A multi-method evaluation of a tailored referral pathway intervention to streamline the diagnostic pathway from GP presentation to specialist referral for people with suspected lung cancer diagnosis in northern Queensland.

Thesis submitted by

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For the degree of Doctor of Philosophy

In the College of Medicine and Dentistry

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Statement of the Contribution of Others

Contribution	Name and Affiliation
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Advisor- mentor supervisor	Professor Sarah Larkins, James Cook University
Advisors-secondary supervisor	Associate Professor Rebecca Evans, James Cook University
Research proposals & protocols	Advisory team as above
Data analysis and statistical advice	Advisory team as above with Dr Amy Brown, Townsville Hospital and Health Service
Scoping review – screening and data Extraction	Advisory team as above and Dr Amy Brown, Townsville Hospital and Health Service
Chart audit data collection	Advisory team as above, Dr Amy Brown, Dr Faisal Hayat and Dinuka Ariyarathna
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Clinicians' interviews	Advisory team as above, Dr Amy Brown, Ms Gail Kingston
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Chapter	Publication	Authors
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5	Otty Z, Brown A, Evans R, Larkins S, Sabesan S. Patient and carer experiences of lung cancer referral pathway in a regional health service, a qualitative study. Internal Medicine Journal 2023, 53(11).	ZO designed the study with help of SL, RE and AB. Recruitment, interviews and transcription were outsourced through a research grant. Thematic analysis was led by ZO, with input from SL, RE, and AB. ZO wrote the manuscript. All authors provided critical revision, editing and approved the final manuscript.
6	Otty Z, Larkins S, Evans R, Brown A, Sabesan S. Clinicians' Experiences and Perspectives about a New Lung Cancer Referral Pathway in a Regional Health	ZO designed the study with help of SL, RE and AB. Recruitment and interviews were conducted by ZO as well as partly outsourced through a research grant. Transcription was outsourced. Thematic analysis was led by ZO, with input from SL,

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Additional Publications During Candidature Demonstrating Research Capacity

- Sabesan S, Senko C, Schmidt A, Joshi A, Pandey R, Ryan CA, Lyle M, Rainey N, Varma S, Otty Z, Ansari Z, Vaughan K, Vangaveti V, Black J, Brown A. Enhancing Chemotherapy Capabilities in Rural Hospitals: Implementation of a Telechemotherapy Model (QReCS) in North Queensland, Australia. J Oncol Pract. 2018 Jul;14(7).

Conference presentations

- American Society of Clinical Oncology (ASCO) annual meeting, Chicago, 2024. Clinicians' experiences and perspectives of a web-based lung cancer referral pathway. J Clin Oncol 42,2024 (suppl 16; abstr e 1339)
- European Lung Cancer Congress, Prague, 2024. Otty Z et al. Improving timeliness of diagnosis of lung cancer patients through implementation of a web-based lung cancer referral pathway. March 2024, ESMO Open 9:102757, DOI:10.1016/j.esmoop.2024.10275
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List of Abbreviations

GP	General Practitioner
GPLO	General practice liaison officer
HCP	Health care professional
HPW	Health Pathway
HREC	Human Research Ethics Committee
JCU	James Cook University
MDM	Multidisciplinary meeting
NSCLC	Non-small cell lung cancer
NQPHN	North Queensland primary health network
OCP	Optimal care pathway
PI	Principal investigator
SCLC	Small cell lung cancer
SIF	Strategic Implementation Framework
THHS	Townsville Hospital and Health Service
TCC	Townsville Cancer Centre
TLCRP	Townsville lung cancer referral pathway
TUH	Townsville University Hospital

Abstract

Introduction

Lung cancer incidence and mortality are higher among people living in rural and remote areas and among Aboriginal and Torres Strait Islander peoples. Initial diagnosis by a GP and appropriate specialist referrals are critical steps in the care of people suspected of having lung cancer. Rural and remote Australians experience more delays than their urban counterparts due to reduced access to medical care and socioeconomic factors. Studies done in North Queensland had reported considerable delays in the diagnosis of people with suspected lung cancer. Therefore, we implemented an online referral pathway, Townsville Lung Cancer Referral Pathway (TLCRP) in 2019, to execute step two of the Cancer Australia lung cancer Optimal Care Pathway (presentation to GP, initial investigations and referral) in the Townsville Hospital and Health Service (THHS). The TLCRP was developed and refined through a co-design approach, after multiple meetings with lung cancer specialists and local GPs. After the final draft of TLCRP had been approved by the hospital administration, it was added to the Townsville HealthPathways portal.

HealthPathways is an online health information portal for GPs, to be used at the point of care. It provides information on how to assess and manage medical conditions, as well as how to refer patients to local specialists in a timely manner. This thesis was a quality improvement initiative, designed to evaluate the TLCRP. TLCRP is the intervention being evaluated and the thesis commenced nearly 12 months after the implementation of TLCRP.

Aim

The overarching aim of this thesis was to evaluate TLCRP after its implementation and explore the benefits and challenges to TLCRP users.

Following Mitchell and Chambers' Strategic Implementation Framework, this study set out to apply the third component of the Framework to evaluate (retrospectively) the impact of the intervention on meeting the timeframes/best-practice guidance of the Cancer Australia lung cancer Optimal Care Pathway (OCP) for step two, and to explore patient and health care provider (HCP) perspectives.

The following research questions guided this thesis:

1. What is known in the existing literature about the implementation and evaluation of optimal care pathways for people with lung cancer internationally?
2. Does implementing TLCRP improve the time interval between initial GP consultation to lung cancer specialist referral and from specialist referral to specialist consultation and other lung cancer OCP- recommended service outcomes for people with suspected lung cancer?
3. What are the experiences of TLCRP among lung cancer patients and their carers ?
4. What are the perspectives of clinicians regarding the use of TLCRP?

Methodology

This thesis employed a pragmatic multimethods design based on implementation science principles and, included four studies to answer the above research questions. A scoping

literature review was initially performed using Arksey and O'malley's approach, to document what is known about implementation and evaluation of a lung cancer OCP. Next, a retrospective cohort study of 316 participants was undertaken to evaluate system outcomes before and after implementing TLCRP. The cohort study compared pre-TLCRP implementation group (2016-2019) and post-TLCRP implementation group (2020-2023) on the following outcomes: Time interval from initial GP consultation of the person with suspected lung cancer to the first specialist referral and from the first specialist referral to initial specialist appointment, the proportion of participants seen in lung cancer specialist clinics within two-weeks of GP referral, proportion of participants whose first GP referral was to respiratory clinic, proportion of participants who had recommended imaging organised by the GP, and the median time interval from GP referral to first specialist clinic appointment for rural participants compared to those living in regional areas.

A qualitative descriptive study employing semi-structured interviews explored the experiences of lung cancer patients and their carers of TLCRP. The interview questions were open-ended, to explore patients' and carers' experiences of the lung cancer pathway from GP consultation to specialist appointment. The questions were mainly about their experience and difficulties faced during the lung cancer diagnostic pathway. Likewise, semi-structured interviews of GPs and lung cancer specialists were conducted to explore their perceptions of the TLCRP and included questions about their awareness and use of TLCRP, its benefits, and barriers to using TLCRP. In both qualitative studies, an iterative inductive thematic analysis was undertaken to derive key codes and themes. Finally, the results were integrated using the third part of the Strategic Implementation Framework (SIF). The COM-B framework was introduced post-study as an explanatory

framework to discuss the possible interventions that can be used to increase uptake of TLCRP.

Results

The scoping review revealed information on lung cancer optimal care pathway implementation in several developed countries, including Australia. Thirty-one articles were included, with varying outcomes, covering topics such as the development and implementation of OCPs, using quality indicators to audit OCPs, and studies on timeliness of care delivery, patient experiences, health care utilisation and costs.

The cohort study found that implementing TLCRP significantly reduced the time interval between patients' initial GP presentation and the initial specialist referral from 15 to eight days (p=0.03). However, TLCRP had minimal impact on achieving other lung cancer OCP recommendations. Although the results may have been affected by the COVID-19 pandemic, only 40% of the pre-TLCRP group and 34% of the post-TLCRP group were seen in the specialist clinic within two weeks of GP referral (as is recommended by the TLCRP). A significant proportion of patients in both groups did not have a chest X-ray done by the GP, and the proportion of patients who were appropriately referred to a respiratory clinic did not improve after implementing the TLCRP. Implementing TLCRP did not reduce the percentage of lung cancer patients diagnosed via the emergency route.

Patient and carer (n=19) experiences of the lung cancer pathway revealed several vital themes, including quality of communication, distress due to delays and the importance of patient advocacy and adequate psychosocial support. Good communication, timeliness and patient advocacy and support positively impacted the care experience. Sub-optimal

communication, long waiting times for investigations and appointments, uncertainty about the process and inconsistent advice from providers negatively impacted the care experience. Participants preferred face-to-face or video-linked consultations over audio-only telephone consultations while on the referral pathway.

Semi-structured Interviews with GPs (n=14) and lung cancer specialists (n=6) regarding their perceptions of TLCRP identified several enablers and barriers to TLCRP uptake. Enablers of TLCRP adoption included the timely education and training of GPs, the usefulness of TLCRP in patient management and the presence of technical support in using TLCRP. Barriers to TLCRP adoption included lack of clinical time, resistance to changing existing referral patterns, lack of familiarity or experience with Health Pathways (HPWs) as a tool and technology issues.

Finally, the findings from these four studies were integrated using the third part of the SIF and the COM-B as an explanatory framework. Several strategies and interventions were then formulated for improving the uptake and sustainability of TLCRP.

Conclusion

Implementing TLCRP reduced the time interval from initial GP presentation to specialist referral. Clinicians' experiences using TLCRP were largely positive, but patient and caregiver interviews suggested areas for improvement in the TLCRP. Although most are aware of the benefits of TLCRP, its uptake among GPS could be further improved.

This health service project fills a knowledge gap regarding lung cancer referral pathway in a regional health service in Australia. Knowledge gained from this project has the potential to help implement remaining components of a lung cancer OCP (steps 3 to 7 of

the OCP) , and thereby, further improve lung cancer patient outcomes. The sustainability of TLCRP and other HPWs in THHS requires ownership and oversight by system leadership and clinical governance involving all end-users.

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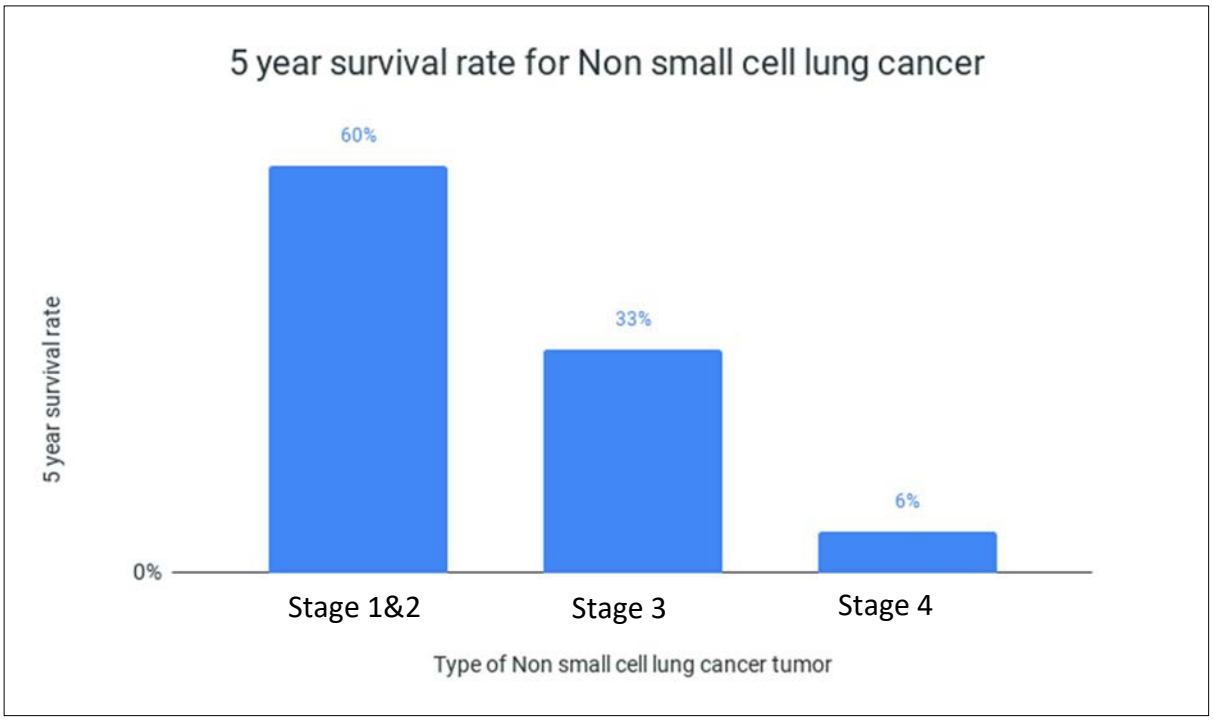
Chapter 1. Introduction

Lung cancer is the leading cause of cancer-related death worldwide and often presents at an advanced stage. [1, 2] In 2020, the Global Cancer Observatory (Globocan) estimated 2.5 million new cases of lung cancer and 1.8 million lung cancer-related deaths worldwide.[3] Its high mortality rate is a result of both a high incidence rate and low survival. The median age at lung cancer diagnosis is 70 years, and many of these patients suffer from other medical comorbidities. [4] Due to a lack of specific symptoms and delayed diagnosis, around 80% of patients with lung cancer are incurable at presentation.[5] Many of these patients are too unwell to have any treatment by the time of diagnosis due to poor functional status. [6-8] There are two main types of lung cancer: non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). NSCLC accounts for about 85% of all lung cancers, while SCLC accounts for about 15%. The treatment and prognosis of lung cancer depend on the stage at presentation as well as the morphology of the tumour. The prognosis of lung cancer can be improved by early diagnosis and treatment, which improves the quality of life, survival rates, healthcare costs, and decreases complications.[9-11]

Based on the radiological extent, there are four clinical stages: Stage 1 being the earliest and Stage 4 being the most advanced. [12] Stages 1 and 2 (localised disease) can be treated with surgical resection, Stage 3 (regional disease) is treated with radiation plus chemotherapy and Stage 4 (distant metastases) is treated with systemic therapies. Five-year survival drops from 66% in Stage 1 NSCLC to 6% in Stage 4 NSCLC and from 30% in Stage 1 SCLC to 3% in Stage 4 SCLC (Figure 1.1). [13]



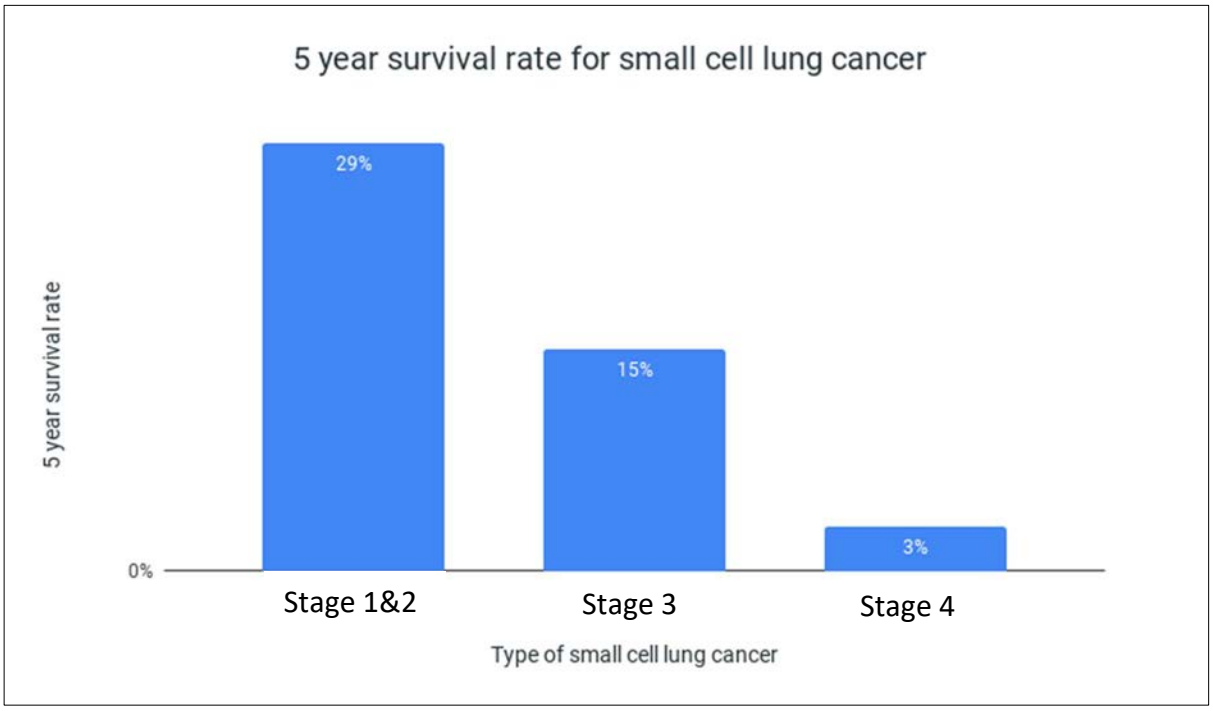


Figure 1.1 Five-year survival by type of lung cancer and stage of lung cancer.

