

ABSTRACT

Title of Dissertation: THE HEALTH LITERACY PROCESS
OLDER ADULT LONG-TERM SMOKERS
USE TO MAKE AN INFORMED DECISION
ABOUT LUNG CANCER SCREENING: A
GROUNDED THEORY STUDY

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Lung cancer is the leading cause of cancer-related death in the United States with 160,000 annual deaths. Recent advances in screening technologies have proven effective in reducing mortality and increasing early stage detection of lung cancer, yet only 3.9% of the 6.8 million eligible Americans were screened in 2015. Potential barriers to lung cancer screening have been examined; however, there is limited research available on the impact of health literacy and the process of informed decision-making about lung cancer screening. To fill this gap, this study explored how health literacy relates to intentions and behaviors to screening for lung cancer among long-term smokers between 55 to 80 years old who have a 30-pack year smoking history, health insurance, and a provider seen in the

past two years. The study was guided by the following research question: “How does health literacy relate to intentions and behaviors to screen for lung cancer?”

Twelve participants ($N=12$) were enrolled in the study. Participants were 58.3% female, 83.3% black, 83.3% had screened for any cancer besides lung cancer, and 75% were current smokers with a 41.8 mean pack-year history. The majority of the sample (91.7%) had adequate health literacy based on the Short Test of Functional Health Literacy in Adults. Data were transcribed verbatim and analyzed using constructivist grounded theory methods, proceeding through four stages of coding (open, focused, axial, and theoretical). Analysis produced a Health Literacy Theoretical Model of Informed Decision-Making about Lung Cancer Screening. The theoretical model is underpinned by a core category: Making an Informed Decision about Lung Cancer Screening. This core category is supported by eight categories characterizing how health literacy relates to lung cancer screening among older adult long-term smokers, including Health Information Seeking Behaviors, Trusted Sources, Knowledge, Trusted Provider, Advocacy, Perceived Risk, Patient-Provider Communication, and Shared Decision-Making.

This is one of the only known studies that describes the health literacy process of informed decision-making about lung cancer screening. The results of this grounded theory study have several implications for public health practice, research, and policy and have the ability to increase lung cancer early detection and survival.

THE HEALTH LITERACY PROCESS OLDER ADULT LONG-TERM SMOKERS
USE TO MAKE AN INFORMED DECISION ABOUT LUNG CANCER
SCREENING: A GROUNDED THEORY STUDY

by

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Dedication

This dissertation is dedicated to my mother, Dana Erlene Platter, who lost her short battle to lung cancer on May 1st, 2011. Her experience with lung cancer has led me to pursue this research and seek to learn from the experiences of others. Mom, I am eternally grateful to you for everything you have taught me throughout my life. I am proud to be your daughter.

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I want to thank my dad for always being there for me, my cousin Tracy for helping me stay positive, and to my partner, Bobby, for always believing in me and telling me I can accomplish anything. I am so grateful to my parents because throughout my life they have always supported my goals and pushed me to be the best I can be. I love you all so much!

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Chapter One: Introduction

Problem Statement

Lung cancer is the leading cause of cancer-related death in the United States and more than 230,000 Americans are diagnosed with lung cancer each year (American Lung Association, 2016). Lung cancer causes 160,000 annual deaths, which contributes to approximately 27% of overall cancer-related deaths in the United States (American Lung Association, 2016; Siegel, Miller, & Jemal, 2016). The American Cancer Society (2018) reports that more American adults die each year from lung cancer than from the combined annual deaths from colorectal, breast, and prostate cancer.

Population-based cancer screening programs are effective in reducing cancer mortality due to early stage detection. Technological developments in the past eight years have improved accuracy for lung cancer screening. The National Lung Screening Trial Research Team (2011) found that low-dose computed tomographic (LDCT) screening reduced lung cancer mortality by 20% in a randomized control trial of more than 53,000 participants. The United States Preventive Services Task Force (USPSTF) (2013) recommends the screening and states that LDCT scans are an effective annual lung cancer screening mechanism that can yield moderate to substantial benefits for individuals considered high-risk. Screening eligibility is for older adults between 55 to 80 years who have a 30 pack-year smoking history and currently smoke or have quit within the past 15 years (US Preventive Services Task Force, 2013). Screening should cease when the person has not smoked for 15 years or if the person develops a health problem that limits life expectancy or capacity to have lung surgery. Despite this recommendation, only 3.9% of

6.8 million eligible individuals were screened for lung cancer in 2015 (Jemal & Fedewa, 2017).

Early stage lung cancer diagnosis is rare; one reason for this is because screening for lung cancer is currently underutilized by individuals considered high-risk for developing lung cancer. Research shows that 15% of new lung cancer diagnoses are identified at a localized stage and only 16% of lung cancer patients are alive after five years (Lewis et al., 2015; National Cancer Institute, 2011; National Lung Screening Trial Research Team et al., 2011). A potential explanation for poor screening adherence in this high risk population is low health literacy. Research demonstrates that individuals with low health literacy are more likely to delay seeking care and less likely to participate in preventive services (Levy & Janke, 2016; von Wagner, Knight, Steptoe, & Wardle, 2007). Recent studies have investigated attitudes towards screening, barriers to screening, and decisions to opt-out of screening, but there is lack of published research available on health literacy-related barriers to lung cancer screening (Carter-Harris, Brandzel, Wernli, Roth, & Buist, 2017; Delmerico, Hyland, Celestino, Reid, & Cummings, 2014; Simmons, Gray, Schabath, Wilson, & Quinn, 2017; Sin, Ha, & Taylor, 2016).

The 2003 National Assessment of Adult Literacy (NAAL) reported that only 12% of adults in the United States have proficient health literacy (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). Adults with basic or below basic health literacy accounted for 36% of the sample, with five percent more men having a basic or below basic health literacy score compared with women (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). Adults aged 65 years and older had the lowest average health literacy

and the percentage of older adults with proficient or intermediate health literacy was lower than the percentage of adults in different age groups (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). Lung cancer is a disease that primarily affects older adults. In 2013, more than 80% of individuals with lung cancer were over the age of 60 years (National Cancer Institute, 2018a). In the United States, 18% of adults aged 45 to 64 years and approximately 9% of adults 65 years and older are current smokers (Centers for Disease Control and Prevention, 2018a).

This study used the new Healthy People 2030 definition to define health literacy: “Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions” (Healthy People 2020 Secretary Advisory Committee, 2017). This definition has evolved from the individual-level of health literacy as the field is shifting to a public health focus that encompasses the role of the health care system, including communicating with patients and providing them information essential for informed decision-making (Brach et al., 2012; Institute of Medicine, 2014). The Institute of Medicine (2003) states that health literacy is not solely based on the skills of an individual, but also the health literacy complexities of the health care system. For example, the health care system has medical documents such as informed consent forms, medical instructions, discharge forms, and health information materials that often include technical language that is difficult for people with low health literacy to understand (Graham & Broome, 2008; Institute of Medicine Committee on Health Literacy, 2004; Rudd, Colton, & Schacht, 2000). Additionally, spoken health care information frequently includes jargon and medical terminology that can be difficult to understand even for people with adequate health literacy (Graham & Broome, 2008).

These complexities can lead to missed medical appointments, poor medication adherence, and worse health outcomes (Graham & Brookey, 2008). This supports the need to investigate the individual, community, and system level health literacy barriers that individuals face. This study explored health literacy factors, such as access and navigation of the healthcare system, patient-provider communication, health information seeking behavior, and shame, to determine if these factors affect older adult long-term smokers' intentions and behaviors related to lung cancer screening recommendations. These factors were also explored in regard to how they influence informed decision-making for lung cancer screening.

Access and navigation of the healthcare system is related to patient navigation skills as well as the complexity and demands of the healthcare system (Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012). A recent study found significant differences between individuals with low and adequate health literacy; individuals with low health literacy were more likely to report delaying or not obtaining care for reasons such as having to wait too long to receive care, lacking transportation, and being too busy to go to the doctor (Levy & Janke, 2016). Access and navigation of the health care system are potentially important barriers related to health literacy and understanding the complexity of individual experiences on access and navigation as barriers for lung cancer screening have yet to be explored (Levy & Janke, 2016).

Inadequate patient-provider communication is a health literacy barrier to screening for lung cancer. Recent studies have found a lack of knowledge about LDCT lung cancer screening among primary care providers as well as low confidence in ability to counsel patients about screening (Rajupet, Doshi, Wisnivesky, & Lin, 2017; Simmons et al., 2017).

Data from the Health Information National Trends Survey in 2014 revealed that only 10% of respondents had a discussion with their provider about having a test to check lung health (Carter-Harris, Tan, Salloum, & Young-Wolff, 2016a). Poor use of health literacy communication techniques and lack of provider knowledge on screening guidelines may be causes of the limited conversations occurring between providers and patients on screening for lung cancer. Additionally, research has demonstrated the importance of shared decision-making, which is where patients and health providers work together to make a shared decision about screening for lung cancer, though this has not yet become a routine process in clinical care (Stiggelbout et al., 2012). Informed by this body of prior research, this study qualitatively explored the experiences individuals at high-risk for lung cancer have with the health care system, with a focus on patient-provider communication and informed decision-making regarding lung cancer screening.

Health information seeking behavioral research demonstrates that adults over 55 years have the highest amount of trust in health care providers, yet provider communication might not be the best method to learn about and become informed on lung cancer screening (Chaudhuri, Le, White, Thompson, & Demir, 2013; Cutilli, 2010). A recently published study on web-based patient-focused educational materials on screening for lung cancer found that these materials were not written for low health literacy populations, which may contribute to the low screening rate in high-risk individuals (Hansberry et al., 2018). Furthermore, health information seeking behaviors are related to how individuals can become informed on a health topic to make an informed decision that can impact their health (McCaffery, Smith, & Wolf, 2010). As such, this study investigated health

information seeking behaviors on lung cancer screening for individuals at high-risk of developing lung cancer and how these behaviors influence informed decision-making.

The association between lung cancer, smoking, and perceived self-infliction has led to increased disease-related stigma among patients, which interferes with effective patient-provider communication (Carter-Harris, Hermann, Schreiber, Weaver, & Rawl, 2014). A study found that 48% of lung cancer patients reported feeling stigmatized by their medical providers; however, good patient-provider communication was associated with lower levels of patient-reported lung cancer stigma (Shen, Hamann, Thomas, & Ostroff, 2016). In addition to experiencing stigma due to lung cancer and smoking, patients may experience shame due to low health literacy (Easton, Entwistle, & Williams, 2013; Parikh, Parker, Nurss, Baker, & Williams, 1996; Wolf et al., 2007). Given these observed relationships, this study explored experiences of shame and stigma and how those experiences impact patient-provider communication.

Research Question

The central research question for this study was “How does health literacy relate to intentions and behaviors to screen for lung cancer?” This grounded theory study included intensive semi-structured interviews with older adult long-term smokers at high-risk for developing lung cancer to identify how health literacy factors influence the process of informed decision-making about screening for lung cancer. Topics such as navigation and access, patient-provider communication, health information seeking behaviors, and shame were explored in addition to participant-led topics that emerged during the intensive interviewing process.

Public Health Implications

Cancer screening is a leading public health priority that improves survivorship through early detection and treatment. The consequences of not screening are a serious concern as fewer than 15% of lung cancer cases are identified at a localized stage (American Lung Association, 2016). Since half of individuals diagnosed with lung cancer when symptoms appear die within one year, it was critical that barriers to screening in high-risk populations were explored in this study (American Lung Association, 2016; Thompson et al., 2014).

The results of this study have numerous implications for public health research, practice, and policy. The results of this study are relevant for training in health literacy and health communication for clinical and public health professionals as well as clinical training on recommended cancer screening guidelines. This study was consistent with the Healthy People 2020 objectives for Health Communication and Health Information Technology to improve the health literacy of the population by improving patient-provider communication, shared decision-making, and personalized health information resources (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2018). The related Healthy People 2020 objectives can be found in Table One. Furthermore, this study may guide improved policy for clinical and public health professional training on health literacy and health communication as well as require screening interventions to include health literacy best practices and techniques to improve informed decision-making for patients.

Table 1	
<i>Healthy People 2020 Related Objectives for Health Communication and Health Information Technology (HC/HIT)</i>	
<u>HC/HIT-1: Improve the health literacy of the population</u>	
HC/HIT-1.1	Increase the proportion of persons who report their health care provider always gave them easy-to-understand instructions about what to do to take care of their illness or health condition
HC/HIT-1.2	Increase the proportion of persons who report their health care provider always asked them to describe how they will follow the instructions
HC/HIT-1.3	Increase the proportion of persons who report their health care providers' office always offered help in filling out a form
<u>HC/HIT-2: Increase the proportion of persons who report that their health care providers have satisfactory communication skills</u>	
HC/HIT-2.1	Increase the proportion of persons who report that their health care providers always listened carefully to them
HC/HIT-2.2	Increase the proportion of persons who report that their health care providers always explained things so they could understand them
HC/HIT-2.3	Increase the proportion of persons who report that their health care providers always showed respect for what they had to say
HC/HIT-2.4	Increase the proportion of persons who report that their health care providers always spent enough time with them
<u>HC/HIT-3: Increase the proportion of persons who report that their health care providers always involved them in decisions about their health care as much as they wanted</u>	
<u>HC/HIT-4: (Developmental) Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health</u>	

This study can inform future implementation science research on lung cancer screening guidelines because it provides a clearer understanding of the ways in which health literacy is related to informed decision-making and lung cancer screening. Additionally, an outcome of this study was a health literacy informed decision-making model on lung cancer screening, which can be quantitatively tested in future research studies. The model can inform public health practice as well as be used in future lung cancer screening interventions to enhance understanding on what this population needs to make an informed decision about lung cancer screening. Through increasing screening of

at-risk populations, thousands of annual deaths could be averted (Ma, Ward, Smith, & Jemal, 2013; National Lung Screening Trial Research Team et al., 2011).

Purpose of the Study

The purpose of this dissertation was to explore the experiences and perceptions of older adult long-term smokers to determine how health literacy factors, such as the patient experience of health information seeking, navigating the health care system, and patient-provider communication, lead to the informed decision-making process about screening for lung cancer. Data was collected by conducting intensive, semi-structured interviews with older adults who met the United States Preventive Task Force eligibility guidelines for lung cancer screening (US Preventive Services Task Force, 2013). Grounded theory, an advanced qualitative methodology, was used to collect and analyze data to construct a health literacy theoretical model on informed decision-making about screening for lung cancer (Charmaz, 2014). The results of this study contribute to theory development in the field of health literacy and cancer prevention, which expands knowledge on the informed decision-making process for screening for lung cancer among older adults.

Despite advances in screening technologies and the recent ability to detect lung cancer at a localized stage through a low-dose computed tomography (LDCT) scan, screening among high-risk populations is severely underutilized (Jemal & Fedewa, 2017). Health literacy is a key factor that has not been closely explored regarding lung cancer screening. Whereas there are research studies on the detriments of low health literacy, there are limited published studies that investigate the health literacy factors that lead to informed decision-making about lung cancer screening. Recent studies have found general barriers to lung cancer screening, but qualitative in-depth explorations of barriers, especially those

related to health literacy, and of informed decision-making for lung cancer screening have yet to be conducted (Carter-Harris et al., 2017; Delmerico et al., 2014; Simmons et al., 2017; Sin et al., 2016). The results from this study can also inform the creation of community-based lung cancer screening interventions to reduce health literacy screening barriers, improve decision-making ability, increase screening and early stage detection, and decrease lung cancer mortality among older adult long-term smokers.

Key Terms and Acronyms

Table 2	
<i>Key Terms and Acronyms</i>	
<u>Word/Acronym</u>	<u>Definition</u>
Open coding	Open coding is a process of coding an interview transcript line-by-line to create codes in the participant's voice (Charmaz, 2014).
<i>In vivo</i> codes	The use of participant phrases or words to create open codes. The process allows researchers to become immersed in the data by preserving the meaning of the participants' words and actions (Charmaz, 2014).
Focused coding	Focused coding is a process where the researcher uses <i>in vivo</i> codes from the open coding stage and turns participant specific codes into broader codes, known as dimensionalizing concepts (Charmaz, 2014).
Axial coding	Axial coding is the process of developing categories and subcategories from concepts that emerged in focused coding (Charmaz, 2014).
Theoretical coding	Theoretical coding is the examination of the relationship between categories produced from the data, which leads to the creation of a theoretical framework (Charmaz, 2006).
Audit trail	An audit trail is used to enhance the rigor and transparency of qualitative research. It is a process used to track methodological and theoretical decisions made throughout the research process (Bowen, 2009).
Health literacy	Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions (Healthy People 2020 Secretary Advisory Committee, 2017).
Low-dose computed tomography (LDCT) scan	Computed tomography (CT) scanning uses special x-ray equipment to produce several detailed pictures, or scans, inside the body. Low-dose computed tomography (LDCT) uses less ionizing radiation than a regular LDCT scan (Radiologyinfo, n.d.; National Cancer Institute, 2013).

Member checking	The presentation of results back to research participants to assess agreement with the researchers' interpretations and findings. The process allows researchers to systematically check their data and results (Charmaz, 2014).
Memo writing or memoing	A process to record emergent ideas and key concepts that occur to the researcher throughout the qualitative research phase of a study (Creswell & Poth, 2018).
Older adults	Older adults in this study are considered to be 55-80 years old, based on USPSTF eligibility guidelines (US Preventive Services Task Force, 2013).
Reflexivity	A process where researchers explore how their interests, positions, and assumptions can influence their research (Charmaz, 2014). A researcher can minimize the effects of bias through being continuously aware and practice reflexivity in all stages of the research process (Kolb, 2012).
United States Preventive Services Task Force (USPSTF) guidelines for lung cancer screening	<ul style="list-style-type: none"> - Adult is between 55 to 80 years old - Adult has 30 pack-year smoking history - Adult currently smokes or has quit smoking in the past 15 years (US Preventive Services Task Force, 2013).
Patient-provider communication	Patient-provider communication includes verbal and nonverbal interactions that form the basis for patient-provider relationships (Lee, Back, Block, & Stewart, 2002). Strong patient-provider communication can help patients of all literacy levels better understand medical information as well as allow for better provider identification of patient needs, perceptions, and expectations (Fong et al., 2006).
Health information seeking behavior	How individuals seek information on their health, illnesses and risks, and preventive health behaviors (Jacobs, Amuta, & Jeon, 2017; Lambert & Loiselle, 2007; Mills & Todorova, 2016).
Shared decision-making	A process where both patients and physicians share information, express treatment preferences and agree on a treatment plan (American College of Obstetricians and Gynecologists, 2014; Charles, Gafni, & Whelan, 1999; Peek et al., 2009).
Stigma	The occurrence of stereotypes, negative labels, status loss, and discrimination in a situation where power is exercised (Hatzenbuehler, Phelan, & Link, 2013).

Chapter Two: Literature Review

The purpose of this study was to explore the experiences and perceptions of older adult long-term smokers to determine how health literacy factors relate to intentions and behaviors on lung cancer screening. The following literature review focuses on the background of lung cancer, including recent statistics, the relationship between cigarette smoking and lung cancer, lung cancer screening guidelines, as well as shared decision-making and informed decision-making. This chapter introduces barriers to screening based on current literature, then discusses health literacy and factors that may impede screening.

Lung Cancer Background

Lung cancer is the leading cause of cancer-related mortality in the United States (American Cancer Society, 2018). There are two main types of lung cancer. Non-small cell lung cancer (NSCLC) is the most common and accounts for approximately 80% of lung cancer cases (American Lung Association, 2017a). Small cell lung cancer (SCLC) is the other main type of lung cancer and it is highly associated with cigarette smoking (American Lung Association, 2017a).

Lung cancer is staged using the American Joint Committee on Cancer Tumor, Node, and Metastases (TNM) system to determine the size and extent of the tumor, whether it has spread to nearby lymph nodes, and if it has spread, or metastasized, to distant sites (American Cancer Society, 2017). Using the TNM system, a formal cancer stage can be prescribed (Table Three). Approximately 80% of lung cancer diagnoses are regional or distant, meaning the cancer has spread to nearby lymph nodes or to distant parts of the body (Siegel, Miller, & Jemal, 2018). Many patients are not aware they have lung cancer because earlier stages are often asymptomatic (Birring & Peake, 2005). When symptoms

do appear, they are non-specific and difficult to diagnosis because of co-existing smoking-related diseases such as chronic obstructive pulmonary disease (Birring & Peake, 2005). Most lung cancer diagnoses are made after cancer symptoms appear, but research shows that patients often ignore early symptoms (Birring & Peake, 2005). Diagnosis and treatment delays lead to higher stage diagnoses and poorer survival rates. Low-dose computed-tomography screening can address diagnosis delays to improve lung cancer survival statistics.

Table 3	
<i>Cancer Stages and Explanations</i>	
<u>Stage</u>	<u>Stage Explanation</u>
Stage 0	Abnormal cells are present, but they have not spread to nearby tissue. These cells are also called carcinoma in situ (CIS). CIS is not cancer, but it may develop into cancer (National Cancer Institute, 2015).
Stage I, II, III	Cancer is present in any of these stages. The higher the stage, the larger the cancer tumor, and the more it has spread to nearby tissues. Stage I cancer is localized, meaning it is limited to the place where it started. Stage II and III cancer may be regional, meaning it has spread to nearby lymph nodes, tissues, or organs (National Cancer Institute, 2015).
Stage IV	Cancer has spread to distant parts of the body. This stage is sometimes called distant (National Cancer Institute, 2015).

Statistics. Cancer is the second leading cause of death in the United States, closely following heart disease by a difference of 22,649 deaths in 2014-2015 (Siegel et al., 2018). Lung cancer is the leading cause of cancer-related deaths in the United States with 153,722 of the 595,930 deaths in 2015 being from lung cancer (Siegel et al., 2018). Lung cancer is also the leading cause of death for males 40 to 80+ years and females 60 to 80+ years (Siegel et al., 2018).

An estimated 234,030 adults in the United States will be diagnosed with lung cancer in 2018 (Siegel et al., 2018). Furthermore, 154,050 are expected to die from lung cancer in

2018 (Siegel et al., 2018). Lung cancer has the second highest cancer diagnosis in the U.S. behind prostate cancer for males and breast cancer for females; however, estimated deaths are higher for lung cancer than any other cancer (Siegel et al., 2018).

Research on the probability of developing lung cancer among men and women from 2012 to 2014 found that males 70 years or older have a one in 16 (6.1%) and females 70 years and older have a one in 21 (4.8%) chance of developing lung cancer (Siegel et al., 2018). The 60 to 69 age group is one in 54 (1.9%) for males and one in 70 (1.4%) for females and 50 to 59 is one in 154 (0.7%) and one in 178 (0.6%), respectively (Siegel et al., 2018).

The 5-year relative lung cancer survival rate for combined stages from 2007 to 2013 is 18% (Siegel et al., 2018). If lung cancer is diagnosed when it is localized, the five-year survival rate is 56%; however, for regional is it 29% and distant is a mere 5% (Siegel et al., 2018). Although the 5-year survival rate is higher when lung cancer is diagnosed at a localized stage, only 16% of cases are localized when diagnosed (Siegel et al., 2018). Regional diagnosis is 22% and distant is the highest at 57% (Siegel et al., 2018).

Mortality rates per 100,000 are highest for black men (66.9) followed by white (56.3) and American Indian/Alaska Native (45.0) males in the United States (Siegel et al., 2018). The racial disparity for women is slightly different with white females experiencing the highest mortality (39.0) followed by black (34.4) and American Indian/Alaska Native (30.0) females (Siegel et al., 2018).

Cigarette Smoking and Lung Cancer. Tobacco use is the leading cause of preventable death and disease in the United States (Jamal, 2018; National Center for Chronic Disease Prevention and Health Promotion, 2014). An estimated 37.8 million adults

in the United States currently smoke cigarettes and more than 16 million adults live with a smoking-related disease (National Center for Chronic Disease Prevention and Health Promotion, 2014). More than 480,000 premature deaths occur each year in the United States due to cigarette smoking and secondhand smoke, which is roughly one in five deaths (National Center for Chronic Disease Prevention and Health Promotion, 2014). Deaths from smoking-related diseases are 36% from cancer, 24% from lung disease, and 39% from heart disease and stroke (National Center for Chronic Disease Prevention and Health Promotion, 2014).

Older adult long-term smokers have a heightened risk for tobacco-related diseases, such as lung cancer, and one in four cancer-related deaths are from lung cancer (American Cancer Society, 2017; Dolan et al., 2004). Furthermore, two out of three individuals diagnosed with lung cancer are at least 65 years old, demonstrating the importance of screening older adult long-term smokers (American Cancer Society, 2017).

Cigarette smoking is a highly addictive behavior that is the primary cause of lung cancer. Cigarette smoking is responsible for approximately 80 to 90% of lung cancer diagnoses (Centers for Disease Control and Prevention, 2018b). Research shows that people who smoke are 15 to 30 times more likely to be diagnosed with lung cancer than nonsmokers (Centers for Disease Control and Prevention, 2018b). Cigarette smoke contains more than 7,000 chemicals and at least 69 are known to cause cancer (Centers for Disease Control and Prevention, 2010). The tobacco smoke that smokers inhale and exhale is a mixture of carcinogens and toxicants that make smokers and secondhand smokers susceptible to developing lung cancer (National Center for Chronic Disease Prevention and Health Promotion, 2014). Nonsmokers have a 30% greater chance of developing lung

cancer if they are regularly exposed to secondhand smoke (Centers for Disease Control and Prevention, 2006). Laws that regulate smoking in public locations, such as restaurants, schools, and healthcare facilities, have been implemented within the past ten years to reduce secondhand smoke exposure (National Center for Chronic Disease Prevention and Health Promotion, 2014).

Lung Cancer Screening. The advent of screening for lung cancer has reduced lung cancer mortality, but lung cancer will continue to be the leading cause of cancer-related mortality in the United States unless barriers to screening are explored and addressed. The consequences from not screening for lung cancer are a serious concern because half of individuals diagnosed when symptoms appear die within one year of diagnosis (American Lung Association, 2014; Thompson et al., 2014). In December 2013, the United States Preventive Services Task Force issued a grade B recommendation for lung cancer screening (Moyer, 2014; U.S. Preventive Services Task Force, 2015). The recommendation came after the National Lung Screening Trial found a significant reduction in lung cancer mortality from the low-dose computed tomography (LDCT) scan (National Lung Screening Trial Research Team et al., 2011; Roth, Carter-Harris, Brandzel, Buist, & Wernli, 2018).

The National Lung Screening Trial (2011) enrolled more than 53,000 participants at high risk for lung cancer from August 2002 through April 2004. Participants were randomly assigned to undergo three annual screenings with either the LDCT scan or a single-view posteroanterior chest radiography (X-ray). The research team collected data on lung cancer cases and mortality until December 31, 2009. Results demonstrated a 20%

reduction in lung cancer mortality with the LDCT screening (National Lung Screening Trial Research Team et al., 2011).

Screening uptake is low despite positive results from the National Lung Cancer Screening Trial and the recommendations from USPSTF as well as similar recommendations from other national organizations (Table Four) (Fuerst, 2018; Graff, 2017; Huo, Shen, Volk, & Shih, 2017; Jemal & Fedewa, 2017). An estimated 6.8 million Americans qualified as high-risk for developing lung cancer in 2015, yet only 3.9% of eligible individuals screened for lung cancer that year, indicating that despite high-risk, very few people have completed a lung cancer screening (Jemal & Fedewa, 2017). Jemal and Fedewa (2017) reviewed data from the 2010 and 2015 National Health Interview Survey to examine screening rates before and after the implementation of USPSTF guidelines for lung cancer screening. Results showed that the percentage of eligible smokers who reported having a LDCT screening in the past 12 months had not significantly changed from 2010 to 2015 (3.3% vs. 3.9%, respectively) (Jemal & Fedewa, 2017). Furthermore, the researchers found no significant sociodemographic differences for screening between groups over time. The primary difference was a reduction in the number of people eligible for screening from 8.4 million in 2010 to 6.8 million in 2015 (Jemal & Fedewa, 2017). This decrease in screening-eligible adults exhibits the progress made in the field of tobacco control.

