Policy lenses for the implementation of lung cancer screening in Australia – A systems mapping approach

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Abstract

The aims of this study were to (i) identify the likely determinants of lung cancer screening uptake, and (ii) identify the relationships and dynamic behaviours between these determinants that may influence the uptake of screening in Australia. A participatory workshop and follow-up meeting with key stakeholders were held which included clinicians in lung cancer care (respiratory physicians, medical oncologists, pulmonologists, specialist lung cancer nurses), a general practitioner (GP), a health economist, and consumer advocates. Data from stakeholder discussions and evidence from existing literature were used to create a causal loop diagram (CLD). The CLD comprised three main perspectives of a lung cancer screening program: the health system perspective, primary care perspective and the patient perspective. Further eight main drivers (feedback loops) were identified as responsible for the dynamics impacting the implementation and uptake of lung cancer screening: patient fear; patient stigma; patient health literacy; patient waiting time for a scan; GP capacity; GP clarity about referral steps; specialist capacity with lung cancer expertise; benefit-cost ratio of a lung cancer screening program. Findings from this study can be used to identify any interventions in the system and inform the development of a quantitative system dynamics model to simulate different intervention scenarios.

Introduction

The burden of lung cancer worldwide and in Australia is significant. In 2020, lung cancer accounted for an estimated 2.2 million new cases and 1.8 million deaths, representing 18% of all cancer deaths globally (1). In Australia, lung cancer is estimated to be the fourth most diagnosed cancer (13,810 new cases in 2021) and leading cause of cancer-related deaths in men and women. An estimated 8,693 people died from lung cancer in Australia, accounting for 19% of all cancer deaths in 2021 (2). When detected at stage I, lung cancer has a 67.7% five-year survival prognosis compared to 17.1% and 3.2% for stages III and IV (3). Early stage lung cancer is usually asymptomatic, and most lung cancers (70%) are diagnosed at a later stage when patients present with symptoms, with limited curative treatment options available and poorer survival prognosis (4). Therefore, screening asymptomatic patients who are at higher risk provides an opportunity to detect lung cancer earlier and potentially improve survival (5). Over the past two decades, evidence from several randomised controlled trials (RCT) have shown that screening high risk patients with low-dose computer tomography (LDCT) can reduce lung cancer mortality by 20% through shifting from late to earlier-stage cancers at diagnosis (6, 7).

As a result, more health systems worldwide have initiated, or are considering, the implementation of nationwide lung cancer screening programs to identify early stage lung cancer by screening asymptomatic patients at risk of lung cancer (8). However, lung cancer screening is complex, and the success of an effective nationwide screening program depends on an array of factors. In settings where a screening program has already been implemented, the uptake has been low. For example, only 7.3% of eligible people in the US have participated in lung cancer screening (9). This highlights the need to better understand the factors that influence the uptake of screening. There is currently no lung cancer screening program in Australia. However, in 2022 the national Medical Services Advisory Committee recommended the implementation of a nationwide screening program comprising 2-yearly LDCT scans among high-risk individuals (defined as aged 50-70 years, a smoking history of at least 30 pack-years; and a current or former smoker who has quit within the past 10 years) (10). Currently, in Australia 12% of lung cancers are diagnosed at stage I (11). It is estimated that in the first 10 years of a national risk-based screening program around 70% of lung cancers could be diagnosed at an early stage, which implies the prevention of over 12,000 deaths and reduction of 20% in lung cancer mortality in Australia (12).

With Australia moving towards a nationwide lung cancer screening program, it is critical to understand the individual, social, economic, clinical and health system factors that enable or impede screening uptake in the Australian context. Most research to date has focused on qualitative studies to investigate these system factors, and have been conducted in settings where a screening program had already been implemented (e.g. USA). The present study uses a participatory system dynamics approach which is a method that explicitly takes a systems-level approach, and aims to capture the complexity of interacting factors that may impact the success of a future screening program. The present study is the first to apply a system dynamics approach to understand these factors, their interconnections and dynamic behaviours, in the Australian context. Cancer screening is an area that is particularly suited for system dynamics modelling, due to potential nonlinearities in the system, delayed feedback, and the delays associated with translation of evidence and policy implementation (13).