The patient journey of a person with lung cancer in Australia is complex and most frequently starts when they present to the General Practitioner (GP) with symptoms (Figure 1.2). The GP clinically evaluates the person and organises necessary investigations. If lung cancer is suspected, the GP refers the person to a lung cancer specialist, usually a respiratory physician. Depending on the presenting symptoms, the GP may refer the person to other specialists, such as general physicians or surgeons. The specialist does further investigations to confirm the lung cancer diagnosis and stage. After diagnosis and staging are completed, the best practice suggests that lung cancer specialists discuss patient management in a multidisciplinary meeting (MDM) and that appropriate referrals be made for patient treatment. The referral to appropriate specialists for treatment usually denotes the completion of the diagnostic and referral pathway.

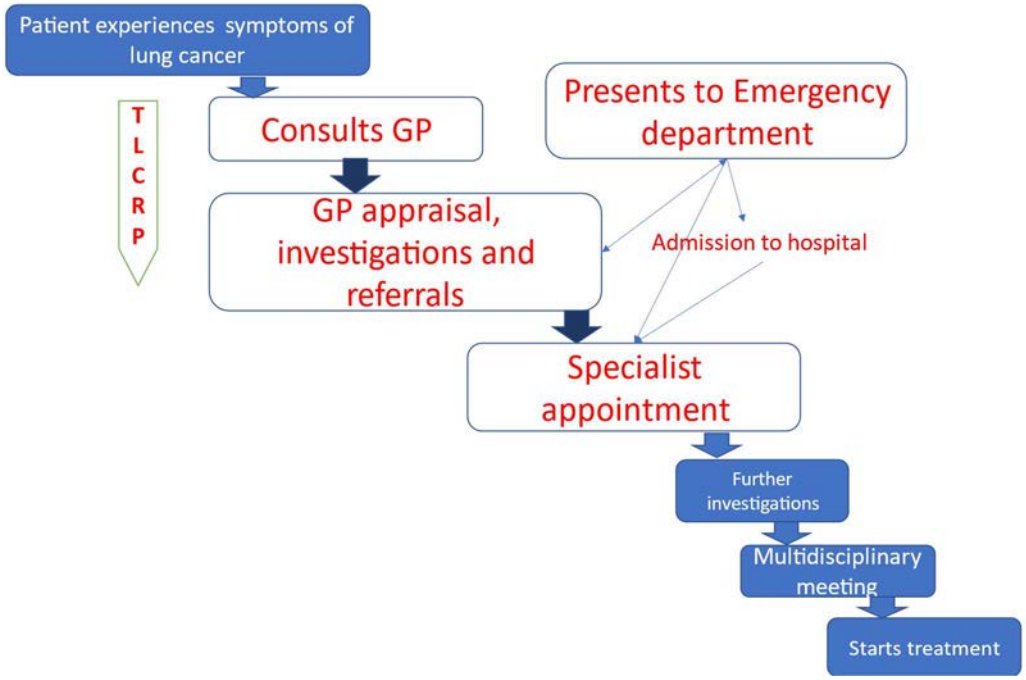


Figure 1.2 The usual diagnostic pathway for a person suspected to have lung cancer in North Queensland.

Diagnosis, staging and treatment of lung cancer require highly skilled practitioners from various specialities. [14] Different types of clinicians are often needed at different phases of patient care, including medical practitioners, nurses and allied health staff. Sometimes, GPs may have misinterpreted the symptoms of lung cancer as those of other lung diseases, thereby prolonging the time to diagnosis.[15] In some instances, GPs may incorrectly refer the person to an oncologist or thoracic surgeon without proper diagnosis. Referral to the wrong speciality can result in unnecessary investigations, and the specialist may have to refer the person to yet another department , resulting in additional delays.[9, 10, 16] Diagnostic processes of lung cancer can be lengthy, and patients often have to consult multiple healthcare providers before receiving a lung cancer diagnosis.[17, 18] Lack of communication and coordination between various specialities is also a barrier to optimal care.[19] As a result of a lack of communication and co-ordination, and lack of a regular GP, people with potential lung cancer in rural and remote areas frequently experience fragmented healthcare journeys and can experience poor continuity of care.[18, 20 21] A study done in South Korea found that people who live in rural areas are more likely to experience fragmentation of lung cancer care.[20]

While there are 'usual referral patterns' (figure 1.2), there can be many variations in the referral pathway of a person with suspected lung cancer. The variation from optimal referral pathways is more common for rural and remote patients.[22] A large proportion of lung cancers (around 35%) are diagnosed following an emergency admission with severe symptoms or are identified incidentally through routine appointments with other specialists. [23] Patients who are diagnosed after emergency admissions have a worse prognosis compared to patients who are diagnosed by a GP, likely due to prior poor health

status and functional capacity of these patients. [23] [24] Patients who present to the emergency department may be discharged back to their GP or admitted to the hospital. During hospital admission, depending upon the presenting symptoms and results of initial investigations, the patient is referred to appropriate specialists. If lung cancer is suspected, the patient is often referred to a specialist in respiratory medicine. Lung cancer incidence and mortality are higher among people living in rural and remote areas and among Aboriginal and Torres Strait Islander peoples (hereby respectfully referred to as Indigenous Australians). [22, 25-28] Indigenous Australians have a higher likelihood of diagnosis at a later stage of cancer and a lower likelihood of receiving treatment. [25] Initial diagnosis by a GP and appropriate specialist referrals are critical steps in the care of people suspected of having lung cancer [29], and many studies in Australia and overseas have shown delays in these steps. [14, 21, 30] Rural and remote Australians experience more delays than their urban counterparts due to reduced access to medical care and socio-economic factors. [22, 31, 32] Delays in the diagnosis and treatment of lung cancer can lead to reduced survival and increased distress for patients.[33-35] There are several deficiencies in the diagnostic and referral pathways of people with suspected lung cancer in north Queensland, including delays in care, incorrect specialist referrals and inadequate psycho-social support for these patients.[36] Incorrect specialist referrals lead to duplication of investigations, inappropriate management and increased healthcare costs.[37]

The inefficiencies in coordination and integration of primary and secondary care services for lung cancer increase the burden of disease-related costs to both the patient (e.g. financial costs, anxiety) and the health budget (e.g. preventable visits to emergency departments and specialist services).[38-40] Specialist referrals for benign lung nodules may unnecessarily use valuable lung cancer clinic slots that could delay the diagnosis of a person with lung cancer.

Other studies have found that healthcare providers do not often use available clinical guidelines due to several factors, such as guideline duplication, inconsistent recommendations, and lack of adequate communication about the guideline.[41] Incorporating local guidelines into online-based localised clinical decision support tools can improve patient care by improving the quality of GP referrals, decreasing specialist clinic wait times by reducing inappropriate referrals and adequate pre-referral investigations organised by the GP. [42, 43] These, in turn, may improve patient outcomes, improve quality of life, and produce efficiencies and savings for health systems.

How the clinical practice guidelines are implemented into daily practice needs to be measured to be able to identify areas for quality improvement and address barriers to care.[44] Quality standards have been proposed for lung cancer management in Australia and internationally.[45-48] These quality indicators can be used to monitor and evaluate various aspects of quality of health care services received by lung cancer patients in daily practice. Optimal referral pathway for lung cancer involves a GP referral to a respiratory physician within two weeks of initial presentation, after completing all necessary investigations, followed by a respiratory clinic appointment within two weeks.[24]

Efficient and streamlined referral of a person with suspected lung cancer is an integral part of providing optimal care for lung cancer patients.[49] The gaps in service provision of people with suspected lung cancer in Australia have led to calls for more integrated care and more efficient alignment between specialist care and primary care. Stemming from this, Health Pathways (HPWs)[50] and Optimal Care Pathways (OCPs) attempt to improve the quality of care by encouraging standardised care in routine practice. [51] Health Pathways deal with the initial part of a disease pathway that occurs in the primary care setting and are useful for

referral to specialist care. Optimal Care Pathways , on the other hand, provide an overarching framework for the delivery of high-quality, evidence-based care for people with cancer.[24 52]

To reduce disparities in care and improve outcomes for people with lung cancer, Cancer Australia has published a lung cancer Optimal Care Pathway (OCP), which outlines the critical steps and recommended timelines in a lung cancer patient's journey from initial diagnosis to treatment.[24] Step two of the lung cancer OCP deals with appropriate primary care investigations and specialist referral.

Previous studies have reported considerable delays in the primary care component of the lung cancer diagnostic pathway in Australia. [36, 53-55] Given the geographical challenges in accessing care in THHS, the referral component of the lung cancer OCP was the initial focus in implementation. We designed and implemented an online HPW, Townsville Lung Cancer Referral Pathway (TLCRP), to execute Step Two of the Cancer Australia Lung Cancer OCP in the Townsville Hospital and Health Service (THHS). The doctoral project described in this thesis began nearly 12 months after the implementation of TLCRP. The TLCRP is the intervention, and it is the focus of evaluation for this PhD project.

Optimal Care Pathways for Lung Cancer

Integrated care focuses on seamless, coordinated health services that meet a person's needs across various settings and providers, often involving primary, specialist, and community care.[56] An OCP is an example of integrated care for a specific illness.

The Cancer Australia Lung Cancer OCP[24] outlines the critical steps in a patient's journey from prevention and early detection to post-treatment follow-up, to promote quality cancer care

and improve patient experiences. The key objectives of this OCP for lung cancer include patient-centred care, safe and quality care, multidisciplinary care and improved coordination and communication[36]. Similar lung cancer OCPs have been implemented in other countries.[52] As described in Figure 1.3, Cancer Australia lung cancer OCP has several components, including primary prevention, early detection, initial evaluation, specialist referral, diagnosis, staging, treatment, and follow-up care. OCP guidelines often also include palliative and supportive care for people with advanced lung cancer.

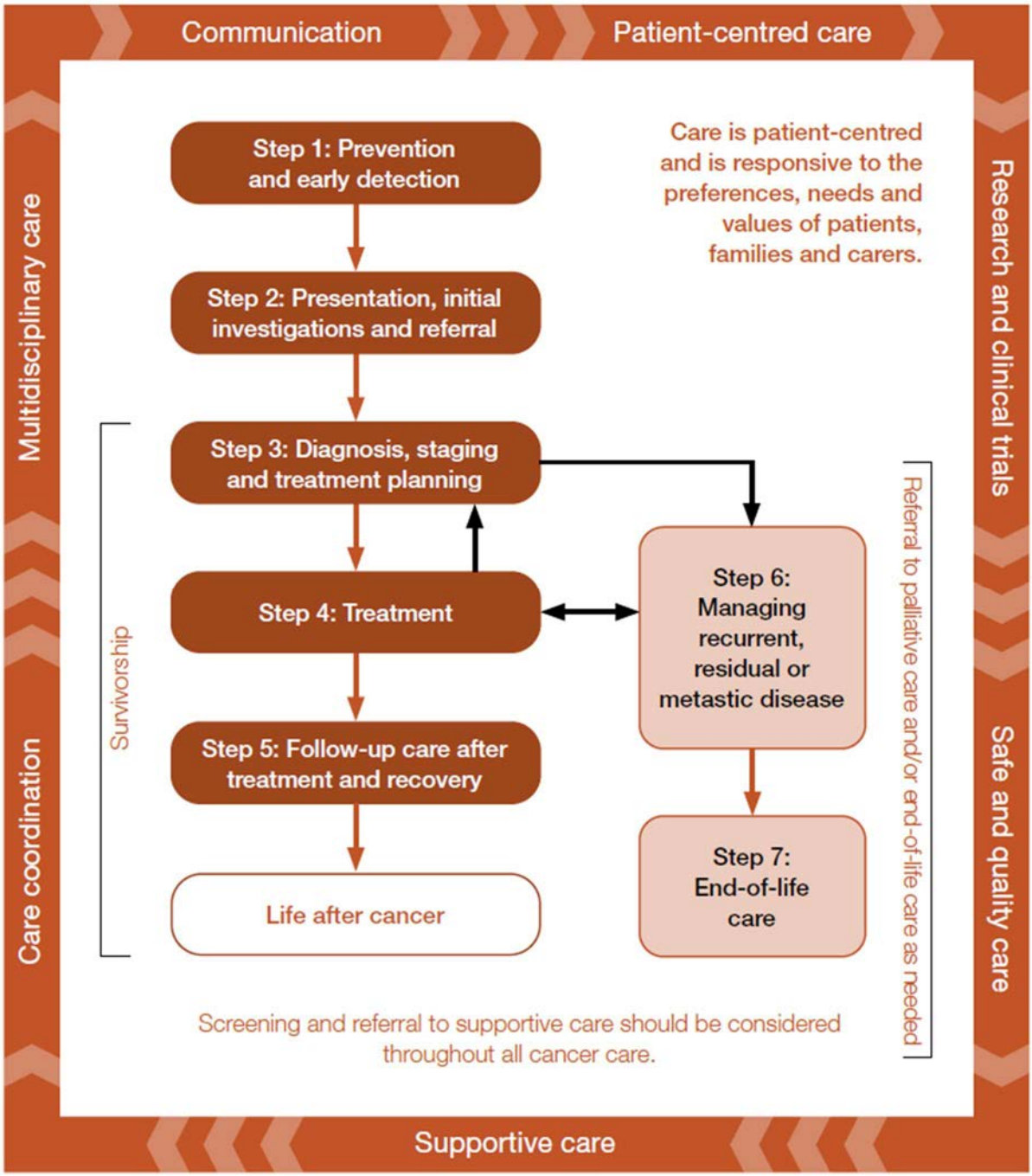


Figure 1.3: Summary of Cancer Australia lung cancer OCP.[24]

The initial phase of the lung cancer OCP is in the primary care setting, starting when the patient presents to the GP with symptoms of lung cancer (Figure 1.3). This phase of lung cancer OCP can be implemented using an online HPW. Research elsewhere has demonstrated that optimal care pathways, including lung cancer OCP, can improve outcomes, reduce waiting times for diagnosis and treatment and improve survival.[57-59] For

example, in Denmark, the introduction of care pathways for lung cancer may have resulted in an increase in three-year survival for people with the disease.[60]

Table 1.1: Cancer Australia Lung Cancer OCP recommendations for the management of a person with suspected lung cancer in primary care.[24]

Steps in the pathway	**Care point**	**Timeframe**
Presentation	Signs and symptoms	Prompt triaging
Investigations	Initial investigations by GP, including chest X-ray and CT chest.	Test results are conveyed to the patient within one week of presenting to the GP and referral to the lung cancer specialist in 2 weeks.
Referral	Referral to lung cancer specialist	Specialist appointment should take place within two weeks of GP referral

Lung cancer management in Townsville Hospital and Health Service

THHS serves a large geographical area of about 150,000 square kilometers in northern Queensland, Australia, with considerable rural, remote and Indigenous populations.[61] The average number of new lung cancer cases diagnosed in the THHS catchment is 161 per year and about 111 patients die from the disease each year. [61] North Queensland has a higher incidence and mortality from lung cancer compared to the state or national average.[26] The higher incidence of lung cancer is likely due to the increased prevalence of risk factors for developing lung cancer, like tobacco use. Higher mortality from lung cancer is associated with reduced socio-economic conditions and poorer access to appropriate health care for

rural, remote and Indigenous communities. [62, 63] There is a shortage of specialist clinicians and a lack of adequate diagnostic facilities for nuclear medicine scans and bronchoscopy, so people with possible lung cancer must travel long distances for diagnostic investigations and medical treatments.[36, 64, 65] Although incorporating new technologies like telehealth has facilitated improvements in healthcare provision by THHS, it is still behind in meeting several target lung cancer outcomes.[64] Indigenous Australians often have a high incidence of medical comorbidities associated with lower socio-economic status.[25] Lower accessibility, acceptability and utilisation of health care make it more challenging to implement health pathways like TLCRP for Indigenous Australians.[66]

