ETHICAL DIMENSIONS OF LUNG CANCER SCREENING IN CANADA

ETHICAL DIMENSIONS OF POPULATION-BASED LUNG CANCER SCREENING USING LOW DOSE COMPUTED TOMOGRAPHY IN CANADIAN JURISDICTIONS

BY MANISHA PAHWA, MPH, HBSC

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Lay Abstract

Lung cancer is the top cause of cancer in Canada. An estimated 30,000 people were diagnosed with lung cancer and 20,700 people died from lung cancer in 2022. Screening is being more widely used to find and treat lung cancer in earlier stages. There are some ethical questions to consider, like how to ensure that screening programs are fair and effective. This research focused on understanding what the ethical issues are and how they could be solved in health policy. Perspectives on ethical issues were collected and analyzed from the public and lung cancer screening leaders. The two major ethical issues were fair access to screening and stigma against people who currently smoke commercial tobacco. There was a lack of ethical guidance to address these issues in health policy. Ethical concepts about justice and individual choice, and ethics research with key communities, may help navigate ethical issues in health policy.

Abstract

Background and aim: Lung cancer is the leading cause of cancer incidence and mortality in Canada. Population-based screening programs using low dose computed tomography are being more widely used. Screening reduces lung cancer mortality. It also introduces potential ethical issues that need to be elucidated to inform the ethical, equitable, and effective implementation of screening programs. This aim of this research was to begin developing an understanding of what the ethical issues are and how they are being, and should be, approached in health policy.

Methods: Using empirical ethics inquiry, this research produced descriptive evidence via three independent studies: a systematic literature review and mixed methods integrative synthesis of public perspectives on screening benefits and harms, and two qualitative description studies about public and key informants' ethical and social values on ethical issues in screening.

Results: The major finding of this research was the preponderance of ethical issues located within health and social systems and structures, including equity of screening access, stigma against people who currently smoke commercial tobacco, commercialization of tobacco, and the need for increased investment in primary prevention of lung cancer. These ethical issues reflect the social, economic, and political determinants of lung cancer and the means available to reduce the burden of lung cancer in Canada, including but not limited to screening. In health policy, there was a lack of ethical frameworks or principles currently being used to address these ethical issues and the sometimes-conflicting perspectives found between the public and key informants.

Discussion: Future empirical and normative research is needed to understand ethical and social values related to screening by populations with high lung cancer incidence and mortality, and to integrate empirical evidence with appropriate ethical theories to make recommendations for ethical, equitable, and effective population-based LDCT lung cancer screening policy in Canada.

Acknowledgments

In the long and isolated days of writing this dissertation it was the reward of writing this very section that urged me to persevere. Arriving here is both joy and relief, and a privileged moment of reflection about what it has meant for me to have had the opportunity to do this work.

I entered my PhD midway through my career in occupational cancer research, having spent a decade working with colleagues in Canada and globally on projects that were highly engaging to me and had impact. The decision to pause my career in pursuit of learning how to conduct research on health ethics and policy was not easy or straightforward. Yet it was intuitive, driven by my lifelong desire to develop my creative scholarly self and engage in the processes of scholarship with others to contribute to health equity and well-being.

My career was formative in shaping the types of questions that I have asked, and attempted to answer, in my dissertation. During my career, I developed questions about what the ethical issues are in cancer prevention and how they are approached in health policy. I was particularly interested in understanding multiple perspectives on ethical issues from groups with high rates of carcinogen exposure and cancer incidence and mortality, and seeing how these perspectives could interface with, and potentially shape, bioethics frameworks used in Canadian health policy to promote their health equity. Perhaps as a second-generation immigrant to Canada I am inherently interested in interstitial spaces where plural ways of being and doing have implications for how we define ourselves as individuals and society, and for how we create political and social spaces of belonging for all. My PhD represents the first step in my exploration of these types of questions.

Through Dr. Meredith Vanstone's doctoral supervision, I have experienced my own processes of scholarly becoming and belonging that have expanded the possibilities for me to contribute to health ethics, policy, and equity in Canada. Dr. Vanstone's mentorship has extended my scholarly identity to become a mixed methods health researcher at the juncture of these three disciplines. The widened sense of who I am as a health researcher is what I most value about my doctoral degree. Not only has this enriched the texture of my life, but it has also created new ways for me to view and ask questions about health and society, and to be equipped with the appropriate theoretical and methodological toolkits for answering these questions in collaboration with others. I am immensely grateful to Dr. Vanstone for giving me conceptual training in health ethics and policy and skills in qualitative and mixed methods research to actualize my scholarly self during my PhD.

Dr. Vanstone's mentorship has also helped me to create new trajectories and greater choices for what I can do as a health researcher in the future. Dr. Vanstone's supervision on my doctoral thesis has stimulated my interest in exploring how bioethics theories and methods could be used as tools for achieving inclusive health policies that promote the health equity of communities disproportionately burdened by disease and its determinants. Although this is a significant shift from the type of research that I was engaged in prior to my PhD, Dr. Vanstone has valued the perspectives accumulated from my occupational cancer research career and has ensured that these have been part of my scholarly growth during my PhD and plans for future research. From Dr. Vanstone I have learned to value all my research experiences and to bring forth different elements in positioning myself as an interdisciplinary health researcher. Dr. Vanstone's supervision during this pivotal moment in my career has given me a profound sense of personal freedoms and fulfilment, and the capacities and confidence for leading interdisciplinary research in the future.

Beyond my scholarly identity, Dr. Vanstone has impressed upon me an inspirational example of how to be a generous, kind, and compassionate leader and mentor. Dr. Vanstone has taught me the skills of hard work, perseverance, humility, and collegiality as a research leader. As a mentor, Dr. Vanstone has been my advocate and ally during my PhD, extending beyond the scope of a conventional doctoral supervisor to provide insights on academic life and help me establish the foundation for my research success that is sensitive to the experiences of South Asian women in academia. Dr. Vanstone also honoured my caregiving responsibilities during my PhD, including as I became a mother to two young children in this period. Being seen and supported for the first time in this way has empowered me to take the next step on my career path, with Dr. Vanstone's mentorship as a role model for how I could be a prospective mentor to racially diverse students and trainees.

I have been fortunate to receive additional mentorship and support from my supervisory committee members, Drs. Julia Abelson, Paul A. Demers, and Lisa Schwartz. Each has been thoroughly engaged in my doctoral dissertation and vested in my scholarly development during my doctoral degree. Their generous time and feedback on my thesis proposal and chapters helped to shape how I have conceptualized and responded to my research questions and postured this research to be in a position of relevance to health policy and ethics in Canada. Each has also provided career mentorship and support through this important transition phase in my career.

I benefitted tremendously in my thinking about my doctoral research from the diverse areas of theoretical, substantive, and methodological expertise of my committee members. Dr. Abelson's expertise in patient partnership significantly impacted how I think about the nature of democratic health policy and issues surrounding representation, inclusion, and equity. Learning the theoretical foundations of health policy from Dr. Abelson also contributed substantially to building my scholarly identity in this field. I am grateful for Dr. Abelson for her teaching and expertise, and for her generous additional mentorship on how to prepare myself for conducting independent research upon the completion of my PhD.

Dr. Demers has been a long-term supervisor, mentor, and friend in my career, having supervised me for over ten years in his role as the Director of the Occupational Cancer Research Centre. The duration and dimensions of this relationship make it challenging to convey my gratitude to Dr. Demers in any matter of conciseness, but here I wish to highlight that during my PhD, Dr. Demers has offered rich insights from his own expertise in occupational cancer epidemiology that have contributed to the policy relevance of my dissertation. Dr. Demers has steadfastly supported my career through providing me with ample opportunities to collaborate widely and to contribute to occupational cancer studies that are tightly connected to health policy. Dr. Demers' leadership of a robust, vibrant research program has provided me with a compelling example and vast appreciation for the ripple effects of his work that are felt globally. I am deeply grateful for Dr. Demers' role in my doctoral degree as part of his long-term mentorship of my career.

Dr. Schwartz has provided expertise in health ethics that has helped me to bring the health equity dimensions of lung cancer screening into sharper focus in my doctoral research. Dr. Schwartz's elegant and open-ended questioning has provided a platform for me to articulate my interests and questions at the intersection of health ethics, equity, and policy and to learn how to engage with others in health ethics discourse. Dr. Schwartz's questions about benefits and harms at the outset of this research particularly helped strengthen my understanding of how to ask questions and what types of questions to ask through the lens of health ethics. Dr. Schwartz has also generously helped me to develop to the next step of my career through mentorship and network building. I am grateful for Dr. Schwartz's support on my doctoral dissertation and career.

The Health Policy PhD program has provided a scholarly home for me in large part due to the program's faculty, staff, and peers. Sheri Burns' administrative support for the program has helped me navigate internal procedures for my doctoral degree, and with remarkable speed and kindness. The friends who I have made in this program have been with me on every step of my doctoral journey, even through COVID-19 and my parental leave. I am tremendously grateful for your support and the friendship that we have found in one another through our shared scholarly interests.

Outside of the Health Policy PhD program, I have been fortunate to receive research support from Dr. Vanstone's lab group, including several research assistants who contributed to data collection, analysis, reviewing, and dissertation preparation. Alexandra Cernat was a wonderful "energy exchange" partner on our systematic literature reviews for our respective doctoral theses. I am grateful to Lawrence Grierson for his mentorship, encouragement, and confidence in my abilities to succeed throughout my degree.

My doctoral research was supported by competitive training funding from the Government of Ontario and McMaster University Ontario Graduate Scholarship, McMaster University Department of Family Medicine Pilot Research Funding, and a Frederick Banting and Charles Best Canada Graduate Scholarship Doctoral Award. I am grateful for this funding, including Dr. Vanstone's supervision on preparing funding applications and for the contributions of co-investigators to funding proposals. I deeply appreciate the contributions of study participants in my doctoral thesis research. Your interest in my research and enthusiasm to read the results helped me to stay motivated about the importance and relevance of my work.

My PhD has also been a period of my life marked by family building. During my PhD my family grew with the birth of my two children, Ajeet and Ajooni, now aged five and two years old. I have held both of my children in every moment of this work, asking myself what I can offer them and their future generations through my research. Though young, my children have shown me patience, grace, and understanding during these formative years of their beautiful and precious lives. Their love and joy upon welcoming me home from long hours of writing on campus has left an imprint on my heart. I hope to repay their love from the opportunities that my PhD will create for me to nurture my children's growth and passions.

Most people have one set of parents, but I have been privileged to have two: my mom and dad, and my mom- and dad-in-love. To my parents, this is for you. You have shown me how to be courageous, kind, and hardworking by showing me who you are. You have supported me in every moment of my doctoral degree, from nurturing my questioning and creativity when I was a child to taking on significant grandparent duties for Ajeet and Ajooni when I became a mother. My PhD is dedicated to my mother, who wanted me to be flourishing in my life. I am because she was.

Patricia S. Weber has been my sister and best friend for 25 years, and fellow scholar during my doctoral degree. Our lifelong dialogue about academic, family, and community life has deepened how I think about my roles and my research in these contexts. Patricia has helped me to see me, and to see me in relation to caring for others. I am grateful to Patricia for centering me in my scholarly journey, which has helped me to articulate who I am and what I wish to achieve through my research. I am grateful for and humbled to be each other's lifelong mirror.

Karanpreet Singh has been my closest witness to the unfolding of my life during my PhD and over the past ten years of our relationship. He has supported me in every way that I needed, from making me countless cups of coffee to quietly putting aspects of his own life on pause for me to complete this stage of my career. My gratitude for his generosity and sacrifice is deep. I am excited to share the rewards of this work with him and with our family.

Impact of COVID-19 restrictions on the research plan

My recruitment efforts for study 2 (chapter 3) were impacted by COVID-19 restrictions on in-person appointments at family medicine clinics in Hamilton, Ontario. In-person clinic recruitment was augmented by recruitment via social media (i.e., Facebook) and researchers' personal and professional networks.

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List of all abbreviations and symbols

Abbreviation	Definition
COVID-19	COronaVIrus Disease of 2019
CI	Confidence interval
CPAC	Canadian Partnership Against Cancer
CTFPHC	Canadian Task Force on Preventive Health Care
IARC	International Agency for Research on Cancer
INESSS	Institut national d'excellence en santé et services sociaux
LDCT	Low dose computed tomography
MMAT	Mixed methods appraisal tool
MRI	Magnetic resonance imaging
NLST	National Lung Screening Trial
NSCLC	Non-small cell lung cancer
OCAP	Ownership, control, access, and possession
PLCOm2012	Prostate, Lung, Cervical, Ovarian Cancer model 2012
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	International prospective register of systematic reviews
RR	Relative risk
SCLC	Small cell lung cancer
SRQR	Standards for Reporting Qualitative Research
U.K.	United Kingdom
U.S.	United States
USPSTF	United States Preventive Services Task Force

Declaration of academic achievement

I led the conduct of this research with supervision from Dr. Meredith Vanstone and supervisory committee contributions from Drs. Julia Abelson, Paul A. Demers, and Lisa Schwartz. I conceived of the research topic, questions, and aims, and conceptualized my doctoral thesis as an empirical bioethics investigation using the empirical bioethics frameworks that I selected from the literature. Dr. Vanstone provided guidance and feedback throughout the conceptualization process, helping me to refine the research questions and aims. Dr. Vanstone also directed my focus on producing knowledge related to the descriptive elements of the empirical bioethics frameworks given the scope and timeline of my doctoral thesis research. Drs. Vanstone and Schwartz provided guidance on later integrating the descriptive ethics evidence produced in this dissertation with relevant ethics theory to make normative recommendations for ethical population-based LDCT lung cancer screening programs in Canada.

Introduction, Chapter 1: I led the structure and writing of this chapter with feedback on draft versions of this chapter from Drs. Vanstone, Abelson, Demers, and Schwartz.

Study 1, Chapter 2: I led the design and conduct of all aspects of the systematic literature review about public perspectives on the benefits and harms of lung cancer screening, including developing the research question and aims, data collection, analysis, and writing. Dr. Vanstone provided supervision on specifying the research question and search strategy. Dr. Vanstone provided feedback on study selection and guidance on methods for conducting the mixed methods integrative synthesis using a narrative approach. Dr. Vanstone reviewed draft versions of the study manuscript, including providing input on reporting and interpreting the study findings. Drs. Abelson, Demers, and Schwartz provided input on the study design and the final draft version of the study manuscript. Alex Cernat served as the main secondary reviewer for study selection and data extraction. Katrina Shen and Mehreen Chowdhury provided additional secondary review for study selection and data extraction. Caroline Higgins provided guidance and feedback on the search strategy.

Study 2, Chapter 3: I led the conduct of this study about public ethical and social values on the ethical aspects of population-based LDCT lung cancer screening in Ontario. I jointly developed the research design with Dr. Vanstone. I conceived of the research questions and aims with feedback from Dr. Vanstone. Dr. Vanstone suggested and provided direction on using the qualitative description methodology. I developed the sampling strategy and data collection instrument (i.e., the interview guide) in collaboration with Dr. Vanstone. I led data collection, analysis, and writing with ongoing feedback from Dr. Vanstone and feedback on the final draft version of the manuscript from Drs. Abelson, Demers, and Schwartz. Katrina Shen contributed to data collection. Katrina Shen and Hadia Shaikh contributed to data analysis.

Study 3, Chapter 4: I led the conduct of this study about key informants' ethical and social values about the ethical aspects of population-based LDCT lung cancer screening in Canadian jurisdictions. I jointly developed the research design with Dr. Vanstone. I conceived of the research questions and aims with feedback from Dr. Vanstone. Dr. Vanstone suggested and provided direction on using the qualitative description methodology. I developed the sampling strategy and data collection instrument (i.e., the interview guide) in collaboration with Dr. Vanstone. I led data collection, analysis, and writing with ongoing feedback from Dr. Vanstone and feedback on the final draft version of the manuscript from Drs. Abelson, Demers, and Schwartz. Katrina Shen contributed to data analysis.

Discussion, Chapter 5: I led the analysis, structure, and writing of this chapter with feedback on draft versions of this chapter from Drs. Vanstone and feedback on the final draft version from Drs. Abelson, Demers, and Schwartz.

Chapter 1: Introduction

Lung cancer is the leading cause of cancer diagnoses and deaths in Canada.[1] Approximately 70% of lung cancers are diagnosed at stages 3 or 4[2] when treatment effectiveness is limited, and net five-year survival is 15% or less.[2] Lung cancer incidence rates show an inverse association with socioeconomic status.[3,4] Lung cancer incidence rates are also elevated in some rural[5] and certain, but not all, Indigenous[5-10] populations. Elevated lung cancer mortality[6] rates and lower survival[5] rates have also been reported in some of these populations, which may be attributed in part to excess late-stage diagnoses.[11]

Screening for lung cancer with low dose computed tomography (LDCT) aims to reduce lung cancer mortality by detecting lung cancer in stages I and II when there are more treatment options and improved treatment effectiveness compared to diagnoses made at stages III and IV.[12] To optimize the benefits to harms ratio associated with the use of LDCT, only individuals in a population who are determined to be at high risk of being diagnosed with lung cancer in a defined period are eligible for lung cancer screening.[13,14] Eligibility, determined by risk prediction modeling, is an important distinction from most current population-based screening programs for breast,[15] colorectal,[16] and cervical[17] cancers, which predominantly use age as the eligibility criterion. LDCT lung cancer screening programs using risk prediction modeling are being implemented more widely in Canadian jurisdictions.[18]

LDCT lung cancer screening introduces potential ethical issues that are key to the effective and equitable implementation of screening programs. Ethical aspects occur at structural/systemic and individual levels, which demonstrate that lung cancer screening is simultaneously a public health and health care activity occurring within health policy.[19,20] For instance, the inequitable distribution of lung cancer incidence and mortality and the use of risk prediction modeling to select individuals in a population for screening are predominantly public health ethics issues for lung cancer screening. The promotion of patient autonomy through processes of informed decision-making about lung cancer screening participation is primarily a health care ethics concern. However, there is little scholarship about the ethical aspects of lung cancer screening as they pertain to health policy[21] and little knowledge about how public health and health care ethical issues are being, and should be, addressed in health policy.

Health policy provides an interdisciplinary and socio-political location for ethical aspects of lung cancer screening to be elucidated, analyzed, and deliberated. Lung cancer screening ethical issues are situated in health policy because decisions about if and how to provide population-based lung cancer screening programs are made here. Policy decision-making about ethical issues, such as whether to create screening programs, who to prioritize for screening, and how to offer screening, involve moral judgments. Yet, there is little knowledge about what these moral judgments are, how they are made, by whom, and what the impacts of these moral judgments might be for society. Efforts to address this knowledge gap involve identifying what ethical concepts are engaged in policy decision-making, and how. It also requires attention to whether and how lung cancer screening programs are congruent with social values and needs.[19]

The purpose of this research is to generate an understanding of the ethical dimensions of lung cancer screening in Canadian health policy informed by the symbiotic interaction of empirical and theoretical perspectives.[22] The guiding questions for this research are:

1. What are the ethical aspects of lung cancer screening? (Studies 2 and 3)

2. How are the ethical aspects currently being addressed in health policy (i.e., with what principles or moral judgments)? (Study 3)
3. How do current social needs and values suggest how the ethical aspects should be addressed in health policy related to lung cancer screening? (Studies 1 and 2)

Study 1 is a systematic literature review of public and patient perspectives on the benefits and harms of LDCT lung cancer screening. Study 2 is a qualitative description study of public, ethical and social values about LDCT lung cancer screening in Ontario. Study 3 is a qualitative description study about key informants' views on the ethical aspects of LDCT lung cancer screening in Canadian jurisdictions.

This research is grounded in the fields of health policy and ethics. It also engages strongly with the field of public health given the moral relevance and implications of inequitable population distribution of lung cancer incidence and mortality rates in Canada on lung cancer screening.

This introductory chapter presents an overview of morally relevant facts about lung cancer screening in Canada that set the context for the research presented in subsequent chapters. This chapter begins with **lung cancer**: describing what it is and presenting a summary of lung cancer statistics in Canada, which provides an understanding of the magnitude of lung cancer, its population distribution, and inequities. An overview of lung cancer causes, risk factors, and burden is provided, followed by a summary of strategies to prevent lung cancer.

The theory and practice of **lung cancer screening** are described next. This section explains how and why LDCT is used to screen for lung cancer, the lung cancer screening pathway, and Canadian national lung cancer screening guidelines. A summary of current lung cancer screening activities in Canada are presented.

The final section addresses why lung cancer screening **ethical aspects are relevant for health policy**. Key normative questions raised by lung cancer screening in health policy are described with reference to what is known about the ethics of cancer screening, ongoing debates or knowledge gaps on the topic of lung cancer screening ethics, and how this dissertation seeks to contribute. The concepts of "ethics" and "social values" are distinguished here and will carry forward in the dissertation. **Research questions, aims, and the empirical bioethics approach** used to guide the conduct of the three studies in this doctoral thesis are described.

1.1 Lung cancer

Definition and classification

Lung cancer is any malignant neoplasm originating in the bronchus or lung.[23] [24] Lung cancers are diverse in morphology, histology, and genetic characteristics. The World Health Organization recognizes epithelial tumors, lung neuroendocrine neoplasms, tumors of ectopic tissues, mesenchymal tumors specific to the lung, and hematolymphoid tumors and is placing increased emphasis on molecular pathology, including genetic testing, across all tumor types.[25] Lung cancer is traditionally and still commonly classified as two major histological types: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC).[26,27] The three most commonly occurring histologic sub-types of NSCLC are adenocarcinoma, squamous cell carcinoma, and large cell carcinoma.[26] In Canada, the Canadian Cancer Statistics Advisory Committee classifies and reports on the following lung cancer histologic sub-types: adenocarcinoma; squamous cell carcinoma; large cell carcinoma; non-small cell lung cancer, not otherwise specified; small cell lung cancer; and unspecified.[2]

Classification of lung cancer is important because lung cancer etiology, pathogenesis, diagnosis, treatment, and outcomes can differ by histological sub-types.[28] For example, adenocarcinoma is the most diagnosed lung cancer histological sub-type in Canada, with a higher incidence rate in women compared to men.[2] It is strongly associated with previous smoking, and it is also the most common type of lung cancer diagnosed in people who have never smoked, especially in women.[29,30] Squamous cell carcinoma is more strongly associated with smoking than adenocarcinoma and large cell carcinoma in men.[30] Approximately half of adenocarcinomas and one-third of squamous cell carcinomas in Canada are diagnosed at stage 4.[2] Adenocarcinomas arise from the bronchial glands with obvious mucous production. Squamous cell carcinoma is often found in squamous cells in the central part of the lung or left or right bronchus. While adenocarcinoma exhibits locoregional spread, squamous cell lung cancer can spread to multiple sites outside of the chest, such as the brain. Treatment varies with disease stage; in stage 1, surgical resection is preferred if possible, and in subsequent stages, chemotherapy, radiation, and palliation are considered. Lung adenocarcinoma is further classified into 4 types that have different outcomes upon resection. The prognosis for adenocarcinoma is worse than squamous cell carcinoma (except for stage 1 diagnosis). These two histological sub-types – adenocarcinoma and squamous cell carcinoma – illustrate how classification of lung cancer is consequential for treatment and prognosis.[31,32]

National portrait of lung cancer in Canada

Lung cancer is the leading cause of cancer diagnoses and deaths in Canada.[1] Most cases are diagnosed at stage 4 in people who are older.. Often for these reasons, prognosis is poor: approximately eighty percent of people diagnosed with lung cancer will die within five years of their diagnosis. There are stark population divides, with markedly higher lung cancer incidence and death, and poorer survival, in low-income populations. Higher lung cancer incidence has been reported among some rural populations and higher incidence and mortality, and poorer survival, has been reported in certain, but not all, First Nations, Inuit, and Metis populations. Geographically, diagnosis and death rates from lung cancer are much higher in Nunavut compared to other Canadian jurisdictions. Adenocarcinoma is the most diagnosed histological sub-type of lung cancer in Canada, comprising almost half of lung cancer cases. Incidence and death rates in men have been declining since the year 1992; however, among women, incidence rates increased between 1992 and 2012 and mortality rates increased between 1992 and 2006. Each have since shown downward temporal trends.[2]

Previous and current smoking continues to drive lung cancer diagnoses in Canada. Inuit in Nunavut have a particularly high prevalence of smoking[33] with a historically young age of daily smoking initiation.[33,34] This population has the highest lung cancer incidence and mortality rates in the country[2], and at younger ages compared to the non-Inuit Canadian population.[35] Commercial tobacco smoking and exposure to second-hand commercial tobacco smoke is also concentrated in people of low socioeconomic status.[36] Canadians in lower income quintiles have higher rates of lung cancer diagnosis, late-stage diagnosis, and death compared to people in higher income quintiles. For each stage of lung cancer diagnosis, there is a positive gradient between income quintile and survival.[2] The lung cancer statistics presented below provide further details about the distribution of lung cancer in Canada. While First Nations, Inuit, and Métis communities are important communities for lung cancer prevention, this research is not well positioned to make normative policy recommendations for these diverse groups. Statistics about lung cancer in First Nations, Inuit, and Métis presented in this chapter provide context for understanding lung cancer epidemiology in Canada.

Canadian statistics

The 2020 Canadian Cancer Statistics publication included a special report on lung cancer.[2] This special report was the source for most data presented below.

Incidence by sex, age, and region

Lung cancer is the leading cause of cancer diagnoses in Canada. Approximately 30,000 people (15,000 men and 15,000 women) were expected to be diagnosed with cancer of the lung and bronchus in 2022, representing an age-standardized incidence rate of 58.7 per 100,000 (61.0 and 57.2 per 100,000 in men and women, respectively, excluding Quebec). Lung cancer accounted for nearly 13% of all new cases of cancer diagnosed in 2022. For comparison, breast cancer diagnoses comprised approximately 12% of all new cancer cases in 2022, followed by prostate and colorectal cancer at just over 10% each.[1]

Between the years 2012 and 2016 in Canada (excluding Quebec), the age-standardized incidence rate of lung cancer was 65.7 per 100,000 in men and women combined. The incidence rate was higher in men compared to women (72.7 versus 60.7 cases per 100,000). Incidence climbed with age, reaching a peak in people between the ages of 75 to 84 years (409.8 cases per 100,000, both sexes combined). Men in this age group had a markedly higher incidence rate of lung cancer compared to women in this age group (477.7 versus 354.5 cases per 100,000). However, men aged 85 years and older had the highest incidence rate of all age groups and sexes, at 483.3 cases per 100,000. Men experienced a higher incidence rate than women for all age groups over 55 years.[2]

Geographically, cases in Nunavut were dramatically higher compared to cases in other Canadian regions, at 168.0 cases per 100,000. Women in Nunavut had a higher incidence rate of lung cancer compared to men in Nunavut (174.3 versus 161.7 cases per 100,000) and the highest incidence rate of lung cancer by Canadian region. The region with the next highest incidence of lung cancer was the Northwest Territories, with an overall incidence of 95.5 cases per 100,000, 103.4 cases per 100,000 in men, and 88.1 cases per 100,000 in women. The remainder of incident cases in Canada generally exhibited an east-to-west gradient, with the lowest rates in British Columbia (59.9 cases per 100,000) and gradually increasing incidence rates traversing eastward to the Maritime provinces, where, for instance, men in New Brunswick have an incidence rate of 99.5 cases per 100,000. Incidence rates were higher in men compared to women in all Canadian regions.[2]

Incidence by histologic type

In Canada (excluding Quebec), adenocarcinoma was the most frequently diagnosed sub-type of lung cancer, with an age-standardized incidence rate of 27.6 per 100,000 in men and women between the years 2012 and 2016 (48% of all lung cancer diagnoses). It was followed by incidence rates for squamous cell carcinoma (11.3 per 100,000; 20% of all lung cancer diagnoses), NSCLC (not otherwise specified, 11.2 per 100,000; 20% of all lung cancer diagnoses), unspecified histology (8.1 per 100,000), SCLC (6.9 per 100,000; 12% of all lung cancer diagnoses), and large cell carcinoma (0.5 per 100,000; 1% of all lung cancer diagnoses). There were some sex differences in the incidence rate of certain histological sub-types. Adenocarcinoma was slightly more diagnosed in women compared to men (28.7 versus 26.8 per 100,000; 53% versus 43% of all sex-specific lung cancer diagnoses), while squamous cell carcinoma was diagnosed much more often in men compared to women (15.3 versus 7.9 per 100,000; 24% versus 15% of all sex-specific lung cancer diagnoses).[2]

Incidence by stage of diagnosis

The incidence rates of lung cancer diagnosis vary by stage of diagnosis. Between 2012 and 2016 in Canada (except Quebec), 30.5 lung cancers per 100,000 are diagnosed at stage 4, when lung cancer has spread to other parts of the body and is therefore more difficult to treat. The age-standardized incidence rates of stage 1, 2, and 3 lung cancer diagnoses are 12.8, 5.0, and 12.0 cases per 100,000, respectively. Stage 4 diagnoses are more frequent in men compared to women (35.1 versus 26.9 per 100,000), while stage 1 diagnoses are slightly more common in women versus men (13.5 versus 12.3 per 100,000). The incidence rate of diagnosis increased with age up to 84 years old for all stages, with the highest incidence rate for stage 4 lung cancer in people aged 75 to 84 years, at 181.9 cases per 100,000. For comparison, in this age group, the incidence rate of stage 1, 2, and 3 lung cancer was 84.2, 32.6, and 74.5 cases per 100,000. The incidence rate of lung cancer lowered in people aged 85 years and older for all stages of diagnosis. By histologic type, the incidence rate of stage 4 diagnoses was highest for adenocarcinoma (13.0 cases per 100,000). All histologic types had a higher incidence rate of stage 4 diagnosis compared to diagnosis at stages 1, 2, or 3. By region in Canada, people in Nunavut had the highest incidence rate of stage 4 lung cancer diagnoses (57.0 cases per 100,000). Maritime provinces had a higher incidence rate of stage 4 diagnoses compared to most other provinces in Canada.[2]

The percent distribution of lung cancer cases by stage and sex mirrors the incidence rates by stage and sex. Approximately half (49%) of lung cancer cases were diagnosed at stage 4 in both sexes in Canada (excluding Quebec) between the years 2012 and 2016. The proportion of stage 4 diagnosis was slightly higher in men (52%) compared to women (47%). Females had a higher proportion of stage 1 diagnoses (24%) compared to men (18%).[2]

There were some important differences in the distribution of cases diagnosed by stage for different histologic types. Stage 4 diagnoses comprised 49% or more of diagnoses for each histologic type except squamous cell carcinoma, where stage 4 diagnoses were 32% of diagnoses. Stage 4 diagnoses were pronounced for SCLC, making up 67% of diagnoses with this histologic type. The proportion of stage 1 diagnoses was highest for adenocarcinoma (20% of adenocarcinoma diagnoses) and lowest for SCLC (4% of SCLC diagnoses).[2]

Incidence trends

Between 1992 and 2016, the age-standardized incidence rate for lung cancer steadily declined for men. The steepest decline occurred between the years 2012 and 2016, when an annual percentage change of -4.0% was observed. Women experienced somewhat of an inverse pattern;

between 1992 and 2012, the annual percentage change in age-standardized incidence was 1.0%, and between 2012 and 2016, incidence declined with an annual percentage change of -1.9%.

Temporal trends by histologic type show some differences. Adenocarcinoma incidence, which was steady between the years 1992 and 2009, began to increase that year, reaching a plateau between 2012 and 2016. Squamous cell carcinoma shared an age-standardized incidence rate similar to adenocarcinoma in the year 1992, but had gradually declining incidence in the years thereafter to 2016. The incidence rates of SCLC and large cell carcinoma showed steadily declining trends between 1992 and 2016. The incidence rate of NSCLC increased between the years 1992 and 2007, peaked in the year 2007, then declined to 2016.[2]

The incidence rates of lung cancer for all histologic sub-types combined generally exhibited declining trends by age and sex. Declines were most consistently observed for younger age groups, with the steepest decline found in 45 to 54 years old men and women between the years 2012 and 2016 (-5.5% annual percentage change, p=0.028). Statistically significant (p<0.001) decreases were found in men in all age groups until 74 years old between 1992 and 2016. Statistically significant (p<0.001) increases in the incidence of lung cancer was found among women aged 65 to 74 years between the years 1992 and 2006, and among women aged 75-84 and 85+years between the years 1992 and 2012. Lung cancer incidence is expected to rise in Canada to 14,866 cases in men and 19,162 cases in women in the year 2042.[37]

By geography and sex, incidence rates for lung cancer declined in both sexes over most time periods between 1992 and 2016, with sharper declines generally found for men compared to women nationally and in most jurisdictions. In Nunavut, the incidence rate of lung cancer in men and women declined by 2.9% (p=0.005) between the years 1992 and 2016. The steepest decrease in lung cancer incidence was found in Ontario men between the years 2012 and 2016, with an annual percentage chance of 6.3% (p<0.001).

By histologic type and sex, the incidence rates of squamous cell carcinoma declined steeply in men and exhibited relatively a lower and consistent trend in women between the years 1992 and 2016. Incidence rates for adenocarcinoma showed a gradual decrease in men and gradual increase in women between the years 1992 and 2006, which is when the rate of increased incidence in women surpassed men. Incidence rates for NSCLC, which were consistently higher in men compared to women and the highest of all histologic sub-types over the period studied, increased for men and women between 1992 and 2007, which is when their rates peaked. They then began to descend until 2016. Incidence rates for SCLC were steady in men and women throughout the period 1992 to 2016, like the incidence rate pattern for squamous cell carcinoma in women. The trend for squamous cell carcinoma in men declined such that the incidence rate in 2016 was less than half of the incidence rate in 1992. Large cell carcinoma incidence exhibited steady and similar declines in slope and magnitude in men and women between 1992 and 2016.[2]

Incidence among First Nations, Inuit, and Métis

Between 1991 and 2010, First Nations people had a significantly higher incidence rate of lung cancer compared to other people in Ontario for both sexes and most age groups. During this period, the age-standardized incidence rate for lung cancer in First Nations men in Ontario was 57.0 per 100,000, which corresponded to a rate ratio (RR) of 1.19 (95% confidence interval: 1.09-1.30). Incidence increased with age. Rate ratios were significantly elevated for First Nations men aged 50-64 years (RR=1.25, 95% CI: 1.08-1.44) and 65 to 74 years (RR=1.20, 95% CI:

1.03-1.39). A similar pattern of consistently elevated incidence rates and RRs was observed for First Nations women compared to other people in Ontario between the years 1991 and 2010. The age-standardized incidence rate for lung cancer in First Nations women during this period was 45.6 per 100,000 (RR=1.47, 95% CI: 1.35-1.61). RRs were significantly elevated for all age groups, with the highest RR observed in First Nations women aged 65 to 74 years (RR=1.58, 95% CI: 1.35-1.83).[6]

Temporal trends comparing the incidence of lung cancer in First Nations men and women compared to other men and women in Ontario were also examined in this cohort. Between 1991 and 2010, incidence rates of lung cancer among First Nations men have shown a steady and parallel decline similar in slope, but greater in magnitude, than incidence rates in other men in Ontario. Incidence rates in First Nations women in Ontario increased during this period while they have been steady among other women in Ontario. These findings are believed to be due to the high prevalence of smoking in First Nations people.[6] In other Canadian jurisdictions, such as British Columbia and Alberta, lung cancer incidence is lower in First Nations compared to non-First Nations people,[7,38,39] while it is higher in First Nations people living in the Atlantic provinces.[7]

Métis men had similar lung cancer incidence to non-Indigenous men in Canada; however, the incidence of lung cancer among Métis women was significantly higher compared to non-Indigenous women (RR=1.34, 95% CI: 1.18-1.52).[8] Métis compared to non-Métis men in Alberta had significantly higher incidence of lung cancer.[9] Among Inuit living in Nunavut, lung cancer represented nearly half of all cancer referrals to The Ottawa Hospital Cancer Centre between 2000 and 2010, compared to 13% of referrals among the total population served by this hospital during this period.[35] Inuit men in Nunangat were over twice as likely to be diagnosed with lung cancer compared to people living in the rest of Canada between the years 1998 and 2007; for Inuit women in Nunangat, the risk was 3.7 times higher.[40]

Incidence by socioeconomic status

There were slight differences in the distribution of lung cancer cases by stage of diagnosis and family income quintile in Canada (excluding Quebec) between the years 2013 and 2015. Among people in the lowest family income quintile, 52% of lung cancers were diagnosed at stage 4 and 20% were diagnosed at stage 1. For people in the highest family income quintile, 49% of lung cancers were diagnosed at stage 4 and 23% diagnosed at stage 1.[2]

Mortality by sex, age, and region

An estimated 20,700 people were expected to die from lung cancer in the year 2022 in Canada (10,600 men and 10,100 women). The age-standardized mortality rate for lung cancer for 2022 was 43.4 per 100,000 (48.6 and 39.5 per 100,000 for men and women, respectively). Lung cancer accounted for approximately 24% of all cancer deaths in 2022.[1]

The overall age-standardized mortality rate for lung cancer in Canada (excluding Quebec) was 47.5 cases per 100,000 in both sexes between the years 2013 and 2017. Men had a higher mortality rate compared to women (55.0 versus 41.9 cases per 100,000). Mortality rates increased by age for both sexes combined and separately. The highest mortality rates were observed in men and women aged 85 years and older (352.1 cases per 100,000), men aged 85 years and older (491.7 cases per 100,000), and women aged 75 to 84 years (277.4 cases per 100,000). Men experienced a higher mortality rate than women for all age groups over 55 years.

Stark regional differences in lung cancer mortality were observed. Females in Nunavut had the highest mortality rate of all regions, at 188.6 cases per 100,000, followed by men in Nunavut, at 172.0 cases per 100,000. Lung cancer mortality generally exhibited a west-to-east gradient, with the lowest mortality in British Columbia (43.9 cases per 100,000 men and women combined) and steadily higher mortality moving eastward to the Maritime provinces (e.g., 62.5 cases per 100,000 in Nova Scotia).

Mortality trends

Lung cancer mortality exhibited a downward slope in men between the years 1992 and 2017, with annual percentage changes of -2.1% (1992-2010) and -3.0% (2010-2017). In women, mortality rates were relatively lower and steadier, showing a 1.0% annual percentage change between the years 1992 and 2006 and -1.2% between 2006 and 2017. By age group, the largest decreases in mortality were observed for men and women between the age of 45-54 years (-7.7% in men aged 45-54 years between 2011 and 2017, and -9.2% in women aged 45-54 years between 2012-2017). The pattern of declining mortality was more consistently found in men than women across different age groups and time periods. By geography, mortality rates generally showed a steeper decline between the years 2010 and 2017 compared to 1992 to 2009 in both sexes combined. For women, mortality rates generally showed an upward trend in earlier compared to later periods, when they began to slope downwards.