Huo and colleagues (2017) examined the intended and unintended uptake of LDCT screening compared to chest radiography for lung cancer screening before and after the release of screening guidelines using data from the Cancer Control Module of the 2010 and 2015 National Health Interview Survey. In addition to reviewing data for screening eligible

individuals, data for low-risk smokers and never-smokers were also examined to determine the unintended uptake of screening. Data analysis found three patterns relevant for current lung cancer screening researchers and programs: 1) a significant, but small, increase for the percentage of individuals who received a LDCT scan was 1.3% in 2010 and 2.1% in 2015; 2) the rate of LDCT scans significantly increased for never-smokers (0.8% vs. 1.2%), low-risk smokers (1.5% vs. 2.7%), and high-risk smokers (2.9% vs 5.8%); and 3) the use of chest radiography as a lung cancer screening method was similar between dates (2.5% vs. 2.7%) (Huo et al., 2017). These results reveal that while the percentage of individuals receiving a lung cancer screening has significantly increased since the release of the USPSTF guidelines, the increase is minimal. Furthermore, it is alarming that there has been a significant increase in the amount of non-eligible individuals (never-smokers and low-risk smokers) who have screened for lung cancer. It is also distressing that despite having a recommended screening technique, providers are still prescribing a chest radiography for lung cancer screening. This demonstrates a provider knowledge gap regarding the latest science on lung cancer screening.

Another study performed a retrospective analysis of electronic medical record data among patients aged 55-80 years with no history of lung cancer who had visited a primary care provider in a large California healthcare system between the years of 2010 and 2016 (Li, Chung, Wei, & Luft, 2018). Results from the study presented an increased use of smoking history documentation to assess screening eligibility (59.2% in 2010 to 77.8% in 2016) as well as an increase in LDCT screening orders (0% in 2010 to 7.3% in 2016) (Li et al., 2018). Factors that increased likelihood of providers ordering the LDCT screening were being a female physician and receiving medical training in the US (Li et al., 2018).

Patient factors associated with increased likelihood of screening orders were being a young patient (55-64 vs 78-80 years), Asian race, current smoker, no severe comorbidity, and visiting own primary care provider (Li et al., 2018). Li and colleagues (2018) conclude that future lung cancer screening interventions may be more effective if accurate documentation of smoking history is completed and targeting former smokers who do not regularly visit their primary care provider.

As demonstrated by the National Lung Screening Trial (2011), the LDCT lung cancer screening can reduce lung cancer mortality. Ma and colleagues (2013) found that if screening was fully implemented among high risk eligible persons, at least 12,250 lung cancer deaths per year could be averted.

Barriers to Screening. The amount of research on barriers to screening for lung cancer has increased since the USPSTF guidelines were released in 2013 (Ali et al., 2015; Carter-Harris, 2015; Delmerico et al., 2014; Jonnalagadda et al., 2012; Li et al., 2018; Raju, Khawaja, Wang, Han, & Mazzone, 2018; Raz et al., 2017; Simmons et al., 2017; Sin et al., 2016; Triplette et al., 2017). Current research on screening participation has found practical barriers, emotional barriers, and barriers related to perceived risk. This section examines the available literature on patient barriers to screening for lung cancer.

Practical Barriers. The UK Lung Cancer Screening pilot trial examined barriers to screening among high-risk individuals who declined participation in the trial (Ali et al., 2015). Ali and colleagues (2015) aimed to examine the demographic and psychological characteristics of individuals who declined screening participation, their self-reported barriers to screening, and the associations between individual characteristics and barriers to screening. Results demonstrated that age, gender, smoking status, and socioeconomic

group were significantly associated with screening uptake. Women, current smokers, older individuals, and people in the lowest socioeconomic group were more likely to decline screening (Ali et al., 2015). Practical barriers to screening included travel and location, lack of public transportation, comorbidities, caregiver responsibilities, and already receiving screening (Ali et al., 2015).

Travel has been noted as an important barrier to cancer screening participation (Ali et al., 2015; Patel et al., 2012). Patel and colleagues (2012) found that half of their respondents listed travel as their most significant reason to decline screening. In addition to travel, studies have shown that a dislike of hospitals, scans, or the healthcare system is associated with low screening (Ali et al., 2015; Patel et al., 2012). The time associated with screening, such as making an appointment and taking off work, has also been cited as a barrier (Simmons et al., 2017).

Another practical barrier to screening is cost or health insurance coverage. Delmerico and colleagues (2014) found that 33% of current smokers and 25% of former smokers cited lack of health insurance as a barrier to screening. One study established that when participants were faced with paying for the screening, intention to screen for lung cancer dropped by 50% (Jonnalagadda et al., 2012). Silvestre and colleagues (2007) reported significant differences between smoker and nonsmoker willingness to pay for a lung cancer screening. Non-smokers were twice as likely as smokers to pay \$200 or \$300 for a screening test (Silvestri et al., 2007). When deciding whether to have a LDCT scan, 78.4% of participants agreed that cost was important, more so than perception of disease risk and convenience (Cataldo, 2016). Simmons and colleagues (2017) reported that focus group participants at high risk for lung cancer had concerns about cost and whether

screening would be covered by their health insurance. A survey of primary care providers found that 86.9% of providers believed that patient costs associated with screening was a primary barrier being screened (Lewis et al., 2015). Approximately 80% of providers believed that lack of insurance coverage was also a barrier (Lewis et al., 2015). Two studies created brief measures of smokers' knowledge on lung cancer screening with low-dose CT. Results from both studies showed that participants had difficulty correctly answering questions about screening eligibility criteria (Houston, Lowenstein, Leal, & Volk, 2018; Lowenstein et al., 2016).

Knowledge and Awareness Barriers. A study by Schnoll and colleagues (2003) found that 77% of respondents were unaware of the LDCT scan for lung cancer screening. Focus group participants discussing what should be included in lung cancer screening information materials had overall positive opinions about lung cancer screening, but their awareness of the LDCT screening for lung cancer was low (Sharma et al., 2018). A study on identifying factors that influence screening delays revealed that participants did not have accurate knowledge of lung cancer risk nor awareness of symptoms (Tod, Craven, & Allmark, 2008). Some focus group participants at high risk for developing lung cancer were aware of a chest X-ray, but had never heard of the LDCT screening and did not understand how it differed from the chest X-ray (Simmons et al., 2017). A survey of primary care providers found that 81.3% of providers believed patients' lack of awareness was a primary barrier to screening (Lewis et al., 2015). Another study revealed that the majority of 54 focus group participants had never heard of lung cancer screening, did not understand the difference between diagnostic and screening tests, but they were supportive of the test (Cardarelli et al., 2017). Although cost and health insurance coverage was listed

under practical barriers, it is also a knowledge barrier since studies found that participants were unsure about whether their health insurance covered the test (Simmons et al., 2017). An intervention using a video-based patient decision aid significantly increased patient knowledge on lung cancer screening from 47.3% to 80.3%, demonstrating that patient knowledge is often low about lung cancer screening but it can be improved (Housten et al., 2018).

Emotional Barriers. Ali and colleagues (2015) found that participants who refused screening experienced emotional barriers such as fear and avoidance of lung cancer information. Current smokers were less likely to report practical barriers and more likely to report emotional barriers such as fear, anxiety, and avoidance of lung cancer information (Ali et al., 2015). These results are similar to other research demonstrating an association between smoking status and low lung cancer screening uptake (McDonald et al., 2014; Patel et al., 2012; Silvestri et al., 2007). Furthermore, Silvestri and colleagues (2007) reported that when compared to never-smokers, current smokers were more likely to have fatalistic attitudes, less likely to believe that early detection from screening would result in better survival rates, and less likely to consider screening for lung cancer. A study by Delmerico and colleagues (2014) uncovered that 33% of current smokers were afraid to find out if they had cancer in a survey of 1290 adults on willingness to screen for lung cancer. Additional studies have established that fearing results of the screening tests, especially cancer positive or false-positive results, as well as fear of radiation, impedes screening (Cardarelli et al., 2017; Cataldo, 2016; Lewis et al., 2015; Simmons et al., 2017).

Research shows an association between low socioeconomic status and low screening uptake (Breen, Wagener, Brown, Davis, & Ballard-Barbash, 2001; Szczepura,

Price, & Gumber, 2008; Webb, Richardson, Esmail, & Pickles, 2004). Low screening rates in lower-income populations may be due to fatalistic beliefs due to smoking-related diseases, such as lung cancer, being prevalent in lower-income communities where tobacco use is greater. Jonnalagadda and colleagues (2012) found that blacks and Hispanics were more likely than non-Hispanic whites to report being afraid or nervous about LDCT scans. Additionally, fatalistic beliefs, fear of radiation exposure, and anxiety were significantly associated with decreased intention to screen (Jonnalagadda et al., 2012).

In a study examining non-participation in a lung cancer screening trial, older adults were more likely to report emotional barriers (Ali et al., 2015). Although associations between gender and self-reported barriers were not significant, cancer researchers have shown that cancer-related fears are more prevalent among women than men (Ali et al., 2015; Ritvo et al., 2013; Stewart, Taylor, & Baker, 1997).

Perceived Risk. Individuals who had a higher affective risk perception were less likely to participate in screening for lung cancer and participants with a higher risk perception were more likely to report comorbidities as a barrier to screening (Ali et al., 2015). Cancer screening researchers have found that high personal cancer risk can cause screening avoidance (Hay, Buckley, & Ostroff, 2005; Trask et al., 2001). This finding is conflicting to other cancer screening research that found higher affective risk perception to be a motivator for lung cancer screening (Patel et al., 2012; van den Bergh, Essink-Bot, van Klaveren, & de Koning, 2009). Long-term smoking and having friends or family with lung cancer or who have died from lung cancer increased perceived risk and screening behaviors (Patel et al., 2012). Individuals who declined to participate in the Lung-SEARCH screening trial were more likely to underestimate or deny their risk than those who did

participate in the trial (Patel et al., 2012). It is possible that a high-risk status can cause avoidance of cancer-related information in some adults as well as perform as a motivator for screening in others.

Shared Decision-Making

Shared decision-making is the process of patients and health providers working together to make a shared decision using the best available evidence (Stiggelbout et al., 2012). The US Preventive Services Task Force describes shared decision-making in 5 stages; one, when a patient understands the health issue; two, is aware of the available clinical services as well as the risks and benefits of these services; three, has considered personal preferences; four, has participated in shared decision-making with a health provider to a desirable level; and five, makes a decision based on personal preferences (Sheridan, Harris, & Woolf, 2004). This shared process is essential to improving patient-provider conversations on lung cancer screening as it gives patients the opportunity to learn about a health issue, treatment, or procedure, such as the benefits and risks of lung cancer screening, and how to balance benefits against risks as well as be involved in making a shared decision that will impact patient health outcomes.

Shared decision-making is influenced by the oral literacy demand in the dialogue between patient and provider, meaning that it is impacted by provider communication skills, such as limiting the use of jargon and high dialogue density (Amalraj, Starkweather, Nguyen, & Naeim, 2009; Roter, Erby, Larson, & Ellington, 2007; N. Williams & Ogden, 2004). Shared decision-making is also impacted by patient health literacy skills and the ability to advocate for personal health. Shared decision-making increases the demands on a patient, which can be difficult for patients with low health literacy since they are less

likely to ask their provider to slow down or clarify unclear health information (Amalraj et al., 2009; Bennett, Cameron, Whitehead, & Porter, 2009; Smith, Dixon, Trevena, Nutbeam, & McCaffery, 2009). Provider use of patient decision aids, videos, and digital support tools that follow health literacy best practices can enhance and improve the shared decision-making experience, but they are not available for many health conditions and most are not designed for or evaluated with adults with limited health literacy (Stiggelbout et al., 2012; Muscat et al., 2016). Research has shown that although shared decision-making is a best practice in clinical care, it is not yet a routine process; many patients do not expect to be involved in decision-making with their provider and providers may assume that patients with limited health literacy or older adults do not want to participate in shared decision-making (Hoffman et al., 2010; Politi, Dizon, Frosch, Kuzemchak, & Stiggelbout, 2013; Stiggelbout et al., 2012).

Studies show that patients with low health literacy report less participation in shared decision-making, but there is limited research available regarding lung cancer screening (Schillinger, Bindman, Wang, Stewart, & Piette, 2004; Yin et al., 2012). A lung cancer screening program implemented a mandated shared decision-making visit and counseling, which found a significant improvement in patients' knowledge about lung cancer screening, influencing the patients ability to make value-based decisions; knowledge decreased at 1-month follow-up, but was still higher than the pre-test (Mazzone et al., 2017). Another study found increased knowledge after seeing a decision aid and 97% of participants reported that the decision aid could be useful for lung cancer screening decision-making (Lau et al., 2015). Brenner and colleagues (2018) recorded patient-provider communications on lung cancer screening, which found that the quality of shared

decision-making was poor, time spent discussing lung cancer screening was minimal, there was no evidence of using decision aids, and the potential harms of screening were not discussed. The results of a national Internet survey of 1,134 participants showed that only 27-38% of participants reported engaging in a shared decision-making process about breast, colorectal, and prostate cancer screening, which could be because few clinicians have received adequate training to implement shared decision-making (Hoffman et al., 2010; Politi, Studts, & Hayslip, 2012). The results of a cluster randomized controlled trial with 18 primary care providers suggested a need for physician training in shared decision-making, especially when working with patients who have low health literacy, as well as training in cancer risk communication (Price-Haywood, Roth, Shelby, & Cooper, 2010). Barton and colleagues (2014) found that lower physician trust was associated with poor shared decision-making communication. Another study examining trust and shared decision-making found that trust was enhanced when shared decision-making occurred, particularly when patients felt educated and listened to by their health provider (Peek et al., 2013). A cross-sectional study examining parental health literacy and shared decision-making found that one in five reported that their child's doctor always, or usually, did not help them feel like a partner in decision-making, more than half strongly preferred to rely on the doctor's knowledge, and 40% strongly preferred to leave decision-making about their child's medical care to their provider (Yin et al., 2012). A research study examining the relationship between shared decision-making and health literacy found that health literacy affects decision-making preferences, with adequate health literacy being significantly associated with preferring shared decision-making; however, it was stated that

more research is needed on factors that influence decision-making preferences, which this study explored.

Informed Decision-Making

Informed decision-making is different from shared decision-making in that it is when a patient becomes informed and a health decision occurs, which may not include direct communication between a patient and provider. This form of decision-making is defined as when a patient identifies personal preferences and ways to learn about a health issue or procedure, deliberates on the decision, and makes a choice that may but does not have to involve a clinician (McCaffery et al., 2010). Informed decision-making is also demonstrated as a process with various stages, including awareness, perception, evaluation, and decision making where health information seeking and gathering behaviors is a key element throughout the process (van der Heide, Uiters, Jantine Schuit, Rademakers, & Fransen, 2015). The decision-making process can therefore be demanding and dependent on an individual's skill and ability to find, understand, appraise, and apply health information about screening. Individuals with lower health literacy skills may find the process difficult since it is focused on the use of health information, which is often written at a high reading level, contains dense sections of text, includes jargon without plain language examples or explanations, and does not include helpful decision aids like easy-to-understand pictures (van der Heide et al., 2015). However, it is critical that the informed decision-making process occurs for all people considering lung cancer screening, especially individuals with limited health literacy, as research shows that there is less decisional regret among individuals who make informed decisions (van der Heide et al., 2015).

A systematic review on health literacy and informed decision making for colorectal cancer screening found that knowledge is the most frequently studied concept of informed decision-making, yet knowledge is only one determinant in the decision to participate in a cancer screening and it is only one aspect of health literacy (van der Heide et al., 2015). This study explored many determinants that impact lung cancer screening, especially those related to health literacy. Stefanek (2011) argues that screening behavior research focuses on how many patients obey a provider recommendation to screen, but the focus needs to shift to examine how many patients have successfully engaged in an informed decision-making process about screening. There are limited measures or models that examine informed decision-making; therefore, this study contributes to the literature by introducing a new health literacy theoretical model on informed decision-making about lung cancer screening.

Health Literacy

Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions (Healthy People 2020 Secretary Advisory Committee, 2017). Health literacy is a multidimensional concept because it is influenced by individual skills and abilities as well as the demands and complexities of the healthcare system. Individual skills include reading ability, such as being able to understand, interpret, and locate specific information within a document, the ability to use quantitative information for tasks like understanding a nutrition label, and the ability to effectively speak and listen (David W. Baker, 2006; “Health literacy,” 1999).

The *National Action Plan to Improve Health Literacy* states that to achieve the vision of a health literacy society, there needs to be a responsive health system that eliminates barriers to using clear communication methods and provides understandable and actionable health information and services (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010). The plan goes on to discuss seven goals that health systems can work towards to accomplish that vision, which includes developing and disseminating accurate, accessible, and actionable health information and improve communication, access to health care services, and informed decision-making. The Institute of Medicine's (2004) report, *Health Literacy: A Prescription to End Confusion*, explains that a clear understanding of health literacy can guide the health system to adopt policies to improve issues between individual needs and the demands of health systems. The economic cost of low health literacy is substantial, with estimates up to 5% of annual healthcare costs (Paasche-Orlow, Parker, Gazmararian, Nielsen-Bohlman, & Rudd, 2005).

The 2003 National Assessment of Adult Literacy (NAAL) measured the health literacy of more than 19,000 adults in the United States (Kutner, Greenberg, Jin, & Paulsen, 2006). Participants were given clinical, prevention, and navigation of the health system tasks to determine their health literacy level. Only 12% of U.S. adults scored proficient health literacy and 36% had basic or below basic health literacy (Kutner et al., 2006). The large percentage of U.S. adults with basic or below basic health literacy is alarming, especially since the majority of older adults, 65 years and up, have the highest percentage of below basic (29%) and basic (30%) health literacy (Kutner et al., 2006). While the health literacy percentages of adults 50-64 are not as poor, 34% have below or below basic health

literacy which is approximately one in every three adults 50-64 years (Kutner et al., 2006). Additionally, older adults 65 years and up are the least proficient in health literacy at 3% (Kutner et al., 2006). The 50-64-year and up group have 12% of adults proficient in health literacy, which means only 15 out of every 100 adults ages 50 years or older are proficient in health literacy.

Age is one of the highest correlates of low health literacy (Cutilli, 2007). The Interagency Forum on Aging-Related Statistics (2016) reports that the number of older adults in the United States, aged 65 years and older, will dramatically increase from now until 2030. It is estimated that this age group will represent at least 20% of the total U.S. population (Interagency Forum on Aging-Related Statistics, 2016). The dramatic increase of individuals in this age range and the high percentage of low health literacy in this group highlights the need to improve how older adults' access, understand, and use basic health information to make appropriate health decisions, such as lung cancer screening.

Studies indicate that low health literacy predicts poor health outcomes (Baker et al., 2007; Berkman et al., 2011; Cartwright et al., 2017; Omachi et al., 2013; Paasche-Orlow & Wolf, 2007; Peterson et al., 2011; Scott et al., 2002; Weiss & Palmer, 2004). Individuals with low health literacy have higher healthcare costs, repeatedly use emergency services, and are less likely to use preventive services (Baker et al., 2007; Scott et al., 2002; Weiss & Palmer, 2004). Individuals with low health literacy are often older, have lower socioeconomic status, are less likely to have a high school education, and have higher rates of comorbidities (Paasche-Orlow et al., 2005; Peterson et al., 2011). Cartwright and colleagues (2017) studied the relationship between health literacy and health outcomes in cancer patients. Low health literacy was associated with more inpatient hospitalizations

and total days spent in the hospital (Cartwright et al., 2017). Furthermore, limited health literacy was associated with lower knowledge and negative attitudes about colorectal cancer screening (Dolan et al., 2004). Another study found that focus group participants did not fully understand the concept of screening for colon cancer even after it was explained many times (Davis et al., 2001). Miller and colleagues (2007) similarly found that patients with limited health literacy were less able to name or describe a colon cancer screening test as well as less knowledgeable about screening compared with adequate health literacy. These results have implications for this dissertation research. The following sections outline the current research on health literacy-related constructs that may be barriers that older adult long-term smokers face.

Patient-Provider Communication. Primary care providers deliver chronic, preventive, and acute care in many in-patient and out-patient settings and are often the first point of contact with the healthcare system for most adults (American Academy of Family Physicians, 2018b). Primary care providers control patient access to additional medical services and provide referrals to specialty health care providers when needed (Kanodra et al., 2016). Preventive healthcare often includes screening to facilitate early disease diagnosis. It is critical that providers know, understand, and can clearly communicate the eligibility, benefits, risks, harms, and procedures of a screening test to engage patients in a shared decision-making process (Wender et al., 2013). A current issue in patient-provider communication is that many clinicians are not trained or competent in the shared decision-making process nor in communication skills or health literacy training, which makes it difficult to clearly discuss lung cancer screening in a way that patients can understand, accept, and act upon (Wender et al., 2013). Wide-scale implementation of lung cancer

screening heavily relies on primary care provider referrals; thus, it is necessary that provider communication about lung cancer screening is explored as a potential barrier that individuals may experience with their provider (Simmons et al., 2017). This section documents the current research on provider communication about lung cancer screening.

Current research demonstrates that many individuals place a high degree of trust in their providers (Chaudhuri et al., 2013; Hillen, de Haes, & Smets, 2011; Kanodra et al., 2016; Roth et al., 2018). Roth and colleagues (2018) found that clinicians who engaged patients in a shared decision-making process encouraged them to consider screening. Furthermore, study participants described their high trust level in their doctor, which motivated them to schedule and complete the lung cancer screening (Roth et al., 2018). Research has shown that individuals who trust their provider were more adherent to screening (Duong et al., 2017). Additionally, even patients who do not believe they are at risk for lung cancer were receptive to screening discussions due to their trusting relationship with their primary care provider (Kanodra et al., 2016). One study examined racial differences in trust and lung cancer patients' perceptions of physician communication which found that initial trust in physicians were high among black and white patients, but black patients had lower post-visit trust with their physician because they were perceived as less supportive, less partnering, and less informative (Gordon, Street, Sharf, Kelly, & Soucek, 2006). Chaudhuri and colleagues (2013) discussed that physicians and nurses are highly valued trusted sources, but that patients thought doctors were too busy to address their needs. It could be that limited time with patients is a reason why conversations about screening for lung cancer are minimal.

Patient-provider communication about lung cancer screening has declined since the release of the U.S. Preventive Services Task Force recommendations (Carter-Harris, Tan, Salloum, & Young-Wolff, 2016b). In 2012, 17% of participants reported having a discussion with their provider about screening, whereas 10% reported having those conversations in 2014 (Carter-Harris et al., 2016b). Current smokers, individuals with health insurance, and individuals with a family history of cancer were more likely to be engaged in discussions about screening with their providers than former smokers or individuals without health insurance (Carter-Harris et al., 2016b). Carter-Harris and colleagues (2016b) discuss that physicians may perceive a lower risk for individuals who have successfully quit smoking, thus not engaging their former smoker patients in a shared decision-making process. This is a critical issue because 60% of lung cancers are diagnosed in former smokers (Carter-Harris et al., 2016b). It is unclear why providers are having fewer conversations about screening for lung cancer, but it could be due to a lack of provider knowledge on current screening guidelines.

Recent studies have found provider knowledge on current lung cancer screening guidelines to be limited and may be a reason for the exceptionally low uptake of screening in high risk populations (Jemal & Fedewa, 2017; Lewis et al., 2015; Marsh et al., 2016; Simmons et al., 2017; Triplette et al., 2017). A focus group of primary care providers found that patients do not inquire about lung cancer screening and those who do request a chest X-ray, so providers do not recommend the low-dose computed tomography screening (Simmons et al., 2017). Providers also shared that they have limited knowledge of the LDCT screening, but they would recommend it if they had more information. Another issue mentioned by providers was the amount of time it takes to discuss screening

thoroughly and complete the shared decision-making process with patients (Simmons et al., 2017). Kanodra and colleagues (2016) completed focus groups with primary care providers who work with the Veterans Health Administration. The researchers found that 58% of participants were aware of the U.S. Preventive Services Task Force guidelines (Kanodra et al., 2016). Participants stated that they assessed eligibility and offered screening when prompted by the EMR, but that time constraints prevented them from discussing the risks and benefits of screening with their patients (Kanodra et al., 2016).

A study on the lung cancer screening practices and attitudes among primary care providers found that 53% of providers knew fewer than three of the six guidelines components for LDCT screening and 24.3% of providers did not know any of the guidelines (Lewis et al., 2015). Ironically, 88.4% of providers reported that the U.S. Preventive Services Task Force is influential to their practice, yet the majority of providers did not know their current guidelines on screening for lung cancer. Knowledge of three or more guidelines was associated with ordering a LDCT or chest x-ray, but more providers reported using a chest x-ray for lung cancer screening (Lewis et al., 2015). A survey of primary care providers found that 89% were aware of U.S. Preventive Services Task Force guidelines, but only 31% answered age and smoking eligibility criteria correctly indicating low knowledge on current LDCT screening guidelines (Duong et al., 2017). Despite that, 75% of providers indicated they had initiated a discussion about lung cancer screening and 58% had ever ordered a LDCT (Duong et al., 2017). A lung cancer screening knowledge study of primary care providers and pulmonologists found that 76% of pulmonologists were aware of the American College of Chest Physicians recommendations versus 38% of primary care physicians, demonstrating that there is a need to further educate primary care

providers about current screening recommendations (Marsh et al., 2016). Triplette and colleagues (2017) also assessed primary care and pulmonary providers and found limitations in provider knowledge of key screening components. A similar study of primary care providers and specialists found that when compared to specialists, primary care providers were less confident in their ability to identify eligible patients for lung cancer screening, were less comfortable counseling patients on LDCT, and reported having less time for sufficient counseling (Rajupet et al., 2017). Educational interventions for primary care providers may improve knowledge and adherence with current lung cancer screening recommendations.

Healthy People 2020 emphasizes the importance of effective patient-provider communication to enhance patient understanding and improve health outcomes (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2018). The American Medical Association created 17 recommended communication techniques for healthcare providers that includes five domains: 1) interpersonal communication; 2) teach-back method; 3) patient-friendly materials and aids; 4) assistance; and 5) patient-friendly practice (Schwartzberg, Cowett, VanGeest, & Wolf, 2007). Techniques within the interpersonal communication and teach-back method domains are considered basic techniques (Weatherspoon, Horowitz, Kleinman, & Wang, 2015). Research demonstrates that communication skills are underutilized by physicians and that physicians often use terms that are considered jargon, which may be due to overestimation of patients' health literacy (Castro, Wilson, Wang, & Schillinger, 2007; Howard, Jacobson, & Kripalani, 2013; Safeer & Keenan, 2005; Schwartzberg et al., 2007; Weatherspoon et al., 2015). Weatherspoon and colleagues (2015) examined the use of

recommended communication techniques by Maryland family physicians and found they routinely used an average of 6.6 of the 17 total techniques and 3.3 of the seven basic techniques. Other studies have found similar results. A survey of dental hygienists in Maryland found similar results with half of respondents stating they routinely use only six of the techniques and a national survey of dentist-patient communication found that dentists routinely used seven techniques and three of the basic techniques (Horowitz, Clovis, Wang, & Kleinman, 2013; Rozier, Horowitz, & Podschun, 2011). Providers that utilize health literacy and communication techniques may be able to better assess patient eligibility for screening, inform current and former smokers about screening guidelines and potential risk for lung cancer, help patients understand the harms and benefits to make an informed screening decision, and engage patients in a shared decision-making process.

Stigma and Shame. Stigma has been defined as the occurrence of stereotypes, negative labels, status loss, and discrimination in a situation where power is exercised (Hatzenbuehler et al., 2013). It is a social process of marginalization by people who stigmatize others and how stigmatized individuals perceive stigma and navigate it (Stuber, Galea, & Link, 2008). Research on stigma and smoking behaviors has been well studied due to the increased social unacceptability of smoking cigarettes (Castaldelli-Maia, Ventriglio, & Bhugra, 2016; Evans-Polce, Castaldelli-Maia, Schomerus, & Evans-Lacko, 2015; Stuber et al., 2008; Stuber, Galea, & Link, 2009). Stuber, Galea, and Link (2008) found that 40% of current and former smokers perceive high stigma and believed that most people think less of someone who smokes. A systematic review examined existing literature on tobacco smoking self-stigma, which found that smokers are aware of stereotypes and the existence of social stigma around smoking (Evans-Polce et al., 2015).

Additionally, Evans-Polce and colleagues (2015) found that many smokers understand and agree with the social stigma and they apply stereotypes and experience consequences associated with self-stigmatization.

The stigmatization of tobacco smoking behaviors has also led to discrimination and stigma against people diagnosed with lung cancer (American Lung Association, 2014; Bresnahan et al., n.d.; Brown et al., 2014; Carter-Harris, 2015; Cataldo et al., 2011; Chapple et al., 2004; Weiss et al., 2014). Individuals with a history of smoking who are diagnosed with lung cancer may be considered as responsible and deserving of their lung cancer diagnosis (Hamann et al., 2014). The perception that lung cancer is self-inflicted is associated with higher levels of depression, shame, guilt, and anxiety for lung cancer patients (Brown et al., 2014; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008). Even though lung cancer is the leading cause of cancer-related deaths in the United States, people recognize disparities in public awareness and resources devoted to lung cancer (Hamann et al., 2014). The stigma about self-infliction is so high and negative that even non-smokers diagnosed with lung cancer find themselves prefacing their diagnosis conversation by stating they were a never-smoker and then have to defend themselves when people state they deny their smoking behaviors (Hamann et al., 2014).