As is common practice in Australia, GPs in the Townsville region refer people with suspected lung cancer to specialist clinics in Townsville University Hospital (TUH), the only tertiary hospital in the region. Some patients must travel thousands of kilometers to attend specialist clinics at TUH. A previous study from our department found that lung cancer patients who lived in rural areas experienced delays in the time from symptom onset to treatment and the time from seeing a GP to seeing a specialist, compared to best practice guidelines.[36] Competing priorities of family and work, and the cost and inconvenience of travel, were perceived as barriers to accessing timely care by rural patients.[36]

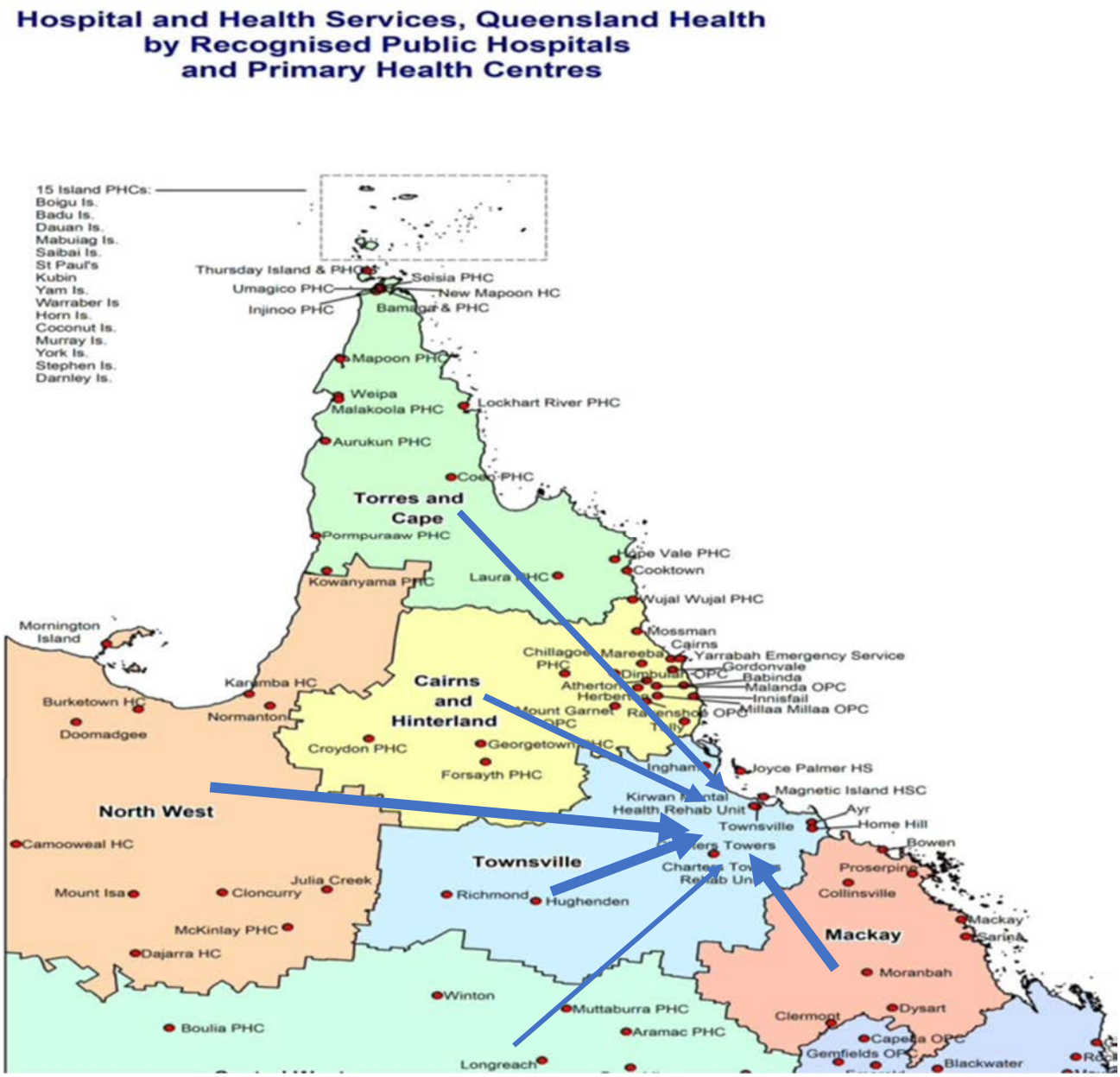


Figure 1.4: Map of North Queensland Health Services.(Arrows depict referral pathways for people with lung cancer to Townsville University Hospital from North Queensland Health Services).

HealthPathways

The HealthPathway framework was used to inform and guide the implementation of TLCRP. 'HealthPathways' is an online health information system developed in Canterbury, New Zealand (NZ)[67] to promote healthcare integration and reduce service fragmentation and demand on specialists. These improvements have been achieved by providing best-practice, evidence-based information relevant to the local region to primary care providers through an online portal.[38] The success of the Canterbury HPW was also due to clinicians of different specialities in primary and secondary care co-designing the pathways at the local and regional level. [38] This clinical information assists healthcare providers in more effectively coordinating patient care between primary, secondary, and community health services. [68] HPWs have been developed for over 550 disease conditions and are localised to health regions by multidisciplinary teams of health professionals. Engagement across the hospital–community spectrum creates opportunities for service improvement, system optimisation, and reform. In some places, GPs have recognised the challenges of keeping their clinical practice current with evidence-based guidelines and value the content of HPWs, increasingly using these as their first source for clinical point-of-care information. [69]

General practices in the health service region use an electronic referral system called Smart Referrals to refer patients to specialist clinics in the public hospital. The HPWs Townsville web portal is partly integrated within the Smart Referrals platform. Whenever a GP makes an electronic referral for a person with suspected lung cancer for specialist care, the TLCRP site can be opened, which prompts the GP to do recommended investigations prior to making the referral.

Studies evaluating various aspects of HPWs have been published in a small number of developed countries, including Australia. [38, 41, 50, 60, 67, 68, 70-84] However, no studies have specifically looked at lung cancer referral pathways. The use of HPWs is associated with improved referral quality from primary care, more timely access to secondary care and standardisation of clinical management decisions by GPs. [38, 70, 85] HPWs align with a move towards developing and implementing integrated care pathways as best practice, [57, 86, 87] and over the last few years, there has been an increase in awareness and use of HPWs in Australia and New Zealand. [41, 79, 82] Increased awareness of the pathways amongst clinicians was identified as essential to improving the uptake of HPWs in Australia.[67, 74]

Some of the barriers to implementing HPWs included a lack of integration with existing GP systems, the inability to make electronic referrals within the system and the demanding work schedules of GPs and specialists. [41, 79] Other studies have reported attitudes, behaviours, and deeply ingrained clinical routines of clinicians as barriers to the uptake of HPWs. [67, 88] On the other hand, facilitators for uptake of HPWs included endorsement by opinion leaders, senior management support, appropriate content, accessibility at the point of care and an increase in acceptance of referrals by specialists if pathways were used. [41, 75, 83] Implementation of HPWs has also been shown to reduce the cost of service, [72] improve primary care management, [74] reduce hospital admissions, [77] improve patient satisfaction and improve survival. [57] The benefits of using HPWs accrue to patients through more personalised and comprehensive care and to clinicians through building relationships between GPs and hospital specialist colleagues. [38] The local context is an important consideration in designing HPWs. [71]

Some ongoing monitoring and review occur automatically with new HPWs, including TLCRP. The Townsville University Hospital GP-link team monitors the web traffic for usage of each health pathway. Various methods have been used elsewhere to evaluate the awareness of HPWs; one study compared pre- and post-data to evaluate the change in awareness of HPWs over time [85], and another study used a mixed methods approach. [89] Google Analytics was the most common data source for analysing usage patterns, such as the number of users per month and the number of times visited. Other methods used to evaluate awareness and use of HPWs were online surveys and telephone surveys. Participants in these studies were mainly GPs, with the remainder comprising specialists, practice nurses and allied health staff.

The current status of HPWs in Queensland, Australia

Queensland State Health Department has implemented HPWs throughout the state. HPWs are used as the point-of-care clinical practice guideline for GPs in the management and specialist referral of various medical conditions [72, 90]. Clinical Prioritisation Criteria (CPC) are embedded into HPWs. CPCs are clinical decision support tools that help ensure that patients referred for public outpatient services in Queensland are assessed according to clinical urgency. If a clinical condition is part of the CPC, all GPs in Queensland are encouraged to use HPWs. CPC ensures that referrers to Queensland public specialist outpatient services can access evidence-based, condition-specific referral requirements. The implementation of CPC relies on strong partnerships between the Primary Health Network (PHN) and the Hospital and Health Service (HHS) of each area.

The current status of HPWs within THHS

The Townsville University Hospital GP Liaison Officer (GPLO) facilitates system integration between the hospital and primary care services in the Townsville Hospital and Health Service (THHS). The GPLO supports integrated health systems, including GP 'Smart Referrals' and HPWs. As part of a Queensland Government initiative to improve health care in the region, an HPWs portal, *'townsville.communityHealthPathways.org',* was created and has been made available to all the health professionals in THHS since 2014. This online portal is designed to help local GPs guide patients through the complex local health system. It provides support in assessing and managing patients in the community, with a clear referral pathway to secondary care services at TUH (where required). A team of GPs and support staff (GP-link team) supervise the development of content and the education of GPs, promoting the uptake of appropriate health pathways.

Design and implementation of Townsville Lung Cancer Referral Pathway (TLCRP)

Given the high rates of morbidity and mortality from lung cancer in the region, there is potential for improving patient outcomes with more efficient and coordinated services for diagnosing lung cancer.

Townsville Lung Cancer Referral Pathway

Background
*About lung cancer**

Assessment-
Consider lung cancer if: *risk factors**

Investigations

*Red flags**

If risk factors or possible signs of lung cancer, arrange chest X-ray.

Consider blood tests – FBC, E/LFT, calcium.

Indications for a CT chest with contrast*

Management

1. If any red flags, request *acute respiratory assessment* (with CT chest with contrast arranged if it doesn't delay referral).
2. If a likely primary pulmonary nodule is visible on chest X-ray or CT scan, *request non-acute respiratory assessment* (mark as urgent) for tissue diagnosis and staging.
3. If a tissue biopsy confirms lung cancer and CT chest shows a lung mass, request *non-acute cardiothoracic surgery assessment .*
4. If consolidation seen on chest X-ray, treat as pneumonia and repeat imaging
5. If any solid nodule < 6 mm present in patient with risk factors , repeat CT chest with contrast in 12 months.

Follow-up

1. Ensure appropriate follow-up, including monitoring of the status of the disease, detection of any metastatic disease, and management of symptoms
2. At each consultation, consider symptoms of possible recurrence or metastases.
3. Provide ongoing support of patient and family and psychosocial management throughout the course of cancer treatment and after.
4. Consider Cancer Support Services.
   Consider Advanced Care Planning (ACP).

Figure 1.5: Summary of TLCRP

To improve the diagnostic pathway of people with suspected lung cancer, TLCRP was added to Townsville Health Pathways in August 2019 (Figure 1.5). A detailed version of TLCRP is available in Appendix 1. TLCRP contains information for GPs to appropriately manage and refer a person with suspected lung cancer. Townsville Lung Cancer Referral Pathway was developed and refined through a co-design approach, loosely based on Canterbury HPWs approach. [75] Activities in the design phase of TLCRP included group discussions involving lung cancer specialists during regular lung cancer multi-disciplinary meetings (MDTs) at TUH over a period of six months in 2018-2019. During an educational event for local GPs, we obtained feedback about the current lung cancer pathway in THHS and how this could be improved. These meetings provided information about deficiencies in the existing lung cancer referral pathway in the region and content to be included in the TLCRP. An initial draft of the TLCRP was created based on lung cancer referral pathways used in other Queensland Health services. Subsequently, we refined the pathway to suit the local context, incorporating the feedback already received and added a section on management of lung nodules. The GP-link team then revised this further and the final version of TLCRP was sent out to all the involved clinicians.

Promotion of TLCRP among GPs

The TUH GP Liaison Officer (GPLO), TUH GP- link team and the North Queensland Primary Health Network (NQPHN) supported the implementation of TLCRP. As with other Townsville HealthPathways, an agreed-upon date for implementation was established, along with an implementation and communication plan. The TLCRP is available on HPWs Townsville web portal, *townsville.communityhealthpathways.org* and can be accessed by all clinicians in the THHS area, to guide appropriate investigations and referrals for people with suspected lung

cancer (Appendix 1). The website is embedded in the electronic referral platform, Smart Referrals, which is used by GPs to refer patients to hospital specialists. It can also be downloaded as an app for use in smart phones. TLCRP contains information guiding GPs on investigations to do prior to referral, which specialist to refer to, as well as links to information on smoking cessation, supportive care and patient information websites.

GPs were informed about TLCRP through emails, flyers and updates on HPWs Townsville website. Engagement with the GPLO and advertising through NQPHN publications, particularly regular email newsletters, were done to inform GPs about the pathway. Specialist clinicians and other health care workers who are involved in the management of people with potential lung cancer were also informed about TLCRP during the lung cancer MDTs and through emails.

Individual HPW usage can be monitored by measuring web traffic, including total views. Data from TUH GP-liaison officer shows that use of TLCRP has increased over time, with total views increasing from 68 in 2020 to 138 in 2024 (personal communication). If any new information on lung cancer pathways becomes available, TLCRP will be revised through a regular monitoring and updating. Clinicians can also provide feedback about TLCRP to the GP-link team.

Implementation science framework

Implementation science focuses on understanding and integrating research findings into everyday practice settings to improve healthcare [91]. Implementation science in healthcare has been defined as 'the scientific study of methods to promote the systematic uptake of clinical research findings and other evidence-based practices into routine practice, and,

hence, to improve the quality and effectiveness of health services'(page 1). [92] There are several different categories, models and frameworks in implementation science. [93] Guidelines exist to guide specific types of implementation research. [94] For this project, the 'Strategic Implementation Framework'(SIF) was adopted, as first proposed by Mitchell and Chambers, as an implementation strategy design proposed explicitly for use in oncology settings. [95] The SIF arranges agreed implementation strategies along the continuum of change, firstly setting the stage and moving to active implementation and then to monitoring and supporting.

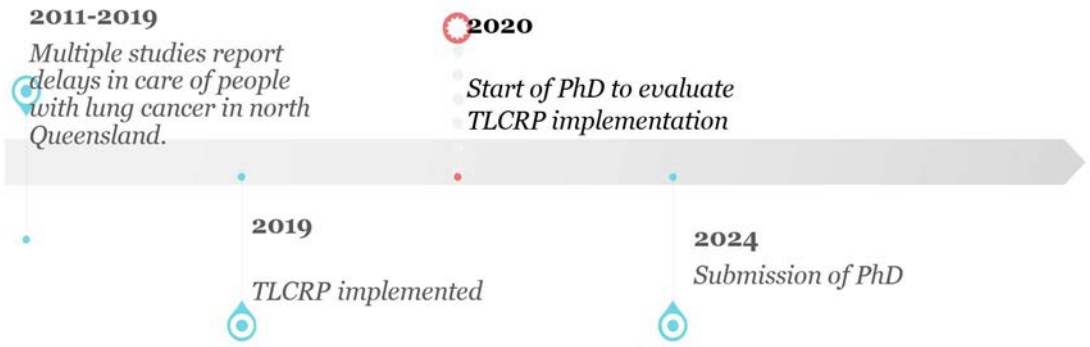
COM-B behavioural change framework

The COM-B framework was introduced post-study as an explanatory framework for the findings of this health services research. Implementation of evidence-based practices like the TLCRP depends on successful behavioural change interventions. Given the findings from this research on barriers to uptake of TLCRP, the COM-B model for behavioural change was thought helpful to apply to the findings as it cites capability, opportunity and motivation as three key factors in changing behaviour.[96]

Thesis Overview

The overarching aim of this thesis was to evaluate TLCRP after its implementation and explore benefits and challenges to TLCRP users. Following Mitchell and Chambers' Strategic Implementation Framework[95], this thesis set out to apply the third component of the Framework to retrospectively evaluate the impact of the intervention on meeting the timeframes and best-practice guidance of the Cancer Australia Lung Cancer OCP for Step 2, and to explore patient and HCP perspectives.

