions tailored for their unique needs.
Gressard	A qualitative analysis of smokers' perceptions about lung	2017	To describe results of a qualitative study examining smokers' perceptions around	Needs	Formative	conducted 12 120-min, gender-specific focus groups with 105 current		Most participants were unaware of all three lung cancer screening tests. The few

	cancer screening.		lung cancer screening tests.			smokers in Charlotte, North Carolina and Cincinnati, Ohio		participants who had been screened recalled limited information about the test.
Hall	Lung Cancer Screening Uncertainty among Patients Undergoing LDCT.	2018	To identify correlates of lung cancer screening uncertainty (LCSU) among lung screening patients.	Needs	Formative	Current and former smokers (N = 169) completed questionnaires, cross-sectional study		Patients (52% current smok- ers) reported high clarity about the reason for their lung screening referral. Less clarity was as-sociated with lower education, not receiving Medicare, and greater stress and anxiety.
Jonnalaggad a	Beliefs and attitudes about lung cancer screening amon g smokers.	2012	Beliefs about lung cancer and screening, particularly across race and ethnicity, and their influence on CT screening utilization	Needs	Non-experiment al	Study recruited asymptomatic, high-risk smokers, 55-74 years of age from primary care clinics in an academic urban hospital.		Intention to screen was similar among minorities and non-minorities (p=0.19); Fatalistic beliefs, fear of radiation exposure, and anxiety related to CT scans were significantly associated with decreased intention to screen (p<0.05). Several

								differences were observed in minority versus non-minority participants' beliefs toward lung cancer and screening.
Kanodra	Primary Care Provider and Patient Perspectives on Lung Cancer Screening. A Qualitative Study.	2016	To identify perceptions of and perspectives on lung cancer screening and implementation among PCPs and eligible veteran patients at high risk for lung cancer.	Needs	Formative	qualitative study using grounded theory in which 28 veterans and 13 PCPs completed a questionnaire and participated in focus groups.		Most patients were willing to undergo LDCT screening and identified smoking as a risk factor for lung cancer, but they did not recall their PCP explaining the reason for the testing. Both parties were willing to explore modalities and decision aid tools to improve shared decision making.
Lathan	Perspectives of African Americans on lung cancer: a qualitative analysis.	2015	To explore African Americans' knowledge of lung cancer, perceived risk, interest in smoking cessation, attitudes toward lung cancer treatment, and lung cancer diagnosis	Needs	Non-experimental	The cohort comprised 32 African-American current and former smokers without a cancer diagnosis who participated in		Participants without a cancer diagnosis were aware of the link between smoking and lung cancer, the common symptoms of the disease, and its

			and treatment experiences.			focus groups and 10 African Americans with lung cancer who participated in in-depth interviews.		poor prognosis. They desired specific, personalized smoking-cessation information. If diagnosed, the majority reported, they would seek medical care.
Mishra	Patient Perspectives on Low-Dose Computed Tomography for Lung Cancer Screening, New Mexico, 2014.	2016	To characterize patient knowledge and attitudes about lung cancer screening, smoking cessation, and shared decision making by patient and health care provider.	Needs	Formative	Semi-structured qualitative interviews with patients with histories of heavy smoking in New Mexico		22 interviews (10 at the FQHC Clinic, 12 at the Chest Clinic). Most patients were unaware of LDCT screening for lung cancer but were receptive to the test. Concerns regarding screening were cost, radiation exposure, and transportation issues. To support decision making, most patients said they preferred one-on-one discussions with a provider. They also valued decision support

								tools (print materials, videos), but raised concerns about readability and Internet access.
Schapira	How Patients View Lung Cancer Screening. The Role of Uncertainty in Medical Decision Making.	2016	(1) describe how patients respond to specific categories of uncertainty in the context of lung cancer screening, and (2) inform strategies for addressing concerns about uncertainty as part of the shared decision making.	Needs	Formative	performed two series of structured interviews on participants in a convenience sample of current or former cigarette smokers		Twenty-two adults participated in the study. Sixty-eight percent were men, 72% were black or African American, and 50% met U.S. Preventive Services Task Force criteria for lung cancer screening. The primary themes to emerge from our study were: (1) the desire to decrease uncertainty may motivate lung cancer screening decisions; (2) uncertainty is an attribute of health states that impacts how patients weigh benefits and harms of lung

								cancer screening; (3) patient understanding and tolerance of uncertainty varies across stochastic, statistical, and evidentiary uncertainty; and (4) provider-patient communication may mitigate intolerance of uncertainty in the context of lung cancer screening.
Silvestri	Attitudes towards screening for lung cancer among smokers and their non-smoking counterparts.	2007	The implications of directing a screening program at smokers has been little explored.	Needs	Non-experimental	A nationwide telephone survey was conducted.		Compared with never smokers, current smokers were less likely to believe that early detection would result in a good chance of survival ($p < 0.05$). Smokers were less likely to be willing to consider computed tomography screening for lung cancer (71.2% (current smokers)

								v 87.6% (never smokers) odds ratio (OR) 0.48; 95% confidence interval (CI) 0.32 to 0.71). More never smokers as opposed to current smokers believed that the risk of disease (88% v 56%) and the accuracy of the test (92% v 71%) were important determinants in deciding whether to be screened ($p < 0.05$).
Simmons	High-risk community and primary care providers knowledge about and barriers to low-dose computed topography lung cancer screening.	2017	To examine knowledge and attitudes about LDCT screening for lung cancer among an ethnically and racially diverse sample of high risk (HR) community members and primary care providers (PCP).	Needs	Formative	Focus group using semi-structured interview guides. Focus groups were conducted with PCPs (by telephone) and HRs (in-person).		The majority of PCPs had limited knowledge of lung cancer CT screening. PCPs cited barriers to recommendation including, cost/insurance barriers and the potential for false positives. PCPs perceived the main benefit to be early detection of lung cancer. The

								majority of HRs had never heard of lung LDCT screening and had never had a healthcare provider recommend it to them. Perceived barriers included fear of results (bad news) and financial costs. The main perceived benefit was early detection.
Sin	Sociocultural Barriers to Lung Cancer Screening Among Korean Immigrant Men.	2016	To explore facilitators of and barriers to lung cancer screening (i.e., low dose CT of the chest) among Korean immigrant men, using qualitative individual interviews and focus groups.	Needs	Formative	Five focus groups (that included between two and five men) and nine individual interviews were conducted.		Facilitators of lung cancer screening included perceptions about positive aspects of the health care system in South Korea, recommendations from others (physicians, family members, and community organizations), existing health problems and respiratory

								symptoms, interest in health, and the health consequences of aging. Barriers included costs of health care in the US, lack of time, lack of knowledge (about lung cancer and screening), attitudes about prevention, and lack of physician recommendation.
Sharma	Focus Groups and In-depth Interviews to Guide the Development of Lung Cancer Screening Informational Materials	2018	To refine educational materials used to inform eligible high-risk individuals about the risks and benefits of lung cancer screening	Needs	Formative	Focus groups (n = 16) and in-depth telephone interviews (n = 5) were conducted among screening-eligible participants recruited from western New York		Main themes that emerged from the discussions included cost of obtaining the exam, eligibility criteria/information about the exam, apprehension regarding results, and an increased desire for discussions with their physician to learn more about the screening
Springer	Lung cancer screening: an emerging cancer control	2018	Michigan implemented a lung cancer screening awareness campaign in	Needs	Formative	Michigan implemented a lung cancer screening		Awareness of lung cancer screening was increased through

	issue presents opportunities for an awareness campaign in rural Michigan		the rural northern, lower peninsula			awareness campaign in the rural northern, lower peninsula.		the use of a variety of media including gas station/convenience store small media, digital media, radio broadcast media, and the use and marketing of a website that provided lung cancer screening information and resources.
Williams	Design of a community-based lung cancer education, prevention, and screening program	2019	To increase community awareness and knowledge about lung cancer screening through education	Needs	Quasi-experimental	Trained CHWs to increase knowledge about lung cancer screening among community-dwelling racial/ethnic minority and low-SES individuals.	4 90 minute group based sessions delivered at 12 community sites over 4 consecutive weeks.	Design paper. Findings not reported.
Dharod	The Reach and Feasibility of an Interactive Lung Cancer Screening Decision Aid Delivered by Patient Portal	2019	Examined the feasibility of this digital health outreach strategy for lung cancer screening.	Support	Quasi-experimental	Patients identified through an EHR algorithm	Identified patients were sent a patient portal initiation to visit a LCS interactive website to assess	40% patients visited the interactive Web site, and 349 patients (35%) completed it. Of the 99 patients who were confirmed

							screening eligibility and included a decision aid.	screening eligible by the Web site, 81 made a screening decision (30% wanted screening, 44% unsure, 26% declined screening), and 22 patients had a chest computed tomography completed.
Erkmen	An Enhanced Shared Decision Making Model to Address Willingness and Ability to Undergo Lung Cancer Screening and Follow-Up Treatment in Minority Underserved Populations.	2018	Employed an enhanced shared decision making (SDM) model to address willingness and ability to undergo lung cancer screening of low dose CT (LDCT) scanning	Support	quasi-experimental	prospective study of patients referred for lung cancer screening	SDM model	All 190 patients have a documented SDM visit addressing the risks and benefits of lung cancer screening and consented to discuss lung cancer treatment if lung cancer is diagnosed. One hundred and seventy-nine (179) of 190 (94%) answered yes to being willing and able to undergo lung cancer treatment. One hundred and eighty-seven