Mortality by Indigenous, socioeconomic, and rural status

Mortality rates from lung cancer were significantly higher in First Nations men and women compared to all other men and women in Ontario, respectively.[6,41] Gradients between lower income quintile and more late-stage diagnoses and poorer survival have been found in Canada.[2,5] Rural and urban residents have similar survival rates in Canada.[5]

Survival by sex, age, histologic type, region

Nearly 70% of lung cancers in Canada are diagnosed at stage 3 or 4 when treatments are limited and less effective compared to earlier stage treatment. Between 2012 and 2014, the one-year predicted net survival is 44% for men and women combined. One-year net survival is worse for men (40%) then it is for women (49%). The five-year net survival is a mere 19% overall (15% for men and 22% for women), making lung cancer one of the most fatal cancers in Canada. One- and five-year net survival steeply declines with increasing age in men and women; for example, at ages 55-64 years in men and women combined, one-year net survival is 49% and five-year net survival is 22%. At ages 85-99 years, one-year net survival is 30% and five-year net survival is 9%.[2]

Survival statistics differ by histologic type. Prognosis is poorest for SCLC (one- and five-year net survival 32% and 7% in men and women combined, respectively) while it is highest for adenocarcinoma (one-and five-year net survival 56% and 27% in men and women combined, respectively). Women have more favourable survival compared to men for nearly all histologic subtypes, although survival is poor for women and men in absolute terms. For men and women separately and combined, five-year predicted net survival was highest for adenocarcinoma followed by squamous cell carcinoma, large cell carcinoma, NSCLC, and SCLC.[2]

Five-year predicted net survival declined for all histologic types by age except for squamous cell carcinoma, where survival in people aged 85-99 years was comparable to survival in people aged 65-74 years. Across age groups, five-year predicted net survival was highest for adenocarcinoma followed by squamous cell carcinoma, large cell carcinoma, NSCLC, and SCLC.[2]

Individuals diagnosed with lung cancer in Manitoba, Ontario, and New Brunswick fare better in terms of five-year net survival compared to people diagnosed with lung cancer in other Canadian provinces. One-year net survival was homogenous across Canadian jurisdictions except Prince Edward Island, where survival was the lowest at 38%. In all Canadian jurisdictions, one- and five-year net survival was more favourable in women compared to men. One-year survival was highest among women in New Brunswick and Newfoundland and Labrador (52%) and five-year net survival was highest among women in Manitoba (24%).[2]

Survival by stage of diagnosis

Individuals diagnosed with stage 4 lung cancer have the poorest survival. The three-year predicted net survival for stage 4 lung cancer is a mere 5% for both sexes (4% for men and 7% for women). Survival is highest for stage 1 diagnoses, followed by diagnoses at stages 2, 3, and 4. Individuals diagnosed with stage 1 lung cancer have a 71% three-year predicted net survival (66% for men and 75% for women). Survival declines to 49% for stage 2 diagnoses and 22% for stage 3 diagnoses. Women have consistently better survival than men for diagnosis at all stages.[2]

Survival among First Nations, Inuit, and Metis

Relative to other men in Ontario, First Nations men in Ontario have significantly poorer five-year net survival. Survival of First Nations women in Ontario was not statistically significantly different from the survival of other women in Ontario.[41]

Survival by socioeconomic status

People diagnosed with lung cancer in the lowest income quintile have consistently shorter survival compared to people diagnosed in the highest income quintile for all stages of lung cancer diagnosis. For example, the three-year age-standardized survival rate for stage 1 lung cancer is 73% for people diagnosed in the lowest income quintile followed by 77%, 79%, 83%, and 84% for people diagnosed in successively higher income quintiles. Even for stage 4 lung cancer, people diagnosed in the lowest income quintile have a 6% three-year survival rate compared to 6%, 7%, 7%, and 8% survival among people in successively higher income quintiles. There is a clear and increasing gradient between survival and income quintile for all stages of lung cancer diagnosis, with the highest survival observed at stage 1 and lowest survival observed at stage 4 diagnosis for all income quintiles.[2]

Survival by rurality

Three-year survival rates are similar in urban and rural dwellers in Canada.[5]

Causes, risk factors, and burden

The International Agency for Research on Cancer (IARC) classifies agents known to cause lung cancer. These agents can be categorized as occupations; dusts and fibres; metals; radiation; biological agents; personal habits; pharmaceuticals; and chemicals and mixtures.[42,43] A number of IARC-recognized lung carcinogens are found in Canadian workplaces and the environment, such as asbestos and diesel engine exhaust.[44]

The Canadian Cancer Society recognizes multiple known and possible risk factors for lung cancer in Canada. Known risk factors are smoking tobacco, second-hand smoke, radon, asbestos, occupational exposure to certain chemicals, outdoor air pollution, personal or family history of lung cancer, personal history of lung disease, exposure to radiation, arsenic in drinking water, pollutants from cooking and heating, weakened immune system, lupus, and beta carotene supplements in smokers. Possible risk factors are occupational exposure to certain chemicals, genetic mutations, smoking cannabis, physical inactivity, and a diet low in vegetables and fruit.[45]

The burden of lung cancer refers to the cumulative consequences of morbidity and mortality on society. It is the social and economic impacts of being sick (incidence) and dying (mortality) and may include direct and indirect health care costs, workforce losses, quality of life, and/or other outcomes relevant to health systems and society.[46] Lung cancer burden studies are particularly informative for modeling the contribution of specific risk factors to lung cancer, which can inform how to allocate resources or establish priorities for prevention and policy. The ComPARe study estimated the current and future burden of cancer in Canada due to modifiable risk factors. Approximately 80% (20,118) of lung cancers were estimated to be preventable in the year 2015. Of these, 72% could be prevented by eliminating commercial tobacco smoking; 2% by passive tobacco smoke exposure; 12% by physical inactivity; 7% by outdoor air pollution (particulate matter 2.5); and 7% by residential radon.[47-49]

Approximately 15% of lung cancers, or 3500 lung cancers, in the year 2011 were due to occupational exposures that included asbestos, diesel engine exhaust, radon, and several other established occupational lung carcinogens. The burden of occupational lung cancer was much higher in Canadian men (24%) compared to women (3%) due to higher prevalence of occupational lung carcinogen exposure in men compared to women. Much of this burden was driven by occupational asbestos exposure. Occupational asbestos exposure alone was responsible for an estimated 9-11.5% of lung cancers in Québec, Saskatchewan, and Nova Scotia, and 7.8-8.9% of lung cancers in Ontario and Alberta. In the year 2011, this amounted to nearly 1,900 lung cancers due to occupational asbestos exposure across all Canadian provinces.[50]

Lung cancer incidence in people who have never smoked commercial tobacco is rising in Canada and estimated to account for 15-25% of lung cancer cases.[51] This finding highlights the importance of occupational and environmental exposures and genetic factors as lung cancer causes. In a study about the burden of residential radon for lung cancer in Canada, reducing radon levels by 50% was estimated to prevent 681 lung cancer deaths. Further reducing radon levels by 85% was found to prevent 1263 lung cancer deaths. Modeling by jurisdiction showed the greatest benefit for Yukon.[52] Radon is estimated to cause approximately 13% of lung cancer deaths in Ontario[53] and 7% of lung cancer cases in Canada.[48] There is large geographical variation in radon levels across Canada. Radon exposure at levels below current Canadian radon exposure guidelines contributes to lung cancer mortality.[53,54]

Familial patterns of lung cancer are believed to be due to a combination of shared environmental exposures, similar lifestyle, and genetic factors.[55] Heritable mutations to the K-RAS, EGFR, B-RAF, HER2, EML4-ALK, ROS1, RET, and TP53 genes are associated with lung cancer and contribute to explaining population differences in the incidence of lung cancer by sex and histologic sub-types, and are also relevant for treatment.[55] These and other potential genetic causes of lung cancer are being actively studied in epidemiologic and basic research. Elevated rates of squamous cell carcinoma and the STK11 mutation in lung cancer tissue samples from Inuit from Nunavut's Qikiqtani (Baffin) region suggests sub-population genetic variation of lung cancer risk that needs further investigation in Canadian contexts.[35]

Lung cancer inequities

The Canadian Partnership on Cancer (CPAC) report on lung cancer and equity highlighted trends in lung cancer by income and geography.[5] CPAC described health inequity as “unfair and unjust systemic differences in health that can be avoided if appropriate interventions are made at the policy and system levels.”[5] People with lower versus higher income were almost twice as likely to be diagnosed with lung cancer, less likely to survive lung cancer at all diagnostic stages, twice as likely to smoke, more likely to be diagnosed at advanced lung cancer stages, and less likely to receive curative surgery. People with lower income are also more likely to be exposed to occupational carcinogens. People who live in rural versus urban communities were more likely to be diagnosed with lung cancer. Survival rates and rates of curative surgery were similar in rural and urban dwelling populations.[5]

The report also provided examples of the disproportionate impact of lung cancer in First Nations, Inuit, and Métis groups. Compared to the non-Indigenous population in Canada, First Nations adults were 35 percent less likely to survive lung cancer five years after diagnosis. Inhabitants of Inuit Nunangat were more than twice as likely to be diagnosed with lung cancer and have some of the highest smoking rates in the world. Métis adults were more likely to be diagnosed with lung cancer and 30 percent less likely to survive it five years post-diagnosis.[5]

CPAC identified three barriers that can be created by health inequities: systemic barriers to medical care due to structural racism and discrimination faced by First Nations, Inuit, and Métis and people of colour; economic barriers, e.g. accessing regular and consistent health care due to low incomes that are more prevalent among First Nations, Inuit and Métis, recent immigrants, the differently abled, and single parents; and geographical barriers to health services and health care options that particularly impact First Nations, Inuit and Métis.[5]

In their report, CPAC urged cancer agencies, governments, and organizations representing underserved communities to work together on making culturally appropriate supports for smoking cessation available as a standalone service and as a part of organized lung cancer screening programs. CPAC recommended that lung cancer screening programs be designed to meet the needs and accessibility needs of underserved populations, including people with lower incomes, rural and remote communities, and First Nations, Inuit, and Métis. CPAC made several recommendations for improved data to measure lung cancer and equity. One of these recommendations was to collaborate with organizations representing underserved groups to co-create data highlighting the relationships between social, economic, and environmental factors and their impact on health and well-being.[5]

Prevention

Prevention of lung cancer can occur at one or more of three levels: primary, secondary, and tertiary (Figure 1). Primary prevention refers to eliminating or reducing exposure to lung cancer causes and risk factors. Primary prevention initiatives prevent people from being diagnosed with lung cancer and as such, it is the most effective type of prevention. Smoke-free legislation is an example of a primary prevention strategy. Secondary prevention refers to the early detection of lung cancer. It does not prevent people from being exposed to lung cancer causes and risk factors, nor does it prevent people from being diagnosed with lung cancer, but it does provide an earlier diagnosis so that people can seek treatment for lung cancer in its earlier stages. Screening for lung cancer with LDCT is an example of secondary prevention. Tertiary prevention is comprised of treatment for lung cancer. Treatment for non-small cell lung cancer, that may be used alone or in conjunction, includes surgery, radiation therapy, chemotherapy, immunotherapy, and/or endobronchial therapies.

Smoke-free legislation, a primary prevention measure, gradually swept across Canada in the 1990s and is largely responsible for declining time trends of lung cancer incidence. Federal asbestos regulation that came into force in 2018 is another primary prevention policy that will prevent Canadians from being exposed to new asbestos and asbestos-containing products. Little else has been done in Canada on the primary prevention of lung cancer at the level of social, political, and economic determinants of lung cancer. Most efforts have concentrated on tertiary prevention alongside rapid advancements in treatment for cancer in general. The use of LDCT to screen for lung cancer – a form of secondary prevention – is being more widely implemented in Canada.[18]

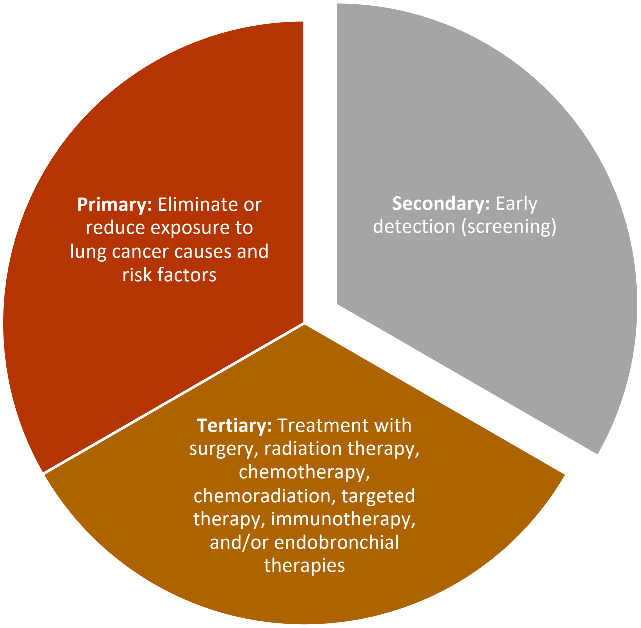

Figure 1. Primary, secondary, and tertiary prevention of lung cancer.

1.2 Lung cancer screening

Purpose

The purpose of lung cancer screening is to reduce lung cancer mortality and the burden of lung cancer treatment. Lung cancer screening accomplishes these aims by detecting and diagnosing lung cancer in an early stage of the disease when there are more treatment options, the disease is more responsive to treatment, and the probability of survival is improved compared to the diagnosis and treatment of lung cancer at a later stage of the disease. “Early stage” for lung cancer is generally considered stages 1 and 2, while “late stage” is considered stages 3 and 4. Screening is intended for people who currently have no clinical symptoms of lung cancer and who have not been diagnosed with lung cancer, but who are at risk of being diagnosed with lung cancer at some point in the future. Screening is offered to eligible candidates on a regular interval to detect the presence of lung cancer.

Different lung cancer screening technologies and approaches have been used and evaluated. Technologies have included radiograph (i.e., x-ray) and magnetic resonance imaging (MRI) of the lungs that aim to screen for potentially cancerous lung nodules. Screening methods involving the use of blood and sputum biomarkers for lung cancer have also been examined. Technologies may be used alone or in conjunction as a part of different screening approaches. For instance, population-based strategies aim to screen people based on either their age and smoking history, or modelling of their individualized risk based on multiple lung cancer risk factors that can include genetic information related to lung cancer risk (e.g., polygenic risk scoring). Artificial intelligence and machine learning methods have been explored as aids for the early detection of lung cancer and prediction of lung cancer risk from lung imaging that may be obtained via population-based strategies.

Low dose computed tomography (LDCT) has emerged as the most effective screening technology for correctly finding lung cancers and reducing lung cancer deaths compared to no screening and other screening methods that have been evaluated in comparison to LDCT. LDCT uses a low dose of radiation to obtain an image of the chest using a conventional CT machine for the screening procedure without the use of contrast dye. LDCT has been evaluated in randomized controlled trials conducted in the United States (U.S.), United Kingdom (U.K.), the Netherlands and Belgium, and Denmark. One of the most influential studies to date comparing LDCT to chest x-ray for the purpose of screening for lung cancer is the U.S. National Lung Screening Trial (NLST). This randomized controlled trial included 53,454 men and women between the ages of 55 to 74 years who smoked for 30 or more pack-years and who were current smokers or quit smoking less than 15 years ago. The use of LDCT was found to be superior to chest x-ray for reducing lung cancer mortality in this trial population. However, in the NLST approximately 95% of positive LDCT screens were false upon subsequent evaluation. A meta-analysis of 8 randomized controlled trials involving over 90,000 participants found an absolute risk reduction of lung cancer mortality of 0.4% when comparing LDCT to usual care or chest radiography (1.72% versus 2.12% mortality rate, respectively).[56]

The NLST is the largest randomized controlled trial of LDCT. A statistically significant lung cancer mortality reduction was found in the NLST upon comparing this outcome between people who were screened using LDCT and those who were screened using chest radiography (x-ray). Despite conflicting and still emerging findings about the impact of LDCT lung cancer screening on lung cancer mortality, the NLST continues to influence the development of LDCT lung cancer screening guidelines and further studies worldwide. LDCT is the screening technology of choice in the widening implementation of population-based lung cancer screening programs in Canadian jurisdictions that are largely informed by, and that improve upon, how LDCT was used in the NLST.

Canadian lung cancer screening guidelines

The Canadian Task Force on Preventive Health Care (CTFPHC) issued its recommendation on screening for lung cancer in 2016. To date this is the only CTFPHC recommendation on lung cancer screening. It is national in scope and aimed at clinicians and policymakers across Canadian jurisdictions where cancer screening is offered.

The CTFPHC recommends annual screening for up to three consecutive times with LDCT for adults aged 55 to 74 years with at least a 30 pack-year smoking history who currently smoke or quit smoking less than 15 years ago (weak recommendation; low quality evidence). The CTFPHC does *not* recommend routine screening using LDCT for all other adults, regardless of age, smoking history, or other risk factors who do not have at least a 30 pack-year smoking history or who quit more than 15 years ago (weak recommendation, low quality evidence). Additionally, the CTFPHC does not recommend chest x-ray for lung cancer screening, with or without sputum cytology (strong recommendation; low quality evidence). Finally, the CTFPHC recommends that screening should only be carried out in health care settings with access to expertise in lung cancer early diagnosis and treatment.[57]

Four major bodies of evidence served as the basis for the CTFPHC lung cancer screening recommendation: efficacy of LDCT to screen for lung cancer, capacity of the lung cancer sub-model of the Cancer Risk Management Model to evaluate cost-effectiveness decisions regarding lung cancer screening in Canada, a systematic review of the benefits and harms of screening asymptomatic adults who are at average and high risk for lung cancer, and patient preferences with respect to the CTFPHC's draft lung cancer screening recommendations.[58]

In the latter study (patient preferences), fifteen participants who would be eligible for screening according to the draft CTFPHC recommendation generally agreed with the recommendation but were concerned about equitable access to LDCT in Canada (especially in remote regions) and the eligible age range, which they believed should be widened. This study was used by the research team to develop suggestions for knowledge translation tools tailored for screen-eligible individuals, such as a tool that explains the age-dependent benefits and harms of LDCT lung cancer screening. As this study was oriented towards knowledge translation, preferences were emphasized over values and an ethics analysis was not conducted.[58]

The complexity of deciding who should be eligible for lung cancer screening is reflected in the number of risk prediction models available to help identify people for whom lung cancer screening would likely provide a favourable ratio of benefits to harms. Risk prediction models are used to inform screening eligibility by estimating risk of lung cancer in a defined period based on self-reported lung cancer risk factors that are inputted as variables in the model. In Canadian jurisdictions, variations of the PLCOm2012 risk prediction model are being used or considered in lung cancer screening programs and activities.[18] This model estimates risk based on age, race or ethnicity, education, body mass index, history of commercial tobacco smoking, personal and family history of cancer and lung cancer, and personal history of chronic obstructive lung disease.[59] Models used elsewhere include variables for other population-specific causes of lung cancer. The Liverpool Lung Project model, for instance, has explored potential inclusion of asbestos-exposed workers in screening activities in the United Kingdom.[60] The inclusion of occupationally exposed populations, especially workers exposed to asbestos, is an area of active scientific and policy debate.[61-65] There is a need for alternative models or eligibility criteria that are more responsive to elevated and younger lung cancer incidence and mortality rates in African American and some Indigenous populations that reflect racial differences in smoking patterns, genetic susceptibility, lung comorbidities, socioeconomic correlates with lung cancer, and higher exposure to environmental lung carcinogens.[66,67]

The result of risk prediction modeling is an estimation of the risk of being diagnosed with lung cancer in a future defined period. This estimate acts as a score, or threshold, upon which screening eligibility pivots. Screening eligibility thresholds reflect assessments or judgments about optimizing the ratio of screening benefits and harms for patients, as well as balancing screening-related costs for health systems. For instance, a low threshold would mean that more people are eligible for lung cancer screening, which would increase the number of false positive screening outcomes and inflate health systems costs for follow-up investigation of false positive results. A high threshold would mean fewer people deemed eligible for lung cancer screening, which would miss lung cancers that could be detected via screening and increase health systems costs for treatment of lung cancer diagnosed at late stages of the disease. Threshold values are therefore contingent on the epidemiology of lung cancer and capacity of health systems which differ across Canadian jurisdictions. Using variations of the PLCOm2012 risk prediction model, eligibility based on the threshold for developing lung cancer over the next six years is greater than 1.5% in Alberta and British Columbia lung cancer screening studies, and 2% or more in the Ontario and Pan-Canadian studies.[18] These differences have implications for which individuals are determined to be at high risk for lung cancer and therefore eligible to be screened for lung cancer, as well as how resources are allocated towards lung cancer screening in health systems.

Screening pathway

The screening pathway for lung cancer is the general sequence of steps that are followed in an organized, population-based lung cancer screening program (Figure 2). The pathway begins with a screening referral of insured patients from a primary care provider, such as a family physician or nurse practitioner; a self-referral (e.g., from individuals who respond to public advertisements about lung cancer screening programs); or a program invitation or recall. The next step is risk assessment, which is when determinations of screening eligibility are made based on individualized risk of being diagnosed with lung cancer in a defined period. Risk prediction modeling is currently being used for risk assessment, which uses lung cancer risk factor variable data reported by potentially eligible screening participants to model their lung cancer risk. People assessed to be eligible for lung cancer screening can participate in LDCT screening. Participants with negative screening results for lung cancer may be recalled to screening according to guidelines; those with positive screening results may be recalled early to LDCT screening or be invited to engage in diagnostic follow-up. Participants with positive LDCT screening or diagnostic follow-up results are then referred to further follow-up evaluation or lung cancer treatment; otherwise, participants with negative results for lung cancer are recalled back to screening according to guidelines. All participants who engage with lung cancer screening and who currently smoke commercial tobacco, even if determined to be ineligible in the risk assessment step, are offered smoking cessation support.

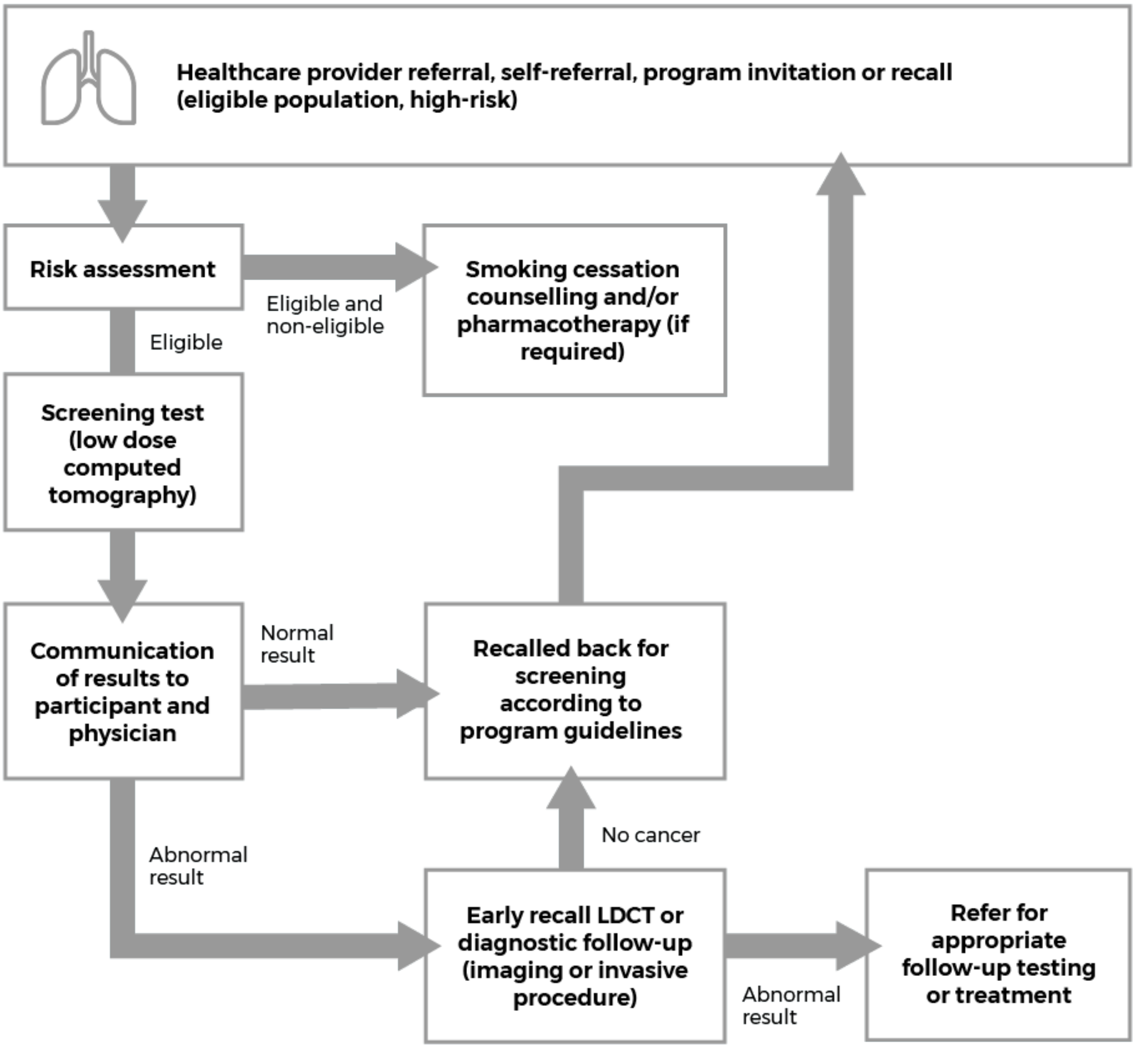

Figure 2. Lung cancer screening pathway in Canada.

Lung cancer diagnosis

Positive LDCT lung cancer screening results require follow-up investigation to evaluate the finding(s) and determine if lung cancer is present. Organized diagnostic assessment (e.g., in Ontario) provides a pathway to evaluate LDCT screening findings and determine a lung cancer diagnosis. Strategies to accelerate the diagnosis of lung cancer detected via screening have been implemented in seven provinces given the rapid progression and high mortality rate of lung cancer. Rapid diagnosis initiatives are coordinated with lung cancer screening programs based on referral, e.g., from the reporting radiologist in Ontario's lung cancer screening program, or the size of the pulmonary nodule detected via screening, e.g., 8mm or greater in Quebec's lung cancer screening demonstration. If lung cancer is suspected upon LDCT screening results, preliminary staging is immediately conducted to avoid diagnostic delays. LDCT screening results combined with other evidence, e.g., patient-reported symptoms and history, additional (interventional) imaging, thoracentesis, and/or biopsy may be used alone or in combination to make a diagnosis of pathological NSCLC or SCLC. Pathology-informed staging is then determined according to sub-type-specific staging protocols. Psychosocial and palliative care may be offered early and across the lung cancer diagnostic pathway.[68]

Lung cancer treatment

Lung cancer treatment, psychosocial and/or palliative care are offered once a diagnosis of lung cancer is made. Lung cancer treatment is generally offered at sites where cancer treatment is provided; these include regional and some local cancer centres. Lung cancer treatment is diverse and often requires options for surgery, radiation and systemic therapy, palliative care and psychosocial oncology, and end of life care planning and bereavement support and follow-up. For this reason, lung cancer treatment centres tend to be located within or around major urban centres in Canadian provinces with fewer treatment centres in rural and remote regions.

Lung cancer treatment options are sub-type and stage dependent and require consideration of the health status of the person diagnosed with lung cancer (e.g., comorbidities). Other salient factors include patient and family willingness to undergo treatment, health system resources, and access to treatment. According to Ontario lung cancer treatment pathways, for NSCLC diagnosed at stage 1, treatment options include surgical resection, systemic therapy, or radiation therapy if the tumor is unresectable and medically inoperable or if a patient declines surgery. NSCLC diagnosed at stage 2 may be resected if operable and treated with radiation and systemic therapy. Radiation and systemic therapies are offered if unresectable or medically inoperable. NSCLC diagnosed at stage 3 may be treated with radiation and systemic therapies and surgical resection. If unresectable or medically inoperable, chemoradiation (systemic and radiation therapies) and immunotherapy are offered; otherwise, palliative care (systemic and/or radiation therapy and end of life care planning) are provided. NSCLC diagnosed at stage 4 treatment options include therapy with palliative intent (chemotherapy, radiation, surgery, etc.), psychosocial oncology and supportive care, and end of life care planning. Resection of metastatic brain lesions and radiosurgery to the brain may be provided as needed, and treatment pathways re-assessed if there are brain metastases.[69]

SCLC diagnosed at stages 1, 2, and 3 may be offered a range of treatment options (i.e., surgical resection, radiation therapy, systemic therapy, stereotactic ablative radiotherapy, prophylactic cranial irradiation, palliative care, psychosocial oncology, and/or end of life care planning) depending on the specific stage and initial treatment response. SCLC diagnosed at stage 4 may be eligible for radiation and/or systemic therapy, palliative care and psychosocial oncology, and end of life care planning. People who receive treatment for any type or stage of lung cancer may proceed to the follow-up care pathway. Bereavement support and follow-up is offered to families for patients who died after receiving end of life care.[70]

Lung cancer screening activities in Canada

Lung cancer screening is the newest entrant to the suite of cancer screening programs in Canada, and the first to use a risk-based approach for assessing the eligibility of target populations for screening. Lung cancer screening is an area of lively scientific research and policy and program development in Canada. As of June 2022, planning or implementation activities have been taking place in all Canadian provinces by provincial cancer agencies. There have been no planning or implementation activities in the territories. All provincial lung cancer screening projects have been funded by the Canadian Partnership Against Cancer (CPAC).[18]

Organized, population-based LDCT lung cancer screening programs have been implemented fully across the province in British Columbia and partially in Ontario (at four sites in Ottawa, Toronto, Oshawa, and Sudbury) following previous pilot or research studies (https://www.cancercareontario.ca/en/guidelines-advice/cancer-continuum/screening/lung-cancer-screening-pilot-people-at-high-risk). A demonstration project is in progress in Quebec at 8 locations, proceeding a pilot study in this province (https://www.quebec.ca/en/health/advice-and-prevention/screening-and-carrier-testing-offer/lung-cancer-screening-demonstration-project). The following provinces are planning for implementation: Alberta, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, Prince Edward Island, and Newfoundland and Labrador. All provinces and the Yukon have produced a standard business case. A research study is ongoing in Alberta (in Calgary, Edmonton, and Fort McMurray) and the Pan Canadian Early Detection of Lung Cancer (PanCan) Study has ended. Except for New Brunswick and Prince Edward Island, all provinces have an advisory committee or working group which is generally comprised of community members, clinicians (including smoking cessation advisory committees), and provincial stakeholders (including Indigenous cancer leads) and provides opportunities to collaborate to varying extents on program creation, implementation, and evaluation; project governance; and shared decision-making.[18]

Strategies are being developed, implemented, or evaluated with respect to referral and recruitment, including the recruitment of specific populations. Physician and self-referral methods have been used in pilots and studies in British Columbia, Alberta, Ontario, the PanCan Study, and Quebec. Facebook has additionally been used as a referral strategy in pilots and studies in British Columbia, Alberta, and Quebec. Smoking cessation referral methods and pharmacotherapy have also been examined in association with lung cancer screening pilots and studies in Canada. People who are eligible for screening may be offered smoking cessation on-site. Otherwise, people who are ineligible for screening are referred to external smoking cessation services. Similarly, pharmacotherapy may be provided through the lung cancer screening program for free or at cost to the patient and may require a prescription from a primary care provider.[18]

Recruitment strategies in pilots and studies of high-risk, screen-eligible people include mass media, social media, physician recruitment, public facing resources, community events, word of mouth, and labs to increase awareness and education about lung cancer screening. Client reminders have also been used to promote participation and access. Specialized strategies have been used to engage First Nations, Inuit, and Métis in lung cancer screening in British Columbia, Ontario, Quebec, and Nova Scotia. These were co-developed with community members in all provinces except Quebec. Strategies used include developing culturally safe materials and resources; promotion of health literacy; providing transportation to screening services; direct community engagement, including with policymakers and clinicians in Indigenous communities; and translation of informational materials. Recruitment strategies are most detailed in Ontario.[18] Community engagement has occurred through the Indigenous Cancer Care Unit, Regional Indigenous Cancer Leads and regional teams to improve education and awareness of lung cancer screening. The Indigenous Tobacco Program and smoking cessation counselling have provided targeted education. Culturally safe and language-appropriate materials have been developed to support this work tailored for specific Indigenous communities, and medical travel benefits have been made available for those who are eligible. Projects, including research about barriers, sharing test results, and facilitating access to follow-up and treatment, are underway and led by First Nations, Inuit, and Métis data governance principles.[18]

Strategies have also been used in British Columbia, Ontario, Quebec, and Nova Scotia to improve the recruitment of underserved populations in lung cancer screening. Racial or ethnic minorities have been consulted during the design and development of lung cancer screening in British Columbia via working group participation and focus testing of screening materials. In Ontario, culturally and linguistically appropriate education, self-referral, and a gender diverse lung cancer screening policy have been co-developed with underserved populations overall, people without a primary care provider, non-English speakers, non-binary and gender diverse people, and underscreened populations as a result of the COVID-19 pandemic. A lung cancer screening advertisement in Montreal newspapers has been used to recruit Montreal ethnic populations. In Nova Scotia, there are plans to directly reach out to organizations serving high-risk communities including people who are low income or who do not have a primary care provider. Travel funding to improve lung cancer screening access has been provided to rural and remote populations in British Columbia and Ontario. A "hub and spoke" model is also being used in Ontario to offer screening at local hospitals close to or within rural and remote areas, and radiologist interpretation at a larger regional hospital. Community engagement is being used in Ontario and will be used in Nova Scotia to meet rural and remote population screening needs.[18]

Eligibility criteria have varied for participation in lung cancer screening pilots and studies in Canadian jurisdictions where these activities have taken place (Table 1). Reasons for variation include jurisdiction-specific lung cancer epidemiology and lung cancer screening program cost-effectiveness for health systems.[18]

Table 1. Lung cancer screening eligibility criteria in Canadian jurisdictions.

Jurisdiction	**Pilot/study name**	**Pilot/study inclusion criteria**	**Guideline inclusion criteria**	**Risk prediction model criteria**
Ontario	Ontario Lung Cancer Screening Pilot for People at High Risk	Current/former smokers ages 55-74 who have smoked cigarettes daily for at least 20 years, with 2% or greater risk of developing lung cancer over the next 6 years as determined by risk assessment using the PLCOm2012 risk prediction model	Age: 55-74 years Smoking: > 20 years	Age, education, family history of lung cancer, body mass index, personal history of cancer and chronic obstructive pulmonary disease, smoking status, smoking duration, smoking intensity, smoking quit-time
British Columbia	BC Lung Screen Trial/Pan-Canadian	USPSTF 2013 guideline or >1.5% risk of developing lung cancer over the next 6 years	Age: 55-80	Age, education, ethnicity, family history of lung cancer, body mass index,

	Early Detection of Lung Cancer Extension Project/ International Lung Screen Trial		Smoking: > 20 years, current or former	chronic obstructive pulmonary disease status, smoking duration, smoking intensity, smoking quit-time, personal history of cancer
Alberta	Alberta Lung Cancer Screening Research Study	NLST criteria or >1.5% risk of developing lung cancer over the next 6 years	Age: 55-75 Smoking: 30 or more pack-years, quit 15 or less years ago	Age, education, ethnicity, family history of lung cancer, body mass index, chronic obstructive pulmonary disease status, smoking duration, smoking intensity, smoking quit-time, personal history of cancer
Pan Canadian Early Detection of Lung Cancer Study		2% or more risk of developing lung cancer over the next 6 years	Age: 55-75 Smoking: >20 years, current or former	Age, smoking duration, pack-years, family history of lung cancer, education level, body mass index, chest x-ray in the past 3 years, history of chronic obstructive pulmonary disease
Quebec	Pilot Study by the Centre Universitaire de Sante McGill	INESSS guidelines	Age: 55-74 years Smoking: current or former with PLCO risk score of 2% or more	Age, education, ethnicity, family history of lung cancer, body mass index, chronic obstructive pulmonary disease, smoking duration, smoking intensity, smoking quit-time
Quebec	Lung Cancer Screening Demonstration Project in Quebec	INESSS guidelines; People aged 55 to 74, smokers or ex-smokers, who have quit for less than 15 years, but have	Age: 55-74 Smoking: >20 years,	Age, education, ethnicity, family history of lung cancer, body mass index, chronic obstructive pulmonary disease

		smoked for more than 20 years	current or former with PLCO risk score of 2% or more	status, smoking duration, smoking intensity, smoking quit-time

Effectiveness of lung cancer screening

Lung cancer screening effectiveness describes comprehensive judgments about how well screening correctly detects true and false cases of lung cancer, including test characteristics such as sensitivity. The sensitivity of LDCT compared to other screening modalities ranges from 71.1 to 93.8%[71-74] in trials and studies using different screening eligibility criteria, number of screening rounds, and follow-up duration of participants; specificity ranges from 62.7 to 98.6%.[71-74] Generally, sensitivity is higher with the use of population-specific multivariable risk prediction models compared to eligibility based on age and smoking variables alone.

Cost-effectiveness of lung cancer screening

Cost-effectiveness studies of LDCT lung cancer screening in Canadian health systems have modelled lung cancer risk and costs associated with lung cancer screening, treatments, and outcomes for screen-eligible populations under different screening scenarios. Screening has been estimated to be cost-effective in these studies; however, importantly, cost-effectiveness remains controversial and highly contingent on the prevalence of the target population who are found eligible for screening, screening participation rates, and costs of conducting LDCT – and may even add to health care expenditures[75]. Cost-effectiveness estimates vary considerably in Canadian jurisdictions, which demonstrates different modelling approaches and assumptions, screening frequency, screening eligibility criteria, the presence and type of smoking cessation intervention, and health systems costs for lung cancer screening and treatment.

Compared to no lung cancer screening, LDCT lung cancer screening has been modelled to be cost-effective for health systems in Canada, Ontario, and Alberta, with incremental cost-effectiveness ratios ranging from $24,000 to $62,000 per quality-adjusted life-years (QALYs), depending on how smoking history and smoking cessation rates are modelled.[76] Use of risk prediction models to limit screening eligibility to people in Canada at high risk for lung cancer, set at a 2% threshold over 6 years, has been modelled to cost $20,724 per QALY gained. This finding mostly reflected cost savings from non-lung cancer outcomes in diverse groups exposed to commercial tobacco.[77] A microsimulation analysis of 576 different lung cancer screening policies in Ontario demonstrated that strict smoking eligibility criteria were more cost-effective compared to less stringent eligibility criteria in annual LDCT screening with little impact on life-years gained.[78] Cost effectiveness was most responsive to costs of LDCT screening.[78] Biennial LDCT screening of eligible Canadians according to NLST criteria was modeled to be more cost-effective and to produce similar QALYs compared to annual screening.[79] In Alberta, lung cancer screening was estimated to save $42 million in health service utilization costs associated with stages 1 or 2 screen-detected diagnoses compared to stages 3 or 4 diagnoses, for a net cost avoidance of $6.65 million after accounting for the cost of the LDCT lung cancer screening program itself.[80]

Addition of a comprehensive smoking cessation intervention generally reduced the average cost-effectiveness by half.[79] Implementing smoking cessation interventions alongside LDCT lung cancer screening has been modeled to be cost-effective in the context of annual screening in Canada and may prevent additional lung cancers and save life-years at a relatively low cost.[81]

1.3 Ethical aspects of lung cancer screening

Normative questions and debates

Ethical aspects of lung cancer screening are relevant for health policy because this is the space where decision-making on lung cancer screening occurs. Normative questions that require health policy decision-making include:

- Should population-based LDCT lung cancer screening programs be publicly funded in Canadian health systems?
- Who should be screened for lung cancer? Who should not be screened for lung cancer, and what might be the implications of screening some and not others?
- How should lung cancer screening be offered to target populations?
- What should be the acceptable trade-off of screening benefits and harms, and how should the benefits and harms be distributed in society?
- How should resources to prevent lung cancer be allocated between screening and other prevention activities in health systems?

Ethical issues related to established cancer screening programs suggest what might be likely ethical aspects for lung cancer screening.[19] Ethical issues relate to justification for the offer of screening, promoting individual autonomy in decision-making to participate in screening, and risks of harms associated with limitations of our knowledge of lung cancer, the intrinsically probabilistic natural history of lung cancer, and values, interests and biases inherent in lung cancer screening policymaking processes.[19,82-84] Screening is an imposition in the lives of people who are asymptomatic for cancer and there are ethical concerns about what and whose values, potentially conflicted and/or biased, motivate the development and implementation of cancer screening policies and programs.[84] Screening may elicit responses based on people's fear of cancer and enthusiasm for the use of technologies in cancer prevention and care. Risk categorization schemes (e.g., risk prediction modelling, risk stratification, risk algorithms, risk scoring, risk-based screening, etc.) using genetic and/or individual information about risk factors has raised ethical concerns about genetic discrimination and privacy, the acceptability of not preventing mortality to avoid psychological harms, and intergenerational equity, e.g., in the case of polygenic risk scoring for breast cancer screening eligibility, which tends to identify more younger compared to older women for screening.[85] Dennison et. al. have used Beauchamp and Childress's principles of medical ethics to highlight that in addition to concern for benefits and harms, risk stratification for cancer screening elicits questions about whether screening participation is the right of individuals and how to support the autonomy of people who cannot or choose not to participate in risk assessment.[86] These features require ethical assessment and justification and demonstrate the challenges of ensuring societal fairness and promoting individual autonomy.[19,83] For lung cancer screening, the use of risk prediction modeling is used to further reduce the number of individuals invited to screen by limiting screening invitations to only those who are high-risk, and mostly based on their current and previous history of commercial tobacco smoking. This has the potential to create or reproduce stigma against people who have a history of commercial tobacco smoking, and especially stigma againt those who currently smoke commercial tobacco, with potential effects on the willingness of these individuals to participate in risk assessment and screening. Lack of transparency about the goals of screening also contributes to compromising public trust and understanding about screening, with further implications for participation of high-risk individuals.