Figure 1.6: Timeline of processes leading up to the PhD



The project evaluated the implementation of the TLCRP on evidence- informed "events" (e.g. timeliness of referral) along the referral pathway. The scoping review findings then informed the specific targets and approaches. Our initial plan was to implement all of Cancer Australia's lung cancer OCP in THHS; hence, a scoping review on lung cancer OCP was conducted. However, because there was evidence of impact from using the HPW approach to strengthen the GP-hospital interface, we decided to change the aim of the PhD project to evaluating TLCRP. This PhD was a quality improvement project to identify problems in the implementation of TLCRP, implement changes and measure the impact of changes to improve lung cancer patient outcomes, processes and clinician experiences.[97]

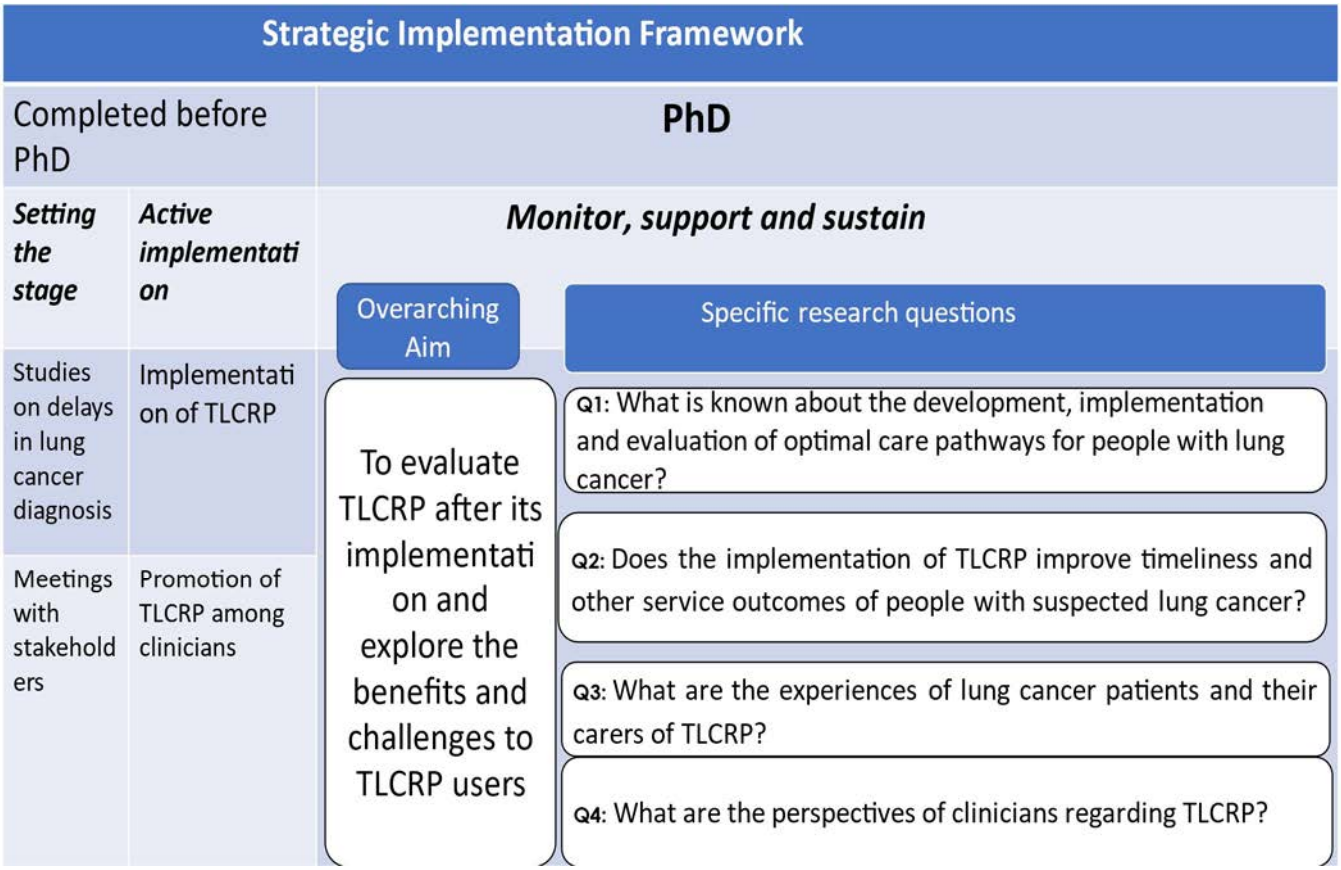


Figure 1.7: The overarching framework including the processes leading up to PhD and content of the PhD.

The thesis is divided into four studies which were undertaken to answer the following questions:

Question 1. What is known in the existing literature about the implementation and evaluation of optimal care pathways for people with lung cancer internationally? A scoping literature review on lung cancer optimal care pathways was conducted and published (Chapter 2). We included optimal care pathway development and implementation in the scoping review, to better understand the foundations of these pathways, even if this is outside of the scope of the thesis.

Question 2. Does implementation of TLCRP improve the time interval between initial GP consultation to lung cancer specialist referral and from specialist referral to specialist

consultation and other lung cancer OCP- recommended service outcomes for people with suspected lung cancer?

This quantitative study was done in order to understand service outcomes following implementation of TLCRP, by comparing the time interval from initial GP consultation of the person with suspected lung cancer to the first specialist referral (T1) and from the first specialist referral to initial specialist appointment (T2), before and after implementation of TLCRP. Other clinical outcomes that were compared were the proportion of participants seen in lung cancer specialist clinics within two-weeks of GP referral, proportion of participants whose first GP referral was to respiratory clinic, proportion of participants diagnosed via emergency admission route, proportion of participants who had recommended imaging organised by the GP, and the median time interval from GP referral to first specialist clinic appointment for rural participants compared to those living in regional areas. Retrospective data collection was necessary for the pre-TLCRP implementation group (2016 to 2019). The data from the post-TLCRP implementation group (2020 to 2023), was collected prospectively in 2023.

Question 3. What are the experiences and perceptions of the TLCRP of lung cancer patients and their carers?

Since it was essential to explore patient and carer experiences of the lung cancer pathway, we did a qualitative study using semi-structured interviews three years after the implementation of TLCRP (2022).

Question 4. What are the perspectives of clinicians on the acceptability and effectiveness of TLCRP?

Finally, we had to document the perspectives of local GPs and lung cancer specialists about the TLCRP. This qualitative study explored these health professionals' viewpoints on TLCRP and its impact on patients' quality of care and was conducted two years after the implementation of TLCRP (2021). Four studies answered these questions and are presented in the chapters outlined in Figure 1.6. Chapters 2, 5, 6, and 7 represent a manuscript, as per JCU Thesis by Publication guidelines. Findings from these studies will be integrated and used to inform subsequent improvements in TLCRP and the care of people with potential lung cancer in North Queensland.

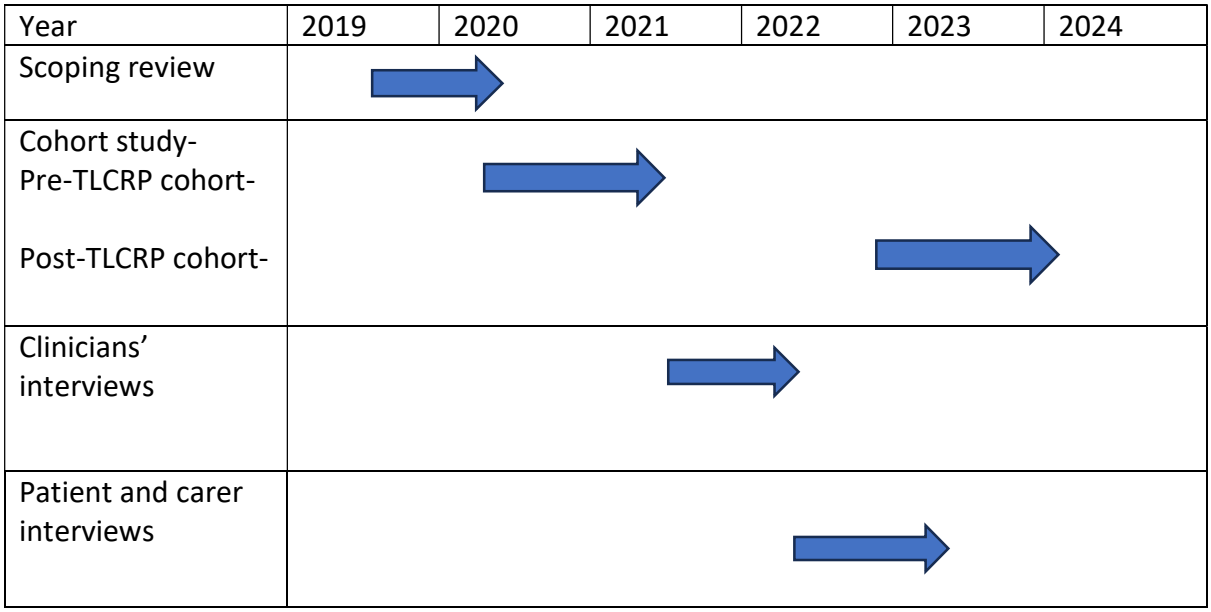


Figure 1.8: Timelines for the thesis

Introduction to thesis chapters

Chapter 2: Scoping review of literature

Note: This study was published in the International Journal of Integrated Care. [52]

A scoping review was undertaken to assess the extent of published literature regarding optimal care pathways for lung cancer and to inform subsequent studies.

Chapter 3: Methodology and methods

Since the project used multiple methods and approaches, this chapter describes the details of each study's methodology and methods and ethics approval process. The Strategic Implementation Framework is used to frame these.

Chapter 4: Effect of TLCRP implementation on service outcomes

Note: This study was published in the Internal Medicine Journal.[98]

This retrospective cohort study was conducted to analyse whether timeliness and other clinical outcomes for people with lung cancer improved after the implementation of TLCRP. This analysis gave us data on the state of the lung cancer pathway over two time periods and information on what needs to be done to improve it in the future.

Chapter 5: Patients and carers' experiences and perceptions of TLCRP

Note: This study was published in the Internal Medicine Journal. [37]

We conducted this qualitative study in order to explore the experiences of lung cancer patients and their carers of the current lung cancer referral pathway.

Chapter 6: Clinicians' perspectives on acceptability and effectiveness of TLCRP

Note: This study was published in the International Journal of Integrated Care. [99]

Next, a qualitative study using phenomenological methods was conducted in order to understand the perspectives of GPs and Specialists about TLCRP. GPs and lung cancer specialists who work in TUH were purposively sampled to obtain their perspectives.

Chapter 7: Discussion

This chapter combines all four studies and integrates what was learned from evaluation of TLCRP and its impact on service outcomes for people with lung cancer. The COM-B framework is used as an explanatory framework for these findings.

Chapter 8: Conclusions and Recommendations

The last chapter describes the practical impacts of the thesis and highlights future directions for clinical practice, policy and research.

Conclusion

This chapter provides an overview of the PhD thesis. In the next chapter, a thorough scoping review of the lung cancer optimal care pathway is described.

Chapter 2. Scoping review of literature

Introduction

A scoping review of literature on lung cancer optimal care pathways was conducted to provide a focus for the studies that were developed and undertaken for this PhD. The scoping review identified the most informative evaluation approaches for OCPs and these findings informed the approaches used in the PhD. The review also informed the evaluation variables included in the cohort study.

A scoping review of the literature on lung cancer OCPs was conducted and published after the implementation of TLCRP The main targets for evaluation in the papers included in the scoping review were the following:

1) Development and implementation of the lung cancer OCPs,
2) Quality indicators for lung cancer OCPs,
3) Effects of implementing OCP on patient experiences and timeliness and health care costs.

We included articles on optimal care pathway development and implementation in the scoping review to gain a deeper understanding of the foundations of these pathways, even if this topic falls outside the scope of the thesis.

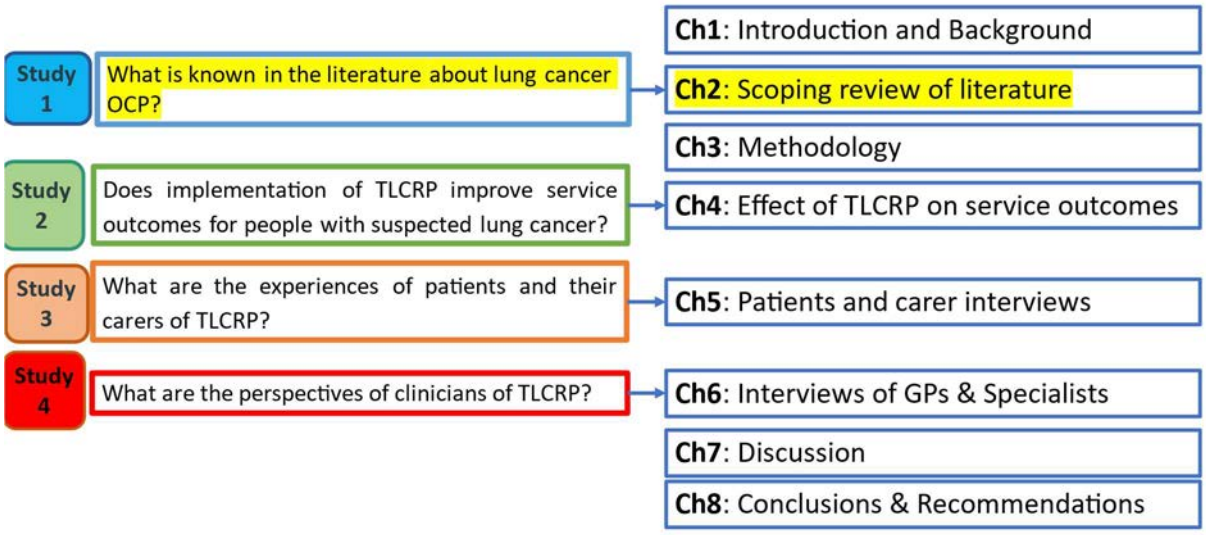


Figure 2.1: Schematic overview of thesis - chapter 2

Otty Z, Brown A, Sabesan S, Evans R, Larkins S. Optimal Care Pathways for People with Lung Cancer- a Scoping Review of the Literature. International Journal of Integrated Care, 2020; 20(3): 14, 1–9.	This chapter includes an edited version of the published manuscript.

Abstract

Introduction Much of the existing work around implementation of cancer optimal care pathways (OCP) has either focussed exclusively on the clinical elements of care or has targeted individual steps in the cancer trajectory, rather than using a patient-centred or service delivery lens to inform the integration of care across the continuum. This review aimed to identify the available literature on lung cancer OCP and inform evaluation approaches for OCPs.

Methods A scoping review was conducted, examining literature across multiple databases and grey literature. Articles were included if the OCP was being used to manage adult patients with lung cancer, reporting on either the development or implementation process and outcomes and/or barriers and facilitators associated with optimal care pathway development and/or uptake.

Results Of the 381 references screened, 31 articles were included. The type of lung cancer pathways varied between hospitals and health services. Several themes were identified including the development and implementation of the OCP, the use of quality indicators to audit the OCP and studies on outcomes of the OCP incorporating timeliness of care delivery, patient experiences and health care utilisation and costs.

Conclusions The articles found in this review may suggest that an OCP for lung cancer is still in its preliminary stages across the broader health systems.