It was critical that stigma in relation to lung cancer was explored in this dissertation because the association between lung cancer, smoking, and perceived self-infliction has led to increased disease-related stigma among patients as well as medical providers, which can interfere with effective patient-provider communication (Carter-Harris et al., 2014). One study found that patients were worried that their diagnosis, access to care, and relationships with their doctors might be negatively affected due to the stigmatizing nature

of lung cancer (Chapple et al., 2004). Lobchuk and colleagues (2008) found that primary caregivers of lung cancer patients who blame, stigmatize, or are angry at their patients may be less empathic, which leads to less-than-optimal care. A cross-sectional study among 94 patients recently diagnosed with lung cancer found that stigma influences help-seeking behaviors for lung cancer symptoms, demonstrating that stigma is a barrier to prompt medical help-seeking behaviors (Carter-Harris, 2015). Another study found that 48% of lung cancer patients ($n=231$) reported feeling stigmatized by their medical providers, but good patient-provider communication was associated with lower levels of patient-reported lung cancer stigma (Shen et al., 2016). Stigma about lung cancer due to smoking behaviors is related to health literacy because it is interfering with patient-provider communication as well as medical seeking behaviors, thus stigma was explored as a barrier to patient-provider communication and screening for lung cancer.

Although research has examined stigma related to tobacco smoking behaviors and lung cancer, fewer studies have examined the relationship between shame and low health literacy, which also may affect conversations with health providers as well as medical seeking behaviors. Parikh and colleagues (1996) examined shame and health literacy, which found that 40% of participants with inadequate or marginal functional health literacy admitted shame related to reading with 67.2% never telling their spouse about their difficulties. Another 19% had never disclosed their reading difficulties with anyone, demonstrating that many patients with low health literacy and reading problems are ashamed and hide their inabilities to understand or read (Parikh et al., 1996). This may affect how low health literate patients interact with their health care providers. A more recent study found that low health literacy stigma can seriously impair patient-provider

communication and the ability to benefit from health services (Easton et al., 2013). Results from the two-stage qualitative study found that participants have difficulty with written communication in healthcare contexts and that medical jargon has led them to miss or be late for appointments, follow instructions, as well as feel anxious and stressed about conversations with clinicians (Easton et al., 2013). Conversations with medical personnel are often difficult because patients experience a strong reluctance to disclose their level of low health literacy and they are unable or unwilling to ask for clarification of jargon for fear of revealing they do not understand what was being discussed (Easton et al., 2013). A similar study found that the stigma of limited literacy was a barrier to accessing medical care (Lincoln et al., 2017). Seo and colleagues (2016) stated that patients experience shame and do not admit their difficulties or seek assistance due to the stigma of low health literacy, which limits their medical decision-making abilities. Patients may feign understanding due to the stigma and shame associated with low health literacy, which may interfere with medical seeking behaviors as well as reduce conversations about lung cancer screening, ultimately decreasing the number of individuals being screened for lung cancer.

Health Information Seeking Behaviors. Health information seeking behavior has been defined as how individuals seek information on their health, illnesses and risks, and preventive health behaviors (Jacobs et al., 2017; Lambert & Loiselle, 2007; Mills & Todorova, 2016). The Pew Research Center (2009) found that when faced with a health or medical issue, 86% of American adults ask a health professional for medical information, 68% ask a friend or family member, and 57% use the internet. The Health Information National Trends Survey (HINTS) asked adults what source they would rely on first to learn health information on cancer. Recent 2018 HINTS data show that 60.4% of adults would

talk to a health professional, 24% would use the internet, and 3% would speak to a friend or family member (National Cancer Institute, 2018b). HINTS data found that 70.3% of adults trust a healthcare professional a lot to learn health information about cancer (National Cancer Institute, 2018c). Source access, trust, and confidence in the information provided are factors that influence health information seeking behaviors (Jacobs et al., 2017). Individuals with low or limited health literacy skills may not have the communication skills needed to engage a health provider or find accurate health information online, therefore leading to uninformed health decisions.

While asking a medical provider or family member has been a consistent trusted source for American adults, online health information is now one of the most common sources for individuals seeking health information (Pew Research Center, 2009; Xiao, Sharman, Rao, & Upadhyaya, 2014). The Social Life of Health Information study found that 61% of adult internet users in the United States have searched for health information online and 60% said the information affected a health care decision (Pew Research Center, 2009). Recent 2017 HINTS data found that 42.2% of adults would rely on the internet first to learn about a health or medical topic (National Cancer Institute, 2017b). In addition to searching for specific health topics online, such as lung cancer screening, patients with access to the internet can potentially view their personal medical records through their electronic health record as well as communicate with their providers. However, similar to difficulties with using interpersonal communication skills, individuals with low health literacy may struggle to access and navigate credible online health information, understand medical jargon, and make informed decisions based on their findings (Gutierrez, Kindratt, Pagels, Foster, & Gimpel, 2014). Advances in online technology and the nation's limited

health literacy has led to the development of Healthy People objectives. Healthy People 2020 has numerous health communication and health information technology objectives which focus on increasing health literacy, increasing access to the internet, increasing the number of quality health-related websites; and increasing individual use of the internet to find health information online (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2018).

Research has found that patients with adequate and limited health literacy report using the internet to obtain health information (Gutierrez et al., 2014). Yet individuals with low health literacy search less for health information, have difficulty interpreting health messages, and choose different health information sources than people with adequate health literacy (Anker, Reinhart, & Feeley, 2011; Diviani, van den Putte, Giani, & van Weert, 2015; Reyna, Nelson, Han, & Dieckmann, 2009; von Wagner, Semmler, Good, & Wardle, 2009). Furthermore, individuals with limited health literacy may be less likely to evaluate the quality of online health information, which may lead to poor health decision-making and adverse health outcomes, which could be one explanation for low lung cancer screening adherence. Diviani and colleagues (2015) found that low health literacy was negatively related to the ability to evaluate and trust online health information. Two studies examined by Diviani and team (2015) assessed the role of health literacy in evaluating online health information which found that low health literacy was associated with a lower eHealth Literacy Scale (eHEALS) score as well as lower quality ratings of a high-quality website (Benotsch, Kalichman, & Weinhardt, 2004; Ghaddar, Valerio, Garcia, & Hansen, 2012).

Health literacy may be a direct influence on the ability to access, navigate, and act upon health information about cancer screening. Smith and colleagues (2008) found that limited health literacy impacted the ability to read dense and complex cancer-related information and participants with poor reading skills stated that decision aids were intimidating and frightening. A study that examined web users seeking health information found that users were more likely to be non-Hispanic white; however, higher health literacy was associated with greater website use for Hispanics (Miller et al., 2007). Another study examined the health literacy and self-efficacy of older adults for participating in cancer screening (von Wagner et al., 2009). The research team concluded that participants with lower health literacy took longer to read their individual health information link and that lower health literacy had a direct impact on information-seeking behaviors (von Wagner et al., 2009).

In addition to lower levels of health literacy affecting information-seeking behaviors, older adults may have a more difficult time locating and understanding online health information, sometimes called eHealth literacy. eHealth literacy is defined as the ability of people to use emerging information and communication technology to improve or enable health and health care (Neter & Brainin, 2012). Almost 60% of adults 65 and older as well as 88% of 50 to 64 year old adults access the internet, many of whom use the internet to find health information (Pew Research Center, 2009). Results from a survey of older adults found that the internet was considered a trusted source of health information, though many older adults have poor eHealth literacy (Medlock et al., 2015; Neter & Brainin, 2012; Norman, 2011). Neter and Brainin (2012) found that eHealth literate individuals were younger and more educated than less eHealth literate individuals. They

were also active consumers of all types of information available on the web, used more search strategies, and closely examined information for credibility (Neter & Brainin, 2012). Tennant and colleagues (2015) examined whether older adults were able to locate and evaluate health information. Results similarly showed that being younger, having more education, and using more electronic devices was associated with greater eHealth literacy among older adults (Tennant et al., 2015). Additionally, higher education level predicted greater use of the web for seeking health information; specifically, college graduates and post graduates were nearly two to seven times more likely than non-high school graduates to use the web for health information (Tennant et al., 2015).

A grounded theory study explored older adult health information seeking behaviors and reported that older adults find the increase in the availability of information online, that of which they did not grow up with, empowering and it allowed them to better control their health (Manafa & Wong, 2012). However, the increased availability of information was a deterrent to information-seeking behaviors due to the amount of information available and ability to know which is accurate and trustworthy (Manafa & Wong, 2012). Another qualitative study found many older adult concerns about using the internet to identify and treat health issues (Silver, 2015). Concerns including limitations in ability, such as misdiagnosing the issue, credibility of online information, anxiety after looking up a health problem, time consuming, potential conflict, and internet scams (Silver, 2015). Furthermore, despite online health information seeking behaviors, participants mentioned barriers to discussing what they had found online with their medical provider due to embarrassment, concerns that the physician would not want to hear about it, belief that there is no need to bring it up, and forgetting to discuss it (Silver, 2015). These results

demonstrate that health literacy has an influence on health information seeking behaviors, especially for older adults, which may affect how older adults decide to inform themselves about lung cancer screening and obtain screened for lung cancer.

Access and Navigation of the Healthcare System. Barriers exist in the healthcare system that make it difficult for individuals with low health literacy to access, navigate, and maintain their health. Zeliadt and colleagues (2018) reported that healthcare systems have been slow to implement lung cancer screening. Reasons for poor implementation include insufficient infrastructure and a lack of personnel (Iaccarino et al., 2015). There are also economic and resource challenges to implementing lung cancer screening in Federally Qualified Health Centers (Zeliadt et al., 2018). A survey completed in 2014 found that 11 states had no LDCT lung cancer screening centers and screening centers in states with high rates of lung cancer incidence and mortality were limited (Eberth et al., 2014). Charkhchi and colleagues (2017) aimed to examine access to lung cancer screening facilities that are a part of the Lung Cancer Screening Registry, which is the only CMS-approved lung cancer screening registry. As of the end of 2016, there were 2,423 participating lung cancer screening facilities (Charkhchi et al., 2017). However, screening facilities in most states were clustered, which restricts access for people who live outside of these grouped areas. Another study examined the availability of LDCT screening to examine disparities in access to care (Eberth et al., 2014). Eberth and colleagues (2014) found that LDCT screening centers were located in counties with the highest lung cancer incidence and mortality in the Northeast and East North Central states, but many other states had few to no screening centers. The average number of centers per state was four, or 0.3 centers per 100,000 persons aged 55 to 79 years old (Eberth et al., 2014). Slow

implementation of lung cancer screening infrastructure due to associated costs and resource constraints influences patient access to care, demonstrating a potential reason why screening adherence is low.

While low health literacy has been found to effect a wide range of health-related outcomes, there is little or inconsistent evidence on how health literacy affects access to care, though it is often discussed (Berkman et al., 2011; Levy & Janke, 2016; Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012). Health literacy researchers often sample individuals who are already inside the healthcare system, which means we are potentially missing the people we are trying to find: those with low health literacy who experience issues with accessing care (Levy & Janke, 2016). Levy and Janke (2016) acknowledge this issue and created a supplemental survey to the Health and Retirement Study, a longitudinal study of 22,000 individuals 51 years and older, to estimate the relationship between self-reported health literacy and four self-reported access to care measures. Significant differences were reported between individuals with low and adequate health literacy who reported delaying or not obtaining care for any reason, due to cost, and for other reasons (Levy & Janke, 2016). Furthermore, individuals with low health literacy reported delaying or not obtaining care due to reasons such as being too busy to go to the doctor, being afraid of what they would find out, having to wait too long to get care, and not having transportation (Levy & Janke, 2016). Participants with low health literacy were significantly different from participants with adequate health literacy in that they reported difficulty finding a provider and they had no usual source of care (Levy & Janke, 2016). There were no significant differences between the reasons for reporting difficulty finding a provider among the two groups of participants (Levy & Janke, 2016). Individuals with

low health literacy were significantly more likely to delay or not obtain care or to report difficulty finding a provider even after controlling for covariates (Levy & Janke, 2016).

Navigation of the healthcare system is another factor associated with health literacy that may influence screening for lung cancer. Access and utilization of the healthcare system is a reflection of patient navigation skills as well as the complexity and demands of the healthcare system (Paasche-Orlow & Wolf, 2007; Sørensen et al., 2012). Paasche-Orlow and Wolf (2007) discuss the need for schools to include curricula to teach youth practical healthcare navigation skills and increase health literacy as a way to combat the complexity of the healthcare system. Patient navigation programs are a promising strategy to help individuals with low health literacy understand the healthcare system as well as increase patient knowledge of diagnoses, treatment plans, and adherence to care (Martinez-Donate et al., 2013). Current research demonstrates that patient navigation programs improve adherence to cancer screening as well as decrease barriers to care and increase patient satisfaction (Guadagnolo et al., 2011; Percac-Lima et al., 2018; Petereit et al., 2008; Robinson-White, Conroy, Slavish, & Rosenzweig, 2010). A recent randomized controlled trial was conducted to evaluate the impact of a patient navigation program for lung cancer screening (Percac-Lima et al., 2018). Patients randomized to the intervention group worked with a lay patient navigator who completed activities such as interviewing the patient to determine smoking history and screening eligibility, identifying barriers to screening, and empowering patients to discuss the risks and benefits of screening with their healthcare provider (Percac-Lima et al., 2018). Results demonstrated that there were significantly more lung cancer screening tests among high-risk current smokers in the intervention group compared with the control group, demonstrating the success of this patient navigation

program (Percac-Lima et al., 2018). Patient navigation programs help combat navigation issues that individuals with low health literacy may often experience.

Filling the Gap

This literature review provided an overview on the background of lung cancer, highlighting the relationship to cigarette smoking, recent lung cancer statistics, current screening guidelines, shared decision-making, and informed decision-making. Furthermore, this chapter featured relevant published literature on barriers to screening for lung cancer. Many practical barriers for screening exist, such as transportation, cost, and health insurance (Delmerico et al., 2014; Jonnalagadda et al., 2012; Patel et al., 2012). Minimal knowledge and awareness of the risks of lung cancer and the LDCT scan are also barriers prevalent in the research literature (Cardarelli et al., 2017; Simmons et al., 2017; Tod et al., 2008). Emotional barriers, such as fear, anxiety, and avoidance, are additional reasons why people report not screening for lung cancer (Ali et al., 2015; McDonald et al., 2014; Silvestri et al., 2007). Additionally, some research has found high perceived risk can lead to cancer screening avoidance (Ali et al., 2015; Hay et al., 2005; Trask et al., 2001). Despite acknowledging these barriers and creating interventions to reduce them, screening for lung cancer is still considerably low with only 3.9% of an estimated 6.8 million Americans being screening in 2015 (Jemal & Fedewa, 2017).

Research has demonstrated that individuals with low health literacy have poorer health outcomes and are less likely to use preventive services; however, health literacy has not been explored as a factor related to poor lung cancer screening adherence (Baker et al., 2007; Cartwright et al., 2017; Scott et al., 2002; Weiss & Palmer, 2004). This chapter reviewed four domains of health literacy that can influence informed decision-making as

well as lung cancer screening behaviors or screening intentions: patient-provider communication; shame; health information seeking behaviors; and access and navigation of the healthcare system. These domains of health literacy were discussed in intensive interviews with older adult individuals who met current USPSTF lung cancer screening eligibility guidelines. The results of this study led to the creation of a health literacy theoretical model on informed decision-making about lung cancer screening. The following chapter details the methodology of this study and demonstrates how these domains were explored in semi-structured intensive interviews with older adult long-term smokers who are at high risk of developing lung cancer.

Chapter Three: Methodology

Restatement of Purpose

The central research question for this study was “How does health literacy relate to intentions and behaviors to screen for lung cancer?” The purpose of this dissertation was to explore the experiences and perceptions of older adult long-term smokers to determine how health literacy factors relate to intentions and behaviors on lung cancer screening. Informed decision-making, shared decision-making, patient-provider communication, healthcare navigation and access, shame, and health information-seeking behaviors were explored.

Grounded Theory: A Primer

This dissertation used a constructivist grounded theory approach for the collection and analysis of qualitative data, specifically, in-depth, semi-structured intensive interviews. Grounded theory is a methodologically systematic, yet flexible, approach to qualitative research, originally developed by Glaser and Strauss (1967). Grounded theory follows specific guidelines to collect, analyze, and synthesize qualitative data to produce a theory ‘grounded’ in the collected data (Charmaz, 2014; Glaser & Strauss, 1967; Saldana, 2015). Grounded theory is a methodology used to explore an unclear phenomenon or gain a new perspective on a common experience, therefore making it appropriate to use for this dissertation (Stern, 1995).

Glaser and Strauss (1967) developed grounded theory to counter mid-century positivistic notions of the scientific method, which focused on objectivity, generalizability, and reduced research of the human experience to only that which could be quantifiably measured (Charmaz, 2014). Since the gap between inductive qualitative and deductive

quantitative research continued to widen in the 1960s, Glaser and Strauss (1967) proposed a systematic qualitative analysis that could generate theory (Charmaz, 2014). The defining concepts of grounded theory include simultaneous data collection and analysis, creation of analytic codes and categories from collected data, use of the constant comparison method, memo-writing to define categories and specify properties and relationships as well as gaps, and finally advancing theory development (Charmaz, 2014).

Grounded theory studies involve an iterative process of data collection, analysis, further data collection, and further analysis, with general principles, strategies, and heuristic devices that support the collection of qualitative data to develop theoretical analyses in order to generate new theory (Charmaz, 2014). Grounded theory follows inductive logic where the researcher allows what they discover to inform how they articulate and understand the problem. Grounded theory allows researchers to start with their initial concepts believed important to examine, but those ideas may change due to topics participants define as crucial. This means that interview questions in this study developed over time to include newer concepts found throughout the data collection process (Charmaz, 2006).

The constructivist approach to grounded theory uses the same methods conceptualized by Glaser and Strauss (1967) detailed above, but emphasizes that these key practices are flexible and responsive to the collected data (Charmaz, 2014). The constructivist approach to grounded theory also posits that social reality is processual and constructed, therefore it was necessary to take the researcher's background, experiences, and interactions into account as a part of the research reality (Charmaz, 2014). Throughout this study, as part of reflexive practice, the researcher continuously reflected on personal

and professional experiences related to lung cancer (Charmaz, 2014). A detailed grounded theory protocol for this study is provided in the following section.

Data Collection Procedures

This study involved in-depth, semi-structured intensive interviews with human subjects. Prior to recruiting participants or collecting data, all procedures and materials (i.e., consent form, interview guide, and demographics form) were reviewed and approved by the University of Maryland, College Park Institutional Review Board. Detailed study procedures, including participant eligibility and recruitment, sampling methods, human subject protections, interviewing procedures, and analytic procedures are described in the subsequent sections. The completed study timeline can be found in Figure One.

Participant Eligibility. The target population for this study were individuals who met U.S. Preventive Service Task Force lung cancer screening eligibility guidelines (US Preventive Services Task Force, 2013). Participants needed to be between the ages of 55 and 80, be a current smoker or a former smoker who has quit smoking within the past fifteen years as well as have a 30 pack-year smoking history. A 30 pack-year smoking history equates to smoking one pack of cigarettes per day for 30 years or two packs per day for 15 years. Additionally, participants had to have any form of health insurance and a regular physician they have seen in the past two years. Exclusion criteria for this study included individuals who did not speak English or did not meet all U.S. Preventive Service Task Force lung cancer screening eligibility guidelines (US Preventive Services Task Force, 2013).

Purposive Sampling: Participant Recruitment. Purposive sampling in grounded theory is a way to establish sampling criteria and plan how to access data (Charmaz, 2014).

There were specific demographic characteristics that needed to be reflected within the study sample to guide inclusion criteria, such as smoker criteria and age. Sampling for this study included community-based methods such as posting flyers at local medical centers as well as posting on Craigslist to share study information.

Potential participants were contacted by telephone, text, or email to assess eligibility and schedule an intensive interview. A screening form, based on the U.S. Preventive Services Task Force (2013) guidelines, inclusion criteria, and exclusion criteria, was created and used to screen potential participants for eligibility on the telephone (Appendix). The number of potential participants who contacted the researcher were recorded, including how many met, or did not meet, eligibility criteria, per the screening form and of those how many completed interviews (Figure Two). Interview data from an initial sample of five participants ($n=5$) was analyzed, then additional participants were recruited who met the eligibility criteria (Breckenridge, 2009). Interviews continued until theoretical saturation was reached.

Theoretical Saturation. Glaser (2001) defined saturation not as the repetition of patterns seen in data, but the ability to conceptualize comparisons to yield new properties of a pattern until no more properties emerge from the data. There is not a specific number of interviews needed to reach theoretical saturation during a grounded theory study, although typical estimates range between 10 and 20 interviews (Charmaz, 2014; Creswell & Poth, 2018; Mason, 2010). For example, whereas Mason (2010) asserts that a skilled interviewer could produce a significant analysis with 10 interviews, Guest and colleagues (2006) found that 12 interviews were sufficient, and Creswell and Poth (2018) recommend

20 interviews to saturate categories. In this study, sample size and saturation was based on the research objectives and quality of collected data (Mason, 2010).

Theoretical saturation was reached in this study after conducting 12 interviews. All data were defined, checked using the constant comparison analysis, and the relationship and range of variation within and between categories was clearly explained (Charmaz, 2014). Additionally, categories were robust and no new properties for these categories materialized during the data collection process (Glaser & Strauss, 1967; Charmaz, 2014). Decisions about saturation was based on the researcher's judgement and sample size decisions were made based upon a realistic assessment of the study timeline and finances (Wiener, 2007).

Study Benefits and Risks to Participation. There were no direct benefits for participants who decided to be a part of this research study. Indirect benefits included being able to inform future implementation science research on lung cancer screening guidelines, inform public health practice for lung cancer screening interventions, and guide improved policy for clinical and public health professional training on health literacy and health communication. It is the hope of the researcher that, in the future, other people might benefit from the published results of this study.

Potential risks to participants during this study were mitigated by the researcher. Participants may have felt uncomfortable answering a question asked during the interview. To mitigate this risk, the researcher emphasized throughout the recruitment and data collection process that any question could be skipped and that participation was optional. Furthermore, it was expressed that participation could be withdrawn at *any* time without consequence. This was also explicitly stated in the consent form.

Participant Compensation. Participant compensation was based on the time and effort that a participant had to devote to being a part of this study (Williams & Walter, 2015). This study compensated participants with a \$50 Visa gift card as compensation for their participation and travel time. Participants signed and received a copy of the receipt to receive compensation. The receipt book was locked in a personal filing cabinet, which was kept separate from recorded and transcribed interview data.

Informed Consent, Participant Confidentiality, and Data Privacy. Participants enrolled in this study signed an informed consent form before participating in an intensive interview. All informed consent forms were read verbatim to participants as they read along, and the researcher stopped after each page to ask whether participants have any questions. Each participant received a copy of the consent form. The completed forms were kept separate from participant interview data and were stored in a locked office and locked cabinet to minimize potential loss of confidentiality.

Participants were asked to choose a pseudonym to protect their identity. The researcher has used pseudonyms in this dissertation and will use pseudonyms in future presentations, reports, and published findings. Furthermore, demographic data have been presented in aggregated form so deductive disclosure is less likely to occur (Kaiser, 2009; Tolich, 2004). The researcher was the only person who had access to the document connecting each participant to their pseudonym, which was kept on a password protected computer.

Intensive Interview Procedures

This study employed intensive interviewing of study participants, which is a strategy often used by grounded theorists as it is a controlled, yet flexible approach that

allowed the researcher to ask follow-up questions and strategically create new questions during the interviews to gather rich data on an idea or theme that previously had not been brought up (Charmaz, 2014). Intensive interviewing has many key characteristics, such as the use of open-ended questions to obtain detailed responses, the focus on understanding the participants' experiences and perspectives, and the ability to sensitively clarify unanticipated areas of inquiry when needed (Charmaz, 2014). This interview strategy allowed for an in-depth exploration of lung cancer screening with a person who has had relevant experiences to the research question. Each interview was a one-sided conversation lightly guided by the researcher to explore the participants' perspectives and personal experiences with the research topic (Charmaz, 2014). The intensive interviews were also an opportunity for the researcher to build trust with each participant and it was essential to leave participants feeling positive about the interview experience when completing the interview (Charmaz, 2014). This was important because the researcher followed up with participants for member checking.

Twenty-seven individuals responded to community sampling methods through phone, text, or email to participate in this study (Figure Two). The researcher assessed eligibility for 23 individuals using the Study Criteria Form (Appendix) and four individuals did not respond to three follow-up attempts. Of the 23 individuals assessed for eligibility, eight were not eligible for the study due to the following reasons: outside age range ($n=5$); no regular doctor ($n=1$); quit smoking more than 15 years ago ($n=1$); and below 30 pack-years ($n=1$). Fifteen individuals were eligible for the study based on study criteria; three individuals did not participate due to the following reasons: declined because wanted cash compensation ($n=1$); did not respond to scheduling interview after three attempts ($n=1$);

and did not show up to interview ($n=1$). Twelve eligible individuals participated in the study.

Intensive interviews were completed over a period of three weeks starting in January until mid-February (Figure One). Intensive interviews for this study took place in a private location of the participant's choosing in the community. Five interviews (41.7%) were completed in Maryland and seven (58.3%) in the District of Columbia; nine of the 12 interviews (75%) were completed in a private room within a public library and the other three (25%) in a private room at the University of Maryland, School of Public Health.

Prior to starting the interview, eligible participants were asked to review and provide their informed consent (see above for detailed procedures). Then the individual was guided through the intensive interview using the semi-structured interview guide (Appendix). Each interview session was audio-taped and the 12 interviews ranged from approximately 38 minutes to 90 minutes, for a total of 11 hours and 48 minutes. The mean interview time was approximately 58 minutes long. When the interview was completed, the audio recording stopped and participants were asked to complete a paper-based demographics form as well as the Short Test of Functional Health Literacy in Adults (S-TOFHLA) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Participants were then provided a \$50 Visa gift card for compensation to offset the costs associated with travel and time spent traveling to and from the interview as well as time spent with the researcher during the interview. Any new questions about lung cancer screening and the research study were answered after the research was finished. All interviews were transcribed verbatim using the professional transcription company, Datagain. The company completed a nondisclosure agreement with the researcher to ensure confidentiality.

Interview Guide. This study used a semi-structured interview guide to structure intensive interviews with study participants. The interview guide was a flexible tool used to guide participants to discuss pivotal issues about the research topic and elicit the participants' experiences (Charmaz, 2014). Interview questions in this grounded theory study were open-ended and non-judgmental so participants felt open to sharing their stories with the researcher. Questions had an emphasis on learning the participants' experiences, views, and actions as per recommendations by Charmaz (2014). Furthermore, the researcher included encouraging follow-up questions to elicit more detail from each participant, such as "That's interesting, could you tell me more?" versus "Why do you think that?" (Charmaz, 2014). Questions that encouraged elaboration and affirmed participant views and stories were used to best respect the participant and extract more information.

Interview Questions. Interview questions were developed based on the broad health literacy domains of interest: patient-provider communication, access and navigation, shame, and health information-seeking behaviors. The interview guide, included in the Appendix, was pilot tested with two adults that represented the intended sample to determine if questions were easily understood and flowed appropriately. Irrelevant, duplicate, or superficial questions were updated or removed. Additionally, throughout the data collection process, new questions emerged and were added to the interview guide as needed.

Demographics Survey and S-TOFHLA. After the interviews, participants completed a brief demographics form (Appendix) and the Short Test of Functional Health Literacy in Adults (S-TOFHLA). Sociodemographic items, including smoking status,

employment status, marital status, health insurance coverage, date of birth, gender identity, and race/ethnicity, were asked on a paper-based self-administered survey following the in-depth interview.

The S-TOFHLA is a widely used, valid and reliable measure of health literacy that examines both numeracy ($\alpha=0.68$) and reading comprehension ($\alpha=0.97$) (Baker, Williams, Parker, Gazmararian, & Nurss, 1999). Based on the instructions, participants had seven minutes to complete the S-TOFHLA. A timer was used and at seven minutes, the researcher made a note of the question the participant was on instead of telling the participant to stop the survey before completing it. This method was used to reduce shame a participant may feel for not completing the S-TOFHLA. Any questions answered after the seven minutes were not counted in the scoring of the S-TOFHLA. Each participant was scored using a sum of correct answers and participant scores were broken up into three levels: Inadequate (score 0-16); Marginal (score 17-22); and Adequate (score 23-36). Health literacy scores were used to characterize the sample to better understand the relationship between health literacy, intentions to screen for lung cancer, and lung cancer screening behaviors.