								(187) patients underwent LDCT (98.4%).
McDonnell	Developing and testing a brief clinic-based lung cancer screening decision aid for primary care settings.	2018	To develop and test a decision aid (DA) and SDM strategy for PCPs and high-risk patients.	Support	Quasi-experimental	The DA was tested with 20 dyads. Each dyad consisted of one PCP and one patient eligible for screening. A prospective, one-group, mixed-method study design	decision aid	Patients and PCPs rated the DA as helpful, easy to read and use and acceptable in terms of time frame (observed t = 11.6 minutes, SD 2.7). Most patients (n = 16, 80%) indicated their intent to be screened. PCPs recommended screening for most patients (n = 17, 85%).
Percac-Lima	Patient navigation for lung cancer screening among current smokers in community health centers a randomized controlled trial.	2018	To evaluate the impact of a patient navigation program on lung cancer screening (LCS) among current smokers in five community health centers (CHCs) affiliated with an academic primary care network	Support	RCT	randomized 1200 smokers aged 55-77 years to intervention (n = 400) or usual care (n = 800)	Navigators contacted patients to determine LCS eligibility, introduce shared decision making about screening, schedule appointments with primary care	Among the 135 eligible participants in the intervention group, 124 (92%) had any chest CT performed. In intention-to-treat analyses, 124 intervention patients (31%) had any chest CT versus 138 control patients (17.3%, P < 0.001). LCS

							physicians (PCPs), and help overcome barriers to obtaining screening and follow-up. Control patients received usual care.	CTs were performed in 94 intervention patients (23.5%) versus 69 controls (8.6%, P < 0.001).
Reuland	A pre-post study testing a lung cancer screening decision aid in primary care.	2018	tested a lung cancer screening decision aid video in screening-eligible primary care patients.	Support	quasi-experimental	single-group study with surveys before and after decision aid viewing and medical record review at 3 months.	video-based patient decision aid	50 participants, knowledge increased from pre- to post-decision aid viewing (mean = 2.6 vs. 5.5, difference = 2.8; 95% CI 2.1, 3.6, p < 0.001). Preferences across the overall sample remained similar such that 54% preferred screening at baseline and 50% after viewing; however, 28% of participants changed their preference (to or

								away from screening) from baseline to after viewing.
Mazzone	Impact of a Lung Cancer Screening Counseling and Shared Decision-Making Visit.	2017	A counseling and shared decision-making visit has been mandated to assist patients with the decision about participation in screening. To our knowledge, the impact of this visit on patient understanding and decisions has not been studied.	Support	Quasi-experimental	surveyed consecutive patients prior to the visit, immediately after the visit, and 1 month after the visit to determine the impact of the visit on their knowledge.	centralized counseling and shared decision-making visit	There was a significant improvement in knowledge noted after the visit for all questions (P = .03 to P < .0001). Knowledge waned by the 1-month follow-up but remained higher than it was before the visit.
Lillie	What factors do patients consider most important in making lung cancer screening decisions? Findings from a demonstration project conducted in the Veterans Health Administration.	2017	To identify the factors patients consider important in making lung cancer screening (LCS) decisions, and explore variations by patient characteristics and LCS participation.	Support	Formative	observational survey study evaluated the Minneapolis VA LCS Clinical Demonstration Project in which LCS-eligible Veterans (N=1388) were randomized to either Direct LCS Invitation (mailed with decision aid, N=926) or Usual Care (provider referral, N=462).		Exposure to Direct LCS Invitation (with decision aid) increased Veterans' attention to specific decision-making factors; compared to Usual Care respondents, a larger proportion of Direct LCS Invitation respondents rated the chance of false-positive results, LCS

								knowledge, LCS convenience, and anxiety as important. Those completing LCS considered screening harms less important, with the exception of incidental findings.
Fraenkel	Shared Medical Decision Making in Lung Cancer Screening: Experienced versus Descriptive Risk Formats.	2016	to compare descriptive versus experienced probability formats on patients' knowledge, beliefs, endorsement of screening for heavy smokers, and preference (choice predisposition) to undergo screening.	Support	RCT	A total of 276 patients attending an outpatient pulmonary practice were randomized to learn about screening using 1 of 3 formats: numbers only, numbers + icon arrays, numbers + a set of slides illustrating LDCT scans of 250 people in random order that displayed the number of normal scans, false-positive lung nodules, cancers found	1 of 3 formats	Knowledge differed between the 3 formats (P= 0.001), with participants randomized to the numbers + icon array format having the highest knowledge score. Beliefs were more favorable among participants randomized to the numbers + experienced format compared with the numbers + icon array format (difference between means [95% confidence interval]= 1.6 [0.4-2.8]).

						leading to a life saved, and cancers found leading to death despite treatment.		Differences in participants' endorsement of screening (P= 0.4) and choice predisposition (P= 0.6) across probability format mirrored those of beliefs but were not statistically significant.
Lau	Evaluation of a Personalized, Web-Based Decision Aid for Lung Cancer Screening.	2015	To assess the efficacy of a web-based patient decision aid for lung cancer screening, www.shouldiscreen.com.	Support	Quasi-experimental	A before-and-after study (August through December 2014) was conducted where participants navigated a web-based decision aid that provided information about low-dose computed tomography lung cancer screening.	web-based decision aid	Knowledge increased after seeing the decision aid compared with before ($p<0.001$), whereas the score on the Decisional Conflict Scale decreased ($p<0.001$). Concordance between a participant's preference to screen and the U.S. Preventive Services Task Force recommendation improved after seeing the decision aid

								(p<0.001). Risk perceptions among the screen-ineligible group changed (n=49), contrary to those who were eligible (n=11). Ninety-seven percent of the participants reported that the decision aid was likely useful for lung cancer screening decision making.
Volk	Feasibility of a patient decision aid about lung cancer screening with low-dose computed tomography.	2014	developed and field tested a brief, video-based patient decision aid about lung cancer screening.	Support	Quasi-experimental	Smokers in a cancer center tobacco treatment program aged 45 to 75 years viewed the video online between November 2011 and September 2012.	video-based patient decision aid	N = 52. Acceptability of the aid was high. Most patients (78.8%) indicated greater interest in screening after viewing the aid. Knowledge about lung cancer screening increased significantly as a result of viewing the aid (25.5% of questions answered correctly before the aid, and 74.8%

								after; P<.01) although understanding of screening eligibility remained poor. Patients reported being clear about which benefits and harms of screening mattered most to them (94.1% and 86.5%, respectively). Patients have high information needs related to lung cancer screening.
Sakoda	Assessing Effectiveness of a Group Education Class on Lung Cancer Screening	2018	assessed the impact of a free 60-minute class on knowledge and decision-making among patients being screened for lung cancer.	Support	Quasi-experimental	Kaiser Permanent patients in the screening program.	60-minute class taught by clinician specialists, mainly pulmonologists	Individuals were asked to complete the survey pre- and post-class. Knowledge increased for some items, patients reporting having the information they need, and the majority (60%) felt they knew what choice was best for them).

Appendix B. Methods

Study Overview

The recent release of lung cancer screening guidelines using low-dose computed tomography (LDCT) and the endorsement of informed decision-making about lung cancer screening with LDCT by major medical organizations provide an opportunity to examine patients' decision-making processes around screening. Given the burden of lung cancer in African Americans, it is particularly important to obtain this information from diverse groups to help inform future interventions that may need to be targeted to promote informed decision-making for this community. The purpose of this study was to describe aspects of decision-making including knowledge and awareness about the test, personal values related to screening, uncertainty about whether to undergo screening, and decision-making preferences among African American adult men and women with a smoking history. Additionally, this study examined the extent to which select components of decision-making were associated with intentions to be screened for lung cancer in the future among those eligible for lung cancer screening using LDCT.

Study Design

A cross-sectional study design was employed to meet the aims of this study. African American adults with a smoking history were recruited to participate in a one-time survey administered online using Qualtrics software, by phone, or in-person.

Study Population

Among African Americans, lung cancer is the second most commonly diagnosed cancer and it accounts for the greatest number of cancer-related deaths in this population (American Cancer Society, 2016). Disparities exist in the burden of this disease such that African American

males' incidence and death rates are higher for lung cancer in comparison to whites (American Cancer Society, 2016). Given the burden of this disease, the priority population identified for this research study were adult African American men and women who are at an increased risk for lung cancer.

Eligibility

Eligible participants included: 1) identified as African American, 2) between the ages of 55 and 80 years old, 3) currently smoked or have quit within the past 15 years, and 5) had not been diagnosed with lung cancer. These criteria mirrored the United States Preventive Services Task Force criteria for screening via LDCT, but did not include the 30 pack-year minimum. Although pack-year was not an exclusion criterion this variable was measured. Results between screening eligible versus ineligible individuals based on the screening guidelines were compared.

Sampling Procedure

Convenience sampling was used to recruit participants into this study. In order to meet the objective of this study, this non-probability sampling procedure was utilized because the pool of individuals were selected based upon two characteristics: self-identifying as African American and having a smoking history. Individuals were invited to participate utilizing multiple active and passive recruitment strategies. **Table B.1** includes the total number enrolled by recruitment strategy. Individuals who participated in the *Religion and Health in African Americans* (RHIAA) study who agreed to be re-contacted for future research were invited to participate in the current proposed project. The majority (78.2%, N = 2,481) of RHIAA participants were willing to be re-contacted. The RHIAA study sought to examine the mechanisms of the religion-health connection in a national sample of African Americans (Holt et al., 2015). The study included 3,173 participants who completed a telephone interview. An external subcontractor executed the probability-based sampling by generating a list of households within the United States and they

also managed the data collection. Eligibility criteria for the study included speaking English, self-identifying as African American, and age 21 years or older. Professional interviewers read participants an informed consent script, and participants provided their verbal consent. The 45-60 minute interviews collected data on a number of topics including, but not limited to: religious involvement, psycho-social variables (e.g., social capital), health-related outcomes (e.g., physical/emotional functioning, depressive symptoms), cancer risk behaviors (e.g., heavy drinking and smoking), cancer prevention behaviors (e.g., fruit/vegetable consumption, physical activity) and cancer screening (e.g., breast, cervical, prostate, colorectal), and background characteristics. Participants were mailed a $25 gift card after completing the interview. The University of Maryland Institutional Review Board approved the study. Past RHIAA participants who agreed to be re-contacted, who were 53-78 years old at the time of the last RHIAA phone interview conducted in 2016, and reported smoking at least 100 cigarettes in their lifetime were sent an invitation letter in the mail (N = 583; See **Appendix F** for Invitation Letter). The letter directed interested participants to the online survey, which included an eligibility screener (See **Appendix G** for Eligibility Screener). Among those eligible, they were prompted to provide informed consent before completing the survey. Online consent was obtained by prompting participants to read the purpose of the study, procedures, potential risks/benefits, confidentiality, compensation, and participants rights (including right to withdraw from the study). The page also included the contact information for the University of Maryland's IRB and the Principal Investigator's contact information (See **Appendix E** for Informed Consent). Participants were prompted to select the response option that they either agree to participate or do not agree to participate and to insert their electronic signature. No one disagreed to participate in the study. For those who agreed, they were directed to start the survey. Some individuals preferred to

complete the survey by phone and the letter included the Principal Investigator's telephone number.

Individuals were also recruited by posting flyers and passing out flyers at local health and community settings within the District of Columbia (DC) and Maryland region (See **Appendix I** for Flyer). If interested, participants were directed to the online survey to complete the eligibility screener and provide informed consent before completing the survey. The Principal Investigator's contact information was included on the flyer for participants who preferred to conduct the survey over the phone.

There was also the opportunity to present the cross-sectional study to individuals at events (e.g., smoking cessation group sessions, Public Housing community gatherings) held by these organizations where advanced site permission was received. The Principal Investigator introduced the research study and individuals who were interested were invited to complete the survey online or in-person. In the cases where the survey was conducted in-person, individuals' eligibility was assessed and if eligible and agreed to participate, written informed consent was obtained, and they were given the survey to complete.