The benefits to harms ratio of screening is marginal,[87] delicate, complex, and challenging to effectively communicate to people who are considering their own participation in screening. Difficulties translating population-level evidence about lung cancer screening benefits and risk of harms to the individual patient may hinder the potential of patients to make informed decisions regarding their own screening participation. Risks of harms inherent to cancer screening technologies include risks of false positive and false negative screening results and overdiagnosis, and the subsequent intervention cascades from the occurrence of each of these potential harms. Overdiagnosis is a major harm of screening and for lung cancer, an estimated 49% of diagnoses are estimated to be overdiagnosed via LDCT screening.[88] Normative and empirical research about cancer screening ethics has identified overdiagnosis as one of the most serious harms of screening, resulting in more harm than good[89] due to overdefinition of disease[90] and overdetection of disease.[91] Overdiagnosis, thus, is due to our limited knowledge of lung cancer and the intrinsically probabilistic natural history of lung cancer. Overdiagnosis of lung cancer via screening causes physical and psychological harm and direct financial and opportunity costs to individuals and families, and preventable use of limited health resources. The inability to identify cases of screen-detected overdiagnosed lung cancers poses a serious limitation on rectifying these harms, or even preventing them. Hofmann et. al. have proposed patient, professional, and population perspectives on overdiagnosis and options for measuring overdiagnoses at each of these levels.[92] For lung cancer screening using LDCT, there is also a risk of incidental chest findings. Physical and psychological harms and financial and opportunity costs may be encountered in the screening process, from decision-making to participate in screening to diagnostic follow-up and treatment.[93] The benefits of screening should be clear and sufficient to outweigh the risks of harms. Balanced, complete, and up-to-date evidence about benefits and harms should be communicated in a variety of formats and allow room for discussion driven by patients to obtain knowledge needed to support their informed choice.[94]

Use of risk prediction models to manage the benefits to harms ratio of lung cancer screening is relevant to the autonomy of patients who rely on their predicted risk of lung cancer using these models to guide decision-making about their own screening participation. Transparency, explanation, and justification about data included (and excluded) and how data are modeled in risk prediction may support patient autonomy, reduce patient-provider inequalities about knowledge of risk, and contribute to building trusting relationships between patients and their health care providers and health systems.[94,95] The requirement to participate in risk prediction to determine screening eligibility may be a deterrent for some who could benefit from screening, as the risk prediction process relies on self-reported personal health information including history of smoking commercial tobacco. The ability of risk prediction modelling to ensure that screening benefits outweigh harms may be uncertain, as the variables and assumptions used in risk prediction models yield different results when applied to different sub-populations.[96] For health systems, the use of risk prediction models to guide patient selection for screening has implications for the number of people screened, who is included in screening (e.g., people with a smoking history) and excluded from screening (e.g., people with little or no smoking history who might have a history of occupational or environmental lung carcinogen exposure or genetic risk factors for lung cancer), and screening program costs.[97]

As cancer screening is simultaneously a health care and public health activity, equity of screening access and outcomes for different types of communities or groups with high rates of lung cancer incidence are also key ethical issues.[19] Clinical ethics and public health ethics frameworks provide guidance about how to address cancer screening ethical issues at individual and structural/systemic levels, respectively. However, these ethics frameworks sometimes conflict and there is little empirical or ethical evidence about how to negotiate between individual and societal needs and values.[19,20]

The population distribution and causes of lung cancer in Canada suggest the need to elaborate upon the public health ethics dimension of lung cancer screening and to examine the interstitial space between public health ethics and clinical ethics frameworks that may be engaged in acting upon the ethical issues. Unequal population patterns of lung cancer are systematic, preventable, and inequitable. Differential patterns importantly include varying and higher incidence and mortality rates and lower survival rates of lung cancer in specific (but not all) Indigenous communities,[6-10] low socioeconomic,[3-5] and certain rural[5] people in Canada. Lung cancer incidence in Canada, including in these populations, is mostly attributed to patterns of commercial tobacco smoking,[98] which engages with the colonization of tobacco for Indigenous populations[99] and the vulnerability of low socioeconomic status populations to commercial tobacco smoking dependence.[100] Higher incidence rates may also be associated with increased prevalence or intensity of exposure to environmental and occupational lung carcinogens along independent as well as intersecting axes involving socioeconomic, immigrant, and Indigenous identities.[101-106] Greater mortality and lower survival rates partly reflect inequitable access to primary and cancer care,[107-109] including a lack of access to timely, comprehensive, and culturally appropriate health care.

Major causes of lung cancer inequities in Canada are political, economic, and social determinants of lung cancer incidence and outcomes in Canadian society that include, but are not limited to, colonialization of tobacco,[99,110] commercialization of asbestos and other lung carcinogens that also involve poorly regulated emissions of lung carcinogens in extraction and manufacturing processes, and anti-Indigenous racism in health systems. Social determinants of smoking in Inuit in Inuit Nunangat differ by sex and include certain measures of education, household income, food insecurity, residential school history, and homes with crowding or current smoking activities.[33] The inequitable distribution of lung cancer incidence, mortality, and survival in Canadian society and the reasons why these inequities exist are bioethical issues.[111] Health policy has the capacity to respond to these bioethical issues; LDCT lung cancer screening is one of several opportunities within the health policy realm. Public health ethics offers concepts such as accountability to different types of communities, reciprocity, solidarity, trust, and justice that may be used to normatively guide policy decision-making about ethical issues or to conduct ethical analysis of public health programs.[112-114] However, there is little known about what ethical concepts are being used, or should be used, to address bioethical issues at structural and systemic levels affecting populations, and how these ideas may engage with ethical frameworks that are centered on ethical issues encountered by individual patients in clinical LDCT lung cancer screening contexts.

Empirical evidence about ethical issues and how they are being resolved can help fill this knowledge gap. Ethical aspects are important to elucidate in Canadian health policy contexts because this can support the design and delivery of lung cancer screening programs that are equitable, effective, and a wise use of limited health resources in Canadian health systems, which are publicly financed and administered. Health policy decision-making about lung cancer screening ethical issues involves ethics frameworks, normative guidance, or moral judgments. There is a gap in knowledge about what the ethical issues are in health policy and how the ethical issues are being, and how they should be, addressed in health policy.

Empirical investigation of what ethics tools are being used to resolve ethical issues, and how and why they are being used and by whom, can provide transparency to populations who have an ethical stake in lung cancer screening and to the public regarding normative justification for the allocation of publicly financed health resources. Eliciting social values about lung cancer screening ethical issues may inform ethical aspects and responses from health policy, which can help create lung cancer screening programs that effectively engage the participation of people prioritized for screening. Empirical investigation of ethical issues can provide insights about how ethical guidance from public health and clinical ethics frameworks may engage with one another in the health policy sphere. This knowledge can advance ethics theory relevant to cancer screening and other disease screening activities in health systems.

This research aims to address a knowledge gap at a time when lung cancer screening activities are occurring and programs are being implemented in Canadian jurisdictions, by asking what the ethical issues are and how may they be resolved in health policy. This research seeks to contribute a comprehensive understanding of the ethical aspects of population-based LDCT lung cancer screening programs in Canadian jurisdictions informed by the mutually nurturing interactions between empirical evidence, ethics theory, and social values. This research uses an empirical bioethics approach to surface ethical issues regarding organized LDCT lung cancer screening and show what moral judgments, normative frameworks, and social values may be in use to address the ethical challenges in Canadian health policy. It aims to add novel empirical evidence that can extend and specify ethics theory and debate about negotiating between the clinical and public health ethics dimensions of cancer and disease screening in health policy. Finally, this research hopes to advance applications of empirical bioethics approaches in the health policy milieu.

Definitions of “ethics” and “social values”

The term “ethics” in this research refers to ethical aspects and the normative guidance, ethics principles, or moral judgments about ethical issues associated with population-based LDCT lung cancer screening programs in Canadian jurisdictions. Ethical issues are informed by cancer screening ethics and morally relevant facts about lung cancer in Canada. The term includes clinical and public health ethics frameworks that may be in use, or that should be used, to address the ethical issues.[115]

"Social values" is commonly used by researchers in reference to "patient values" or "public values in aggregate." Patient values are relevant to patients, individuals, and caregivers, whereas public values are related to social groupings of patients or individuals that may be of particular interest in a health technology assessment (EUnetHTA). Social values may affect resource allocation decision-making and priority-setting in health systems.[116] In this research, the term "social values" refers to the value judgments, attitudes, and beliefs of the public about the ethical issues associated with population-based LDCT lung cancer screening programs in Canadian jurisdictions. This use is congruent with how the term "social values" has been used to elicit social values and ethics in health technology assessment.[115] This research is undertaken for descriptive purposes; that is, to solely describe what social and ethical values are, and not which ethical and social values ought to drive policy. The descriptive ethical and social values evidence generated from this research may be later and separately analyzed using ethics theory relevant to the research data to produce normative recommendations for addressing ethical issues in policy.

It is important to understand social values towards the ethical issues associated with lung cancer screening to design screening programs that are equitable, inclusive, and attentive to social needs – and therefore more likely to effectively engage people who could benefit from screening.[83,115] Social values regarding mammography screening elicited from women in Ontario[94] and Canada[117] have yielded important insights about how to support people to make informed choices about breast cancer screening. Research about social values and cancer screening has emphasized patient values regarding their own participation in cancer screening. This research has drawn attention to the values related to cancer screening as an individual *health care* intervention. Social values research can contribute to informing policy priorities and allocating resources within health systems[116]; however, social values related to population or structural/systemic aspects of cancer screening are under-researched. As a result, little is known about social values held towards cancer screening as a *public health* intervention. This research proposes to elicit social values regarding LDCT lung cancer screening as both a *health care and public health intervention*.

1.4 Research objective, questions, and approach

The objective of this research is to elucidate the ethical aspects of population-based LDCT lung cancer screening programs in Canadian jurisdictions. Ethical issues in organized LDCT lung cancer screening have not been investigated in the Canadian context. There is a lack of empirical approaches to understanding ethical issues occurring in both public health and health care dimensions and there is a gap in knowledge about how these ethical issues are being, and should be, deliberated and acted upon in health policy. Ethical and social values evidence produced from this research must be considered to inform the equitable, effective, and ethically and socially acceptable implementation of lung cancer screening programs in Canada.

To attain this objective, the following research questions are examined in this thesis:

1. **What are the ethical aspects** of screening people for lung cancer in population-based programs using LDCT in Canadian jurisdictions? (Studies 2 and 3)

2. **How *are* the ethical issues being addressed in health policy?** Specifically, what ethical principles, normative guidance, or moral judgments may be in use in policy decision-making about the development and implementation of population-based LDCT lung cancer screening programs, and how are these ethical ideas being used? (Study 3)
3. **How *should* the ethical issues be addressed in health policy?** Specifically, what do social values and ethics theory suggest for how the ethical issues ought to be approached in policy decision-making about the development and implementation of population-based LDCT lung cancer screening programs? (Studies 1 and 2)

This research is guided by empirical bioethics, which includes a range of approaches that integrate empirical evidence with bioethics theory to make normative recommendations for practice. This research draws upon elements of two empirical bioethics frameworks: the "Bristol framework",[118] and symbiotic empirical bioethics.[22]

The Bristol framework landscapes the process of how empirical and ethics data are collected, analyzed, and harmonized. It is comprised of three phases: mapping, framing, and shaping. In the mapping phase, the research area is surveyed for the current state of knowledge, gaps in knowledge, and existing proposals for addressing these gaps.[118] The mapping phase of the research is a systematic literature review (Study 1 in Chapter 2) of public perspectives on the benefits and harms of LDCT lung cancer screening.

The purpose of the framing phase is to look at areas of the mapped research that need further investigated or to explore areas that have not yet been mapped, often using primary empirical research about how the research issue is approached by relevant stakeholders.[118] In this research, the framing phase is comprised of two qualitative description studies to elicit ethical and social values about LDCT lung cancer screening from key informants and the public (Studies 2 and 3 in Chapters 3 and 4, respectively).

In the shaping phase, empirical findings from the mapping and framing phases are integrated with relevant ethics theory to generate normative recommendations for future research, practice, or policy.[118] The shaping phase in this research is where conclusions will be made about how ethical issues of LDCT lung cancer screening ought to be navigated in health policy. Chapter 5 draws on the empirical data from the three studies in this dissertation to suggest relevant ethics theories and directions for future normative analysis.

Elements of the symbiotic empirical ethics methodology are used to integrate empirical and ethics evidence in this research. Symbiotic empirical ethics acknowledges the mutually generative relationship that occurs between ethics theory and practice.[22] Existing knowledge about ethical issues in cancer screening and theoretical frameworks or principles for addressing ethical issues are used in this research to identify potential ethical issues and moral guidance for lung cancer screening. Ethical aspects of lung cancer screening and the policy environs in which these ethical aspects occur and are resolved are elucidated through empirical investigation. Due to the nature of symbiosis, empirical results are expected to demonstrate how ethics principles are interpreted and applied to guide action in health policy, which in turn helps understand ethics principles themselves.[22]

This research sets the stage for future ethics analysis, when relevant ethics theories and principles elicited from empirical findings will be used as tools for analyzing empirical data from multiple perspectives. This step is when the naturalistic fallacy[119] may be addressed. Analysis of empirical data from multiple angles afforded by ethics theory can protect the translation of empirical evidence about ethical and social values to prescribe recommendations about what values should be implemented or used to guide policy decision-making about ethical issues. Ethics analysis provides the opportunity for critical analysis of empirical findings which can guard against the reproduction of existing biases in normative policy suggestions arising from this research. Although ethics analysis is outside of the scope of this descriptive research, in the descriptive phase, existing biases or problematic ethical and social values will be identified as findings that need to be addressed critically or cautiously in future ethics analysis. Ethics analysis will also add nuance to ethical theory in real-world health policy contexts. Collectively, this research and future ethics analysis can be used in the future to produce normative conclusions or reasoned arguments about what ought to be the solutions to LDCT lung cancer screening ethical issues in Canadian health policy.[22]

Reflexivity

A constructivist understanding of qualitative research sees knowledge as co-created between researchers and participants, so it is important for readers to understand who the researcher is. I use the term “reflexivity” here to think about how, why, and when I have made research decisions, and how these decisions affected the research process and product.[120]

I approached my doctoral research with an interest in surfacing the ethical issues and moral judgments that are made in health policy regarding the prevention of cancer, and implications for health equity. This interest was developed during my pre-doctoral research career where I contributed to studying the causes, prevention, and impact of occupational cancer in Canada and globally using epidemiologic methods and public and global health lenses. While undertaking this research, I questioned how epidemiological data and other types of evidence are used in policy deliberation about cancer prevention; particularly, what and whose ethical and social values may be used in policy decision-making and what impacts are produced as a result; why ethical and social values are rarely made explicit; and what benefits to society and health policy could arise from making ethical and social values transparent.

These questions compelled me to make explicit the ethical issues, ethical frameworks, and decision-making logics about the ethical issues, in my doctoral research. I was also interested in seeing how populations with a high burden of cancer identify and think about the ethical issues and what they value regarding cancer prevention in health policy. I was motivated to explore the idea that policymaker and public ethical and social values may not completely overlap, and what happens when differences arise in democratic governments where health policy decisions are made. What is ethically at stake when it comes to preventing cancer, and for whom? What happens when there are conflicts between parties of interest regarding what is ethically at stake in cancer prevention policy? These questions drove me to use the theories and methods of qualitative and mixed methods research in this dissertation.

Using these research methods also prompted me during the course of this research to state and continuously revisit my own attitudes to lung cancer screening and how they influenced my research decisions and the resulting research directions. I entered this research with a skepticism about lung cancer screening, given that it is a significant investment of limited health care resources (as I observed and understood in my pre-doctoral research career at a provincial cancer agency in charge of provincial cancer screening policies and programs) and with potentially marginal benefits and certain harms as reflected by the use of risk prediction models to identify eligible individuals for screening. I also entered this research with concern about how decisions are made about who is eligjble for screening, and was particularly interested in the reasons why occupationally exposed populations had not been included given the strong and established associations between occupational carcinogen exposures and lung cancer, the prevalence of occupational lung carcinogen exposures in Canada, and the burden of occupational lung cancer in Canada – research projects to which I contributed in my pre-doctoral research career.

How policymakers make ethical and values-based judgments about this evidence base in devising lung cancer screening policies was of great interest to me. As my doctoral research progressed (including my own readings about cancer and disease screening ethics, and the collection and analysis of my study data), I attempted to keep open-minded about the potential benefits of screening and was moved by the way that participants and key informants expressed their values about screening benefits for their own lives and for society. Nevertheless, my ambivalence towards lung cancer screening grew throughout this research, culminating in concerns about the harms and inequitable harms of lung cancer screening for individuals and communities, as well as concerns about about how scarce resources are allocated towards the prevention of lung cancer in health systems, which reflected on my values of health equity and primary prevention of disease at the level of health determinants that endured throughout my doctoral research.

My background has informed the attention that I have given in my doctoral thesis to opportunities for bioethics research to respond to the structural and systemic causes of lung cancer and the epidemiology of lung cancer incidence, mortality, survival, and access to care in Canada. My interest in health equity is what motivated my career in health research; I had been thinking about pluralistic concepts of justice since my pre-doctoral work in global health. In my dissertation, I am using an empirical bioethics approach to engage empirical data with ethics theory that may further be used to produce normative recommendations for ethical, equitable, and effective organized LDCT lung cancer screening programs in Canada.

Chapter 2: Public perspectives on the benefits and harms of lung cancer screening: a systematic review and mixed-method integrative synthesis

Manisha Pahwa[1,2], Alexandra Cernat[1], Julia Abelson[3], Paul A. Demers[2,4], Lisa Schwartz[3], Katrina Shen[5], Mehreen Chowdhury[5], Caroline Higgins[6], Meredith Vanstone[5]

1. Health Policy PhD Program, Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
2. Occupational Cancer Research Centre, Ontario Health, Toronto, Canada
3. Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
4. Dalla Lana School of Public Health, University of Toronto, Toronto, Canada
5. Department of Family Medicine, McMaster University, Hamilton, Canada
6. Caroline Higgins MISt, Medical Librarian consultant

Abstract

Objective: Screening for lung cancer with low dose computed tomography (LDCT) significantly reduces lung cancer mortality, but there is a lack of knowledge about how target populations consider its value. The aim of this study was to understand patient and public perspectives on benefits and harms of LDCT lung cancer screening.

Methods: A systematic literature review using an integrative meta-synthesis technique was conducted to identify primary empirical studies published in any jurisdiction since the year 2002. An information scientist-designed search strategy was deployed in six health and social science databases. Two reviewers independently screened resulting titles, abstracts, and potentially eligible full-text studies. Quantitative assessments and open-ended perspectives on benefits and harms were extracted and convergently integrated at analysis using a narrative approach. Design-specific study quality was assessed.

Results: Forty-nine studies (26 quantitative, 18 qualitative, 5 mixed methods) were included. Study quality was acceptable. Participants perceived screening as a personally beneficial tool for early detection and providing reassurance. Radiation exposure and overdiagnosis and false positives were viewed as inherent, concerning harms frequently justified by early detection benefits. Stigma, anxiety, and fear related to screening procedures and results were pervasive among current smokers and unalleviated by consideration of early detection benefits. Low socioeconomic status groups were deterred by potential out-of-pocket costs and geographical access.

Conclusions: Populations targeted for LDCT lung cancer screening tended to overestimate personal screening benefits and rationalize physical but not psychological harms. Screening

programs should be clear about benefits, use non-stigmatizing design, and prioritize access for high-risk, under-screened populations.

Introduction

Lung cancer is the second-most incident cancer and leading cause of cancer mortality in men and women worldwide.[121,122] In 2020, an estimated 2.2 million people were newly diagnosed with lung cancer globally, accounting for 11.4% of incident cancers that year.[122] Increasing incidence and mortality trends are occurring in women[123,124] and people aged 50 years and older,[124] and rates are higher in wealthier and more developed countries, mostly reflecting smoking patterns.[124] Within highly developed countries, rates are higher in current smokers,[125,126] those with low socioeconomic status,[127] specific Indigenous communities,[128,129] and racialized groups.[127] Most lung cancers are diagnosed at advanced stages III or IV[130] when treatment options are limited, and treatment effectiveness is poor.[131] Three-year net survival for the major histologic sub-type, non-small cell lung cancer, diagnosed at stage IV is less than 10% in high-income countries.[131]

The causes of lung cancer are believed to involve exposure to diverse lung carcinogens and genetic characteristics.[121] In 2017, an estimated 63.2% of lung cancer deaths globally were caused by commercial tobacco smoking.[132] A growing number of lung cancer diagnoses and deaths occur in never-smokers.[121,122] Primary prevention has prioritized reducing exposure to prevalent lung carcinogens such as commercial tobacco[133] and outdoor air pollution.[134] However, lung cancer continues to be diagnosed at alarming rates worldwide with poor prognosis. Screening programs are emerging in multiple jurisdictions, employing low dose computed tomography (LDCT) to detect lung cancer in earlier, more treatment-responsive stages I and II among eligible asymptomatic individuals.

The principal aim of lung cancer screening with LDCT is to lower population lung cancer mortality. Ebell et. al., in a meta-analysis of 8 randomized controlled trials with over 90,000 participants, found an absolute risk reduction of mortality of 0.4% with the use of LDCT (2.12% and 1.72% in the control and intervention arms, respectively).[56] Other trials from the Netherlands and Belgium (NELSON)[135] and the United Kingdom (UKLS)[136] have shown similar reduced mortality for older people with a moderate to heavy smoking history. Ancillary benefits of lung cancer screening are embedded smoking cessation support[137] and information about lung health.[138] Lung cancer screening could be cost-effective for health systems given the appropriate choice of high-risk population.[139]

To provide benefits, lung cancer screening entails harms, and many ethicists have worried that overdiagnosis is among the most serious of harms. Overdiagnosis and its related harms (e.g., overtreatment) arise from a combination of limitations in knowledge about lung cancer and the inherently probabilistic natural history of lung cancer. In addition, the accuracy of LDCT to screen for lung cancer involves a trade-off between how effectively the screening method correctly identifies true cases of lung cancer (sensitivity) and the true absence of lung cancer (specificity). LDCT sensitivity and specificity ranged from 59-100% and 26.4-99.7%, respectively.[140] False positive findings may be accompanied by follow-up investigation involving additional scans or lung biopsy. Rates of false negative findings are relatively lower in trials[141] and their detection via LDCT needs careful consideration with respect to the diagnosis of screen-detected lung cancers that would not have caused harm (overdiagnosis)[88,140,142] and overtreatment. To mitigate harm and maximize benefit, screening eligibility has been limited to those at high risk of being diagnosed with lung cancer in a defined period in specific populations with different prevalence rates of lung cancer, often based on age and smoking history and determined with risk prediction modelling.[143,144]

Lung cancer screening programs have been established longest in the United States (U.S.), yet a mere 14% of eligible individuals participate.[145] Screening rates in the U.S. and elsewhere are even lower among eligible racialized,[146,147] low socioeconomic status,[147] and currently smoking[148] populations who bear the burden of lung cancer. Reasons include lack of access to primary care and lung cancer screening and treatment,[149] low awareness and education about screening among the public and health care providers,[149,150]and uneven program implementation.[151] Evidence about lung cancer screening barriers and facilitators suggests that how eligible groups perceive screening benefits and harms impacts their participation in, and ultimately the success of screening programs.[149] However, there is a lack of knowledge focused on how populations targeted for lung cancer screening value this intervention. Little is known about what screening elements are conceived by potential participants as a benefit or harm and why, how discrete benefits and harms are judged with respect to their importance or worth, and how benefits and harms are weighted against each other in contemplation, deliberation, or decisions about screening. Uncovering these perspectives can address gaps or limitations in how screening programs are implemented, for whom, and how patient values about benefits and harms are discussed with those considering participation in screening.

The objective of this study was to understand how patients and the public view the benefits and harms of lung cancer screening with LDCT. The perspectives of interest in this review are those held by the public, including people who are and are not eligible for lung cancer screening, and patients, defined as lung cancer screening participants. The perspectives of low socioeconomic status, racialized, and currently smoking populations were given additional attention in this study given the disproportionate impact of lung cancer on these groups.

Methods

Methodology

We conducted a mixed methods systematic review and integrative synthesis of published evidence about patient and public perspectives on the benefits and harms of LDCT lung cancer screening. A convergent integrated mixed methods design was used.[152-154] Quantitative data from quantitative and mixed methods studies, and qualitative data from qualitative and mixed methods studies, were collected concurrently and integrated at the data analysis stage using a narrative approach.[155]

Search strategy

We searched for original studies conducted in any global jurisdiction from January 1, 2002 until the October 6, 2022, which spans the emergence and use of LDCT for lung cancer screening. Six health and social science databases were searched: MEDLINE, Cumulated Index to Nursing and Allied Health Literature (CINAHL), Embase, Emcare, Scopus, and Social Science Citation Index (SSCI). The search strategy was developed in partnership with a medical librarian (CH) and topic experts (MP, PD). Search terms for lung cancer screening were combined with search strings for qualitative and quantitative research using validated search filters[156,157] (Appendix 1). The search was first conducted on MEDLINE and then adapted using keywords and syntax specific to remaining databases. A search validation exercise was conducted by identifying five known articles prior to the search and looking for their inclusion in the MEDLINE search results.

Records from all databases searched were consolidated and duplicates removed. Remaining records were screened for eligibility.

Study eligibility

Two independent reviewers (MP and one of AC/KS/MC) screened titles and abstracts for eligibility according to a set of inclusion and exclusion criteria established *a priori* (Appendix 2). Studies were eligible for inclusion if they included the perspectives of the public or patients on the benefits and harms of lung cancer screening with LDCT. "Perspectives" were considered knowledge, attitudes, beliefs, perceptions, values, opinions, judgments, and preferences. "Benefits" and "harms" included overall benefits, overall harms, the relationship between benefits and harms, and discrete or specific types of benefits and harms. Full-text articles for eligible titles and abstracts were retrieved and screened for eligibility by two independent reviewers (MP and one of AC/KS/MC). Screening discrepancies were resolved via consensus. Interrater reliability for title and abstract screening and full-text screening was calculated using percentage agreement and estimated with the Cohen's Kappa statistic (Appendix 3).

Data extraction

One reviewer (MP) extracted quantitative and qualitative study data. The completion and correctness of data extraction was verified by a second independent reviewer (AC, KS, or MC). Data were extracted when they described benefits or harms as identified by the study author or data extractor. Benefits and harms were considered widely as physical, psychological, social, financial, and other phenomena reported in literature including patient and public perspectives. For quantitative studies, we extracted and tabulated outcomes and measurements, and any related tests of statistical significance for between-group comparisons by intervention (e.g., pre-post), socioeconomic status, race/ethnicity, and smoking status (Appendix 4). For qualitative studies, we extracted two elements: findings (i.e., the authors' own summary and interpretation of results), and illustrations (i.e., participant quotes) corresponding to each finding. Findings and illustrations were inductively coded as outcomes using NVivo software (QSR International). Codes were directly copied from or stayed close to the results categories, themes, or ideas as they were reported by authors.

Data analysis and synthesis

A taxonomy of lung cancer screening harms[158] was identified from the literature prior to the conduct of this review. For this review, the taxonomy was modified to accommodate participants' perspectives on benefits, forming a six-category analytic framework: overall perspectives, physical benefits, psychological benefits, physical harms, psychological harms, and financial and opportunity costs (Table 2). Each category contained thematically related sub-categories created by inductively grouping outcomes extracted from quantitative and qualitative studies that shared a similar idea, concept, or theme. Sub-categories were given a label to encompass the shared theme. Within each sub-category, quantitative and qualitative data were integrated using a narrative approach.[155] This approach allowed us to analyze heterogeneous outcomes and measurements across the quantitative data in narrative format and integrate them with qualitative findings. Quantitative and qualitative data were woven together by grouping extracted data from studies from each method by analytic outcome and synthesizing findings on the same analytic outcome in narrative form.[155] Where available, results by socioeconomic status, race/ethnicity, and smoking status were narratively integrated and reported separately. A detailed analytic framework, which displays which outcomes were derived from quantitative and qualitative studies, is presented in Appendix 5.

Table 2. Analytic framework

Category	**Sub-category**	**Included outcomes**
1. Overall perspectives	1.1 Favourable perspectives	Benefits (overall)
		Harms (overall)
		Benefits versus harms
		Acceptability
	1.2 Concerns about efficacy	Efficacy
	1.3 Desire for wider eligibility	Eligibility
2. Physical benefits	2.1 Valuing early detection	Early detection
		Mortality reduction
		Early treatment
		Improved survival
	2.2 Influence on smoking behaviour	Motivation to quit smoking
		Self-reflection about smoking
		Smoking futility vs screening ease
3. Psychological benefits	3.1 Desire for lung health information	Information about health
		Health monitoring
		Health protection
	3.2 Reassurance about lung health	Reassurance
	3.3 Reduction of uncertainty	Tolerance of inherent uncertainty
	3.4 Preparation before death	Preparing family and personal affairs before death
4. Physical harms	4.1 Need for accuracy	False positives
		False negatives
		Incidental findings

		Follow-up investigation
		Biopsy
		Overdiagnosis
		Overtreatment
		Accuracy
	4.2 Concerns about radiation exposure	Radiation exposure
	4.3 Worries about discomfort or pain during screening	Physical discomfort
		Pain
5. Psychological harms	5.1 Fear of screening result	Fear of lung cancer
		Fear of screening results
		Fear of lung cancer treatment
	5.2 Fear and anxiety associated with screening protocol	Waiting for screening result
		Fear of CT scan
	5.3 Feelings of stigma	Stigma
	5.4 Shame, self-blame, and futility	Shame, self-blame, and futility
	5.5 Feelings of distrust	Distrust
	5.6 Feelings of fatigue	Fatigue with smoking information
6. Financial and opportunity costs	6.1 Screening important but unaffordable	Financial costs
	6.2 Screening important but inaccessible	Time off work
		Travel time
		Convenience
	6.3 Screening important but burdensome	Burden

Quality assessment

Two reviewers (MP and AC) independently evaluated study quality using the Mixed Methods Appraisal Tool (MMAT).[159] The MMAT addresses key quality domains associated with each of the five study designs included in this review. Quality assessment was conducted to contextualize the strength of study findings, rather than to exclude studies based on their quality.[160] Differences between reviewers' quality assessments were resolved by consensus.

Reporting

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 reporting checklist was used to guide the reporting of this study (Appendix 6).[161] The protocol for this study was registered and published on PROSPERO on September 19, 2022, as #CRD42022358765. The methods used to conduct the study aligned with the registered protocol.

Results

Included studies and participants

The search of all databases yielded 10,038 records (duplicates removed). After title and abstract screening, 176 full-text articles were screened for eligibility, resulting in 49 unique studies for inclusion (Figure 3). This review included 20,120 participants from 26 quantitative, 18 qualitative, and 5 mixed methods studies (Table 3). Most participants (81%) were from 18 quantitative descriptive studies. Thirty-seven studies representing 42% of participants were conducted in the U.S. The number of people in the largest race or ethnicity category from each study was white (11,647 participants from 28 studies). Half of participants were current smokers (Tables 4-6).

Patient and public perspectives about benefits and harms were elicited as a part of studies that aimed to understand social values about screening, expose or improve decision-making about lung cancer screening, understand screening barriers and facilitators, or increase screening participation. Benefits and harms were conceptualized as those affecting individual persons rather than populations or health systems. Qualitative studies frequently employed semi-structured individual interviews and focus groups, while quantitative studies mostly used surveys to collect data (Table 2).

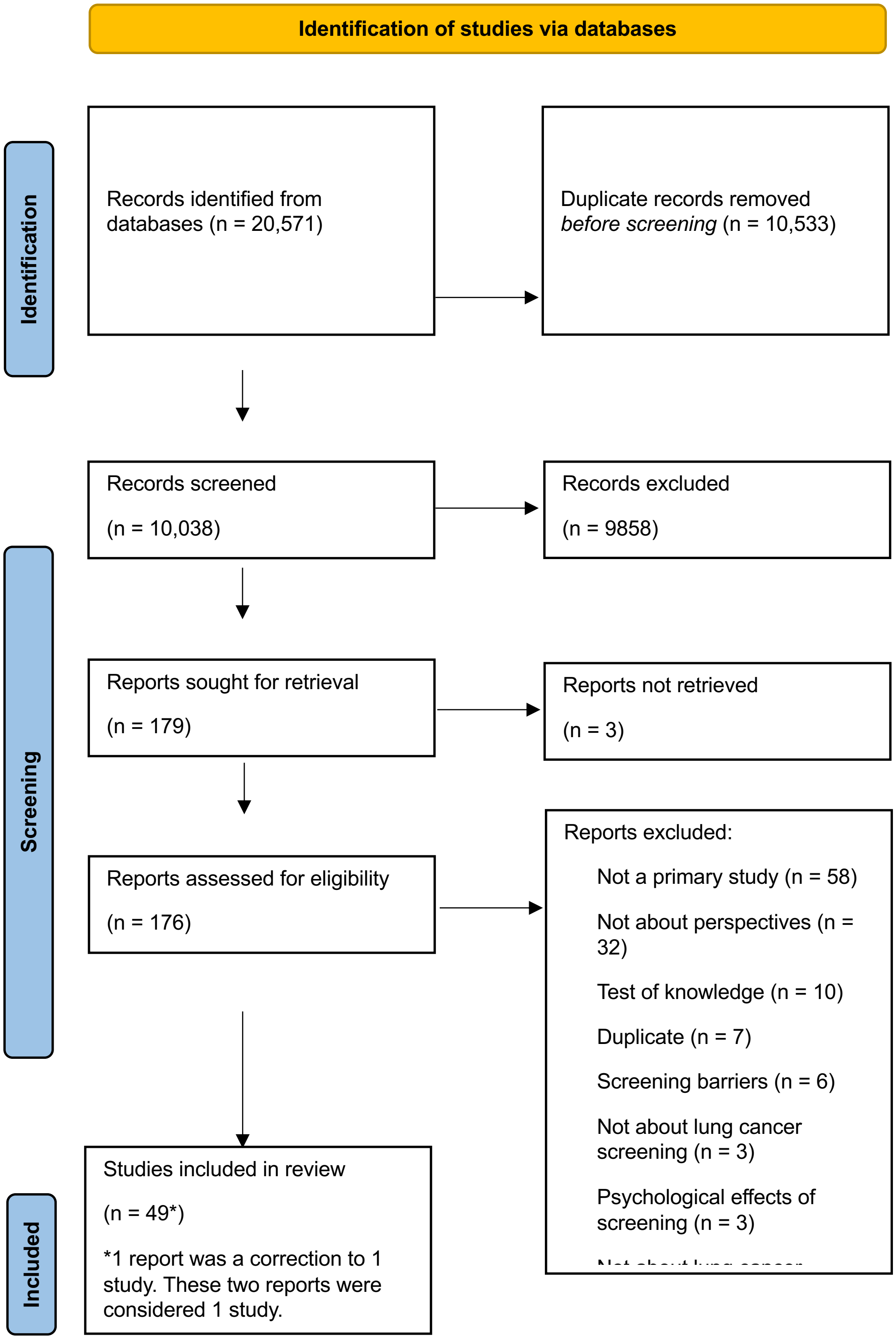

Figure 3. PRISMA Flow Diagram

Table 3. Characteristics of included studies by study design (number of studies)

Study ID	**Region**	**Aim**	**N**	**Lowest SES category N (%)**	**Smoking status N (%)**	**Largest race or ethnicity category N (%)**	**Data collection methods**	**Outcomes**
Quantitative randomized controlled trial (RCT) (N=2)								
Lillie 2017 [153]	USA	To identify which factors patients consider most important in making screening decisions (overall and by patient characteristics) and to evaluate if perceived importance of screening benefits and harms varied by screening completion	588	$20,000 or less: 190 (32%)	Current: 267 (45%); Former: 321 (55%)	White: 531 (90%)	Survey	False positives; Incidental findings; Radiation exposure; Incidental findings; Waiting for screening result
Clark 2022 [154]	USA	To examine if inclusion of incidental findings information in a lung cancer screening	348	<$10,000: 26 (8%)	Current: 245 (70%)	White: 254 (73%)	Survey	Mortality reduction; Biopsy; False positives; Incidental findings; Overdiagnosis; Financial costs

		video decision aid affects screening intent						
Qualitative non-randomized (N=6)								
Sakoda 2019[155]	USA	To determine class effectiveness in increasing patient knowledge and supporting shared decision making regarding lung cancer screening	680	NA	Current: 365 (54%); Former: 302 (44%)	White: 448 (76%)	Survey	Information about health; Reassurance; Follow-up investigation; Radiation exposure; Fear of screening results; Stigma
Hoffman 2018[156]	USA	To understand how patients who have viewed a patient decision aid value the potential benefits and harms of lung	30	NA	Current: 20 (67%)	Non-White: 11 (37%)	Survey	Early detection; False positives; Overdiagnosis; Radiation exposure

		cancer screening						
Lowenstein 2020[157]	USA	To evaluate the effectiveness and feasibility of implementing counselling and shared decision making in the screening setting at the time of screening using decision coaches	81	NA	NA	NA	Survey	Early detection; False positives; Overdiagnosis; Radiation exposure; Fear of lung cancer treatment; False positives; Acceptability; Radiation exposure

Raju 2020 [158]	USA	To identify differences in demographic, clinical, and socioeconomic characteristics between eligible screening participants and non-participants; to identify potential barriers to screening participation	818	NA	Current: 445 (54%)	White: 687 (84%)	Survey; chart review	Early detection; Mortality reduction; Follow-up investigation; Radiation exposure; Fear of screening results; Financial costs; Travel time
Clark 2021 [159]	USA	To evaluate the ability of a decision aid to improve screening knowledge, to determine what benefits and harms individuals value most when considering screening, and to examine	219	<$10,000: 9 (4%)	Current: 147 (67%); Former: 72 (33%)	White: 185 (75%)	Survey	Mortality reduction; Reassurance; Biopsy; False positives; Follow-up investigation; Financial costs

		relationships between knowledge, values, and screening intentions						
Bouchard 2022 [160]	USA	To assess the feasibility and preliminary efficacy of the Lung AIR intervention and adaptations made to mode of intervention delivery	292	\$0-19,999: 9 (10%)	Current: 153 (52%); Former: 92 (32%); Never: 47 (16%)	African American or Black: 167 (57%)	Survey	Benefits versus harms; Early detection; Health protection; Physical discomfort; Fear of lung cancer; Fear of screening results
Quantitative descriptive (N=18)								

Williams 2020 [161]	USA	To describe knowledge and awareness about screening, personal values about screening, screening uncertainty, decisional control and resources; and examine associations between decisional needs and participant intentions to discuss or undergo screening	119	<$5000: 25 (21%)	Current: 95 (79%)	African American: 119 (100%)	Survey	Harms (overall)

Cataldo 2015 [162]	USA	To describe older smokers' health risk beliefs related to cigarette smoking and lung cancer; identify demographic, smoking history, health risk perceptions, knowledge, and attitude factors related to whether a smoker would agree to screening; and provide a predictive model of factors to explain an older smoker's willingness to have a scan	338	$10,000 or less: 27 (8%)	Current: 314 (93%); Former: 24 (7%)	White: 295 (87%)	Survey	Early detection; Mortality reduction; Reassurance; Accuracy; Physical discomfort; Radiation exposure; Fear of CT scan; Fear of lung cancer; Convenience; Financial costs

Nishi 2019 [163]	USA	To describe the quality of shared decision making among patients recently screened for lung cancer	266	NA	Current: 103 (39%)	White: 231 (87%)	Survey	False positives; Follow-up investigation; Overdiagnosis; Radiation exposure
Loh 2018 [164]	Malaysia	To assess Malaysians' knowledge of lung cancer and willingness to undergo screening	385	NA	Current/Former: 73 (19%); Never: 312 (81%)	Malay: 175 (46%); Chinese: 175 (46%)	Survey	Early detection; Accuracy; Stigma; Financial costs
Silvestri 2007 [165]	USA	To compare demographic, clinical characteristics, and attitudes about lung cancer screening among current, former, and never smokers	2001	<$40,000/year: 840 (42%)	Current: 559 (28%); Former: 517 (26%); Never: 925 (46%)	White: 1481 (74%)	Survey	Early detection; Accuracy; Financial costs; Travel time

Jonnala-gadda 2012 [166]	USA	To assess the influence of health beliefs on lung cancer screening among asymptomatic smokers	108	$15,000 or less: 58 (54%)	Current: 40 (37%)	Black: 40 (37%)	Survey	Mortality reduction; Reassurance; Physical discomfort; Radiation exposure; Fear of CT scan; Fear of screening results
Park 2016 [167]	Korea	To use the health belief model to identify factors and beliefs significantly associated with cancer screening intentions	275	<300: 154 (56%) (10,000 won/month)	NA	Korean: 275 (100%)	Survey	Benefits (overall); Harms (overall)
Bui 2018 [168]	Korea	To examine the intentions of Korean males aged 40 years and older to be screened after exposure to information on the benefits and harms of lung	1730	< 2,999: 409 (24%)	Current: 1128 (65%); Former: 290 (17%); Never: 312 (18%)	Korean: 1730 (100%)	Survey	Early detection; Pain; Radiation exposure

		cancer screening						
Williams 2020 [169,170]	USA	To identify positive and negative factors specific to lung cancer screening and develop statements to capture values about the screening test for use in a new measure of decisional values	119	<$5,000: 25 (23%)	Current: 94 (79%)	African American: 119 (100%)	Survey	Benefits (overall); Harms (overall); Mortality reduction; Health protection; Accuracy; Follow-up investigation; Incidental findings; Stigma; Financial costs; Early detection; Information about health; Financial costs
Maki 2021 [171]	USA	To examine the association between screening behaviour and beliefs aligned with informatio	204	NA	No change during study: 123 (60%); Quit before study: 26 (13%); Quit	White: 142 (70%)	Survey	Early detection; False positives; Overdiagnosis; Radiation exposure

		n presented in a decision aid			during study: 49 (24%); Relapsed during study: 6 (3%)			
Tanner 2013 [172]	USA	To evaluate beliefs and attitudes toward lung cancer screening among veterans	209	Less than $40,000: 102 (49%)	Current: 41 (20%); Former: 66 (32%); Never: 102 (49%)	White: 197 (51%)	Survey	Early detection; Accuracy; Financial costs; Travel time
Smits 2018 [173]	Wales	To assess the influence of demographic variables, smoking status and beliefs about lung cancer and early symptomatic detection on lung cancer screening attitudes	1007	NA	Former: 291 (29%); Never: 445 (44%)	NA	Survey	Efficacy; Mortality reduction; Fear of screening results

Percac-Lima 2019 [174]	USA	To compare beliefs about lung cancer, knowledge and interest in lung screening, and possible barriers to lung screening	460	NA	Non-Latino current: 147 (43%); Former: 195 (57%)	Non-Latino: 342 (74%)	Survey	Mortality reduction; Information about health; Accuracy; Follow-up investigation; Pain; Radiation exposure; Fear of screening results; Financial costs; Time off work; Travel time
Stephens 2019 [175]	USA	To evaluate whether race, ethnicity, and socioeconomic status affect screening perceptions that could influence uptake	756	$0-19,999: 139 (19%)	Current: 286 (38%); Former: 466 (62%)	White: 568 (76%)	Survey	Benefits (overall); Harms (overall)

