

Ethical Dimensions of Population-Based Lung Cancer Screening in Canada: Key Informant Qualitative Description Study

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Normative issues associated with the design and implementation of population-based lung cancer screening policies are underexamined. This study was an exposition of the ethical justification for screening and potential ethical issues and their solutions in Canadian jurisdictions. A qualitative description study was conducted. Key informants, defined as policymakers, scientists and clinicians who develop and implement lung cancer screening policies in Canada, were purposively sampled and interviewed using a semi-structured guide informed by population-based disease screening principles and ethical issues in cancer screening. Interview data were analyzed using qualitative content analysis. Fifteen key informants from seven provinces were interviewed. Virtually all justified screening by beneficence, describing that population benefits outweigh individual harms if high-risk people are screened in organized programs according to disease screening principles. Equity of screening access, stigma and lung cancer primary prevention were other ethical issues identified. Key informants prioritized beneficence over concerns for group-level justice issues when making decisions about whether to implement screening policies. This prioritization, though slight, may impede the implementation of screening policies in a way that effectively addresses justice issues, a goal likely to require justice theory and critical interpretation of disease screening principles.

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Introduction

This study examines the ethical justification for lung cancer screening policies, soliciting data from key informants to illuminate normative issues associated with policy design and implementation. Lung cancer is the leading type of cancer diagnosis and cause of cancer mortality in Canada. An estimated 30,000 people were newly diagnosed with lung cancer and 20,700 died from this disease in 2022 (Brenner *et al.*, 2022). Lung cancer in Canada mostly reflects historical and current exposure to lung carcinogens that include commercial tobacco smoke (70 per cent of incident cases) (Poirier *et al.*, 2019) and over 30 occupational and environmental agents (de Groot *et al.*, 2018) with differential prevalence by region and subpopulation (Hystad *et al.*, 2014; Labreche *et al.*, 2019; Fenton *et al.*, 2022; Goss *et al.*, 2022). Nearly 50 per cent of lung cancers in Canada are diagnosed at stage 4. At this stage, treatment options are limited, treatment effectiveness is poor and 3-year net survival is merely 5 per cent (Canadian Cancer Statistics Advisory Committee, 2020). Survival rates are lower for people of low socioeconomic status, who also face higher risks of lung cancer incidence, mortality and stage 4 diagnosis (Mao *et al.*, 2001; Mitra *et al.*, 2015; Canadian Cancer Society's Advisory Committee, 2020; Canadian Partnership Against Cancer (CPAC), 2020; Hajizadeh *et al.*, 2020). Some Indigenous (Carrière *et al.*, 2012; Nishri *et al.*, 2015; Sanchez-Ramirez *et al.*, 2016; Withrow *et al.*, 2017; Mazereeuw *et al.*, 2018a,b; Jamal *et al.*, 2021) and rural communities (Canadian Partnership Against Cancer (CPAC), 2020, Shah *et al.*, 2021) may also be disproportionately impacted by lung cancer.

In 2016, the Canadian Task Force on Preventive Health Care recommended population-based lung cancer screening with low dose computed tomography (LDCT) for people aged 55–74 years with a history of 30 pack-years of commercial tobacco smoking. Screening aims to decrease morbidity and mortality of lung cancer by detecting malignant neoplasms at early stages when there are more treatment options and improved treatment responsiveness. Screening is gradually being implemented in Canadian jurisdictions as evidenced by one province-wide program in British Columbia, a partial program at four sites in Ontario, and pilot projects, research studies and economic evaluations of varying methods and results (Goffin *et al.*, 2015; Cressman *et al.*, 2017; Canadian Partnership Against Cancer, 2022; Thanh *et al.*, 2022).

The slow pace of lung cancer screening policy implementation in Canada attests that screening is a