Table B.1 Total Enrolled by Recruitment Strategy

Recruitment Source	**N**
Public Housing Communities	78
Newspaper Advertisement	21
Community-based Settings	10
RHIAA Study Participants	7
Smoking Cessation Clinics	2
Health Clinics	1
Total	*119*

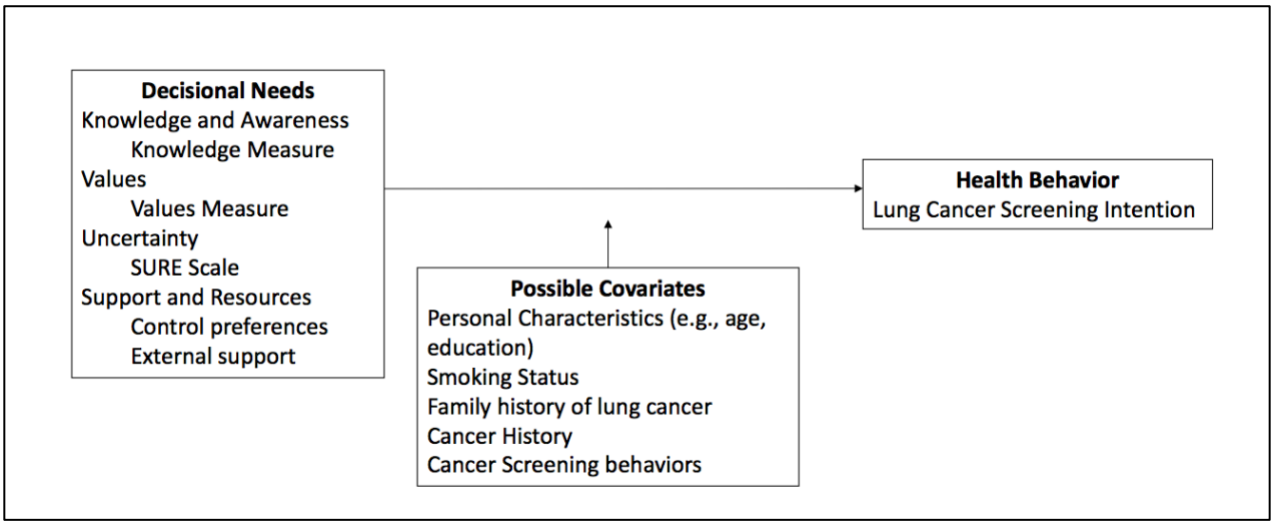
The survey took an average of 20 minutes to complete (See **Appendix H** for Survey). Participants were provided $10 upon completing the survey. They were also provided a reproducible patient page from the American Lung Association to help facilitate informed decision-making on testing for lung cancer (See **Appendix J** for Patient Informational Page).

This study was approved by the University of Maryland's Institutional Review Board (IRB) [IRB# 1300307] in August 2018.

Conceptual Model

The Ottawa Decision Support Framework guided the conceptual model for this study (O'Connor et al., 1998). The Framework posits that participants' decisional needs will affect decision quality, which ultimately impacts behavior. As seen in the model developed (**Figure A.1**), this study describes: knowledge and awareness about LDCT screening, personal values related to the test, level of uncertainty about screening, and perceived decisional support and resources to make a decision among African American smokers (**Aim 1**). Additionally, this study examined the extent to which these components of decision-making were associated with intentions to undergo lung cancer screening in the future among a subset of individuals who were eligible for screening (**Aim 2**).

Figure A.1 Conceptual Model



Data Collection

The survey found in **Appendix H** was developed using a number of items adapted from the literature (Carter-Harris et al., 2018; Duong et al., 2017; "Health Information National Trends Survey | HINTS," n.d.; Lau et al., 2014; Légaré et al., 2010; Lowenstein et al., 2016) and was pre-tested before being administered to study participants. Pre-testing helped to confirm the survey items were worded clearly, to ensure the online version of the survey did not have any glitches, and to determine the approximate length of time it took to complete the survey. One individual who met the study inclusion criteria, three study team members, and a behavioral scientist and professor of oncology with expertise in cancer screening and informed decision-making completed the survey prior to administration to study participants. A brief description of the lung cancer screening procedure including a picture of a patient in the machine was included in the survey.

Measures

Decisional Needs

A series of items were included to measure the decisional needs of individuals who may be eligible for LDCT lung cancer screening. These concepts included, knowledge and awareness about lung cancer screening, personal values about being screened, uncertainty (decisional conflict) about the course of action to take, and perceived decisional support and resources. The specific measures for each of these concepts are described below.

Knowledge & Awareness. To gauge participant's general awareness about the screening test, the following items were asked, 'Low-dose computed tomography (CT) screening is used to detect lung cancer. Have you read or heard about this type of lung cancer screening before taking this survey?' (Lau et al., 2014). The response options include: Yes, No, Don't Know/Not Sure. Among those who responded yes, they were asked, 'At any time in the past year, have you talked with your doctor or other health professional about having a test to check for lung cancer using

low-dose computed tomography?' The response options include: Yes, No, Don't Know/Not Sure ("Health Information National Trends Survey | HINTS," n.d.). Also, a knowledge measure was used to assess participant's understanding of concepts related to lung cancer and lung cancer screening using LDCT (e.g., 'Factors that increase the chances of getting lung cancer include: smoking tobacco, family history of lung cancer, getting the flu, COPD, age, drinking alcohol'). Participants were asked to indicate whether the statements were true, false or if they were unsure. These items include several domains: risk factors for developing lung cancer, screening benefits, screening risks, age eligibility, and false positives. The internal consistency of the final scale was acceptable in previous research (Lau et al., 2014).

Values. Prior to administering the survey, key informant interviews (N=9) were conducted at the provider- and patient-level to obtain values that salient to the priority population under study and general items for this construct. The instructions and phrasing were adapted from a validated decisional values scale and other values items used in the literature (O'Connor; Taylor). The final 17-item self-administered measure included statements framed in the context of pros of getting screened for lung cancer and the cons of getting screened which can be found in survey (**Appendix H**). Individuals were asked to respond to the statements using a 5-point Likert-type scale (Extremely important to Not at all important). Sample pros of screening items include: "How important is lowering your risk of dying from cancer?"; "How important is getting peace of mind to find out you do not have lung cancer?". Example items highlighting possible cons of screening include: "How important is the idea lung cancer screening may lead to more testing if there is an abnormal result?"; "How important is the idea that getting screened for lung cancer would make you feel badly about your smoking history?".

Participants were also be asked to identify any other factors important to them that may not be included on the list in an open-ended item.

Decisional Support & Resources. Decisional support was operationalized as participants' preferences regarding the amount of control they want in making a decision about lung cancer screening. This was measured using the Control Preferences Scale (Degner et al., 1997). This is a widely-used measure with evidence of reliability and validity (Cronbach's alpha= 0.76). The item asks, 'Please select the statement that sounds like you: 1) I prefer to make the decision about lung cancer screening; 2) I prefer to make the final decision about lung cancer screening after seriously considering my doctor's opinion; 3) I prefer that my doctor and I share responsibility for deciding whether to get screened for lung cancer; 4) I prefer that my doctor makes the final decision about lung cancer screening, but seriously considers by opinion; and 5) I prefer to leave all decisions regarding lung screening to my doctor. Participants were also asked 'Other than your doctor, is there anyone else you would involve in making a decision about lung cancer screening?' Responses: Yes, No, Don't Know/Not Sure. Among those who responded yes, they were asked to identify who would they involve in the decision (Response Options: Spouse, Significant other, Family, Friend(s), Member(s) of faith community, Co-worker(s), Other, please specify. To assess *decisional resources*, respondents were asked if they have the information they need, a type of external support, to make and implement a decision. The following items will be asked: 1) 'Do you feel you have all of the information that you need to make an informed decision about whether or not to screened for lung cancer using CT?' The response options included: Yes, No, Don't Know/Not Sure and 2) 'What additional information would you like to receive to help you decide about lung cancer screening using CT?'. Participants could select all the response options that applied including: More information about the test itself, More information about any risks of the test, More information about any benefits of the test, Other, please specify. Participants were also asked, 'How would you most prefer to receive information about lung cancer screening using CT?'. Response options included:

Personal counseling from your doctor, Personal counseling from a trained lay (non-healthcare professional) worker/community member, Informational materials in a booklet, Discussion groups of people facing the same decision, Informational materials on the internet, Other, please specify (O'Connor et al., 2003).

Decisional Conflict. Uncertainty about the course of action to take was measured using the SURE (Sure of myself; Understand information; Risk-benefit ratio; Encouragement) tool (Ferron Parayre et al., 2014; Légaré et al., 2010). The 4-item measure asks: 'Do you feel sure about the best choice for you?'; 'Do you know the benefits and risks of each option?'; 'Are you clear about which benefits and risks matter most to you?'; and 'Do you have enough support and advice to make a choice?'. The response option for each item is Yes or No. SURE has adequate internal consistency (KR-20 coefficient of 0.70).

Lung Cancer Screening Intention

A single item was included to measure intention to be screened in the future, 'How likely is it that you will get tested for lung cancer screening test using low-dose computed tomography (CT) in the next six months?' (Duong et al., 2017). The response options include: Extremely likely, Somewhat likely, Neither likely nor unlikely, Somewhat unlikely, Extremely unlikely. Participants were also asked if they intend to talk with their doctor, family, or friends about lung cancer screening by asking, 'How likely is it that you will talk with your doctor about lung cancer screening using low-dose computed tomography (CT) in the next six months?; How likely is it that you will talk with your family about lung cancer screening using low-dose computed tomography (CT) in the next six months?; How likely is it that you will talk with your friends about lung cancer screening using low-dose computed tomography (CT) in the next six months?' Response options: Extremely likely, Somewhat likely, Neither likely nor unlikely, Somewhat unlikely, Extremely unlikely.

Covariates

Age. A single item was used to confirm the age of participants by asking 'What is your age?'.

Gender. The gender of the participant was collected by asking 'What is your gender?' and the response options include: Male, Female, Non-binary/third gender, Prefer to self-describe.

Education. Educational attainment was measured through a single item: 'What is the highest grade or year of school you completed? The response options are: 1) Never attended school or only attended kindergarten, 2) Grades 1 through 8 (Elementary), 3) 3 Grades 9 through 11 (Some high school), 4) Grade 12 or GED (High school graduate), 5) College 1 year to 3 years (Some college or technical school), 6) College 4 years or more (College graduate), 7) Masters degree, and 8) Doctoral or other advanced degree (e.g., Law, Medicine).

Marital status was assessed asking 'What is your marital status?' and the response options include: Never been married, Currently Married, Living with Partner, Separated or Divorced, or Widowed.

Employment. 'Do you currently work for pay outside of the home' was included to capture employment status. Participants were asked to indicate if they are full-time employed, part-time employed, not currently employed, retired, or receiving disability.

Income was collected by asking 'What is the total income of everyone in your household per year, before taxes?'. Participants were provided a set of ranges from less than $5,000 to more than $50,000.

Health Insurance status was collected using the item: 'Which, if any, types of health insurance do you have?' Participants selected all options that apply: Medicaid, Medicare, Insurance through an Employer/Work (ex. Blue Cross, HMO), Any other Form of Health Insurance, or None.