Raz 2019[176]	USA	To understand current smokers' perspectives on lung cancer risk and lung cancer screening	185	<$25,000: 30 (16%)	Current: 185 (100%)	White: 110 (60%)	Survey	Benefits versus harms; Early detection; Mortality reduction; Information about health; Reassurance; Radiation exposure; Distrust; Fear of screening results; Stigma; Financial costs; Travel time
Monu 2020[177]	USA	To describe knowledge, attitudes, and beliefs regarding lung cancer screening among individuals at high risk for lung cancer	240	<$25,000: 67 (28%)	Current: 148 (62%)	White: 219 (91%)	Survey	Early detection
Quaife 2021[178]	UK	To evaluate psychological correlates of lung cancer screening uptake	7730	Quintile 1 (most deprived): 2149 (28%)	Current: 2835 (37%); Former: 3832 (49%); Never: 272 (4%); Other	White: 5623 (73%)	Survey	Early detection; Early treatment; Improved survival

					tobacco (current/former): 322 (4%);			
See 2020 [179]	Australia	To gauge the lung cancer screening preference among Australian ever-smokers, identify associations between perceived lung cancer risk and screening eligibility on screening preference, and assess relative importance of possible screening drivers and barriers	283	NA	Current: 59 (21%); Former: 224 (79%)	White: 261 (92%)	Survey	Early detection; Mortality reduction; Reassurance; Overdiagnosis; Radiation exposure; Fear of screening results; Time off work; Travel time
Qualitative (N=18)								

Carter-Harris 2015[180]	USA	To explore long-term smokers' perceptions of lung cancer, lung cancer risk factors and lung cancer screening	26	<$20,000: 7 (27%)	Current: 12 (46%); Former: 14 (54%)	White: 20 (77%)	Focus group	Efficacy; Early detection; Reassurance; Motivation to quit smoking; Convenience; Stigma; Distrust
Lei 2022[181]	USA	To explore health beliefs toward lung cancer screening among Chinese American high-risk smokers	12	<$20,000: 2 (17%)	Current: 4 (33%); Former: 8 (67%)	Chinese-American: 12 (100%)	Interview	Fear of screening results; Early detection; Self-reflection about smoking; Time off work; Convenience; Financial costs; Pain; Reassurance; Stigma
Richman 2022[182]	USA	To understand residual screening barriers among eligible screening non-participants	16	NA	NA	Black: 9 (56%)	Interview	Burden; Early detection; Fear of screening results; Physical discomfort; Tolerance of inherent uncertainty

Roberts 2021[183]	USA	To examine how current heavy and former smokers engaged in lung cancer screening understand and respond to personalized estimates for lung cancer screening risks and to provide insights into how this tool may influence risk perceptions and/or decision making	10	NA	Current: 6 (60%); Former: 4 (40%)	NA	Interview	Benefits versus harms; False positives; Mortality reduction; Fear of lung cancer

Zeliadt 2015[184]	USA	To understand views on smoking cessation from current smokers in the context of being offered lung cancer screening as a routine service in primary care	37	NA	Current: 37 (100%)	White: 23 (62%)	Interview	Motivation to quit smoking; Self-reflection about smoking; Smoking futility versus screening ease; Early detection; Information about health; Health protection; Early treatment
Schapira 2016[185]	USA	To describe how patients respond to specific categories of uncertainty in the context of lung cancer screening, and inform strategies for addressing concerns about uncertainty as part of the shared decision making	22	NA	NA	Black or African American: 16 (72%)	Interview	Benefits versus harms; Stigma; Overdiagnosis; Tolerance of inherent uncertainty

Mishra 2016 [186]	USA	To characterize patient knowledge and attitudes about lung cancer screening, smoking cessation, and shared decision making	22	<$20,000: 14 (64%)	Current: 9 (41%); Former/never: 13 (59%)	Hispanic: 14 (64%)	Interview	Benefits versus harms; Early detection; Efficacy; False positives; Fear of screening results; Follow-up investigation; Motivation to quit smoking; Time off work; Convenience; Financial costs; Burden; Travel time; Radiation exposure; Reassurance; Tolerance of inherent uncertainty; Accuracy; Distrust
Carter-Harris 2017 [187]	USA	To explore patient decisions to opt out of lung cancer screening after receiving a provider recommendation for screening	18	NA	Current: 11 (61%); Former: 7 (39%)	White: 16 (89%)	Interview	Efficacy; False positives; Fear of screening results; Fear of lung cancer treatment; Time off work; Financial costs

Simmons 2017 [188]	USA	To examine screening barriers, including knowledge and attitudes about screening, among an ethnically and racially diverse sample of high-risk community members and physicians, nurse practitioners, and physician assistants	38	NA	Current: 29 (76%)	Not Hispanic/ Latino: 28 (74%)	Focus group	Benefits versus harms; Early detection; False positives; Fear of screening results; Convenience; Financial costs; Time off work; Tolerance of inherent uncertainty; Accuracy

Seaman 2018 [189]	USA	To examine screening knowledge, attitudes, and decision-making preferences	19	NA	Current: 3 (16%); Former: 16 (84%)	White: 19 (100%)	Interview	Benefits versus harms; Fear of screening results; Early detection; False positives; Follow-up investigation; Fear of CT scan; Time off work; Financial costs; Acceptability; Overtreatment; Radiation exposure; Tolerance of inherent uncertainty
Roth 2018 [190]	USA	To explore patient motivations for agreeing to receive screening for lung cancer in the same healthcare system	20	NA	Current: 7 (35%); Former: 13 (65%)	White: 18 (90%)	Interview	Benefits versus harms; Early detection; Distrust

Greene 2019 [191]	USA	To identify barriers to informed decision-making about screening offered during a routine primary care visit	37	NA	Current: 37 (100%)	Black or minority race or ethnicity: 10 (27%)	Interview	Information about health; Fear of lung cancer; Acceptability; Shame, self-blame, and futility
Tonge 2019 [192]	UK	To explore the acceptability of targeted lung screening and uptake decision-making intentions	33	NA	Current: 11 (33%); Former: 22 (67%)	White: 29 (88%)	Focus group	Acceptability; Eligibility; Information about health; Time off work; Self-reflection about smoking
Lowen-stein 2019 [193]	USA	To understand the attitudes and priorities among physicians and patients that inform shared decision-making in real-world settings, and explore physician and patient perception	30	NA	Current: 20 (65%); Former: 10 (32%)	White: 20 (65%)	Interview	Fear of lung cancer; Fear of lung cancer treatment; Reassurance

		s of shared decision-making in real-world practice						
Draucker 2019 [194]	USA	To describe how current and long-term smokers explain their decisions to participate or not in lung cancer screening	39	<$25,000: 13 (33%)	Current: 18 (46%); Former: 21 (54%)	White: 35 (89%)	Interview	Early detection; Efficacy; Fear of screening results; Self-reflection about smoking; Financial costs

Ruparel 2019 [195]	UK	To explore what screening-naïve individuals from an 'at-risk' population and lung cancer and public health care providers believe screening participants know and perceive about lung cancer treatment, and know, perceive and want to know about screening	35	NA	Current: 17 (49%); Former: 18 (51%)	White: 26 (74%)	Interview; Focus group	Benefits versus harms; Early detection; False negatives; False positives; Fear of screening results; Mortality reduction; Overdiagnosis; Radiation exposure; Efficacy; Distrust

Broadbent 2022[196]	UK	To explore the perspectives of HL survivors towards a future LCS programme to understand the motivating factors and barriers to LCS participation.	30	NA	Current: 1 (3%); Former: 11 (37%); Never: 18 (60%)	English/Welsh/Scottish/Northern Irish/British: 27 (90%)	Interview	Benefits versus harms; Tolerance of inherent uncertainty; Biopsy; Early detection; False positives; Fear of screening results; Time off work; Acceptability; Radiation exposure; Reassurance; Tolerance of inherent uncertainty; Waiting for screening result

Jallow 2022 [197]	UK	To understand the acceptability of using a standalone written information leaflet to invite and inform high-risk adults about lung cancer screening	40	NA	Current: 20 (50%); Former: 20 (50%)	White: 25 (63%)	Interview	Benefits versus harms; Biopsy; Early detection; Fatigue with smoking information; Fear of screening results; Incidental findings; Mortality reduction; Overdiagnosis; Radiation exposure; Reassurance; Accuracy; Waiting for screening result
Mixed methods (N=5)								

Quaife 2016 [198]	UK	To investigate screening attitudes among lower SES communities to understand in depth how attitudes might differ by smoking status and identify factors that could be targeted in screening communication strategies	163	Quintile 1 (most deprived): 83 (51%)	Current: 45 (28%); Former: 71 (44%); Never: 47 (29%)	White: 128 (79%)	Interview; Survey	Efficacy; Reassurance; Fear of lung cancer; Stigma; Benefits versus harms; Tolerance of inherent uncertainty; Early detection; Preparing family and personal affairs before death; Radiation exposure; Reassurance; Shame, self-blame, and futility; Stigma
Crothers 2016 [199]	USA	To determine, in a low-income racially diverse population, participants' experience, preferences, and reactions to web-based and paper decision aids, and	45	<$5000: 4 (9%)	Current: 34 (76%); Former/never: 11 (24%)	White: 26 (58%)	Focus group; Survey	Benefits versus harms; Reassurance; Follow-up investigation; Radiation exposure; Fear of screening results; Early detection; Efficacy; False positives; Overdiagnosis;

		understanding of harms and benefits of lung cancer screening						Reassurance; Stigma
Schapira 2021[200]	USA	To explore whether patients conceptualize the attributes of lung cancer screening differently from expert-driven taxonomies	23	NA	NA	Non-Hispanic African American or Black: 14 (61%)	Interview; Card sort activity	Mortality reduction; Health monitoring; Biopsy; False positives; Follow-up investigation; Incidental findings; Overdiagnosis; Overtreatment; Radiation exposure; Benefits versus harms; Tolerance of inherent uncertainty; False positives; Fear of screening results; Information about

								health; Mortality reduction; Reassurance
Broad-bent 2022 [201]	UK	To describe the design and development process for a decision aid targeted towards HL survivors for use in a future trial of lung	38	NA	Current: 1 (3%); Former: 12 (32%); Never: 25 (66%)	White: 30 (79%)	Focus group; Survey	Efficacy; Radiation exposure; Reassurance; Distrust

		cancer screening						
Tseng 2019[202]	USA	To investigate knowledge, attitudes, and smoking cessation needs for African Americans who receive screening in an effort to reduce the health burden of lung cancer	15	<$20,000: 10 (67%)	NA	African American: 15 (100%)	Interview; Survey	Benefits versus harms; Early detection; Reassurance; Accuracy; Fear of CT scan; Financial costs; Fear of screening results; Self-reflection about smoking; Information about health; Reassurance

Table 4. Identities of participants from included studies

Characteristic	**Studies (N)**	**Participants (N)**
Total number of participants	49	20,120
Socioeconomic status[a]	23	4,367
Low	23	4,367
Not reported	26	NA
Race or ethnicity[b]		
White	28	11,647
African American or Black	9	390
Hispanic/Latino	1	14
Asian	4	2,367
Other	4	408
Not reported	3	NA

Smoking status		
Current	41	10,134 (50.4%)
Former	28	7,014 (34.9%)
Never	10	2,505 (12.5%)
Current/former	2	395 (2.0%)
Former/never	2	24 (0.1%)
Not reported	6	NA
Eligibility for lung cancer screening in study jurisdiction		
Eligible	39	7,705
Not eligible	12	7,708
Lung cancer screening participation		
Participated	19	3,981
Did not participate	26	9,107

[a] Number of people in the lowest socioeconomic status category from each study

[b] Number of people in the largest race or ethnicity category from each study

Table 5. Methodologies of included studies

Methodology	**Studies (N)**	**Participants (N)**
Qualitative		
Qualitative, not defined	18	484 (2.4%)
Quantitative		
Quantitative randomized controlled trial (RCT)	2	936 (4.7%)
Quantitative non-randomized	6	2,120 (10.5%)
Quantitative descriptive	18	16,296 (81.0%)
Mixed methods		
Mixed methods, not specified	5	284 (1.4%)

Table 6. Region of included studies

Region	**Studies (N)**	**Participants (N)**
United States (USA)	37	8,371 (41.6%)
United Kingdom (UK)	7	8,069 (40.1%)
Korea	2	2,005 (10.0%)
Wales	1	1,007 (5.0%)
Malaysia	1	385 (1.9%)
Australia	1	283 (1.4%)

1. Overall perspectives

Overall, participants had positive views on lung cancer screening with LDCT. There was wide acceptance of the idea of lung cancer screening as a tool for early detection and treatment akin to screening programs for other cancers[162,163] that could also reduce anxiety about cancer.[164] Some participants who believed strongly in screening benefits thought that eligibility should be expanded[162] and that screening should be offered widely at no cost.[165] A minority of participants were tentative about the value of screening, believing it was unnecessary, redundant with other chest examinations, low benefit, and a waste of time, effort, and expense.[166-168]

Participants generally believed that the benefits of early detection outweighed potential harms[169,170] independent of their eligibility, lung cancer screening participation[171,172] and engagement with educational and decision aid interventions.[171,173,174] Participants trusted that the offer of screening implies its overall benefit and rare harm. Some considered screening a prudent precautionary measure to "be safe not sorry".[175(p8)]

Harms were either completely unrecognized ("why would there be cons?"[175(p8)])[169,175,176] or acknowledged and rationalized by early detection benefits. Concerns about radiation exposure were consoled by the low dose of CT. Harms related to false positives and overdiagnosis were considered unavoidable, but not as readily justified as radiation exposure. While some desired more health intervention, even from follow-up investigation of suspicious findings,[169,175-179] others, such as African American smokers, were less confident in screening reliability and potential for personal benefit.[172,174,175,179] Socioeconomically deprived and current smokers were less agreeable with the idea that lung cancer screening can produce beneficial outcomes.[180,181] Participants in several studies expressed a desire to assess benefits and harms for themselves.[166,174,182,183]

2. Physical benefits

Participants overwhelmingly valued screening as a tool for the early detection and treatment of lung cancer [162,163,167,169,171,173,175,178,183-194] that could reduce the risk of dying from lung cancer.[163,170-172,175,178,180,188,194-199] Former smokers, wealthier, and white participants more often believed in the benefits of early detection, expressed a willingness to be screened and undergo lung cancer treatment, and perceived good chances of surviving screen-detected lung cancer.[180,181,200-202] Current smokers considered screening as the medical community doing something helpful for smokers.[166,169,186] Quit intentions pivoted on screening results; participants considered a positive result a concrete motivator to quit and a negative result a reassuring signal to continue smoking, at least until seeing the results of a future LDCT lung cancer screen.[165,166,172,186] Some current smokers denied and deflected risk by believing that they were not susceptible to lung cancer even if a nodule was found via screening.[165] They also believed that smokers with symptoms, heavy smoking behaviour, or people with exposure to occupational and environmental carcinogens needed screening more than themselves.[162,165]

3. Psychological benefits

Participants viewed LDCT lung cancer screening as an opportunity to gain knowledge about their lung health[162,163,170,172,173] via all aspects of the screening pathway including incidental findings, overdiagnosis, and invasive procedures.[170] Screening was perceived to reduce uncertainty and anxiety about lung health status by providing either a negative or actionable positive screening result.[164,166,177,181-185] Reassurance for oneself and family, and protection provided by a negative screening result were widely reported by participants.[165,171,172,174,181,183,188,194,199,203] Current smokers viewed negative screening results as a relief [165,170] and motivator to stop[174,181,188,199,203] or continue smoking until screening showed evidence of lung cancer.[172,174]

Participants also believed that LDCT could provide definitive information about the presence, absence, and risk of developing lung cancer.[165,171,176] Former and current smokers concerned about the degree of lung damage caused by smoking perceived screening as providing measurements that might be reassuring or satisfy curiosity.[162,165,186] Some recognized that screening results are not completely certain[182] and wanted to minimize uncertainty through additional investigation of positive screening findings.[170] Incidental findings and false positives were perceived as a relief by some, reflecting greater worry about cancer compared to other lung diseases.[170] Even if late-stage lung cancer was detected upon screening, participants stated that this could help them prepare their personal affairs and gain additional time with family[181,183]

Knowledge avoidance was found among participants who expected late-stage diagnosis, had difficulties accessing screening, felt smoking-related stigma, held smoking-related fatalistic beliefs, or minimized smoking-related health risks.[162,182] Participants expressed reassurance with screening programs that could provide clear explanations about the screening invitation and procedures, and that engage patients with supportive networks of family/friends and health providers.[175,204]

4. Physical harms

Screening errors and radiation exposure were considered intrinsic to screening[178] and generally acceptable in exchange for early detection benefits.[162,163,170,174,175,178,189,191-193,197,198,203-205] Participants thought reducing rates of false positive screening results and overdiagnosis was important[163,172,188,190,201,202] and perceived that LDCT could accomplish this.[183,206] Participants were concerned with the risks of false positive[168,170,174,178,184] and false negative[178] screening results, as well as the possibility for misdiagnosis,[184] overdiagnosis,[170,175,182] overtreatment,[175,177]

Some participants were reticent about screening upon learning about the likelihood of a false positive result,[168,170,174,175,177,178] Avoiding false positive results, biopsy, and follow-up investigation was more important for low versus high income participants[198] with mixed findings for Latino populations.[198,206] There was greater concern for false negative versus false positive screening results due to the absence of additional investigation.[178] Participants expressed moderately strong concern[189,191,192,197] and confusion about the concept of overdiagnosis with some viewing it as a benefit and others a harm.[170,178,182] Overdiagnosis was considered a benefit to avoid the risk of not treating an indolent cancer with indeterminate prognosis[170,178] and a harm due to the life-changing effects of being diagnosed with lung cancer and potential impacts on future lung health.[170] Overtreatment was considered a harm[170,175,177]; one participant stated not wanting to be treated for “something that I haven’t even got”.[175(p6)]

There was low to moderate concern about screening-related radiation exposure.[171,174,187-189,191-194,199,203,206,207] Participants generally accepted radiation exposure from a single scan but were concerned about possible harms from multiple scans.[181,183] Participants’ lack of clarity about LDCT radiation dose and potential side effects[166,183] was buffered by trust that physicians use a safe dose of radiation.[164] Worries about physical discomfort or pain during the lung cancer screening procedure[173,187,188,199,206] were related to machine enclosure[162,185] and uncertainty about the use of contrast dye[186] among participants who had no previous experience with CT.[177]

5. Psychological harms

Participants reported fear and anxiety about possible screening outcomes. Fear and anxiety were most often related to being diagnosed with lung cancer detected by screening.[162,166-168,172,173,184-186,188 171,181] Participants were also afraid of false positive results[170,175], incidental findings,[175] follow-up investigation,[175] and lung cancer treatment. Nearly two-thirds of participants were anxious about having abnormal CT results.[171,173-175,203] People who currently smoked were more concerned about lung cancer diagnosis, indeterminate nodules,[178] what screening would reveal about their lung health due to smoking and other lifestyle factors,[167,168,177,181] and the care sequelae for each of these possible outcomes.[164,168,181,191] Fear about lung cancer was influenced by experiences of a family member or friend who had died from lung cancer.[162,164,166,176,181,184] Participants who currently smoked expressed that they would rather not pursue screening to avoid learning about their lung health.[162,168,181,185,186]

Nearly one-third of participants in three studies reported fear and anxiety about CT scans.[172,188,199] Participants described waiting for screening and follow-up results for protracted and unpredictable periods as a “worrying time”.[162,175,183(p6)] Invitation to screening and interaction with physicians in medical settings also provoked anxiety.[162,181] Fear and anxiety were mitigated among participants who had previous experience waiting for CT results, held positive screening attitudes,[183] or believed in the benefits of early detection.[176] Anxiety about the screening process and results was somewhat alleviated by a program that aimed to detect multiple lung conditions,[162] Participants thought that other lung cancer risk factors warranted greater attention[162,165,174] and that screening invitations should be for lung health worded with respect to age to prevent smokers from feeling targeted.[181]

Participants who currently smoked held worries about blame and discrimination due to the emphatic association between smoking and lung cancer[163,171,181 174] that deterred some from discussing screening with their physician,[186] especially if their physicians were younger who “don’t know the culture we grew up in”[208(p65)]: “I think that if you’re a smoker or an ex-smoker a lot of doctors treat you like you’re a leper. It’s a dirty disease because you smoke.”[162(p168)] In a study of Chinese Americans, the desire for discreet screening was expressed to preserve a favourable public image.[186] Negative self-perceptions related to smoking skewed views of screening benefits among people who currently smoke. These participants generally expected a positive screening result and had perceptions of low screening benefit, lung cancer treatment effectiveness, and fatalistic beliefs about lung cancer. These factors prompted some current smokers to either quit and adopt a healthier lifestyle, avoid knowledge of their lung health by not participating in screening, or smoke more as a coping mechanism.[165] Older smokers considered screening to be futile, assessing low tolerance of lung cancer treatment and poor survival probability compared to younger adults.[176,181] Few current smokers reported fatigue with repeated messages about smoking cessation[175] and suggested that these would be a deterrent.[181]

6. Financial and opportunity costs

Participants were dissuaded from screening participation due to real or perceived out-of-pocket financial costs for screening, potential follow-up investigation, and treatment.[163,166-168,177,184,186] At least 70% of participants agreed that screening cost is an important decision-making factor.[172,188] In health systems where screening incurred a cost to the patient, financial concerns were raised related to insurance status, especially among current smokers.[166-168,171,177,184,186,201,202,206] Distance to LDCT lung cancer screening and time-related variables were important convenience considerations for participants,[162,168,171,177,184,186,188,193,194,206] low-income rural residents,[166] current and former smokers,[202] and non-Latinos.[206] Time needed to participate along the entire screening pathway limited participants' engagement with screening.[162,166,168,183,184,186,206] Participants with medical issues requiring ongoing care reported that screening could pose an additional burden on their time.[162,185] Participants stated a need for greater geographical and daily availability of LDCT lung cancer screening,[162,184] employer support for time off work, and family help with travel to a screening centre.[183]

Quality assessment

Study quality was considered acceptable according to the assessments of two independent reviewers using the mixed methods appraisal tool[159] (Table 7). Study methodology was rarely reported for qualitative studies, which resulted in reviewers' inability to determine the appropriateness of the qualitative approach to answer the research question (MMAT question 1.1). Most quantitative studies were descriptive and found to be of acceptable quality. There was a lack of detailed information about randomization and blinding methods for quantitative randomized controlled trials. Participant representativeness was a concern for some quantitative non-randomized studies due to high, unexplained non-response rates. Integration was a concern for some mixed methods studies.

Table 7. Mixed Methods Appraisal Tool (MMAT) used to assess the quality of included studies

Study design	**Methodological quality criteria**	**Yes (N)**	**No (N)**	**Can't tell (N)**
1. Qualitative (N=18 qualitative, N=5 mixed methods)	1.1. Is the qualitative approach appropriate to answer the research question?	0	0	23
	1.2. Are the qualitative data collection methods adequate to address the research question?	23	0	0
	1.3. Are the findings adequately derived from the data?	5	0	18
	1.4. Is the interpretation of results sufficiently substantiated by data?	23	0	0
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?	23	0	0
2. Quantitative randomized controlled trials (N=2)	2.1. Is randomization appropriately performed?	0	0	2
	2.2. Are the groups comparable at baseline?	2	0	0
	2.3. Are there complete outcome data?	1	1	0
	2.4. Are outcome assessors blinded to the intervention provided?	0	0	2
	2.5 Did the participants adhere to the assigned intervention?	2	0	0
3. Quantitative non-randomized (N=6 quantitative non-randomized, N=2 mixed methods)	3.1. Are the participants representative of the target population?	6	0	2
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?	8	0	0
	3.3. Are there complete outcome data?	7	0	1
	3.4. Are the confounders accounted for in the design and analysis?	6	0	2
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?	8	0	0
4. Quantitative descriptive (N=18 quantitative	4.1. Is the sampling strategy relevant to address the research question?	18	0	3
	4.2. Is the sample representative of the target population?	21	0	0

descriptive, N=3 mixed methods)	4.3. Are the measurements appropriate?	21	0	0
	4.4. Is the risk of nonresponse bias low?	3	5	13
	4.5. Is the statistical analysis appropriate to answer the research question?	21	0	0
5. Mixed methods (N=5)	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5	0	0
	5.2. Are the different components of the study effectively integrated to answer the research question?	1	4	0
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	2	3	0
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	3	2	0
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?	4	0	1

Discussion

The aim of this study was to understand how patients and the public consider the benefits and harms of screening for lung cancer with LDCT. Participants viewed screening benefits favourably. Most believed that they could personally experience the benefits of early detection by participating in screening. The early detection benefits most valued by participants were early diagnosis and treatment from a true positive screening result. Participants also valued reassurance from a true negative screening result. The perceived personal benefits of early detection were used to rationalize screening error and radiation exposure risks, which were viewed as rare harms inherent to screening. Participants' evaluations of the benefits of screening against its harms exposed normative logics that could be used to justify screening decisions.

This study was the first to synthesize evidence about perspectives on lung cancer screening benefits and harms that centers patients and the public. This study identified patterns in the literature about how currently smoking, low socioeconomic status, and racialized participants perceive screening benefits and harms. Currently smoking participants expressed tension between concurrent desires to obtain and avoid lung health information via screening. This tension had strong emotive underpinnings in a high prevalence of fear and anxiety about being diagnosed with lung cancer, worries about stigma and blame, and fatalistic beliefs about lung cancer. Current smokers' heightened expectations and fears of being diagnosed with lung cancer were not completely allayed by early detection benefits. Real or perceived out-of-pocket financial costs of screening in some health systems, and opportunity costs in the jurisdictions studied, were acutely felt by low socioeconomic status populations. These harms were not able to be overcome by their otherwise supportive views of early detection benefits. Few studies included in this review focused on racialized or non-White populations. These studies suggest some reluctance towards screening mediated by smoking, socioeconomic status, and cultural norms.

Individual and public health dimensions of screening benefits and harms

The findings of this review were congruent with related literature about patient and public values of cancer screening. Like most cancer screening, participants in this study tended to apply overstated assessments of personally benefitting from early detection towards rationalizing screening harms. Populations targeted for cancer screening frequently hold favourable preconceptions that emphasize benefits and minimize harms.[209] This phenomenon might reflect social bias for health surveillance to satisfy population values aside from mortality reduction, such as reassurance and gaining personal health information, a finding that was echoed in this review.[210]

Participants' evaluations of benefits and harms demonstrate the complex interface of the public health and health care dimensions of lung cancer screening.[20] The main benefit of screening, a reduction in lung cancer mortality, is observable at the population level. To achieve this gain, harms are experienced by individuals in terms of physical and psychological effects and financial and opportunity costs. Communicating population risk and benefits information to individuals is vulnerable to the ecological fallacy, which may reflect bias introduced by screening programs themselves,[211] and informed decision-making about lung cancer screening is challenging to assess. Risk prediction models for LDCT lung cancer screening aim to help mitigate ecological fallacy and to optimize the delicate balance of benefits and harms.[14] As risk stratified cancer screening proliferates, it remains crucial that screening programs transparently, effectively, and equitably communicate evidence about benefits and harms and engage with high-risk patient values in efforts to promote and support autonomy.[212]

Strengths and limitations

The inclusion of quantitative, qualitative, and mixed methods primary studies from a robust search of the LDCT lung cancer screening literature was a strength of this review. Convergent integration of perspectives data from quantitative and qualitative studies created a rich narrative about the magnitude and pluralistic types of views on screening benefits and harms. There was significant variability in how LDCT lung cancer screening benefits and harms have been conceptualized and evaluated in the included literature. Heterogeneous outcomes were irreconcilable across quantitative studies which limited the ability to conduct quantitative meta-analysis or other forms of quantitative synthesis.

Policy implications

This study was the first to center the views of people targeted for lung cancer screening. Participants were from numerous jurisdictions with LDCT lung cancer screening programs. This study highlighted differential views by race/ethnicity and socioeconomic status, which are salient in lung cancer incidence and mortality in the included jurisdictions. The results of this study could be used to inform the ethical and effective design of LDCT lung cancer screening programs. Participants' perspectives on benefits and harms may contribute to health technology assessments by providing policymakers with an understanding of how, and how much, patients and the public value screening. Non-stigmatizing language and cultural safety could help mitigate fear and anxiety and improve participation among current smokers from racialized backgrounds. As lung cancer screening programs are being developed in jurisdictions worldwide, it is important that screening is geographically and economically accessible for high-risk, low socioeconomic status communities.

There is a need to increase awareness about the public health dimensions of lung cancer screening to provide clarity about benefits that could support autonomy. Social and ethical acceptability is a guiding principle for cancer screening programs which can help promote autonomy.[213] Screening participation rates dramatically improved as the result of culturally sensitive adaptations to existing breast, colorectal, and cervical cancer screening programs appealed to population benefits and the ethical principle of community.[214]

Additional research needs

The results of this review suggest that additional research is needed on understanding social values about lung cancer screening among populations who have high lung cancer incidence and mortality, poor survival, and limited or no screening participation. There is a particular need to probe the values and moral reasoning that high-risk populations apply towards navigating benefits and harms as a part of screening decision-making. This knowledge can help primary care providers engage more sensitively in shared decision making with high-risk patients whose fears and anxieties related to lung cancer might prevent them from attending screening.

Perspectives on lung cancer screening may be mediated by culture. There is a great need for studies on LDCT lung cancer screening ethical and social values in Western non-white populations and Asian, South American, and African regions where there is or soon will be high lung cancer burden. These research gaps will be crucial to address for ethical and effective lung cancer screening programs worldwide.

Conclusion

In conclusion, populations targeted for LDCT lung cancer screening view it as a potentially life-saving intervention for themselves. Harms associated with false positive findings and overdiagnosis and radiation exposure were seen as a rare personal occurrence that were rationalized by early detection benefits. Currently smoking, low socioeconomic status, and non-White racial and ethnic groups were more reluctant towards screening due to a greater concern about psychological harms and financial and opportunity costs of screening. As LDCT lung cancer screening programs emerge worldwide, increased research is needed on population values and exposing the dynamic interface of this public health and health care intervention. There is also a need for accessible, non-stigmatizing screening programs that alleviate lung cancer burden in high-risk groups.

Credit author statement[215]

MP: Conceptualization, methodology, formal analysis, investigation, resources, data curation, writing – original draft, writing – review and editing, supervision, project administration, funding acquisition

AC, KS, MC: Validation, formal analysis, investigation, writing – review and editing

MV: Conceptualization, methodology, formal analysis, resources, writing – review and editing, supervision, project administration, funding acquisition

JA, PAD, LS: Writing – review and editing, supervision, funding acquisition

CH: Methodology

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Competing interests

The authors have no competing interests to declare.

Chapter 3: Ethical and social values about screening for lung cancer with low dose computed tomography: A qualitative description study of people in Ontario, Canada

Manisha Pahwa[1,2], Julia Abelson[3], Lisa Schwartz[3], Paul A. Demers[2,4], Katrina Shen[5], Hadia Shaikh[5], Meredith Vanstone[5]

7. Health Policy PhD Program, Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
8. Occupational Cancer Research Centre, Ontario Health, Toronto, Canada
9. Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
10. Dalla Lana School of Public Health, University of Toronto, Toronto, Canada
11. Department of Family Medicine, McMaster University, Hamilton, Canada

Abstract

Objective: Lung cancer is the leading cause of cancer incidence and mortality in Canada. Most cases are diagnosed at late stages, with poor prognosis. A population-based screening program using low dose computed tomography (LDCT) was introduced in Ontario, Canada in 2021. Future expansion will require social values to inform policy decisions about whether, how, where, and for whom to offer screening. The aim of this study was to elicit ethical and social values regarding population-based LDCT lung cancer screening from potentially eligible Ontarians.

Methods: Using an empirical bioethics approach, a qualitative description study was conducted with Ontarians aged 55 to 85 years. Participants were recruited via family medicine clinics, social media, and personal networks. Semi-structured, one-on-one interviews were conducted to elicit screening-related values, perspectives on ethical aspects, and reasoning about how ethical issues should be addressed in policy.

Results: Participants (N=26) were enthusiastic about screening and endorsed informed decision-making about screening participation. Participants thought screening should be offered widely to people at high risk of being diagnosed with lung cancer and that equity-promoting efforts should be made to engage high risk sub-populations. Participants favoured expanding screening for occupationally exposed populations over people who currently smoke commercial tobacco. Participants supported investment in screening, reasoning that early detection is cost saving for health systems.

Conclusion: Participants were supportive of an organized LDCT lung cancer screening program in Ontario. Social stigma against people who currently smoke commercial tobacco needs to be addressed to obtain public support of risk-based screening approaches.

Introduction

Lung cancer accounts for one-quarter of cancer deaths in Canada, more than colon, breast, and pancreatic cancer deaths combined.[216] In 2022, an estimated 20,700 people in Canada died from lung cancer.[216] Seventy per cent of lung cancers are diagnosed in stages 3 and 4 when there are few treatment options. Treatments that do exist are aggressive, costly, and of limited effectiveness.[2] Between the years 2012 and 2014, the three-year net survival rate for lung cancers diagnosed at stage 4 was merely 5.3% in men and women combined.[2] Higher lung cancer incidence and mortality, and lowered survival rates, are associated with low socioeconomic status in Canada.[3,4] Some Indigenous[6-9,40,41,110] and rural[5] populations are also disproportionately impacted by lung cancer. The causes of different sub-types of lung cancers are diverse and include environmental, occupational, behavioural, and genetic risk factors.[217,218] Approximately 72% of currently diagnosed cases in Canada are driven by commercial tobacco smoking.[219]

Early diagnosis is an important avenue for reducing lung cancer mortality.[220] Lung cancers diagnosed at stage 1 have a 71% three-year net survival rate in Canada.[2] In 2016, the Canadian Task Force on Preventive Health Care recommended lung cancer screening using low dose computed tomography (LDCT).[57] Population-based LDCT lung cancer screening programs are being more widely implemented in Canada[18] to detect malignant neoplasms in earlier stages when there are more treatment options with greater effectiveness for preventing lung cancer death. Two organized screening programs currently exist in the Canadian provinces of Ontario and British Columbia.[18] Screening program development activities, including research and pilot studies and economic evaluations, are taking place in most other Canadian jurisdictions.[18]

Organized LDCT lung cancer screening programs are a large investment of health system resources that can significantly reduce lung cancer mortality given optimal participation rates. Participation depends in no small part on clinical, social, and ethical acceptability, which is a guiding principle of population-based disease screening.[221,222] It is important to understand public ethical and social values about LDCT lung cancer screening to ensure that programs will engage the support and participation of people in screening. However, little research has been conducted to elicit the public's perspectives on the ethical and social aspects of LDCT lung cancer screening programs. This knowledge is needed to develop programs in Canada that are effective, fair, and responsive to social needs.

Ethical and social examination of other types of cancer screening provides insight about which ethical and social issues might arise in relation to LDCT lung cancer screening programs. Screening is an intrusion in the lives of people who are asymptomatic for cancer. Invitations originate from health systems and could leverage people's fear of cancer with bias towards technological health interventions to create a health burden and opportunity costs. These factors may limit autonomy and require strong justification.[19,223] The major benefit of screening, a population reduction in lung cancer mortality,[220] is counterbalanced by harms to individuals emanating from false positive findings and overdiagnosis.[158] Knowledge about how people value the benefits and harms of screening can support informed decision-making regarding individual participation. This knowledge can also help answer normative questions in health policy about how much and what kind of harm to individuals is acceptable to achieve population-level benefits. Public ethical and social values about the use of risk prediction models, which are being used to optimize the ratio of screening benefits and harms in organized LDCT lung cancer screening programs in Canada,[18,224] may also inform ongoing scientific and policy debates about who should be prioritized for screening and why. Additionally, the asymmetric distribution of lung cancer diagnoses and deaths in Canada (e.g., along a socioeconomic gradient), the preponderance of cases caused by commercial tobacco smoking[219], and the greater effectiveness of secondary prevention for higher compared to lower socioeconomic status groups, are likely to raise distinct ethical issues related to equity and stigma.

Research about public ethical and social values for breast, cervical, colorectal, and prostate cancer screening has helped to identify new or specify known ethical issues that could be used to inform the ethical implementation of these programs in response to specific population needs and values, and health system structures. Framing cancer screening as a scientific endeavour and social process involving moral judgments can help make cancer screening policies accountable and transparent to the public and more effective at addressing contested cancer screening guidelines.[225] Public perspectives about the ethical aspects of personalized breast cancer screening have been elicited in Canada and are likely to help inform the design and implementation of these programs. However, there is no similar research about lung cancer screening despite gradual implementation and similar use of a risk-based approach.

In the province of Ontario, Canada, a population-based LDCT lung cancer screening program was introduced in 2021 with the aim of detecting lung cancer in earlier stages among high-risk individuals identified primarily based on their age and smoking history. The program represents a significant investment of health care resources from Ontario's publicly financed and administered provincial health system. However, there is currently very little knowledge about public ethical and social values and how the public thinks ethical issues should be resolved in health policy. This knowledge is needed to ensure screening programs respond to social needs and values in the context of Ontario's health system. Accordingly, the aim of this study was to elicit public ethical and social values about population-based LDCT lung cancer screening and public perspectives about how these ethical issues should be addressed in health policy.

Methods

Theoretical framework and methodology

This study was guided by an empirical bioethics approach using two empirical bioethics frameworks. The "framing" phase of the Bristol framework[226] was used to elicit individual participants' perspectives on ethical issues in cancer screening in need of exploration specifically for lung cancer screening. Participants were asked to identify and speak about known ethical issues and propose policy solutions as framed by their own ethical and social values, with the goal of looking for in-depth responses from multiple perspectives. Descriptive elements of Frith's symbiotic empirical ethics[22] framework contributed to the study design and were used to compose a semi-structured interview guide which addressed the particularities of LDCT lung cancer screening that correspond to ethical issues in cancer screening.

Qualitative description methodology[227,228] was used to collect and analyze empirical data. This study design stayed close to the data and participants' own subjectivities with little interpretive inference, which was important for accurately understanding what the public articulated as ethical facets and rationalized as their solutions in health policy. In data analysis, the Bristol framework was used to draw out how and why participants framed the ethical issues as a reflection of their own ethical and social values about lung cancer screening. The qualitative description study was carried out from a pragmatic position, permitting a slight degree of interpretive inference within the methodology's descriptive intent. Standards for Reporting Qualitative Research (SRQR)[229] were used to guide qualitative description study reporting (Appendix 7).

Sampling and recruitment

Eligible participants were individuals aged 55 to 85 years inclusive without personal history of lung cancer who were residents of Ontario, Canada and could complete an interview in English. A diversity of experiences was sought to produce a fulsome understanding of social and ethical values. Thus, maximum variation sampling[227] was used to invite participants located across Ontario independent of their eligibility for, or participation in, LDCT lung cancer screening activities in Ontario or elsewhere. Participants were recruited via study advertisements placed at two family medicine clinics in the city of Hamilton, Ontario with diverse patient populations. Participants were additionally recruited via social media advertisements (Facebook). Additional purposive sampling was operationalized through personal and professional networks to recruit individuals who met theoretically relevant criteria absent in the sample (e.g. current smoker who lives in rural area, older adult with occupational exposure and no personal smoking history).

Data collection

A semi-structured interview guide informed by population-based disease screening principles[221,222] and ethical issues in disease/cancer screening[19,223] was developed and piloted (Appendix 8). The interview guide sought responses to questions about if, how, and to whom lung cancer screening with LDCT should be offered in organized programs to people in Ontario. The interview guide was broad in scope, with the aim of asking participants about a wide range of potential ethical issues in lung cancer screening. The interview guide was progressively refined to reflect emerging analytic ideas as the study progressed. All questions for all topics in the interview guide were asked to all participants. Questions were skipped if participants had answered them as part of their response to a previously asked question in the interview guide. While no topics or questions in the interview guide were given priority, there were relatively more questions and more detailed questions asked for some topics (e.g., decision-making and eligibility) than others (e.g., resource allocation), reflecting both the tendency of public participants in qualitative research to speak from their own experiences and values, as well as the need to understand ethical and social values around risk-based approaches to lung cancer screening, which is an important feature distinguishing lung cancer screening from the use of age-based eligibility for current breast, cervical, and colorectal cancer screening programs in Ontario.

Interviews were conducted and audio-recorded by MP and KS between June 20, 2022 and May 12, 2023 via Zoom and telephone. Interviews were transcribed verbatim and de-identified. Demographic information was collected from participants via an intake survey at the time of recruitment. The concept of information power[230] guided sample size by signaling when sufficient data were collected in response to the research objectives.

Data analysis

Participant demographic characteristics were aggregated in tabulated frequencies and percentages. Conventional (inductive) qualitative content analysis (QCA)[231] of de-identified transcripts was used to inductively develop codes that remained close to the ideas expressed by participants in their own words. Analysts were informed by an understanding of ethical issues relevant to other types of cancer screening,[19,20] as conceptualized within the Bristol and Frith frameworks. This prior knowledge acted as a sensitizing concept, or broad background context which informed the analysts understanding of what might be present or relevant in the data.[232] Codes sharing a similar concept were iteratively constituted into higher-level sub-categories. Subsequently created categories encompassed sub-categories, also based on shared concepts. QCA was conducted by MP, KS, and HS to include different perspectives on analysis. Divergent perspectives were discussed and resolved.

Rigor

Reflexivity and transparency were practiced from study design to reporting to enhance auditability and credibility. MP designed and conducted this study with guidance from MV and critical input from JA, PD, and LS on the study proposal, protocol, and analysis and interpretation of results. MP documented and discussed methodological and analytic decisions with co-authors.