significant allocation of limited public resources requiring the gradual building of expertise and infrastructure. It may also indicate that ethical issues in lung cancer screening make it challenging to design and implement policies. To begin understanding what the ethical issues are, we need to consider screening what screening is, which is an imposition into the lives of people asymptomatic for lung cancer who have not initiated a request for screening (Ustun and Ceber, 2003; Carter, 2016). Lung cancer screening does not merely target *anybody* who is asymptomatic for lung cancer. Rather, lung cancer screening uses multivariate risk assessment to identify and invite people for screening only if they are *high risk* for being diagnosed with lung cancer in a defined future period (Tammemägi *et al.*, 2013, 2019, 2022). The use of multivariable risk assessment to categorize and select screening candidates distinguishes lung from other types of cancer screening policies where eligibility is based on age alone. Many ethical issues in lung cancer screening pivot on this fact. Furthermore, because lung cancer screening is simultaneously a public health and clinical intervention, it elicits ethical principles that may conflict. Consider the public health ethics principle of health equity and the clinical ethics principle of autonomy. While lung cancer screening may promote health equity by inviting the participation of potentially high-risk people who may not have initiated a screening request on their own, the fact that it is an invitation may diminish autonomy by suggesting a high risk of being diagnosed with lung cancer and the benefit of screening. As a result, policy processes must grapple with competing ethical claims.

Potential harms and opportunity costs of lung cancer screening are among the key ethical issues salient to policy. It is unclear whether harms and opportunity costs incurred by individuals justify the main benefit of screening, which is a population reduction in lung cancer mortality (Carter, 2016). Knowledge about potential harms is still being constructed through research on screening effectiveness. Overdiagnosis is arguably the most serious harm because it results in overtreatment of indolent cancers that would not progress to cause any symptoms and therefore does not benefit patients. An estimated 50 per cent of screen-detected lung cancers are overdiagnosed (Brodersen *et al.*, 2020) in part because of limited knowledge about lung cancer and the intrinsically probabilistic natural history of disease (Bach *et al.*, 2012; Harris *et al.*, 2014; Jonas *et al.*, 2021). Overtreatment causes physical (e.g. pain), psychological (e.g. anxiety) and financial (e.g. direct payment) harm and opportunity costs (e.g. time off work) for individuals

and unnecessary health care expenditures for populations. These types of harms and opportunity costs similarly arise from follow-up investigation of positive lung cancer screening results and incidental detection and evaluation of smoking-related comorbidities that are more prevalent in high-risk populations (Kucharczyk *et al.*, 2011; Pinsky *et al.*, 2022). Decisions of health policymakers to allocate limited public resources for screening may be susceptible to bias (Plutynski, 2012; Parker *et al.*, 2017) where the potential harms and opportunity costs of screening are accepted at the expense of pursuing alternate or additional policy pathways that could be relatively more beneficial and equitable for preventing lung cancer.

Informed and shared decision-making tools have been developed to help potential screening participants understand and evaluate benefits and harms as part of their screening participation decision-making processes. Informed decision-making is a cornerstone for promoting autonomy in lung cancer screening. However, drawing from experiences with screening for other types of cancers, three aspects of informed decision-making could undermine efforts to promote autonomy in lung cancer screening: the complexity of information about benefits and harms, bias in how information about benefits and harms is communicated (Clark *et al.*, 2020), and a lack of knowledge about how patients value benefits and harms (Parker *et al.*, 2017; Biddle, 2020; Hofmann, 2020; Elton, 2021; Bolt *et al.*, 2022). The effectiveness of informed decision-making tools varies, and shared decision-making is difficult to implement in primary care. Pro-screening attitudes and fear of lung cancer may further limit autonomy in lung cancer screening.

Potential harms disproportionately impact low socioeconomic status groups because these groups are most likely to be assessed as high risk for lung cancer in models that emphasize commercial tobacco smoking. The emphasis on commercial tobacco smoking in lung cancer screening risk assessment contributes to social and medical stigmatization of people who smoke commercial tobacco (Bayer and Stuber, 2006; Bell *et al.*, 2010). Groups with high prevalence of commercial tobacco smoking in Canada (Li *et al.*, 2009; Corsi *et al.*, 2013; Wallace, 2014; Bougie and Kohen, 2017) may encounter other forms of stigmatized health and social surveillance associated with their identities and have limited health care access (St-Jacques *et al.*, 2013; Mema *et al.*, 2017; Tobias *et al.*, 2020; Sayani *et al.*, 2021; Cao *et al.*, 2022). Concerns for health equity with respect to screening access (Wilson and Rosenberg, 2004; Rodrigo

et al., 2020) and stigma, discrimination, cultural safety and trust (Brock *et al.*, 2021; Jamal *et al.*, 2021) suggest incommensurability with the principle of beneficence framed in utilitarian terms. Indeed, the individuals most likely to benefit from lung cancer screening are those with access to lung cancer screening and treatment, and resources to navigate potential stigma and discrimination associated with a diagnosis of screen-detected lung cancer. Health equity effects of high- versus low-risk stratification, and how these effects could be mitigated, are largely unknown (John, 2013; Knoppers *et al.*, 2021; Roux *et al.*, 2022; French *et al.*, 2023).