Keywords integrated care; lung cancer; care pathways; scoping review

Background

Lung cancer is a major cause of morbidity and the leading cause of cancer mortality in Australia.[1] In 2016, lung cancer accounted for about 9% all new cancers diagnosed and 18% of all cancer deaths in Australia.[1] Limited data exists detailing how lung cancer patients flow through the healthcare system, and the delays and barriers that may interfere with the patient journey. The availability of evidence-based guidelines and multidisciplinary meetings has improved clinical effectiveness but does not automatically translate into improved quality of care.[100] Various studies done in Australia and other countries have revealed delays in lung cancer diagnosis and treatment, especially for rural patients.[32, 36, 101-103] The limited

access to cancer care services is an important issue faced by residents of rural, remote and regional communities.[30, 64, 104]

Cancer patients utilise a wide range of services from multiple providers at various points during their cancer journey, including oncologists, primary care physicians, nurses, pharmacists, physiotherapists and social workers[102]. They frequently experience fragmented health care journeys and suffer from lack of continuity of care[21]. Given the high cost and complexity of their evolving needs from the point of diagnosis to either survivorship or palliative care, cancer patients require care that is integrated across providers and settings over time[105, 106]. Implementation of a 'Optimal Cancer Care Pathway' may be a way of improving patients' care experiences and to improve the efficiency of the health system[57].

Optimal care pathways are structured, multidisciplinary care plans for a specific clinical condition, which describe the tasks to be pursued, their timing, sequence and the professionals involved[51, 56]. Implementation of optimal care pathways has been shown improve the outcomes of cancer patients, improve patient satisfaction and reduce costs[107]. Although the elements and frameworks are similar for many cancer-related pathways, each type of cancer requires specific approaches in terms of investigations and management modalities and applications; thus requiring adaptations of pathways to both the kind of cancer and to local needs and settings[108]. Various international oncology societies have published criteria for the development and implementation of oncology pathway programs within their jurisdictions, as listed in Table 2.1. Cancer Australia has published optimal care pathways for common cancers, including lung cancer, to guide the delivery of consistent, safe and high-quality care for cancer patients in Australia.[24]

Table 2.1: List of Lung Cancer Optimal Care Pathway Guidelines.

Organisation	Guideline	Year of publication
Cancer Council, Australia[24]	Optimal cancer care pathways for people with Lung Cancer.	2021
National Health Service (England)[109]	Implementing a timed lung cancer diagnostic pathway	2023
Cancer Care Ontario, Canada [110]	Lung Cancer Pathway Map	2019
Swedish Lung Cancer Study Group, Sweden[111]	Recommendations from the Swedish Lung Cancer Study group	1999
UK Lung Cancer Coalition, UK [112]	Implementing national optimal lung cancer pathway	2018

However, there is currently only limited consensus internationally around the definition of the optimal care pathway, and there are various terminologies used interchangeably in the literature[113, 114]. Little is known about how optimal care pathways for cancer patients are developed, including the definition of core activities, the specifications for facilitators and the determination of indicators for assessing impact[115]. There is also only limited data to guide the implementation of optimal care pathways for lung cancer patients in the cancer centre environment. While major metropolitan cancer centres have the capacity to access all components of the optimal care pathway, including access to clinical trials, many regional centres may not have access to various components of the pathway[51]. This may mean that the patients may not receive the recommended investigations and care[25]. Due to the large geographical catchment area and the greater travel distances for patients, our regional cancer centre has embarked on developing cancer care pathways suitable for our region.

As part of developing our own lung cancer pathway to cater for our population, this review aims to identify and summarise the available literature on lung cancer pathways. A scoping

review was conducted in order to explore the key components of lung cancer care pathways, identify the facilitators and barriers associated with their use and to examine the outcome measures that have been determined in order to assess their impact.

Methodology

This review of the literature used the scoping review methodology as defined by Arksey and O'Malley[116]. Scoping reviews are commonly used to understand the existing breadth of published research on a topic, identify gaps in the existing literature and assess the need for further research[116]. Arksey and O'Malley described five stages of methodological framework for a scoping review-

Stage 1: Identifying the research question

Stage 2: Identifying relevant studies

Stage 3: Study selection

Stage 4: Charting the data

Stage 5: Collating, summarising and reporting the results.

Our research question was refined to;

What is known in the existing literature about the development, implementation and evaluation of optimal care pathway for people with lung cancer?

Identifying relevant studies

Published articles were identified from electronic literature databases including MEDLINE, PubMed, Embase, and Google Scholar. Hand searching of reference lists and grey literature,

including Cancer Institute publications, government websites, websites of cancer societies and cancer foundations was also done. The literature search was done using key search terms; ('optimal care pathways' or 'integrated care pathways' or 'critical pathways' or 'clinical care pathways, protocol') AND ('lung cancer' or 'lung neoplasm'). Only articles in the English language were selected. Papers were accepted irrespective of the methodology used. Grey literature included documents that were not formally published in academic sources, such as reports, conference proceedings, cancer websites, and policy documents. Including grey literature can broaden the scope of the literature search and provide a more complete view of available evidence[117]. A grey literature search was done using Google online search engine, targeted cancer society website exploration and hand searching, using the above key search terms. Grey literature was critically evaluated for relevance, credibility and potential bias before being synthesised with peer-reviewed publications, to create a comprehensive picture of lung cancer optimal care pathways.

Two authors (ZO and AB) independently reviewed and screened the abstracts for selection, using the following inclusion criteria:

- The optimal care pathway was being used to manage adult patients with lung cancer and published between 1990 and 2019.
- The article reported on the development or implementation of lung cancer OCPs .
- Articles on outcomes and/or barriers and facilitators associated with optimal care pathway implementation or uptake.

Articles were excluded if:

- The optimal care pathway was used for the management of cancers other than lung cancer.
- The articles were concerned with only the screening and prevention of lung cancer.
- The articles purely focused on treatment algorithms of specific sub-specialities.

Quality of evidence was not assessed as we wanted to include all the available information on lung cancer OCP implementation.

Results

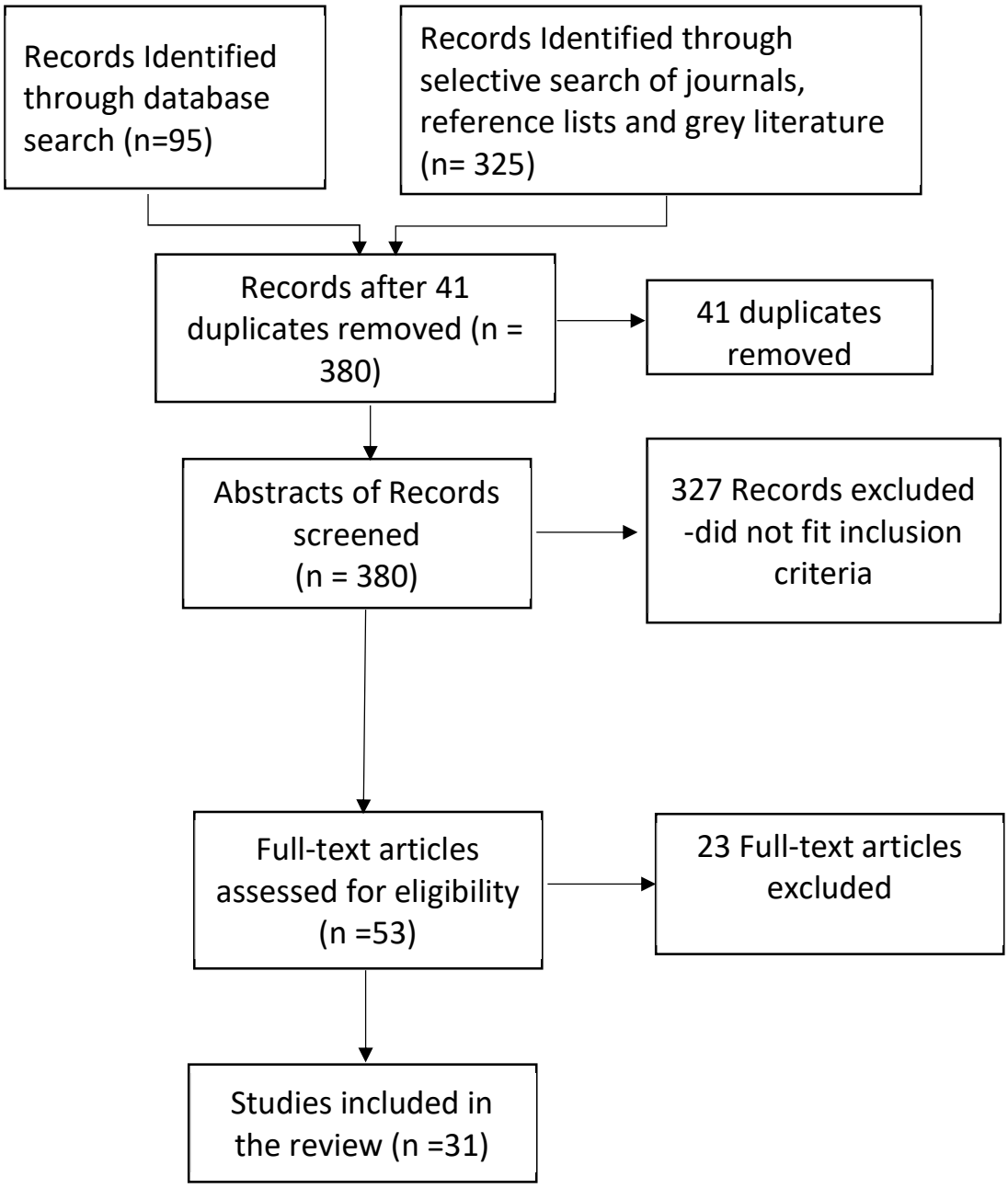


Fig. 2.2: PRISMA Flow chart for selection of articles[118]

We identified a total number of 420 records at the outset. Out of this, 95 were identified through database search (PubMed, Scopus, CINAHL and Embase). 325 articles were identified by searching the reference lists of journal articles and grey literature. Out of the 420 articles, 41 were removed as they were duplicates. The remaining 380 abstracts were reviewed by the PI and co-author (A B) and 327 abstracts were excluded as they did not fit the inclusion criteria. Out of the 53 full text articles assessed by the two reviewers, 22 were excluded for the following reasons :

Articles dealing only with post-operative care (six), studies looking at systemic therapy in lung cancer (five), articles that included other types of cancers apart from lung cancer (four), articles dealing with molecular pathways (four) and articles that consisted of systematic review (three). Table 2.2 summarises all the studies included in the scoping review.

Table 2.2: Summary table of included studies.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Studies on developing and implementation of lung cancer pathways					
Evans WK, Ung YC, Assouad N, Chyjek A, Sawka C 2013, Canada[119]	Prospective Implementation study. Quality improvement framework	Large public health care system-urban & rural.	Cancer care Ontario lung cancer disease pathway which formulated evidence-based guidelines for prevention, screening, diagnosis, treatment, palliative care and survivorship during the lung cancer patient's management. Multidisciplinary, focus-group meetings held to develop quality improvement projects for lung cancer pathway.	Standardised diagnostic and treatment pathways for lung cancer were developed. An audit has been undertaken to better understand the barriers to the uniform uptake of specific evidence-based practices across the province.	Regional cancer centres can undertake adequate quality improvement initiatives and develop standardised diagnostic and treatment pathways. Ongoing measurement of a broad range of metrics is needed.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Fung-Kee-Fung M, Maziak DE, Pantarotto JR, Smylie J, Taylor L, Timlin T, et al. 2018, Canada[120]	Prospective implementation study. Learning health system (LHS) framework	University Hospital.	Regional process redesign of lung cancer care by lean optimization of diagnostic procedures and patient education including coordinated referral review and integrated navigation.	Twelve major processes in referral, review, diagnostics, assessment, triage, and consultation were redesigned. The Ottawa Hospital now provides a diagnosis to 80% of referrals within 28 days. The median patient journey from referral to initial treatment has decreased by 48%, from 92 to 47 days.	The initiative optimised regional integration from referral to initial treatment. Transformation initiatives across the continuum of care are needed to incorporate best practice and optimise delivery systems for regional populations.
Manley S, Delaney L 2015 Australia[121]	Descriptive study (no implementation framework reported)	Rural population.	GP can access same day chest radiograph and CT scan. Daily lung cancer clinics were set up, staffed by dedicated consultants. A non-clinical patient navigator was appointed to coordinate patient flow in the new pathway.	Developing a lung cancer referral and diagnostic pathway in a regional setting.	Established the preferred pathway utilising the information gathered from stakeholders.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Bennett A, Patrick C, 2019 UK[122]	Retrospective audit. (no implementation framework identified/reported)	113	An audit of the value of the lung cancer nurse specialist in reducing pathway timings in the local optimal lung cancer pathway. The Cancer Nurse Specialist being notified of abnormal Chest X-rays requested by the GP, contacting the patient and notifying the GP. They then request a CT scan and if abnormal refer in for a 2-week outpatient appointment with a respiratory specialist.	During that period 113 abnormal CXRs were flagged to the Cancer Nurse Specialist. Of these 53 patients had normal CT scans and were discharged back to the GP. 60 patients were diagnosed with lung cancer. In the previous year 320 patients were referred for 2WW OPAs with only 67 diagnoses.	With the introduction of the pathway, a significant number of unnecessary outpatient appointments have been avoided.
Woznitza N et al. 2017 UK[123]	Randomised trial. Evaluation framework	Urban hospital 8732 patients 4128 in the immediate radiographer reporting arm	Impact of immediate reporting by radiographer of chest x-rays from general practice on the lung cancer pathway. Half of the sessions per week (5) were randomised to an immediate or routine chest x-ray (CXR) report by a reporting radiographer, with an immediate CT where indicated. Time taken to diagnosis of lung cancer or discharge from the lung cancer pathway was determined and Mann-Whitney test used.	Time to diagnosis of lung cancer for patients in the immediate arm was a median of 21.5 days compared with 30 days in the routine CXR arm (p=0.012). For patients with a suspicious CXR, diagnosis of lung cancer was achieved in a median of 18 days compared with 32 days in the routine arm (p=0.0375).	Immediate reporting of CXRs referred from primary care by radiographers reduced time to diagnosis of lung cancer by a median of 14 days.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Lloyd KL, Rice A, Robertus JL, Brambilla C, Popat S, Kemp S, et al. 2019 UK[124]	Retrospective audit. (no implementation framework identified/reported)	40	Retrospective data collection from a 3-month period on turnaround times of pathology diagnostic reports of lung cancer.	60% of cases had diagnosis reports available within 1–3 days, with all available within 9 calendar days. Delays were either due to logistics (transport, delays in antibody replacement), or molecular requests occurring post-diagnosis.	The results of the retrospective data analysis have led to the introduction of a standardised molecular request form.
Fuller L, Robson S, Tasker C. 2017 UK[125]	Descriptive study (no implementation framework identified/reported)		Implementing a One-Stop Lung Cancer Clinic in South Tyneside. Following a CT scan, diagnostic tests are being combined so that patients are able to have multiple diagnostic tests in one day.	Implementation of One-Stop clinic led to improved chances of achieving the 62-day pathway timeline.	One-stop lung cancer clinic is feasible and effective.
Gill B 2016 UK[67]	Qualitative survey (no implementation framework identified/reported	20	Lung Cancer Pathways Cluster Qualitative Research Results by Cancer Research UK. The telephone interviews were conducted to gather qualitative information as well as information about pathway configurations.	Strengths of the local lung cancer pathways included leadership, teamwork, good relationship among team members, strong patient tracking arrangements and quick turnaround times for some tests. Challenges faced by the local pathways included inadequate capacity for radiology and pathology, insufficient clinical information in GP referrals and waiting time for MDT decision.	Concerted effort by local Teams can achieve significant positive change.
Studies on use of quality indicators in Lung Cancer care pathways					

Fasola G, Menis J, Follador A, De Carlo E, Valent F, Aresu G, et al 2018 Italy[126]	Retrospective audit and analysis	University hospital *169.*	Quality of care of lung cancer patients was measured through fifteen indicators: Respiratory medicine 1. Number of diagnostic bronchoscopies 2. Time between the first visit of chest physician and diagnosis 3. Time between the first visit to chest physician to the first oncological visit. Thoracic surgery 4. Patients that underwent mediastinoscopy if N2 positive node in PET scan 5. Time between diagnosis and surgery 6. Time between PET scan and surgery Pathology department 7 time between the diagnostic procedure and diagnosis. 8 Percentage of extemporary cytological diagnosis during bronchoscopy 9 Concordance between histological diagnosis on the surgical sample and on biopsy 10 Percentage of NSCLC not otherwise specified diagnosis Radiotherapy	Eight of fifteen indicators were not in line with the benchmarks.	Integrated care pathways confirmed to be feasible and to be an effective practical tool. Periodic measurement of quality indicators is necessary to ensure clinical governance of patient pathways.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
			11. percentage of concomitant radiotherapy treatments for stage 3 patients. Medical oncology 12. time between diagnosis and the first chemotherapy administration for stage 4 patients 13. percentage of patients enrolled in clinical trials 14. percentage of patients treated with three or more chemotherapy lines 15. percentage of patients dead within 30 days of last chemotherapy.		