Reflexivity

MP conducted this study as part of her doctoral thesis in health policy supervised by MV at a Canadian university. MP's background in occupational cancer research and policy stimulated an interest in lung cancer screening ethics. MP designed this study as an empirical bioethics project. Supervisory committee members MV, LS, JA, PD contributed expertise in qualitative research, empirical bioethics, health policy, and lung cancer epidemiology.

Ethics approval

Approval to conduct this study was obtained from the Hamilton Integrated Research Ethics Board (protocol number #8310). All participants provided written informed consent prior to data collection.

Results

Participants and analytic categories

Twenty-six participants from Ontario were interviewed. Participants were mostly female of various education levels who reported no or previous history of smoking commercial tobacco. Few participants were exposed to lung carcinogens or reported a first-degree family history of lung cancer (Table 8). Interviews ranged from 12 to 66 minutes in length (mean: 41 minutes).

Five categories of ethical aspects were elucidated from conventional QCA of interview data: 1. Screening beneficial overall; 2. Risk-based screening eligibility; 3. Informed decision-making; 4. Resource allocation; and 5. Equity of screening access. Table 9 describes and defines each category.

Table 8: Participant characteristics

Characteristic	**N (%)**
Total number of participants	26
Age (years)	
50-60	5
61-70	14
71-80	3
81-85	0
Not reported	4
Sex/gender	
Male	8
Female	17
Non-binary	1
Highest level of educational attainment	
High school diploma	1
College diploma	8
University degree	11
Other	2
Not reported	4
Commercial tobacco smoking status	
Never	12
Former	9
Current	0
Not reported	5
Lung carcinogen exposure	
No exposure	11
Second hand smoke	5
Asbestos	2
Not reported	9
First degree relative with lung cancer	
No	15
Yes	2
Not reported	9

Table 9: Analytic categories

Category name	**Category description**	**Included sub-categories**
1. Perspectives on screening benefits and harms	Participants' perspectives on the relationship between the benefits and harms of LDCT lung cancer screening	1a. Desire to know 1b. Early detection, early treatment

		1c. Reassurance 1d. Organized screening program
2. Risk-based eligibility	Participants' perspectives on who should be prioritized for LDCT lung cancer screening, and why	2a. Voluntariness of lung carcinogen exposure 2b. Stigma
3. Informed decision-making	Participants' perspectives on how decision-making about one's own participation in LDCT lung cancer screening should be made	3a. Informed decision-making for one's own screening participation
4. Resource allocation	Participants' perspectives on how health and social systems resources should be allocated to prevent lung cancer mortality	4a. Limit screening to high-risk individuals
5. Equity of screening access	Participants' perspectives on what constitutes fair and equitable access to LDCT lung cancer screening	5a. Promoting the autonomy of high-risk sub-populations 5b. Trust and transparency

1. Perspectives on screening benefits and harms

Participants were generally enthusiastic about screening, believing that early detection would benefit themselves, their families, and society if they were at risk of being diagnosed with lung cancer. Participants were driven by a desire to know about their personal lung cancer status and what stage of lung cancer they may have. Participants explained that this knowledge was desirable because it would lead to faster, more successful treatment for early-stage lung cancer and potentially treatment for other findings. Some participants stated that they would want to participate in risk prediction modeling to gain knowledge about their lung cancer risk. For a few participants, they described that this information might prompt them to take action to reduce their risk, e.g., by adopting a healthier lifestyle. Few participants believed that their screening participation could help elucidate the causes of lung cancer. A minority were concerned about radiation exposure and claustrophobia from the CT machine but stated that these factors would not deter their participation.

Some participants reported that incidental findings from the CT or follow-up investigation would also be desirable knowledge that would inform if they had any potential, previously undetected medical issues needing treatment. Most participants stated that they would participate in screening even if they would most likely obtain a negative result, which was described as reassuring or a relief.

When asked to consider the relative likelihood of a true positive result and the risks of screening harms from false positive findings and overdiagnosed lung cancers, participants were conflicted within themselves. Some tempered their enthusiasm while others expressed that they would still participate in screening to avoid decisional regret, especially if they were invited to screening because they were identified as being at high risk for lung cancer:

> "But see, the big negative, the bigger, problem for me is not knowing and then you find out that, actually, it's too late. So again, I think the screening, even though there are negatives associated with it, I still think overall it's a good idea." (9173)

Several participants expressed that they would want to know about their lung cancer risk and statistical probabilities of different screening outcomes to inform decision-making about their own screening participation and to prepare themselves psychologically for the risk of a false positive finding. One participant added that the emotional impact of experiencing a false positive result would be felt by themselves and their family and they were concerned about protecting family members from this harm. One participant suggested that effective communication about screening results from a physician and rapid follow-up could alleviate anxiety from receiving a false positive screening result. Few were distrustful of screening. One participant expressed that, "I would like them to refine the test further, I think, before I took it so that there was a greater chance of a correct result as opposed to a non-correct result." (6790). Participants drew parallels to their knowledge and experiences with breast and colorectal cancer screening programs to explain that organized lung cancer screening could mitigate harm by patient-provider communication and defined pathways for screening, diagnosis, and treatment.

2. Eligibility based on risk, except people who currently smoke commercial tobacco

Participants extensively described their rationales about who they think should be prioritized for screening. Participants explained that inclusion criteria should be broad and based on comprehensive evidence and estimates about personal lung cancer risk relative to the costs and risks of screening itself:

> "I would take the information from the from science. So, anybody who's at risk, anybody who's at enough risk to warrant the expense and the risks of screening." (3251)

Most participants in this study stated that they would prioritize asbestos-exposed workers, and sometimes also family and community members, over people who are exposed to commercial tobacco smoke. Some stated that they would need detailed information about an individual's occupational lung carcinogen exposure metrics (i.e., duration, frequency, intensity) to inform prioritization for each person. Participants justified this decision by stating government responsibility for preventing lung cancer death among asbestos-exposed workers, and by making judgments about the voluntariness of exposure to lung carcinogens. One participant used secondhand smoke exposure to illustrate the point about voluntariness:

> “, I would say [prioritize] anybody who is exposed to a carcinogen, through no fault of their own through no responsibility of their own. That would be somebody who’s exposed to asbestos. But say, somebody had a good job where they were exposed to second-hand smoke. That’s a tobacco smoke issue, but it would actually be giving them that priority. So, I would say, I would have to prioritize asbestos over smoking.” (3647)

Other participants further explained that they would prioritize occupationally exposed groups, people with high levels of environmental radon exposure, or people with a family history of lung cancer over people who currently smoke commercial tobacco. Some participants acknowledged that their views reflected stigma against current smokers. Yet, when asked about prioritizing people who currently versus previously smoked commercial tobacco, responses diverged from previous responses de-prioritizing people who currently smoke commercial tobacco. Most participants explained that they would prioritize current versus former people who smoked commercial tobacco based on judgments about stratified lung cancer risk associated with cumulative lifetime exposure and duration since quit time:

> “I think the people who are current or recently quit should be prioritized, and then you work backwards. If somebody, I think they’ve got enough studies that say that the lungs actually, the cells rejuvenate, after I don’t know what it is, but there’s a number of years where there’s 5 years, 2 years, 10 years. I think it’s close to the probably 10, if you’ve not been a smoker for 10 years, your lungs will now have a nice reddish color as opposed to the carbon type of deposits that have on the alveoli. But so yeah, I definitely think that, rather than you know, targeting non-smokers.” (3765)

Participants who believed that commercial tobacco smoking is an addiction displayed greater sympathy towards people who currently smoke commercial tobacco in their responses about who should be prioritized for screening. Participants who believed that smoking commercial tobacco is a behavioural choice explained that society should not take responsibility for health-related choices of individuals by prioritizing current smokers for lung cancer screening. Some participants stated that it is both a behavioural choice and addiction, with one expressing that screening people who currently smoke commercial tobacco might inform their decision to quit. Most participants were supportive of providing smoking cessation resources as an adjunct to screening.

Participants were divided about whether participation in screening carries stigma. Some described that social stigma around lung cancer screening could be reduced by equating lung cancer screening to breast, cervical, and colorectal screening; labeling programs as “lung screening” or “lung health check” rather than “lung cancer screening”; educating society that smoking commercial tobacco is an addiction rather than a personal choice; and talking about lung cancer screening, drawing analogies to social dialogue about mental health. Several participants stated that lung cancer screening participation status information should be kept private and confidential to protect screening participants from stigma.

3. Informed decision-making

Most participants expressed that they would like to make their own voluntary and informed lung cancer screening participation decisions with guidance from their primary care provider only as requested, with some drawing analogies to how they make decisions to participate in breast and colorectal cancer screening. Participants were receptive to lung cancer screening navigators and telephone hotlines providing information to support decision-making given limited availability and time of primary care providers. Participants described their desire for personalized information about their lung cancer risk and honest and comprehensive information about lung cancer screening procedures and outcomes to support informed decision-making about their own participation:

> “I would want to know everything. I would want to know what is it that you’re looking for, what would the test determine, how is the testing done, what do I have to do to prepare for the test, is there medication involved, are you going to do a scope and look at my lungs or are you just going to do an x-ray, ultrasound, CT, MRI, like what is the procedure? What is going to happen and what is it that you’re looking for and what are you going to tell me at the end?” (2458)

4. Resource allocation

Participants generally endorsed screening as an efficient use of limited health care resources if provided only to people at high risk of being diagnosed with lung cancer, including people with occupational lung carcinogen exposure. Participants expressed that offering screening to everyone in society would be unethical because it would cause many false positive results which would lead to physical and psychological harms and unnecessary health care expenditures:

> “So, you know, our medical resources are so few and far between that you we would want to be very careful about expenditure of those resources. I’m talking about for society as a whole. So, you know, just testing everybody, obviously, willy nilly is going to be a problem if because it’s gonna take up more resources than necessary. So, you know, if whoever is doing the testing is really careful about testing strictly for high-risk candidates, I can see that that that would be a more appropriate expenditure from you know, sort of a macro point of view.” (6025)

5. Equity of screening access

Participants believed that screening should be a fair, non-discriminatory process that is available and accessible to sub-populations with high rates of lung cancer incidence and mortality. Participants felt strongly that information should be provided equitably to promote informed decision-making and autonomy. One explained that equity could be promoted by using different strategies to engage different high-risk groups in screening. There was concern about screening access in rural and remote communities lacking primary care providers. One participant suggested that access to screening could be provided within communities to respond to socioeconomic and cultural needs:

> "Those people go to [names of smaller cities] to have a screening test done, but they would be less likely to go to [major city] you know, perhaps the same thing with Indigenous or Métis or Inuit people that don't feel comfortable going out of their own communities, you know, if there are a mobile screening involved that could come to them. I think in a lot of cases that you know socioeconomic things and sort of the cultural things, you know, bringing them the screening to the community probably works better." (5066)

A few participants were conflicted about who should be prioritized for screening due to concerns about the experimental nature of screening and community trust in health systems. One stated that the screening technology and process should be perfected first before being offered to equity-deserving groups to avoid the perception that these individuals are "being used as guinea pigs to experiment, to make sure this thing works." (2486). A few suggested that trust needs to be built between communities and health care providers as a prerequisite to inviting high-risk groups to screening. One participant described the principle of restitution/reconciliation as guiding prioritization decisions, stating that there is a greater moral obligation to provide fair access to screening to certain Indigenous and racialized communities who have been put at high risk of lung cancer due to previous political choices made by the Canadian government affecting the health of these groups.

Discussion

The aim of this study was to elucidate public ethical and social values about organized LDCT lung cancer screening in Ontario, alongside public perspectives about how ethical issues should be addressed in health policy decision-making. Older Ontario residents were enthusiastic about screening, describing a willingness to accept risks of harms associated with false positive findings and overdiagnosis in favour of early detection, knowledge about their lung health, and reassurance from a negative screening result. Participants were adamant about the importance of being adequately informed to support decision-making about their own participation in screening, and to promote trust and the autonomy of high-risk sub-populations. Participants described that screening priority should be based on stratified lung cancer risk and positioned numerous risk factors ahead of people who currently or formerly smoke commercial tobacco, reflecting stigma and moral judgments about voluntariness of exposure to lung carcinogens and individual versus collective responsibility for lung cancer mortality prevention.

This research contributes primary empirical public perspectives that may be used to support the ethical design and implementation of population-based LDCT lung cancer screening programs. This research may contribute to health technology assessments and lung cancer screening policies as screening programs are currently being developed and implemented in Canadian jurisdictions. Findings were congruent with public perspectives on the ethical dimensions of personalized breast cancer screening among women in four Canadian provinces who were accepting of risk-stratified screening and informed decision-making.[212]

Public ethical and social values in this study may contribute to processes such as health technology assessment and health policy decision-making about ethical issues associated with organized LDCT lung cancer screening programs. When using these data to help inform normative policy recommendations, public ethical and social values should be analyzed carefully for the presence of harmful biases and efforts should be made to avoid reproducing them in screening policy. This research suggests that social stigma against people who currently smoke commercial tobacco may be a deterrent for public support of organized LDCT lung cancer screening programs, which could also hinder the participation of priority groups. Future ethics analysis of these data should acknowledge and guard against stigma in making suggestions for ethical screening programs.

This research was based in a large Canadian province that introduced a population-based LDCT lung cancer screening program in 2021. Participants had little to no awareness of the existence of this program prior to their participation in this study. To our knowledge, this study is the first ask the public in Ontario to describe their values, what they identify as ethical aspects of population-based LDCT lung cancer screening, and how they believe the ethical issues should be addressed in health policy. The qualitative description methodology centered participants' own words with little interpretive inference. It was situated in an empirical bioethics approach, which informed data collection about ethical issues in cancer screening and generated novel descriptive evidence on ethical issues specific to lung cancer screening with LDCT. Descriptive results may be further analyzed using ethics theory relevant to study data to produce normative recommendations for population-based LDCT lung cancer screening policy in Ontario.

Another strength of this study was methodological technique which enabled a high level of engagement with ethical concepts from lay participants with little former exposure or experience with this issue. When asked open-endedly in the beginning of their interview what they think are the ethical aspects of lung cancer screening, most stated that there are no ethical issues; however, as their interviews progressed, participants were keen to explain their normative logics in response to questions about specific ethical issues. Incorporating concepts from the ethical aspects of cancer screening alongside descriptive questioning, using approaches in the Bristol and Frith frameworks, was effective in encouraging deliberation on these new ideas. After the interview, some participants expressed that the interview made them realize their biases against people who currently smoke commercial tobacco, which suggested self-reflection, trust, and rapport built during their interview.

A limitation of this study was the limited demographic and socioeconomic diversity of the participants and the large number of missing data for participant characteristics. Efforts to recruit participants through two family medicine clinics in Hamilton, Ontario were impacted by the COVID-19 pandemic. Social media recruitment via Facebook was of limited effectiveness for recruiting sincere participants. Future research may consider community engaged research with sub-populations who have high lung cancer incidence and mortality rates to understand their ethical and social values and bring this knowledge to inform pathways for equitable lung cancer screening and prevention activities. The high number of missing participant characteristics, possibly due to participants' challenges with using REDCap to collect these data, limits the ability to draw conclusions about whose ethical and social values are reported in this research.

This study aimed to produce ethical and social values evidence for ethical aspects broadly. The amount and depth of interview response data was proportional to the number and amount of detail asked about each topic in the interview guide, which is why there was relatively greater depth of responses to questions about screening eligibility compared to informed decision-making and resource allocation. Probing ethical and social values about specific ethical issues, especially ethical issues that may be self-identified by priority sub-populations, will add greater depth and plural perspectives on particular ethical dimensions of lung cancer screening. Given the disparities in lung cancer incidence and mortality in specific Indigenous populations, community-engaged research to elicit priorities and values of these groups in accordance with Ownership, Control, Access, and Possession (OCAP) principles will be an essential step to ethical implementation of lung cancer screening programs. Future research may also prioritize people who currently smoke commercial tobacco. This group was not well represented among the participants of this study and will be important to engage in future lung cancer screening ethics research given their potentially high risk of lung cancer and preponderance of stigma against this group found in this research.

Conclusion

Screening high-risk people for lung cancer with LDCT was seen as an overall benefit by twenty-six public participants in this qualitative description study of ethical and social values. Prioritization of different groups for access to organized LDCT programs was a core ethical issue. Participants described that people at high risk of being diagnosed with lung cancer should be prioritized for screening and endorsed risk stratified eligibility and equitable screening access. Stigma against people who currently smoke commercial tobacco was embedded in many participants' ethical reasoning. Public ethical and social values evidence from this study will require careful consideration of biases in future ethical analysis of these data to help inform health policy decision-making about equitable and effective organized LDCT lung cancer screening programs.

Credit author statement[215]

MP: Conceptualization, methodology, formal analysis, investigation, resources, data curation, writing – original draft, writing – review and editing, supervision, project administration, funding acquisition

JA, PAD, LS: Writing – review and editing, supervision, funding acquisition

KS: Investigation, writing – review and editing

HS: Data curation, writing – review and editing

MV: Conceptualization, methodology, formal analysis, resources, writing – review and editing, supervision, project administration, funding acquisition

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Competing interests

The authors have no competing interests to declare.

Chapter 4: Ethical dimensions of low dose computed tomography lung cancer screening in Canada: Key informant qualitative description study

Manisha Pahwa[1,2], Julia Abelson[3], Paul A. Demers[2,4], Lisa Schwartz[3], Katrina Shen[5], Meredith Vanstone[5]

1. Health Policy PhD Program, Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
2. Occupational Cancer Research Centre, Ontario Health, Toronto, Canada
3. Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Canada
4. Dalla Lana School of Public Health, University of Toronto, Toronto, Canada
5. Department of Family Medicine, McMaster University, Hamilton, Canada

Abstract

Objective: Programs to screen for lung cancer with low dose computed tomography (LDCT) are being implemented more widely in Canada. Ethical issues are key to implementation, but little is known about what the ethical issues are and how they are approached in practice. The objectives of this study were to expose ethical aspects of LDCT lung cancer screening in Canada and produce normative policy considerations.

Methods: This empirical bioethics study used qualitative description to elicit ethical issues from the perspectives of key informants involved with Canadian LDCT lung cancer screening. Key informants, defined as policymakers, scientists, and clinicians in Canadian jurisdictions, were purposively sampled and interviewed using a semi-structured guide informed by disease screening principles and cancer screening ethics. Interview data were analyzed using qualitative content analysis. Integration with disease screening principles and capabilities theory generated normative considerations for screening policy.

Results: Fifteen key informants from five provinces were interviewed. Virtually all endorsed screening, describing that population benefits outweigh individual harms if screening is delivered to high-risk people in organized programs. Key informants specified how disease screening principles ensured overall benefit but lacked normative guidance for addressing the greatest ethical issues identified, stigma and equity of screening access. Capabilities theory suggests primary prevention and implementing organized LDCT lung cancer screening programs in communities with elevated lung cancer incidence and mortality, regardless of commercial tobacco smoking status.

Conclusions: Lung health and well-being can be promoted in Canada through primary prevention of lung cancer and equitable access to organized LDCT screening programs.

Introduction

Lung cancer is the most diagnosed cancer and leading cause of cancer mortality in Canada.[233] In 2022, it is anticipated that 30,000 people in Canada will be newly diagnosed with lung cancer and 20,700 will die from this disease.[233] Nearly 50% of lung cancers in Canada are diagnosed at stage IV[234] when treatment options are limited, and treatment effectiveness is poor. Three-year net survival of lung cancers diagnosed at stage IV is a mere 5%.[234] Higher incidence and mortality rates, more late-stage diagnoses, and lower survival are associated with low socioeconomic status[234-238] and have been observed among some Indigenous[6,8,9,239-242] and rural[236,243] populations in Canada.

Lung cancer rates and trends mostly reflect commercial tobacco smoking patterns in Canada. Between 1992 and 2016, incidence and mortality rates decreased for men and increased for women.[234] An estimated 70% of lung cancer cases in Canada are caused by commercial tobacco smoking.[98] Other causes include genetic factors and over 30 occupational and environmental agents[244] with differential prevalence among people in Canada.[245-248]

The use of low dose computed tomography (LDCT) to screen for lung cancer is actively being considered in Canadian jurisdictions.[224,249] Guidelines for LDCT lung cancer screening were published by the Canadian Task Force on Preventive Health Care in 2016.[250] Two formal LDCT lung cancer screening programs exist in Ontario and British Columbia.[249] Screening activities are gaining momentum in other regions as evidenced by pilot projects, research studies, and economic evaluations.[76,77,80,249] Screening is expected to considerably reduce lung cancer burden in Canada by detecting malignant neoplasms at stages I and II, when there are more treatment options and improved treatment responsiveness.

Clinical, social, and ethical acceptability is a guiding principle of cancer screening programs.[213,251] Evidence about LDCT lung cancer screening ethics is sparse[252-254] and there are no studies situated in the Canadian context during this critical juncture for program diffusion. Ethical aspects include features inherent to disease[213,251] and cancer screening in general[255] with several important distinctions. The main benefit of screening, a population reduction in lung cancer mortality, is delicately balanced by harms to individuals arising from the use of screening is used to detect true cases of lung cancer, which is limited by our knowledge of lung cancer and the intrinsically probabilistic natural history of disease.[140,158,256] It is unclear what types of harms and how much harm individual screening participants are willing to incur to attain lowered population mortality.[223,257] This duality invokes clinical and public health ethics principles with a conflicting relationship to one another in screening policy.[255] Further, complexity of information about benefits and harms in preventive medicine, and a lack of knowledge about how patients value benefits and harms, could undermine efforts to support autonomy in informed decision making processes.[83,258-261]

Risk prediction modeling is being used to optimize the balance of benefits and harms.[59,73,262] Models forecast risk of lung cancer diagnosis in a defined period and inform eligibility for screening by categorizing people into high- and low-risk strata. Modeling used in Canada incorporates variables about individuals' age, smoking history, race/ethnicity, and other self-reported lung cancer risk factors.[263] There is still emerging evidence about who should be screened as reflected in research about appropriateness of age and smoking setpoints,[264] risk prediction model variables,[265-268] and eligibility threshold scores.[269] Screening high-risk populations may incidentally detect an elevated prevalence of smoking-related comorbidities leading to further evaluation.[270,271] Psychological and health equity effects of stratification, and how these effects could be mitigated, are largely unknown.[85,272-274]

Enthusiasm for LDCT lung cancer screening engages with fear of the disease tempered by stigma. The emphatic relationship between commercial tobacco smoking and lung cancer, and decades of anti-smoking policies, have led to social and medical stigmatization of people who smoke commercial tobacco.[275,276] Groups with high prevalence of commercial tobacco smoking in Canada[277-280] may encounter other forms of stigmatized health and social surveillance associated with their identities and have limited health care access.[281-285] Collectively, these aspects surface equity screening opportunity and outcome[286,287] and cultural safety and trust.[6,288]

Screening involves an imposition into the lives of people asymptomatic for lung cancer who have not initiated a request for screening.[255,289] The health burden and opportunity costs of screening need to be compelling for this reason.[255] Finally, the decisions of health policymakers to invest in screening may be susceptible to bias[83,290] that impacts how limited resources in Canadian health systems are put towards other known lung cancer prevention strategies.

How these ethical issues are deliberated and resolved in policy decisions related to LDCT lung cancer screening in Canada are unknown. Previous research has surfaced that key informants engage with both evidence and complex, wide-ranging, and sometimes conflicting ethical and epistemological values about cancer screening that can reflect their own interests and biases.[84] Evidence about ethical perspectives and values are needed for lung cancer screening to enhance public transparency, accountability, and trust; stimulate or advance dialogue focused on the ethics of lung cancer screening policy[21]; and inform the development of socially and ethically acceptable screening programs. The primary aim of this research was to expose ethical dimensions of LDCT lung cancer screening and how they are addressed in Canada. The secondary goal of this research was to produce normative considerations for LDCT lung cancer screening programs in Canada.

Methods

Theoretical framework and methodology

This was an empirical bioethics study guided by two frameworks articulated by Huxtable and Ives ("Bristol")[226] and Frith.[22] Empirical ethics is the collection and integration of empirical evidence with ethical theory to produce normative recommendations for practice.[22,226] In this study, empirical description of the ethical aspects of LDCT lung cancer screening were collected and integrated with principles for population-based disease screening and capabilities theory to generate considerations for ethical implementation of LDCT lung cancer screening programs in Canada (Figure 4). The screening principles used were an update to Wilson and Junger's 1968 disease screening principles that showed consistency with contemporary health systems and screening programs in Canada (Table 10).[213] Capabilities theory was additionally used as a justice-oriented normative framework to address screening equity issues.[291,292] A consensus-based reporting standard for empirical bioethics research was used to locate this study, and acted as a tool for ongoing dialogue about the conduct of empirical bioethical research (Appendix 10).[293]

The qualitative description methodology was chosen to collect and analyze empirical data because this study design stays close to the data with little interpretive inference,[227,228] which was important for accurately understanding what key informants articulate as ethical facets and their solutions in LDCT lung cancer screening programs. It allowed a full investigation of ethical aspects of screening in participants' own subjectivities and the language of their practice. The qualitative description study was carried out from a pragmatic position, permitting a slight degree of interpretive inference within the methodology's descriptive intent. Standards for Reporting Qualitative Research (SRQR) were used to guide qualitative description study reporting (Appendix 11).[229]

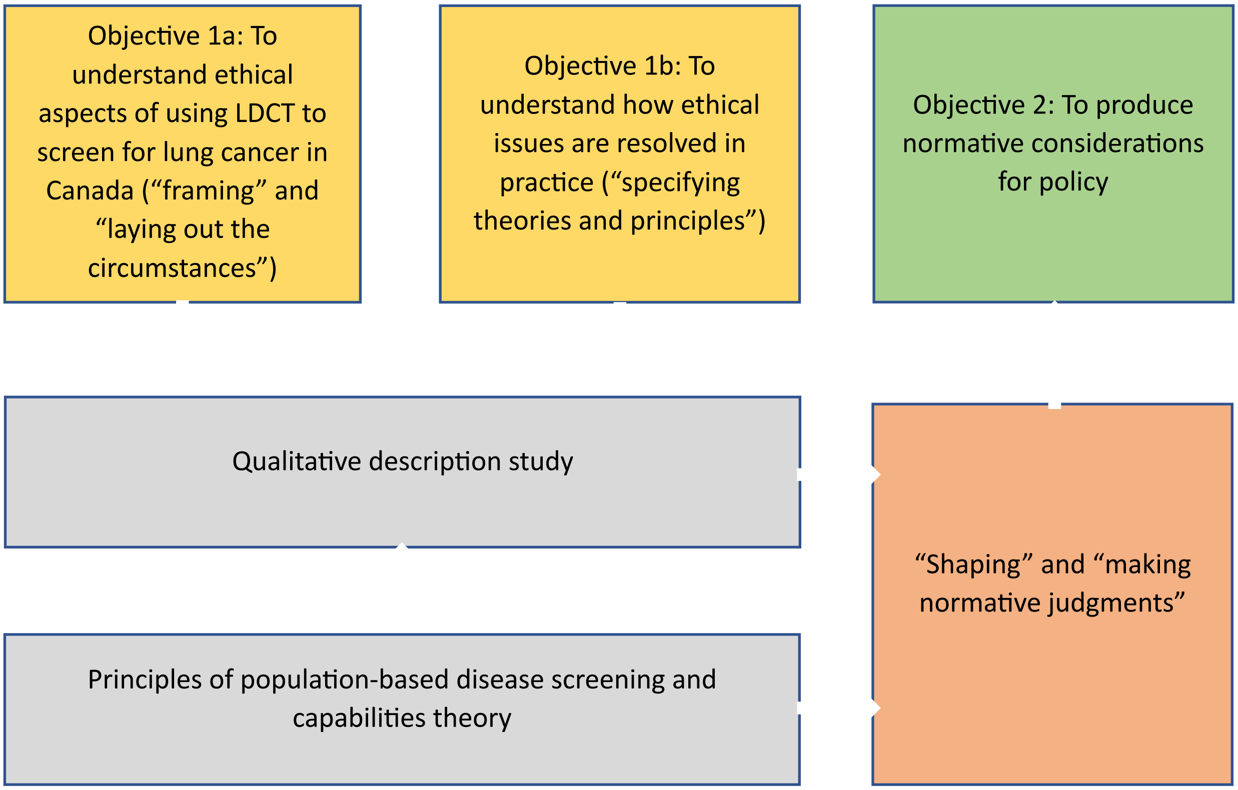

Figure 4. Theoretical framework and methodology[22,213,226,291,292]

Table 10: Consolidated principles for population-based disease screening[213] and related sample interview guide questions

Domain	Consolidated screening principles (after systematic review and modified Delphi consensus process)	Sample interview guide questions	Justification and supporting evidence from cancer screening ethics literature
Disease/ condition principles	**1. Epidemiology of the disease or condition** The epidemiology of the disease or condition should be adequately understood, and the disease or condition should be an important health problem (e.g., high or increasing incidence or prevalence, or causes substantial morbidity or mortality).	Should we prioritize screening people who are current smokers? Former smokers? Never smokers? What did you think about when making this decision? We know that asbestos and other workplace exposures put people at greater risk of lung cancer. Should we prioritize screening for people who are or were exposed to asbestos? What do you think about when making this decision?	To uncover normative logics that guide decisions about defining the target populations eligible for lung cancer screening in Canada[213,251]; specifically, to understand the moral justification for and implications of using risk stratification to determine eligibility[252].
	2. Natural history of disease or condition The natural history of the disease or condition should be adequately understood, the disease or condition is well-defined, and there should be a detectable preclinical phase.		
	3. Target population for screening The target population for screening should be clearly defined (e.g., with an appropriate target age range), identifiable and able to be reached.	Some people hesitate to be screened for lung cancer because they were or are a smoker. Some people whose lung cancers have been detected by screening – and whose lives were saved because of lung cancer screening - face backlash from society because they were smokers. Do you think that lung cancer screening carries stigma? Why or why not? Should something be done to	

Domain	Consolidated screening principles (after systematic review and modified Delphi consensus process)	Sample interview guide questions	Justification and supporting evidence from cancer screening ethics literature
		reduce the stigma related to lung cancer screening? If so, what can be done?	
Test/ intervention principles	**4. Screening test performance characteristics** Screening test performance should be appropriate for the purpose, with all key components specific to the test (rather than the screening program) being accurate (e.g., in terms of sensitivity, specificity and positive predictive value) and reliable or reproducible. The test should be acceptable to the target population and it should be possible to perform or administer it safely, affordably and efficiently.	What do you think are the benefits of lung cancer screening? What do you think are the harms of lung cancer screening? What strategies do you think can be used to optimize the benefit and harm relationship (i.e., to maximize benefit and minimize harm)?	To understand if key informants think that screening should be pursued in organized programs in Canadian jurisdictions, and why; to explore what key informants conceive of as the benefits and harms of lung cancer screening, and why; to interrogate how key informants explain the relationship between benefits and harms; to examine how key informants manage the benefits and harms relationship in their practice
	5. Interpretation of screening test results Screening test results should be clearly interpretable and determinate (e.g., with known distribution of test values and well-defined and agreed cut-off points) to allow identification of the screening participants who should (and should not) be offered diagnostic testing and other postscreening care.		
	6. Postscreening test options There should be an agreed on course of action for screening participants with positive screening test results that		

Domain	**Consolidated screening principles (after systematic review and modified Delphi consensus process)**	**Sample interview guide questions**	**Justification and supporting evidence from cancer screening ethics literature**
	involves diagnostic testing, treatment or intervention, and follow-up care that will modify the natural history and clinical pathway for the disease or condition; that is available, accessible and acceptable to those affected; and that results in improved outcomes (e.g., increased functioning or quality of life, decreased cause-specific mortality). The burden of testing on all participants should be understood and acceptable, and the effect of false-positive and false-negative tests should be minimal.		
Program/ system principles	**7. Screening program infrastructure** There should be adequate existing infrastructure (e.g., financial resources, health human resources, information technology, facilities, equipment and test technology), or a clear plan to develop adequate infrastructure, that is appropriate to the setting to allow for timely access to all components of the screening program.*	Certain populations in Canada have higher lung cancer incidence and mortality, and lowered survival, than other groups. Often these groups also have low participation in lung cancer screening. In Canada, these groups include certain First Nations, Inuit, and Métis communities as well as people of low socioeconomic status. a. What reasons do you think may explain why there is low uptake of lung cancer screening in	To explore how key informants rationalize who should be screened and why; to see how key informants might apply equity of screening access and outcome as a guiding principle in decision-making about screening programs.[213,251,286]

Domain	Consolidated screening principles (after systematic review and modified Delphi consensus process)	Sample interview guide questions	Justification and supporting evidence from cancer screening ethics literature
		jurisdictions where there are lung cancer screening programs? b. Should additional efforts be made to engage these populations in lung cancer screening? What additional efforts might need to be made? Who should be making these additional efforts? c. Should we prioritize these groups for screening? Why or why not? What principles do you think we should use to make this decision?	
	8. Screening program coordination and integration All components of the screening program[*] should be coordinated and, where possible, integrated with the broader health care system (including a formal system to inform, counsel, refer and manage the treatment of screening participants) to optimize care continuity and ensure no screening participant is neglected.		

Domain	**Consolidated screening principles (after systematic review and modified Delphi consensus process)**	**Sample interview guide questions**	**Justification and supporting evidence from cancer screening ethics literature**
	9. Screening program acceptability and ethics All components of the screening program* should be clinically, socially and ethically acceptable to screening participants, health professionals and society, and there should be effective methods for providing screening participants with informed choice, promoting their autonomy and protecting their rights.	What do you think are the ethical issues associated with lung cancer screening? In other words, can you think of an aspect of lung cancer screening that might be a moral challenge? Why?	To understand how key informants open-endedly "frame"[226] and "lay out the circumstances"[22].
		How are these ethical issues being addressed by you, your community of practice, or in your discipline?	To gain insight about how key informants open-endedly "specify theories and principles"[22] in addressing ethical aspects of screening programs.
		What do you consider to be an informed choice? How do you know if patients are adequately informed and making a free choice?	To understand how key informants conceptualize and justify informed choice and promote autonomy and rights in lung cancer screening programs.[213,251]
	10. Screening program benefits and harms The expected range and magnitude of benefits (e.g., increased functioning or quality of life, decreased cause-specific mortality) and harms (e.g., overdiagnosis and overtreatment) for screening participants and society should be clearly defined and acceptable, and supported by existing high-quality scientific	How can the harms of lung cancer screening for individuals be negotiated with the benefits of lung cancer screening for society?	To understand how key informants weigh the distribution of screening benefits and harms across individuals and populations[213,251], and negotiate conflicting principles from clinical bioethics and public health ethics in organized screening programs[223,255].

Domain	Consolidated screening principles (after systematic review and modified Delphi consensus process)	Sample interview guide questions	Justification and supporting evidence from cancer screening ethics literature
	evidence (or addressed by ongoing studies) that indicates that the overall benefit of the screening program outweighs its potential harms.		
	11. Economic evaluation of screening program An economic evaluation (e.g., cost-effectiveness analysis, cost–benefit analysis and cost–utility analysis) of the screening program, using a health system or societal perspective, should be conducted (or a clear plan to conduct an economic evaluation) to assess the full costs and effects of implementing, operating and sustaining the screening program while clearly considering the opportunity costs and effect of allocating resources to other potential nonscreening alternatives (e.g., primary prevention, improved treatments and other clinical services) for managing the disease or condition.	What principles should decision-makers use to decide whether to fund lung cancer screening? What do you think about other ways to prevent lung cancer, such as reducing air pollution levels or asbestos exposure? Is lung cancer screening more or less important than other prevention options?	To understand the principles that key informants use to guide economic evaluations of screening and the allocation of limited resources towards lung cancer prevention in Canadian health systems.[213,251]
	12. Screening program quality and performance management The screening program should have clear goals or objectives that are explicitly linked to program planning, monitoring, evaluating and reporting activities, with dedicated information systems and		

Domain	Consolidated screening principles (after systematic review and modified Delphi consensus process)	Sample interview guide questions	Justification and supporting evidence from cancer screening ethics literature
	funding, to ensure ongoing quality control and achievement of performance targets.		

*Components of a screening program include recruitment, testing, information access, diagnosis, referral, treatment, follow-up, patient education and support, staff training and program management and evaluation.

Sampling and recruitment

Eligible key informants were individuals with significant expertise in LDCT lung cancer screening research, clinical practice, or policymaking who could provide overarching views about ethical aspects in the Canadian context. A diversity of experiences was sought to produce a fulsome understanding of the ethical landscape in Canada.[226] Thus, maximum variation sampling was used to invite key informants located in academic, government, and clinical settings in all Canadian jurisdictions with current LDCT lung cancer screening activities. Key informants were identified from publications about LDCT lung cancer screening in Canada such as screening guidelines, policy documents, health technology assessments, and peer-reviewed literature; authors' professional networks in Canadian cancer research and policy; and professional profiles on organizational websites. Snowball sampling was used to capture perspectives from key informants whose identities were not published, known to the authors, or publicly accessible. Key informants were recruited via an e-mail study invitation sent up to three times. Written informed consent to participate in the study was obtained from each key informant prior to data collection. An audit trail was maintained to record sampling and recruitment decisions and outcomes.

Data collection

A semi-structured interview guide informed by population-based disease screening principles and ethical issues in disease/cancer screening was developed and used to collect data towards both study objectives (Table 10; Appendix 10). The interview guide generally sought responses to questions about if, how, and to whom lung cancer screening with LDCT should be offered in organized programs to people in Canada. The interview guide underwent iteration as study data were collected. Interviews were conducted and audio-recorded by MP between April 4, 2022, and May 5, 2023, via Zoom and telephone. Interviews were transcribed verbatim and de-identified. The concept of information power[230] guided sample size by signaling when sufficient data was collected in response to the research objectives.

Data analysis

Participant characteristics were aggregated in tabulated frequencies and percentages. Conventional (inductive) qualitative content analysis (QCA)[231,294] of de-identified transcripts was used to inductively develop codes that remained close to the ideas expressed by key informants in their own words. Codes sharing a similar concept were iteratively constituted into higher-level sub-categories. Subsequently created categories encompassed sub-categories, also based on shared concepts. QCA was also conducted by KS to include different perspectives on analysis. Divergent perspectives were discussed and resolved.

Ethics analysis

MP conducted the ethics analysis with guidance from MV and critical input from JA, PD, and LS. Ethics analysis was guided by the "specifying theories and principles" element in the symbiotic empirical ethics methodology.[22] Relationships between analyzed qualitative description study data and population-based disease screening principles[213,251] were examined to understand if and how these principles were used by key informants to justify courses of action on LDCT lung cancer screening in Canada. Where empirical evidence did not engage with population-based disease screening principles, additional ethics theory relevant to that empirical data were identified and similarly integrated to expose key informants' normative logics. Conclusions were drawn out of ethics analysis to propose reasoned arguments about how screening people for lung cancer with LDCT ought to be approached in Canadian jurisdictions; this step was aligned with the empirical bioethics concepts of "shaping"[226] and "making normative judgments".[22]

Rigor

Reflexivity and transparency were practiced from study design to reporting to enhance auditability and credibility.[295] MP designed and conducted this study with guidance from MV and critical input from JA, PD, and LS on the study proposal, protocol, and analysis and interpretation of results. MP documented and discussed methodological and analytic decisions with co-authors. KS provided verification of QCA outputs (i.e., codes, sub-categories, and categories).

Reflexivity

MP conducted this research as part of her doctoral thesis in health policy supervised by MV at a Canadian university. MP's background in occupational cancer research and policy stimulated an interest in lung cancer screening ethics. MP's value of justice influenced the amount of attention given to equity in the design and conduct of this study. MP designed this study as an empirical bioethics project as a part of becoming a health policy and ethics researcher, and to inform ethical LDCT lung cancer screening programs in Canada. Supervisory committee members MV, LS, JA, PD contributed expertise in qualitative research, empirical bioethics, health policy, and lung cancer etiology and treatment.

Ethics approval

Approval to conduct this study was obtained from the Hamilton Integrated Research Ethics Board (protocol number #11285) and all participants provided informed consent.

Results

Participants and analytic categories

Fifteen key informants from five Canadian provinces were interviewed. Most were specialty physicians acting in policy, scientific, and clinical roles related to LDCT lung cancer screening activities (Table 11). Interviews ranged from 39 to 78 minutes in length (mean: 56 minutes).

Five categories describing ethical aspects were identified: 1. Benefits and harms; 2. Equity of screening access; 3. Promoting autonomy and rights; 4. Resource allocation; and 5. Stigma causes and implications. For each category, key informants provided descriptions of the ethical issues and stated what is being done to approach the ethical issues in practice (Table 12).