Key informants—collectively, scientists, policymakers and clinicians—who are leading lung cancer screening policies in Canadian jurisdictions are intimately engaged with this complex nexus of public health and clinical ethical issues where competing ethical claims need to be evaluated and acted upon through policy decision-making. Key informants integrate clinical evidence with ethical and epistemological values about cancer screening that can reflect their own interests and biases (Parker *et al.*, 2015). However, there is sparse empirical evidence about normative judgments being used to justify and guide lung cancer screening implementation (Kyle, 2006; Chan, 2015; Røe, 2020) and no studies in the Canadian context during this critical juncture for policy diffusion. To help address this knowledge gap, the aim of this research was to understand the ethical justification for developing and implementing lung cancer screening policies, and normative judgments used to navigate ethical issues that arise. This research also aimed to help anticipate potential ethical issues or values conflicts to alert future policy decision-makers on areas that may require ethical attention. This research was framed by three questions that asked: (i) What reasons are key informants using to justify the development and implementation of lung cancer screening policy? (ii) What ethical issues in lung cancer screening do key informants experience via policy development and implementation? (iii) What are key informants doing to address these ethical issues?

Methods

Methodology

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 (Sandelowski, 2000, 2010), which was important for accurately understanding real-world ethical

issues in lung cancer screening policy based on the words that key informants state to explain the ethical justification for screening, ethical issues and approaches that are being used to address ethical issues. It allowed a full investigation of ethical issues 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 and scope. Standards for Reporting Qualitative Research (SRQR) were used to guide qualitative description study reporting (Supplementary Appendix 1) (O'Brien *et al.*, 2014).

Sampling and Recruitment

Eligible key informants were individuals with significant expertise in lung cancer screening research, clinical practice or policymaking who could provide overarching views about ethical aspects in the Canadian context (Pahwa, 2023). A diversity of experiences was sought to produce a fulsome understanding of the ethical landscape in Canada (Huxtable and Ives, 2019). Thus, maximum variation sampling was used to invite key informants located in academic, government and clinical settings in all Canadian jurisdictions with current lung cancer screening activities. Key informants were identified from publications about 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 was developed and used to collect data toward both study objectives (Supplementary Appendix 2). The interview guide was informed by population-based disease screening principles that were an update to Wilson and Junger's (1968) disease screening principles (Wilson *et al.*, 1968), which showed consistency with contemporary health systems and screening programs in Canada (Dobrow

et al., 2018). 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 4 April 2022 and 5 May 2023, via Zoom and telephone. Interviews were transcribed verbatim and de-identified. Participant numbers were limited by the small pool of lung cancer key informants in Canada, but data sufficiency was still achieved using the concept of information power (Malterud *et al.*, 2016). Information power is a theory that guides considerations of data sufficiency by examining the richness of dialogue, specificity of study aim, existence of a guiding theory, density of expertise in the sample and analytic strategy. In this manuscript, a smaller sample size is acceptable when engaging in a highly specific research aim with individuals who have a great deal of expertise and provide rich data.

Data Analysis

Participant characteristics were aggregated in tabulated frequencies and percentages. Conventional (inductive) qualitative content analysis (QCA) (Hsieh and Shannon, 2005; Elo and Kyngäs, 2008) 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 subcategories. Subsequently created categories encompassed subcategories, also based on shared concepts. QCA was also conducted by KS 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 (Sandelowski, 1986). 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 coauthors. KS provided verification of QCA outputs (i.e. codes, subcategories 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 and 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). All participants provided informed consent.

Results

Participants and Analytic Categories

Fifteen key informants from seven Canadian provinces were interviewed. Most were specialty physicians acting in policy, scientific and clinical roles related to lung cancer screening activities (Table 1). Interviews ranged from 39 to 78 minutes in length (mean: 56 minutes).

Five categories describing ethical aspects were identified: (i) Benefits and harms; (ii) Equity of screening access; (iii) Promoting autonomy and rights; (iv) Resource allocation; and (v) 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 2).