Grounded Theory Data Analysis

This study was not conducted to test hypotheses, but to create a theoretical model relevant to lung cancer screening that can help generate hypotheses for future studies. In grounded theory, data collection and data analysis are inextricably linked in an iterative process of initial data collection and analysis that informs subsequent data collection and analysis driven by emerging theoretical categories. The following section describes the constant comparative analysis and how it was used as a framework for the four stages of grounded theory coding during this study.

Constant Comparative Analysis. The study used the constant comparative analysis as a general framework, which was a combination of data collection, coding, and analysis to generate theory based on the data (Conrad, 1993). The method involved coding and organizing data at the same time, with the researcher consistently returning to the data, memoing, coding, comparing data, developing categories, and eventually creating the theory once the categories were saturated (Creswell & Poth, 2018).

Constant comparative analysis allowed the researcher to make comparisons at each analytical step, which started with comparing interviews for similarities and differences that led to sequential comparisons of earlier and later interviews as well as comparing discussions from the member checking process (Charmaz, 2014). The researcher continuously sorted through, analyzed, and coded the raw data, which reinforced the generation of a theory (Kolb, 2012). The researcher avoided assumptions or judgements based on prior knowledge of theories that explain behavior or personal beliefs (Charmaz, 2014). Through reducing personal biases through an open approach and using the constant comparative method, codes, categories, and the final theory were able to clearly emerge (Charmaz, 2014). This methodology was a labor-intensive task that required the researcher to dedicate much time to data collection and analysis (Kolb, 2012).

Coding in Grounded Theory. Qualitative coding in this study was the process of defining what data were about so that analytic interpretations could be made (Charmaz, 2014). Coding allowed the researcher to put labels on sections of data to give meaning to each segment as well as extract and sort data, which was used to make comparisons with other data (Charmaz, 2014). Through coding, comparing data, and memoing, analytical categories started to emerge. In this grounded theory study, data were collected, studied,

compared, and then more data were sought to answer questions and fill gaps, which led to the culmination of a grounded theory (Charmaz, 2014).

During this study, collected data were analyzed according to the four coding stages in grounded theory methodology: 1) open coding, also known as line-by-line, *in vivo*, or initial coding; 2) focused coding; 3) axial coding; and 4) theoretical, or selective, coding. Before coding, recorded interview data were submitted and transcribed by Datagain, a professional transcription company. Recorded interviews were submitted as they were completed and transcribed documents were immediately saved when received. After the transcriptions were received, they were cleaned by the researcher, who listened to each audio recording while reviewing the transcript for mistakes and making corrections throughout the file. This step served the double purpose of ensuring accuracy of the transcription and immersed the researcher in the data prior to beginning analysis. After the data was cleaned, the file was saved on a password protected computer as well as uploaded to NVivo. All qualitative coding for this dissertation was completed with NVivo for Mac, version 12.2.0 (QSR International, n.d.).

Codebook. Grounded theory methodology posits that a codebook should be informed by the collected data from the first few intensive interviews. In this study, five interviews were completed, transcribed, cleaned, and open coded. The open codes, which were very close to the data and often quite idiosyncratic in the use of participants' own words (i.e., *in vivo* codes), were used to develop focused codes that were less specific to an individual participant and could be broadly applied to coding other interviews. The codebook was a working document that remained open to revision throughout the analytic

process. Updates to the codebook were documented in research memos, described in more detail below.

Open Coding. Coding during this study began with open coding, the first phase of coding completed during a grounded theory study. Strauss and Corbin (1991) state that open coding is the breakdown of qualitative data into discrete parts to be closely analyzed and compared for similarities and differences. In grounded theory studies, the goal of open coding is to “remain open to all possible theoretical directions suggested by your interpretations of the data” (Charmaz, 2014, p.114). Open coding was completed so the researcher could search for analytic ideas to pursue in future intensive interviews (Charmaz, 2014). This initial coding method guided the researcher’s learning and shaped the direction of future data collection and analysis throughout the study. It helped the researcher find gaps in the data and gather additional data to fill them, which is an advantage of grounded theory (Charmaz, 2014). Unlike quantitative research, which often applies predetermined codes to data, codes in this study were created and defined based on the meaning participants associate with the data (Charmaz, 2014). This active coding method allowed the researcher to continuously interact with the data.

In line with the recommendations from Charmaz (2014), analysis for this study began with line-by-line coding and creating *in vivo* codes during this initial coding step. Line-by-line coding is a heuristic device and the researcher closely reviewed and interacted with the transcript line-by-line then constructed codes in the participants’ voice. Using the participants’ own words as the codes (*in vivo* coding) allowed the researcher to become immersed in the data by preserving the meaning of the participants’ words and actions (Charmaz, 2014). This is important because the researcher constantly interacted with the

participants; first in the interview, and then again by studying their statements, defining codes in their voice, and refining them as needed (Charmaz, 2014). Glaser (1978) states that this intimate participation in coding obeys the first grounded theory decree: “study your emerging data.” Throughout the open coding process, the researcher memoed before, during, and after coding to reflect on coding decisions, what has been learned, curiosities, potential emerging codes or categories, and next steps (Saldana, 2015).

Focused Coding. For this dissertation, five interviews were completed, transcribed, and open coded before moving on to focused coding. As described previously, the focused codes were used to create a codebook, which was used to code all additional interviews. The codebook was edited as needed throughout the data analysis process to include emerging codes from newer interviews.

During the focused coding process, *in vivo* codes from the open coding stage were distilled into broader codes, known as dimensionalizing concepts (Creswell & Poth, 2018). The researcher closely assessed the initial codes and compared them with the data from each interview to distinguish which had the strongest analytical power (Charmaz, 2014). By comparing the codes created during open coding, a focused code was able to emerge. Focused coding allowed the researcher to organize the data and direct the analysis, which included removing unimportant open codes and creating focused codes with the most theoretical reach and direction (Charmaz, 2014). However, focused coding was not a clear linear process. Later interviews expanded upon open codes that were originally too implicit to initially distinguish. Focused coding was an emergent process where new ideas appeared, which required the need to perform constant comparisons between the data. There was also flexibility in the focused coding process. For example, initial codes could

become a part of the codebook as a new focused code if it emerged in later interviews and was deemed important. The researcher consistently memoed about ideas, comparisons, potential patterns, and decisions made about coding. There were much fewer focused codes than open codes, leading to a solid analysis with developing patterns from the data.

Axial Coding. Axial coding began with the researcher developing larger categories and subcategories (properties and dimensions) based upon the identified focused codes and research memos written in response to open and focused coding. The intention of this coding stage was to develop and connect emergent categories with subcategories; the researcher also began to explain potential causal and intervening conditions during this stage, including the illumination of properties and dimensions of each category (Charmaz, 2014).

Charmaz (2014) discusses how properties are characteristics or attributes of a category and dimensions are components such as the causes, conditions, and consequences. Axial coding helped answer the cause and condition questions such as “when, where, why, who, how” and consequences answer on “what happens” (Strauss, 1998). The researcher created a model to chart the causes, conditions, and consequences of the phenomenon to clarify the emerging ideas and to bring codes and memos to life to determine the direction of the story (Charmaz, 2014; Saldana, 2015).

Memo writing was critical during the axial coding stage and it focused on the codes as well as the categories’ properties and dimensions (Saldana, 2015). Through memoing and the constant comparison analysis, the researcher continually compared cases to each other as well as the experience of each category, until it reached saturation and was fully developed (Creswell & Poth, 2018; Saldana, 2015). Strauss and Corbin (1991) explain that

saturation is reached when no new information appears during coding, which is no new properties, dimensions, conditions, causes, or consequences.

Theoretical Coding. Theoretical coding is the examination of the relationship between categories produced from the data, which leads to the creation of a theoretical framework (Charmaz, 2006). The researcher sorted and diagramed during this stage of coding to refine categories as well as integrate and link them to create theory. Sorting was the process of comparing categories, considering how the order of categories echoed the participants' experiences, how the order fit the logic of the categories, and finally creating the best balance between the studied experience, the created categories, and theory. Diagramming allowed the researcher to have a visual representation of the categories and their relationships (Charmaz, 2014). Diagramming is a recommended process to test potential relationships to see the power, scope, and direction of and between categories (Charmaz, 2014; Clarke, 2005; Corbin & Strauss, 2007).

A core category representing the data and eventual theory emerged to the researcher during axial coding and expanded throughout theoretical coding due to constant comparison analysis, conceptual memoing, sorting, and diagramming. The primary function of a core category in this study was to integrate the theory and ensure that it was dense and saturated (Holton, 2010). The core category continuously emerged in data collection and was connected to other categories and their properties as well (Holton, 2010).

Trustworthiness

Member Checking. Member checking was used in this study as a well-established method for enhancing rigor and validity of qualitative studies. Member checking has been described as a technique that is critical to use to establish trustworthiness in a study and is defined as taking ideas or results back to the research participants to assess their agreement with the study results (Lincoln & Guba, 1985; Charmaz, 2014). The process gave the researcher the opportunity to systematically check if interpretations were correct. Though there are many ways in which member checking can be completed, the researcher performed member checking by discussing the results of this dissertation research with participants individually over the phone (Creswell & Miller, 2000). The theoretical model and final categories were explained to participants ($n=6$) and the researcher inquired about how they related to each participant's experience and whether they were realistic (Charmaz, 2014). This was an opportunity to engage participants to update categories and incorporate participants' comments in the final narrative. The method adds credibility to this study.

Peer Debriefing. Throughout data collection and analysis, peer debriefing was used to further enhance credibility and validity of this grounded theory study. Lincoln and Guba (1985) described peer debriefing as a process of working with a peer who is not engaged in the research project to discuss and explore the findings and researcher's interpretations. The peers, the dissertation committee members and two doctoral candidates with experience in health literacy and qualitative research, were able to probe for the researcher's biases, assess emerging working hypotheses, and develop or test emerging codes, categories, and next steps (Lincoln & Guba, 1985). Additionally, debriefing sessions

helped the researcher with emotions and clarity of mind that could impede judgement or interpretations due to naturalistic inquiry of being a person and qualitative research being a lonely journey (Lincoln & Guba, 1985).

Reflexivity. Reflexive practices, such as reflexive journaling and memoing, were built in throughout this study to increase transparency and reduce potential bias introduced into the study by the researcher's personal and professional experiences. The researcher in this study was a threat to validity because of the researcher's preconceptions and experiences which could introduce bias to the study through decision-making and interpretations (Charmaz, 2014). To negate this bias, the researcher practiced reflexivity by exploring interests, positions, and assumptions and how they influenced this dissertation research (Charmaz, 2014). The effects of bias were minimized in this study because the researcher practiced being continuously aware and demonstrated reflexivity in all stages of the research process (Kolb, 2012). The researcher's reflexive statement was updated throughout the study to include new information that occurred throughout the research process. The researcher also practiced reflexive journaling to document feelings and experiences that occurred throughout this study. Additionally, the researcher expressed reflexivity in peer debriefing meetings as well as meetings with the dissertation committee.

Reflexive Statement. I was raised in a household where my parents were smokers, but they urged me to never start smoking because it was very addicting, and they could not stop. I grew up hating cigarettes, but it was not until I left for college at 18 that I realized how much. When I would visit home, I would get sick after a few hours due to the second and third-hand smoke. I remember my parents trying to smoke only outside while I was home, but it did not help much. In college I learned more about the detriments of smoking,

especially the secondary smoke effects on a child. After growing up with different health problems, I wondered if any of my childhood health issues were connected to my parents smoking habits. This led me to want to work in the field of tobacco to help addicted users quit and to restrict the use of tobacco products through changes in policy.

My mom got sick in early 2011 during the second semester of my Master of Science degree. I had recently started my thesis examining how smoke-free signage could change the smoking behaviors of people attending public parks. After a misdiagnosis in March, we found out in April she had lung cancer. She was diagnosed on the 12th with lung cancer and we learned it had already metastasized to her brain on the 14th. She had her first chemo treatment on my birthday, the 19th of April, had a stroke on the 27th, and died on May 1st. The hardest experience of my life, the loss of my mom still affects me to this day. It guided me to do my PhD, so I could continue my work in tobacco control and start research in cancer prevention and screening for lung cancer.

I understand that I have preconceptions that emanate from my experiences and standpoints, such as class, race, gender, age, and culture. It was important for me to be aware of my preconceptions as I engaged in the analytical research process of collecting data, memoing, and coding, especially because I want smokers to quit using tobacco products and I want them to be screened for lung cancer if they are eligible. I do not want anyone else to be affected the way I was... to lose a partner, mother, sister, or best friend.

Even though I felt this way, throughout the interview process it was like a switch that turned off. Not one person had been screened for lung cancer with the LDCT scan and only one had a doctor mention it as something they should do with their yearly primary care exam. Most of my participants were current smokers still and although these were

things I thought I normally would dislike, I found myself becoming more understanding and empathetic throughout the interviews. When participants shared reasons why they have not been able to quit, I was able to relate that to my personal experiences of my parents smoking habits, especially my dad's smoking habit since we lost my mom. It is difficult for people to quit smoking because they are stressed, anxious, or depressed and smoking helps with those difficult emotions. Many participants even describe smoking as a crutch for those and that better coping mechanisms are needed, but those are difficult to access or learn how to do. The other thing was most participants specifically shared that they want to quit, and have tried to quit, but so far they have been unsuccessful, just like my dad. Although most participants had doctors ask about their smoking habits, they rarely provided the support that people need to quit smoking, whether it be discussing and recommending smoking cessation tools or providing a referral for free or low-cost cessation counseling. I see myself writing an academic paper on interactions with providers about patient smoking behaviors with the goal of improving patient-provider communication about quitting resources and support.

Another piece that emerged during the interview process that I want to be reflexive of is how participants treated or considered me as a trusted source. These people are all different from me, whether it be age, behaviors, or race, but they were comfortable enough to answer my questions and furthermore, share their stories and experiences with me. I was awed when people shared personal aspects of their lives like I was a trusted old friend. I felt incredibly honored when a participant told me that they are normally a private person who does not share much, but that he felt comfortable with me because of how I conducted myself and truly care about what I am doing.

Another special piece I want to reflect on is that most participants did not know much about lung cancer screening and several had never even heard of it, despite all of them being eligible for the screening. The act of talking to me was a way for them to become aware of the screening and led them to want to look up information on it or bring it up to their doctor. One participant even answered that I helped them with making an informed decision to screen for lung cancer because now they know about it and can take steps to learn more about the screening. Earlier in my reflection I discussed wanting people who are eligible for lung cancer screening to be screened so that if they have lung cancer we can catch it at an earlier stage and increase survival rates. The act of conducting this research may lead these participants to make an informed decision to screen for lung cancer and that makes me feel good.

This experience was difficult, time-consuming, stressful, and anxiety-producing at times, yet it was also the best research experience of my life because of the people I got to meet, the stories I learned, and the implications this research has for improved public health. I hope to spend the rest of my life conducting behavioral research focused in health literacy, health communication, cancer prevention and control, and tobacco prevention and control research.

Reliability

There are many ways in which reliability can be enhanced in qualitative research (Silverman, 2013). This study utilized a good-quality recording device for each of the interviews so that transcriptions can be clearly understood and accurate. Furthermore, the researcher stored recorded data carefully as well as saved it to three places before it was transcribed. For this study, the researcher hired a professional transcription company to

accurately transcribe recorded interviews. The researcher requested interviews be transcribed verbatim and include pauses, overlaps, and emotional responses, such as laughing (Creswell & Poth, 2018). When a transcription was complete and received, the researcher saved the file in two places. To enhance reliability, the researcher fully listened to each interview before starting the coding process. The researcher also engaged in peer debriefing to assess the reliability of the codes. The reliability of the study was enhanced interpretive convergence, which was the process of reviewing and updating code names and categories with a peer (Creswell & Poth, 2018).

Audit Trail

An audit trail is a transparent record of the research plan that details what steps were taken and what decisions were made throughout a research project (Robert Wood Johnson Foundation, 2008). The researcher created a digital audit trail through engaging in extensive research memoing for this study. The following section details what memoing is and how it was used in this study to create an audit trail.

Memoing. The researcher engaged in the process of memoing to record emergent ideas and key concepts that occurred to the researcher throughout the study (Appendix). The researcher used memoing as a system to take notes while reading interview transcripts and draft reflective thinking and summarize interviews, all which led to code development. Miles and colleagues (2014) define memos as more than descriptive data summaries written by the researcher, but rather a way to synthesize data into higher level analytic meanings. Memoing was a way for the researcher to create a digital audit trail that becomes a validation strategy for the decisions made by the researcher (Creswell & Poth, 2018). The

researcher's audit trail gives credibility to this study because it allows an auditor to review the steps the researcher took to arrive at their findings.

The researcher prioritized memoing throughout the analytical process and memoed during each analytic session as well as each phase of the research study (Creswell & Poth, 2018). Memoing occurred whenever an idea occurred to the researcher and all other work paused so it could take place (Miles et al., 2014). Memoing was used as a tool to track code and category development, which allowed the researcher to express the emergent categories throughout the analytical process of a grounded theory study as well as define potential codes. Due to the importance of memoing, the researcher kept memos well organized by time, content, data form, and participant (Creswell & Poth, 2018). Additionally, the researcher dated memos and used classifiable headings for organization.

Chapter Four: Results

This chapter provides a thorough description of the 12 study participants, then introduces the health literacy theoretical model on informed decision-making about lung cancer screening, which is grounded in the data collected throughout this study. Each category of the model and the properties of each category are clearly described, using participant quotes as examples and evidence of each property.

Participant Demographics

Participants ($N=12$) had a mean age of 61.9 years (range 55 to 71 years) and the majority used Medicaid (58.3%) or Medicare (41.7%) for health insurance. Most participants were Black (83.3%) and 41.7% of the sample was retired. Gender identity was close to evenly split with seven females (58.3%) and five males (41.7%). Three quarters (75%) of participants were current smokers and three (25%) participants were former smokers. Former smokers had quit smoking for a period of nine, 12, and 36 months. Participants all remarked that they had started smoking very young or in their teens, with ages ranging from 11 to 19 years old. Participant smoking pack-year history ranged from 30 pack-years to 66 pack-years with the mean being approximately 42 years. All 12 participants ($N=12$) have tried to quit smoking in the past. Nine participants (75%) shared barriers to quitting smoking such as stress, anxiety, depression, and family who smoke.

When asked to describe their health, participants stated their health was fair ($n=3$, 25%), fair to good ($n=2$, 16.7%), good ($n=6$, 50%), or very good ($n=1$, 8.3%). Factors influencing perceived health included whether or not participants had a chronic illness (e.g., COPD, HIV, hypertension, diabetes, arthritis, overweight, kidney or liver issues), leading an active lifestyle (e.g., “I walk, I ride my bike”; “I work out a minimum of five

days a week”), eating healthy foods (e.g., “We eat lots of fruits, veggies, salads every day, cook healthy”), and being a current or former smoker (“The worst habit I have is smoking cigarettes”). All 12 participants (100%) reported having a primary care provider they visit on a regular basis, ranging from once a month to every two years, and most had other specialists they saw besides a primary care provider (e.g., urologist, COPD specialist, infectious disease specialist, neurosurgeon, oncologist, cardiologist, liver or kidney specialist, podiatrist, OB-GYN). When participants were asked how likely they are to follow their medical provider’s recommendations, the majority said they would, but some had reservations. There were eight participants (66.7%) who were extremely likely to follow their medical provider’s recommendations; three participants (25%) said they sometimes would, but it would be based on if they feel the same way or on the strength of the provider’s argument and their presented facts; and one participant (8.3%) noted that she does not trust doctors, so she would not trust their recommendations, though she said she would if they said “Go take a screening, go have a screening.” Ten of the 12 participants (83.3%) have screened for any type of cancer besides lung cancer and eight (66.7%) had a family history of cancer. Two participants (16.7%) had experienced a prostate cancer diagnosis. No participants had completed a low-dose computed tomography lung cancer screening, though one participant (8.3%) shared they had a chest x-ray once in an emergency room. Seven participants (58.3%) had never heard of lung cancer screening, one participant (8.3%) received a recommendation to screen, two participants (16.7%) may have seen it on tv or in an email, and two participants (16.7%) said they perhaps heard or seen it, but they did not pay attention because they did not have symptoms or a family history of lung cancer. Two participants (16.7%) did not complete the S-TOFHLA within

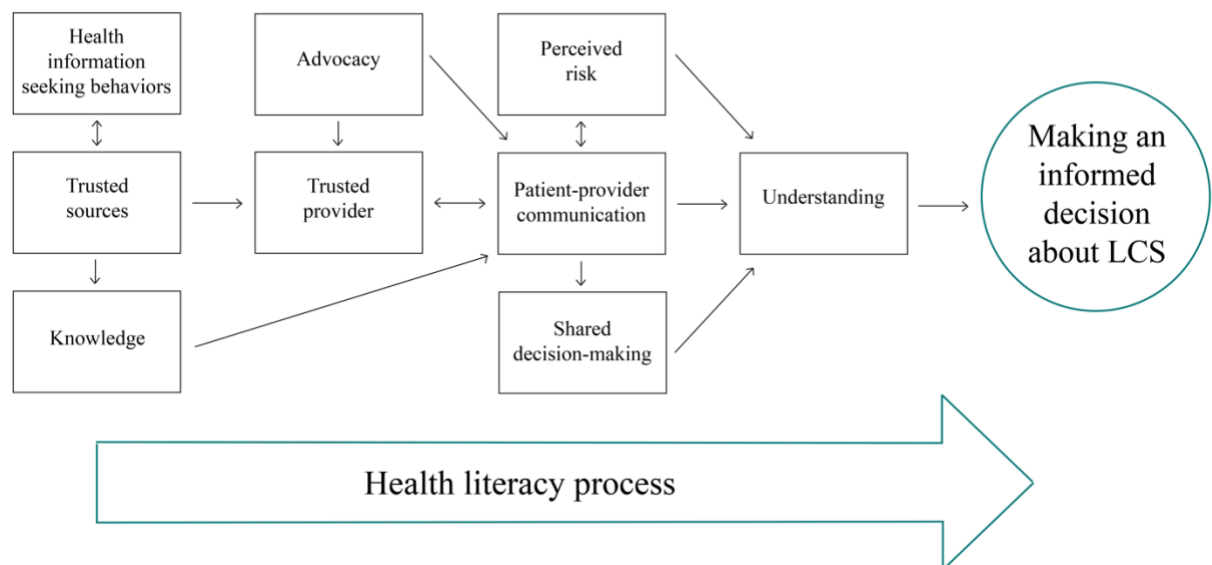
a seven-minute time limit. One participant (8.3%) had marginal functional health literacy level and 11 participants (91.7%) had adequate functional health literacy. The health literacy screener data was used as a description of the sample, and it is important to note that the majority of the sample had adequate health literacy.

Table 5					
<i>Participant Demographics (N=12)</i>					
	<u>Variable</u>	<u>n</u>	<u>%</u>	<u>Mean (SD)</u>	<u>Range</u>
Age		12	100	61.9 (5.36)	55-71
Sex					
	Male	5	41.7	-	-
	Female	7	58.3	-	-
Race/Ethnicity					
	Black	10	83.3	-	-
	White	2	16.7	-	-
Marital Status					
	Married	3	25	-	-
	Divorced	4	33.3	-	-
	Cohabiting	1	8.3	-	-
	Single	3	25	-	-
	Widowed	1	8.3	-	-
Health Insurance*					
	Private Employee	2	16.7	-	-
	Medicaid	7	58.3	-	-
	Medicare	5	41.7	-	-
Employment					
	Employed	4	33.3	-	-
	Retired	5	41.7	-	-
	Other	3	25	-	-
Smoking Status					
	Current Smoker	9	75	-	-
	Former Smoker	3	25	-	-
Mean Pack-Year History		12	100	41.8 (11.1)	30-66
S-TOFHLA – Functional Health Literacy Level					
	Marginal (17-22)	1	8.3	20	20
	Adequate (23-36)	11	91.7	33.9	24-36
Screened for any Cancer besides Lung Cancer					
	Yes	10	83.3	-	-
	No	2	16.7	-	-
*Total does not equal 100%; two participants on Medicaid and Medicare					

Health Literacy Theoretical Model on Informed Decision-Making

Constructivist grounded theory analysis led to the development of a theoretical model (Figure Three) that demonstrates the health literacy process followed by older adult long-term smokers to make an informed decision about screening for lung cancer. The core category of the model (“Making an Informed Decision about Screening for Lung Cancer”) is supported by eight interconnected theoretical categories characterizing how older adult long-term smokers develop an understanding of the need for screening and make a decision about whether or not to screen for lung cancer. These theoretical categories include: Health Information Seeking Behaviors, Trusted Sources, Knowledge, Advocacy, Trusted Provider, Perceived Risk, Patient-Provider Communication, and Shared Decision-Making. Each theoretical category has a number of properties, described in detail below.

Figure 3. Health literacy theoretical model of informed decision-making about lung cancer screening



Core Category: Making an Informed Decision about Lung Cancer Screening

Making an informed decision about lung cancer screening is characterized by eight supporting categories that are Health Information Seeking Behaviors, Trusted Sources,

Knowledge, Trusted Provider, Advocacy, Perceived Risk, Patient-Provider Communication, and Shared Decision-Making. Table six show the properties that make up these theoretical categories.

Table 6	
<i>Theoretical categories and their properties</i>	
<u>Theoretical Category</u>	<u>Category Properties</u>
Health Information Seeking Behaviors	<ul style="list-style-type: none"> - General Health Information Seeking Behaviors - Lung Cancer Screening Seeking Behaviors and Informed Decisions
Trusted Sources	<ul style="list-style-type: none"> - Who and What is Trusted Information - Determine Online Credibility
Knowledge	<ul style="list-style-type: none"> - Lung Cancer Knowledge - Lung Cancer Screening Knowledge
Trusted Provider	<ul style="list-style-type: none"> - Influences of Provider Trust or Distrust - Trusted Recommendations
Advocacy	<ul style="list-style-type: none"> - Expected Traits and Doctor Deal-Breakers - Question Preparation - Questions About Jargon
Perceived Risk	<ul style="list-style-type: none"> - People at Risk for Lung Cancer - Similar Nonsmoker Comparison
Patient-Provider Communication	<ul style="list-style-type: none"> - Reason Not Screened - Provider Communication Training - Providers Inform Decisions to Screen
Shared Decision-Making	<ul style="list-style-type: none"> - Openness to Shared Screening Conversations - Improved Understanding

Throughout the four coding schemes of grounded theory, informed decision-making continuously emerged from the data. Participants were asked how easy or hard would it be for them to make an informed decision about lung cancer screening. Two participants (16.7%) thought it might be hard for some people to make an informed decision. Max shared “I think, um, being misinformed, not having information available

because they got information out there for everybody else, for every other thing except for, um, lung cancer and, and um, the questions you're supposed to ask your doctor when you go." Participants ($n=9$, 75%) said it would easy or extremely easy for them to become informed about lung cancer screening. Jojo believed making an informed decision would be extremely easy due to "all of the information such as what's on here, on the Internet, what you see in paper products, when I say pamphlets, what you hear from the doctor, the doctor's office, the doctor's staff, the doctor's whole aura of what they have, there's a wealth of knowledge out there. And if somebody even thought they had lung cancer, come to the library, look it up. You know what I'm saying? If you can't spell lung, get someone to help you, you know, a staff member in the library to help you look up lung cancer."

Three participants (25%) described what an informed decision means to them. Shirley stated "That means I know exactly what's going to happen, I know who's going to do it and where I got to go, or who's going to pay for it, and – and all that. Uh, how long is it going to take? Um, what are they exactly looking for and if they see anything, what's going to happen then?" Jojo shared that an informed decision is when he understands the evidence about screening for lung cancer and the potential diagnoses. JB gave a comprehensive explanation of an informed decision:

"Okay, an informed decision is something that you've really exercised all of your options, your- your research. You've checked on the procedure. You've checked on the doctors. You've checked on the symptoms, the diagnosis you know cause there could be more than one way to treat something you know um if your doctor's suggesting surgery, but it could actually be done a different way you know or instead of just major surgery, it could be done

laparoscopically, something like that but your doctor's not always gonna tell you that, or uh another professional may not always tell you that. So an informed decision to me is not something that just comes from – the information comes from your doctor. It's the person that actually you need to go and find out these things on your own, and that takes time and patience but to me, that's the informed decision. You get all the information that you need before you make your decision.”