Table 11: Participant characteristics

Characteristic	**N (%)**
Jurisdiction (province)	
Ontario	4 (27)
Alberta	4 (27)
British Columbia	3 (20)
Québec	1 (7)
Saskatchewan	1 (7)
Manitoba	1 (7)
Nova Scotia	1 (7)
Organization	
Government ministry or agency	9 (60)
Academic institution	5 (33)
Hospital or healthcare organization	1 (7)
Position/role	
Scientist	4 (27)
Clinician-Scientist	3 (20)
Clinician	2 (14)
Policymaker	6 (40)
Terminal degree(s)	
MD	7 (47)
PhD	4 (27)
PhD-MD	1 (7)
Other	3 (20)

Table 12: Categories developed from conventional qualitative content analysis of semi-structured interview data collected from eleven key informants

Category name	Category description	Included sub-categories
1. Benefits and harms	What key informants describe as the benefits and harms of LDCT lung cancer screening in Canada, and what is being done in practice to manage benefits, harms, and their relationship to one another	Benefits[a]
		Harms[a]
		Evidence-based screening protocol[b]
2. Equity of screening access	What key informants describe as equity challenges related to access to LDCT lung cancer screening in Canada, and what is being done in practice to approach equity issues	Equity of screening access[a]
		Defining the target population[b]
3. Promoting autonomy and rights	What key informants describe as moral issues related to promoting autonomy and rights for LDCT lung cancer screening in Canada, and what is being done in practice to mitigate these difficulties	Promoting autonomy and rights[a]
		Culturally safe care[b]
4. Resource allocation	What key informants describe as the ethical aspects of allocating resources towards preventing lung cancer in Canada, and what is being done in practice to distribute prevention resources	Resource allocation[a,b]
5. Stigma causes and implications	What key informants describe as the ethical aspects of stigma and what is being done in practice to redress stigma	Stigma causes and implications[a,b]
		Bias[a,b]

[a] Linked to study objective 1a: To expose ethical dimensions of LDCT lung cancer screening in Canada ("framing" and "laying out the circumstances" in empirical ethics frameworks[22,226])

[b] Linked to study objective 1b: To expose how ethical dimensions of LDCT lung cancer screening in Canada are being addressed in practice ("specifying theories and principles" in empirical ethics frameworks[22])

1. Benefits and harms

All but one key informant endorsed that screening benefits outweigh harms. Reasons for disagreement cited by the outlier key informant were evidentiary uncertainty about the scope of harms, competing health priorities in populations at high-risk for lung cancer, and challenges meeting informed consent requirements given patient and primary care characteristics. The remaining ten key informants cited established evidence that screening benefits outweigh harms. Two main benefits of screening were described: stage shift and health systems cost savings.

Key informants explained that screening for lung cancer with LDCT can shift diagnosis from late to early stage, providing an opportunity for curative treatment that saves lives, improves survival, and improves quality of life. Numerous key informants stated that screening reduces the human and economic burden of lung cancer:

> "If we won't do an effective intervention for the number one cause of cancer…why are we in the healthcare business in the first place…I'll just go back to treating and diagnosing stage four lung cancer, you know that makes no sense whatsoever. That's extremely expensive and it doesn't work." (9607)

Other reported benefits were smoking cessation and patient reassurance from a negative screening result. Some considered detection and follow-up intervention of incidental findings beneficial: "we actually look at the whole person and how we can improve their general health." (403).

Key informants recognized numerous physical, psychological, and economic harms and opportunity costs. There was greater concern for psychological harms along the screening pathway, including screening wait time due to limited access and health systems capacity. One key informant explained that fear about being diagnosed with lung cancer engages with stress that Indigenous and racialized people feel when they interact with the health care system. Patient and health system harms from false positive findings and overdiagnosis were considered unavoidable and acceptable if minimized. There was uncertainty about whether these screening harms have been well quantified. Key informants did not offer prioritization of which harms were considered more severe or unacceptable, and why.

Offering screening in organized, population-based programs that tightly adhere to prescribed, up-to-date, and evidence-based protocols and procedures were strongly stated as mitigating of potential harms to provide overall benefit:

> "So if all of the harms are following evidence-based follow-up algorithms then absolutely yes, the benefits do outweigh the harms." (388).

> "we have to get the right patient, on the right table, scanned with the right protocol, right with the trained radiologist using the right follow-up algorithm, and then also, you do need to have access to a treatment center. Because detecting the lung cancer

> early is only one thing, then you have to have the opportunity that cancer can be treated in a timely fashion, otherwise, there's no point just diagnosing it early. So the whole pathway needs to be in place." (388)

There was agreement that organized screening programs are inherently equitable in comparison with ad hoc screening because they are organized and can distribute benefits across society: "It would be unethical to do ad hoc screening…you end up with only a certain segment of people get the benefit and then they may not have full benefit either because they have one shot screening." (403). Communication with patients and coordination between screening and diagnostic assessment programs were emphasized to mitigate harms:

> "for those who are negative, the nurse navigator will make sure that everybody is coming back for their scheduled intervals. And for those individuals who are positive, that they are getting handed over to a thoracic surgeon who then can treat the lung cancer and resect it in a timely fashion." (388)

2. Equity of screening access

All key informants explicitly named equity of access to LDCT lung cancer screening, diagnosis, and treatment as the most important ethical issue. When thinking about equity, key informants thought of four broad populations (Indigenous, racialized, low socioeconomic status, rural and remote) along two access dimensions (primary care and LDCT lung cancer screening). Key informants explained contributing health and political system barriers to lung cancer care in rural and remote areas and reserves:

> "we have patients who have cancer diagnoses that live far in the North that don't seek treatment because of poor access, lack of transportation, or lack of money because for example, maybe they're not status and therefore their travel is not paid for, and they can't afford to come to the city to get their treatment." (198).

Key informants also described three barriers to equity: to have provincial health insurance to participate in organized provincial cancer screening programs, to be referred to screening by a primary care provider, and to meet standardized rather than population-specific criteria for screening. As one key informant stated:

> "And there was a lot of frustration about the age eligibility criteria being 55 and the Inuit context, where life expectancy is dramatically younger than others, not to mention, very early smoking initiation, highest lung cancer rates in the world, highest tobacco smoking rates in the world, like staggering statistics." (7009)

Key informants described their perceptions that Indigenous populations rightly have a healthy mistrust of the healthcare system and expressed a desire to build trusting relationships. One key informant explicitly stated that high rates of commercial tobacco use in Indigenous communities are linked to colonization and systemic racism.

Key informants described extrinsic screening program approaches to reach target populations where they live as preferable to incentivizing target populations to travel to an LDCT lung cancer screening centre. Several key informants contemplated mobile CT screening vans to increase rural and remote access but estimated that high visibility might elicit smoking-related stigma. Expansion of screening referrals originating from nurse practitioners and regional primary care leads in rural and remote areas were described as helpful structural policy reforms, but insufficient to reach people unattached to any primary care. There was an expressed need to establish indicators of screening and treatment availability and accessibility, and to engage with communities and primary care providers to increase screening awareness and education using translated, inclusive language.

Key informants extensively described intrinsic screening program approaches. These were improved identification of target populations and expanding health system capacity to provide care along the screening pathway. The relationship between these two approaches was inverse and dependent on the threshold used in risk prediction modeling. Key informants described that lowering the threshold widens eligibility and better selects racialized people into screening, but also introduces higher risks of incidental and false positive findings with costly follow-up. What cut-off to use was described as a value judgment. As stated by one key informant: "We chose to start screening in [province] on a threshold of 2% risk or higher for six years, and that was based on performance of the model…but it was mostly driven by cost." (8760).

Tension between identifying the target population and health system cost was rooted in the need for Canadian data to refine risk prediction models, and the structure of publicly financed health systems in Canada, respectively. One key informant hesitated that the "race" variable in risk prediction models developed from United States (U.S.) data would effectively identify high-risk populations in Canada given diversity of Indigenous and racialized immigrant populations:

> "So, you know, are a Black Canadian and a Black American the same in terms of lung cancer risk because we don't think these are necessarily only genetic issues. These are markers for other social economic exposure status, you know whether it's occupation or nutrition, or, you know, where people live in cities, you know, with closer to industrial areas. So those may not be the same in Canada and the U.S." (9607).

Overall, key informants agreed that ethical programs should select "high risk" populations for screening, but which specific individuals should be screened was a topic of ongoing deliberation. For example, there was agreement that risk prediction models should reflect unique population needs, but many differences in how key informants thought this could be achieved. Key informants described how risk prediction models could be enhanced by accounting for population-specific patterns of exposure to lung cancer risk factors. This was also articulated as helping to reduce race-based lung cancer mortality disparities. A key informant stated the need to systematically collect provincial data about race/ethnicity to understand which racialized communities may have high rates of lung cancer incidence and mortality and how they could be engaged in screening. Key informants reported that certain Canadian provinces are currently collecting race/ethnicity data as a part of risk prediction modeling, warranting relationship-building with Indigenous and racialized communities.

3. Promoting autonomy and rights

Some key informants compared screening to other medical interventions, finding that the demands of informed consent for screening were burdensome, disproportionate to risks, and a deterrent for participation, especially among people with language barriers and of low socioeconomic status. One expressed concern about potential coercive effects of promoting lung cancer screening akin to breast cancer screening. Another raised the risk communication challenge of interpreting population-level statistics at an individual level.

A proposed solution to these challenges was screening nurse navigator-led, honest, and culturally and linguistically appropriate dialogue about benefits, harms, how likely individual screening participants are to experience certain screening outcomes, and personal values, traditions, and cultural features that engage with screening decision-making. While this was valued by many, few described ongoing or new collaborations with community groups to create this form of care, even when identifying the importance of these activities, for instance with Indigenous communities. One proposed that community autonomy could be explored for tight knit, high-risk groups. Similarly, two key informants thought that communities should decide if and how to engage with screening given their competing health priorities. Key informants also suggested synchronizing cancer screening intervals with the same health centre and care provider team to support care continuity and minimize travel-related burdens.

Key informants suggested that people with compromised informed consent abilities should have an advocate who can help them understand the screening offer and decision. To reduce decisional burden, key informants suggested that information should be freely and easily accessible in multiple formats so that people can decide how much information to consider at their own pace.

4. Stigma causes and implications

All key informants acknowledged overwhelming, deeply entrenched stigma against people who smoke that stalls screening program development and perpetuates lung cancer disparities. Key informants recognized that people most likely to benefit from screening are "upper middle class, reformed smokers" (9917) who face the least amount of stigma owing to their smoking and socioeconomic status, and resources to cope with lung cancer diagnosis and treatment. One key participant detailed how this stigma impacts lung cancer screening programs in Canada:

> "We have a huge bias, we tend to blame these patients for their illness, they blame themselves as well. So they're not out in the street advocating like you have for other cancer sites. [pause]. So that, it's honestly been the hardest, the main reason there's been

> a delay in implementing this. I mean as we speak, this is the only Canadian task force recommendation that's not funded in most provinces. Every other recommendation gets funded. This one, it's been what, six years now, it's been recommendation, it remains unfunded in the vast majority of provinces. So that bias is fairly clear. And it's not just perceived it's been shown in research, and we see it day to day when we meet with our administrators. And they say we can't do this, they're still smoking." (9607)

Slow and piecemeal progress towards ameliorating stigma was described. Key informants provided examples of non-stigmatizing language for programs (e.g., lung screening program, lung health check), target populations (e.g., people who smoke, people who never smoked), and in nurse navigator scripts. One key informant suggested that healthcare systems need to take responsibility for stigma and build trust with people who experience stigmas intersecting from smoking, socioeconomic, Indigenous, and/or racialized statuses. Another was hopeful that the emphatic link between lung cancer and commercial tobacco smoking will dissociate as more lung cancers are diagnosed in people who never smoked commercial tobacco.

5. Resource allocation

Key informants described resource allocation challenges at different locations within health systems. In primary care, discussions about lung cancer screening were hindered by competing health priorities and appointment duration. Key informants described that trained nurse navigators alleviate this burden for physicians. Still, they expressed the need for more investment in primary care to situate screening in the context of patients' whole health.

In screening programs, key informants articulated that scarce CT resources need to be carefully allocated for acute and preventive uses. Use of artificial intelligence to read chest x-rays, refined eligibility criteria, and rapidly incorporating emerging evidence about screening were proposed solutions to mitigate demands on CT for screening and improve risk-benefit and cost-benefit ratios over time. Key informants stated the need for greater investment in training more medical specialists to operate population-based programs. Key informants acknowledged the opportunity cost of funding screening in health systems: "What are we gonna have to give up?" (198).

Nearly all expressed the need for political responsibility for population impacts of commercial tobacco. Primary prevention was seen as complementary to screening; however, no concrete actions in Canadian jurisdictions were cited. One key informant explained how bias among lung specialists impacts resource allocation for lung cancer prevention: "What they can do is close to them, which is 'Hey, let's use our wonderful technology to screen.' But the problem is way out there in the community. That's where the best use of the money would be." (9917).

Discussion

Empirical findings revealed the textured ethical terrain of using LDCT to screen for lung cancer in Canada. Key informants involved in Canadian LDCT lung cancer screening activities agreed about the overall benefit of this intervention if delivered in evidence-based, procedurally correct, organized population-based programs for high-risk people. However, key informants described how the requirements of organized programs exacerbate lung cancer disparities and limit program efficiency. There was ongoing deliberation about which high-risk people should be screened and how to create non-stigmatizing programs that are both accessible and acceptable to communities, and cost-effective for Canadian health systems.

To our knowledge, this is the first primary study on the ethics of screening for lung cancer with LDCT. The empirical bioethics approach was situated in the realities of Canadian health policy ethics, offering a rich case study for exploring contemporary ethical issues in cancer screening policy. Results intersected with and intertwined ethical issues salient in screening programs for other cancers, such as risk stratification,[85,272-274] overdiagnosis,[296] delicately balanced benefits and harms and promoting autonomy[297] in breast cancer screening with mammography, as well as stigma and Indigenous cultural safety associated with cervical cancer screening.[298,299] Stigma related to lung cancer screening was distinct because in Canada, lung cancer is primarily caused by commercial tobacco smoking, which is a stigmatized addictive substance with systematically higher rates in low socioeconomic and certain Indigenous populations who may encounter other forms of stigmatized surveillance related to their identities. Key informants described that stigma inhibits screening program investment and public participation and thus, the opportunity for high-risk populations to benefit from screening.[300-302] Despite multiple and potentially intersecting forms of stigma and surveillance that need to be cautiously addressed in LDCT lung cancer screening program design and implementation, key informants stated that stigma was a social phenomenon outside of their scope of practice.

Key informants applied population-based disease screening principles as a working ethical framework to produce clinically ethical LDCT lung cancer screening programs in Canada. Key informants frequently cited principles to justify how screening programs are being organized to ensure overall benefit. The most important ethical challenge identified by key informants, however, was that screening is systematically and unjustifiably inaccessible to populations in Canada who could benefit from it the most. Although not explicitly stated by key informants as an ethical issue, stigma consistently emerged in interviews with key informants as a barrier to screening program implementation and participation. Key informants considered primary prevention of lung cancer and political responsibility for the health effects of commercial tobacco smoking as adjunct ethical imperatives to screening. However, few actions were described, and none were articulated as being guided by a normative framework. Could the capabilities approach provide a path for addressing equity of screening access, screening-related stigma, and primary prevention of lung cancer?

Capabilities theory suggests what opportunities can be created for people to achieve substantive freedoms or well-being.[291,292] It is oriented to justice, inclusive of political systems and individual agency, and accommodating of cultural differences. In this study, capabilities theory urges consideration of what opportunities can be created for people in Canada with high lung cancer incidence and mortality to concretely achieve lung health.

Through the lens of capabilities, publicly financed and administered health systems in Canada come into sharp focus as the locus of creating opportunities and promoting agency, rights, and freedoms. Established causes of lung cancer are diverse and require a coupling of non-stigmatizing primary prevention with lung cancer screening to reduce lung cancer incidence and mortality. Primary prevention of exposure to lung cancer risk factors has ripple effects for the prevention of incidence and morbidity of other associated diseases, such as asthma from outdoor air pollution, thus amplifying capabilities related to overall health. Primary prevention also means providing meaningful paths to reduce commercial tobacco smoking.

Commercial tobacco smoking is the leading cause of lung cancer in Canada. For diverse Indigenous communities in Canada, it is a colonizing activity that has caused elevated rates of lung cancer and smoking-related diseases that are preventable and unjust. Key informants in this study expressed significant concern about lung cancer in Indigenous communities in Canada. Some scholars have expressed the need to decolonize tobacco for Indigenous communities on Turtle Island.[99] Decolonization of tobacco could promote capabilities impacted by commercial tobacco smoking as those capabilities are articulated and valued by diverse Indigenous communities. It involves critically examining how colonization of tobacco disproportionately constrains the substantive freedom to health for Indigenous communities with respect to lung cancer and other associated diseases. Decolonization provides both moral and political frameworks for prevent lung cancer and concomitant health, social, and economic effects of commercial tobacco.

The capabilities approach can help address the need for culturally appropriate, self-determined LDCT lung cancer screening for diverse racial, ethnic, and Indigenous groups in Canada. The approach can guide our understanding about what capabilities people with high lung cancer incidence and mortality in Canada wish to see promoted through primary prevention and early detection and treatment of lung cancer. This understanding can be achieved using community-engaged approaches described by key informants who participated in this study. There is also a need to understand which of these capabilities health systems ought to promote, which engages with ideas about the principles, purpose, scope, and structure of public health and health care in Canada. For instance, principles of population-based disease screening could be iterated to formally incorporate normative guidance about capabilities.

Research on social and ethical values about LDCT lung cancer screening held by racially, geographically, and socioeconomically diverse high-risk groups is needed to define capabilities for promotion via screening.[83] More research is needed about how to apply capabilities theory as a normative tool for formulating health policy; specifically, what capabilities screening programs can and ought to promote. Finally, research is needed about effective interventions to reduce stigma attached to LDCT lung cancer screening.

The number of key informants who participated in this study reflects the small size of lung cancer screening leadership in Canada, and recruitment challenges of engaging with this very busy group. However, recurrent identification of participants via snowball sampling suggests comprehensive sampling and recruitment. Information power was attained. The research aim, which was to understand ethical aspects and their resolution from a diversity of perspectives and Canadian jurisdictions, prevented in-depth investigation of moral issues pertaining to specific groups and regions. Nevertheless, integration of empirical data with ethics theories was broadly applicable to Canadian health policy, providing reasoned moral considerations that could be used to support the health, rights, and freedoms of communities disproportionately impacted by lung cancer in Canada.

Conclusion

Population-based disease screening principles guided clinically ethical LDCT lung cancer screening in Canada but contained limited normative guidance to address stigma and equity of screening access. The capabilities approach may be considered by collaborations of preventive health, primary and cancer care, and community leaders to create substantive options for preventing, screening for, and treating lung cancer that are accessible, acceptable, and meaningful to the lives of people who are disproportionately impacted by this disease in Canada. Research is needed on what and whose capabilities ought to be promoted in LDCT lung cancer screening policy in Canada.

Credit author statement[215]

MP: Conceptualization, methodology, formal analysis, investigation, resources, data curation, writing – original draft, writing – review and editing, supervision, project administration, funding acquisition

KS: Formal analysis, investigation, writing – review and editing

MV: Conceptualization, methodology, formal analysis, resources, writing – review and editing, supervision, project administration, funding acquisition

JA, PAD, LS: Writing – review and editing, supervision, funding acquisition

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Competing interests

The authors have no competing interests to declare.

Chapter 5: Discussion

5.1 Results summary

This dissertation included three studies designed to answer the questions:

1. **What are the ethical aspects** of screening people for lung cancer in population-based programs using LDCT in Canadian jurisdictions? (Studies 2 and 3)
2. **How *are* the ethical issues being addressed in health policy?** Specifically, what ethical principles, normative guidance, or moral judgments may be in use in policy decision-making about the development and implementation of population-based LDCT lung cancer screening programs, and how are these ethical ideas being used? (Study 3)
3. **How *should* the ethical issues be addressed in health policy?** Specifically, what do social values and ethics theory suggest for how the ethical issues ought to be approached in policy decision-making about the development and implementation of population-based LDCT lung cancer screening programs? (Studies 1 and 2)

Three separate, interconnected studies were conducted and guided by empirical ethics frameworks.[22,226] Study 1 (Chapter 2) used a systematic literature review and mixed methods integrative synthesis[155] to understand public perspectives on the benefits and harms of LDCT lung cancer screening. Studies 2 and 3 (Chapters 3 and 4) used the qualitative description methodology[227,228] to elicit the ethical and social values of the public and key informants, respectively, about ethical aspects of LDCT lung cancer screening in Canadian policymaking. The findings of this research provided empirical descriptive data that may be subsequently integrated with ethics theory relevant to these data to produce normative conclusions for ethical lung cancer screening programs in Canadian jurisdictions.[22,226]

The first study (chapter 2) was a systematic literature review and integrative mixed methods synthesis of patient and public perspectives on the benefits and harms of LDCT lung cancer screening (“patent and public participants” in the remainder of this chapter). Benefits and harms are canonical principles in bioethics in Canada, providing the moral impetus and rationale for developing and offering health interventions.[303] Understanding how people think about benefits, harms, and their relationship could support the ethically and socially acceptable implementation of screening programs in Canada. This review importantly included the perspectives of people who are racially diverse and/or of low socioeconomic status since lung cancer incidence and mortality are elevated in these groups in Canada; the perspectives of these groups are rarely represented in bioethics research and health policy in Canada.

Results from this review of 49 studies showed a general enthusiasm for screening that was tempered by fear and anxiety among and stigma towards patient and public participants who currently smoke commercial tobacco. The review found that willingness to participate in screening was limited by financial and opportunity costs encountered by patient and public participants with low socioeconomic status and people lacking access to screening due to geographic location. The review also revealed common intersections amongst four identities associated with higher risk of lung cancer: people who currently smoke commercial tobacco, who have low socioeconomic status, and/or who have geographic challenges accessing lung cancer screening, people who are racially diverse. Results suggested the need for non-stigmatizing screening programs that are accessible in fair ways to people who currently smoke commercial tobacco, people with low socioeconomic status, rural and remote residents, and racially diverse groups.

The second and third studies (chapters 3 and 4) were mirror image qualitative description studies that looked at what public participants in Ontario and key informants in Canada, respectively, described as screening ethical issues and their solutions. In the remainder of this chapter, chapter 3 participants will be called "public participants" and chapter 4 participants will be called "key informants". These two studies demonstrated normative logics that guide decisions, or that may be considered to guide decisions, about ethical issues in screening in Canadian policymaking spheres and clinical settings.

Public participants were generally supportive of screening and would be willing to participate despite the likelihood of different screening outcomes, including false positive screening results that could lead to physical and psychological harms to individual patients, and excess health systems costs. Beyond discussing their own willingness to participate, participants described their priorities for screening in the limited resource context of Canadian health systems, with most supportive of using risk-based approaches favouring access for occupationally exposed populations (e.g., to asbestos). They were less likely to suggest that those who currently smoke commercial tobacco should be prioritized, suggesting stigma against this group. Public participants supported equitable screening access, stating that different efforts should be made to engage different high-risk populations in screening. Public participants felt strongly that lung cancer screening decisions should be made on their own rather than by or with their primary care provider, and that lung cancer screening should be accompanied by established pathways for lung cancer diagnosis and treatment.

Key informants included clinicians, scientists, and policymakers engaged with LDCT lung cancer screening activities in Canadian jurisdictions. Key informants drew upon population-based disease screening principles[221] to guide the design of screening programs to ensure overall population and health system benefit. However, these principles were insufficient to guide action on the most important ethical issues identified by key informants: smoking-related stigma and equity of screening access. Two other key ethical issues identified by key informants were tobacco commercialization and investments in the primary prevention of lung cancer. Like stigma and equity, these ethical issues were also structurally oriented and lacking normative guidance in disease screening principles and health policy related to lung cancer prevention.

In considering the findings of all three studies together, several ethical issues are visible. These ethical issues may be conceived of as two overarching contradictions salient in the field of health policy and ethics: between the self and society, and the public and policymakers. The first contradiction, between self and society, was expressed by the fact that LDCT lung cancer screening is simultaneously a health care and public health activity with sometimes conflicting ethical frameworks, especially the principles of autonomy and justice, respectively.[19,223] Tension between self and society was also identified in expressions of concern, which centered individual responsibility for lung cancer mortality prevention above responsibility related to social systems and structures that contribute to the determinants of lung cancer incidence and mortality. This finding was exemplified most clearly by public participants, who considered use of commercial tobacco to be an individual behavioral choice rather than a dependency shaped by structural and systemic determinants.[304,305]

The second contradiction was the optimal role and extent of public perspectives in LDCT lung cancer screening policymaking. This tension is highlighted in the conflict between public and key informant perspectives on who should be prioritized for lung cancer screening and whether descriptive evidence about ethical issues is fair, sufficient, and necessary to inform normative guidance about ethical issues (i.e., the naturalistic fallacy).[119] In cases like LDCT lung cancer screening where public, policy, and ethical perspectives conflict, and where descriptive findings are from limited perspectives, how are, and how should, democratic and ethical policy choices be made? This research identified what ethics principles are being used by policy actors and what ethical and social values expressed by public participants are stigmatizing, underscoring the need for critical ethics analysis to guide policy decisions to address these contradictions and the choices that they bring about. I end this chapter by outlining a proposal that the capabilities approach[291,306] be considered as a lens to analyze the ethical issues identified in this research and to produce justifiable normative recommendations for addressing the ethical issues in health policy.

5.2 Contradictions

Self and society

Autonomy versus justice: can risk prediction modelling negotiate the health care and public health dimensions of organized LDCT lung cancer screening in Canada?

I identified normative conflicts between the health care and public health dimensions[19,20] of organized LDCT lung cancer screening programs in this research; particularly, tensions between promoting autonomy and justice in screening. This research provided some insight about how these conflicts could be negotiated in practice via the use of risk prediction modelling.

The aim of LDCT lung cancer screening, as it is currently being implemented in Canadian jurisdictions, is to select asymptomatic individuals from the population whose risk of being diagnosed with lung cancer in a defined future period is predicted to exceed a certain threshold and to evaluate the potential presence or absence of lung cancer in these individuals using LDCT,[263] which is a relatively rapid, clinically effective, and cost effective medical method and technology.[223] Screening is not a diagnostic tool; rather, it acts as a filter to separate asymptomatic individuals in a population who are predicted to have lung cancer now or in the future from those who do not have lung cancer.[223,307] Those whose screening results are positive are offered follow-up investigation to determine their diagnosis and then offered treatment if a lung cancer diagnosis is made.[18]

As a public health activity, screening aims to reduce lung cancer mortality that is observed at the population level overall and may also be observed among specific sub-groups. Asymptomatic screening is intended to capture large numbers of people to detect lung cancer in early, pre-symptomatic stages among people who have been exposed to risk factors for lung cancer. Screening acts in the opposite direction of the usual contact between individuals and health care systems, where individuals initiate contact with a care provider when they are feeling unwell. Instead, the initial invitation to participate in LDCT lung cancer screening is issued to potentially eligible individuals from a primary care provider or public health organization, such as a provincial cancer agency. Invitations may be directed to individual patients in primary care or to people in high-risk sub-populations, e.g., via public advertising, which enables individuals to self-refer into screening.[18,223]

The public health and health care dimensions of lung cancer screening elicit corresponding ethical frameworks, which sometimes conflict.[19,223] As a public health intervention, screening may promote justice by prompting people to request medical evaluation of their risk of lung cancer (via risk prediction modelling) and the presence or absence of lung cancer (via LDCT screening) if their predicted risk exceeds a certain threshold. As an individual health care intervention, it is important that screening promotes the autonomy of individuals throughout the screening pathway, e.g., by asking individuals for their informed consent to participate in screening. The screening invitation or offer is nevertheless an intrusion in the lives of people who are asymptomatic for lung cancer. This feature of screening may reduce the autonomy of individuals and cause unnecessary physical and psychological harm.[19,223]

Key informants in this study engaged strongly with principles of population-based disease screening[221] to ensure that LDCT lung cancer screening programs in Canada have a net clinical benefit, and are therefore a justifiable intrusion in the lives of asymptomatic people, only a small proportion of whom may have lung cancer or be at high risk of being diagnosed with lung cancer in a defined future period. Key informants described the need to balance clinical benefit to populations and cost-savings to health systems, with the need to reduce the potential for clinical harm to individuals. Key informants explained that this balance is achieved in practice by identifying and inviting only people at high risk for lung cancer to screening, and by establishing comprehensive screening programs that provide evidence-informed pathways for screening, diagnosis, treatment, and psychosocial, palliative, and end-of-life care. Inviting only people at high risk for lung cancer is important because this reduces the incidence rate of false positive screening findings and associated physical and psychological harms for patients and families, as well as costs of follow-up investigation of false positive findings for health systems. Providing corollary healthcare is important because this ensures that people who participate in screening have established pathways to follow for choosing to receive timely and appropriate medical and psychosocial lung cancer screening follow-up care.

Key informants described that identifying and inviting only high-risk people to screening is currently being implemented in two parts: first, as an invitation for people with potentially screen-eligible age and smoking history to participate in risk prediction modeling, and second, as an invitation for people whose predicted risk upon modeling meets or exceeds the jurisdiction-specific threshold for being diagnosed with lung cancer.[18] The use of risk prediction modeling was explained by key informants as a tool for optimizing the ratio of screening clinical benefits and harms for individuals; specifically, by acting as a fine filter to separate individuals who are most likely to receive a true positive screening result from individuals who are most likely to receive other screening outcomes. Key informants explained that thresholds for who is considered “high risk” are specific for jurisdictions, depending on the jurisdiction’s epidemiology of lung cancer and health system costs of screening.[18,263] Risk prediction models have been shown to outperform age- and smoking-based screening eligibility criteria (a crude filter) with respect to LDCT screening sensitivity and specificity for lung cancer.[308] Population-based LDCT lung cancer screening programs are the first in Canada to use risk prediction models for all potentially eligible participants, for similar reasons that risk stratification approaches using personalized breast cancer risk data are currently being evaluated for use in population-based breast cancer screening programs in Canada.[309-313]

This research suggests that risk prediction modelling may act as a mechanism for balancing autonomy and justice by providing transparency and dialogue about personalized lung cancer risk that can support individuals' decision-making processes about their own screening participation (autonomy) and by identifying who in a population could benefit the most from receiving an invitation to participate in lung cancer screening (justice). Neither interview guide asked key informants or public participants about the potential impacts of risk prediction modelling on autonomy and justice. However, public participants expressed that being provided with information about their personalized risk of being diagnosed with lung cancer would help them make informed decisions regarding their own participation in lung cancer screening. Key informants described the use of screening navigators to conduct risk prediction modelling and to provide fulsome explanations to modelling participants about what variables are included in the model, how variables in the model are analyzed, and the implications of modelled risk on screening eligibility and ways to reduce lung cancer risk.

Public participants and key informants strongly believed that screening should be offered to people at high risk of being diagnosed with lung cancer as a public health service to ensure that these individuals can increase their chances of early diagnosis and treatment and survival from lung cancer. Both entities also stated that screening processes should be offered in different ways to meet the needs of different sub-populations. Some stated that screening should be made available and accessible in culturally safe ways to Indigenous communities and should promote their autonomy. Some key informants described equity- and autonomy-promoting efforts that are being implemented or that can be considered to engage Indigenous, rural and remote, and racially diverse people in screening processes.[18]

Based on these findings, the ability of risk prediction modelling to promote autonomy and justice appears to depend on how risk prediction modelling processes are conducted, by whom, for whom, and what efforts are being used in risk prediction modelling to mitigate potential constraints on autonomy or limits on justice. Key informants described that risk prediction modelling needs to be offered in the preferred language of participants using non-stigmatizing language and public participants supported the idea of equitable access to inclusive screening processes. However, this research did not ask key informants about what is being done, or what should be done, to address potential ways that risk prediction modelling might hinder autonomy and justice. Patient and public perspectives from study 1 (chapter 2) indicate that people may feel either compelled or stigmatized, anxious, and fearful to participate in screening upon being categorized as high risk. These responses leverage people's fear of lung cancer and depend on smoking status. Screening participation decisions based on high-risk categorization from risk prediction modelling could widen screening participation disparities between people who currently smoke commercial tobacco and those who do not.

This research found that reticence of people who currently smoke commercial tobacco to participate in screening was in part due to the emphasis on commercial tobacco smoking in risk prediction models. Some key informants and public participants expressed that risk prediction models could promote equity and reduce stigma by potentially including more non-smoking lung cancer risk factors relevant to the target screening population, such as genetic, occupational, and environmental risk factors.[314] Current studies about if and how to leverage the use of lung cancer screening to screen for other diseases might help alleviate stigma associated with commercial tobacco smoking and lung cancer.[315] In conducting this research, I also identified the potential need for psychosocial supports in health systems and society for people who become aware of their high risk of being diagnosed with lung cancer upon participating in risk prediction modelling.

Support for individuals who were invited to participate in risk prediction modeling and who took part, but were found to be ineligible for screening, should be provided to mitigate potential anxiety caused by this process and to outline a path for potential medical and psychosocial care that may include chronic disease management and/or support for commercial tobacco smoking cessation. People who were invited to participate in risk prediction modeling but who decided not to take part, or who participated in risk prediction modeling and declined to participate in a subsequent screening invitation, should also be supported in their decision and offered appropriate follow-up care. This support may include opportunities to build trusting relationships with primary care providers and/or community health supports as needed or desired by individuals.

Further research, possibly using empirical ethics approaches, could provide an understanding about how risk prediction modeling processes can support autonomy and justice in Canadian LDCT lung cancer screening programs. Future research could increase health justice for communities if it aims to elucidate and center community concepts of justice and values about justice regarding the design and implementation of risk prediction modelling in organized LDCT lung cancer screening programs.

Individual versus collective responsibility for lung cancer prevention: can the burdens of deciding whether to participate in screening, and participating in screening, be alleviated?

Tension between the self and society also arose in this research with respect to individual responsibility for lung cancer elicited by the offer of LDCT lung cancer screening, and the causes of lung cancer that originate from social, political, and economic conditions. The causes of lung cancer are myriad.[43,316] While most lung cancers currently being diagnosed in Canada are caused by commercial tobacco smoking,[317] exposure to environmental and occupational lung carcinogens such as asbestos, radon, and outdoor air pollution are believed to contribute at least in part to the 15-25% of lung cancers that are diagnosed in people in Canada who have never smoked commercial tobacco.[318] Thus, lung cancer incidence is determined to some extent by political and economic causes.

This fact was recognized by key informants who talked about the commercialization of tobacco. Key informants stated that the Canadian government should take political responsibility for lung cancers caused by commercial tobacco smoking. However, in Canadian social policy, there is little political responsibility for the impacts of exposure to commercial tobacco smoke and other carcinogens on lung cancer incidence, morbidity, and mortality. The Framework Convention on Tobacco Control (FCTC),[319] a multilateral agreement that guides tobacco control activities globally that is endorsed by the Canadian federal government, does not provide pathways for meaningful accountability of the tobacco industry for lung cancer prevention, screening, and treatment. Calls to decolonize the production, sale, and use of commercial tobacco in Indigenous communities have not yet been responded to by governments in Canadian jurisdictions.[99] The Canadian federal government's 2018 asbestos regulation is helping to prevent exposure to new asbestos in Canadian workplaces and environments; however, there is still exposure to legacy asbestos and this regulation does not outline responsibilities of the asbestos industry towards people who were or are currently exposed to asbestos.[320]

Incongruence between the structural and systemic causes of lung cancer and the offer of screening to individuals is a bioethical issue. An invitation for lung cancer screening downloads the burden of decision-making about the prevention of lung cancer mortality to individuals rather than holding accountable governments and industries that previously or currently produce, market, and enable exposure to commercial tobacco and lung carcinogens in workplaces and environments. Primary prevention of lung carcinogens could not only affect lung cancer incidence, but also the rates of diagnosis of other diseases caused by their exposure, such as asthma and chronic obstructive pulmonary disease. Emphasis of individual responsibility for the primary prevention of lung cancer abounds in public health and medicine in messaging and support for commercial tobacco smoking cessation, and relatively less attention is paid to government and collective responsibility for primary prevention, which could produce much greater gains for public health. Public participants in this research were adamant about making their own informed screening decisions, and few perceived this to be disproportionately burdensome or unjust. Yet the concerns about political responsibility raised by key informants and public participants suggested the need for greater political support to individuals and communities in the screening process.

Equitable access to screening decision-making supports, including equitable access to primary care, can offer solidarity and decisional burden-sharing with individuals, especially those whose high risk of lung cancer is associated with exposure to commercial tobacco smoking and occupational and environmental lung carcinogens. Shared decision-making approaches have been evaluated with respect to alleviating some of the decisional burden shouldered by individuals.[321,322] Policies to provide equitable access to commercial tobacco smoking cessation support within organized LDCT lung cancer screening programs are being explored.[18] Because exposure to lung carcinogens is also associated with other diseases, such as asthma and cardiovascular disease, in conducting this research, I also identified that equitable access to primary care could support chronic disease management and applications to workers' compensation for cases of occupational disease.

Financing of LDCT lung cancer screening programs, including CT machines, to improve equity of screening access could also be investigated as a joint endeavour between Canadian governments and industries implicated in causing lung cancer in Canada. Further empirical and normative research could identify what sorts of lung cancer screening-related accountabilities people desire from Canadian governments and industries. This research may also contribute empirical evidence for making normative justifications about why and to what extent social policy outside of health systems should centre health.

Public and policymakers

The second contradiction found in this research was conflicting ethical and social values between the public and key informants, particularly around normative justification about who should be prioritized for lung cancer screening. Public participants and key informants agreed that only people who are at high risk of being diagnosed with lung cancer should be screened for lung cancer. While key informants emphasized that this means prioritizing people who currently or formerly smoked commercial tobacco in moderate or high cumulative lifetime amounts, public participants placed people with occupational lung carcinogen exposure, as well as people with environmental carcinogen exposure and a family history of lung cancer, ahead of people with a commercial tobacco smoking history. Public participants gave the least priority to people who currently smoke commercial tobacco, explaining that the public should not be responsible for people's behavioural choices.

This finding revealed stigma and conflicting logics about whether and to what extent commercial tobacco smoking is a dependency shaped by social, political, and economic determinants, or a freestanding behavioural choice. Some public participants admitted that their interview had made them realize that they harbour stigmatized views against people who currently smoke commercial tobacco, believing that this was a behavioural choice. Key informants were more likely to recognize commercial tobacco smoking as a dependency and stated that social, medical, and political stigma against this group is a barrier to obtaining public buy-in and implementing lung cancer screening more widely in Canadian jurisdictions.

This finding also raises questions about how health policy in democratic government systems should be made in response to public values when public ethical and social values disagree with the perspectives of key informants, or when there are disagreements between the public and key informants on how mutually recognized ethical issues should be solved. Whose values are being represented in this research are important to consider. Public participants were mostly white women of high socioeconomic status who spoke English as their first language. This demographic is consistent with patient partners in health system decision-making activities, where inclusivity of communities with poor health outcomes remains a challenge.[323,324] The lack of diversity of public participant identities in this study limits the potential to make democratic and equitable policy decisions about ethical issues due to a lack of diverse perspectives,[324] especially from people in populations with high rates of lung cancer incidence and mortality. Public and key informants in this research mostly did not represent equity-denied groups relevant to lung cancer screening (e.g., some Indigenous communities), thus, their various ideas about increasing screening uptake in these groups risk perpetuating rather than disrupting harmful (e.g., colonial) health policy. Further research is likely needed to understand the perspectives on ethical aspects of lung cancer screening held by these populations and to center their voices and values in creating equitable lung cancer screening programs. Lack of clarity from the public and key informants about how to address the structurally and systemically oriented ethical issues raised in this research should be addressed, e.g., how to balance harm reduction and resource allocation with expanding risk categories in the desire to promote equity, and how to allocate resource towards primary and secondary prevention of lung cancer.

Bioethical plurality from diverse populations worldwide suggests a multitude of ideas about what constitutes an ethical issue when it comes to cancer, screening, and prevention and different principles, values, and ways of approaching the ethical issues in relation to self, others, and nature.[325-333] Bioethics frameworks have been critiqued as normatively white,[334] which has contributed to stalled action on health equity for marginalized populations and which has denied the recognition of a broader range of ethical issues and frameworks for resolving them across societies and cultures worldwide. There is a need for more pluralistic ethical theory to guide equitable and inclusive health policymaking, particularly in diverse societies such as Canada and especially about issues (such as lung cancer) that mainly affect historically excluded groups (such as people of low socioeconomic status, rural and remote residents, and certain Indigenous communities and racially diverse groups).

This research has revealed the need to understand the health ethics and values of diverse communities in Canada and how to respond to these in health policy, including when the pluralistic values of different groups may conflict. This research may be informed or guided by community engaged approaches. Engagement with Indigenous communities for breast, cervical, and colorectal cancer screening programs is being used in some Canadian provinces to develop culturally safe and accessible programs.[335] Some community engagement is also being conducted in Canada for LDCT lung cancer screening activities.[18] Further research is needed to understand if, how, and to what effect lung cancer screening programs in Canada might promote justice for these communities.

Conflicting and incomplete ethical and social values about lung cancer screening ethical issues underscore the role of bioethicists in identifying these differences and gaps and proposing ways for approaching their resolution in health policy. Bioethicists may raise questions about how to manage disagreements between key informants and the public about what the ethical issues are and how they should be resolved in lung cancer screening policy, and the policy implications of incomplete information on public ethical and social values. Bioethicists may also ask how much and how should ethical and social values from the public influence lung cancer screening policy, signalling the dangers of the naturalistic fallacy in empirical bioethics research.[119] Ethics analysis of the descriptive empirical data collected from public participants in this research can judge whether these data are fair, sufficient, and necessary for making normative recommendations about addressing ethical issues in lung cancer screening policy. Ethics analysis can also flesh out the limitations of the descriptive data for informing normative conclusions and how to guard against biases and stigmas in policy decision-making.