Benefits and harms

All but one key informant stated that screening benefits outweigh harms. Reasons for disagreement cited by the outlier key informant were insufficient evidence 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 key informants cited 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 can shift diagnosis from late to early stage, providing an opportunity for curative treatment that saves lives, improves survival and improves quality of life.

Table 1. 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	
Policymaker	6 (40)
Scientist	4 (27)
Clinician-Scientist	3 (20)
Clinician	2 (14)
Terminal degree(s)	
MD	7 (47)
PhD	4 (27)
PhD-MD	1 (7)
Other	3 (20)

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

Table 2. Categories developed from conventional qualitative content analysis of semi-structured interview data collected from eleven key informants

Category name	Category description	Included subcategories
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 Harms Evidence-based screening protocol
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 Defining the target population
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 Culturally safe care
4 Resource allocation	What key informants describe as the ethical aspects of allocating resources toward preventing lung cancer in Canada, and what is being done in practice to distribute prevention resources	Resource allocation
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 Bias

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 comprehensive and 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)

Equity of screening access

All key informants explicitly named equity of access to 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 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 approaches to reach target populations where they live as preferable to incentivizing target populations to travel to a lung cancer screening center. 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 approaches that could be done within screening programs to engage high-risk groups. These were improved identification of target populations and expanding health system capacity to provide care along the screening pathway. 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 cutoff 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 USA 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.

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 or low education levels. One informant expressed concern about the potential coercive effects of promoting lung cancer screening similar to breast cancer screening, highlighting that coercion could originate with the invitation to screen itself and a lack of clear communication about potential screening harms. 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 center 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.

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 toward 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.

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 the 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

Key informants in this qualitative description study recognized lung cancer screening as a comprehensive pathway encompassing primary care, screening, diagnosis and treatment. Despite key informants' nearly unanimous support for implementing lung cancer screening on the grounds of beneficence, once decisions to implement lung cancer screening were made, there was substantial concern for equitable access, stigma, informed decision-making burdens and resource allocation. Conflicts between the principles of beneficence, justice, autonomy and cost-effectiveness elicited by these issues were unresolved through key informants' use of principles of population-based disease screening. Ethical issues in screening for other types of cancers may offer insights relevant for lung cancer. However, lung cancer screening is somewhat distinct because group-level justice issues are amplified by policies that prioritize screening for people who currently or previously smoked commercial tobacco, who are disproportionately low socioeconomic status. It is likely that policy decision-makers will need to engage justice theory to

more fully approach group-level justice issues surfaced in this study.

Key informants used the ethical principle of beneficence to justify their decisions to implement screening. Multiple key informants described their understanding that the main benefits of lung cancer screening are reduced population lung cancer mortality. They described health systems cost-savings as a secondary perceived benefit. Utilitarian framings of beneficence are commonplace in cancer screening despite unclear evidence about benefits and harms and a lack of cost-effectiveness evidence that fully accounts for harms. The perceptions of benefit expressed by key informants reflect beliefs that the allocation of large amounts of limited resources for screening should correspondingly result in large scale gains in public health and cost-savings in health care. Key informants in this study were not solely concerned with perceived aggregate benefit; they were also worried about *who* benefits as evidenced by their efforts to promote equity of screening access. For instance, by expanding referral privileges and contemplating mobile CT vans and the lowering of screening eligibility thresholds. However, equity of screening access is unlikely to mitigate the potential harms of screening. The potential harms of screening were not addressed in-depth by key informants when asked in this study. Where key informants expressed concern for harms, they centered around social harms and psychological effects; namely, stigma against people who currently smoke commercial tobacco.

Key informants described that stigma inhibits screening program investment and public participation and thus, the opportunity for high-risk populations to benefit from screening (Yang *et al.*, 2007; Hamann *et al.*, 2018; Vrinten *et al.*, 2019). Independent of screening access, low versus high socioeconomic status groups are more likely to experience stigma that could undermine informed decision-making processes and cause dis- or underinvestment in primary prevention of lung cancer where the primary beneficiaries would be low socioeconomic status groups. Stigma within lung cancer screening may be considered a consequence constructed by categories to inform screening eligibility. Commercial tobacco smoking is a stigmatized addictive substance with higher prevalence in low versus high socioeconomic groups who may encounter other forms of stigmatized health and social surveillance related to their identities. Perhaps for this reason, in this study, stigma was considered a social phenomenon outside of key informants' scope of practice. A small number of interventions to prevent or reduce stigma have been