Smoking Status. To capture current smoking status among the participants, a single item was asked 'When did you last smoke a cigarette (even one or two puffs)?'. The response options are: I smoked a cigarette today (at least one puff), 1 to 7 days ago, 8 days to 1 month ago, More than 1 month ago to 1 year ago, More than 1 year ago, Don't know/Don't Remember.

Family history of lung cancer. Participants were asked 'Have any of your blood relatives ever had lung cancer?' and they indicated Yes, No, Does Not Apply, Unknown/Prefer Not to Answer. They were prompted about their Father, Mother, Brother(s) including half brothers, Sister(s) including half sisters, child (biological), Other Relatives (please specify).

Lung Cancer Screening. To determine if participants had been screened for lung cancer in the past the following items were asked: 'Has a doctor ever recommended lung cancer for you in the past?' Response options: Yes, No, Don't Know/Not Sure and among those who indicate Yes, they were asked 'Did they suggest a….?' The response options are: LDCT, Chest X-Ray, Other, please specify, Don't Know/Not Sure. Next, participants were asked 'Did you get tested for lung cancer following your doctor's recommendation?' and response options included Yes, please explain why (open-ended format) and No, please explain why not (open-ended format). Finally, they were asked 'What type of screening did you have?'. The response options are: LDCT, Chest X-Ray, Other, please specify, Don't Know/Not Sure.

Cancer Screening behaviors. Participants were asked about other cancer screening behaviors 'Have you ever used a test called Fecal Occult Blood Test (FOBT)?'; 'Have you ever had a colonoscopy?'. Men were asked 'Have you ever had a prostate specific antigen test?'; 'Have you ever had a digital rectal exam, or DRE test?'. Women were asked 'Have you ever had a mammogram?'; 'Have you ever has a Pap test?' The response options for these screening variables included: Yes, No, Don't Know/Not Sure. A brief description of each test was included on the survey.

Additional Exposures. Several risk factors increase an individuals' chances of lung cancer and these known factors include: tobacco smoking, contact with second-hand smoke, contact with radon, asbestos and other cancer-causing agents, history of other cancer, history of lung disease, and family history of lung cancer ("NCCN Guidelines for Patients® | Lung Cancer Screening," 2017). To characterize those who completed the cross-sectional survey, items were added to capture additional risk factors for lung cancer. The items added include: 1) Have you ever been diagnosed with cancer, except for non-melanoma skin cancer? (Response Option: Yes/No/Don't Know-Not Sure), 2) Have you lived with a smoker for more than half of your life? (Response Option: Yes/No/Don't Know-Not Sure), 3) Have you ever worked with any of the following things known to cause lung cancer without proper protection? These include radon, asbestos arsenic, beryllium, cadmium, chromium, nickel, coal smoke, soot, silica, and diesel fumes. (Response Option: Yes/No/Don't Know-Not Sure), and 4) Have you ever been told you have COPD (chronic obstructive pulmonary disease) or pulmonary fibrosis? These are both lung diseases that make it hard to breathe. (Response Option: Yes/No/Don't Know-Not Sure).

Data Analysis

SPSS Version 23.0 was used for all analysis. Two manuscripts were prepared for this study to: 1) Manuscript #1 - Describe the development and validation of the decisional values measure and 2) Manuscript #2 – Report the main findings from the study.

Manuscript #1. Descriptive statistics (e.g., frequencies, means, and standard deviations) were computed for the personal values items to evaluate the distribution of the data. The factorability of the data was verified using the Kaiser-Meyer Olkin Measure of Sampling Adequacy & Bartlett's Test of Sphericity. An exploratory factor analysis was conducted to identify potential factors. Also, internal consistency reliability was computed for the overall scale and subscales.

Manuscript #2. There were two aims guiding the study including: Aim 1: Describe knowledge and awareness about LDCT screening, personal values about LDCT screening, uncertainty (decisional conflict) about the test, as well as decisional support and resources (e.g., decisional preferences, external support). Descriptive statistics (e.g., frequencies, means, and standard deviations) were conducted for all closed-ended items to describe knowledge about LDCT, personal values, decisional preferences, decisional conflict, external support, and personal characteristics. Aim 2: Examine the extent to which knowledge, control preferences, decisional conflict, and external support are associated with participant intentions to undergo lung cancer screening in the future among those eligible for the LDCT test. It was hypothesized that individuals with greater knowledge about lung cancer screening, who prefer to make a decision about lung cancer screening with their doctor, who have lower levels of uncertainty about the course of action, and who report having the information they need to make a decision about getting screened would be more likely to report intention to be screened for lung cancer in the next six months. Bivariate analyses were conducted to assess associations between the decisional needs variables, the covariates and the screening intention items. Chi-square tests were conducted for categorical variables, correlation coefficients for continuous variables, and one-way analysis of variance (ANOVA) for categorical and continuous variables. The variables that were statistically significant (alpha level <.05) at the bivariate level or deemed as important were controlled for in the multi-variable analysis. Linear regressions were conducted to determine whether the decisional needs variables predict screening intention as a continuous variable. These models were conducted to evaluate the unique contribution of each predictor on the outcome variables of interest (e.g., likelihood to discuss screening with doctor, family members, or friends). Among participants with a 20 or more pack-year smoking history, these regression models were conducted to examine predictors of screening intention.

Missing Data

Strategies were employed to limit missing data. The Qualtrics survey included prompts for participants who skipped items. While their response was not forced, this feature aimed to reduce the amount of missing items. Participants were also able to select 'don't know/not sure' for most items. Analysis of missing data patterns were conducted to determine whether items with missing data are missing completely at random (MCAR), missing at random (MAR) or missing not at random (MNAR). All items were missing 10% or less data. The Pattern Frequencies did not indicate there was anything about the items with missing data that were different with respect to the pattern of missing data than the other items included in the analysis. It was determined these data were mostly likely MCAR, meaning there is no systematic reason for the missing cases.

Power Analysis

A post-hoc power analysis was conducted with the known sample size of N=119 participants. Based on the results, an effect size of .14 was used as an estimate of the relationship between the decisional needs variables and screening intention. The alpha level was set at 0.05. The achieved power was 91% to detect a significant association.

Appendix C. IRB Application

INITIAL APPLICATION PART 2

1. Abstract:

Lung cancer is the most commonly diagnosed cancer and it is also the leading cause of cancer death in the United States. In 2018, it is expected there will be 234,030 new cases of lung cancer and 154,050 deaths due to the disease. African Americans are disproportionately affected by lung cancer having the highest lung cancer death rates compared to all other racial and ethnic groups. The National Lung Screening Trial compared two methods of detecting lung cancer and found a 20% disease-specific mortality reduction among those screened using low-dose computed tomography compared with the radiography group. While there are benefits of screening, there are also limitations to low-dose computed tomography (e.g. false positives, radiation exposure). Low-dose computed tomography is a screening test done to check for lung cancer by using x-rays to take many images of the lungs. In 2013, the United States Preventive Services Task Force (USPSTF) provided a recommendation for annual low-dose computed tomography screening, however, given the limitations the USPSTF and other medical organizations endorse informed decision-making a process by which individuals weigh the benefits and harms of the lung cancer screening test (low-dose computed tomography). The Ottawa Decision Support Framework, an evidence-based model for making health decisions, suggests that patients' decisional needs (e.g. knowledge) impact decisional quality (e.g. being informed) which ultimately influences behavior (e.g. use of health services). The recent release of the lung cancer screening guidelines and the promotion of informed decision-making provides a unique opportunity to examine patients' decision-making processes around screening. The purpose of this study is to describe aspects of decision-making including knowledge and awareness about low-dose computed tomography, values related to the screening, uncertainty about low-dose computed tomography, and decision-making preferences among African American adults who are eligible for lung cancer screening. Additionally, this study will examine the extent to which decision-making components are associated with intentions to be screened for lung cancer in the future. Drawing from a national, probability-based sample of African American adult men and women, eligible individuals will be recruited to participate in a cross-sectional survey. Given racial disparities in lung cancer, it is particularly important to determine the decisional needs of African Americans to help inform future interventions promoting informed decision-making in this community.

2. Subject Selection:

Recruitment: There are two parts associated with the proposed project – key informant interviews and a cross-sectional survey. The sections below are organized by these components: Key Informant Interview Recruitment: Prior to the conduct of the cross-sectional survey key informant interviews will be conducted at the provider- and patient-level (three to five providers/three to five patients) to obtain information about decisional values that may be salient

to the priority population under study. Providers will be recruited using a purposive sampling method, which will include snowball sampling. Our team has a list of providers who are a part of lung cancer screening programs at their respective institutions and they will be sent an invitation letter via email (See Supporting Documents for A_Decisional Needs Invitation Letter for Key Informant Interview). If interested, the providers will email the Principal Investigator directly and a convenient date and time will be selected to conduct the interview over the phone.
A purposive sampling method will be utilized to invite patients to complete the key informant interview. Individuals will be invited to participate in the study through flyers (See Supporting Document for B_Decisional Needs Study Flyer Key Informant Interview) distributed at the University of Maryland's primary care clinic and during the Community Health Awareness, Messages, and Prevention (CHAMP) research lab's community events and word of mouth. If interested, participants will be directed to contact the Principal Investigator who will assess their eligibility and if eligible arrange a date, time and location to complete the interview in-person.
Cross-sectional Survey Recruitment: Individuals will be recruited primarily by re-contacting participants from the Longitudinal study of religion and cancer-related behaviors in Black Americans study [IRB# 319457-20] who agreed to be contacted in the future about similar research and who are potentially eligible for this dissertation research project. Past participants who agreed to be re-contacted, who were 53-78 years old at the time of the last phone interview conducted in 2016, and reported smoking at least 100 cigarettes in their lifetime will be sent an invitation letter in the mail (N = 954; See Supporting Documents for F_Decisional Needs Invitation Letter). The letter will direct interested participants to the online survey, which will include an eligibility screener (See Supporting Documents for G_Decisional Needs Eligibility Screener). The prior study will serve as the primary mechanism to recruit participants and data collected from the previous research will not be utilized for this dissertation study. My dissertation chair and faculty advisor, Dr. Cheryl Holt, is the Principal Investigator (PI) of the longitudinal study. I also currently serve as Program Manager of this project and assist with data analysis and manuscript writing for this study. As PI, Dr. Holt has granted permission to have access to the identifiable information for only the participants who agreed to be re-contacted and who meet the criteria stated above. This information will only be used for the purposes of inviting them to participate in the planned study and will be stored separately from the survey data collected.
Additionally, individuals will be invited to participate in the study through flyers (See Supporting Document for H_Decisional Needs Study Flyer) distributed at the University of Maryland's primary care clinic and during Baltimore City Cancer Program community events. If interested, participants will be directed to the online survey to complete the eligibility screener and provide online informed consent before completing the survey. The Principal Investigator's contact information will be included on the flyer should participants have questions or prefer to conduct the survey over the phone. In a small number of cases, there could be the opportunity to administer the survey at the outreach events. In these cases, individuals' eligibility will be assessed and if they meet the inclusion criteria and agree to participate, written informed consent will be obtained, and they will be given the survey to complete.