5.3 Choices

This research revealed the tragic choices that need to be made in LDCT lung cancer screening policy in Canadian jurisdictions. Tragic choices are decisions about how to allocate tragically limited resources in society and depend on how much of the resource should be made available and to whom the resource should be provided.[336] Resource allocation is a policy dilemma in Canadian health systems where there are limited resources (human resources and equipment) for implementing equitable access to population-based LDCT lung cancer screening programs. This includes limited numbers of CT machines and associated resources available in limited geographic regions and at limited times for use for LDCT lung cancer screening. There are also limited resources for lung cancer diagnosis, treatment, and care (especially culturally appropriate care); these services are not available uniformly and not for many populations with the highest rates of lung cancer incidence and mortality.

Ethical decision-making about the allocation of tragically scarce resources is particularly important for understanding why tragic choices are made (i.e., using what ethical guidance, frameworks, principles, logics, values, or precedents) and who benefits and who is harmed from these choices. The following tragic choices emerged from this research:

- Which individuals in a population should be offered screening for lung cancer using LDCT?

- Who should be defined as high risk for being diagnosed with lung cancer, and on what basis?
- What supports should be made available and accessible to people with lung cancer risk factors, but defined as low risk for being diagnosed with lung cancer?
- Should screening be offered ad hoc where there is a persistent lack of a population-based LDCT lung cancer screening program, or should screening only be offered as part of an organized program where it exists?
- Where, to whom, and how should services for primary care and lung cancer screening, diagnosis, treatment, and psychosocial, palliative, and end-of-life care be offered?
- What and whose ethical theories and social values should be used to guide lung cancer screening policy making?
- How much should public ethical and social values be taken into consideration when identifying and approaching lung cancer screening ethical issues, and at what places in the screening policy making process should these values contribute?
- Should privately financed CT machines be used as a part of population-based LDCT lung cancer screening programs?
- What should be the roles of the Canadian federal government and relevant industries for taking responsibility for the health effects of commercial tobacco smoking, colonization of tobacco, and primary prevention of lung cancer, if any?
- How much should be invested in lung cancer screening versus primary prevention of lung cancer?

This is not a comprehensive list, but merely an indication of the breadth and depth of tragic choices that were raised in conducting this research about the ethical dimensions of population-based LDCT lung cancer screening in Canada. Principles of population-based disease screening,[221] which is the only ethical framework being used by key informants to guide lung cancer screening policy decision-making in Canada, offers limited capacity for responding to these tragic choices. There is a need to augment or enrich population-based disease screening principles to prompt explicit normative deliberation about ethical decision-making about resource allocation for lung cancer screening in health policy. For example, the principle of accessibility in the Canada Health Act[337] may be formally incorporated in principles of population-based disease screening to support deliberation between governments and communities about the meaning of equitable screening access and implementation and evaluation of equitable screening access. Additional frameworks to consider are the capabilities approach,[291,306] human rights,[338,339] the Truth and Reconciliation Commission of Canada Calls to Action,[340] and decolonization of tobacco in Indigenous communities.[99]

5.4 Capabilities

This research has shown that different interest groups have varying perspectives about what the lung cancer screening ethical issues are and how they should be resolved in health policy. This finding was most clearly observed between key informants and public participants, who had multiple views about who should be prioritized for screening. Ethical and social values within patient and public participants showed some variation as well. These findings suggest bioethical plurality, or multiple ideas held simultaneously in society about what constitutes an ethical issue in lung cancer screening and what principles, values, or ideas may be used to approach the ethical issues in health policy.

Lung cancer screening can also be thought of as a tool for achieving broader types of pluralistic values about living a fulfilling life that vary across and within different groups and individuals. The capabilities approach offers a normative framework for understanding what and whose values ought to be promoted via lung cancer screening. It focuses on the substantive capabilities that people have to achieve the lives they value, or what choices people have available to them to attain well-being. People's substantive capabilities can be created by social, political, and economic conditions that improve opportunities to access tools and resources that people need to live the lives that they value, such as the tools and resources of lung cancer screening. Capabilities theory also considers the distribution of these opportunities in society.[291,306]

When applied to lung cancer screening, capabilities theory may be used to ask what people value as living fulfilling lives related to lung cancer screening and how screening could be offered to support the capabilities of people to achieve these lives. Bioethics research could help respond to these questions. Virtually no bioethics research has focused on understanding the values and lives that people aspire to achieve related to lung cancer screening and their capabilities for doing so. This research might ask people what they value and wish to achieve in their lives because of the early detection and treatment of lung cancer. Some patient and public participants in study 1 (chapter 2) of this dissertation expressed their favourable views about the benefits of lung cancer screening as buying them additional time with their grandchildren, which suggests that people may conceive of screening in terms of capabilities. However, research on lung cancer prevention and cancer screening ethics has not explicitly aimed to understand capabilities and to justify the offer screening in terms of promoting capabilities. It would be especially important to understand and prioritize the capabilities of populations with high rates of lung cancer incidence and mortality to help inform equitable access to lung cancer screening needed for these populations to achieve fulfilling lives.

Lung cancer screening is one of many pathways for preventing lung cancer mortality in Canada. The determinants of lung cancer incidence and mortality are diverse, each representing an opportunity for prevention and creating real capabilities for people to live fulfilling lives. Determinants importantly include social, political, and economic structures and systems that create or perpetuate exposure to lung carcinogens, such as the production and sale of commercial tobacco, the production and use of occupational lung carcinogens, and the emission of environmental lung carcinogens. A growing proportion of lung cancers in Canada are being diagnosed in people who have never smoked commercial tobacco, highlighting the contributions of occupational, environmental, and genetic causes. These causes are currently underrecognized in lung cancer screening eligibility criteria in Canadian jurisdictions, and their social and structural determinants are underappreciated in efforts to prevent lung cancer.

The capabilities approach can draw attention to these causes and can be used to propose a moral justification for investing in the primary prevention of lung cancer. As with screening, the capabilities approach asks what social, political, and economic conditions are needed to provide people with substantive opportunities to access the resources they need to live a fulfilling life. For instance, ethics research on lung cancer primary prevention guided by capabilities theory might ask what policies could be implemented to reduce industrial emissions that contribute to lung cancer diagnoses in heavily impacted regions and argue that these policies ought to be implemented to provide people with capabilities to achieve longer and healthier lives with lowered lung cancer risk.

The capabilities approach is pragmatic due to its emphasis on the tangible capabilities of persons to attain the lives they value. This characteristic extends claims that people have the rights or freedoms to achieve their self-determined values and lives. Capabilities theory has been used with human rights to produce an account of health justice.[341] For populations for whom lung cancer prevention, screening, and care is a matter of justice, capabilities theory may be considered in conjunction with rights-based approaches such as the United Nations Declaration on the Rights of Indigenous Peoples[338] and the Truth and Reconciliation Commission of Canada Calls to Action[340] to make a health justice argument.

5.5 Strengths and limitations

This is the first study to comprehensively investigate the ethical aspects of LDCT lung cancer screening using an empirical ethics approach in the Canadian context. This research contributes to scientific and policy debate about ethical issues related to screening for lung cancer with LDCT. Literature about this debate is sparse and has focused on who should be screened for lung cancer. There is relatively more literature published about the ethical aspects of breast cancer screening, which overlaps to some extent with some of the ethical issues identified in this research. For example, ethical issues associated with the use of risk stratification in personalized approaches to breast cancer screening have been researched from the perspectives of policymakers, clinicians, and the public in Canada. The research in this dissertation contributes primary empirical evidence about the ethical implications of using personal information about lung cancer risk to determine screening eligibility from the perspectives of key informants, patients, and the public. Public participants (Chapter 3) were supportive of providing personal information to estimate their lung cancer risk as a part of risk prediction modeling for screening. This finding was congruent with acceptance of the use of risk stratification for breast cancer screening in a study conducted among women in four Canadian provinces[311] and could inform ongoing research and policy dialogue about the ethical aspects of using precision approaches in preventive medicine.

A limitation of this research is the lack of perspectives on the ethical aspects of population-based LDCT lung cancer screening from populations with high rates of lung cancer incidence and mortality. These populations arguably have the most at stake when it comes to ethical lung cancer screening, yet this research was unable to elucidate what these populations self-determine to be ethical issues and to understand how they approach ethical issues or think they should be approached in health policy. Key informants who collaborate with these populations were unresponsive to recruitment efforts. Future research on elucidating the ethical aspects of lung cancer screening could consider using community-engaged approaches with disproportionately impacted sub-groups and relevant key informants to understand what these communities self-determine to be ethical issues impacting their lives and what ethical and social values they would use to navigate these ethical issues with respect to lung cancer, screening, and prevention. This research may contribute to developing effective and ethically and socially acceptable lung cancer screening for equity-deserving groups.

A strength of this research was the application of descriptive elements of the symbiotic empirical ethics approach.[22] Ethical issues known to me *a priori* via literature about cancer and disease screening ethics were used to develop the semi-structured interview guides for the two qualitative description studies.[19,223] The semi-structured design allowed room and flexibility for engaging public participants (in study 2, chapter 3) in identifying and describing the ethical issues and how they would go about addressing them. While the interview guides engaged public participants and key informants in thoughtful reflections and responses to the questions asked, and elicited new thoughts driven by public participants and key informants themselves, the interview guides did not sufficiently cover all ethical angles of lung cancer screening. For instance, no questions were asked about how people who have a familial history of lung cancer should be prioritized in screening. As 15-25% of lung cancers in Canada are diagnosed among people who have never smoked commercial tobacco,[318] it will be important to further investigate the ethical implications of potentially including genetic information in risk prediction models.

5.6 Contributions

Empirical

Cancer screening ethics is multifaceted and numerous ethical issues have been identified and drawn out of established screening programs worldwide for breast, cervical, colorectal, and prostate cancers. Little research has been conducted about how the public and key informants consider the ethical aspects of cancer screening and their solutions. This research generated novel empirical evidence about the ethical aspects of population-based LDCT lung cancer screening relevant to Canadian health policy from these perspectives. This is the first study of this type in Canada and one of the few to explicitly use an empirical ethics approach for understanding cancer screening ethics.

Primary empirical evidence about ethical issues was ascertained from two mirror image qualitative description studies with key informants and public participants who were asked to identify, describe, and address ethical issues. Semi-structured interview guides used in these studies were informed by literature about cancer screening ethics with room for participants to respond, reflect, and extend the literature through their own identification and normative logics about addressing ethical issues. Analyses stayed close to the words expressed by participants to show how the ethical issues are perceived and navigated in policy, and in the everyday lives of participants.

Secondary empirical evidence about public perceptions of benefits and harms of organized LDCT lung cancer screening programs was generated through a systematic literature review and integrative synthesis of qualitative and quantitative studies. This study provided insights about how people from a variety of demographic backgrounds in jurisdictions with varying health system administrative structures view benefits and harms. Collectively, the primary and secondary empirical evidence collected and analyzed in this research broadens the landscape of ethical issues related to population-based cancer screening due to the distinct epidemiology and burden of lung cancer in Canada. Empirical findings may contribute to developing LDCT lung cancer screening programs in Canada that are ethical, effective, and equitable for health systems and society.

Methodological

This research applied empirical bioethics as the overarching methodological approach for the three independent studies contained in this dissertation. Empirical bioethics encompasses a diversity of methodologies and theories; it is the integration of empirical evidence with bioethics theory that qualifies research as empirical bioethics. This research provides an example of how mixed methods and qualitative methodologies may be used as part of empirical bioethics research. In particular, this research provides a methodological application of descriptive elements of the symbiotic empirical ethics approach[22] and the Bristol framework,[226] showing their usefulness in health policy ethics research.

Theoretical

This research extends cancer screening ethics for the particularities of the lung cancer screening technology currently being implemented in Canada (LDCT), the epidemiology and determinants of lung cancer in Canada, and in the context of publicly financed and administered health systems in Canada where accessibility is a principle enshrined in the Canada Health Act. It intersects with the ethics of risk stratified screening[342] via the use of risk prediction modeling to identify and invite to screening only individuals who are categorized as high risk of being diagnosed with lung cancer. Personalized approaches for selecting individuals in a population for screening are currently being used or explored for breast cancer screening in Canada.[313] Ethics research on this topic suggest that promoting autonomy and ensuring equitable access to risk assessment may be relevant to lung cancer screening.

Empirical evidence about ethical and social values from this research may be used to advance theoretical frameworks from public health ethics and clinical ethics that are relevant for approaching ethical issues in screening for lung and other cancers. The use of risk prediction modelling in lung cancer was identified as needing further ethical research to determine its effects on balancing the principles of autonomy with justice. Integration of descriptive empirical data from this research with relevant ethical theory can produce normative recommendations for addressing ethical issues in health policy. I have proposed the capabilities theory as a potential ethical theory; however, additional or alternative frameworks may be used, such as the principle of accessibility in the Canada Health Act, human rights, and decolonization principles.

This research synthesizes and contributes new social values evidence that contend with the meaning of democratic health policy. This research brings the perspectives of key informants and the public and patients into dialogue with one another to create an interstitial space for bioethical research in health policy. As a result, this research might elaborate the study of health policy ethics as its own disciplinary field.[21]

5.7 Policy implications

Population-based LDCT lung cancer screening is a significant investment of public resources in Canadian health systems. Not only should lung cancer screening programs be clinically beneficial at a population level, but they must also be cost-effective for health systems and ethically and socially acceptable to the public. This research contributes ethical and social values evidence that may contribute to current scientific and policy discourses about the effective, equitable, and ethical design, implementation, and evaluation of population-based LDCT lung cancer screening programs in Canada. Results may engage with ethical and social values evidence collected and analyzed as a part of health technology assessments that have been conducted in some Canadian jurisdictions. This study may enrich existing evidence by providing insights on a wide range of ethical issues informed by a systematic review of the literature (study 1, chapter 2) and public perspectives in Ontario (study 2, chapter 3).

Results from this research about the ethical allocation of resources to prevent lung cancer might stimulate or augment existing policy debate about how to engage health and social systems in the primary prevention of lung cancer. Key informants interviewed in this research (study 3, chapter 4) expressed strongly that the Canadian government should take responsibility for the harmful health effects of commercial tobacco and ban tobacco from being sold commercially in Canada. Epidemiologic projections show increasing lung cancer incidence primarily due to commercial tobacco smoking, and a large proportion of lung cancers in Canada being diagnosed in people who have never smoked commercial tobacco. These findings demonstrate the need for lung cancer screening in parallel with strategies that prevent exposure to occupational and environmental lung carcinogens known to be present in Canadian workplaces and environments, with varying prevalence and levels of exposure in different populations.

These findings also emphasize the need for ongoing etiologic and epidemiologic research about the environmental, occupational, genetic, and behavioural causes of lung cancer and how these causes may engage with one another to impact risk differentially in sub-populations in Canada. This research is likely to lead to new approaches to estimating lung cancer risk to determine screening eligibility.

5.8 Clinical implications

Organized lung cancer screening programs using LDCT are being implemented more widely in Canadian jurisdictions. The major clinically relevant finding of this research is the need for greater transparency and understanding about the benefits and harms of screening to support informed decision-making about screening participation and to promote autonomy. Findings from this research about patient and public perspectives on benefits and harms (Chapter 2) may inform the development of approaches to communicate to the public and patients more effectively about screening benefits and harms, including the translation of population-level risk of benefits and harms information to the individual level. Communication strategies informed by this research may include non-stigmatizing messaging and different formats (e.g., web-based with compatibility on a variety of mobile devices, in-clinic brochures, universal and accessible formats for people with different abilities and language needs, interactive tools, use of graphics, etc.) and methods (e.g., community campaigns, integrated with other cancer screening services, etc.).

Results from this research about public perspectives on lung cancer screening ethics (Chapter 3) suggest the need for non-stigmatizing messaging about lung cancer screening and an understanding about the use of risk prediction models to determine screening eligibility. These elements may be especially important for people who participate in risk prediction modeling upon the recommendation of their primary care provider but who do not meet the eligibility threshold to be invited to screening. This research may suggest how primary care providers and lung cancer screening navigators can engage with patients in counselling and processes of shared decision-making about their participation in lung cancer screening in non-stigmatizing ways that are attentive to their unique risk factors for lung cancer, cultural safety needs, language needs, socioeconomic status, and financial and geographic access to lung cancer screening, treatment, and psychosocial care.

5.9 Research implications

This research is an example of how bioethics research can contribute to health policy in Canada. The framing of population-based LDCT lung cancer screening programs as a topic for normative inquiry allowed ethical issues to be elucidated in the context of Canadian health policy and systems. Ethics analysis of the empirical ethical and social values evidence ascertained in this research will produce recommendations about how the ethical issues should be addressed in health (and social) policy. Bioethics offers the unique capacity to do the normative work intrinsic to health policy, but rarely made explicit through research dedicated to this task. The empirical bioethics approach used in this research was particularly valuable for producing an understanding of the ethical issues grounded in the experiences and perspectives of key informants who are most intimately engaged with lung cancer screening policy and programs in Canada, as well as in the values held toward screening by the public, who all contribute to funding health systems and who may additionally be eligible for their own participation in lung cancer screening. Further analyses of empirical data with bioethics theory relevant to these data will result in concrete normative policy recommendations for addressing the ethical issues described in this research. This knowledge gained from this research and future recommendations may be translated to lung cancer screening policymakers to support the ethical implementation of screening programs.

This research also demonstrates how bioethics research may contribute to health equity in Canada. Through empirical investigation, equity of lung cancer screening access was identified as the foremost ethical issue by key informants in this research. In this research, equity of screening access was defined from the empirical data collected in all three studies as equity of geographical, financial, educational, sociocultural, and language access to organized LDCT lung cancer screening programs. Key informants explained that equity of screening access was an ethical issue because of the asymmetrical distribution of benefits, i.e., that people who could benefit the most from lung cancer screening are the least likely to participate in screening. However, this research identified a lack of normative frameworks currently being used to guide ways for providing equitable access to lung cancer screening in Canada. Bioethics theory offers these frameworks. For instance, different concepts of justice from public health ethics and clinical ethics frameworks may be used to analyze epidemiological evidence about lung cancer disparities and health care access and empirical data collected in this research related to equity of screening access. The results of these analyses would be different normative recommendations for how to provide equity of screening access that are oriented for use in Canadian health policy. This research shows how bioethical inquiry can identify, explain, and offer solutions to health equity in lung cancer screening access in Canada using integration of empirical data and theory.

5.10 Additional research needs

In pursuit of answering the research questions in this dissertation, more have arisen, suggesting the need to consider ethical and social values specific to groups with high rates of lung cancer incidence and mortality, which may include self-determined ethical issues; and specific ethical and social values one at a time, which would provide greater depth than afforded by the broad approach taken in this research.

Future research about the ethical aspects of population-based LDCT lung cancer screening programs may be pursued to deepen the relatively broad approach to elucidating ethical dimensions taken in this research. Further inquiry may focus on specific ethical issues identified in this research, such as equity of screening access, the use of risk prediction to select individuals in a population for screening, and the allocation of resources in health and social systems to prevent lung cancer, among others. This research may use theoretical approaches, for instance, by examining alternative concepts of justice that could be used to guide policy decision-making about how to provide equitable access to lung cancer screening for sub-populations in Canada who are disproportionately impacted by lung cancer.

Empirical bioethics research may also contribute; for instance, by investigating social values about justice, equity, and fairness that can support democratic processes in health policy decision-making about equitable screening access. On this ethical issue, empirical bioethics research may focus on understanding ethical and social values about screening access and center the voices of equity-deserving groups in policy. Empirical approaches may also be used to surface normative logics that guide people in their decision-making about participating in risk prediction modeling and screening, which could inform ways to promote the autonomy of patients in the lung cancer screening pathway.

Additional normative and empirical research may support the development of ethical principles, frameworks, or considerations unique to navigating ethical issues in health policy and existing ethical guidance from the fields of public health and health care that are relevant to screening. For instance, principles for population-based disease screening, used by key informants in this research, could be further developed with the input of empirical ethics research on lung cancer screening ethics in Canada.

Conclusions

Ethical aspects of lung cancer screening with LDCT are the issues that elicit moral concern, judgment, deliberation, and/or decision-making. The aim of this research was to elucidate specific ethical issues and describe how they are being addressed in Canadian health policy to make normative recommendations of how lung cancer screening might be ethically implemented. Using empirical ethics inquiry, this research engaged the perspectives of lung cancer screening leaders and the public who identified and described ethical issues in the dimensions of health care, public health, and health policy. The major finding of this research was the preponderance of ethical issues located within health and social systems and structures, including equity of screening access, commercialization of tobacco, stigma against people who currently smoke commercial tobacco, and the need for increased investment in primary prevention of lung cancer. These ethical issues reflect the social, economic, and political determinants of lung cancer and the means available to reduce the burden of lung cancer in Canada, including but not limited to screening. In health policy there was a lack of ethical frameworks or principles currently being used to address these ethical issues. Future research could contribute to addressing this gap by offering ethical frameworks through which the empirical data in this research may be analyzed and by making normative recommendations for ethical, equitable, and effective lung cancer screening policy in Canada.

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Appendices

Appendix 1. Search strings, search date, and number of search results by database

Database	Search strings	Search date
MEDLINE via Ovid	1. exp Lung Neoplasms/ 2. ((lung* or bronch* or pulmon*) adj3 (cancer* or neopla* or tumor* or tumour* or carcinoma* or adenocarcinoma* or small cell or squamous)).ti,ab,kf 3. (NSLC or NSCLC or SLC or SCLC).ti,ab,kf 4. or/1-3 5. Mass Screening/ 6. “Early Detection of Cancer”/ 7. (screen* or early detect*).ti,ab,kf 8. or/5-7 9. 4 AND 8 10. Qualitative Research/ 11. Interview/ 12. (theme$ or thematic).mp. 13. qualitative.af. 14. Nursing Methodology Research/ 15. questionnaire$.mp. 16. ethnological research.mp. 17. ethnograph$.mp. 18. ethnonursing.af. 19. phenomenol$.af. 20. (grounded adj (theor$ or study or studies or research or analys?s)).af. 21. (life stor$ or women* stor$).mp. 22. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. Or participant observ$.tw. 23. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp. 24. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp. 25. (humanistic or existential or experiential or paradigm$).mp. 26. (field adj (study or studies or research)).tw. 27. human science.tw. 28. biographical method.tw. 29. theoretical sampl$.af. 30. ((purpos$ adj4 sampl$) or (focus adj group$)).af.	June 20, 2022

	31. (account or accounts or unstructured or openended or open ended or text$ or narrative$).mp. 32. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp. 33. ((lived or life) adj experience$).mp. 34. cluster sampl$.mp. 35. observational method$.af. 36. content analysis.af. 37. (constant adj (comparative or comparison)).af. 38. ((discourse$ or discurs$) adj3 analys?s).tw. 39. narrative analys?s.af. 40. heidegger$.tw. 41. colaizzi$.tw. 42. spiegelberg$.tw. 43. (van adj manen$).tw. 44. (van adj kaam$).tw. 45. (merleau adj ponty$).tw. 46. husserl$.tw. 47. foucault$.tw. 48. (corbin$ adj2 strauss$).tw. 49. glaser$.tw. 50. or/10-49 51. 9 AND 50 52. Limit 51 to (english language and yr="2002 - Current") 10. Attitude to Health/ 11. Health Knowledge, Attitudes, Practice/ 12. Patient Participation/ 13. Patient Preference/ 14. Attitude of Health Personnel/ 15. *Professional-Patient Relations/ 16. *Physician-Patient Relations/ 17. Choice Behavior/ 18. (choice or choices or value* or valuation* or knowledg*).ti. 19. (preference* or expectation* or attitude* or acceptab* or point of view).ti,ab,kf. 20. ((clinician* or doctor* or (health* adj2 worker*) or patient*1 or personal or physician* or practitioner* or professional*1 or provider* or user*1 or women or men) adj2 (participation or perspective* or perception* or misperception* or	

	perceiv* or view* or understand* or misunderstand* or value*1 or knowledg*)).ti,ab,kf. 21. health perception*.ti,ab,kf. 22. *Decision Making/ 23. (clinician* or doctor* or (health* adj2 worker*) or patient*1 or personal or physician* or practitioner* or professional*1 or provider* or user*1 or women or men).ti. 24. 22 and 23 25. (decision* and mak*).ti. 26. (decision mak* or decisions mak*).ti,ab,kf. 27. 25 or 26 28. (clinician* or doctor* or (health* adj2 worker*) or patient*1 or personal or physician* or practitioner* or professional*1 or provider* or user*1 or women or men).ti,ab,kf. 29. 27 and 28 30. (discrete choice* or decision board* or decision analy* or decision-support or decision tool* or decision aid* or latent class* or decision* conflict* or decision* regret*).ti,ab,kf. 31. Decision Support Techniques/ 32. (health and utilit*).ti. 33. (gamble* or prospect theory or health utilit* or utility value* or utility score* or utility estimate* or health state or feeling thermometer* or best-worst scaling or time trade-off or TTO or probability trade-off).ti,ab,kf. 34. (preference based or preference score* or preference elicitation or multiattribute or multi attribute).ti,ab,kf. 35. or/10-21,24,29-34 36. 9 and 35 37. limit 36 to (english language and yr="2002 -Current"	
CINAHL via EBSCO	(MH "Lung Neoplasms+") (((TI lung* OR AB lung* OR SU lung*) OR (TI bronch* OR AB bronch* OR SU bronch*) OR (TI pulmon* OR AB pulmon* OR SU pulmon*)) N3 ((TI cancer* OR AB cancer* OR SU cancer*) OR (TI neopla* OR AB neopla* OR SU neopla*) OR (TI tumor* OR AB tumor* OR SU tumor*) OR (TI tumour* OR AB tumour* OR SU tumour*) OR (TI carcinoma* OR AB carcinoma* OR SU carcinoma*) OR (TI adenocarcinoma* OR AB adenocarcinoma* OR SU adenocarcinoma*) OR (TI "small	August 19, 2022

	cell" OR AB "small cell" OR SU "small cell") OR (TI squamous OR AB squamous OR SU squamous))) ((TI NSLC OR AB NSLC OR SU NSLC) OR (TI NSCLC OR AB NSCLC OR SU NSCLC) OR (TI SLC OR AB SLC OR SU SLC) OR (TI SCLC OR AB SCLC OR SU SCLC)) S1 OR S2 OR S3 (MH "Mass Screening") (MH "Early Detection of Cancer") ((TI screen* OR AB screen* OR SU screen*) OR (TI "early detect*" OR AB "early detect*" OR SU "early detect*")) S5 OR S6 OR S7 S4 AND S8 (MH "Qualitative Research") (MH Interview) (theme? OR thematic) qualitative (MH "Nursing Methodology Research") questionnaire? "ethnological research" ethnograph? ethnonursing phenomenol? (grounded W1 (theor? OR study OR studies OR research OR analys#s)) ("life stor?" OR "women* stor?") (emic OR etic OR hermeneutic? OR heuristic? OR semiotic?) OR ((TI data OR AB data) N1 (TI saturat? OR AB saturat?)) OR (TI "participant observ?" OR AB "participant observ?") ("social construct?" OR (postmodern? OR post-structural?) OR ("post structural?" OR poststructural?) OR "post modern?" OR post-modern? OR feminis? OR interpret?) ("action research" OR "cooperative inquir?" OR "co operative inquir?" OR "co-operative inquir?") (humanistic OR existential OR experiential OR paradigm?) ((TI field OR AB field) W1 ((TI study OR AB study) OR (TI studies OR AB studies) OR (TI research OR AB research)))	

	(TI "human science" OR AB "human science") (TI "biographical method" OR AB "biographical method") "theoretical sampl?" ((purpos? N4 sampl?) OR (focus W1 group?)) (account OR accounts OR unstructured OR openended OR "open ended" OR text? OR narrative?) ("life world" OR life-world OR "conversation analys#s" OR "personal experience?" OR "theoretical saturation") ((lived OR life) W1 experience?) "cluster sampl?" "observational method?" "content analysis" (constant W1 (comparative OR comparison)) (((TI discourse? OR AB discourse?) OR (TI discurs? OR AB discurs?)) N3 (TI analys#s OR AB analys#s)) "narrative analys#s" (TI heidegger? OR AB heidegger?) (TI colaizzi? OR AB colaizzi?) (TI spiegelberg? OR AB spiegelberg?) ((TI van OR AB van) W1 (TI manen? OR AB manen?)) ((TI van OR AB van) W1 (TI kaam? OR AB kaam?)) ((TI merleau OR AB merleau) W1 (TI ponty? OR AB ponty?)) (TI husserl? OR AB husserl?) (TI foucault? OR AB foucault?) ((TI corbin? OR AB corbin?) N2 (TI strauss? OR AB strauss?)) (TI glaser? OR AB glaser?) S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 S9 AND S50 "Limit 51 to" ("english language" AND	

	"yr="2002 -Current"") (MH "Attitude to Health") (MH "Health Knowledge, Attitudes, Practice") (MH "Patient Participation") (MH "Patient Preference") (MH "Attitude of Health Personnel") (MM "Professional-Patient Relations") (MM "Physician-Patient Relations") (MH "Choice Behavior") ((TI choice) OR (TI choices) OR (TI value*) OR (TI valuation*) OR (TI knowledg*)) ((TI preference* OR AB preference* OR SU preference*) OR (TI expectation* OR AB expectation* OR SU expectation*) OR (TI attitude* OR AB attitude* OR SU attitude*) OR (TI acceptab* OR AB acceptab* OR SU acceptab*) OR (TI "point of view" OR AB "point of view" OR SU "point of view")) (((TI clinician* OR AB clinician* OR SU clinician*) OR (TI doctor* OR AB doctor* OR SU doctor*) OR ((TI health* OR AB health* OR SU health*) N2 (TI worker* OR AB worker* OR SU worker*)) OR (TI patient*1 OR AB patient*1 OR SU patient*1) OR (TI personal OR AB personal OR SU personal) OR (TI physician* OR AB physician* OR SU physician*) OR (TI practitioner* OR AB practitioner* OR SU practitioner*) OR (TI professional*1 OR AB professional*1 OR SU professional*1) OR (TI provider* OR AB provider* OR SU provider*) OR (TI user*1 OR AB user*1 OR SU user*1) OR (TI women OR AB women OR SU women) OR (TI men OR AB menOR SU men)) N2 ((TI participation OR AB participation OR SU participation) OR (TI perspective* OR AB perspective* OR SU perspective*) OR (TI perception* OR AB perception* OR SU perception*) OR (TI misperception* OR AB misperception* OR SU misperception*) OR (TI perceiv* OR AB perceiv* OR SU perceiv*) OR (TI view* OR AB view* OR SU view*) OR (TI understand* OR AB understand* OR SU understand*) OR (TI misunderstand* OR AB misunderstand* OR SU misunderstand*) OR (TI value*1 OR AB value*1 OR SU value*1) OR (TI knowledg* OR AB knowledg	

	* OR SU knowledg*))) (TI "health perception*" OR AB "health perception*" OR SU "health perception*") (MM "Decision Making") ((TI clinician*) OR (TI doctor*) OR ((TI health*) N2 (TI worker*)) OR (TI patient*1) OR (TI personal) OR (TI physician*) OR (TI practitioner*) OR (TI professional*1)OR (TI provider*) OR (TI user*1) OR (TI women) OR (TI men)) S22 AND S23 ((TI decision*) AND (TI mak*)) ((TI "decision mak*" OR AB "decision mak*" OR SU "decision mak*") OR (TI "decisions mak*" OR AB "decisions mak*" OR SU "decisions mak*")) S25 OR S26 ((TI clinician* OR AB clinician* OR SU clinician*) OR (TI doctor* OR AB doctor* OR SU doctor*) OR ((TI health* OR AB health* OR SU health*) N2 (TI worker* OR AB worker* OR SU worker*)) OR (TI patient*1 OR AB patient*1 OR SU patient*1) OR (TI personal OR AB personal OR SU personal) OR (TI physician* OR AB physician* OR SU physician*) OR (TI practitioner* OR AB practitioner* OR SU practitioner*) OR (TI professional*1 OR AB professional*1 OR SU professional*1) OR (TI provider* OR AB provider* OR SU provider*) OR (TI user*1 OR AB user*1 OR SU user*1) OR (TI women OR AB women OR SU women) OR (TI men OR AB menOR SU men)) S27 AND S28 ((TI "discrete choice*" OR AB "discrete choice*" OR SU "discrete choice*") OR (TI "decision board*" OR AB "decision board*" OR SU "decision board*") OR (TI "decision analy*" OR AB "decision analy*" OR SU "decision analy*") OR (TI decision-support OR AB decision-support OR SU decision-support) OR (TI "decision tool*" OR AB "decision tool*" OR SU "decision tool*") OR (TI "decision aid*" OR AB "decision aid*" OR SU "decision aid*") OR (TI "latent class*" OR AB "latent class*" OR SU "latent class*") OR (TI "decision* conflict*" OR AB "decision* conflict*" OR SU "decision* conflict*") OR (TI "decision*	

	regret*" OR AB "decision* regret*" OR SU "decision* regret*")) (MH "Decision Support Techniques") ((TI health) AND (TI utilit*)) ((TI gamble* OR AB gamble* OR SU gamble*) OR (TI "prospect theory" OR AB "prospect theory" OR SU "prospect theory") OR (TI "health utilit*" OR AB "health utilit*" OR SU "health utilit*") OR (TI "utility value*" OR AB "utility value*" OR SU "utility value*") OR (TI "utility score*" OR AB "utility score*" OR SU "utility score*") OR (TI "utility estimate*" OR AB "utility estimate*" OR SU "utility estimate*") OR (TI "health state" OR AB "health state" OR SU "health state") OR (TI "feeling thermometer*" OR AB "feeling thermometer*" OR SU "feeling thermometer*") OR (TI "best-worst scaling" OR AB "best-worst scaling" OR SU "best-worst scaling") OR (TI "time trade-off" OR AB "time trade-off" OR SU "time trade-off") OR (TI TTO OR AB TTO OR SU TTO) OR (TI "probability trade-off" OR AB "probability trade-off" OR SU "probability trade-off")) ((TI "preference based" OR AB "preference based" OR SU "preference based") OR (TI "preference score*" OR AB "preference score*" OR SU "preference score*") OR (TI "preference elicitation" OR AB "preference elicitation" OR SU "preference elicitation") OR (TI multiattribute OR AB multiattribute OR SU multiattribute) OR (TI "multi attribute" OR AB "multi attribute" OR SU "multi attribute")) S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 ,24,29-34 S9 AND S35 "limit 36 to" ("english language"	

	AND "yr="2002 -Current"")	
Embase via Ovid	exp "Lung Neoplasms"/ ((lung* OR bronch* OR pulmon*) ADJ3 (cancer* OR neopla* OR tumor* OR tumour* OR carcinoma* OR adenocarcinoma* OR "small cell" OR squamous)).tw,kf. (NSLC OR NSCLC OR SLC OR SCLC).tw,kf. 1 OR 2 OR 3 "Mass Screening"/ "Early Detection of Cancer"/ (screen* OR "early detect*").tw,kf. 5 OR 6 OR 7 4 AND 8 "Qualitative Research"/ Interview/ (theme$ OR thematic).mp. qualitative.af. "Nursing Methodology Research"/ questionnaire$.mp. "ethnological research".mp. ethnograph$.mp. ethnonursing.af. phenomenol$.af. (grounded ADJ (theor$ OR study OR studies OR research OR analys?s)).af. ("life stor$" OR "women* stor$").mp. (emic OR etic OR hermeneutic$ OR heuristic$ OR semiotic$).af. OR (data ADJ1 saturat$).tw. OR "participant observ$".tw. ("social construct$" OR (postmodern$ OR post-structural$) OR ("post structural$" OR poststructural$) OR "post modern$" OR post-modern$ OR feminis$ OR interpret$).mp. ("action research" OR "cooperative inquir$" OR "co operative inquir$" OR "co-operative inquir$").mp. (humanistic OR existential OR experiential OR paradigm$).mp. (field ADJ (study OR studies OR research)).tw. "human science".tw. "biographical method".tw. "theoretical sampl$".af.	August 19, 2022

	((purpos$ ADJ4 sampl$) OR (focus ADJ group$)).af. (account OR accounts OR unstructured OR openended OR "open ended" OR text$ OR narrative$).mp. ("life world" OR life-world OR "conversation analys?s" OR "personal experience$" OR "theoretical saturation").mp. ((lived OR life) ADJ experience$).mp. "cluster sampl$".mp. "observational method$".af. "content analysis".af. (constant ADJ (comparative OR comparison)).af. ((discourse$ OR discurs$) ADJ3 analys?s).tw. "narrative analys?s".af. heidegger$.tw. colaizzi$.tw. spiegelberg$.tw. (van ADJ manen$).tw. (van ADJ kaam$).tw. (merleau ADJ ponty$).tw. husserl$.tw. foucault$.tw. (corbin$ ADJ2 strauss$).tw. glaser$.tw. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 9 AND 50 "Limit 51 to" ("english language" AND "yr="2002 - Current"") "Attitude to Health"/ "Health Knowledge, Attitudes, Practice"/ "Patient Participation"/ "Patient Preference"/ "Attitude of Health Personnel"/ *"Professional-Patient Relations"/ *"Physician-Patient Relations"/ "Choice Behavior"/ (choice OR choices OR value* OR valuation* OR knowledg*).ti.	

	(preference* OR expectation* OR attitude* OR acceptab* OR "point of view").tw,kf. ((clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men) ADJ2 (participation OR perspective* OR perception* OR misperception* OR perceiv* OR view* OR understand* OR misunderstand* OR value*1 OR knowledg*)).tw,kf. "health perception*".tw,kf. *"Decision Making"/ (clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men).ti. 22 AND 23 (decision* AND mak*).ti. ("decision mak*" OR "decisions mak*").tw,kf. 25 OR 26 (clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men).tw,kf. 27 AND 28 ("discrete choice*" OR "decision board*" OR "decision analy*" OR decision-support OR "decision tool*" OR "decision aid*" OR "latent class*" OR "decision* conflict*" OR "decision* regret*").tw,kf. "Decision Support Techniques"/ (health AND utilit*).ti. (gamble* OR "prospect theory" OR "health utilit*" OR "utility value*" OR "utility score*" OR "utility estimate*" OR "health state" OR "feeling thermometer*" OR "best-worst scaling" OR "time trade-off" OR TTO OR "probability trade-off").tw,kf. ("preference based" OR "preference score*" OR "preference elicitation" OR multiattribute OR "multi attribute").tw,kf. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 ,24,29-34 9 AND 35 "limit 36 to" ("english language" AND "yr="2002 - Current"")	

Emcare via Ovid	exp "Lung Neoplasms"/ ((lung* OR bronch* OR pulmon*) ADJ3 (cancer* OR neopla* OR tumor* OR tumour* OR carcinoma* OR adenocarcinoma* OR "small cell" OR squamous)).tw,kf. (NSLC OR NSCLC OR SLC OR SCLC).tw,kf. 1 OR 2 OR 3 "Mass Screening"/ "Early Detection of Cancer"/ (screen* OR "early detect*").tw,kf. 5 OR 6 OR 7 4 AND 8 "Qualitative Research"/ Interview/ (theme$ OR thematic).mp. qualitative.af. "Nursing Methodology Research"/ questionnaire$.mp. "ethnological research".mp. ethnograph$.mp. ethnonursing.af. phenomenol$.af. (grounded ADJ (theor$ OR study OR studies OR research OR analys?s)).af. ("life stor$" OR "women* stor$").mp. (emic OR etic OR hermeneutic$ OR heuristic$ OR semiotic$).af. OR (data ADJ1 saturat$).tw. OR "participant observ$".tw. ("social construct$" OR (postmodern$ OR post-structural$) OR ("post structural$" OR poststructural$) OR "post modern$" OR post-modern$ OR feminis$ OR interpret$).mp. ("action research" OR "cooperative inquir$" OR "co operative inquir$" OR "co-operative inquir$").mp. (humanistic OR existential OR experiential OR paradigm$).mp. (field ADJ (study OR studies OR research)).tw. "human science".tw. "biographical method".tw. "theoretical sampl$".af. ((purpos$ ADJ4 sampl$) OR (focus ADJ group$)).af. (account OR accounts OR unstructured OR openended OR "open ended" OR text$ OR narrative$).mp.	October 6, 2022

	("life world" OR life-world OR "conversation analys?s" OR "personal experience$" OR "theoretical saturation").mp. ((lived OR life) ADJ experience$).mp. "cluster sampl$".mp. "observational method$".af. "content analysis".af. (constant ADJ (comparative OR comparison)).af. ((discourse$ OR discurs$) ADJ3 analys?s).tw. "narrative analys?s".af. heidegger$.tw. colaizzi$.tw. spiegelberg$.tw. (van ADJ manen$).tw. (van ADJ kaam$).tw. (merleau ADJ ponty$).tw. husserl$.tw. foucault$.tw. (corbin$ ADJ2 strauss$).tw. glaser$.tw. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 9 AND 50 "Limit 51 to" ("english language" AND "yr="2002 - Current"") "Attitude to Health"/ "Health Knowledge, Attitudes, Practice"/ "Patient Participation"/ "Patient Preference"/ "Attitude of Health Personnel"/ *"Professional-Patient Relations"/ *"Physician-Patient Relations"/ "Choice Behavior"/ (choice OR choices OR value* OR valuation* OR knowledg*).ti. (preference* OR expectation* OR attitude* OR acceptab* OR "point of view").tw,kf. ((clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men) ADJ2 (participation	

	OR perspective* OR perception* OR misperception* OR perceiv* OR view* OR understand* OR misunderstand* OR value*1 OR knowledg*)).tw,kf. "health perception*".tw,kf. *"Decision Making"/ (clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men).ti. 22 AND 23 (decision* AND mak*).ti. ("decision mak*" OR "decisions mak*").tw,kf. 25 OR 26 (clinician* OR doctor* OR (health* ADJ2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men).tw,kf. 27 AND 28 ("discrete choice*" OR "decision board*" OR "decision analy*" OR decision-support OR "decision tool*" OR "decision aid*" OR "latent class*" OR "decision* conflict*" OR "decision* regret*").tw,kf. "Decision Support Techniques"/ (health AND utilit*).ti. (gamble* OR "prospect theory" OR "health utilit*" OR "utility value*" OR "utility score*" OR "utility estimate*" OR "health state" OR "feeling thermometer*" OR "best-worst scaling" OR "time trade-off" OR TTO OR "probability trade-off").tw,kf. ("preference based" OR "preference score*" OR "preference elicitation" OR multiattribute OR "multi attribute").tw,kf. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 ,24,29-34 9 AND 35 "limit 36 to" ("english language" AND "yr="2002 - Current"")	
PsycInfo via Ovid	exp "Lung Neoplasms"/ ((lung*.ti,ab,id. OR bronch*.ti,ab,id. OR pulmon*.ti,ab,id.) ADJ3 (cancer*.ti,ab,id. OR neopla*.ti,ab,id. OR tumor*.ti,ab,id. OR tumour*.ti,ab,id. OR carcinoma*.ti,ab,id. OR adenocarcinoma*.ti,ab,id. OR "small cell".ti,ab,id. OR squamous.ti,ab,id.))	October 6, 2022

	(NSLC.ti,ab,id. OR NSCLC.ti,ab,id. OR SLC.ti,ab,id. OR SCLC.ti,ab,id.) 1 OR 2 OR 3 "Mass Screening"/ "Early Detection of Cancer"/ (screen*.ti,ab,id. OR "early detect*".ti,ab,id.) 5 OR 6 OR 7 4 AND 8 "Qualitative Research"/ Interview/ (theme#.mp. OR thematic.mp.) qualitative.af. "Nursing Methodology Research"/ questionnaire#.mp. "ethnological research".mp. ethnograph#.mp. ethnonursing.af. phenomenol#.af. (grounded.af. ADJ (theor#.af. OR study.af. OR studies.af. OR research.af. OR analys?s.af.)) ("life stor#".mp. OR "women* stor#".mp.) (emic.af. OR etic.af. OR hermeneutic#.af. OR heuristic#.af. OR semiotic#.af.) OR (data.ti,ab. ADJ1 saturat#.ti,ab.) OR "participant observ#".ti,ab. ("social construct#".mp. OR (postmodern#.mp. OR post-structural#.mp.) OR ("post structural#".mp. OR poststructural#.mp.) OR "post modern#".mp. OR post-modern#.mp. OR feminis#.mp. OR interpret#.mp.) ("action research".mp. OR "cooperative inquir#".mp. OR "co operative inquir#".mp. OR "co-operative inquir#".mp.) (humanistic.mp. OR existential.mp. OR experiential.mp. OR paradigm#.mp.) (field.ti,ab. ADJ (study.ti,ab. OR studies.ti,ab. OR research.ti,ab.)) "human science".ti,ab. "biographical method".ti,ab. "theoretical sampl#".af. ((purpos#.af. ADJ4 sampl#.af.) OR (focus.af. ADJ group#.af.)) (account.mp. OR accounts.mp. OR unstructured.mp. OR openended.mp. OR "open ended".mp. OR text#.mp. OR narrative#.mp.)	