Theoretical Category One: Health Information Seeking Behaviors

There are many ways older adult long-term smokers seek health information related to making an informed decision about lung cancer screening, as shared by study participants. There are two properties of this category, which include General Health Information Seeking Behaviors and Lung Cancer Screening Seeking Behaviors and Informed Decisions. These describe how older adult long-term smokers find health information, how they would find health information on lung cancer screening, and what would lead them to an informed decision.

Property One: General Health Information Seeking Behaviors. Participants ($N=12$, 100%) explained the health information seeking behaviors they use to find health information or learn about a health problem. Eleven participants (91.7%) shared that they would talk to their health provider, demonstrating how older adult long-term smokers rely on their health provider for learning about a health topic or issue. David, the oldest participant in the study at 71 years, shared that he relies on his nurse practitioners or doctor to find health information and he would only use Google as a last resort. Participants ($n=5$, 41.7%) reported that they seek health information from friends and family. Max shared

that he relies on his friends to find health information, “Well, you know, my friends. I mean, you know, we all got different health issues, so, uh, it’s like, if, if you say something, then I say, well, I got that too. So, what do you do to help yourself during the daytime and, uh, you know, that’s informative.”

The internet was the tied with health providers as a way to find health information ($n=11$, 92.7%). Nine of the 11 participants (75%) who use the internet shared that they use Google to find health information, whether it is on their phone or a computer. Rose discussed her process of finding information on Google: “What I do is what comes up, like right there it says, treat, diagnosis, treat your symptoms, and I’ll click on, click on that thing where it says symptoms, and it’ll, you know, to me that’s the -- I don’t know what website they’re using, but it pops up automatically right there. Because I don’t, the other ones, underneath it, I don’t go to those. I’ll go to the one that pops up first.” Three participants (25%) mentioned using WebMD to find online health information and one participant (8.3%) finds health information on Men’s Health. Rez said he liked using WebMD to find health information because “it’s for the layman. It’s not like, it’s not too technical.” JB explained “WebMD is my friend” and she does “most of my research online you know, and then if it’s something that’s specific I’ll wait and see my doctor and ask my doctor about it.” Only one participant (8.3%) used medical apps to find health information. Participants ($n=6$) find health information through more traditional sources, such as going to the library ($n=2$, 16.7%), reading the newspaper or a journal ($n=2$, 16.7%), and TV or radio ($n=2$, 16.7%).

Max discussed the many ways he learns about health information which includes reading, Google, TV, radio, talking to friends or doctors, and his “radar is open for anything

to do with health.” After being diagnosed with prostate cancer, Max used every resource to learn about it. When his surgeon said surgery was the only way to go, Max replied “Bullshit. It got to be some other method. He said no.” From Max’s readings, he knew that was not always true and he picked a different treatment that he was comfortable with, demonstrating how health information seeking behaviors leads to increased knowledge, how advocacy impacts patient-provider communication, and how the process leads to making an informed decision. This is also an illustration of how prior experiences with cancer may inform future actions and decisions about lung cancer screening.

Property Two: Lung Cancer Screening Seeking Behaviors and Informed Decisions. The purpose of this category was to explore how older adult long-term smokers find health information on lung cancer screening, and the health information seeking process that would best help participants make an informed decision about lung cancer screening. Three participants (25%) remarked that they would just go to their doctor to learn about lung cancer screening, but most ($n=9$, 75%) said they would use the internet to look up health information on lung cancer screening to increase their knowledge so they can be prepared for a discussion with their doctor. Dolly shared she would Google first, “then I would know what to ask the physician because I would narrow it down more to my situation. I guess I would find a physician, you know, and um take it from there.” Max said he would get information first, even though he trusts his doctors, and that he does not “care where I get information from; I’m – I trust myself. I’m – I think, um – I didn’t get to be this age being stupid, so like, you got to, you know, get informed.” JB echoed these responses stating “I’d go online first. I really would. That’s usually my first source you know and create my own list of questions or concerns, whatever, then seek out a

professional to do it you know.” One participant (8.3%) stated they would visit a local cancer center and check out any written health information on lung cancer screening to learn about it.

Participants ($n=7$, 58.3%) stated that their doctor would best help them make an informed decision about lung cancer screening. Rose mentioned the best way to become informed would be to talk to a doctor or someone at a cancer institute because they would know more about lung cancer screening. Scout shared the best way to make an informed decision would be to have her doctor duplicate the information she found on the internet. Shirley ($n=1$, 8.3%) stated using the internet to find health information on lung cancer screening would best help her make an informed decision, because her doctor may say she does not need it right now.

Theoretical Category Two: Trusted Sources

Theoretical category two is Trusted Sources, which is composed of two properties characterizing the sources older adult long-term smokers trust and how they evaluate sources of health information to determine their degree of trustworthiness.

Property One: Who and What is Trusted Information. A trusted medical provider was the most cited trusted source, whether it was a primary care physician, nurse practitioner, or a medical specialist ($n=11$, 91.7%). Five participants (41.7%) were very clear that they trust their health provider most, but the other six participants (50%) expressed they also trust their own research. Shirley explained “I trust my doctor too after I trust the – you know, after I find my own information.” Scout shared “I would say um, at this point in my life I have to rely on my general practitioner the most because he coordinates all my body parts. Um, but you know, at my ideas and the strengthening of his

questions and ideas is a lot of times through these blogs on the internet and my own research on the internet.” Two participants (17%) shared they would trust someone who had completed a lung cancer screening. Internet sources like WebMD, public health organizations, or other online sources found via Google were cited as trusted sources to learn about lung cancer screening ($n=7$, 58%). JB shared “I trust WebMD, but I don’t put 100% in to it. You know if I were to speak in terms of percentages, I would say I’d give them like a 70% or something. Okay, yes, I trust them about 70%, but I still need to back up what they say cause I don’t know who’s putting this information on WebMD. Are they medical professionals or are they just individuals who’s getting information from somewhere else and putting it there?” Three participants (25%) reported that they trust health organizations such as the American Lung Association and American Cancer Society. Rez stated that he trusts “sources like the government, like the National Institution of Health. I think um, organizations that have been around like I said for, for a number of years for me would have the most like freight.”

Property Two: Determine Online Credibility. Participants ($n=9$, 75%) described how they determine the credibility of an online source. Four participants (33.3%) shared that they would look at the consistency of information across sources. Malcolm shared he checks “several different sources and the one that seems to have the most comprehensive information is the one I just generally, generally rely on.” Two participants (16.7%) mentioned they know a specific source is credible, in this case WebMD, because the information they used was accurate. Shirley shared “I use [WebMD] so much that – and they turned out to be credible... I don’t just take anybody’s – I mean, some old messed up

website [laughs], so I try to get the good ones that I've, you know, used in the past." This demonstrates that having a trusted source can lead to health information seeking behaviors.

Two participants (16.7%) also mentioned trusting themselves or their intuition to determine if online health information is credible. JB shared "The trust I'm putting mainly in myself and what I'm reading. I have to take that and you know think about it, process it you know and uh this just doesn't sound uh – you know that kind of thing. Participants also identified ($n=2$, 16.7%) that they did not know how to determine source credibility. Patty shared that she had "Never really thought about that. I don't know. How are you supposed to know what's true? I mean, if I Google something, I'm hoping it's true, so, yeah." Dolly expanded on this stating "I would realize that I'm not a doctor, I need to go to a doctor because that's too confusing and too all over the place. Yeah, and I don't know, and you know, I don't know how to narrow it down to my case, my situation." Only one participant (8.3%) mentioned looking at the resources and references listed at the bottom to determine source credibility.

Theoretical Category Three: Knowledge

Theoretical category three, Knowledge, is composed of two properties that characterize what older adult long-term smokers know about lung cancer and lung cancer screening. Property one, Lung Cancer Knowledge, explains what participants knew about lung cancer, such as what it is; the connection between smoking cigarettes, secondhand smoke, and lung cancer; and symptoms of lung cancer. Property two, Lung Cancer Screening Knowledge, focused on knowledge of the lung cancer screening test; who should get a screening and how often; and lung cancer screening benefits and barriers.

Property One: Lung Cancer Knowledge. Three participants (25%) reported they knew nothing about lung cancer and one participant (8.3%) only knew that “it's within your lungs, it's a disease.” Kori shared that she knows very little about it, but she thinks “it's like maybe one of the top five causes of death in, I think it's, and especially in women. I remember hearing something or reading a billboard somewhere that I think it's outranks breast cancer, if I'm not mistaken, if I was thinking for women... I know it's one of like the top three causes of death in people or causes of lung –of cancer in individuals.” Two participants (16.7%), Jojo and Rez, offered definitions of lung cancer, such as “Lung cancer, um, uncontrollable growth of cells in the lungs, is my definition. You know, you have your cells everywhere in your body, but there's a specific part, uh, we're talking the lung, where cells or uh, membranes or whatever it is, uh, they just grow out of control and you just can't control them.”

Five participants (41.7%) stated that lung cancer kills people and three participants (25%) identified that lung cancer as a disease that can also be caused by secondhand smoke. Dolly shared “It kills people who smoke and secondhand smoke... lung cancer is real and it comes from smoking cigarettes.” Malcolm also connected cigarette smoking and lung cancer, stating that “The smoking industry tried to deny it for years saying there was no connection. There is a connection uh, [clears throat] between smoking and cigarettes and, and lu- cancer, lung cancer and other forms of cancer.” Scout believed “there's a survival rate and it's probably gotten better over the years... Healthcare with diagnosis has gotten better... our healthcare system has more diagnostic tools and, and there's better um, cures for things like that for a lot of stuff, cancer.” Participants ($n=5$, 41.7%) reported symptoms

of lung cancer, such as persistent hacking cough, buildup of phlegm, virulent throat discharge, shortness of breath or difficulty breathing, wheezing, chest pain, and arm pain.

Property Two: Lung Cancer Screening Knowledge. Six participants (50%) knew nothing about lung cancer screening and five participants (41.7%) identified that lung cancer screening could be done with an x-ray. Participants ($n=4$, 33.3%) believed that people with a family history of lung cancer should complete a screening. Eight participants (66.7%) stated that smokers should get a lung cancer screening. David mentioned that “if you're an acknowledged smoker or if you're hanging around with somebody and you're subjected to secondhand smoke, I think that, uh, you should like let your, uh, the physician or nurse practitioner know that, and let them make the call, whether it should be part of your, uh, health checkup.” Only one participant (8.3%) mentioned that a former smoker should be screened if they recently quit smoking, illustrating the gap in knowledge about screening guidelines for former smokers. Participants reported how often people should be screened for lung cancer, which included three months ($n=1$, 8.3%), six months ($n=2$, 16.7%), once a year ($n=4$, 33.3%), and every two to three years ($n=1$, 8.3%). Only one participant (8.3%), Scout, mentioned cancer screening guidelines; “It would depend how fast lung cancer, the trajectory of, of someone, you know, how fast it develops. You know, they, they do different, um, schedules like for colon cancer and breast cancer, and they'd have to have a met, matrix or whatever.”

Five participants (41.7%) stated that there is no risk to screening for lung cancer, demonstrating a lack of understanding about cancer screening. Other participants ($n=5$, 41.7%) were unable to think of risks but mentioned things such as pain from the screening, charging too much money for the test, irrational fear of having the disease, and Dolly

explained “they say when you open cancer up, you know, it spread like, you know, so that’s the risk, you know? That’s it.” Jojo was the only participant (8.3%) to state “Inadequate information. Inadequate diagnosis” as risks of lung cancer screening.

Five participants (41.7%) mentioned that knowing the truth about whether you have lung cancer would be a benefit. Early detection was also a benefit stated by nine participants (75%) and many added that the earlier you know, the better you can treat and survive it. Two participants (16.7%) mentioned a benefit would be to quit smoking and that it may be easier to quit after knowing their diagnosis.

Theoretical Category Four: Trusted Provider

Theoretical category four, Trusted Provider, describes two properties. One property focuses on influences of provider trust among older adult long-term smokers and the other on how a trusted provider leads to older adult long-term smokers following their providers’ recommendations offered during a patient-provider communication.

Property One: Influences of Provider Trust or Distrust. Eleven participants (91.7%) reported that they trust their medical provider and gave examples of what characteristics influence their trust. Shirley recently found a new doctor who she trusts: “She even went as far as to go get her boss to come into the room because I – was the first time there and introduced me and discussed some of my issues and, you know, I mean, that made me feel good, like, you know, it means she will go and get a second opinion and, you know, I mean, it’s not just a job it seems like. It seems like she’s concerned about what she does and I like that.”

Two participants (16.7%) distrust their physician. Patty does not trust her new medical providers because they “mostly are on the run, you know, trying to hurry up and

get to the next patient, so they really don't give you that much time to go into detail about what's wrong with you, what you thinking about it, noth-, nothing, none of that” and “every time a doctor comes into the room, he asks me a question, I get to talk then his phone rings, and oh, hold on, I be right back, you know, and it's, no need for me to even start talking no more, I'm not even getting into it, I don't want to do it. I'm finished, I'm going to go.” However, Patty does trust the nurses who care for her in dialysis. Unlike Patty who will trust doctors who practice patience and listening skills, Dolly does not trust any doctor. She explains, “Well, because over the years I’ve seen what doctors have... That’s why they call it ‘practicing’ because that’s what they’re doing [chuckles] so I just don’t trust doctors. I don’t trust doctors at all like that. I don’t think they know what they’re talking about. All that, “My doctor...” stuff is not something I go for. But they do a lot of good, they do a lot of good for people. A lot of people need doctors.”

Property Two: Trusted Recommendations. Participants who trust their providers ($n=9$, 75%) reported that this trust leads them to follow their provider’s recommendations shared during patient-provider communications. Jojo shared he was “100 percent” likely to follow his physician’s recommendations “because I’ve built trust in him. He’s really been there for me.” Eleven participants (91.7%) stated they would follow a provider’s recommendation, but three (25%) explained that it would be due to the strength of the provider’s argument and presented facts. Dolly ($n=1$, 8.3%) was asked if she would follow her doctor’s recommendations given her lack of trust, she replied “Well, if I was... I would follow it if they say, ‘Go take a screening, go have a screening.’ Yeah, I would. I wouldn’t want to, but I would.”

Theoretical Category Five: Advocacy

Advocacy is theoretical category five, which encompasses three properties: 1) identifying traits wanted in a physician and switching physicians if expectations are not met, which leads to provider trust; 2) preparing questions prior to a visit to see their physician; and 3) asking their doctor to explain jargon or complicated health information in a way they can understand. Properties two and three influence patient-provider communication because participants have the ability to advocate for improved communication with their physician to enhance their understanding.

Property One: Expected Traits and Doctor Deal-Breakers. Traits wanted in a physician included good bedside manner, experience, patience, associated with a university, clear communication, respect, spends enough time with patient, knowing the patient's medical history, and not being afraid to touch the patient to examine them. Shirley says the traits she looks for in a good doctor are someone who knows her history, is interested in what she is saying about her health, focuses on her as the most important person in the moment together with her doctor, and works with her to figure out solutions. She also mentioned that she wants a doctor who "reminds you of when it's time for you to have lung cancer screenings, [laughs] you know, and other screenings because, I mean, I don't necessarily know when I'm – according to whoever, when I'm supposed to have one, you know, but I'm realizing now, nobody's ever asked me and I'm 55. I should have had one. I think it's time."

Seven participants (58.3%) reported that they would switch their provider if they did not receive the care they expected to receive and another participant ($n=1$, 8.3%) mentioned advocating to keep their trusted provider when their health insurance changes.

Rez brought up deal-breakers about his relationship with a physician. “If I didn’t have a good rapport with them, um, that would be a deal-breaker and I would find somebody else... If I felt disrespected in any way by my physician [snorts] goodbye... If I have any inkling of, that something just isn’t right, um, that’s a deal breaker for me.” David also brought up that if he does not trust or feel comfortable with a doctor that “I’m out the door” and he is “without a doubt” looking for a new doctor. Two participants (16.7%) discussed when a provider is not willing to touch them and both look for a new doctor when this occurs. Max describes “how do you think I’m going to trust you to operate on me and you didn’t put your hands on me, you know, or didn’t explain what you’re going to do, you know?” Shirley expands on this by saying “I don’t like a doctor that really doesn’t pay any attention to what I’m trying to say, that don’t want to touch me... if I tell you I have something wrong with me somewhere that’s – you don’t want to look at it or whatever the problem is with you, then you’re not my doctor. You’re not a good doctor to me.”

Property Two: Question Preparation. Four participants (33%) discussed writing down questions to ask their doctor and another participant ($n=1$, 8.3%) said she would try to remember to ask questions she thought of before an appointment, but she did not write them down. JB shared that she first uses health information seeking behaviors to “create [her] own list of questions or concerns” then she will seek out a medical professional to answer them. Scout stated, “I have a list of questions I want to bring up, and I listen to him respectfully and ask questions back.”

Property Three: Questions About Jargon. All participants ($N=12$, 100%) shared experiences where they did not understand medical jargon or language that a doctor used. Two participants (16.7%) shared they might ask to clarify information. David shared that

if he sensed what the doctor was saying was important then he would ask, but he does not ask for clarification when he thinks it is really not that important. When asked if Dolly has ever requested her doctor to clarify something, she replied with “I’m sure I did,” but that her doctor using hard to understand language does not bother her. “Well, I want my doctor to be smarter than me. [laughs] So, he better be, or she better be talking over my head. So you know, so that doesn’t bother me.” However, when asked how she feels when she does not understand something, she replied “Like I need to find out what they’re talking about. I would look it up, you know. I would look it up. If they said it then it would be in my mind.” This particular case is interesting as it is unclear if Dolly advocates for herself during interpersonal situations with her health provider, but she may look up information to figure out what the provider said.

Participants ($n=10$, 83.3%) claimed that they felt comfortable, confident, or very confident asking their provider to explain something. Jojo stated “Doc, hold up one second. Break that down to my terminology. Make that, make me understand what you are saying. You know he might use some 23-letter word that I don’t understand what it means. So no, no. Back up. Stop. Let’s, let’s talk at my language.” JB echoed Jojo stating that she experiences hearing something she does not understand regularly: “Every time you go to the doctor’s office you know, but I don’t have a problem telling him, “What does that mean? What did you just say to me? Okay, you just used your terminology. I am not up on the medical jargon, so break it down to elementary for me, doctor. Just tell me what it is. That’s just me. If I don’t understand something, I’m gonna ask you know.” Kori ($n=1$, 8.3%) expressed that she is very confident advocating for herself, but also for her family members.

Given that 91.7% of this sample of participants had adequate health literacy, participants were asked if they think everyone can advocate for themselves by speaking up. JB responded “People don’t like to feel as though their intelligence is being tested or you know made to feel dumb or ignorant or something like that. You know sometimes people don’t wanna ask the question of “what does that mean” out of fear. Uh you know at least that’s the way I look at it. I don’t know.” Jojo further elaborated on the potential experiences of others.

“[They] might not know what to say or the questions to ask. All they know are the symptoms they might have, but they don't know how to actually describe what's going on. They might not have the time or not might not take the time. And some people, fortunately I'm a, as you can tell, an articulate person and I can speak for myself and I can do, you know, pretty much for myself. But there are individuals out there probably that don't – they have a literacy, a literacy problem. You know, they can't read, they can't write, they don't understand. They don't have people in their lives that can tell them, because they're in the same boat, same situation. Um, I, they don't understand. You know. Um, well what happens if? You know, they don't know how to ask that question. You know, some people just, they just don't know. They just don't know. They don't know how to advocate for themselves. Um, they don't know how to speak for themselves. They don't know what questions to ask. Uh, how relevant tho-- or relevant those questions are, in reference to the diagnosis. So you know, they could be ashamed and I think that's a lot, in a lot of cases that's what the situation might be.”

Theoretical Category Six: Perceived Risk

Theoretical category six is Perceived Risk, which encompasses two properties: 1) People at Risk for Lung Cancer; and 2) Similar Nonsmoker Comparison, which is how participants compare their risk for lung cancer to a nonsmoker very similar to them. Both properties demonstrate what older adult long-term smokers understand about risk, which can influence informed decision-making about lung cancer screening.

Property One: People at Risk for Lung Cancer. The majority of participants ($n=9$, 75%) responded that smokers are at the highest risk for lung cancer. Two participants (16.7%) mentioned that lung cancer is heredity, which puts those people at high risk. Malcolm said chronic smokers are at the highest risk as well as “people who have the gene. Some people have the, and, and cancer can also be hereditary. You know, there are people that, that you know, uh, a lot of them, yeah, it just runs in their families, mm-hmm.” Two participants (16.7%) shared that lung cancer could be from secondhand smoke. Kori stated “They do say people, I mean, I don't know how true this is. I've heard that people get, can get lung cancer through secondhand smoke. I find that hard to believe.” Three participants (25%) shared that people who work around or have been exposed to certain chemicals would be at high risk, with two participants (16.7%) mentioning asbestos. Three participants (25%) stated that smokers are at risk for lung cancer, but the people at most risk were “children in the home with cigarette smokers,” “firefighters,” and “family history of cancer.”

Property Two: Similar Nonsmoker Comparison. All participants ($N=12$, 100%) responded that their risk for lung cancer was higher than a nonsmoker similar to them. Six participants (50%) did not give a specific number, but all agreed they had a higher risk

compared to a nonsmoker similar to them. The remaining six participants (50%) offered a percentage to demonstrate their risk compared to a nonsmoker. Jojo shared the highest percentage “Oh my, it's tremendous, tremendously high... 90 percent” followed by Scout “70% higher than a nonsmoker.” Two participants, JB and David, shared they had a 50% higher chance “because of the fact that I’m a smoker, and they’ve never smoked so yeah.” Malcolm guessed saying “I don’t know, 25% maybe? Yeah” and Rez stated “I would guess that I have probably a greater, my odds, the odds of my getting lung cancer are, are 5 or 10% higher than a nonsmoker but not necessarily, um, totally.”

Theoretical Category Seven: Patient-Provider Communication

Patient-Provider Communication is theoretical category seven. This includes three properties: 1) Reason Not Screened; 2) Provider Communication Training; and 3) Providers Inform Decision to Screen. These properties demonstrate the influences patient-provider communication has on participant understand of lung cancer and lead to informed decisions about screening for lung cancer.

Property One: Reason Not Screened. Most participants ($n=8$, 67.7%) reported they had not completed a lung cancer screening because their physician had not asked them to screen or they had never brought it up to their physician themselves. Scout shared “No one’s asked me... It’s not part of the agenda for most general practitioners.... It’s [her former smoker status] certainly in my medical records since we’ve started, um, keeping things online, you know, since we’ve had that presence. So um, I don’t know. It just doesn’t seem to be the kind of thing, um, that doctors put in the agenda for someone.” JB echoed Scout’s response, stating “I’ve never thought about it to be honest with you. I have never thought about it and when I go to the doctor, it’s not something that they say this is what

you should do. They'll send me for EKGs, uh stress tests. They'll do the bloodwork you know coz they'll test my thyroid levels and all of that and – but as far as a lung screening, I don't think my doctor in all of my 55 years has ever asked.”

Two participants (16.7%) were not sure why they had not been screened. Shirley stated, “I don't know and I'm – the next time I go to the doctor, I'm going to find out” and Patty also did not know why she has not screened for lung cancer, and shared that she does not know how to go about doing it. The other two participants (16.7%) introduced the idea of patients bringing up lung cancer screening to their doctor. Rose said, “I don't know, I guess I never brought it up to my doctor and I never thought about it.” Rez expanded on this idea by stating “I think really because I've never asked for it. I think it's, I think, you know, the, a lot of times I think it's incumbent upon people to take sort of responsibility for their health and not be guided by the, by the hand by their physicians.” Only one participant (8.3%) had a provider recommend that she complete a lung cancer screening when she was at her annual wellness exam, but did not help Rose understand why she should complete the screening. Rose did not screen for lung cancer because she did not have any noticeable symptoms, demonstrating the need for patients to become informed.

Property Two: Provider Communication Training. Four participants (33.3%) identified that physicians need health communication training to improve patient understanding of spoken health information about lung cancer screening. David and Scout ($n=2$, 16.7%) explained that physicians may have improved how they speak to patients over the years, but “it needs to be increased even more.” Scout explained that she has seen different provider communication skills based on the “hospital they come from” and

“where they been the intern.” She gives a specific example of a hospital system and said, “I think they just don’t have no – sometimes they just don’t have no social skills.”

Property Three: Providers Inform Decisions to Screen. Participants ($N=12$, 100%) shared that a conversation with their doctor would inform their decision to screen for lung cancer. Scout explained “If I spoke to him how would it affect my decision? Um, it would encourage me to do it. Um, well I think to have the doctor say, ‘We do this, this, and this,’ and then to find that on the internet as being the most common route, and have that duplicated would be, you know, a slam dunk for me.” Max stated that he could bring it up to his doctor at any time and his physician’s recommendation would influence his decision to screen for lung cancer. Even Dolly, who does not trust doctors, shared that a conversation with her doctor would make her more informed. “Well, I hope so because my doctor, he better know what he’s talking, or she better know what she’s talking about in order to, you know, if they’re gonna bring it up then know what you’re talking about.” However, Dolly did say it was not something she could see herself talking to her doctor about in the future because she has stopped smoking, again identifying gaps in understanding about lung cancer screening guidelines for former smokers.

Several ($n=10$, 83.3%) participants stated that a recommendation from their provider would be enough for them to make a decision about screening for lung cancer or increase their consideration of completing the screening test. Rez explained “When, when do I go? Where, where do I go? What time is the appointment? [chuckles] I mean if she’s gonna, if she’s going to suggest it, if she’s going to advise that of me, then oh, I’m there. It wouldn’t be, ‘Well, maybe, maybe not.’” Malcolm clearly illustrated the connection between provider trust and patient-provider communication leading to making an informed

decision. “Oh, if he told me that I should screen for it I would go ahead and do it. ‘Cause I trust him, yeah. I trust his judgment, yeah.” This demonstrates that not all patient-provider communications about lung cancer lead to shared decision-making and patient-provider communication alone, in the form of a recommendation to screen, can lead to understanding and making an informed decision.

Theoretical Category Eight: Shared Decision-Making

Shared Decision-Making is theoretical category eight, and the properties include Openness to Shared Screening Conversations and Improved Understanding. Shared decision-making is a process of patients and health providers working together to make a shared decision using the best available evidence, but it may not occur all the time (Stiggelbout et al., 2012). Specific examples were given to participants to explain shared decision-making, such as an easy-to-understand explanation of the risks and benefits of lung cancer screening and what the screening process looks like before, during, and after.

Property One: Openness to Shared Screening Conversations. Participants ($N=12$, 100%) were all open to having a shared conversation about lung cancer screening with their physician or health provider. Rez said he would be open to discussing lung cancer screening with his provider and he thinks it is “incumbent upon them as... the caretakers of my health to, to be more vigilant perhaps and more aggressive” about recommending lung cancer screening. Furthermore, eight participants (66.7%) said they would most likely discuss lung cancer screening with their provider after discussing it in their interview with the researcher. Jojo stated that it is absolutely something he will bring up with his doctor, “In fact, I’m going to do that, well when I meet with him, what is this? This is February? March, April. I meet with him in April, because I just saw him last month, so I’ll bring that

up to him.” David shared that he was open to it and that “now after having this conversation with you [Laughter] I’m going to, you know, stop in, see my, uh, she’s right down two blocks down here; so I might say that, it—what she thinks about it.”

Property Two: Improved Understanding. All participants ($N=12$, 100%) shared that engaging in the shared decision-making process with their physician, someone from their healthcare system, or even someone from a lung cancer organization would better help them understand lung cancer screening to prepare them to make an informed decision about screening. JB explained he would want to engage in the shared decision-making process, “Well, yeah, because you know you’d have somebody there that’s actually explaining it to you, so long as it was explained in a manner that was easy to understand but yeah, cause doing that takes some of the pressure off, takes some of the worry off if you know what to expect so.”

Participants described that the shared decision-making process would be a helpful way to make it easier to become informed. Rose stated, “I’m assuming that ... the doctor would explain it to me in detail... if it came to that point, when I decided that I do want to get this screening” Scout shared “Oh definitely. I think there’s a huge learning curve with uh, lung cancer. You know, I, I consider myself a fairly intelligent individual and I don’t know um, as we’re going through this interview I don’t know, um, what those steps are. And it’s something I’m going to review afterwards. So, yeah, I think it’d be a great um, a great thing and I can’t believe we’re lacking that.” She also gave an example of how health systems could start engaging patients in a shared decision-making process about lung cancer screening.

“I think in combination with my appointment with my general practitioner once a year for my physical or something, if that could be built into the process where it followed; you know, where you were a smoker and you are identified to be at risk, that you um, that your healthcare system, United Healthcare, Kaiser, be it whatever, you know, assigned some sort of personnel to you to go over your risk factors and, and what you could do to um, uh, find out uh, you know, the screening procedures. I think that would be great.”