Eligibility Criteria: Key Informant Interview Eligibility: Healthcare providers who have experience administering lung cancer screening, who work in the area of lung cancer and lung cancer screening will be invited to participate in the key informant interview. The following eligibility criteria will be used: 1) 21 years of age or older, 2) currently works in a healthcare setting, and 3) works in the area of lung cancer and lung cancer screening.

In-person key informant interviews will also be conducted with individuals (patients) who are 55 to 80 years old, identify as African American, have a smoking history and who have not been diagnosed with lung cancer.
Cross-sectional Survey Eligibility: African American adult men and women who are eligible for lung cancer screening according to the United States Preventive Services Task Force will be invited to participate. The following eligibility criteria will be used: 1) identifies as African American, 2) between the ages of 55 and 80 years old, 3) have at least a 30 pack-year smoking history, 4) currently smoke or have quit within the past 15 years, and 5) have not been diagnosed with lung cancer.

Rationale: Key Informant Interview Rationale: Since the United States Preventive Services Task Force's recommendations for lung cancer screening using low-dose computed tomography were released in 2013 there has been no significant change in the percentage of eligible individuals screened (3.3% in 2010 to 3.9% in 2015). Only 262,700 of the 6.8 million smokers eligible received the test (Jemal & Fedewa, 2017). The reasons for the slow uptake of this screening test are multi-layered, but include the need for more information about the benefits and limitations of the test for both patients and providers (Jemal & Fedewa, 2017). Other major cancers (e.g., colorectal cancer screening) that have screening tests available have seen lower adherence to screening among African Americans which results in disparities. While the barriers identified among African Americans for other cancers may be similar for lung cancer screening (e.g., fatalistic beliefs, medical distrust, access to care), there may be other considerations specific to the lung cancer screening test for this population. The goal of the key informant interviews is to gain more information about reasons for and against lung cancer screening. The reasons cited will be used to inform two close-ended items on the cross-sectional survey.
Cross-sectional Survey Rationale: Among African Americans, lung cancer is the second most commonly diagnosed cancer and it accounts for the greatest number of cancer-related deaths in this population (American Cancer Society, 2016). Disparities exist in the burden of this disease such that African American males' incidence and death rates are higher for lung cancer in comparison to whites (American Cancer Society, 2016). Relative to their white counterparts, African American women are at a lower risk of getting the disease, but have higher lung cancer death rates (American Cancer Society, 2016). Given the burden of this disease, the priority population identified for this research study are adult African American men and women who are at high risk for lung cancer.

Enrollment Numbers: Key Informant Interview Enrollment Numbers: Prior to the administration of the cross-sectional survey key informant interviews (three to five providers/three to five patients) will be conducted at the provider- and patient-level to obtain information about decisional values that may be salient to the priority population under study. The responses from these interviews will assist in the development of the response options for two items on the final survey administered to the N=182 African American adult men and women.
Cross-sectional Survey Enrollment Numbers: One-hundred eighty-two African American men and women who are eligible will be enrolled into this study.

Rationale for Enrollment Numbers: Key Informant Rationale for Enrollment Numbers: It is expected that interviewing three to five providers and patients, respectively, will

meet the goals of this phase of the project which is to identify possible response options for two cross-sectional survey items. However, this will be guided by saturation (i.e. when no new insights are found by adding new cases). If additional interviews are need, we will request an amendment to the enrollment numbers.
Cross-sectional Survey Rationale for Enrollment Numbers: Based upon the power analysis conducted 91 participants will be needed, but this study will oversample (N = 182) to allow for sub-group analysis as well as possible missing values.

3. Procedures:

Key Informant Interview Procedure: Key informant interviews will be conducted at the provider- and patient-level to obtain information about decisional values that may be relevant to the priority population under study. Phone interviews will be conducted with providers and it is expected that the interview will take about 30 minutes to complete. Providers will be asked to describe how lung cancer screening has been done within their organization, what are some of the successes/challenges associated with providing lung cancer screening, and reasons why patients may get tested and reasons why patients may choose not to get tested. The interview will also gauge what resources providers think patients need to support their decision about lung cancer screening. The interview will be recorded with the use of an audio recorder.
In-person interviews will also be conducted with individuals (patients) who are interested and who meet the eligibility criteria. The in-person interviews will take place in a reserved, quiet space (e.g., conference room) within the School of Public Health or a neighborhood library. Prior to administration of the interview, written informed consent will be obtained. It is expected the interview will take about 30 minutes to complete. Individuals will be asked about their general awareness of low-dose computed tomography, whether the test has been recommended by their doctor, their screening history, and reasons why they may get screened versus reasons why they may not get screened for lung cancer. Additionally, we will collect information about their smoking history (e.g., when did you last smoke a cigarette). Upon completion of the interview, participants will be provided a $10 compensation as a thank you for their participation. The questions/prompts for these interviews are included in this application (See Supporting Documents for E_Decisional Needs Study Key Informant Interview Guide).

The responses from these key informant interviews will assist in the development of the response options for two items on the final survey administered to the N=182 African American adult men and women.

Cross-sectional Survey Procedure: A cross-sectional study design will be employed to meet the aims of this study which are to: 1) describe knowledge and awareness about low-dose computed tomography screening (LDCT), personal values about LDCT screening, uncertainty about the screening test, as well as decisional support and resources among African American adult smokers and 2) examine the extent to which knowledge, control preferences, decisional conflict, and external support are associated with participant intentions to undergo lung cancer screening in the future. One hundred eighty-two African American adults who are lung cancer screening-eligible will be recruited to participate in a one-time online survey. The purpose of this research project is to understand what people know and how they feel about lung cancer and lung

cancer screening. Specifically, we are interested in learning more from individuals at high risk for developing lung cancer so that we can find the best ways to help smokers and former smokers make a decision about whether to get tested for lung cancer. It is expected that the survey (See Supporting Documents for L_Decisional Needs Study Survey) will take 15-20 minutes to complete.
Interested participants will be directed to the online survey. Among those eligible, they will be prompted to provide electronic informed consent before completing the survey. For those who agree, they will be directed to start the survey. If participants do not complete the survey one week after the invitation letter is mailed, the Principal Investigator will make up to five attempts to contact the individuals by phone. The goal of this contact will be to assess the individuals' interest in participating in the study. Among interested participants, the Principal Investigator will ask if they would like to complete the survey online or over the telephone. In a small number of cases, there could be the opportunity to administer the survey at outreach events. In these cases, individuals' eligibility will be assessed and if they meet the inclusion criteria and agree to participate, written informed consent will be obtained, and they will be given the survey to complete. In-person administration of the survey will be done in a place that is away from others who may be attending the event.

Participants will be mailed $10 upon completing the survey. They will also be provided a reproducible patient page from the American Cancer Society to help facilitate informed decision-making on testing for lung cancer (See Supporting Documents for M_Lung Cancer Patient Page – American Cancer Society).

4. Risks:

There are minimal risks associated with the study. Some study participants may experience distress or worry in learning about lung cancer. However, the presentation of the information is sensitive to the nature of the topic being addressed. Individuals may stop participating at any time if they feel uncomfortable. If individuals stop participating at any time, they will not be penalized or lose any benefits to which they otherwise qualify. Loss of confidentiality is a risk associated with research, but have proposed strategies (see Confidentiality Section) to minimize this issue.

5. Benefits:

There are no direct benefits from participating in this research. We hope that, in the future, other people might benefit from this study through improved understanding of making a choice about getting tested for lung cancer.

6. Confidentiality:

Key Informant Interview Confidentiality: The key informant interviews will be audio-recorded, however, participants will be given the option to choose an alias during the administration of this interview. Their name will not be included on the interview or any other collected data. The audio-recorded files will be password-protected and will be downloaded and stored on the University of Maryland server that can only be accessed

by the Principal Investigator.

Cross-sectional Survey Confidentiality: All data will be transferred from Qualtrics to SPSS, the electronic database. This database will be password-protected and will be stored on the University of Maryland server that can only be accessed by the Principal Investigator.

The risk of a breach of confidentiality will be addressed by assigning all participants a 4-digit study identification number versus using their name. This information will be stored electronically in a secure, password protected database. Each study participant will be identified in the system using a unique identification number that does not include personal identifiers. A file (master key) linking the study data to the participants will be password protected and the Principal Investigator will only have access to this information. The written signed informed consent forms will be stored in a secure area in a locked file cabinet separate from any study data. All other hard copy files will be stored in a locked file cabinet.

Federal regulations require research records to be retained for at least 3 years after the completion of the research (45 CFR 46). Data generated from this study will be retained for seven years following completion of the research. After which time, the participants' personal and contact information and research records will be destroyed in compliance with the methods of destroying the data that have been set by the university including shredding paper records, erasing records stored on a computer, and physically destroying audiotapes. Records will be kept regarding what was destroyed, when, and how.

7. Consent Process:

Data collection for this study will take place in-person, online, and over the phone. Written informed consent will be obtained in-person, online consent will be obtained for those participants who complete the survey electronically, and oral consent will be obtained for those interviews/surveys conducted over the phone.

Key Informant Consent Process: The key informant interviews conducted with the providers will be administered over the phone and oral consent will be obtained (See Supporting Documents for C_Decisional Needs IRB Consent Form Oral Interview Guide Provider). Thus, we are requesting a waiver of written consent for these participants, because (1) the research involves no more than minimal risk to the subjects – there are minimal risks to participants involved in this study. Loss of confidentiality is always a risk with human participants, but we have adopted multiple safeguards to ensure confidentiality is protected, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects – the participants reserve the right to make their own decision about participating in the key informant interview and have the right to stop at any time without penalty or loss of benefits, (3) the research could not practicably be carried out without the waiver or alteration – Providers will be recruited through electronic correspondence. Among interested and eligible individuals, it will not be possible to consent participants in-person for completion of this interview. The interviews will be conducted via phone and will not have face-to-face interaction with the

Principal Investigator during this time, and (4) whenever appropriate, the subjects will be provided with additional pertinent information after participation – Participants will indicate their willingness to participate in the interview prior to completing it. The Principal Investigator and the UMD IRB Office will be included in all materials in case any questions about the study or one's rights arise. Additionally, participants will have the opportunity to ask question about the project before providing their informed consent.

The key informant interviews with the patients will be administered in-person and written informed consent will be obtained during that meeting using IRB approved forms (See Supporting Documents for D_Decisional Needs IRB Consent Form Written Interview Guide Individual). The document will be read and reviewed by the participants and they will have the opportunity to ask about the project prior to providing their informed consent. All participants will receive a copy of the consent for their records.

Participation in the key informant interviews is not contingent on the audio-recording of the interview.