	("life world".mp. OR life-world.mp. OR "conversation analys?s".mp. OR "personal experience#".mp. OR "theoretical saturation".mp.) ((lived.mp. OR life.mp.) ADJ experience#.mp.) "cluster sampl#".mp. "observational method#".af. "content analysis".af. (constant.af. ADJ (comparative.af. OR comparison.af.)) ((discourse#.ti,ab. OR discurs#.ti,ab.) ADJ3 analys?s.ti,ab.) "narrative analys?s".af. heidegger#.ti,ab. colaizzi#.ti,ab. spiegelberg#.ti,ab. (van.ti,ab. ADJ manen#.ti,ab.) (van.ti,ab. ADJ kaam#.ti,ab.) (merleau.ti,ab. ADJ ponty#.ti,ab.) husserl#.ti,ab. foucault#.ti,ab. (corbin#.ti,ab. ADJ2 strauss#.ti,ab.) glaser#.ti,ab. 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42 OR 43 OR 44 OR 45 OR 46 OR 47 OR 48 OR 49 9 AND 50 "Limit 51 to" ("english language" AND "yr="2002 - Current"") "Attitude to Health"/ "Health Knowledge, Attitudes, Practice"/ "Patient Participation"/ "Patient Preference"/ "Attitude of Health Personnel"/ *"Professional-Patient Relations"/ *"Physician-Patient Relations"/ "Choice Behavior"/ (choice.ti. OR choices.ti. OR value*.ti. OR valuation*.ti. OR knowledg*.ti.) (preference*.ti,ab,id. OR expectation*.ti,ab,id. OR attitude*.ti,ab,id. OR acceptab*.ti,ab,id. OR "point of view".ti,ab,id.)	

	((clinician*.ti,ab,id. OR doctor*.ti,ab,id. OR (health*.ti,ab,id. ADJ2 worker*.ti,ab,id.) OR patient*1.ti,ab,id. OR personal.ti,ab,id. OR physician*.ti,ab,id. OR practitioner*.ti,ab,id. OR professional*1.ti,ab,id. OR provider*.ti,ab,id. OR user*1.ti,ab,id. OR women.ti,ab,id. OR men.ti,ab,id.) ADJ2 (participation.ti,ab,id. OR perspective*.ti,ab,id. OR perception*.ti,ab,id. OR misperception*.ti,ab,id. OR perceiv*.ti,ab,id. OR view*.ti,ab,id. OR understand*.ti,ab,id. OR misunderstand*.ti,ab,id. OR value*1.ti,ab,id. OR knowledg*.ti,ab,id.)) "health perception*".ti,ab,id. *"Decision Making"/ (clinician*.ti. OR doctor*.ti. OR (health*.ti. ADJ2 worker*.ti.) OR patient*1.ti. OR personal.ti. OR physician*.ti. OR practitioner*.ti. OR professional*1.ti. OR provider*.ti. OR user*1.ti. OR women.ti. OR men.ti.) 22 AND 23 (decision*.ti. AND mak*.ti.) ("decision mak*".ti,ab,id. OR "decisions mak*".ti,ab,id.) 25 OR 26 (clinician*.ti,ab,id. OR doctor*.ti,ab,id. OR (health*.ti,ab,id. ADJ2 worker*.ti,ab,id.) OR patient*1.ti,ab,id. OR personal.ti,ab,id. OR physician*.ti,ab,id. OR practitioner*.ti,ab,id. OR professional*1.ti,ab,id. OR provider*.ti,ab,id. OR user*1.ti,ab,id. OR women.ti,ab,id. OR men.ti,ab,id.) 27 AND 28 ("discrete choice*".ti,ab,id. OR "decision board*".ti,ab,id. OR "decision analy*".ti,ab,id. OR decision-support.ti,ab,id. OR "decision tool*".ti,ab,id. OR "decision aid*".ti,ab,id. OR "latent class*".ti,ab,id. OR "decision* conflict*".ti,ab,id. OR "decision* regret*".ti,ab,id.) "Decision Support Techniques"/ (health.ti. AND utilit*.ti.) (gamble*.ti,ab,id. OR "prospect theory".ti,ab,id. OR "health utilit*".ti,ab,id. OR "utility value*".ti,ab,id. OR "utility score*".ti,ab,id. OR "utility estimate*".ti,ab,id. OR "health state".ti,ab,id. OR "feeling thermometer*".ti,ab,id. OR "best-worst scaling".ti,ab,id. OR "time trade-off".ti,ab,id. OR TTO.ti,ab,id. OR "probability trade-off".ti,ab,id.)	

	("preference based".ti,ab,id. OR "preference score*".ti,ab,id. OR "preference elicitation".ti,ab,id. OR multiattribute.ti,ab,id. OR "multi attribute".ti,ab,id.) 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 ,24,29-34 9 AND 35 "limit 36 to" ("english language" AND "yr="2002 - Current"")	
Scopus	INDEXTERMS("Lung Neoplasms") TITLE-ABS-KEY((lung* OR bronch* OR pulmon*) W/3 (cancer* OR neopla* OR tumor* OR tumour* OR carcinoma* OR adenocarcinoma* OR "small cell" OR squamous)) TITLE-ABS-KEY(NSLC OR NSCLC OR SLC OR SCLC) #1 OR #2 OR #3 INDEXTERMS("Mass Screening") INDEXTERMS("Early Detection of Cancer") TITLE-ABS-KEY(screen* OR "early detect*") #5 OR #6 OR #7 #4 AND #8 INDEXTERMS("Qualitative Research") INDEXTERMS(Interview) TITLE-ABS-KEY(theme? OR thematic) ALL(qualitative) INDEXTERMS("Nursing Methodology Research") TITLE-ABS-KEY(questionnaire?) TITLE-ABS-KEY("ethnological research") TITLE-ABS-KEY(ethnograph?) ALL(ethnonursing) ALL(phenomenol?) ALL(grounded W/1 (theor? OR study OR studies OR research OR analys*s)) TITLE-ABS-KEY("life stor?" OR "women* stor?") ALL(emic OR etic OR hermeneutic? OR heuristic? OR semiotic?) OR TITLE-ABS(data W/1 saturat?) OR TITLE-ABS("participant observ?") TITLE-ABS-KEY("social construct?" OR (postmodern? OR post-structural?) OR ("post structural?" OR poststructural?) OR "post modern?" OR post-modern? OR feminis? OR interpret?)	October 12, 2022

	TITLE-ABS-KEY("action research" OR "cooperative inquir?" OR "co operative inquir?" OR "co-operative inquir?") TITLE-ABS-KEY(humanistic OR existential OR experiential OR paradigm?) TITLE-ABS(field W/1 (study OR studies OR research)) TITLE-ABS("human science") TITLE-ABS("biographical method") ALL("theoretical sampl?") ALL((purpos? W/4 sampl?) OR (focus W/1 group?)) TITLE-ABS-KEY(account OR accounts OR unstructured OR openended OR "open ended" OR text? OR narrative?) TITLE-ABS-KEY("life world" OR life-world OR "conversation analys*s" OR "personal experience?" OR "theoretical saturation") TITLE-ABS-KEY((lived OR life) W/1 experience?) TITLE-ABS-KEY("cluster sampl?") ALL("observational method?") ALL("content analysis") ALL(constant W/1 (comparative OR comparison)) TITLE-ABS((discourse? OR discurs?) W/3 analys*s) ALL("narrative analys*s") TITLE-ABS(heidegger?) TITLE-ABS(colaizzi?) TITLE-ABS(spiegelberg?) TITLE-ABS(van W/1 manen?) TITLE-ABS(van W/1 kaam?) TITLE-ABS(merleau W/1 ponty?) TITLE-ABS(husserl?) TITLE-ABS(foucault?) TITLE-ABS(corbin? W/2 strauss?) TITLE-ABS(glaser?) #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 #9 AND #50 "Limit 51 to" ("english language" AND "yr="2002 - Current"")	

	INDEXTERMS("Attitude to Health")	
	INDEXTERMS("Health Knowledge, Attitudes, Practice")	
	INDEXTERMS("Patient Participation")	
	INDEXTERMS("Patient Preference")	
	INDEXTERMS("Attitude of Health Personnel")	
	INDEXTERMS("Professional-Patient Relations")	
	INDEXTERMS("Physician-Patient Relations")	
	INDEXTERMS("Choice Behavior")	
	TITLE(choice OR choices OR value* OR valuation* OR knowledg*)	
	TITLE-ABS-KEY(preference* OR expectation* OR attitude* OR acceptab* OR "point of view")	
	TITLE-ABS-KEY((clinician* OR doctor* OR (health* W/2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men) W/2 (participation OR perspective* OR perception* OR misperception* OR perceiv* OR view* OR understand* OR misunderstand* OR value*1 OR knowledg*))	
	TITLE-ABS-KEY("health perception*")	
	INDEXTERMS("Decision Making")	
	TITLE(clinician* OR doctor* OR (health* W/2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men)	
	#22 AND #23	
	TITLE(decision* AND mak*)	
	TITLE-ABS-KEY("decision mak*" OR "decisions mak*")	
	#25 OR #26	
	TITLE-ABS-KEY(clinician* OR doctor* OR (health* W/2 worker*) OR patient*1 OR personal OR physician* OR practitioner* OR professional*1 OR provider* OR user*1 OR women OR men)	
	#27 AND #28	
	TITLE-ABS-KEY("discrete choice*" OR "decision board*" OR "decision analy*" OR decision-support OR "decision tool*" OR "decision aid*" OR "latent class*" OR "decision* conflict*" OR "decision* regret*")	
	INDEXTERMS("Decision Support Techniques")	
	TITLE(health AND utilit*)	

	TITLE-ABS-KEY(gamble* OR "prospect theory" OR "health utilit*" OR "utility value*" OR "utility score*" OR "utility estimate*" OR "health state" OR "feeling thermometer*" OR "best-worst scaling" OR "time trade-off" OR TTO OR "probability trade-off") TITLE-ABS-KEY("preference based" OR "preference score*" OR "preference elicitation" OR multiattribute OR "multi attribute") #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 ,24,29-34 #9 AND #35 "limit 36 to" ("english language" AND "yr="2002 - Current"")	
SSCI	LOOK UP SAVED SEARCH 18 TS=interview* 19 TS=(theme*) 20 TS=(thematic analysis) 21 TS=qualitative 22 TS=nursing research methodology 23 TS=questionnaire 24 TS=(ethnograph*) 25 TS= (ethnonursing) 26 TS=(ethnological research) 27 TS=(phenomenol*) 28 TS=(grounded theor*) OR TS=(grounded stud*) OR TS=(grounded research) OR TS=(grounded analys?s) 29 TS=(life stor*) OR TS=(women's stor*) 30 TS=(emic) OR TS=(etic) OR TS=(hermeneutic) OR TS=(heuristic) OR TS=(semiotic) OR TS=(data saturat*) OR TS=(participant observ*) 31 TS=(social construct*) OR TS=(postmodern*) OR TS=(post structural*) OR TS=(feminis*) OR TS=(interpret*) 32 TS=(action research) OR TS=(co-operative inquir*) 33 TS=(humanistic) OR TS=(existential) OR TS=(experiential) OR TS=(paradigm*) 34 TS=(field stud*) OR TS=(field research) 35 TS=(human science) 36 TS=(biographical method*) 37 TS=(theoretical sampl*)	October 6, 2022

	38 TS=(purposive sampl*) 39 TS=(open-ended account*) OR TS=(unstructured account) OR TS=(narrative*) OR TS=(text*) 40 TS=(life world) OR TS=(conversation analys?s) OR TS=(theoretical saturation) 41 TS=(lived experience*) OR TS=(life experience*) 42 TS=(cluster sampl*) 43 TS=observational method* 44 TS=(content analysis) 45 TS=(constant comparative) 46 TS=(discourse analys?s) or TS =(discurs* analys?s) 47 TS=(narrative analys?s) 48 TS=(heidegger*) 49 TS=(colaizzi*) 50 TS=(spiegelberg*) 51 TS=(van manen*) 52 TS=(van kaam*) 53 TS=(merleau ponty*) 54 TS=(husserl*) 55 TS=(foucault*) 56 TS=(corbin*) 57 TS=(strauss*) 58 TS=(glaser*) 59 #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 60 #17 AND #59	

Appendix 2. Study eligibility criteria

Criterion	**Include if…**	**Exclude if…**
Study design	Qualitative Quantitative Mixed methods (qualitative and/or quantitative portion(s))	Single clinical case study Modelling study Systematic review

Population	Patients from any clinical practice (e.g., family medicine, oncology, etc.) General public People at high risk of being diagnosed with lung cancer or special populations of interest for lung cancer screening, e.g., African Americans, Indigenous, low income, women, etc.	Clinicians Policymakers Scientists Occupational populations
Perspectives	Knowledge, attitudes, beliefs, perceptions, values, opinions, judgments, and preferences	Test of knowledge of the benefits and harms of lung cancer screening with LDCT Evaluation of an intervention to increase participation in lung cancer screening with LDCT Evaluation of an intervention to improve (shared) decision making about lung cancer screening with LDCT
Benefits and harms	Open-ended questions about benefits and/or harms Specific benefits and/or harms Relationship between benefits and harms Benefits and harms may be identified from eligible studies, or they could be known benefits and harms such as reduced lung cancer mortality and morbidity; prolonged survival from lung cancer; economic cost-savings to health systems or workers' compensation systems; financial costs to individuals; psychological effects (e.g., distress or relief with screening results or the screening process, etc.); physical effects (e.g., radiation effects, invasive follow-up testing, etc.)	Barriers to lung cancer screening Enablers/facilitators of lung cancer screening Decision-making about lung cancer screening Lung cancer screening behaviour

Lung cancer screening	Screening for lung cancer with low-dose chest computed tomography Population-based lung cancer screening programs or pilot studies using low-dose chest computed tomography Clinical trials of lung cancer screening using low-dose chest computed tomography	Screening for lung cancer with x-ray, biological or respiratory samples, or based on patient symptoms Screening for lung cancer in occupational populations using any screening method Opportunistic screening, i.e., screening for lung cancer outside of a population-based screening program, pilot study, or a clinical trial, with any screening method

Appendix 3. Interrater reliability

Reviewer 1	**Reviewer 2**	Cohen's Kappa	Percentage agreement
Title and abstract screening			
MP	AC	0.46	97.8
MP	MC	0.10	88.7
MP	KS	0.66	98.2
Full text screening			
MP	AC	0.62	87.0
MP	MC	0.61	81.2
MP	KS	0.44	74.5

Appendix 4. Data extraction form for quantitative studies

Category[1]	**Study ID**	**Author and Year**	**Outcome**	**Group 1**				**Group 2**				**Between-group statistical test, result, and p value**
				Description	**N**	**Statistic**	**Result**	**Description**	**N**	**Statistic**	**Result**	

[1]Categories determined deductively and inductively based on outcomes of relevance for this review: Health protection, Early detection, Mortality reduction, Reassurance, Information about health, Health monitoring, Follow-up investigation, Fear of screening results, Fear of lung cancer, Fear of lung cancer treatment, Radiation exposure, Physical discomfort, Pain, False positives, Biopsy, Financial costs, Time off work, Travel time, Waiting for screening result,

Benefits versus harms, Fear of CT scan, Convenience, Accuracy, Overdiagnosis, Incidental findings, Stigma, Benefits (overall), Harms (overall), Early treatment, Improved survival, Distrust, Efficacy, Overtreatment

Appendix 5. Detailed analytic framework

Category	**Sub-category**	**Included outcomes from quantitative and qualitative studies**	**Quantitative outcome measurement**	**Included codes from qualitative studies**
1. Overall perspectives	1.1 Favourable perspectives	Benefits (overall)	Odds ratio, mean	
		Harms (overall)	Odds ratio, mean	
		Benefits versus harms	Mean, %	Benefits versus harms; Desire to be informed; Fear vs early diagnosis; Discordance between patient and expert valuations
		Acceptability	NA	Acceptability; Overall perspective
	1.2 Concerns about efficacy	Efficacy	%	Efficacy; Skepticism
	1.3 Eligibility	Eligibility	NA	Eligibility criteria
2. Physical benefits	2.1 Valuing early detection	Early detection	Mean, %, median, beta coefficient, odds ratio	Early detection; Identification of nodules seen as early detection of cancer
		Mortality reduction	%, mean, median	Mortality reduction
		Early treatment	Odds ratio	Reduced likelihood of needing cancer treatment
		Improved survival	Odds ratio	
	2.2 Influence on smoking behaviour	Motivation to quit smoking	NA	Motivation to quit smoking

		Self-reflection about smoking	NA	Self-reflection about smoking; Smoking; Belief of lack of personal harm from smoking;
		Smoking futility vs screening ease	NA	Smoking futility vs screening ease
3. Psychological benefits	3.1 Desire for lung health information	Information about health	%	Ability of LCS to quantify and measure risks and harms; Information about lung health; Emotions; Informational benefits; Informational harms; Lung damage shown by screening
		Health monitoring	%	
		Health protection	Mean	Protection offered by screening
		Autonomy and agency	NA	Autonomous decision making
	3.2 Reassurance about lung health	Reassurance	%, mean, median	Reassurance
	3.3 Reduction of uncertainty	Tolerance of inherent uncertainty	NA	Reduction of uncertainty; Evidentiary uncertainty; Be proactive; Confusion; Rely on doctor's recommendation; Statistical (imprecision) uncertainty; Comfort with statistical uncertainty; discomfort with statistical uncertainty; Stochastic (random) uncertainty; Uncertainty as an attribute of expected health states in LCS; Risk assessment and tolerance for uncertainty; Uncertainty vs knowing
	3.4 Preparation before death	Preparing family and personal	NA	Preparation before death

		affairs before death		
4. Physical harms	4.1 Need for accuracy	False positives	Mean, N, %, median, range, odds ratio	False positives
		False negatives	NA	False negatives
		Incidental findings	%, Mean	Incidental findings
		Follow-up investigation	Mean, range, %	Follow-up investigation
		Biopsy	%, mean	Biopsy
		Overdiagnosis	%, mean, median, range, odds ratio	Overdiagnosis
		Overtreatment	%	Overtreatment
		Accuracy	%, mean	Screening accuracy
	4.2 Concerns about radiation exposure	Radiation exposure	%, mean, median, range, odds ratio	Radiation exposure
	4.3 Worries about discomfort or pain during screening	Physical discomfort	%, mean	Pain or discomfort
		Pain	%, mean	Pain or discomfort
5. Psychological harms	5.1 Fear of screening result	Fear of lung cancer	Mean, %	Avoidance; Fear of lung cancer; Risk of lung cancer diagnosis
		Fear of screening results	Mean, %, median	Concerns about screening results; Fear of screening results; Anxiety associated with indeterminate nodules
		Fear of lung cancer treatment	%	Fear of treatment

	5.2 Fear and anxiety associated with screening protocol	Waiting for screening result	%	Waiting for screening and follow-up results
		Fear of CT scan	%	LDCT scan procedure
	5.3 Feelings of stigma	Stigma	Mean, %	Reinforced cognitive biases about lung cancer risk; Stigma; Supportive language
	5.4 Shame, self-blame, and futility	Shame, self-blame, and futility	NA	Shame, self-blame, and futility; Too late for smoking damage and older age
	5.5 Feelings of distrust	Distrust	%	Trust or distrust
	5.6 Feelings of fatigue	Fatigue with smoking information	NA	Fatigue with smoking information
6. Financial and opportunity costs	6.1 Screening important but unaffordable	Financial costs	%, mean	Financial costs
	6.2 Screening important but inaccessible	Time off work	%, median	Practicalities; Logistical concerns; Time off work
		Travel time	%, median	Transportation
		Convenience	%	Convenience
	6.3 Screening important but burdensome	Burden	NA	Burden; Screening frequency

Appendix 6. PRISMA 2020 reporting checklist[161]

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Title
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Abstract
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Introduction
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Introduction
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Study eligibility; Appendix 2; Data analysis and synthesis
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Search strategy; Appendix 1
Search strategy	7	Present the full search strategies for all databases, registers, and websites, including any filters and limits used.	Appendix 1
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the	Study eligibility

Section and Topic	Item #	Checklist item	Location where item is reported
		review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Data extraction
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Data extraction; data analysis and synthesis
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Data extraction; data analysis and synthesis

Section and Topic	Item #	Checklist item	Location where item is reported
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	Quality assessment
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	Data analysis and synthesis
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Data analysis and synthesis
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	Data analysis and synthesis
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Not applicable
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and	Data analysis and synthesis

Section and Topic	Item #	Checklist item	Location where item is reported
		extent of statistical heterogeneity, and software package(s) used.	
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	Not applicable
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	Not applicable
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	Not applicable
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	Quality assessment
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Figure 3
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	
Study characteristics	17	Cite each included study and present its characteristics.	Table 2

Section and Topic	Item #	Checklist item	Location where item is reported
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	Table 7
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	Not applicable
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	Results sections 1-6 and Table 7
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	Not applicable
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	Not applicable
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	Not applicable
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting	Not applicable

Section and Topic	Item #	Checklist item	Location where item is reported
		biases) for each synthesis assessed.	
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	Not applicable
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Discussion
	23b	Discuss any limitations of the evidence included in the review.	Discussion
	23c	Discuss any limitations of the review processes used.	Discussion
	23d	Discuss implications of the results for practice, policy, and future research.	Discussion
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Reporting
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Reporting
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	Reporting
Support	25	Describe sources of financial or non-financial support for the review, and the role of	Funding

Section and Topic	Item #	Checklist item	Location where item is reported
		the funders or sponsors in the review.	
Competing interests	26	Declare any competing interests of review authors.	Competing interests
Availability of data, code, and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Appendices 4 and 5

Appendix 7. Standards for Reporting Qualitative Research (SRQR)

No.	**Topic**	**Item**	**Location**
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Abstract
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Introduction
S4	Purpose or research question	Purpose of the study and specific objectives or questions	Introduction
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale[b]	Theoretical framework and methodology
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Theoretical framework and methodology
S7	Context	Setting/site and salient contextual factors; rationale[b]	Sampling and recruitment
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Sampling and recruitment
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review bard and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Ethics approval
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop	Data collection

		dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Data collection
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Participants
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Data analysis
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Data analysis
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Rigor
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Results
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Results
	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Discussion
S19	Limitations	Trustworthiness and limitations of findings	Discussion
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Competing interests
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Funding

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Appendix 8. Semi-structured interview guide

Your knowledge and experience of lung cancer and lung cancer screening

1. How did you find out about the study and what made you interested in participating?

2. Have you ever been diagnosed with lung cancer?

3. Have you ever participated in lung cancer screening yourself? For example, has your doctor sent you to get a CT scan of your lungs?

General

4. When I talk about "ethics", I mean the moral principles or values that we should use to make decisions about health care, or in this case, about lung cancer screening. What do you think are the ethical issues of lung cancer screening? In other words, what aspects of lung cancer screening do you think are moral challenges? Why?

Benefits and harms

5. What do you think is the purpose of lung cancer screening?

6. What do you think are the benefits of lung cancer screening?

7. What do you think are the harms of lung cancer screening?

8. How do you feel about participating in a lung cancer screening program if there was a small chance that you might personally benefit from screening? For instance, would you be willing to participate if there was a small chance that screening would correctly find lung cancer?

9. How do you feel about participating in a lung cancer screening program if you might be personally harmed from screening? For instance, would you be willing to participate in screening if there was a chance of receiving a positive result that turned out to be wrong or false, because you didn't really have lung cancer?

10. How do you feel about participating in a lung cancer screening program if there was a small chance of personal benefit and a greater chance of personally experiencing harm?

11. Do you think that your participation in lung cancer screening is an action that could benefit you or society? Or both? Why?

Eligibility

12. How do you feel about providing your primary care provider with information about your smoking history and age to help decide if you may benefit from lung cancer screening?

13. Combining information about your smoking history, age, race, education, body mass index, personal and family history of cancer, and history of diagnosis with chronic obstructive pulmonary disease can help estimate your risk of being diagnosed with lung cancer. Would you be concerned about providing any of this information to a health care provider to help make a lung cancer screening decision? If yes, what about this information or process concerns you?

14. We know that smoking puts people at greater risk of getting lung cancer. Should we prioritize screening people who are current smokers? Former smokers? Never smokers? What did you think about when making this decision? For example, sometimes people think about how many smokers might need to be screened, or about how long a person may have smoked for, or how many cigarettes a day they have smoked on average.

15. We know that asbestos and other workplace exposures put people at greater risk of lung cancer. Should we prioritize screening for people who are or were exposed to asbestos? What do you think about when making this decision? For example, sometimes people think about how many workers might need to be screened, how long a person may have been exposed to asbestos, or how much asbestos they were exposed to, and even the employer's responsibilities to protect workers from asbestos exposure.

16. Imagine that you're a policymaker and you have 100 spots for screening, and you have 100 people who are smokers and 100 people who are exposed to asbestos. When thinking about smoking and asbestos, what are you thinking about? How would you make a decision about prioritizing which individuals should be screened? What would your options be? What options would you consider/not consider? What other information would you want to know about these people before deciding who should be screened?

17. If there wasn't a limited number of spots, or you could create more spots for screening, who would you want to be screened, and why?

Decision-making: Informed choice, consent, shared decision-making, and autonomy

18. Have you ever been offered screening for lung cancer? Did you decide to participate?

19. How did you make that decision? What things did you consider? What mattered to you, and why?

20. What information did you or would you need to help decide whether to be screened for lung cancer?

21. Were there any challenges with how this information was presented to you? Was there any information you wanted to help with this decision that you weren't able to access?

22. Aside from information, what factors might affect your decision about whether to be screened for lung cancer?

23. Some people who are screened for lung cancer receive a positive result for lung cancer even though their lung cancer wouldn't go on to cause any symptoms or problems. This is called overdiagnosis, and it's one of the possible harms of lung cancer screening. If you knew that you might get overdiagnosed from lung cancer screening, would you participate anyway? Is it acceptable to you to participate in screening where there is some possibility of overdiagnosis or other harms? How would you feel about being overdiagnosed or experiencing some other harm?

24. Most people who are screened for lung cancer receive a negative result. If you knew that you would most likely get a negative result- that means you don't have lung cancer- would you decide to participate anyway? Is it acceptable to you to participate in screening where it is most likely that you will receive a negative result? How would you feel about receiving a negative result?

25. People who participate in lung cancer screening who are current smokers can receive information and support about how to stop smoking. Is it acceptable to you to participate in screening to receive this benefit?

26. Would you want to know your risk of being diagnosed with lung cancer even if you were not eligible for lung cancer screening according to the Canadian lung cancer screening guidelines? What would you do with knowledge of your lung cancer risk? Would knowledge of your lung cancer risk change your behaviours in any way to reduce your lung cancer risk?

27. Making a decision about whether to be screened for lung cancer is challenging because of the complicated information about lung cancer screening benefits and harms. Is it important that family doctors provide benefits and harms information to patients so that patients can make a screening decision based on this information? Is it important for family doctors to be equal decision-makers along with patients?

28. Do you feel pressures to be screened for cancer by your family doctor? Do you think that there is pressure among society to be screened for cancer? If so, does this pressure impact your ability to make a decision about whether to be screened for lung cancer?

Equity and stigmatization

29. Some groups have high rates of lung cancer and low participation in lung cancer screening. Should we prioritize these groups for screening? Why or why not? What principles or considerations do you think we should use to make this decision?

30. Some people hesitate to be screened for lung cancer because they were or are a smoker. Some people whose lung cancers have been detected by screening – and whose lives were saved because of lung cancer screening - face backlash from society because they were smokers. Do you think that lung cancer screening carries stigma? Why or why not? Should something be done to reduce the stigma related to lung cancer screening? If so, what can be done?

Social values and resource allocation

31. In Canada, we have a limited amount of money to dedicate to the health care system and often have to make difficult decisions about what to fund. What principles or considerations should decision-makers use to decide whether to fund lung cancer screening?

32. Do you think that lung cancer screening is important for preventing lung cancer? What do you think about other ways to prevent lung cancer, such as reducing air pollution levels or asbestos exposure? Is lung cancer screening more or less important than other prevention options?

Final remarks

33. Is there anything else that concerns you about lung cancer screening? What excites you about this technology? What concerns you about this technology?

34. What would an unethical lung cancer screening program look like in the Canadian context? What should we definitely avoid?

35. Are there any other comments or feedback that you may like to share before we conclude the interview?

Appendix 9. Semi-structured interview guide

Concept	**Question**
Knowledge and experience of lung cancer screening	How did you become engaged in lung cancer screening research?
	What interests you the most about lung cancer screening?
General	What do you think are the ethical issues associated with lung cancer screening? In other words, can you think of an aspect of lung cancer screening that might be a moral challenge? Why?
	How are these ethical issues being addressed by you, your community of practice, or in your discipline?
	Do you think of lung cancer screening as a health care intervention for individuals or public health intervention for society, or both? Why?
Benefits and harms	What do you think are the benefits of lung cancer screening?
	What do you think are the harms of lung cancer screening?
	Do you think that the benefits of lung cancer screening outweigh its harms? Why or why not?
	How can the harms of lung cancer screening for individuals be negotiated with the benefits of lung cancer screening for society?
	What strategies do you think can be used to optimize the benefit and harm relationship (i.e., to maximize benefit and minimize harm)?
Eligibility	In 2016 the Canadian Task Force on Preventive Health Care published a guideline for lung cancer screening, which uses age and smoking history to help determine an individual's eligibility for lung cancer screening. These two criteria have been widely used in trials and studies of lung cancer screening. In some jurisdictions an alternate or additional approach is risk prediction modeling. Risk prediction models account for age, smoking history, and other personal and health variables to identify individuals more accurately at high risk of being diagnosed with lung cancer. a. What are the opportunities and challenges of each approach (age and smoking, and risk prediction modeling)? b. Specifically, what do you think might be the ethical issues that arise in each approach? Consider potential ethical issues such as benefits and harms, and the ethics of placing people into categories of low and high risk for lung cancer.
	How can a lung cancer screening program effectively identify all individuals at high risk of being diagnosed with lung cancer, and invite them to be screened? Alternatively, how can a lung cancer screening program effectively identify all individuals who are at *low* risk of being diagnosed with lung cancer, and ensure that they are *not* invited to screening?
	Should we prioritize screening people who are current smokers? Former smokers? Never smokers? What did you think about when making this decision?
	We know that asbestos and other workplace exposures put people at greater risk of lung cancer. Should we prioritize screening for people who are or were exposed to asbestos? What about people who are or were exposed to

	other workplace exposures that increase the risk of lung cancer, like diesel engine exhaust? What do you think about when making this decision?
Decision-making: Informed choice, consent, shared decision-making, and autonomy	Making a decision about whether to be screened for lung cancer is challenging because of the risk scoring that may be involved, complicated information about lung cancer screening benefits and harms, and a potentially lengthy screening pathway that could involve a false positive result, for instance. When you think about an individual person who has been invited to lung cancer screening and who is trying to make a decision about lung cancer screening, what would you want the person to understand, and why?
	What do you consider to be an informed choice? How do you know if patients are adequately informed and making a free choice?
	What can health care providers or health policy makers do to help patients understand the benefits and harms of lung cancer screening and make an informed choice?
Equity and stigmatization	Certain populations in Canada have higher lung cancer incidence and mortality, and lowered survival, than other groups. Often these groups also have low participation in lung cancer screening. In Canada, these groups include certain First Nations, Inuit, and Métis communities as well as people of low socioeconomic status. d. What reasons do you think may explain why there is low uptake of lung cancer screening in jurisdictions where there are lung cancer screening programs? e. Should we prioritize these groups for screening? Why or why not? What principles do you think we should use to make this decision? f. Should additional efforts be made to engage these populations in lung cancer screening? What additional efforts might need to be made? Who should be making these additional efforts?
	Some people hesitate to be screened for lung cancer because they were or are a smoker. Some people whose lung cancers have been detected by screening – and whose lives were saved because of lung cancer screening - face backlash from society because they were smokers. Do you think that lung cancer screening carries stigma? Why or why not? Should something be done to reduce the stigma related to lung cancer screening? If so, what can be done?
Social values and resource allocation	In Canada, we have a limited amount of money to dedicate to the health care system and often have to make difficult decisions about what to fund. What principles should decision-makers use to decide whether to fund lung cancer screening? Where CT is a limited resource, what principles should decision-makers use to decide if CT should be prioritized for lung cancer screening participants or for people who are sick/unwell?
	Do you think that lung cancer screening is important for preventing lung cancer and reducing lung cancer disparities in Canada? What do you think about other ways to prevent lung cancer, such as reducing air pollution levels or asbestos exposure? Is lung cancer screening more or less important than other prevention options?

	Most people who are screened for lung cancer receive a negative result. What do you think about this? For instance, do you think that a negative result is reassuring for the person screened? Do you think that it is a good use of health care resources?
Final remarks	Is there anything else that concerns you about lung cancer screening? What excites you about this technology? What concerns you about this technology?
	What would an unethical lung cancer screening program look like in the Canadian context? What should we definitely avoid?
	Are there any other comments or feedback that you may like to share before we conclude the interview?
Snowball sampling	Do you have any recommendations for other clinicians, scientists, clinician-scientists, or policymakers that I may ask to be interviewed as a part of this research?

Appendix 10. Consensus-based reporting standards for empirical bioethics research[293]

Item	**Standard**	**Reporting item**	**Location**
1	Empirical bioethics research should address a normative issue that is oriented towards practice	The extent to which the research aimed to address a normative issue oriented towards practice should be explicitly stated.	Introduction
2	Empirical bioethics research should integrate empirical methods with ethical arguments in order to address this normative issue	Any integration should be clearly articulated so that it is intelligible to the reader.	Discussion
3	Empirical bioethics researchers ought to be explicit about how the research question(s) asked address the normative issue identified in the aims	It should be clearly articulated how the normative aims of the project were met and the research questions answered.	Introduction; Theoretical framework and methodology
4	The theoretical position on integration (i.e., the theoretical views on how the empirical and the normative are related) should be made clear and explicit	The report should clearly articulate the meta-ethical and epistemological positions that allowed knowledge claims to be made.	Epistemological assumptions
5	The method of integration should be explained and justified, including details of what is integrated with what, how and by whom	The report should include a clear account of how the integrated analysis was undertaken, such that it can be understood by the reader.	Ethics analysis
6	There should be transparency, consistency and rigour in the execution and reporting of the integrating analysis	The report should be transparent in explication of the analytic processes.	Ethics analysis
7	Empirical bioethics research ought to attend to the rigorous implementation of empirical methods, and import accepted standards of conduct from appropriate research paradigms	The report ought to provide an account of how empirical methods were rigorously implemented.	Theoretical framework and methodology; sampling and recruitment; data collection; data analysis; rigor; epistemological assumptions; reflexivity; reporting; ethics approval
8	Empirical bioethics research should, if and where	The report ought to provide an explanation and explicit	(No amendments made to qualitative

	necessary, develop and amend empirical methods to facilitate collection of the data required to meet the aims of the research; but deviation from accepted disciplinary standards and practices ought to be acknowledged and justified	justification of any amendments made to standard empirical methods.	description methodology used to collect empirical data)
9	Empirical bioethics research should reflect on and justify the appropriateness and fit of the chosen empirical methods in relation to (a) the normative aims (b) the stated approach to integration	The report should provide an account of the compatibility of the chosen empirical methods with the normative aims and the approach to integration taken.	Theoretical framework and methodology
10	Empirical bioethics research should consider and reflect on the implicit ethical and epistemological assumptions of the chosen empirical method	The report should acknowledge the ethical and epistemological assumptions behind the project's empirical method(s), and consider the ways in which these might place limitations on the conclusions that have been drawn.	Epistemological assumptions
11	In empirical bioethics research, there should be thorough delineation of the ethical issue(s), paying attention to, and locating them within, the relevant disciplinary literature	The report should clearly and explicitly articulate how the project has engaged with the ethical issues that drove it, situating its own treatment of them within the wider literature from relevant disciplines.	Theoretical framework and methodology;
12	In empirical bioethics research, there should be explicit and robust normative analysis. 'Normative analysis' includes attempts to justify position X to person Y with the use of ethical reasoning, providing suggestion for improvement to position X based on ethical reasoning, or attempts to break down and make explicit a complex normative issue in order to	The report should contain a clear explication of the normative analysis, including its process and its conclusions.	Ethics analysis; Discussion; Policy recommendations

	gain a better understanding of it		
13	The empirical bioethics researcher, or the research team as a whole, should possess competence in ethical inquiry, empirical inquiry and methods of integration	NA	MP, JA, PD, LS, MV have expertise in one or more of ethical inquiry, empirical inquiry, and methods of integration
14	The empirical bioethics researcher(s) should have at least a basic knowledge of bioethics, and an understanding of whatever aspects of other disciplines or fields that are engaged with	NA	MP, JA, LS, MV have expertise in one or more of health policy, bioethics, public health ethics, disease screening ethics
15	Provision should be made for ensuring that any team members can acquire or enhance competence in empirical bioethics research	NA	MP conducted this study as a doctoral student in Health Policy under the primary supervision of MV and supervisory committee consisting of JA, PD, and LS

Appendix 11. Standards for Reporting Qualitative Research (SRQR)[a229]

No.	Topic	Item	Location
	Title and abstract		
S1	Title	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Abstract
	Introduction		
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Introduction
S4	Purpose or research question	Purpose of the study and specific objectives or questions	Introduction
	Methods		
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale[b]	Theoretical framework and methodology
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Reflexivity
S7	Context	Setting/site and salient contextual factors; rationale[b]	
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale[b]	Sampling and recruitment
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review bard and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Ethics approval
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative	Data collection

		process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale[b]	
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Data collection
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Participants
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	Data analysis
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale[b]	Data analysis
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale[b]	Rigor
	Results/findings		
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Results
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Results
	Discussion		
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Discussion
S19	Limitations	Trustworthiness and limitations of findings	Discussion
	Other		
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Competing interests
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Funding

[a] The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

[b] The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together