Problem statement

The aims of this study were to (i) identify the likely determinants of lung cancer screening uptake, and (ii) identify the relationships and dynamic behaviours between these determinants that may influence the uptake of screening in Australia.

Methods

A participatory system dynamics approach was used for this study (14). This methodology was chosen because conventional research methodologies used in program design and evaluation often overlook, or simplify, the complexity of systems and the dynamic behaviours between components in the system. Complex problems often are approached through examining 'risk factors' as single causes of a given 'outcome', with a linear and immediate relationship between cause and effect. In contrast, in dynamically complex systems, cause and effect are often distant in time and space, and can involve circular feedbacks and time delays for effects to emerge (13). In the present study, through applying a system dynamics approach, a more comprehensive representation of system complexity can be provided to inform lung cancer screening program design and implementation, through examining the likely non-linear interactions between system components such as individual behaviours and preferences, social and economic context, clinical decision making, and health system capacity.

This study included the development of a causal loop diagram (CLD) as part of a wider project aiming to inform the development of a subsequent quantitative system dynamics model which will be used to simulate the relationships identified in the CLD, and test intervention scenarios to optimise lung cancer screening uptake. CLDs are tools to provide a conceptual overview of the participants' mental models (that is, their understanding and assumptions of a system's structure and behaviour) and help to communicate the boundaries of a system, and to inform the behaviour of the subsequent simulation model.

For the present study, a participatory workshop and a follow-up meeting with key stakeholders were held beginning of 2023. The first stakeholder workshop was held in January 2023 in Sydney, New South Wales, with six key stakeholders including two specialist lung cancer nurses, a health economist, a general practitioner, a patient representative and an Aboriginal patient representative. The 4-hour workshop included three sessions comprising a mix of individual, small group and plenary exercises. In the first session, participants were asked to elicit variables that would most likely have an impact on the total number of people screened. The second and third sessions included a connection circle exercise where participants were asked to identify direct relationships between these variables, and then to identify potential feedback loops between variables. The feedback loops together with data from field notes and audio recordings of the sessions were thematically analysed and used to create a preliminary CLD. Evidence from existing literature was also used to validate the variables and confirm relationships in the CLD. A follow-up meeting with ten clinicians in lung cancer care was also held (during the Australian Lung Cancer Conference at the Gold Coast, Queensland in February, 2023), which included respiratory physicians, a medical oncologist, pulmonologists, specialist lung cancer nurses, and a consumer advocate. The CLD was further refined based on feedback and insights from this stakeholder group. Ethics approval for this study was obtained from St Vincent's Hospital Human Research Ethics Committee (HREC Approval Number: 2022/ETH01568).

Results

A CLD was developed based on the information extracted from the stakeholder workshop and follow-up meeting and existing evidence from the wider literature (Figure 1 and Table 1). The CLD that was developed with stakeholders comprised three main perspectives of a lung cancer screening program: the health system perspective, primary care perspective and the patient perspective (Figure 1). Each of these perspectives included a set of key variables and feedback loops that were identified by stakeholders as responsible for the dynamics impacting the implementation and uptake of lung cancer screening in the Australian context (Table 1). Additionally, there were eight main feedback loops (either balancing or reinforcing) that were identified. There are four main drivers in the patient perspective, two in the primary care and two in the health system perspective, and the structure of each of these system perspectives is described in more detail below.