Cross-sectional Survey Consent Process: Participants who complete the survey online are going to provide an electronic signature following online consent. Online consent will be obtained by prompting participants to read the purpose of the study, procedures, potential risks/benefits, confidentiality, compensation, and participants rights (including right to withdraw from the study) (See Supporting Documents for I_Decisional Needs IRB Consent Form Online Survey). This page will also include the contact information for the University of Maryland's IRB and the Principal Investigator's contact information. Participants will then be prompted to select the response option that they either agree to participate or do not agree to participate and to insert their electronic signature. For those individuals who disagree, they will re-directed to a page that thanks them for their consideration and will ask them to provide a reason for not participating in the study. For those who agree, they will be directed to start the survey. The eligibility and online consent page will be a separate webpage from the survey's webpage where data are collected to maintain confidentiality of the participants. The survey data that will be downloaded from Qualtrics to SPSS will be de-identified.

For those participants who prefer to complete the survey by phone, oral informed consent will be obtained (See Supporting Documents for J_Decisional Needs IRB Consent Form Oral Survey). Respondents will then be prompted to state whether they agree to participate or do not agree to participate in the study. Thus, we are requesting a waiver of written consent for these participants, because (1) the research involves no more than minimal risk to the subjects – there are minimal risks to participants involved in this study. Loss of confidentiality is always a risk with human participants, but we have adopted multiple safeguards to ensure confidentiality is protected, (2) the waiver or alteration will not adversely affect the rights and welfare of the subjects – the participants reserve the right to make their own decision about participating in the cross-sectional survey and have the right to stop at any time without penalty or loss of benefits, (3) the research could not practicably be carried out without the waiver or alteration – Participants will be recruited primarily through mailed correspondence and will be called following the invitation letter being sent to them. Among interested and

eligible individuals, it will not be possible to consent participants in-person for completion of this survey. For those who are unable to take the survey online, it will be conducted via phone and they will not have face-to-face interaction with the Principal Investigator during this time, and (4) whenever appropriate, the subjects will be provided with additional pertinent information after participation – Participants will indicate their willingness to participate in the survey prior to completing it. The Principal Investigator and the UMD IRB Office will be included in all materials in case any questions about the study or one's rights arise.

For the small number of cases who complete the survey in-person, they will be given a hard copy of the consent form which will be described orally by the Principal Investigator (See Supporting Documents for K_Decisional Needs IRB Consent Form Written Survey). This will be done in an area that is away from others who may be attending the event. The participant will then be asked to read the form and sign it if they agree to participate in the study. Participants will have the opportunity to ask questions prior to providing their consent. All participants will receive a copy of the consent form for their records.

8. Conflict of Interest:

No Conflict of Interest.

9. HIPAA Compliance:

Not Applicable

10. Research Outside of the United States:

Not Applicable

11. Research Involving Prisoners:

Not Applicable

Appendix D. IRB Approval

UNIVERSITY OF MARYLAND
INSTITUTIONAL REVIEW BOARD

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:	August 27, 2018
TO:	Randi Williams, MPH
FROM:	University of Maryland College Park (UMCP) IRB
PROJECT TITLE:	[1300307-1] Decisional Needs of African American Smokers Eligible for Lung Cancer Screening
REFERENCE #:	
SUBMISSION TYPE:	New Project
ACTION:	APPROVED
APPROVAL DATE:	August 27, 2018
EXPIRATION DATE:	August 26, 2019
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 August 26, 2019.

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.

Generated on IRBNet

Appendix E. Informed Consent Forms

CONSENT TO PARTICIPATE

Project Title	*Decisional Needs of African American Smokers Eligible for Lung Cancer Screening – Oral Consent for Key Informant Interview (Provider)*
Purpose of the Study	*Hi, my name is [NAME] and I wanted to thank you so much for expressing interest in talking with me today. I would like to give you more details about what is involved. Do you have any questions right now?* *This research is being conducted by Randi Williams, MPH a Doctoral Student at the University of Maryland, College Park. We are inviting you to participate in this research project because you are a healthcare professional who works in the area of lung cancer prevention and control. The purpose of this research project is to understand what people know and how they feel about lung cancer and lung cancer screening. Specifically, we are interested in learning more from you as a healthcare provider so that we can find the best ways to help smokers and former smokers make a decision about whether to get tested for lung cancer.*
Procedures	*The procedures involve completion of a one-on-one interview where we will have a conversation. This interview will take about 30 minutes to complete. The interview will be recorded with the use of an audio recorder. You will be asked to describe how lung cancer screening is done within their organization, what are some of the successes/challenges associated with providing lung cancer screening, and reasons why patients may get tested and reasons why patients may choose not to get tested. The interview will also gauge what resources providers think patients need to support their decision about lung cancer screening.*
Potential Risks and Discomforts	*There may be some risks from participating in this research study. The risk is unlikely and may involve some minor discomfort in talking about lung cancer screening programs within your organization. You may choose not to answer any questions that make you feel uncomfortable or you may stop the interview at any time.*

Potential Benefits	*There are no direct benefits from participating in this research. We hope that, in the future, other people might benefit from this study through improved understanding of how individuals make a choice about getting tested for lung cancer.*
Confidentiality	*Any potential loss of confidentiality will be minimized by storing your identifying information in password protected databases and hard copies will be stored in locked file cabinets. In order to reduce the risk of loss confidentiality, access to your personal identification information will be limited to Randi Williams and the research staff.* *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.*
Compensation	*There is no compensation for participation in this one-on-one interview.*
Right to Withdraw and Questions	*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.* *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:* **Randi M. Williams, MPH** **University of Maryland, College Park** **School of Public Health Building** **College Park, MD 20742** **Telephone: 301-405-7875** **Email: rwili25@umd.edu**
Participant Rights	*If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:* 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 *This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.*
Statement of Consent	*So, now that I've told you all of the details of the study, would you like to participate?* *By stating yes, it 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.* *Would you like to participate?* _____ *No, I do not want to participate in this study* _____ *Yes, I do want to participate in this study*

CONSENT TO PARTICIPATE

Project Title	*Decisional Needs of African American Smokers Eligible for Lung Cancer Screening – Written Consent for Key Informant Interview (Individual)*
Purpose of the Study	*This research is being conducted by Randi Williams, MPH a Doctoral Student at the University of Maryland, College Park. We are inviting you to participate in this research project because you are an African American adult with a history of smoking. The purpose of this research project is to understand what people know and how they feel about lung cancer and lung cancer screening. Specifically, we are interested in learning more from you so that we can find the best ways to help smokers and former smokers make a decision about whether to get tested for lung cancer.*
Procedures	*The procedures involve completion of a one-on-one interview where we will have a conversation. This interview will take about 30 minutes to complete. The interview will be recorded with the use of an audio recorder. You will be asked questions about what you know about a test used to detect lung cancer, whether the test has been recommended by your doctor, and reasons why you may get tested for lung cancer versus reasons why you may not get tested for lung cancer. Additionally, we will collect information about your smoking history (e.g., when did you last smoke a cigarette).*
Potential Risks and Discomforts	*There may be some risks from participating in this research study. The risk is unlikely and may involve some minor anxiety that you may feel when thinking about cancer during this survey. You may choose not to answer any questions that make you feel uncomfortable or you may stop the interview at any time.*
Potential Benefits	*There are no direct benefits from participating in this research. We hope that, in the future, other people might benefit from this study through improved understanding of making a choice about getting tested for lung cancer.*
Confidentiality	*Any potential loss of confidentiality will be minimized by storing your identifying information in password protected databases and hard copies will be stored in locked file cabinets. In order to reduce the risk of loss confidentiality, access to your personal identification information will be limited to Randi Williams and the research staff.* *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.
Compensation	*You will receive $10 for completion of the survey. You will be responsible for any taxes assessed on the compensation.* *If you will earn $100 or more as a research participant in this study, you must provide your name, address and Social Security Number to receive compensation.* *If you do not earn over $100 only your name and address will be collected to receive compensation.*
Right to Withdraw and Questions	*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.* *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:* **Randi M. Williams, MPH** **University of Maryland, College Park** **School of Public Health Building** **College Park, MD 20742** **Telephone: 301-405-7875** **Email: rwili25@umd.edu**
Participant Rights	*If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:* 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 *This research has been reviewed according to the University of Maryland, College Park IRB procedures for research*

	involving human subjects.	
Statement of Consent	*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.* *If you agree to participate, please sign your name below.*	
Signature and Date	**NAME OF PARTICIPANT** **[Please Print]**	
	SIGNATURE OF PARTICIPANT	
	DATE	

CONSENT TO PARTICIPATE

Project Title	*Decisional Needs of African American Smokers Eligible for Lung Cancer Screening – Written Consent for Cross-Sectional Survey*
Purpose of the Study	*This research is being conducted by Randi Williams, MPH a Doctoral Student at the University of Maryland, College Park. We are inviting you to participate in this research project because you are an African American adult with a history of smoking. The purpose of this research project is to understand what people know and how they feel about lung cancer and lung cancer screening. Specifically, we are interested in learning more from you so that we can find the best ways to help smokers and former smokers make a decision about whether to get tested for lung cancer.*
Procedures	*The procedures involve completion of a one-time survey that should take about 15-20 minutes to complete. This survey is going to ask you some questions about lung cancer and testing for it. You may not have any knowledge about lung cancer and this is OK. Even if you have not heard of lung cancer or the lung cancer screening test, this is important for us to know.*
Potential Risks and Discomforts	*There may be some risks from participating in this research study. The risk is unlikely and may involve some minor anxiety that you may feel when thinking about cancer during this survey. You may choose not to answer any questions that make you feel uncomfortable or you may stop the survey at any time.*
Potential Benefits	*There are no direct benefits from participating in this research. We hope that, in the future, other people might benefit from this study through improved understanding of making a choice about getting tested for lung cancer.*
Confidentiality	*Any potential loss of confidentiality will be minimized by storing your identifying information in password protected databases and hard copies will be stored in locked file cabinets. In order to reduce the risk of loss confidentiality, access to your personal identification information will be limited to Randi Williams and the research staff.* *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.
Compensation	*You will receive $10 for completion of the survey. You will be responsible for any taxes assessed on the compensation.* *If you will earn $100 or more as a research participant in this study, you must provide your name, address and Social Security Number to receive compensation.* *If you do not earn over $100 only your name and address will be collected to receive compensation.*
Right to Withdraw and Questions	*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.* *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:* **Randi M. Williams, MPH** **University of Maryland, College Park** **School of Public Health Building** **College Park, MD 20742** **Telephone: 301-405-7875** **Email: rwili25@umd.edu**
Participant Rights	*If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:* 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 *This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.*	
Statement of Consent	*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.* *If you agree to participate, please sign your name below.*	
Signature and Date	**NAME OF PARTICIPANT** **[Please Print]**	
	SIGNATURE OF PARTICIPANT	
	DATE	

Appendix F. Invitation Letters

Name
Address

Dear *insert participant name*,

I hope this note finds you well. I am writing to invite you to participate in my dissertation research project entitled, *Decisional Needs of African American Smokers Eligible for Lung Cancer Screening*. The purpose of this study is to describe aspects of decision-making including knowledge and awareness about lung cancer screening using low-dose computed tomography (LDCT), values related to the screening, uncertainty about LDCT, and decision-making preferences among African American adults who are eligible for LDCT. Additionally, this study will examine the extent to which decision-making components are associated with intentions to be screened for lung cancer in the future. Drawing from a national, probability-based sample of African American adult men and women, eligible individuals (N = 182) will be recruited to participate in a cross-sectional survey.