implemented. These include patient-focused decision aids and continuing clinical education to address nihilism, bias and stigma for lung cancer screening (Hamann *et al.*, 2018) and emotive narratives for cervical cancer screening (Akin-Odanye and Husman, 2021). The effects of risk categorization on stigma in this research is relevant to other types of cancers that use risk-stratified screening (John, 2013; Knoppers *et al.*, 2021; Roux *et al.*, 2022; French *et al.*, 2023). Future research is needed to understand lung cancer screening stigma effects and potential intersections with social and economic stigma related to the identities of people assessed to be high risk for lung cancer.

Compared to beneficence and health equity, promoting autonomy appeared less important to key informants, despite complexity of information about benefits and harms in preventive medicine, bias in how information about benefits and harms is communicated (Clark *et al.*, 2020), and a lack of knowledge about how patients value benefits and harms in informed decision-making processes about screening participation (Parker *et al.*, 2017; Biddle, 2020; Hofmann, 2020; Elton, 2021; Bolt *et al.*, 2022).

Key informants applied population-based disease screening principles as a working ethical framework to justify how screening programs are being organized to ensure overall benefit, which is how key informants defined an 'ethical' screening program. The most important ethical challenge identified by key informants was that screening is systematically inaccessible to populations who they believed could benefit from the most. It was unclear in this research if judgment of beneficence is sufficient reason to justify the offer of screening given significant concerns for equity, potential harms and autonomy; however, it was clear that key informants prioritized beneficence in their decisions to implement screening. Key informants considered primary prevention of lung cancer and political responsibility for the health effects of commercial tobacco smoking as ethical issues. However, few actions were described to address group-level justice issues, suggesting a possible need for additional normative guidance.

Normative guidance may be found from further and critical engagement with principles of population-based disease screening. For instance, principles about screening program infrastructure, benefits and harms, acceptability and ethics and economic evaluation may be most relevant for supporting policy deliberation about equitable screening and stigma. Justice theories may provide additional and more specific considerations for navigating group-level equity concerns described by key

informants in this research. Analysis of empirical findings through the lens of restorative justice may suggest policy pathways to help improve access to lung cancer screening and treatment among low socioeconomic status groups and can help widen the scope of lung cancer prevention to include addressing environmental and occupational lung carcinogen exposures that may be more prevalent in low versus high socioeconomic status groups. More research is needed about interventions to reduce stigma.

Strengths and Limitations

There are several strengths and limitations of this study. The number of key informants who participated in this study reflects the small size of lung cancer screening leadership in Canada, and challenges recruiting this very busy group. Recurrent identification of participants via snowball sampling suggested comprehensive sampling and recruitment. Information power was attained. Nevertheless, recruitment only from within provinces where lung cancer screening activities are currently happening may have missed strong dissenting voices from other provinces. The research aim, which was to understand normative judgments in lung cancer screening policies from a diversity of perspectives and Canadian jurisdictions, prevented in-depth investigation of ethical issues pertaining to specific subpopulations and regions. The topic of the potential tobacco industry influence on lung cancer screening was not addressed explicitly in interviews and key informants did not surface this topic when asked broader questions about potential harms of lung cancer screening. The issue of cost-effectiveness and the underlying assumptions and evidence that support perceptions of cost-effectiveness were not probed in-depth in interviews. Future research may explore potential tobacco industry influence. Evidence generated in this study helps to enhance public transparency, accountability, trust and dialogue on the ethics of lung cancer screening policy (Kenny and Giacomini, 2005). Future research may engage with justice theory to inform pathways for equitable lung cancer screening in Canada.

Conclusion

The principle of beneficence was used as the normative basis for decisions to implement population-based lung cancer screening in this study of key informants in Canadian jurisdictions. Prioritization of beneficence over concerns about group-level justice, even though

slight, is likely to hinder policy responses to equitable screening, stigma, autonomy and resource allocation. There was a lack of ethical guidance being used to address group-level justice issues in screening policy decision-making. Critical and further engagement with population-based disease screening principles, in combination with justice theory, may support key informants in developing policy approaches for addressing group-level justice issues.

Supplementary Material

Supplementary material is available at *Public Health Ethics* online.

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