Patient perspective

- Patient fear of having lung cancer was highlighted as one of the main reasons for why patients might not seek help and consult with a GP in the first place, and this potentially led to patients becoming sicker, and not presenting until symptomatic (Reinforcing loop – R1).
- Stakeholders also reported that patients would also not consult with a GP due to shame and guilt due to their smoking status, which in turn would lead to patients becoming sicker and not presenting until symptomatic (R2). The relationship between patient's fear of a negative lung cancer screening outcome, the patient perceived stigma and the reluctancy to seek help or attend screening has also been reported in previous studies (15, 16, 17, 18, 19). It was emphasised by stakeholders that patient perceived stigma would have a significant impact not only on help-seeking behaviour but also on the entire patient journey, from consulting with a GP to follow-up examinations and adhering to treatments. Unlike other types of cancer where the healthy population is being screened based on age (breast, cervical, colorectal), lung cancer screening targets primarily smokers. Smokers may therefore experience stigma due to the perception that lung cancer is preventable and self-inflicted due to the frequent perception it is mostly caused by tobacco smoking, further reinforced by anti-tobacco campaigns (20, 21).
- Whether a patient is seeking help or not would also depend on their health literacy (R3). This has been noted previously in a United Kingdom (UK) study to be a barrier for lung cancer screening, particularly in culturally diverse communities with lower socio-economic status (22).
- Stakeholders noted that patient waiting time as an important driver, with long waiting times for patients to receive an appointment for a scan (e.g. up to 6 months) associated with patients declining a scan (Balancing loop – B1).

Other factors of relevance from the patient perspective that were elicited included lack of patient awareness around lung cancer and lung cancer screening, the geographic remoteness and distance to healthcare centres equipped with LDCT scanners and the patient's possibility to travel, and the associated direct and indirect costs (e.g. taking a day off work) of screening which were significant reasons for patients to not attend for screening (23, 24, 25, 26).

Primary care perspective

- There was consensus among stakeholders that a lack of GP capacity (B2), particularly in rural or remote areas, is a significant issue in the implementation of lung cancer screening. Stakeholders referred to the problem around availability of GPs in general, but also lack of time during a consultation with the patient to discuss the benefits and harms of screening for lung cancer. With a screening program in place, the number of referrals would add additional pressure on GPs since patients would need to see the GP again after receiving a scan. The lack of clinical time to address lung cancer screening in clinical practice and inform patients about benefits and risks of screening (e.g. exposure to radiation) in the context of patient's medical history is also consistent with previous findings (27, 28).

- Stakeholders indicated that GPs often are unclear about the referral pathway after receiving an abnormal lung scan for a patient (B3). The likelihood of a GP referring the patient for a scan would therefore also depend on whether the GP has an understanding about the next referral steps. According to stakeholders, pathways for cancer care currently not only differ across states but also across hospitals within local jurisdictions.

Other factors of relevance from the primary care perspective that were identified included the GP concerns relating to exposure to radiation, false-positive tests, and the invasive nature of the follow-up test for diagnosing the patient following a suspicious scan (28), which could potentially impact GP perceived benefit of a referral to screening. The stakeholder group also discussed the impact of healthcare provider stigma and nihilistic views on lung cancer treatment on lung cancer care, which were perspectives that were also evident in previous studies (21, 28).

Health system perspective

- There was consensus among stakeholders that availability of specialists with expertise in lung cancer was currently an issue, but would be further exacerbated with an increase in patient volume once a screening program is implemented (B4). This is due to an expected increase in demand for specialists in radiology, pulmonary and particularly in thoracic surgery. A simulation model in Canada predicted a possible shortage of thoracic surgeons given the expected increase in operable early-stage lung cancers (29). Specialist capacity in a screening program will therefore likely impact on the timely treatment of patients and subsequent costs for the healthcare system.
- A second driver from the health system perspective identified by stakeholders related to the benefit-cost ratio of a screening program, which would be expected to increase if more patients are being treated at an earlier stage of lung cancer as opposed to costly late-stage treatments. With a possible increase in the overall cost benefit ratio, the Australian government might then be more inclined to further invest in the screening infrastructure (B5). This may include increasing the number of facilities with LDCT scanners in rural and remote areas, reducing the threshold for screening (e.g. including other non-smoking related risk factors as well), providing investments in IT-infrastructure to support IT-interoperability across service contexts (currently a significant issue (30)), implementing public awareness campaigns to reduce stigma and to increase awareness of lung cancer and lung cancer screening, and developing nodule management standards to better educate GPs on the patient pathway.