Max described that his current doctor includes him in a shared decision-making process where they make joint decisions. “Yeah, I think she’s – I think she, um, makes herself clear on the direction um, which we decide to go. It’s not what she wants, it’s what we decide. That makes me feel good too.” He further explained that a shared decision-making process would be helpful to better understand the information to know where he stands, but also because he wants to agree to it himself and does not want nothing forced on him. “If I made the decision and you make it so, then I’m, then I’m all in.” These statements demonstrate that shared decision-making leads to understanding and making an informed decision to screen for lung cancer.

Chapter Five: Discussion

This study sought to understand the experiences older adult long-term smokers have related to screening for lung cancer. The process of conducting intensive semi-structured interviews with 12 older adult long-term smokers resulted in a wealth of rich data and led to the development of a health literacy theoretical model on informed decision-making about lung cancer screening. The data collected during this grounded theory study also allowed the researcher to identify health literacy barriers and facilitators to lung cancer screening, which will be discussed in a future paper. This chapter provides an overview of study results and theoretical model, presents the strengths and limitations of this study, describes implications for the field of public health, and ends with a brief conclusion.

Overview of Findings

Participants shared how they prefer to find and learn about health information. Almost every participant ($n=11$, 91.7%) reported that they would use the internet to find health information. Only one participant (8.3%) stated they did not trust the internet and would use Google as a last resort. Not all participants ($n=4$, 33.3%) knew how to determine what health information was reliable or trustworthy on the internet. Another participant (8.3%) said WebMD seemed to be credible since she had used it in the past and it seemed to be correct, but she did not explain how she determines if health information is reliable. Four participants (33.3%) shared they would look for similar information on multiple websites, while one (8.3%) participant stated she would examine the references.

Every participant shared they would rely on their health provider, primarily their physician, to find and learn about health information, though the internet came first for most participants. Five participants (41.7%) shared they would rely on family and friends

to learn about health information and four participants (33.3%) reported using either the library, a journal, or newspaper to find health information. Finally, two participants (16.7%) stated they would become informed on a health topic via the tv or radio.

There were two main answers presented when participants were asked how they would learn about lung cancer screening. One was to research it on the internet and the other was to talk to their health provider, most often a physician. Most participants ($n=10$, 83.3%) reported the preference to become informed using their trusted sources, primarily online sources, before speaking to their physician to become informed on lung cancer screening. This percentage is higher in this study than the reported 42.2% of adults who rely on the internet to first learn about a health or medical topic, which may be because the majority of this sample had adequate health literacy ($n=11$, 91.7%) (National Cancer Institute, 2017b). Two participants (16.7%) stated they would just speak to their physician to learn about lung cancer screening. A trusted provider was the most cited trusted source ($n=10$, 83.3%), which is similar to the HINTS data which showed that 70.3% of adults trust a healthcare professional a lot to learn health information about cancer (National Cancer Institute, 2018c). Internet sources like WebMD, public health organizations, or other online sources found via Google were also cited as trusted sources to use to learn about lung cancer screening ($n=7$, 58.3%). Participants also shared they would trust someone who had completed a lung cancer screening ($n=2$, 16.7%).

Knowledge of lung cancer screening was low, which is consistent with the current literature (Cardarelli et al., 2017; Schnoll et al., 2003; Sharma et al., 2018; Simmons et al., 2017; Tod et al., 2008). No participants mentioned the low-dose computed tomography scan as a way to screen for lung cancer, though five participants (41.7%) mentioned x-rays

as a method of screening for lung cancer. HINTS data from 2014 showed that 75.6% of participants had never heard of tests to find lung cancer before the cancer creates noticeable problems, so these data are consistent that most adults do not know lung cancer screening options (National Cancer Institute, 2014).

Although participants knew that smokers should be screened for lung cancer, they did not know any recommended guidelines for lung cancer screening. Four participants (33.3%) believed that people with a family history of lung cancer should screen. This was an interesting finding because health professionals often do not focus on family history of lung cancer since nearly 90% of lung cancer deaths are attributable to smoking, yet research does show that family history of lung cancer gives a two to threefold increased risk for developing the disease (Chen & Kaphingst, 2010). There was only one participant (8.3%) who identified a risk of lung cancer screening, while the majority reported ($n=9$, 75%) the benefit of screening to be early detection.

There were four ways that participants identified how they advocated for themselves, which included preparing questions prior to a visit to see their physician, identifying traits wanted in a physician, switching physicians if expectations are not met, and asking their physician to explain jargon or complicated health information in a way they can understand. Four participants (33.3%) discussed writing down questions to ask their physician and another participant said she would try to remember to ask questions she thought of before an appointment, but she did not write them down. Traits wanted in a physician included bedside manner, experience, patience, associated with a university, clear communication, respect, knowing the patient's medical history, and not being afraid to touch the patient to examine them. Seven participants (58.3%) reported that they would

switch their provider if they did not receive the care they expected to receive and another participant (8.3%) mentioned advocating to keep their trusted provider when their health insurance changes.

All participants ($N=12$, 100%) perceived their risk for developing lung cancer to be higher than a non-smoker similar to them in other ways, but the range of that comparison was wide. Six participants (50%) shared that their risk was much higher, or triple that of a nonsmoker. The other six participants (50%) showed a range of increased perceived risk of 5 or 10% to 90% higher than a non-smoker. When asked who was at the highest risk for lung cancer, the majority reported that smokers are at the highest risk for developing the disease ($n=9$, 75%), demonstrating that participants understand that they have an increased risk for lung cancer compared to a nonsmoker. It is interesting to note that several participants mentioned that this interview discussion made them want to look up information on lung cancer screening or talk to their physician about it, which demonstrates that being aware of their perceived risk may lead to patient-provider communication about lung cancer screening.

The majority of participants reported that they had not screened for lung cancer because their physician had not brought it up or asked them to screen, or they had never brought it up with their physician ($n=8$, 66.7%). Only one participant (8.3%) had a physician who suggested lung cancer screening, but the reason for the screening was not clearly explained. This is consistent with research stating that only an estimated 4.2% of adults have had a conversation with their physician about lung cancer screening (National Cancer Institute, 2017a). Each participant shared that a conversation with their physician would inform their decision to screen for lung cancer and many stated that a

recommendation from their physician would be enough for them to make a decision about screening for lung cancer. However, all 12 participants (100%) shared that engaging in a shared decision-making process would better help them make an informed decision about lung cancer screening as well as make it more likely for them to screen.

Making an informed decision about lung cancer screening emerged as the core category in this study. The previous summary of results gave numerous examples of how participants described the process of how they would become informed to make a decision about lung cancer screening, including which sources they trust the most, how they find health information, and how they advocate for themselves to better understand lung cancer screening, all so they can make an informed decision about screening. There were nine participants (75%) who stated it would be easy for them to become informed about lung cancer screening so they could make a decision about whether they should complete the screening, whereas two participants (16.7%) said it might be hard to make an informed decision. There was one participant (8.3%) who shared that experiencing symptoms would make her want to become more informed and screen, identifying a knowledge gap about screening lead time.

Overview of the Theoretical Model

Data analysis using the four stages of coding in grounded theory and a constant comparison analysis led to the defining of eight categories that make up the health literacy process of informed decision-making about lung cancer screening. The categories of this theoretical model encompass the *Health Information Seeking Behaviors* participants use to develop *Trusted Sources* to increase *Knowledge* on lung cancer screening. The best source

to help participants make an informed decision about lung cancer screening was a *Trusted Provider*.

Advocacy is a category that represents how participants advocate for themselves to develop better patient-provider relationships as well as increase their understanding of lung cancer screening information from their medical providers. Participants discussed how *Shared Decision-Making* about lung cancer screening is preferred, and how *Perceived Risk* is influenced by and influences *Patient-Provider Communication*, all which lead to *Understanding and Making an Informed Decision about Lung Cancer Screening*.

Each category in the theoretical model is a component of health literacy that lead to understanding of lung cancer screening so a person can make an informed decision. The categories within this *Health Literacy Process* also represent multi-level variables at three levels: intrapersonal level – individual skills, behaviors, cognition, values; the interpersonal level – individual skills to interact with health providers, friends, and family; and the health-care system level; demonstrating that an informed decision is not solely based on an individual's skill.

Discussion

This study offers a better understanding of informed decision-making by showing the health literacy process of how older adult long-term smokers become informed about lung cancer screening. Informed decision-making is starting to emerge as a focus in health literacy research. Brach (2019) argues the need for a paradigm shift in healthcare where patients are able to make a proactive informed choice, instead of consenting to medical treatments without full, clear information from a health provider. Brach (2019) also states that patients may not advocate for their own decision-making authority if they expect health

information to be confusing or unclear, but people do want to engage in shared decision-making when the provided information and options are clear. Advocacy is a component of health literacy and a skill that participants in this study demonstrated, which could be attributed to 91.7% of participants having adequate health literacy. Advocacy can improve patient-provider communication because participants are able to select a health provider who meet personal expectations, which leads to having a trusted provider, and participants who advocate for themselves through preparing questions or asking clarifying questions are able to better understand the information their provider shares with them.

Most participants in this study shared that a recommendation from their physician would make them want to screen for lung cancer, but every participant said they would prefer to engage in a shared decision-making process that would make it easier for them to make an informed decision about lung cancer screening. Additionally, most participants explained their preferred sequence to find health information using their own trusted sources to increase their knowledge of lung cancer screening; engage in a conversation with their provider to better understand the information they found; and finally, get a second opinion, ideally one that replicates the information they found. These findings support what Stefanek (2011) states about the need to also measure screening success by the number of patients informed and that there is a need to make the public understand screening options instead of persuading them to screen without being informed.

The United States healthcare system is shifting from a paternalistic model, where patients experience a passive role in their healthcare, to a patient-centered approach focused on active engagement in decision-making (Brody, 1980; Braddock, Edwards, Hasenberg, Laidley, & Levinson, 1999; Epstein, Alper, & Quill, 2004). This active

approach to healthcare is when patients make an informed decision based on the health information they find and discuss with friends, family, or a health provider, where shared decision-making may also occur. Switching to a healthcare model that emphasizes informed decision-making will be difficult as it heavily relies on providers' health literacy and communication skills to make health information easier to understand for all patients as well as reduced difficulty for patients in becoming fully informed on a health topic, such as lung cancer screening.

Although advances have been made, medical providers still fall short of delivering health literate care to everyone using a health literacy universal precautions approach (Liang & Brach, 2017). This shortfall demonstrates the need for greater efforts to increase providers' health literacy and communication skills, which can start with better, earlier, and more consistent education and training. Ali and colleagues (2014) found that physicians in residency programs as well as medical and physician assistant students feel unprepared to help people with low health literacy and were not prepared to communicate with people of limited health literacy skills, demonstrating the need for health literacy and health communication training of healthcare professionals. Mandatory, sustained education while in school and training followed by lifelong continuing education is an opportunity to improve the health literacy and communication skills of healthcare providers. Another option would be for professional schools to require prospective students to demonstrate strong communication skills as part of admittance criteria, then communication skills of admitted students could be reinforced over time.

Participants in this study reported that their providers used jargon and sometimes did not explain things in a way they could understand; however, they were able to ask

questions in an attempt to better understand what their providers were saying. Not all individuals have the health literacy skills needed to engage in patient-provider discussions and since participants identified a trusted provider as the best source to help them make an informed decision about lung cancer screening, it is critical that healthcare providers are trained to communicate clearly so that all patients can fully understand the eligibility, benefits, risks, harms, and procedures of a lung cancer screening test in order to make an informed decision about lung cancer screening.

The need for clinical training in health literacy and health communication is necessary if we are to improve patient-provider communications about lung cancer screening. However, this training will be less impactful if providers have limited awareness and knowledge about current lung cancer screening guidelines using the low-dose computed tomography (LDCT) scan. Although lung cancer screening with LDCT is recommended by the US Preventive Services Task Force (USPSTF) and several other national organizations (Table Four), research shows that less than half of primary care providers are aware that USPSTF recommends LDCT for current and former smokers at high-risk for lung cancer (Raz et al., 2017). No participants in this study had completed a LDCT scan and only one participant was recommended to screen for lung cancer, but the provider did not clearly explain the screening and the participant did not know which screening test was recommended. Research demonstrates that physician understanding of LDCT guidelines is associated with a higher likelihood of discussing lung cancer screening with patients as well as referring patients to a lung cancer screening program that utilizes LDCT (Raz et al., 2017). Given the results of this study, it is critical that medical providers, especially primary care physicians, are knowledgeable of LDCT guidelines so they can

correctly identify clinical scenarios where LDCT is recommended and engage those patients in a shared and informed decision-making process. Furthermore, it is important that guidelines about screening former smokers are clear and known by providers as the results of this study demonstrate that only one participant recognized that former smokers who have recently quit smoking should be screened.

Study Strengths

This study has many strengths. A primary strength of this study is the grounded theory methodology, as it allowed the researcher to develop understanding of the social phenomena of older adult long-term smokers and lung cancer screening without using existing theories or predetermining a *priori* what would be found. The researcher originally sought to explore the experiences and perceptions of older adult long-term smokers to determine how health literacy factors relate to intentions and behaviors on lung cancer screening as well as to better understand the health literacy barriers and facilitators to screening for lung cancer. Although these barriers and facilitators appeared, the core category and main results of this study emerged from the data during the four coding steps of data analysis.

Another strength of the study was the demographic diversity of the participants in this study. There was a diverse representation of males and females, current and former smokers, as well as a range of ages. There was less representation of diverse races/ethnicities, though participants who identify as black and white were represented in the study, and health literacy level based on the Short Test of Functional Health Literacy in Adults was homogenous.

The researcher completed many steps to enhance the reliability of this study, which is another strength. In addition to using a good recording device and carefully storing recorded data in three locations, the researcher fully listened to each interview transcript and made updates to make every transcript as accurate as possible before uploading the file to NVivo for data analysis.

Another strength of this dissertation is that peer debriefing was consistently performed, which enhances the credibility and validity of this grounded theory study. The researcher often met with dissertation committee members to engage in peer debriefing to assess the reliability of focused codes, initiate the axial coding process, and review and improve the final theoretical model after theoretical coding was complete. In addition to meeting with dissertation committee members, the researcher also completed peer debriefing with two doctoral candidates who have experience in health literacy and qualitative research. This process was helpful to probe for any biases, develop and test emerging codes and categories, and review and update the final theoretical model.

Throughout this study the researcher documented every decision made in the research memos document as well as shared experiences, thoughts, feelings, and ideas by consistently writing memos (Appendix). These methods provide an audit trail that gives credibility and validation to the study results as it allows an auditor to examine the steps the researcher took to arrive at the findings of this study. In addition to providing an audit trail to document the decisions made throughout this study, reflexivity was practiced throughout the study to reduce potential biases from the researcher's personal and professional experiences. Reflexive journaling and peer debriefing helped the researcher with emotions and clarity of mind.

Finally, another strength of this study was the inclusion of member checking with participants to determine accuracy of results and the final health literacy theoretical model. Although not all participants responded to contact attempts to discuss the results and perform member checking, this method still enhances the rigor and validity of this study.

Study Limitations

This study does have some limitations. Purposive sample was used to find the initial sample of participants for the study. Due to time and financial limitations, theoretical sampling was not completed during the axial coding stage of data analysis. However, even though the sample size was relatively small, saturation of categories was reached. Future research should be conducted with participants of inadequate health literacy and moderate health literacy to better understand the properties and dimensions of the categories that emerged from the data.

Another limitation is that using the grounded theory methodology produces a very large amount of data, which can make it difficult to present in one dissertation. Although this dissertation presents a final theoretical model grounded in the collected data, there is still much more rich data to write about in future academic papers. Although grounded theory allows for data depth and richness, generalizability is a limitation. However, the goal of qualitative research is not generalizability, but to develop a rich, contextualized understanding of a human experience, in this case informed decision-making about lung cancer screening. Future studies can operationalize and quantitatively test individual categories of the theoretical model as well as the entire theoretical model.

Finally, there is a possibility that study results were influenced by the researcher's emotions, perspectives, and expertise. However, many steps were taken to reduce and avoid biases related to the researcher's subjectivity.

Implications for the Field

The findings from this grounded theory study have several implications for public health research, practice, and policy. This study led to the creation of a health literacy theoretical model of informed decision-making about lung cancer screening. This theoretical model can inform public health practice as it can be used to create a multi-layered lung cancer screening intervention to better understand the health literacy process older adult long-term smokers use to make an informed decision about lung cancer screening. Furthermore, this model is relevant for clinical providers because it demonstrates that although many patients trust their providers and follow their recommendations, patients also want to understand lung cancer screening, so they are prepared to make an informed decision. This theoretical model can be quantitatively tested in future research studies, whether it is to test the entire model or to operationalize particular categories of the model.

The results of this study also have implications for improved policy for clinical and public health professional training on health literacy and health communication. Many participants discussed several doctor dealbreakers related to poor provider communication and how their doctors used jargon and did not always explain things in ways they could understand. Healthcare providers need to be trained how to communicate clearly and provide neutral explanations, meaning that they need to present the benefits and risks of lung cancer screening. Although this group of participants shared how they can advocate

for themselves, they also made it clear that not every patient knows how to advocate the opportunity to develop understanding and engage in decision-making.

Furthermore, the results of this study demonstrate the need for required provider training on lung cancer screening guidelines recommended by national organizations, such as the US Preventive Services Task Force. None of the participants in this study had been screened for lung cancer using the LDCT scan, no participants knew about the LDCT scan, and although participants shared that long-term current smokers should be screened for lung cancer, only one participant mentioned the need to screen former smokers who have recently quit smoking. Given that participants in this study identified their medical provider as the best trusted source to help them make an informed decision about lung cancer screening, clinical providers need annual training on cancer screening guidelines to become knowledgeable on current recommendations.

Finally, the results of this study can inform implementation science research on lung cancer screening guidelines. The results provide new information about the ways in which health literacy is related to informed decision-making about lung cancer screening.

Conclusion

Lung cancer screening using a low-dose computed tomography scan can better identify lung cancer at an earlier stage in older adult long-term smokers, which can improve lung cancer survival rates. Although current research has examined barriers and facilitators of lung cancer screening, there is limited research on the process of informed decision-making about lung cancer screening among older adult long-term smokers.

This study has shown that informed decision-making about lung cancer screening is a health literacy process that involves a range of activities or actions that older adult

long-term smokers complete to understand lung cancer screening and make an informed decision. This process of informed decision-making is relevant for older adult long-term smokers with adequate health literacy and can be tested in the future with individuals of lower health literacy. By understanding the process of informed decision-making about lung cancer screening, which is affected by multi-level variables, we can better address the gaps in older adult long-term smokers' understanding and enhance the informed decision-making process about lung cancer screening.

Appendices

Figures

Figure 1. Dissertation timeline

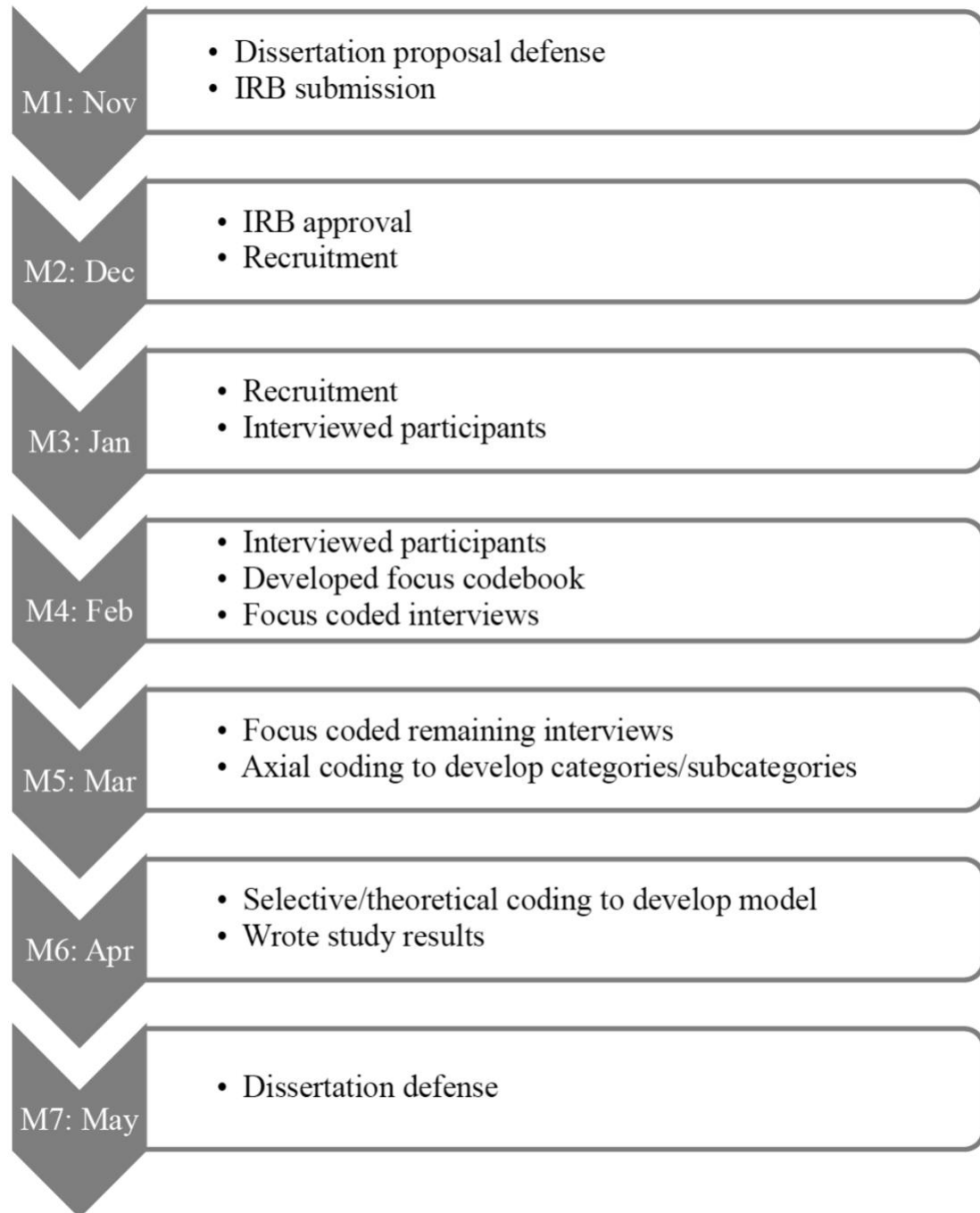


Figure 2. Consort diagram

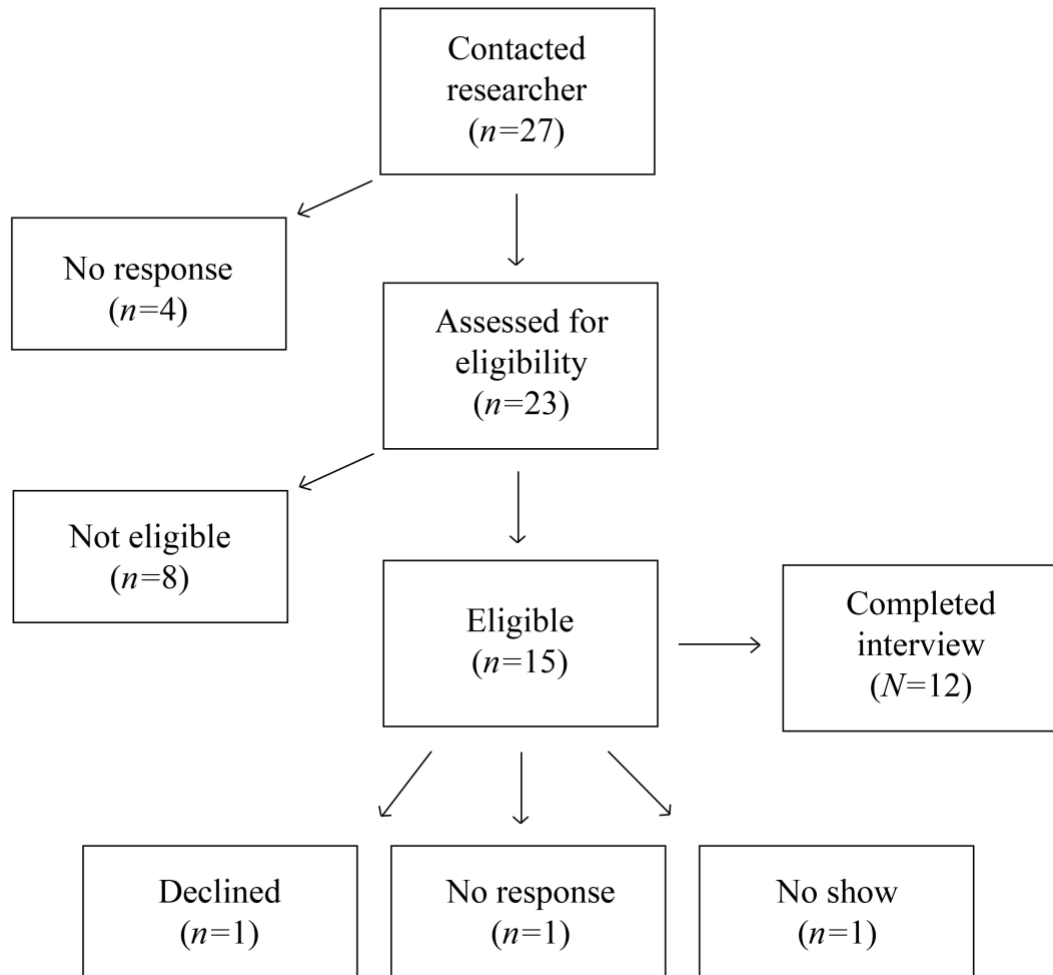
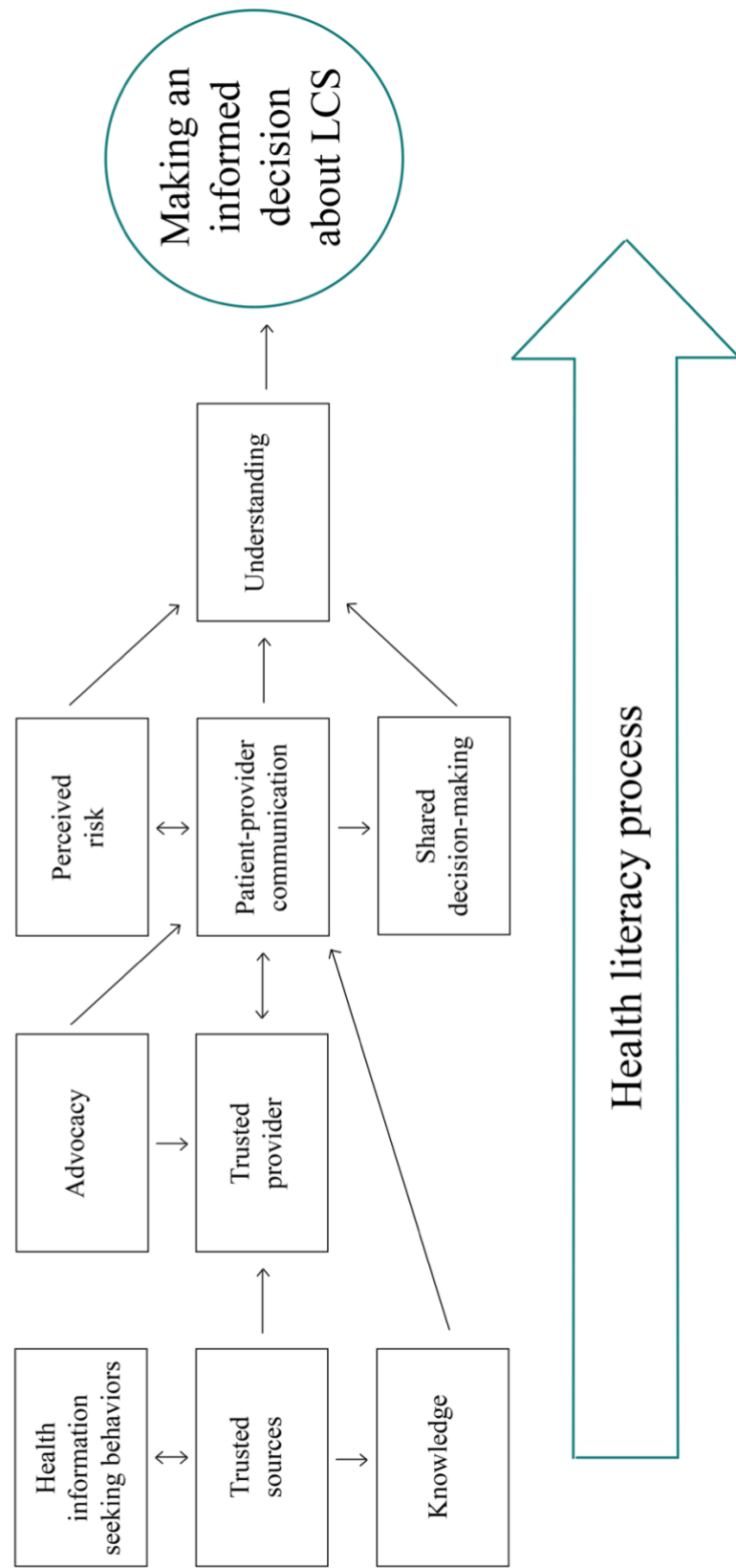


Figure 3. Health literacy theoretical model of informed decision-making about lung cancer screening



Tables

Table 1	
<i>Healthy People 2020 Related Objectives for Health Communication and Health Information Technology (HC/HIT)</i>	
<u>HC/HIT-1: Improve the health literacy of the population</u>	
HC/HIT-1.1	Increase the proportion of persons who report their health care provider always gave them easy-to-understand instructions about what to do to take care of their illness or health condition
HC/HIT-1.2	Increase the proportion of persons who report their health care provider always asked them to describe how they will follow the instructions
HC/HIT-1.3	Increase the proportion of persons who report their health care providers' office always offered help in filling out a form
<u>HC/HIT-2: Increase the proportion of persons who report that their health care providers have satisfactory communication skills</u>	
HC/HIT-2.1	Increase the proportion of persons who report that their health care providers always listened carefully to them
HC/HIT-2.2	Increase the proportion of persons who report that their health care providers always explained things so they could understand them
HC/HIT-2.3	Increase the proportion of persons who report that their health care providers always showed respect for what they had to say
HC/HIT-2.4	Increase the proportion of persons who report that their health care providers always spent enough time with them
<u>HC/HIT-3: Increase the proportion of persons who report that their health care providers always involved them in decisions about their health care as much as they wanted</u>	
<u>HC/HIT-4: (Developmental) Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health</u>	

Table 2	
<i>Key Terms and Acronyms</i>	
<u>Word/Acronym</u>	<u>Definition</u>
Open coding	Open coding is a process of coding an interview transcript line-by-line to create codes in the participant's voice (Raz et al., 2017).
<i>In vivo</i> codes	The use of participant phrases or words to create open codes. The process allows researchers to become immersed in the data by preserving the meaning of the participants' words and actions (Charmaz, 2014).
Focused coding	Focused coding is a process where the researcher uses <i>in vivo</i> codes from the open coding stage and turns participant specific codes into broader codes, known as dimensionalizing concepts (Charmaz, 2014).
Axial coding	Axial coding is the process of developing categories and subcategories from concepts that emerged in focused coding (Charmaz, 2014).
Theoretical coding	Theoretical coding is the examination of the relationship between categories produced from the data, which leads to the creation of a theoretical framework (Charmaz, 2006).
Audit trail	An audit trail is used to enhance the rigor and transparency of qualitative research. It is a process used to track methodological and theoretical decisions made throughout the research process (Bowen, 2009).
Health literacy	Health literacy occurs when a society provides accurate health information and services that people can easily find, understand, and use to inform their decisions and actions (Healthy People 2020 Secretary Advisory Committee, 2017).
Low-dose computed tomography (LDCT) scan	Computed tomography (CT) scanning uses special x-ray equipment to produce several detailed pictures, or scans, inside the body. Low-dose computed tomography (LDCT) uses less ionizing radiation than a regular LDCT scan (Radiologyinfo, n.d.; National Cancer Institute, 2013).