Prior to the administration of the cross-sectional survey, I am conducting key informant interviews at the provider- and patient-level to obtain information about decisional values that may be salient to the priority population under study. While the barriers identified among African Americans for other cancers may be similar for lung cancer screening (e.g., fatalistic beliefs, medical distrust, access to care), there may be other considerations specific to the lung cancer screening test for this population. The goal of the key informant interviews is to gain more information about reasons for and against lung cancer screening. The reasons cited will be used to inform two close-ended items on the cross-sectional survey.

Phone interviews will be conducted with healthcare providers who work in the area of lung cancer and lung cancer screening. Providers will be asked to describe how lung cancer screening is done within their organization, what are some of the successes/challenges associated with providing lung cancer screening, and reasons why patients may get tested and reasons why patients may choose not to get tested. The interview will also gauge what resources providers think patients need to support their decision about lung cancer screening. The interview will be recorded with the use of an audio-recorder. It is expected that the interview will take about 30 minutes to complete.

The eligibility criteria to participate in this key informant interview include: 1) being 21 years of age or older, 2) currently working in a healthcare setting, and 3) working in the area of lung cancer and lung cancer screening.

This interview will be conducted over the phone. If you are interested in participating, please respond to this email indicating the best time, date, and phone number where I may reach you.

Please feel free to contact me if you have any questions about this project.

Sincerely,

Randi M. Williams, MPH
PhD Candidate
Department of Behavioral and Community Health
School of Public Health
University of Maryland, College Park
301-405-7875
rwilli25@umd.edu

CC: Cheryl L. Holt, PhD

UNIVERSITY OF MARYLAND
SCHOOL OF PUBLIC HEALTH
Department of Behavioral and Community Health

2387 School of Public Health Bldg
College Park, Maryland 20742-2611
301.405.7875 TEL

DATE

Name
Address

Dear *insert participant name*,

We hope this letter finds you well. As you may recall, you participated in the "Health and Wellness in the African American Community" project. This was a national telephone survey with over 3,000 other African American men and women taking part. The interviewer asked you questions about things like your health, social life, and faith life. Once again we want to **thank you** for your help in making the project a success.

During the Health and Wellness survey, we asked if you would be interested in being re-contacted about similar projects in the future. We are writing to invite you to participate in my dissertation project that will focus on health screenings including tests that can find lung cancer early. The goal of this research study is to understand what people know and how they feel about lung cancer and lung cancer screening. Specifically, we are interested in learning more from you so that we can find the best ways to help smokers make a decision about whether to get tested for lung cancer.

Each person who completes the research survey will receive $10 in the mail, as a token of our appreciation. We ask you to complete this one-time survey, which should take about 15-20 minutes of your time. You may complete the survey online (Link to Survey). Once you click the link to the survey, it will first ask some questions to determine if you are eligible to participate in this study. If you prefer, the survey can be completed over the telephone by calling 301-405-7875 between the hours of 9am and 9pm Eastern Time (Monday to Friday).

This letter is our first attempt at reaching you. We will follow-up with a phone call within the week to make sure the invitation was received and to answer any questions you may have.

Please feel free to contact myself or Cheryl L. Holt, PhD, Principal Investigator of the Health and Wellness project.

SURVEY LINK
Sincerely,

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Appendix G. Eligibility Screener

Thank you for your interest in the lung cancer screening study. The goal of this project is to understand what people know and how they feel about lung cancer and lung cancer screening. Specifically, we are interested in learning more from you so that we can find the best ways to help smokers or former smokers make a decision about whether to get tested for lung cancer. Before starting the survey, we would like confirm you are eligible to participate in the study.

What is your age?

Do you identify as Black or African American?
Yes
No

Have you ever been told you have lung cancer?
Yes
No

Do you currently smoke cigarettes?
Yes
No

OR Have you quit smoking cigarettes within the past 15 years?
Yes
No

On average, how many cigarettes do/did you smoke per day?

Please enter the total number of years you smoked.

Appendix H. Study Survey

Lung Cancer Screening Decisional Needs Study Survey	
ID: _____	Date Completed:_____
This survey is going to ask you some questions about lung cancer and testing for it. You may not have any knowledge about lung cancer and this is OK. Even if you have not heard of lung cancer or the lung cancer screening test, this is important for us to know. You can mark 'don't know/not sure' for any question if you don't know the answer. Once the survey is completed, we will send you $10 to thank you for your time. Please read each question carefully. If you have any questions, please contact us at 301-405-7875 or rwilli25@umd.edu. The survey should take approximately 15-20 minutes to complete. Thank you for your participation in this project!	
LUNG CANCER SCREENING KNOWLEDGE AND AWARENESS	
This survey is going to ask you about a lung cancer screening test – low-dose computed tomography (CT). This test is done to check for lung cancer. It is done in the doctor's office. A scan uses x-rays to take images of your body. Instead of taking one picture, like a regular x-ray, this scanner takes many pictures as it rotates around you while you lie on a table. A computer then combines these pictures into images of slices of your lungs.	



1)	**Low-dose computed tomography screening is used to detect lung cancer. Have you read or heard about this type of lung cancer screening <u>before taking this survey</u>?** 1 Yes 0 No [Skip to Item 3] 88 Don't Know/Not sure 99 Refused
2)	**If Yes to Item 1, At any time in the past year, have you talked with your doctor or other health professional about having a test to check for lung cancer using low-dose computed tomography?** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused
3)	**Has a doctor ever recommended lung cancer screening for you in the past?** 1 Yes 0 No [Skip to Item 7]

<table>
<tr><td></td><td>88 Don’t Know/Not sure
99 Refused</td></tr>
<tr><td>4)</td><td>If Yes to Item 3, did they suggest a….
1 Low-dose computed tomography
2 Chest X-Ray
3 Other, please specify_____
88 Don’t Know/Not sure
99 Refused</td></tr>
<tr><td>5)</td><td>Did you get tested for lung cancer following your doctor’s recommendation?
1 Yes, If Yes, Why? Open-ended response
0 No, If No, Why not? Open-ended response
88 Don’t Know/Not sure
99 Refused</td></tr>
<tr><td>6)</td><td>If Yes to Item 5, What type of screening did you have?
1 Low-dose computed tomography
2 Chest X-Ray
3 Other, please specify_____
88 Don’t Know/Not Sure
99 Refused</td></tr>
<tr><td>7)</td><td>Below are some statements about lung cancer screening using low-dose computed tomography. Please mark whether you think they are true, false, or you are not sure by selecting one of these options.
<table>
<tr><td></td><td>1 True</td><td>2 False</td><td>3 Unsure</td></tr>
<tr><td>Factors that increase chances of getting lung cancer include:</td><td></td><td></td><td></td></tr>
<tr><td>Smoking</td><td></td><td></td><td></td></tr>
<tr><td>Family History of lung cancer</td><td></td><td></td><td></td></tr>
<tr><td>Getting the flu</td><td></td><td></td><td></td></tr>
</table></td></tr>
</table>

	Chronic obstructive pulmonary disease (COPD)			
	Age			
	Drinking alcohol			
	Possible benefits of lung cancer screening are:			
	It can cure cancer			
	It lowers your chances of dying from lung cancer			
	It lowers your chances of developing lung nodules			
	Possible harms of lung cancer screening include:			
	You may find some things in your lungs that are not cancer but would need to do an extra test to check			
	You may need to get an extra test which can cause complications			
	There are no harms associated with screening			
	Mark whether individuals would be eligible for lung cancer screening based on the age.			
	Age: 45 years old			
	Age: 55 years old			
	Age: 60 years old			
	Age: 85 years old			
	What percentage of nodules, which is a small round or oval-shaped growth, found on your lung by the lung cancer screening test is NOT going to be cancer? 1 More than 90% 2 50%-60% 3 10%-20% 4 Less than 5% 88 Don't Know/Not sure			

DECISIONAL SUPPORT & RESOURCES	
8)	**Please select the statement that sounds like you:** 1 I prefer to make the decision about lung cancer screening 2 I prefer to make the final decision about lung cancer screening after seriously considering my doctor's opinion 3 I prefer that my doctor and I share responsibility for deciding whether to get tested for lung cancer 4 I prefer that my doctor makes the final decision about lung cancer screening, but seriously considers by opinion 5 I prefer to leave all decisions regarding lung screening to my doctor
9)	**Other than your doctor, is there anyone else you would involve in making a decision about lung cancer screening?** 1 Yes 0 No [Skip to Item 11] 88 Don't Know/Not sure 99 Refused
10)	**If, Yes to Item 9, who would you involve in your decision? [Mark all that apply]** 1 Spouse 2 Significant other 2 Family 3 Friend(s) 4 Member(s) of your faith community 5 Co-worker(s) 6 Other, please specify_____
11)	**Do you feel you have all of the information you need to make an informed decision about whether or not to undergo lung cancer screening using low-dose computed tomography?** 1 Yes 0 No 88 Don't Know/Not sure

	99 Refused					
12)	**What additional information would you like to receive to help you decide about lung cancer screening using low-dose computed tomography?** 1 More information about the test itself 2 More information about any risks of the test 3 More information about any benefits of the test 4 Other, please specify					
13)	**How would you most prefer to receive information about lung cancer screening using low-dose computed tomography?** 1 Personal counseling from your doctor or healthcare professional 2 Personal counseling from a trained lay (non-healthcare professional) worker/community member 3 Informational materials 4 Discussion groups of people facing the same decision 5 Internet 6 Other, please specify					
DECISIONAL VALUES						
14)	**Below are listed some things people consider when making a decision about lung cancer screening using low-dose computed tomography. Please indicate how important these are to you by selecting extremely important to me to not at all important to me.**					
	How important is…	Extremely important	Very important	Moderately important	Somewhat important	Not at all important
	…lowering your risk of dying from lung cancer?					
	…getting a lung cancer screening test that may help you live longer?					

	…getting peace of mind to find out you do not have lung cancer?					
	…making you feel like you are doing everything you can for your health?					
	…following your doctor's opinion about lung cancer screening?					
	…thinking about family or friends who have dealt with lung cancer?					
	…knowing the test has little risk?					
	…the out of pocket cost of the screening?					
	…where you have to go (testing location) to get lung cancer screening?					
	…the idea that lung cancer screening may lead to more testing if there is an abnormal result?					
	…the idea that you would prefer to focus on other					

	things in your life than thinking about screening for lung cancer?					
	…the idea that lung cancer screening will make you worry about lung cancer?					
	…the idea that lung cancer screening will not find all lung cancers or all lung cancers early?					
	…the idea that not all patients who have lung cancer diagnosed by screening will avoid death from lung cancer?					
	…the idea that the lung cancer screening test might show something wrong that turns out not to be cancer?					
	…the idea that getting screened for lung cancer would make you feel badly about your smoking history?					
	…the feeling that if you had lung cancer you would feel like it was your fault?					