Fasola G, Rizzato S, Merlo V, Aita M, Ceschia T, Giacomuzzi F, et al. 2012 Italy[127]	Retrospective audit and analysis	University hospital 175.	Flowcharts were drawn for management of early, locally advanced and metastatic lung cancer disease respectively. Evaluated the lung pathway using 11 quality indicators to identify problem areas: 1a-- Time from 1st admission to the Pulmonary Unit to 1st oncology visit (stage I-IIIA), 1b – Time from 1st admission to the Pulmonary Unit to 1st oncology visit (stage IIIB-IV), 2 – Time from CT-PET to surgery, 3 – Time from the 1st invasive diagnostic procedure to pathological diagnosis, 4 – Time from 1st admission to the Pulmonary Unit to pathological diagnosis, 5a – Time from pathological diagnosis to surgery, 5b – Time from pathological diagnosis to chemotherapy, 6 – Patients who underwent a cervical mediastinoscopy following a CT-PET before surgery 7 – Patients for whom there was evidence of a multidisciplinary evaluation, 8 – ECOG PS > 1 patients receiving a doublet chemotherapy, 9 – Patients receiving more than three treatment lines,	The gap between "desired" and "actual" performance has been measured by benchmarking current practice against key quality indicators. Diagnostic workup, multidisciplinary team care and medical treatment of advanced disease have emerged as areas of good performance. Conversely, the management of early-stage disease offers room for improvement.	Analysing the process of caring for non-small cell Lung Cancer patients is feasible. Acquired knowledge may be shared with hospital administrators, guide the revision of Integrated Care Pathways

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
			10 – Per-patient yearly number of oncology visits, average number 11 – Patients who received an active medical treatment within 30 days of death.		
Rizzato S, Merlo V, Aita M, Sibau A, Menis J, Gurrieri L, et al 2011 Italy[127] (same as previous study, but with different results)	Retrospective audit and analysis	University hospital 175	A multidisciplinary quality improvement project on assessing quality of existing Lung Cancer Pathway.	Eleven quality indicators were identified to assess clinical, organizational and economic aspects of patient care.	By means of a limited set of quality indicators, adherence to clinical guidelines in the care of lung cancer patients could be monitored

Kaltenthaler E, McDonnell A, Peters J. 2001, UK[128]	Prospective implementation study Quality improvement framework.	University hospital (urban) 53	Development of paper-based forms to monitor the progress of lung cancer patients and auditing key standards within the pathway. Three stages: i) development of a paper version of the form for each point of care on the lung cancer pathway; ii) trial period of use; and iii) evaluation of the paper form in terms of its success as a tool to capture appropriate data. Quality indicators used: 1. Time between receipt of referral and first out-patient appointment and reasons for any delay. 2. •Time between outpatient visits, completion of treatment and any further communication with the GP 3. Reasons why bronchoscopy is not performed 4. The dates of booking investigations and performing investigations 5. All multidisciplinary team decisions 6. Dates of referral, treatment decision and start of treatment as well as details of treatments, 7. All follow-up appointments	Completed preclinical record forms were available for 68% of patients with 42% of these patients also having a record of the decisions made at the multidisciplinary team meeting. Completion of forms that covered the later stages of the care pathway was limited.	The forms were acceptable to users and provided accurate information at key points on the patients' journey in the lung cancer pathway.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
			The involvement or not of the Macmillan service and additional services		
Studies on evaluating patient experience of Lung Cancer Care Pathways					
Bravi F, Ruscio ED, Frassoldati A, Cavallesco GN, Valpiani G, Ferrozzi A, et al 2018 Italy[129]	Cross-sectional study.	77 patients and 38 health professionals.	Opportunity for Treatment in Oncology (OPTION) questionnaires were administered to 77 patients, and the Care Process Self-Evaluation Tool (CPSET) questionnaires were given to 38 health care professionals.	In an Integrated Care Plan, the views of patients and health care professionals overlap on aspects considered important, namely a person-centred approach. Their perception of weaknesses is also similar, in particular a relative lack of patient communication and cooperation between hospital staff and GPs.	The lung cancer pathway is a patient-centred intervention that enables care to be shaped for patient needs in order to improve the quality and efficiency of service and clinical outcome.
Hagglund M, Bolin P, Koch S 2015 Sweden[130]	Descriptive Qualitative study	University hospital 9 patients with lung cancer	Describes the lung cancer care process as experienced by the patients and analyses the problems they encounter throughout the journey. Focus group interviews of patients.	Identified problems faced by lung cancer patients.	Designing eHealth to improve the patient journey will therefore require flexibility and adaptability to the individual's needs.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Kedia SK, Ward KD, Digney SA, Jackson BM, Nellum AL, McHugh L, et al 2015 USA[131]	Qualitative evaluation study	22 patients and 24 care givers	A 'one-stop shop' model of care was tried, where all the concerned specialists reviewed patients at the same time. Focus group interviews of patients and caregivers comparing multidisciplinary model of lung cancer care with serial model of care.	Multidisciplinary care improved physician collaboration, patient-physician communication, and patient convenience, while reducing redundancy in testing. Negative experiences of serial care included poor communication among physicians, insensitive communication about illness, delays in diagnosis and treatment, misdiagnosis and mistreatment. Physician-to-physician communication and patient education were suggested areas for improvement in the multidisciplinary model.	Multidisciplinary care was perceived as more patient-centred, effective, safe, and efficient than standard serial care.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
McDowell G 2014 UK[132]	Patient experience questionnaire		Patient experience questionnaire about Optimal Lung Cancer Care Pathway was distributed in the outpatient setting within The Beatson Oncology Centre over a period of 6 weeks.	• 90% Felt their doctors were sensitive in breaking bad news • 71% Completely understood the purpose of investigations • Nearly 50% had not been offered written information on lung cancer. • 94% Felt there was enough privacy during a consultation. • 80% Felt their emotional needs were met throughout the investigation & treatment process. • 93% were given contact information of cancer specialist nurse or support network	The questionnaire highlights the excellent quality and quantity of communication supplied throughout the diagnosis and treatment process, adequately addressing both the emotional and physical needs in the majority of patients.
Studies on timeliness of care in Lung Cancer care Pathways					

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Bakewell F, Hodgkiss M, Perumpalath B, Wright-Morris D, Severn H, Anwar S 2019 UK[133]	Retrospective cohort study	452	The patient cohort was defined as those referred on a 2ww pathway due to an abnormal CXR at NUH between 03/07/2017 and 30/06/2018. We retrospectively reviewed the time from CXR to CT and the time from 2ww referral to decision to treat (DTT), comparing patients on the new 'straight to CT' pathway with those on the conventional pathway.	Of those 189 (41.8%) underwent a CT on the conventional pathway and 242 (53.5%) on the new pathway. Median time from CXR date to CT report was 12 days on the conventional pathway and 7 days on the new pathway. Of the eligible cohort, 135 patients (29.9%) were diagnosed with lung cancer: 18.7% on the conventional pathway and 39.5% on the new pathway. Median time from 2ww referral to DTT was 42 days on the conventional pathway and 36 days on the new pathway.	implementation of a 'straight to CT' pathway has led to a reduction in the time to CT and Decision to Treat.
Moneke J, Khan S, Hussain I. 2019 UK[134]	Retrospective study	University hospital 106+ 86	Patients who were diagnosed with lung cancer within the time period of January 2018 to February 2018 (n=86) were used as a control and compared to those in May to June 2018 (n=106).	Referral start date to diagnosis showed a significant improvement falling from an average of 51 days in the January– February 2018 period to 19 days in the May 2018 period. The diagnosis to treatment and the referral start date to treatment stages showed a similar trend falling from 24 days to 11 days and 65 days to 25 days respectively.	The findings have shown a significant reduction in waiting times across most stages of the patient referral pathway within the post-implementation period.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Kutubudin F, Robinson R, Deus P, Hughes K, Wight A 2017 UK[135]	Implementation study (no implementation framework identified/reported)	Regional patients 210	IT-driven lung cancer pathway, linking primary care with secondary care radiology, respiratory and outpatient booking services (including endoscopy). A daily consultant virtual clinic. All further diagnostic investigations are pre-arranged.	Time from virtual review to formal cancer clinic - mean 5.8 days (target 5 days). Time Flagged CXR to MDT discussion (target 21 days)- 23.9 days. Patients informed of treatment plan within 28 days	Diagnostic timeframe has been shortened by average of 15 days and are on target to meet the 95% target by 2020. 28-day target is achievable even outside tertiary centres.
Aasebo U, Strom HH, Postmyr M 2012 Norway[136]	Retrospective cohort study.	University hospital 69	Study of workup times for patients with lung cancer using the "Lean quality improvement process" (using mechanisms to identify and sustain high-value encounters and eliminate obstacles) to improve patient flow.	Decrease in the workup time from a mean of 64 days to 16 days, and the median time from diagnosis to surgery was reduced from 26.5 days to 15 days.	It is feasible to improve patient flow for patients with lung cancer by employing the Lean method as a pathway instrument.
Jiang T, Ren S, Li X, Su C, Zhou C, O'Brien M 2017 China[137]	Retrospective analysis	4000 patients in university hospital	Fast-track diagnostic pathway for lung cancer patients.	In this pathway, the median time for initial respiratory consultation to treatment decision making was only 4 days.	Detailed information on the diagnostic pathway for a new patient in the department provided.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Treatment pathways: studies on health care utilisation and costs					
Jackman DM, Zhang Y, Dalby C, Nguyen T, Nagle J, Lydon CA, et al. 2017 USA[138]	Cost-effectiveness analysis	370	Study comparing cost effectiveness of the Dana- Farber lung cancer pathway, which is a web-based platform for real-time decision making and data collection on systemic therapy.	Reduced costs after implementation of the lung cancer pathway.	After the introduction of a clinical pathway in metastatic NSCLC, cost of care decreased significantly, with no compromise in survival.
Neubauer MA, Hoverman JR, Kolodziej M, Reisman L, Gruschkus SK, Hoang S, et al 2010 USA[139]	Cost-effectiveness analysis	1409 Outpatient oncology clinics.	Electronic pathway incorporating expert recommendations for systemic therapy for various stages and lines of non-small cell lung cancer patients in the outpatient community setting. Study comparing cost-effectiveness of treating patients with chemotherapy, on or off the pathway.	The average cost of care for patients on the pathway was 35% less compared with that of patients treated off the pathway. Patient survival was not affected.	Treating patients according to evidence-based guidelines is a cost-effective strategy for delivering care to those with non-small cell lung cancer, treated in the outpatient community setting.

Author, year of publication, country	Design	Setting and sample size	Description of the study	Results	Conclusion of the authors
Ellis PG 2013 USA[140]	Retrospective audit of pathway compliance	University Cancer Centre	Interactive software that allows for real-time decision-making Pathways for Best Treatment option. Regularly updated by expert committee of clinicians. Retrospective audit of compliance.	75% of non-small cell lung cancer patients treated according to the pathway.	Physician involvement is integral to a successful clinical pathway programme. In addition, an agile user interface and pragmatic layout of the tool are essential for incorporating pathways into the daily workflow of physicians.
Shamji FM, Deslauriers J 2013 Canada[29]	Review	Tertiary hospital	Review on benefits of fast-tracking investigation and staging of patients with lung cancer	Standardised clinical care pathways for the investigation of patients with lung cancer allow for a reduction in the time interval between suspicion of lung cancer and treatment, lower costs, increased patient satisfaction, and quality of care.	Reducing delays is essential to improve quality of care and reduce costs through more efficient use of resources.

A total of 420 articles were located, and from these 31 articles were selected for the final review. Out of these, six were guidelines published by professional organisations on implementing optimal care pathways for lung cancer, in their respective countries (Table 2.1). Some care pathways were used in a single hospital, while others were used in multiple hospitals or health services. Implementing a care pathway across multiple hospitals in a healthcare service requires additional resources and is significantly more challenging than implementing it in a single hospital. Eight of the articles dealt with development and implementation of optimal lung cancer care pathways. Four articles were on auditing lung cancer care pathways using quality indicators, four on evaluating patients' experience of lung cancer care pathways, five articles were on timeliness of care using lung cancer care pathways and four articles on health care utilisation and costs associated with lung cancer care pathways. The care pathways varied in their format and implementation, depending on the the country's health system. Articles originated from a range of countries, including both public and private health systems. Out of 31 articles, thirteen were from the United Kingdom, four were from the United States, four from Canada, two from Australia, four from Italy, and the rest from other countries. Five government organisations and professional bodies have published guidelines for the implementation of optimal lung cancer pathways (Table 2.1). Although there are variations in the recommended investigations and timeframes, all the guidelines aim to provide timely and effective care for people with suspected lung cancer. These pathways chart an optimal journey of a person with suspected lung cancer from diagnosis to treatment and follow-up. They also contain information on lung cancer prevention, supportive care and palliative care. A wide range of

clinicians, peak health organisations, consumers and carers were consulted for and participated in their development [141].

Studies on the development and implementation of lung cancer care pathways

Eight studies focused mainly on the processes and challenges of implementing lung cancer care pathways. The implementation of lung cancer pathways was made in multiple steps, involving multi-disciplinary teams within the oncology community. One of the first steps in implementing a lung cancer pathway is 'process mapping', in which the existing lung cancer pathway in the region is mapped and weak points identified [112]. Streamlining administration and use of the best information technology tools also form important parts of implementing the pathway [120].

Most of the care pathways were designed by multidisciplinary teams, consisting of clinicians who are directly involved in lung cancer management and health care researchers [119, 126, 130, 131, 136, 137, 140]. Patient involvement in the design of care pathways was quite limited, with only few studies reporting patient engagement [128, 131]. The care pathways needed to be revised over time, and there were specific teams who were tasked with monitoring the uptake of the pathway [119, 127, 136, 138, 139]. The care pathways were often linked to patients' electronic medical records [136, 139, 142]. By using computer-based platforms, the processes of aggregating data on treatment decisions and care delivery were facilitated [139].There was a strong emphasis placed upon sharing information between teams and across organisations in most care pathways [138-140, 142].

In the 'Cancer Care Ontario Lung Cancer Disease Pathway', diagnostic and treatment pathways for lung cancer were mapped and posted on 'Ontario Health' website, so that all

the clinicians and health service managers can use the pathway for their patients [119]. Representatives from primary care, public health, occupational medicine, oncology, patient groups and their care givers all participated in formulating the cancer care Ontario lung cancer pathway [119]. Health researchers in another Canadian hospital addressed the delays in lung cancer care by redesigning the regional model of care [120]. This 'Ottawa Hospital Model' operationalised the lung cancer diagnostic pathway and optimised patient flow from referral to initiation of treatment. All the stakeholders, including health care professionals, patients, caregivers and administrators, participated in re-designing the Ottawa hospital lung pathway [120]. Manley et al (2015) described implementation of lung cancer care pathways in regional New South Wales, where GPs had access to same-day chest X-ray and CT scan and there was adequate staffing of daily lung cancer clinics [121]. In this care pathway, a full-time lung cancer patient navigator coordinated patient referrals from a large rural catchment area [121].

Modifications to the lung cancer care pathways like employment of a lung cancer nurse specialist [122, 133], straight-to CT pathway [133] and immediate reporting of chest x-rays by a radiographer [143] have reduced delays to lung cancer diagnosis. Quick turnaround time for pathology reporting is essential for implementing an optimal lung cancer pathway and delays in pathology reporting can be due to logistical issues or requests for molecular testing [124]. Qualitative studies on local lung cancer care pathways in the National Health Service, Great Britain, showed that the strengths of the services included leadership, good teamwork, good relationships within the service, ownership, and quick turnaround times for some of the tests [144]. The challenges included radiology and oncology capacity, insufficient clinical information from GPs and lack of consistency and delay in MDT decisions [144]. One-

Stop Clinics, at which the patients are seen by multiple specialists on the same day and multiple investigations are organised have also been successfully trialled [144].

Some of the studies included in the scoping review mentioned Implementation science frameworks used in the study. These included learning health systems framework[120], quality improvement framework[128] and evaluation framework[123]. None of the studies used SIF or COM-B framework.