Member checking	The presentation of results back to research participants to assess agreement with the researchers' interpretations and findings. The process allows researchers to systematically check their data and results (Charmaz, 2014).
Memo writing or memoing	A process to record emergent ideas and key concepts that occur to the researcher throughout the qualitative research phase of a study (Creswell & Poth, 2018).
Older adults	Older adults in this study are considered to be 55-80 years old, based on USPSTF eligibility guidelines (US Preventive Services Task Force, 2013).
Reflexivity	A process where researchers explore how their interests, positions, and assumptions can influence their research (Charmaz, 2014). A researcher can minimize the effects of bias through being continuously aware and practice reflexivity in all stages of the research process (Kolb, 2012).
United States Preventive Services Task Force (USPSTF) guidelines for lung cancer screening	<ul style="list-style-type: none"> - Adult is between 55 to 80 years old - Adult has 30 pack-year smoking history - Adult currently smokes or has quit smoking in the past 15 years (US Preventive Services Task Force, 2013).
Patient-provider communication	Patient-provider communication includes verbal and nonverbal interactions that form the basis for patient-provider relationships (Lee et al., 2002). Strong patient-provider communication can help patients of all literacy levels better understand medical information as well as allow for better provider identification of patient needs, perceptions, and expectations (Fong et al., 2006).
Health information seeking behavior	How individuals seek information on their health, illnesses and risks, and preventive health behaviors (Jacobs et al., 2017; Lambert & Loiselle, 2007; Mills & Todorova, 2016).
Shared decision-making	A process where both patients and physicians share information, express treatment preferences and agree on a treatment plan (American College of Obstetricians and Gynecologists, 2014; Charles et al., 1999; Peek et al., 2009).
Stigma	The occurrence of stereotypes, negative labels, status loss, and discrimination in a situation where power is exercised (Hatzenbuehler et al., 2013).

Table 3	
<i>Cancer Stages and Explanations</i>	
<u>Stage</u>	<u>Stage Explanation</u>
Stage 0	Abnormal cells are present, but they have not spread to nearby tissue. These cells are also called carcinoma in situ (CIS). CIS is not cancer, but it may develop into cancer (National Cancer Institute, 2015).
Stage I, II, III	Cancer is present in any of these stages. The higher the stage, the larger the cancer tumor, and the more it has spread to nearby tissues. Stage I cancer is localized, meaning it is limited to the place where it started. Stage II and III cancer may be regional, meaning it has spread to nearby lymph nodes, tissues, or organs (National Cancer Institute, 2015).
Stage IV	Cancer has spread to distant parts of the body. This stage is sometimes called distant (National Cancer Institute, 2015).

Table 4	
<i>Lung Cancer Screening Guidelines</i>	
<u>Organization</u>	<u>Eligibility Criteria and Recommendations</u>
American Academy of Family Practice (American Academy of Family Physicians, 2018a)	<ul style="list-style-type: none"> Evidence is insufficient to recommend for or against screening for lung cancer with low-dose computed tomography in persons at high risk for lung cancer based on age and smoking history.
American Association of Thoracic Surgery (Jaklitsch et al., 2012)	<ul style="list-style-type: none"> Age 55 to 79 years with a 30 pack-year history of smoking. Long-term lung cancer survivors should have annual low-dose computed tomography to detect second primary lung cancer until the age of 79 years. Age 50 years with a 20 pack-year history if there is an additional cumulative risk of developing lung cancer of 5% or greater over the following 5 years.
American Cancer Society (Wender et al., 2013)	<ul style="list-style-type: none"> Are aged 55 to 74 years and in fairly good health Currently smoke or have quit within the past 15 years Have at least a 30-pack-year smoking history
American College of Chest Physicians (R. S. Wiener et al., 2015)	<ul style="list-style-type: none"> Age 55 to 74 years with ≥ 30 pack-year smoking history Either continue to smoke or have quit within the past 15 years, without severe comorbidities that limit life expectancy.
American Lung Association (American Lung Association, 2017b)	<ul style="list-style-type: none"> Age 55 to 74 years with ≥ 30 pack-year smoking history and no history of lung cancer
American Society of Chest Physicians and American Society of Clinical Oncology (Bach et al., 2012)	<ul style="list-style-type: none"> Age 55 to 74 years with ≥ 30 pack-year smoking history and either continue to smoke or have quit within the past 15 years.
National Comprehensive Cancer Network (Bach et al., 2012)	<ul style="list-style-type: none"> Age 55 to 74 years with ≥ 30 pack-year smoking history and smoking cessation < 15 years. Age ≥ 50 years and ≥ 20 pack-year smoking history and one additional risk factor (other than secondhand smoke).

U.S. Preventive Services Taskforce (US Preventive Services Task Force, 2013)

- 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.

Table 5					
<i>Participant Demographics (N=12)</i>					
	<u>Variable</u>	<u>n</u>	<u>%</u>	<u>Mean (SD)</u>	<u>Range</u>
Age		12	100	61.9 (5.36)	55-71
Sex					
	Male	5	41.7	-	-
	Female	7	58.3	-	-
Race/Ethnicity					
	Black	10	83.3	-	-
	White	2	16.7	-	-
Marital Status					
	Married	3	25	-	-
	Divorced	4	33.3	-	-
	Cohabiting	1	8.3	-	-
	Single	3	25	-	-
	Widowed	1	8.3	-	-
Health Insurance*					
	Private Employee	2	16.7	-	-
	Medicaid	7	58.3	-	-
	Medicare	5	41.7	-	-
Employment					
	Employed	4	33.3	-	-
	Retired	5	41.7	-	-
	Other	3	25	-	-
Smoking Status					
	Current Smoker	9	75	-	-
	Former Smoker	3	25	-	-
Mean Pack-Year History		12	100	41.8 (11.1)	30-66
S-TOFHLA – Functional Health Literacy Level					
	Marginal (17-22)	1	8.3	20	20
	Adequate (23-36)	11	91.7	33.9	24-36
Screened for any Cancer besides Lung Cancer					
	Yes	10	83.3	-	-
	No	2	16.7	-	-
*Total does not equal 100%; two participants on Medicaid and Medicare					

Table 6	
<i>Theoretical categories and their properties</i>	
<u>Theoretical Category</u>	<u>Category Properties</u>
Health Information Seeking Behaviors	<ul style="list-style-type: none"> - General Health Information Seeking Behaviors - Lung Cancer Screening Seeking Behaviors and Informed Decisions
Trusted Sources	<ul style="list-style-type: none"> - Who and What is Trusted Information - Determine Online Credibility
Knowledge	<ul style="list-style-type: none"> - Lung Cancer Knowledge - Lung Cancer Screening Knowledge
Trusted Provider	<ul style="list-style-type: none"> - Influences of Provider Trust or Distrust - Trusted Recommendations
Advocacy	<ul style="list-style-type: none"> - Expected Traits and Doctor Deal-Breakers - Question Preparation - Questions About Jargon
Perceived Risk	<ul style="list-style-type: none"> - People at Risk for Lung Cancer - Similar Nonsmoker Comparison
Patient-Provider Communication	<ul style="list-style-type: none"> - Reason Not Screened - Provider Communication Training - Providers Inform Decisions to Screen
Shared Decision-Making	<ul style="list-style-type: none"> - Openness to Shared Screening Conversations - Improved Understanding

IRB Approval Letter



UNIVERSITY OF
MARYLAND

INSTITUTIONAL REVIEW BOARD

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

DATE: December 19, 2018

TO: Heather Platter, MS
FROM: University of Maryland College Park (UMCP) IRB

PROJECT TITLE: [1350283-1] Identifying and Understanding Health Literacy Barriers to Screening for Lung Cancer among Older Adult Long-Term Smokers: A Grounded Theory Study

REFERENCE #:

SUBMISSION TYPE: New Project

ACTION: APPROVED

APPROVAL DATE: December 19, 2018

EXPIRATION DATE: December 18, 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 December 18, 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.

Study Criteria Form



SCHOOL OF
PUBLIC HEALTH

Health Literacy and Lung Cancer Screening Study Criteria Form	
How old are you in years? <i>(If not between 55 to 80 years, thank them for their time)</i>	_____ Years Old
Do you currently smoke cigarettes? <i>(Skip the next question if person currently smokes)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you ever smoked cigarettes? <i>(If no, thank them for their time)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
How many years, total, have you smoked? <i>(Even if person has quit smoking.)</i>	_____ Years
What is/was the average number of packs you smoke(d) per day?	_____ Packs Per Day
If you have quit, how long many years has it been since you quit? <i>(If more than 15 years, thank them for their time)</i>	_____ Years
Do you have health insurance? <i>(If no, thank them for their time)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Do you have a regular doctor? <i>(If no, thank them for their time)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Have you seen your regular doctor in the past two years? <i>(If no, thank them for their time)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No
Are you fluent in English? <i>(If no, thank them for their time)</i>	<input type="checkbox"/> Yes <input type="checkbox"/> No

Informed Consent Form



Initials: _____ Date: _____

Institutional Review Board

irb@umd.edu

**CONSENT TO PARTICIPATE:
HEALTH LITERACY AND LUNG CANCER SCREENING**

Project Title	Identifying and Understanding Health Literacy Barriers to Screening for Lung Cancer among Older Adult Long-Term Smokers: A Grounded Theory Study
Purpose of the Study	This research is being conducted by Heather Platter, MS, PhD Candidate at the University of Maryland, College Park. You are invited to participate in this research project because your perspectives, intentions, and experiences about screening for lung cancer are important. The purpose of this research project is to explore the barriers or problems that current or former long-term smokers may experience or have experienced in relation to screening for lung cancer.
Procedures	<p>The procedures are one-on-one interviews with the principal investigator, Heather Platter. The interview will last about an hour and a half (90 minutes). Interviews will be recorded. No identifiable information will be collected.</p> <p>Here are a few examples of questions you will be asked:</p> <ol style="list-style-type: none"> 1. Could you tell me about your history with smoking cigarettes? 2. What kind of experiences have you had with cancer and screening for cancer? 3. What do you think would help increase screening for lung cancer among older adult long-term smokers?
Potential Risks and Discomforts	<p>There are no known risks involved in this project. However,</p> <ol style="list-style-type: none"> 1. Please know that your participation is optional. It is completely your choice whether or not to participate, and whatever you decide to do will never affect the health services you receive from your health provider or the relationship you have with any medical organization. 2. Please know that you are always welcome to skip a question and you can ask questions about the study at any time. If you want to stop participating in the study at any time, you can stop without any penalty to you.
Potential Benefits	There are no direct benefits to being part of this study. However, the results of this study may benefit other people through improved understanding of what barriers people face to screening for lung cancer.



Initials: _____ Date: _____

Institutional Review Board

301-405-0678 irb@umd.edu

Confidentiality	<p>Any potential loss of confidentiality will be minimized by meeting with you in a quiet, private location. In addition, all data will be stored in a locked office, locked cabinet, and password-protected computer. Your real name will never be connected with what you said during this research study. You will be asked to use a pseudonym, or fake name, for the study.</p> <p>Only I will have access to the information (data) that you share today. If I write a report about this research project, your identity will be protected to the maximum extent possible.</p>
Compensation	<p>You will receive a \$50 Visa or Mastercard gift for your participation today for your participation today. Your name and address will be collected to receive compensation.</p>
Right to Withdraw and Questions	<p>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</p> <p>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report an injury related to the research, please contact the investigator:</p> <p>Heather Platter, MS, PhD Candidate 4200 Valley Dr., office 1242U, College Park, MD 20742 E-mail: hplatter@umd.edu Telephone: 301-314-1921 (Office); 443-354-8571 (Cell)</p>
Participant Rights	<p>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</p> <p>University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: irb@umd.edu Telephone: 301-405-0678</p> <p>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</p>



Initials: _____ Date: _____

Institutional Review Board

1204 Marie Mount Hall • 7814 Regents Drive • College Park, MD 20742 • 301-405-4212 • irb@umd.edu

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	

Interview Guide

Health Literacy and Lung Cancer Screening Semi-Structured Interview Guide

Note to interviewer [not recorded]: Please have the participant select a pseudonym.

Introduction [not recorded]: Thank you so much for joining me today. My name is Heather Platter and I'm a PhD candidate at the University of Maryland, College Park in the School of Public Health, Department of Behavioral and Community Health. This interview today is to hear about your experiences and thoughts about screening for lung cancer. I want to understand what barriers, problems, or roadblocks you may have experienced with lung cancer screening. This may include your visits to and talks with healthcare providers such as your doctor, difficulties you may have had with getting or using the healthcare system, and where and how you find health information.

This conversation will be recorded to make sure I do not miss anything you say. Please understand, there are no "right" or "wrong" answers to any of the questions I will ask today. After we finish talking, I will see what you and other participants in this study have experienced with screening for lung cancer to potentially improve peoples' experience with screening.

When sharing the information that we discuss today, I will protect your confidentiality so your real name will never be connected with anything you said. You can choose a "fake name" or pseudonym for us to use. What name would you like to use? [Fill in below and use throughout interview.]

Are there any questions so far? [Pause any answer any questions.]

Okay, thanks. [Pass out consent form.]

So, because this is a research study, I want to make sure you are completely informed about what kinds of things we will be talking about today and what will happen with the information you share. It is totally up to you whether you want to participate in this discussion today. Let's start our time together by reviewing this form I have. We are going to read it together to make sure we get any questions answered. [Read consent form verbatim, stopping to answer any questions after each page. If anyone declines participation, politely escort them out of room. Collect all forms before proceeding.]

[Begin audio recording.]

Okay, now that we've gotten all of our questions answered and have signed our forms, let's get started. Today's date is _____ and this is an interview with _____
[pseudonym].

Introduction

1. Thank you again for spending some time with me today. Let's start by talking a little bit about you. How would you describe your health?
2. Could you tell me about your history with smoking cigarettes?
 - a. Prompts:
 - i. When did you start smoking cigarettes?
 - ii. How long have you smoked cigarettes?
 - iii. Why did you quit/not quit smoking cigarettes?
3. What do you know about lung cancer?
 - a. Prompts:
 - i. Who do you think gets lung cancer?
 - ii. Who is at high risk for lung cancer?
 - iii. Do you know someone who has or had lung cancer?
4. What do you know about lung cancer screening?
 - a. Prompts:
 - i. Who do you think should be screened for lung cancer?
 - ii. How often do you think someone should be screened for lung cancer?
 - iii. What are the benefits or risks to lung cancer screening?
5. What experiences have you had with cancer and screening for cancer?
 - a. Prompts:
 - i. How often have you been screened for cancer?
 - ii. Do you have a family history of cancer?
 - iii. Have you ever gotten a medical recommendation to screen for cancer?
6. Have you ever been screened for lung cancer?
 - a. If yes follow-up: Can you share that experience?
 - b. Prompts:
 - i. Was your screening in the past year?
 - ii. How did you make your decision to screen for lung cancer?
 - c. If no follow-up: Why have you not screened for lung cancer?

Patient-Provider Communication

I appreciate you sharing that with me. It really helps me to understand your smoking history and experiences with screening for cancer. I'd like us now to talk about interactions with your doctors.

7. Who are the types of doctors you see on a regular basis?
 - a. Prompts:

- i. Under what circumstances do you go to the doctor?
 - ii. How often do you go to the doctor?
 - iii. What kind of doctors do you see?
- 8. What have your experiences been with your main doctor, often called a primary care doctor?
 - a. Prompts:
 - i. Show respect for what you have to say?
 - ii. Listen carefully to you?
 - iii. Spend enough time with you?
 - iv. Explain things in a way you can understand?
- 9. How would you describe your relationship with your doctor?
 - a. Prompts:
 - a. Do you feel comfortable talking with your doctor and do you trust your doctor's recommendations?
 - b. How likely are you to follow your doctor's recommendations?
- 10. Has your doctor ever asked about your smoking history?
 - a. If yes follow-up: Please tell me about that experience
 - i. Did your doctor assess your risk for lung cancer and discuss screening with you?
 - ii. Did your doctor advise you to quit smoking?
 - b. If no follow-up: Okay.
 - i. Have you tried to talk with your doctor about any health questions or concerns related to smoking?
 - ii. What are your thoughts about your doctor asking you about your smoking history and risk for lung cancer?
- 11. Has your doctor ever recommended you for lung cancer screening?
 - a. If yes prompts:
 - i. Please tell me about that experience.
 - ii. Did your doctor explain the screening test in a way that is easy to understand?
 - iii. Did your doctor give you a referral to a specialist?
 - 1. Was it easy for you to see a specialist?
 - iv. Were you given any written documents to taken home with you?
 - 1. Were the documents easy to understand?
 - b. If no prompts:
 - i. Is this something you would want to talk to your doctor or someone else about? Who?
- 12. If you spoke to your doctor about lung cancer screening, how would the conversation affect your decision to screen for lung cancer?

- a. Follow-up: If the conversation would not help you with your decision, what type of information on lung cancer screening would you prefer?
- b. What if it was written information on lung cancer screening you got from your doctor instead of a conversation?

Stigma/Shame

Thank you for sharing that with me. Now I'm going to ask some other questions about your conversations with your doctor.

- 13. Doctors may use unfamiliar language to describe health problems, and sometimes people have trouble understanding what their doctors say. Have you had an experience when you did not understand a word or phrase your doctor used?
 - a. Prompts:
 - i. Were you able to ask what the word or phrase meant?
 - ii. What happened when you asked? / Why not?
 - iii. How often would you say your doctor uses language that is hard to understand?
- 14. Medical terms, words, or phrases are often difficult to understand. How do you feel when you don't understand something your doctor says?
- 15. Medical forms in a doctor's office and in hospitals can be complex and hard to understand. What do you do when you have to fill out a medical form?
 - a. Follow-up: How do you feel when you're not sure how to complete the form?
- 16. How easy or hard is it for you to read and understand medical information?
 - a. Follow-up: How does this affect learning about lung cancer screening?
- 17. Do you ever ask someone to help you when you don't understand a medical term?
 - a. If no prompt: Would you ever ask someone to help you when you don't understand a medical term?
 - b. Follow-up: How do you feel about asking your doctor to explain words in a way that is easier to understand?
- 18. How easy or hard is it for you to make an informed decision about screening for lung cancer with the information available to you?

Health Information Seeking Behaviors

Thank you for telling me that. Now we are going to talk about how you like to find and learn about health information, such as lung cancer screening.

- 19. Who do you like to talk with to learn about a health issue or problem?
 - a. Prompts: Where do you like to go to learn about a health issue or problem?
 - a. Follow-up: What or who do you rely on most to learn about a health problem?

- 20. Where do you find health information about lung cancer screening?
 - a. Prompt: Internet search? Library? Friends or family? Doctor?
- 21. Where, if anywhere, have you heard about lung cancer screening?
- 22. [If participant has heard about lung cancer screening] How did you respond to hearing about lung cancer screening?
 - a. Follow-ups:
 - i. Did that advertisement make you look up additional information or make you want to discuss it with your doctor?
 - ii. Did you discuss it with your doctor or someone else (who)?
- 23. When you think about who or what you rely on for learning about lung cancer screening, which sources do you trust the most?
- 24. Which source would best help you to make an informed decision about screening for lung cancer?

Access and Navigation of the Healthcare System

Thank you for sharing how you get your health information with me. Now we're going to discuss how you get to or use the healthcare system.

- 25. How hard is it for you to get to your medical appointments?
- 26. Can you tell me about your experiences making medical appointments?
 - a. Prompts:
 - i. What has helped you make and keep your medical appointments?
 - ii. What has made it hard for you to make or keep your medical appointments?
 - b. Follow-up: Have you tried to make an appointment to screen for lung cancer? If so, what was your experience?
- 27. Have you ever delayed getting medical care when you felt sick because you thought doctors might treat you differently because you were/are a smoker?
- 28. Does anyone help you get healthcare?
 - a. Prompts:
 - i. Who goes to medical appointments with you?
 - ii. Who explains things that are confusing to you?
 - iii. Who helps you with medical decisions?
- 29. Would you be more willing to screen for lung cancer if someone helped you fully understand the screening benefits and risks, explained the screening process, and answered all of your questions?

- a. Follow-up: What if someone scheduled the screening for you and provided reminders about the screening?

Wrap-up

Thanks for sharing all of that with me. It's really helpful to hear about your thoughts and experiences. We're going to wrap up now.

30. What would you say are the most important reasons people don't get screened for lung cancer?
31. What do you automatically think about when you hear the word cancer?
32. Do you have any fears related to screening for lung cancer?
 - a. Follow-up: Could you share those fears with me?
33. How do you feel when people say that smokers are responsible for getting lung cancer?
 - a. Follow-up: Do you think you would feel guilty if you were diagnosed with lung cancer?
34. Compared to other people your same age who have never smoked, what do you think your risk is for lung cancer?
35. Would your family or friends be supportive of you screening for lung cancer?
36. What do you think would most help increase screening for lung cancer among older adult long-term smokers?
37. Thank you so much for sharing all of that. Is there anything else you'd like to add about what we've discussed today or anything else?
38. I've asked you a lot of questions today. Do you have any questions for me?

Thank you very much for talking with me today. After I meet with other participants, I will look at the themes of what people have said. If it's okay with you, I will get back in touch with you so you can hear the results. You can also get in touch with me through the phone number or email listed on your copy of the study consent form. The last thing for us to do today is for you to complete a short survey.

[End Recording]

Final Interview Instructions

1. Have participant complete S-TOFHLA and demographics form
2. Provide participant with compensation and have them sign the receipt
3. Upload audio recording as soon as possible. Do not delete it from your device until it has been transcribed.

Demographics Survey

Health Literacy and Lung Cancer Screening Participant Demographics Form

Are you a current or former cigarette smoker?

- ☐ Current smoker
- ☐ Former smoker

Are you currently employed or retired?

- ☐ Retired
- ☐ Employed
- ☐ Other (please specify) _____

What is your marital status?

- ☐ Married
- ☐ Widowed
- ☐ Cohabiting
- ☐ Single
- ☐ Divorced

What type of health insurance do you have?

- ☐ Private employer sponsored
- ☐ Private individual plan
- ☐ Medicaid
- ☐ Medicare
- ☐ Other (please specify) _____

What is your date of birth? ____/____/____

What is your current gender identity?

- ☐ Woman
- ☐ Man
- ☐ Transgender Woman
- ☐ Transgender Man
- ☐ Other (please specify) _____
- ☐ Prefer not to answer

What is your race/ethnicity? (check all that apply)

- ☐ African American or Black
- ☐ Asian
- ☐ Hispanic or Latino
- ☐ Native American (American Indian) or Alaskan Native
- ☐ White
- ☐ Other (please specify) _____
- ☐ Prefer not to answer

Study Codebook

Health Literacy Barriers to Screening for Lung Cancer among Older Adult Long-term Smokers				
Qualitative Codebook				
Focused Code	Definition	When to use code	When not to use	Example
Advocacy	Any way a participant advocates or sticks up for them self and their health	When a participant mentions advocating for them self, or someone advocating for them, or reasons why people have difficulty advocating for them self or their health		"Anyone can advocate for themselves if they so choose to. But like I said, a lot of people won't and don't because they want to get in and out, they've got other things that are more important to them as opposed to me. It's, my health care is very important to me."
Best informed decision source	The source or sources a participant mentions that would help to make informed decision to screen for lung cancer	When a participant mentions the source(s) that would help them make best informed decision to screen for lung cancer		"Well I think to have the doctor say, "We do this, and this," and then to find that on the internet as being the most common route, and have that duplicated would be, you know, a slam dunk for me."
Causes of Lung Cancer	Any reason why someone would get lung cancer	When participant mentions reasons lung cancer occurs		"a chronic condition that's uh, that's caused by perhaps a number of factors aside from just smoking. Um, I'm thinking, um, pollution. I, I, I would tend to think that heredity might have a, a, play a part in making you more susceptible to um, uh, getting lung cancer."
Clinicians need HL and HC communication training	Clinicians need health literacy and health communication training to improve interactions/communication with patients	When participants mention clinicians should have health literacy or health communication training		H: Do you think that's something that they should be trained on? Scout: Oh yeah. And I think they definitely have done that in the last 50 years or something; that's been a concern. Um. But you know, there's, it needs to be increased even more, yeah.
Delayed Medical Care	Has delayed medical care for any reason, including because they were/are a smoker	When a participant mentions they have delayed medical care for any reason		"can I say possibly? But uh, I mean yeah, there's, I mean I, I've had the kind of um... I've had that sort of um, mm, that sort of, like sort of apprehension to reveal that I'm a smoker. But I don't think that it's, it's impacted me enough to, to make me not seek medical attention..."
Determine credibility online	How participant determines if health information is credible online	When a participant discusses how they determine online health information is credible or trustworthy		"Well, I think I would go through a couple of them [websites]"
Difficulty Medical Apts	Whether or not it is difficult to get to and keeping medical appointments and why	When a participant discusses difficulty getting to medical appointments, keeping medical apts, and why		"And that, to me, that to me... I don't miss appointments. I mean, there's no excuse for me missing those, missing those appointments and that's why. I mean, if I have to travel very far it's like, "Oh, well maybe I can go next week or next month." [chuckles] you know, and you put it off."
Doctor Dealbreakers	Any reason why a participant would stop seeing a doctor or change doctors; also could include what they look for in a doctor	When a participant mentions something that would make them change doctors or a reason why they would stop seeing a certain doctor; also what they look for in a doctor		"If, if I felt disrespected in any way by my physician... [snorts] goodbye."
Doctor risk assessment + LC screening conversation	Whether a doctor has assessed participant risk for developing lung cancer and discussed lung cancer screening with participant	When a participant mentions if their doctor has talked to them (or not) about their risk for lung cancer and screening for lung cancer	that focus on being open (or not) to having this conversation with doctor	"And of course there, she chides me about, you know, quitting. Um, but she's never said, "Have you ever had, have you ever been screened for lung cancer?"
Doctor trust	Any situations where trusting a doctor is discussed	When a participant mentions if they trust or do not trust their doctor		"Would you say that you trust your primary care doctor, for example? Rez: Oh yeah. That's absolute."
Doctor types	Types of doctors participant sees	When a participant mentions the types of doctors they see		"I have a cardiologist. I have a general practitioner. I have um, and then I've seen other specialists this year but those are the main doctors that I have."