Discussion

This paper describes the development of a causal loop diagram (CLD) that aimed to understand the factors associated with the uptake of a future lung cancer screening program in Australia. Based on participatory workshops and evidence scans of the literature, the resulting CLD identified three main perspectives of central importance for consideration in the design and implementation of a national lung cancer screening program: a health system perspective, a primary care perspective and the patient perspective. If the CLD is a valid systems-level characterisation of Australian lung cancer screening, there are number of key drivers that emerged during the discussion including patient fear, patient stigma, patient health literacy, patient waiting time for a scan, GP capacity, GP clarity about referral steps, specialist capacity with lung cancer expertise and benefit-cost ratio of a lung cancer screening program. Consideration of these drivers in the system can be used in subsequent stakeholder and policy discussion to identify potential interventions to ensure the optimisation of lung cancer screening uptake among the eligible population.

The current study is the first to apply a participatory system dynamics approach to map the complexity of the range of system-level factors and the dynamic behaviours in the system that can inform the design, implementation and evaluation of an optimal national lung cancer screening program in Australia. This CLD developed in the current study can also subsequently be used to inform the development of a quantitative system dynamics model to simulate the interacting relationships identified in the CLD, which has been achieved for other complex health outcomes like obesity, diabetes, suicide, osteoporosis, and COVD-19 (11, 31, 32, 33). Insights from the simulation model can then be used to inform the implementation of an effective nationwide lung cancer screening program through testing different "what-if" intervention scenarios individually and in combination, to assess how they might impact the uptake of screening. Additionally, this CLD may help in identifying potential unintended consequences of a nationwide screening program.

This study also has limitations. This study relies on the quality of stakeholder input and findings from qualitative research. Existing evidence is predominantly from other countries and findings may not be replicable to the Australian context. In addition, the CLD includes the aggregate level of information and does not account for subpopulations such as Aboriginal and Torres Straight Islanders where smoking history and lung cancer incidence and mortality are historically higher (8). However, a computational simulation model could overcome these drawbacks.

Conclusion

This CLD may be used to support decision-makers gain a better understanding of how the system operates and what influences lung cancer screening uptake. Findings from this study can be used in follow-up stakeholder discussions to identify any interventions in the system that could be used to increase the uptake of screening. This CLD can also subsequently be used to inform the development of a quantitative system dynamics model to simulate the interacting relationships identified in the CLD, and test different “what-if” intervention scenarios and how they may impact the uptake of screening under different health policy scenarios.

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Figure 1. Causal loop diagram of lung cancer screening in Australia