Studies on using Quality Indicators to auditing Lung Cancer Care Pathways

There were four studies on quality indicators and auditing lung cancer pathways [126-128, 145] .The group from the University of Udine in Italy selected quality indicators and after discussions with the local multidisciplinary thoracic malignancy group [126] from international guidelines. These quality indicators can be used to identify problems in the local lung cancer pathway, such as delays and non-adherence to clinical guidelines [127]. Investigators from the University of Sheffield interviewed professionals from primary, secondary, tertiary and palliative care and developed paper-based forms to monitor the progress of lung cancer patients and audit the key standards within the pathway [128]. Quality indicators can also be used to verify adherence to clinical practice guidelines and elicit some critical issues in the care of lung cancer patients [145]. The results from auditing studies are shared with hospital managers , with the aim of redesigning lung cancer care pathways and improving the efficiency of care [145].

Studies on the effect of lung cancer pathways on the timeliness of care

Optimal care pathways aim to reduce the time delays experienced by patients in seeing a specialist to do specific investigations and to start treatment[24]. Five studies described the

processes that were implemented in the respective hospitals to reduce the time to diagnosis and treatment [133-137]. This was done using novel management systems [136], and by the provision of adequate resources and improved communication between departments [137]. The 'Lean Model' programme was a quality improvement instrument which was successfully utilised to reduce the delays in the lung cancer pathway and to improve patient flow in a referral hospital[136]. Information technology-driven optimal care pathways and virtual clinics shortened diagnostic timeframes even in regional hospitals [135]. One of the methods used to reduce delays in diagnosis of lung cancer is to automatically trigger a referral for CT scan if the chest x-ray is abnormal [133].

Studies on the effect of lung cancer pathways on health care utilisation and costs

Fast-tracking care pathways for lung cancer treatment allow for a reduction in the time interval between suspicion of lung cancer and treatment, lowered costs and increased patient satisfaction and quality of care [29]. Few studies on treatment pathways dealt with the best systemic treatment options for a lung cancer patient at a certain point of care. In these studies, systemic therapy was selected based on its efficacy, toxicity profile and cost-effectiveness [138-140] and the treatment pathways reduced the cost of lung cancer treatment without compromising survival [138, 139].

Studies on the patient experience of Lung Cancer Care Pathways

One of the aims of implementing an optimal lung cancer care pathway is to improve patients' experience and satisfaction with their care [141]. Perspectives of patients, evaluated using the OPTION (Opportunity for Treatment in Oncology) questionnaire, give the highest scores to 'respect', 'satisfaction', and 'trust' [129]. Offering written communication about

diagnosis and maintaining patient privacy during consultations improves patient satisfaction [132]. Hagglund et al. (2015) from the Karolinska Institute in Sweden, studied patients' experiences of living with lung cancer and created a 'patients journey model' [130]. The problems experienced by patients in each phase were identified and eHealth solutions for these problems were proposed [130]. Investigators from the University of Memphis compared patients' perspectives of multidisciplinary lung cancer care to routine serial care[131]. Usual care of a person with lung cancer in University of Memphis hospital would mean series of specialist appointments for diagnostic workup and treatment. This resulted in delays and lack of co-ordination between specialists. The study found that participants preferred multiple physicians working together as a team to decide on the best plan of care.

Barriers to the implementation of optimal lung cancer care pathways

Barriers to implementing lung cancer care pathways can occur at various levels. Some of the common challenges include resource limitation, diagnostic and treatment capacity and complex patients[144, 146]. Some hospitals did not have access to specialist investigations like PET scans or endobronchial ultrasounds and needed to refer patients to other centres, thereby delaying the diagnosis and staging of lung cancer [146]. There were also limitations to the number of CT scans or biopsies that can be done in a day. Following the initiation of a new lung cancer pathway, there was an increased number of primary care requests for CT scans[144]. Collaborative working and good communication between various departments were able to overcome these issues [112]. Another barrier to implementing lung cancer pathway was that some of the clinicians may be reluctant to use new forms or pathways [128, 136]. Two common barriers to implementing the pathway in the Cancer Care Ontario study were slow referral processes and lack of administrative support [119]. During the

implementation of the lung cancer optimal care pathway in the United Kingdom, members of the some of lung cancer pathway teams had concerns about overburden and increased workload [112]. In the UK lung cancer coalition paper, part-time GPs and lack of the ability to review X-ray and CT reports on a daily basis also posed a challenge [112]. One of the findings of this paper was that it was challenging to validate loocal lung cancer pathway data for quality control [112]. In the UK, some of the health services had difficulty in funding the implementation of an optimal lung cancer pathway [10, 109].

Table 2.3: List of studies with approaches used, barriers, and enablers.

Study	Approaches used	Barriers	Enablers
Fuller L [147]	One-stop shop lung cancer clinic	Resource limitation, diagnostic and treatment capacity and complex patients.	Engaging with patients, executive-level leadership, and identifying clinical champions.
U K Lung Cancer Coalition[112]	Optimal lung cancer pathway implementation	Concerns about increased workload. Part-time GPs and lack of the ability to review X-ray and CT reports daily.	Collaborative working and good communication between various departments .
Asebo U [136]	Lean thinking	Scepticism from doctors	Sense of ownership of the programme.
KaltenthalerE[128]	Audit tool	Clinicians may be reluctant to use new forms or pathways	Involving key personnel in the development of the audit tool.
Evans WK[119]	Disease management pathway	Slow referral processes and a lack of administrative support	Support from the senior management team, strong clinical leadership, and broad engagement of service providers.

Discussion

Optimal cancer care pathways map the cancer patient's journey for specific tumour types in order to promote quality cancer care and improve the patient's experiences. The optimal care pathway for lung cancer has been endorsed by health authorities in Australia and its key features include the following: patient-centred care, safe and quality care, multidisciplinary care, and improved coordination and communication. This pathway outlines seven critical steps in a lung cancer patient's journey which are prevention, initial investigations and referral, diagnosis and treatment planning, treatment, follow up after treatment completion, management of recurrent cancer and end-of-life care [141]. Similar lung cancer care pathways have been implemented in other countries [127, 130, 131, 136, 137].

Previous reviews on optimal lung cancer care pathways were focused on timeliness of care [10, 55] or barriers to early diagnosis [148].The most frequently reported barriers to early presentation and diagnosis of lung cancer reported by patients and carers concerned poor relationships between GPs and patients, a lack of access to services and care for patients, and a lack of awareness of lung cancer symptoms and treatment [148]. Addressing these barriers offers opportunities for improvement in the rates of early diagnosis of lung cancer. This review included studies conducted in various countries, with different types of cancer pathways. Despite the fact the studies were done in various health systems, most of the studies demonstrated improvements in various aspects of patient care after the implementation of a lung cancer pathway. Implementation of the care pathway reduced waiting times for diagnosis and treatment [133-137] . This appears to be associated with better patient outcomes and increased patient satisfaction [29, 129-132]. The cost of cancer therapies is a major issue, and it has been rising with the introduction of new (and often more

expensive) therapies [106]. Studies examining the cost effectiveness of lung cancer pathways demonstrated reduced costs [29, 138, 139].

Some common themes emerged from this review. Electronic and web-based platforms seem to be more widely used in the implementation of lung cancer pathways [119, 130, 140, 142]. With the widespread use of smartphones and tablets, these pathways should be accessible to most providers and patients. Electronic flowcharts should be flexible in order to accommodate changes in recommendations. Patient data can be extracted and used for audits and for improving the care pathway. In developing the pathway, the involvement of physicians who use the lung cancer pathway was found to be important [119, 140]. Multidisciplinary involvement in implementing the pathways is also a key feature of most studies [119, 127, 128, 136]. Some of the studies in this review have selected quality indicators based on previous research on lung cancer pathways [127, 128, 145, 149]. Even after the cancer care pathway is implemented, it must be audited periodically in order to ensure that all aspects of pathway are running optimally. This requires a dedicated team of professionals, who can periodically allot time to hold meetings and monitor the performance of the care pathways, and continuously adjust and improve their content.

The type and scope of lung cancer pathways in this review varied considerably. Most of the studies were focussed on a single aspect of the pathway, such as chemotherapy use or diagnostic investigation. Cancer care pathways have either focussed exclusively on the clinical elements of care or have targeted individual stages in the cancer trajectory, rather than considering integrated care along the continuum [150, 151]. Since study quality is not considered in scoping reviews, it is not possible to draw reliable conclusions about the outcomes of optimal care plans from the trends observed. Some studies included only a

small number of patients, and most were from a single hospital or health service. Large hospitals can allocate resources into fast tracking diagnosis, staging and molecular genotyping of lung cancer [137], which may not be possible in community settings. There were no studies found on implementing care pathways in predominantly rural populations. Since we did not include studies which dealt with patients with other types of cancers in this review, much important data on cancer care pathways may have been missed.

This review contains limited data describing the methodology to implement lung cancer optimal care pathways. The engagement of providers facilitates the implementation of lung cancer pathways by helping to foster a sense of ownership and accountability [119, 136, 140]. Structural factors enabling implementation include a dedicated team of professionals to oversee the implementation of the care pathway and an advanced information technology capacity [127, 140]. Barriers to implementing the lung cancer pathway included inadequate support from clinicians, inadequate resources, lack of training for providers regarding the pathway and inadequate information technology support. If the care pathway is not integrated into patients' medical records, clinicians will have increased workload [128]. Most of these barriers can be overcome if there is adequate planning, involvement of providers in all the phases of pathway development, provision of adequate resources to providers and the provision of an easy-to-use electronic platform. Since different health services have different types of referral patterns for lung cancer, local workflow issues must be considered. Therefore, problems with the lung cancer pathways need to be solved at the local level. Development and implementation of the lung cancer pathway should be driven by clinicians and health scientists.

Strengths and limitations

This article comprehensively reviewed all the available studies on lung cancer optimal care pathways. An essential strength of the review was that it included articles from grey literature and different health systems.

One of the limitations of this scoping review was that it did not include articles on Health Pathways. The initial plan of the investigators was to evaluate optimal lung cancer pathway in Townsville. Later this was changed to evaluation of TLCRP. The majority of the studies included in this scoping review were not randomised and hence the results may not be applicable to our health system. None of the articles mentioned methodology used to generate pathways and guidelines.

Conclusion

The articles found in this review suggests that implementing an optimal care pathway for lung cancer improves patient outcomes but has many challenges. Multidisciplinary involvement, especially the involvement of clinicians and the provision of a user-friendly platform for documenting the pathway are critical for the successful implementation of a lung cancer care pathway. More research is needed on the implementation and evaluation of lung cancer care pathways. Depending on the geographical location and resource constraints, the optimal lung cancer pathway needs to be modified for successful delivery.

Addendum:

The results of the scoping review informed the development of the next stages of the PhD. The scoping review identified several of the quality indicators which were used as outcomes in the quantitative study (Chapter 4). The scoping review also identified the barriers and

enablers of lung cancer pathway which were used to formulate interview questions for the qualitative studies (Chapters 5 and 6). The articles in the scoping review also suggested that the initial part of lung cancer OCP, where the patient is managed in the primary care setting, is a critical part of the pathway. Hence, evaluation of TLCRP (which addresses step two of Cancer Australia lung cancer OCP) was made the focus of this PhD project. During the course of this project, PI reviewed all the available articles on HealthPathways. The next chapter discusses the methodologies used in individual studies and how they were integrated using the overarching framework.

Chapter 3. Methodology

Chapter overview

In this chapter, the rationale and overview of the methodology used in this project informed by implementation science principles, is discussed. The rationale and description of the detailed methodologies and methods chosen for each of the component studies are described in separate sections in this chapter. The project intervention is the TLCRP, and the implementation process was through Townsville HealthPathways. The key outcomes of interest in this project are timeliness of care(time from first appointment with the GP to specialist referral being sent and the time interval from GP referral to first patient appointment with the specialist), rural/urban differences in the above timepoints and acceptability of TLCRP among clinicians and patients.

Strategic Implementation Framework

The overarching framework for this multimethod project was the Strategic Implementation Framework (SIF), as described by Mitchell and Chambers.[95] The SIF arranges implementation stages along the continuum of change, beginning with setting the stage and moving through to active implementation and then to monitoring, supporting and sustaining change.[91] The third part of SIF [95] (monitor, support and sustain), was used to integrate the findings from the four studies of this thesis (Figure 3.1).

Table 3.1: Strategic implementation framework used for this project.[95]

Setting the stage	**Active implementation**	**Monitor, support and sustain**
Completed before the PhD		Scoping review of Literature on Lung cancer optimal care pathways[52]
		Quantitative analysis of system outcomes after implementing TLCRP
		Clinicians' interviews on their perspectives on acceptability and effectiveness of theTLCRP[99]
		Patient and Carer interviews on experiences and acceptability of TLCRP[37]

Model of care interventions like the TLCRP must be evaluated periodically to assess their effectiveness over time and inform iterative improvement efforts[67]. The need for practice improvement in oncology has resulted in an increasing array of practice guidelines and care pathways [152] and greater availability of metrics that identify unwarranted practice variation, gaps in care quality and adverse outcomes [153, 154]. The provision of cancer care in the Townsville region is complex because it requires multimodal treatment and interdisciplinary care delivery models, all implemented across geographically diverse settings. Strategic implementation science offers theory and methods well suited to address these complexities of lung cancer diagnosis.

Most implementation science frameworks can be used to inform evaluation of barriers and facilitators, identify stakeholders and guide the selection of implementation strategies. SIF guides the selection of implementation strategies for a given implementation need [95]In the SIF, the strategies proposed for each stage interact, allowing components of active

implementation to occur alongside efforts to set the stage for change. The SIF also includes strategies to monitor, support, and sustain practice changes through cyclical evaluations.

In cancer care, implementation strategies can be used at the patient, provider, organization and system levels. Strategies to improve uptake of any health intervention in cancer care needs to engage diverse individuals from different organisations. [155] Like other cancers, lung cancer care is delivered across several settings, from primary care to specialist respiratory clinics to oncology services. Using the SIF as a framework allows us to accommodate the challenges in coordination that occur as a patient moves from one setting to another [95] and the impact of different organisations and actors on the implementation of the TLCRP. Guided by the SIF, we focused on identifying barriers and facilitators to TLCRP from the perspective of clinicians and patients/carers, as well as auditing the clinical outcomes. But SIF face several limitations, including resistance to change, inadequate resources, lack of accountability and poor communication.[156]

Multimethods approach

Once the TLCRP was implemented, the next step was to evaluate its usefulness and acceptability to patients and clinicians. No single study was adequate to fulfil the task of evaluating all the study components. Therefore, a multi-methods design[157], using both qualitative and quantitative methods was employed for the thesis.

Using a multi-methods approach allowed for greater understanding of the focus areas of patient and clinician perspectives, service outcomes and integration of the research context. Initially, a scoping review of the literature was done to understand the evaluation of lung cancer OCPs. Studies of patients' and/or their carers' experiences of TLCRP and differing

perspectives of clinicians about TLCRP and the service outcomes of implementing TLCRP also required analysis.

Multimethod research design involves using two or more different methods of research within the same project, which can include qualitative, quantitative or both.[158, 159] This approach allows researchers to explore a topic from multiple perspectives and potentially gain a more comprehensive understanding.[157] Conducting a multimethod research project can encompass a broad range of methodologies and methods.[160] In multimethod research, different methods are used in parallel or sequence, but are not integrated until inferences are made.[161]

Complex health service interventions like the TLCRP are difficult to evaluate. Quantitative studies alone will not be able to capture the effectiveness of complex health interventions.[162] A multimethod study design allows for a comprehensive evaluation of the TLCRP as it captures not only the service outcomes, but also how the patients, carers and clinicians experienced the TLCRP. This is consistent with a mixed methods design used for literature reviews to build evidence for complex interventions[162], also incorporating the perspectives of intervention decision makers, providers and recipients.[163] The scoping review of literature on OCPs[52] included all types of studies and captured important data that would have been missed otherwise.