LC screening conversation	Participant is open or has openness to discuss their risk for lung cancer and screening with their doctor	When a participant shares if they would want to discuss their risk for lung cancer and screening with their doctor		"she's definitely aware of my use. Um, I'm thinking that, you know, it might be, it might be a good idea... to um, to, it, for her to be a, a little more encouraging to pursue um, and actually you've got me thinking about it."
LCS in consciousness	Participant mentions wanting to learn more about lung cancer screening or screen for lung cancer due to doing the interview	When a participant mentions wanting to learn more about lung cancer screening or screen for lung cancer due to doing the interview		"I mean I've never really thought about having, being screened for lung cancer, um, or, or getting lung cancer screening. But I'm taking that, I mean it's now in my, in my consciousness."
Learn about health issue	Who or where participant likes to learn about health issues or health information	When a participant discusses who or where they like to learn about health information or a health issue		"I like to Google... and you know, and I like to... And then I decide uh, between the things that are brought up first, which things are advertisements and which, you know, are relevant topics to pursue."
Learn about lung cancer screening	Where or from who participant would go to learn about lung cancer screening or lung cancer	When a participant discusses how they would learn about lung cancer and lung cancer screening		"just Googling 'lung cancer screening.' Uh, the American Pulmonary Institute or whatever it's called, uh, Heart and Lung"
Lung Cancer Knowledge	Any information the participant knows about lung cancer	When participant mentions what they know (or do not know) about lung cancer	Does not include information known/not known about screening for lung cancer	"I would assume that uh, cancer is, is uh, is cells multiplying so that means that there are cells that are mutating, lung cells that are mutating within the uh, within the lung... and that's what causes the cancer."
Lung Cancer Screening Fears	Any fears related to screening for lung cancer	When a participant discusses fears they have (or don't) or fears people in general may have about screening; includes fear of screening results		"I think the, I think like saying, like I'm saying not knowing exactly what the process is about, of what happens during a screening, um, [clears throat] because I, I mean I'm thinking it's, it's a chest x-ray. I mean, that's nothing."
Lung Cancer Screening Knowledge	Any information the participant knows about lung cancer screening	When participant mentions what they know (or do not know) about lung cancer screening		"Well, I'm, uh, this is, this is once again I don't know anything really. I mean, once again I'm just going to be guessing. I'm thinking that uh, lung cancer screening would, would have to be x-raying of the lungs, um, to, to, uh, try and uh, identify humn, abnormalities in the physical makeup of the lung."
Lung Cancer Symptoms	Any potential symptoms of lung cancer	When a participant mentions potential symptoms of lung cancer, whether they are correct or not		"I don't know, I mean I'm thinking like from what, from what I know like a shortness of breath, cough, um, are, are sort of, sort of the symptoms."
Medical forms	How participant fills out medical forms, ease or difficulty, how they feel, what they do with something they do not understand	When a participant discusses how they fill out medical forms, what helps them, difficulty they have with them, whether they ask questions or look up information		"I'll fill in what I feel comfortable filling in and then go back and do the harder things later if, if I don't feel like going from one step to the other."
Doctor medical rec to screen for LC	Doctor medical recommendation to screen for lung cancer	When a participant discusses what and how a doctor would say about screening for lung cancer to influence decision to screen	Do not include other reasons why people would screen	"There wouldn't, there would be nothing that would stop me...because if I was, if, if my doctor had suggested to me or advised me or [chuckles] required of me to have a lung cancer screening [clears throat] it would be because."
Most common cancers	Cancers that appear to be the most common	When participant mentions specific cancers that they believe are most common		"All of them, all, all of the like breast cancer for example, you hear, there's a, there's a lot of press...about breast cancer, so uh, I, I would tend to think that that's pretty pervasive. Um, I, I would tend to think uh, there seems to be a big push on uh, colon cancer, um, being a, a real issue. Um, leukemia"
Participant risk for lung cancer	Participant risk for lung cancer compared to a nonsmoker	When a participant discusses risk of developing lung cancer compared to a nonsmoker, whether they believe there is a bigger, same, or lesser risk		"the odds of my getting lung cancer are, are 5 or 10% higher than a nonsmoker but not necessarily, um, totally."

People at Risk for Lung Cancer	Any person at risk for getting lung cancer	When participant mentions certain people at risk for getting lung cancer or explains who gets lung cancer		"Well, I would tend to think that it's, it's somebody who, who, who smokes... Who smokes [chuckles], first."
Personal cancer screening experiences	Screening for any type of cancer	When participant mentions screening for any type of cancer (lung, breast, prostate, cervical, colon)		"a yearly mammogram, um, colonoscopies."
Prepares questions for Dr Visit	When a participant prepares questions to ask doctor	When participant mentions writing down questions or remembering questions to ask doctor, being prepared for doc visit		"Um, I have a list of questions I want to bring up, um, and I listen to him respectfully and ask questions back. Um, he does a good job of recording uh, what I have to say. So, it works."
Questions about jargon	Participant is comfortable (or not) and has ability to ask doctor to explain what they meant about a word, phrase, or any health information	When a participant discusses if they are comfortable or able to ask doctors to clarify jargon		"I mean, I'm not gonna have those fly over my head without, you know, it being, getting sinking in."
Quit Attempts	Attempt to quit smoking cigarettes whether successful or not; also includes other people's experiences about quitting	Any time a quit attempt is discussed or quit attempt was successful		"Yeah, you know, I changed from... I started like with menthols and then I went to regular and you know, I went to light. And um, and a lot of that's been found to be, be BS, you know, those different. You're still getting a ton of nicotine. But um, and then I would try and stop for periods of days and weeks and months. And you know, some things were successful um, you, you know, like I didn't smoke during the, the um, my pregnancies. But um, you know, I always restarted and kept going."
Read-understand medical information	Ability to read and understand written health/medical information, whether this would affect learning about lung cancer screening and if it would affect their ability to learn about LCS	When a participant discusses how easy or hard it is for them to read and understand written health/medical information		"reading like medical information like for instance, the, the uh, like the um... Like the um, description of a, of a, of a medication, um, it, for me it can be daunting because there's nobody that I can necessarily ask if I... If I come across a word that I don't understand or a phrase or a, a condition or something, a description that I don't know of, there's nobody for me to, to ask and I have to go to another source to, to, to find it sort of on my own."
Reason has not screened for lung cancer	Explanation of why participant has not screened for lung cancer	When participant explains why they have not screened for lung cancer		"I think really because I've never asked for it. I think it's, I think, you know, the, a lot of times I think it's incumbent upon people to take sort of responsibility for their health and not be guided by the, by the hand by their physicians. Now, my doctor, my primary care doctor knows that I smoke."
Reasons for not screening for LC	Any reason why someone would not or has not screened for lung cancer	When a participant discusses reasons why people do not get screened for lung cancer		"I wonder if they, if maybe they're just not aware [clears throat] that it's an option that they can take advantage of. Excuse me [clears throat]. Um, I think that's, that's probably the greatest."
Reasons to screen for lung cancer	Any reason a participant says that would influence them to screen for lung cancer	When a participant discusses a reason that would influence them to screen for lung cancer	Do not include medical recommendation to screen from doctor	"Something uh, chronic to happen, uh, some condition that's suddenly going to like sort of slap me and wake me up, um, and, and say, 'Well, this is it. You've got a choice now.'" Um, so I think... But I think it's, it, it would be, it, it would be my... Something, if, if I was, if the, if my doctor was to hear something or, or, or like detect a symptom, or if I was to detect a symptom, um, I would definitely be asking..."
Screening Benefits	Any benefits associated with screening for lung cancer	When participant mentions benefits associated with screening for lung cancer		"Oh, oh, the benefits, I mean I don't... I can't think of any risks offhand, but I think of course the benefits are knowing, I mean, to, to think of cancer developing and not being aware of it early enough so that it could possibly be treated in whatever ways that it's, it's treated, um, that's the greatest benefit."
Screening Risks	Any risks associated with screening for lung cancer	When participant mentions risks associated with screening for lung cancer, even if they say there are no risks		"And the risk, they say when you open cancer up, you know, it spread like, you know, so that's the risk, you know? That's it."

Shared decision making	Engagement in the shared decision making process, whether by a doctor or someone else, to explain benefits and risks of screening, screening process, and answered questions	When a participant responds if shared decision making process would make them more willing to screen for lung cancer		"Without any um, sort of alarm bells going out she suggested that I do this, and she said, "Well, I'm gonna have Frank come in and explain to you. He's with the American Lung Institute," or something like that, "and he's gonna explain to you what's going to happen," that would be, I think, uh... Yeah, I would, um, that would be a big help. I could see that as being very beneficial and, and, and helping to um, induce me [chuckles] to do it."
Smoker responsibility for lung cancer	Response to statement "How do you feel when people say that smokers are responsible for getting lung cancer?"	When a participant responds to how they feel or what they think about the statement of smokers being responsible for lung cancer		"What? Wait a minute. Smokers are responsible. I don't know. I guess, you know, I guess they're right. I don't know, because, I don't know. I don't know how you get lung cancer, so I can't answer that question. You know."
Smoking Age of Initiation	The age of when participant started smoking	When participant states age they started smoking		"I didn't smoke regularly until maybe I was maybe about 21 or 22. I think like about, I was maybe about 19 when I first picked up a cigarette and actually like puffed on it and then uh, but around 21 or 22 I started smoking on a regular basis."
Smoking behavior conversation with doctor	Any conversation with doctor about smoking history, smoking behaviors, quitting information	When a participant mentions if their doctor has talked to them about their smoking history or smoking behaviors		"And of course there, she chides me about, you know, quitting. Um, but she's never said, "Have you ever had, have you ever been screened for lung cancer?"
Smoking History	Participant history or experience with smoking cigarettes	When a participant discusses history with smoking	Do not include stigma or keeping it secret or feeling ashamed as a smoker	"And um, my father smoked, my husband smoked, and um, and so I think I just picked it up just to be cool, you know, just TV, you know, and actors when they were sitting around, you know. And I thought it was cool, so, and peer pressure, school, you know, you know. Um, all my friends were smoking."
Smoking Stigma	Feelings about or ashamed of smoking, feelings about if they were treated differently (medical or not) since they were a smoker, or whether they think doctors would treat people	When a participant discusses hiding smoking behavior, feeling embarrassed or ashamed of smoking	Do not include smoking history	"many years I kind of kept it secret. I didn't um, it was like I, I didn't admit to myself I was a smoker. I was ashamed of it. So, maybe that's part of the problem"
Support from family/friends	Any type of support from family and friends in regards to screening for lung cancer	When a participant discusses if family or friend would support screening for lung cancer		"Oh yeah. I think that that's, that's definitely having, having that um, would be uh, would, would make a difference. I think it, it, it would definitely, having that kind of encouragement would, you know, is, is very helpful."
Support getting healthcare	Any form of support from friends and family to get healthcare, like medical decision making, attending appointments, driving participant to appointment, defining or clarifying information from doctor	When a participant discusses any support (or none) they receive from friends and family to get healthcare		"And if I had to take somebody with me I probably wouldn't go [chuckles], you know? I'd go by myself. I would. I'd go by myself. That's what I'd do, you know?"
Tech-back	How a participant would feel about a provider checking understanding by using a method like teach-back	When a participant discusses providers checking health information knowledge with them and how they feel about that		"Well yeah. I mean, it, yeah, I, I think that I... That, that would be problematic for me if, if she would say, "Now explain to me what I just explained to you." That I, I would not appreciate that."
Traits wanted in a doctor	Any traits a participant wants in a provider	When a participant mentions any traits they would want in their doctor		"I'll tell you the one thing I'm, I don't know if this, this is good – when I, when I was first diagnosed with HIV, to me, um, the, the ideal was to, to be, to find a, to find a specialist who was associated with a university because they are at the, they are, have the cutting edge of knowledge about the situation as opposed to a standalone physician. Not to diminish, you know, a standalone doctor may be as brilliant as you know, somebody [clears throat] but to me, having a, having a, a specialist who's associated with a university gives them a little extra, for me gives them a little extra credence because I think that they're at the cutting edge and their knowledge is a, a little more advanced."
Trusted online sources	Any online source or printed source (book) that participant trusts for health information	When a participant discusses an online source they trust for health information	Do not include people	"I think I, I think that I would, you know, I would look at the source. I mean if it's like the National Institutes of Health I'd feel pretty confident... about the, the information that's provided. Um, I, I think... if, if, if I, I, I'm thinking that... I'm thinking that like a, like an association that's been around for years like the American Cancer Society, if that's what that's called, um, I, I tend to think that that, that's who I would give the most like credence to."

Trusted people sources	Any person that participant trusts for health information	When a participant discusses a person they trust for health information	Do not include online sources	"I think my doctor only because um, I, I think the, like, like I said, if a symptom or if a situation presented itself that would, that it would be advisable for me to have my, be screened considering my history, um, I think that that, that would be like the start of a conversation about what I can expect, um, what they're looking for, what's going to happen, where is it gonna happen, how is it gonna happen, when is it gonna happen, that sort of thing."
Who-when should screen for lung cancer	Types of people who should screen for lung cancer and how often	When a participant discusses who should screen for lung cancer and how often they should screen		"Well, I think a, a person who, who has smoked in their life, any, any person who has smoked in their life, um, definitely."
Word Cancer Thoughts	What participants automatically think of when they hear the word cancer	What a participant thinks of and says when they hear the word cancer		"I'm not gonna panic. Uh, I'm just one of the many. Um, you know, I... There's alternatives, there's choices. Um, you know, it's just one of those things we go through in life. There's so many of them, you know, get over it."
Written LCS health information	If a participant believes written health materials on lung cancer screening would inform them and influence them to screen for lung cancer	When a participant discusses influence of written health materials on LCS		"It's just gonna go in one ear and out the other. I mean, I think it needs to be like anchored to a situation... that would uh, provide, would, would be like offered as to provide me information that, you know, I, I'm, to persuade me or convince me more to go in this direction. I think just a pamphlet without my asking for it, um, I won't, I don't think I would take it quite as seriously."

Reflexive Journal

This section includes examples of the Reflexive Journal document, which was close to 50 pages long. Each example entry starts after the date.

1/24/19

Today I completed my first interview! The participant got there more than 30 minutes early, so I'm glad I've decided to always be to interview locations an hour early. This interview took place at UMD and I used a private office with a meeting table in the Horowitz Center. I felt really comfortable talking with my participant and completing the interview. I realized, again, how much I enjoy doing qualitative research and how thankful I feel that people are willing to share their life and their stories with me.

I scheduled another four interviews today! I can't believe I already have six scheduled. This makes me feel more confident that I can complete this project on time. My goal is to finish ten interviews in the next two weeks, clean the transcripts by listening to the audio file and reviewing the transcript, analyze the first five using *in vivo* coding, create my codebook by creating focused codes, then code the other five interviews. After that I will have the minimum number of interviews and I can then use theoretical sampling to find additional participants.

1/29/19

Completed two interviews today at a library in DC. This time the experience was much different from the first two interviews. The library was in a lower-income neighborhood of DC, so many people were waiting at the door for the library to open at 9:30am. When I came up to the door, a man who seemed under the influence wouldn't leave me alone for a bit, which was quite uncomfortable. I just kept saying I'm sorry and no thank you. At the end, he put his hand in my face with two smoked cigarettes in it and asked for a lighter. He was so close that I could smell the tobacco. I said no and turned away. The other 10 people standing around didn't say or do anything. Once I got inside everything was fine; I was able to change the room time for my afternoon interview to an hour earlier (participant worried about weather, and so was I!). The library itself and the staff were nice and accommodating.

A woman came up to my study room asking to throw away an orange in the waste basket. I said of course and opened the door and lifted the trash can. I noticed her hands were covered in orange, so I offered her a tissue to clean them. She said God bless you many times and asked to give me a hug. I accepted the hug and returned it, and said God bless you as well. Though it was kind of an odd situation, it was lovely at the same time.

The interviews both went well, though they were shorter than my last two. I'm at the point where I just want to clean my data (listen again to the interviews), and start coding. I really want to get interviews coded so I can see which direction my data is taking me!

After my first interview this morning I had some extra time, so I called some potential participants and did eligibility checks. I was able to schedule two individuals for next week!

2/3/19

I listened to Scout's audio file and cleaned the transcript today. I really enjoyed listening to the interview again and felt like I got really rich data from this participant. I found a few small errors in the transcript. For example, a "would" instead of "could" or missing an um or uh here or there. I'm excited to start open coding!

As I'm sitting here, I'm realizing that I'm not sure if I remember how to open code in NVivo. I'm struggling a bit, so I've been going through my notes from class. I finally remember and I also just found my notes about open coding in NVivo. There is a "Code In Vivo" option, but you can't write/edit the code and it does not create a new node under the participant, just lists it as a code under reference in their node. I remembered that I have to create a new node and then place that under the participants node. Happy to start open coding!

2/5/19

Yesterday both of my participants for today confirmed our meeting times. This morning I received a call from my morning interview participant around 8:20 saying he would be there late, like 9:30am. That was fine with me because I left my house at 7:30 and was still stuck in traffic, so I wasn't sure if I would make it by 9am exactly. I ended up being there by 9:15am and received a call while I was walking over to the library from the parking garage saying that apparently his bus did not arrive and he would not be coming. He mentioned rescheduling for another time.

My first no show. I knew this would eventually happen, but it's frustrating. I woke up early today, it took almost 2 hours of driving in traffic to get here, and then the participant can't make it. I understand things happen and he can't control the bus or the driver. I was tempted to say let's see how much an Uber is and I would cover it, but he didn't answer his phone when I called back a few minutes later. At least I was able to have some quiet time to work and finish my resubmission for my manuscript to Health Literacy Research and Practice. My paper was accepted for publication and they only had a few small comments about a table they wanted me to update. Happy I got that done.

I got to DC and had trouble finding parking for the Shaw library. This library has street parking but most of the signs said you had to have a neighborhood parking zone pass, so I was worried about being ticketed or towed. I finally found parking (thankfully got here early enough) in a garage a few streets down. A bit tough walking to the library since I had a good amount of ankle pain, but I made it. I couldn't check into my room because it was occupied by another person. I waited a bit, used the restroom, then was able to go into my room about 5 minutes before 2pm. I called my participant at 2pm to give an update on where I was.... No answer and I left a voicemail. At 2:10pm I went to the front desk to ask if anyone had came by asking where the room was or asked for me, and no one had. Two in one day! I am going to call again, then I'll probably start calling people to assess eligibility. Let's hope my Thursday and Friday participants show up. It must be hard depending on public transportation to get around... when you think about accessing services, it must be so hard to find healthcare, resources, or organizations near you. Not everything is central to people, so it is difficult to get what you need to stay healthy.

I decided to use my time wisely and call some participants back. I spoke with one who is in Baltimore (yay, closer to me!) and he is eligible. I'm working to find a library close to the participant. The first two libraries I called do not have any study rooms. I called a third one and they don't have study rooms either, but they do have a meeting room. However, the only way to book the meeting room is if you are a 501c3 status organization and submit your paperwork as well as an application for the room. I spoke with some nice people on the phone and got the information I needed to apply. Then I called UMD and asked for them to share our tax-exempt status with me via email. I figured out how to print and scan here at Shaw library and sent the email to the library in Baltimore. I called back, which the librarian instructed me to do, but apparently she was occupied. Now I'm waiting for a call back to make sure I have secured the room. Once I know it is secure I will call my participant to let him know. Thankfully this library seems to be close to where he is located.

4/10/19

Sent Drs. Baur, Feldman, and Horowitz my updated chapters 1-3. I hope that I receive good feedback so I can make necessary edits now before my defense. I worked on my model for several hours today. I realized that the core category in the center didn't make much sense, because this is a process that leads to informed decision-making (IDM). I moved it to the right and then started the process of IDM. The model is really developing and taking shape. I feel like I finally have a solid model that needs to be discussed. I'm meeting with Dr. Aparicio and Dr. Baur on Friday, but I'd really like to peer debrief this model before then. I'm going to reach out to some peers in the doctoral program who have experience in qualitative research to see if they can meet with me today or tomorrow to do some peer debriefing.

Now that I feel I have a solid model that I need to talk through before I can make further changes, I felt that I needed to really take my focused codes and put them into sections; basically a main category and sub-categories, but not all of them are necessarily a part of the model. I ended up creating 9 categories, based on related topics (navigation, screening, IDM, shame/stigma, smoking, provider experiences, HISB/sources, knowledge/PR, personal experiences). Organizing them in this way was helpful because I see how everything is connected under this broad category. This will make it easier to do barriers/facilitators as well as contribute further to model development.

Had an excellent meeting with Tracy today to peer debrief my model! Took several notes in my research memos and made some changes to the model after talking through. Main developments were in regard to direction, removing awareness/PR at beginning of model, focusing on PR at end of model, and removing PR from trusted sources. I also got to meet with Catherine to do another round of peer debriefing after updating the model from earlier meeting with Tracy. Busy day! Catherine recommended to add understanding to knowledge since Dr. Horowitz says they are related but separate; I'll bring this up in meeting on Friday. Also, realized that having (a) trusted source(s) leads to HISB and vice versa. Instead of having a box for HL skills, it was decided that it's best to have an arrow across the bottom that leads to IDM. I feel like the model is really solid now and ready to present to Drs. Baur and Aparicio!

Research Memos

This section includes some examples of the Research Memo document, which was close to 40 pages long. Each example entry starts after the date.

2/7/19

- Called participant in the morning as reminder of meeting; participant answered and said was coming
- Completed interview with participant at Cleveland Park library
- Great, rich interview, approximately an hour
- Discussed transitions experienced in healthcare with doctors in terms of their communication skills
- Uploaded audio file to Datagain
- Called another participant to remind/confirm meeting tomorrow (2/8/19) and participant answered and confirmed that she is coming
- Received the rest of transcriptions from Datagain – big coding party this weekend at my place!
- Called participant who missed appointment back and got VM. Left message thanking her for her message, said I understand things happen, and would like to reschedule.

Coding Scout – finished on 2/7/19

- Healthcare decisions mainly independent
- Arrogant doctors, don't want to be interrupted, poor communication skills
- Need additional communication training for providers
- Society doesn't stress LCS bc of smoker stigma – you did this to yourself
- As a former smoker, sometimes say smokers responsible for getting LC, but if you understand addiction and that sometimes it's not a choice, you can be more compassionate with these people
- Need communication campaign to SIMPLY educate people about LCS
- Need doctors to suggest and offer LCS

3/9/19

- Started focused coding by using Rez interview because longest transcript with the most open codes
- Created focus codebook “LCS Study Codebook” in Drive Excel
 - o Focused code, Definition, When to use code, When not to use code, Example
 - o Providing an example of my decision making below in a table format

Focused Codebook Decisions Example

Best informed decision source	Decided to create this code because want to focus on what sources people believe best help them make an informed decision to perform a preventive health action, such as screening for lung cancer
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Causes of Lung Cancer	This code was created to examine participant knowledge of lung cancer causes. Can be reviewed against correct information to see how informed people are
Clinicians need HL and HC training	This code was created because there are several questions surrounding patient-provider communication, with a focus on jargon and communication techniques used by providers; participant(s) have noted that additional training is needed for provider, making this code relevant
Delayed Medical Care	Created this code because a question asks about delaying medical care, and whether medical care has been delayed due to being a smoker. Want to explore what people who delay care have to say about screening.
Determine credibility online	It's important to understand if and how participants determine if the health information they find online is credible, so this code will focus on how people determine if information is trustworthy or credible
Difficulty Medical Apts	This focused code was created to encompass navigation of the health care system, which is relevant for LCS
Doctor Dealbreakers	This code focuses on the consumer experience – shopping for a doctor – and the idea of changing doctors if doctor does not meet set participant expectations
Doctor risk assessment + LC screening conversation	This focus code was created to determine if a participant's doctor has assessed their risk for developing lung cancer and discussed lung cancer screening with participant
Doctor trust	While there is a code for experience with doctor, and trust is a part of that experience, trust seems to be a category appearing regularly, so I made a separate focused code for it
Doctor types	Basic code for which types of doctors participants see – this could become demographic data
Doctor visit schedule	Basic code for how often participant sees their doctors – this could become demographic data
Doctors discern knowledge-health literacy level	This code came up because a participant discussed his doctor being able to determine his knowledge through talking to him

3/12/19

- Meeting with Dr. Aparicio to review focused codes
 - o Patterns emerging – Memo!
 - o Detail why you created each focused code
 - o The process of informed decision making
 - o Knowledge of lung cancer (causes) compared to truth

- Memo about specific papers → every time something comes up that is there (pathways to screening) then keep noting that
- Can call participant on phone if you missed a question.
- Triangulating information – multiple sources
- “WebMD” or other online sources for “laymen” people
- Choosing your doctor based on what you expect – dealbreakers! Could be a part of theoretical model
- Peoples’ expectations of medical care – and where they’re willing to change a doctor or care or not; consistency in care
 - Healthcare consumerism – consumer experience – consumers of healthcare
 - Doctor shopping → Direct consumer drug literature
- Doctor types → demographics → anything that describes the sample → could add to demographics table
- Doctors discern knowledge-health literacy level → could follow into larger concepts
- Broad ideas + concepts – axial coding – before getting into theory
 - When do people know they feel comfortable with doctor?
 - Selecting your doctor
- Compare conflict (or not) between following physician recommendations and informed decision-making being influenced by physician
- Good health could become health status if you find someone who does not say they have good health
- Social marketing – advertise LCS using these tactics

Concept (health literacy)

- Categories (patient provider communication)
 - Properties (kind of like subthemes) – jargon, HL, asking questions, trust
 - Properties have dimensions – what are dimensions of trust?
 - How does trust to show up? – willingness to be vulnerable and ask questions;
 - Trust making process may include provider adjusting their use of language (not using jargon)

4/5/19

- **Core Category**: Making an informed decision about lung cancer screening
 - Causes
 - Health information seeking behaviors (HISB) → knowledge/awareness
 - Perceived risk → knowledge
 - Selecting your provider + doctor dealbreakers →
 - Relationship / trust to provider →
 - Patient-patient communication → Shared decision making

Peer Debriefing Meeting with Tracy

- Having trusted sources can cause you to engage in HISB

- If you don't have trusted sources you don't know where to go, so this should be bi-directional
- Awareness of LCS → perceived risk → HISB
 - Interview experience – LCS in consciousness
 - Heard of LCS related to awareness → leads to HISB → however, this isn't clear enough to be in the model, especially since LCS in consciousness based on study participation is a reason → can discuss this in results
 - The problem with this is that even with awareness, perceived risk is a major factor; if people don't have a high perceived risk (data focused on not having symptoms, so they are okay) then it won't lead to HISB
 - Think it's not relevant to them bc they don't understand or have knowledge
- Trusted providers impacted by PPC and trusted provider impact PPC
- PPC → increased or decreased PR → making an informed decision
- PPC also increases knowledge and knowledge leads to PPC

How does advocacy play into model?

- Doesn't have to be in the model, but could be explained in results as to how it fits (in PPC, in provider selection/DD).
- HL skills → due to the fact that S-TOFHLA scores were high; these participants had strong HL skills → that leads to this model

Peer debriefing with Catherine –

- HL skills supports this process
 - Box or a line → line is better idea all the way across because it also represents/ leads to IDM versus the process being boxed
- Knowledge and understanding → add understanding (Dr. H likes this).
- Is PR bi-directional as well? Risk influences PPC and vice versa.
 - Lower risk – may not ask as many questions; clarify
 - Need to clarify this with my data
- Model really taking shape! Now I'm ready to discuss with committee members

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