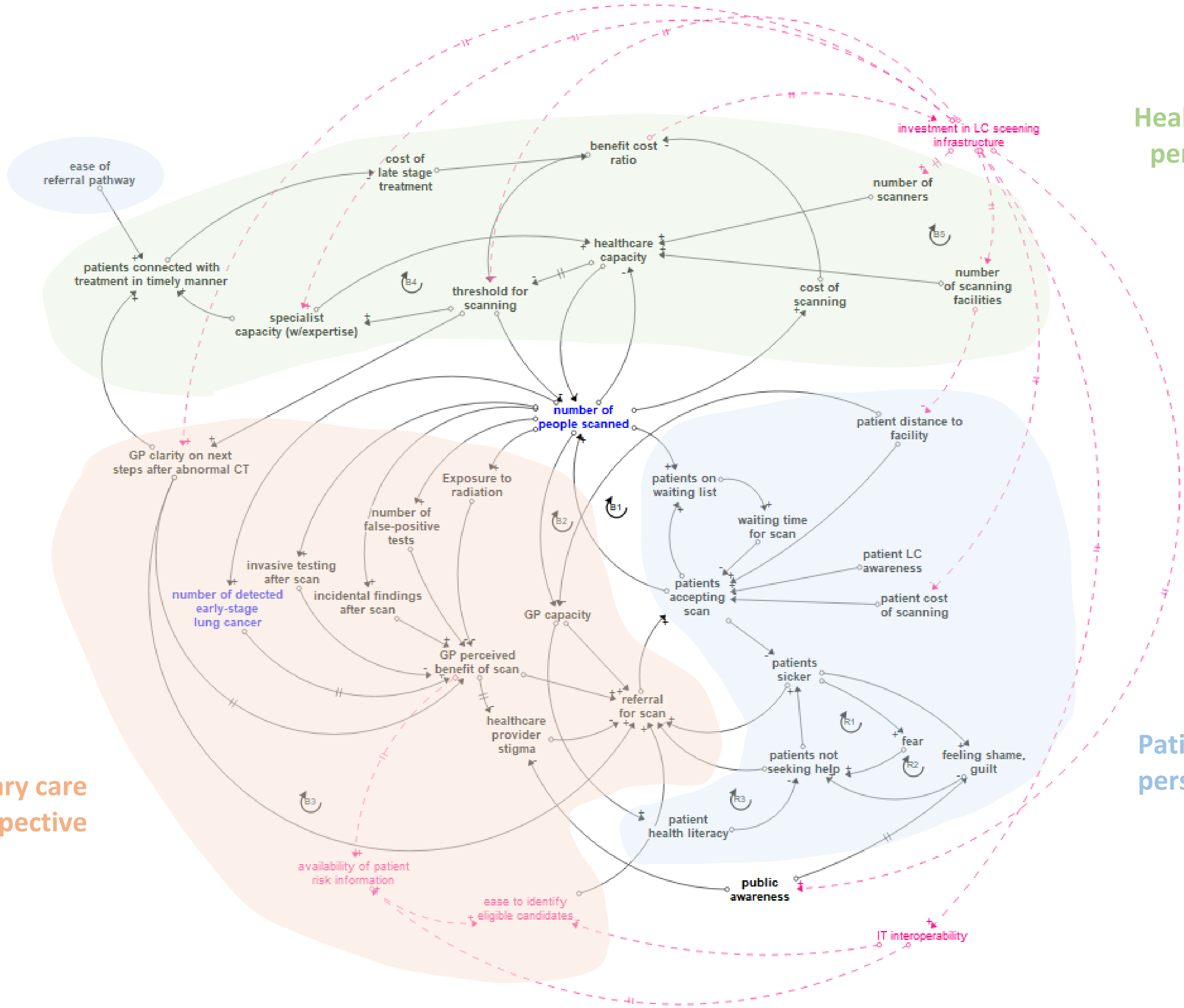

Table 1. Variables included in the causal loop diagram

Perspective	Variable
Health system perspective	• Healthcare capacity • Threshold for a LDCT • Specialist capacity with expertise in lung cancer • Patients connected with treatment in timely manner • Cost of late-stage treatment • Benefit cost ratio of lung cancer screening • Cost of scanning with LDCT • Number of LDCT scanners • Number of scanning facilities
Primary care perspective	• General practitioner (GP) capacity • Patient referral for a LDCT scan • GP perceived benefit of a LDCT scan • Healthcare provider stigma • Exposure to radiation • Number of false-positive tests • Incidental findings after a LDCT scan • Invasive testing after a LDCT scan • Number of detected early-stage lung cancer • GP clarity on the next steps after an abnormal LDCT scan
Patient perspective	• Patients accepting to receive a LDCT scan • Number of patients on waiting list • Waiting time for an appointment to receive a LDCT scan • Health literacy • Help-seeking behaviour • Fear • Feeling of shame and guilt • Patients' costs of getting a LDCT scan • Lung cancer awareness • Patient distance to scanning facility