DECISIONAL CONFLICT			
	We would now like to ask you some questions about making a choice about whether or not get tested for lung cancer.	1 Yes	0 No
15)	**SURE Scale**		
	Do you feel sure about the best choice for you?		
	Do you know the benefits and risks of each option?		
	Are you clear about which benefits and risks matter most to you?		
	Do you have enough support and advice to make a choice?		
LUNG CANCER SCREENING INTENTION			
16)	**On average, how many cigarettes do/did you smoke per day?**		
17)	**Please enter the total number of years you smoked.**		
18)	**If pack-year is >20, how likely is it that you will get tested for lung cancer using low-dose computed tomography in the next six months?** 1 Extremely Unlikely 2 Unlikely 3 Neutral 4 Likely 5 Extremely Likely		
19)	**How likely is it that you will talk with your doctor about lung cancer screening using low-dose computed tomography in the next six months?** 1 Extremely Unlikely 2 Unlikely 3 Neutral 4 Likely 5 Extremely Likely		
20)	**How likely is it that you will talk with your family about lung cancer screening using low-dose computed tomography in the next six months?**		

	1 Extremely Unlikely 2 Unlikely 3 Neutral 4 Likely 5 Extremely Likely				
21)	**How likely is it that you will talk with your <u>friends</u> about lung cancer screening using low-dose computed tomography in the next six months?** 1 Extremely Unlikely 2 Unlikely 3 Neutral 4 Likely 5 Extremely Likely				
BACKGROUND CHARACTERISTICS					
Last please tell us a little bit about you and your family.					
22)	**When did you last smoke a cigarette (even one or two puffs)?** 4 I smoked a cigarette today (at least one puff) 3 1 to 7 days ago 2 8 days to 1 month ago 1 More than 1 month ago to 1 year ago 0 More than 1 year ago 88 Don't know/Don't remember				
23)	**Have any of your blood relatives ever had lung cancer…**	0 No	1 Yes	2 Does not apply	3 Unknown/I prefer not to answer
	Father				
	Mother				

	Brother(s), including half brothers:				
	Sister(s), including half sisters:				
	Child (biological				
	Other relatives (please specify):_____				
24)	**Have you ever had a test called a Fecal Occult Blood Test or FOBT? [For All]** **Have you ever had a colonoscopy? [For All]** **Have you ever had a prostate specific antigen or PSA test? [For Males]** **Have you ever had a digital rectal exam or DRE? [For Males]** **Have you ever had a mammogram? [For Females]** **Have you ever had a Pap test? [For Females]** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused				
25)	**Have you ever been diagnosed with cancer, except for non-melanoma skin cancer?** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused				
26)	**Have you lived with a smoker for more than half of your life?** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused				

27)	**Have you ever worked with radon without proper protection?** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused
28)	**Have you ever worked with any of the following things known to cause lung cancer without proper protection? These include asbestos arsenic, beryllium, cadmium, chromium, nickel, coal smoke, soot, silica, and diesel fumes.** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused
29)	**Have you ever been told you have COPD (chronic obstructive pulmonary disease) or pulmonary fibrosis? These are both lung diseases that make it hard to breathe.** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused
30)	**What is your age?** _____
31)	**Where were you born?** 1 In the United States, Enter name of state_____ 2 Outside the United States, Enter name of country_____ 99 Refused
32)	**What is your gender?** 1 Male 2 Female 3 Non-binary/third gender 4 Prefer to self-describe

	99 Refused
33)	**What is the highest grade or year of school you completed?** 1 Never attended school or only attended kindergarten 2 Grades 1 through 8 (Elementary) 3 Grades 9 through 11 (Some high school) 4 Grade 12 or GED (High school graduate) 5 College 1 year to 3 years (Some college or technical school) 6 College 4 years or more (College graduate) 7 Masters degree 8 Doctoral or other advanced degree (e.g., Law, Medicine) 99 Refused
34)	**What is your marital status?** 1 Never been married 2 Currently Married 3 Living with Partner 4 Separated or Divorced 5 Widowed 99 Refused
35)	**Do you currently work for pay outside of the home?** 1 Full-time employed 2 Part-time employed 3 Not currently employed 4 Retired 5 Receiving disability 99 Refused
36)	**What is the total income of everyone in your household per year, before taxes?** 1 less than $5, 000 2 $5,001 - $10,000

	3 $10,001 - $20,000 4 $20,001 - $30,000 5 $30,001 - $40,000 6 $40,001 - $50,000 7 more than $50,000 99 Refused
37)	**Which, if any, types of health insurance do you have? [Mark all that apply]** 0 1 Medicaid 0 1 Medicare 0 1 Insurance through an Employer/Work (ex. Blue Cross, HMO) 0 1 Any other Form of Health Insurance 0 1 None
38)	**Where do you usually go to receive medical care?** 1 Primary Care Physician's Office 2 Urgent Care 3 Emergency Room at the Hospital 4 Other, please specify_____ 99 Refused
39)	**Does the doctor you visit most often use an electronic medical record (computer)?** 1 Yes 0 No 88 Don't Know/Not sure 99 Refused
40)	**Would you be willing for us to contact you again to conduct a one-time phone interview to ask more in-depth questions about your health and about lung cancer screening? This phone interview would last for 1-hour.** 1 Yes 0 No

	99 Refused
41)	Please let us know how you learned of this Health and Wellness study survey. 1 Mailed letter from University of Maryland 2 Posted flyer advertising about the survey 3 Newspaper advertisement about the survey 4 Other, please specify_____
Thank you for your participation! Please press the submit button to complete the survey. We will send you $10 as a thank you for your time. If you have any questions, please contact us at 301-405-7875 or rwilli25@umd.edu.	

Appendix I. Study Flyer

Health and Wellness Project





UNIVERSITY OF MARYLAND 18 56

Complete a one-time research survey!

The University of Maryland's School of Public Health is inviting African American adults who have a history of smoking to participate in a one-time survey which should take about 15-20 minutes to complete. The purpose of this research study is to help learn more about health screenings including tests to find lung cancer early. To participate in this research study, you must: 1) be an African American adult between 55 and 80 years old, 2) have a history of smoking, 3) currently smoke or have quit within the past 15 years, and 4) have not been diagnosed with lung cancer.

As a token of our appreciation, we will send you $10 once the survey is returned. You may complete the survey online by visiting **https://go.umd.edu/healthsurveydc**. Once you click on the survey link, it will first ask questions to confirm you are eligible to participate in the study.

For more information, please contact Randi Williams at 301-405-7875 or rwilli25@umd.edu.

Appendix J. Patient Information Page

AMERICAN LUNG ASSOCIATION. | LUNG FORCE

Is lung cancer screening right for me?

Screening is a test used to detect lung cancer before any symptoms appear. Screening with low-dose CT (LDCT) scans can reduce deaths in those at high risk. The test is not recommended for everyone and it has risks as well as benefits. Below are key points you may want to use in discussion with your doctor if you are worried about your risk for lung cancer.

Q: Am I a candidate for lung cancer screening?

A: If you meet the following criteria, you are considered to be at "high risk" for developing lung cancer and screening is recommended:

- 55-80 years of age
- Have a 30 pack-year history of smoking (this means 1 pack a day for 30 years, 2 packs a day for 15 years, etc.)
- AND, are a current smoker, or have quit within the last 15 years

At this time, there is not enough evidence to show that screening is recommended for other groups.

A note on insurance coverage:

If you are 55-80 years old and have private insurance or 55-77 years old and have Medicare, and meet the other high-risk criteria listed, the initial scan will be covered without cost-sharing.

Be sure to check with your insurance plan for screening coverage and for any additional procedures—there may be other costs associated even if the actual screening is free. Visit the Lung Cancer Screening Insurance Checklist for questions to ask your insurance provider.

Q: Why is lung cancer screening only recommended for a certain group of people?

A: Experts look at the available data and use complex equations to determine who should be screened. If you are not in the high-risk group that means data has shown the benefits of screening do not outweigh your risks. However, there are still important ways you can reduce your lung cancer risk, such as eliminating your exposure to tobacco smoke, radon in your home and other hazardous chemicals.

Join the American Lung Association's fight to increase federal funding for cancer research at the National Institutes of Health so there can be improved early detection for lung cancer, as well as better treatments and cures for all. Sign up today at LungAction.org.

1-800-LUNGUSA | SavedByTheScan.org

Q: How can I reduce my lung cancer risk if I am not a candidate for screening?

A: The best way to reduce your risk is to take steps to avoid exposure to the dangerous substances most likely to cause lung cancer.

- The best way is to never smoke or stop smoking now. If you smoke, talk to your doctor or contact the Lung HelpLine (1-800-LUNGUSA) about ways to help you quit. Visit Lung.org/stop-smoking for more information.
- Avoid exposure to secondhand smoke.
- Test your home for radon, an odorless gas that causes lung cancer. Radon can be found in any home. If your home tests high for radon, take steps to repair your home to remove the radon. A certified radon contractor can fix the problem. Learn more at Lung.org/radon.
- Make sure you are safe around hazardous materials in the workplace and at home.

Q: Should I get a low-dose CT scan to screen for lung cancer?

A: If you are at high risk, talk with your doctor about getting a low-dose CT scan to screen for lung cancer. Screening for lung cancer may save your life. Discuss your complete health history and ask for a clear explanation about the possible benefits and risk. There are some risks and not everyone should be screened for lung cancer. Only low-dose CT scans are recommended for screening. Chest X-rays are not recommended for lung cancer screening.

Q: What happens if I choose to get a low-dose CT scan for lung cancer?

A: There is some radiation risk with a low-dose CT scan and you may need to have additional tests and procedures. You should go to a hospital or screening center that has a team of experts who will clearly explain the procedure to you. The team should tell you about all the risks and benefits of the screening. They should also discuss what the results can mean and how they will follow up with you after the initial screening.

Q: What do the results mean?

A: A "positive" result means that the low-dose CT scan shows something abnormal. This is usually a nodule of a concerning size. You may need to have additional scans or other procedures to find out exactly what it is. These next steps should be discussed with you by your physician and/or the team of experts at the screening center.

A "negative" result means there were no abnormal findings at this time on this scan. Your doctor should discuss when and if you should be tested again.

There may also be an "indeterminate" result and your doctor may recommend watchful follow-up and further imaging at a later time.

The best way to reduce your lung cancer risk is to never smoke or stop smoking. If you smoke, talk to your doctor about ways to help you quit.

Q: Where can I get more information about lung cancer and lung cancer screening?

A: The American Lung Association has a variety of lung cancer screening resources for patients and healthcare professionals. Visit SavedByTheScan.org or call the Lung Cancer HelpLine at 1-844-ALA-LUNG for more information.

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