COM-B Framework

The COM-B framework[164] was introduced post-study as an explanatory framework to conceptualise how quality improvement solutions can be implemented. Implementation of evidence-based practices like the TLCRP depends on successful behavioural change. Given the findings from this research on barriers to uptake of TLCRP, the COM-B model for

behavioural change was thought helpful to apply to the findings as it cites capability, opportunity and motivation as three key factors in changing behaviour that are useful in understanding the results.[96]

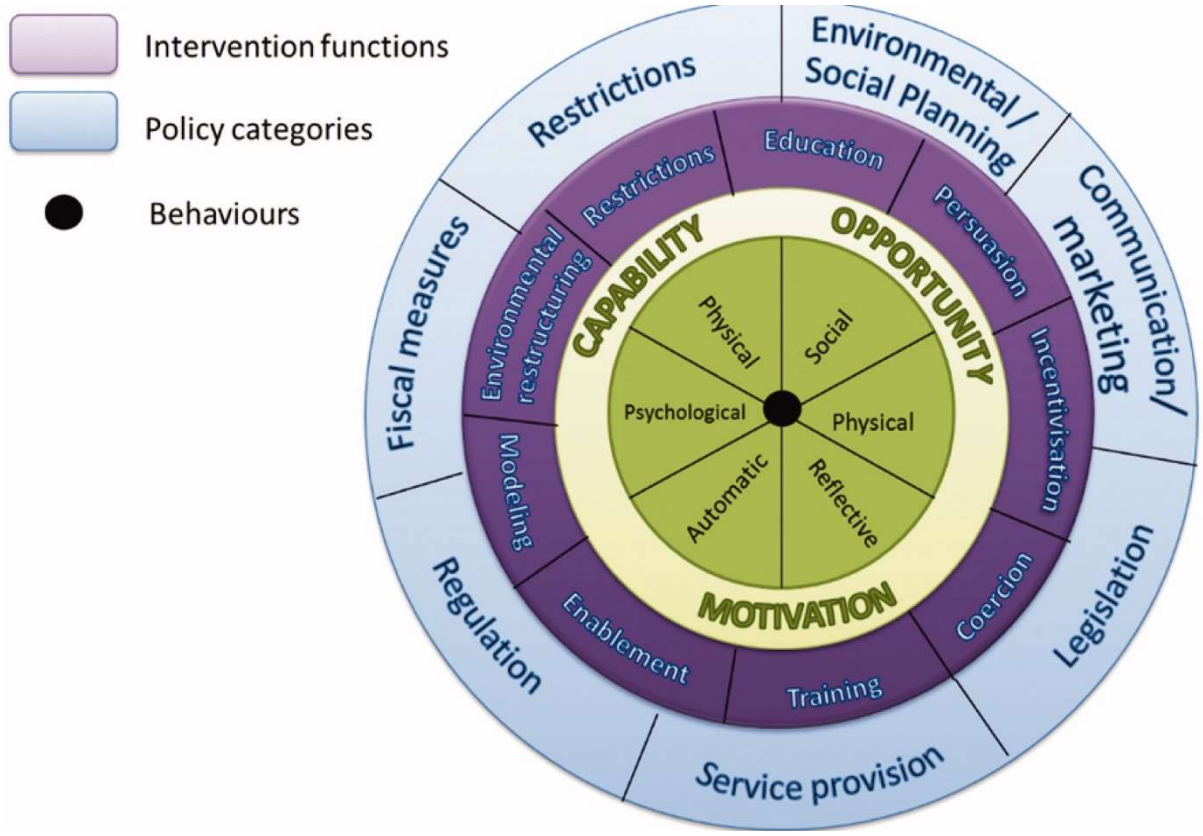


Figure 3.1 COM-B behavioural change wheel[164]

Studies

The initial part of the thesis involved a scoping review of all the available evidence on lung cancer OCPs (Chapter 2). This review of the literature used the scoping review methodology as defined by Arksey and O'Malley. [116] The lessons from the scoping review (used to guide the subsequent studies) were the following (as reported in Chapter 2);

1. OCPs recommended investigations for a person with suspected lung cancer and the timeframes for referrals.

2. The implementation of lung cancer pathways involved multiple steps and multidisciplinary teams within the oncology community.

3. Most of the care pathways were designed by clinicians who are directly involved in lung cancer management and health care researchers.

4. Lung cancer patient navigators and cancer care coordinators are essential in improving patient care.

5. Many studies used quality indicators to identify problems in the local lung cancer pathway, such as delays and non-adherence to clinical guidelines.

6. Lung cancer OCPs aim to reduce the time patients spend waiting to see a specialist for specific investigations and to start treatment.

7. Implementing an optimal lung cancer care pathway aims to improve patients' experience and satisfaction with their care.

8. Barriers to implementing lung cancer care pathways can occur at various levels of patient care. Some of the common challenges include resource limitation, diagnostic and treatment capacity. Collaborative working and good communication between various departments can overcome these issues.[112]

Study 2: Retrospective cohort study of service outcomes after implementing TLCRP

The scoping review of literature (Chapter 2) informed the next phase of this study, which was to analyse the system-level level outcomes of implementing the TLCRP. This was an exploratory retrospective cohort study, where the exposure intervention was the TLCRP. Data from the medical records were used to observe changes in timelines and document secondary variables of interest.

Background and context to study 2

A retrospective cohort study was conducted of lung cancer patients seen at the Townsville Cancer Centre (TCC). Lung cancer services at TCC (within the Townsville University Hospital) are part of the government-funded public healthcare system and comprise respiratory medicine, cardiothoracic surgery, radiation and medical oncology, palliative care, pathology and radiology. Patients with suspected lung cancer are referred to TCC by GPs in the community, other specialists, or by the Emergency Department. TCC also accepts referrals of patients outside the THHS region, as it is the tertiary referral centre for North Queensland.

Information about the TLCRP was distributed to all the GPs in the THHS region through the local North Queensland Primary Health Network (NQPHN) and the TUH GP Liaison Officer. We anticipated that 12 months after the implementation of the TLCRP would provide enough time for all the GPs to become aware of it and start using it; thus, this was the start date for the post-implementation part of the cohort study.

Australian Lung Cancer OCP [24] recommends a maximum of two weeks' time period from initial presentation to GP to initial specialist referral, and two weeks from initial GP referral

to first lung cancer specialist appointment. The rest of the study outcomes were chosen as they were clinically relevant for the participants and context of health service provision in north Queensland. Since THHS serves a large proportion of rural and remote residents, we decided to compare their timeframes to those of Townsville (non-rural) residents. Rural, regional and remote definitions were adopted from the Modified Monash Model[165]. Since the TLCRP was implemented to improve GP referral patterns for a person suspected of having lung cancer, the primary outcome of this study was the time interval from initial GP consultation to initial specialist referral.

Research question and aim

Does the implementation of TLCRP improve the timeliness of referral and other system level outcomes of people with suspected lung cancer? The aim of the study was to compare the time intervals from initial GP consultation of the person with suspected lung cancer to the first specialist referral and from the first specialist referral to initial specialist appointment, before and after implementation of TLCRP. Other service outcomes that were compared were the proportion of participants seen in lung cancer specialist clinics within two-weeks of GP referral, proportion of participants whose first GP referral was to respiratory clinic, proportion of participants diagnosed via emergency admission route, proportion of participants who had recommended imaging organised by the GP, and the median time interval from GP referral to first specialist clinic appointment for rural participants compared to those living in regional areas. These were determined based on the literature about OCPs in lung cancer.

Participants and setting

A retrospective cohort study of 316 patients was conducted and descriptive statistical analysis of the data was used to discern any difference in timelines and other clinical outcomes, in the pre-pathway implementation group compared to the post-pathway implementation group.

All patients with lung cancer seen in TCC during the following time periods were included:

- Pre-Pathway implementation group from August 2016 to July 2019
- Post-Pathway implementation group from August 2020 to July 2023

People who were diagnosed via emergency admission or from other specialist referrals were excluded from this analysis, as this study focussed on the GP referral pathway. When we started collecting the data, we found that we needed to include people seen over a period of three years before and after implementing TLCRP to have an adequate number of participants. The post-implementation period started 12 months after implementing TLCRP to give adequate time for all GPs in THHS to be informed of TLCRP.

Sample size calculations

About 100 new lung cancer patients are seen in TCC annually.In the absence of literature to guide us, investigators reached a consensus to consider 20% improvement as clinically impactful. Hypothesising an improvement of 20% in the time from initial GP consultation to specialist referral post-implementation of TLCRP, 182 cases in total were needed to determine the difference between the two groups with a power of 90% and Type 1 error of 0.05 (two-tailed test). The sample size was calculated using OpenEpi Version3 software [166].

Outcome measures

Primary outcome

The time interval (T1) from initial presentation to GP to referral to a lung cancer specialist (respiratory physician, oncologist or thoracic surgeon)[24, 108].

Secondary outcomes

- Time interval (T2) from GP referral to initial appointment with a lung cancer specialist[24].
- Median time interval from GP referral to first specialist clinic appointment for rural and remote patients compared to regional patients. Rurality was measured using Modified Monash Method 2019 version[165].
- Proportion of patients seen in the specialist clinic within two weeks of referral from the GP [141].
- Proportion of patients with suspected lung cancer referred by GP directly to respiratory clinic.
- Proportion of patients who had chest Xray and CT scan of chest organised by the GP.
- Proportion of lung cancer patients diagnosed via emergency admission rather than in the outpatient clinic.

Instruments

The quality indicators were informed by the scoping review of literature.[52] The data collection form was developed after several meetings and revisions by the investigators.

The data collection form was an excel spreadsheet containing all the required variables . A copy of the data collection form is provided in Appendix E.

Data collection

Data was collected from participants' hospital-based electronic health records, PowerChart® (Cerner Corporation, Kansas City, Missouri) and MOSAIQ® (Elekta Inc., Sunnyvale, California, USA), by the first author and two medical registrars. Cerner PowerChart is an enterprise-wide, multifacility, multi-entity, longitudinal electronic medical record. MOSAIQ is the patient management software used by the Townsville Cancer Centre (TCC) and captures all the details of patients from diagnosis to treatment and follow up. A MOSAIQ automatic report was generated in liaison with the MOSAIQ data manager to capture the key data. Where data was not available/missing in this report, it was collected from PowerChart and from GP correspondence. The data were initially collected by two junior doctors and entered into the data collection form . Later, all the data was rechecked by the PI, by going back into records. The variables collected included basic demographics (including rurality and Indigenous status), date of diagnosis, date of initial GP presentation, date of specialist referral, date of first specialist appointment, pathway of diagnosis, and investigations done by the GP prior to referral.

We could not obtain the correct date of initial GP presentation for 12 patients (6% of total), who had to be excluded from final analysis. Other data that were missing included route of diagnosis (three patients), investigations done by GP (17 patients), Indigenous status (25 patients), stage of lung cancer (22 patients) and treatment intent (18 patients).

Statistical analysis

Simple univariate descriptive statistics were used to compare the outcomes of both groups. Chi-square tests with the calculations of odds ratios and 95% confidence intervals were used to compare proportions pre and post TLCRP implementation. Fischer's exact tests were used for time comparisons where the numbers were small. T-tests were used to compare parametric demographics.

The study was reported according to SQUIRE 2.0 guidelines[167].

Data storage

The data was stored as per current departmental protocol on the computer systems and relevant databases within the Queensland Health information systems. These computer systems and databases are password-protected and accessible only by relevant clinicians. This data is routinely backed up on the hospital network and kept for a minimum of seven years. No identifying data were extracted, and the extracted data database was securely stored in a password- protected file.

Ethics approval

Ethics approval was obtained for the study from the TUH Human Research Ethics Committee (HREC/2020/QTHS/58635). Reciprocal acknowledgement was obtained from JCU (JCU HREC/ H8189). This part of the project carried negligible risk, as it did not seek to gather information about a patient beyond that collected in routine care. The project also followed the Australian Privacy Principles. It was not practical to obtain consent from all the patients as some of the data was retrospective and many patients would have died and some of

them may be very sick. Obtaining consent for these patients may have caused distress to family members. Most of these patients would have completed treatment by the time we started this study. This study protocol met the NHMRC guidelines for waiver of consent[168] and this was sought and obtained through TUH HREC.

Study 3: Patients' and their carers' experiences of the TLCRP

Another important part of this thesis was to understand the views of lung cancer patients and their carers regarding their experiences on the diagnostic pathway and their acceptability of this. We conducted a descriptive qualitative study using semi-structured interviews with lung cancer patients and their carers.

Objective

As part of evaluating TLCRP, this study aims to explore the experiences and perceptions of individuals with lung cancer and their carers about the acceptability of the TLCRP.

Research team and reflexivity

A research grant from THHS Research Trust Fund (SERTA) was obtained to employ a research nurse for conducting interviews of patients and/or their carers. Since the PI treat patients with lung cancer, PI did not recruit participants nor conduct the interviews, to avoid any perception of coercion amongst participants. The research nurse had many years of experience in clinical research and -Co-investigators provided her training on conducting qualitative interviews. PI prepared the interview guide for the semi-structured interview, which went through multiple revisions after discussions with the supervisors (Appendix 2).

Study design

Theoretical framework

The study used a qualitative exploratory framework[169] to understand the experiences of lung cancer patients and their carers. A qualitative exploratory framework is an approach used to investigate a new phenomenon and gain a deeper understanding of the topic[170]Exploratory approaches were used as we intended to explore and describe participant's experiences to understand what worked and what did not work for them, acceptability of the model, how this made them feel, and the consequences of their care.

Inclusion criteria

Newly diagnosed lung cancer patients and/or their carers, attending the University Hospital Oncology Clinic from 1st October 2020 to 30th March 2021 were eligible to participate if they were aged over 18 years, able to provide informed consent and participate in an English language interview. Patients were purposively sampled (for gender, rurality, different stages of lung cancer and treatment modalities) to ensure a range of perspectives and experiences were captured. Carers of lung cancer patients were also invited to be interviewed along with the patients. Also, if the patient was too sick to participate, only the carer was interviewed with the permission of the patient. In some cases, if both patient and carer were present, both were interviewed together. The clinic nurse who initially reviewed the patient give the study information sheet to the patient/ carer. Interviews were conducted at a time and place preferred by the patient.

Setting

The initial plan was to conduct only face to face interviews but very few patients consented for face-to-face interviews due to various reasons. There were also restrictions on hospital visits and strict infection control measures due to the COVID19 outbreak at the time. So, the protocol was amended to allow telephone interviews, and we were able to recruit an adequate number of patients and carers by using this approach. To have the interview data captured effectively, all interviews were recorded verbatim. The research nurse was employed for six months, and recruitment was completed within this period. Recruitment was stopped after 19 participants were interviewed, as no new themes were emerging and data saturation was reached.

Data collection

A semi-structured interview is a data collection method that combines a pre-determined set of open questions with the opportunity for the interviewer to explore particular responses further. [171] We chose semi-structured interviews as it was the best suited to capture all the necessary data for our study. Semi-structured interviews are both versatile and flexible and they enable reciprocity between the interviewer and the participant [172]. In a qualitative study, rigorous data collection and analysis procedures are the main factors that influence quality and trustworthiness [173]. Semi-structured interviews allowed us to collect a similar type of information from each participant and thus improve study rigour. The interview questions are based on previous knowledge, and PI had adequate knowledge of the lung cancer and consumer literature to prepare the interview guides [174]. The research team developed a semi-structured qualitative interview guide, focusing on patients' and carers' experiences of the lung cancer referral pathway and their perspectives on the acceptability

and appropriateness of the care provided (Appendix B). The initial interview questions were open-ended, in order to facilitate an inductive approach to patient experiences that did not unnecessarily "lead" participants. Follow-up probing questions were used to elicit deeper responses. Interview questions were piloted with two volunteers (a lung cancer patient and a junior doctor), and two members of the research team (ZO and AB) were present. Relevant changes were made before use to ensure the questions' appropriateness and clarity.

After obtaining written consent, a research assistant trained in oncology nursing conducted semi-structured interviews with patients and/or their carers. The interviews were conducted face-to-face or by telephone (as indicated by participant choice), at a time convenient to the patient/carer. All the interviews were audio-recorded and transcribed verbatim through an external transcribing service. The research assistant also took field notes during the interviews.

Data analysis

An iterative inductive thematic analysis was undertaken to derive key codes and themes regarding participant experiences. [175] Inductive thematic analysis is a qualitative research method where themes are derived directly from line-by-line coding applied to the data, without pre-defined criteria. Concurrent analysis was done by three investigators, including the PI, who separately read through a proportion of transcripts to familiarize themselves with the data. NVivo 12 software (QSR international, Melbourne, Australia) was used to facilitate data analysis. A co-investigator and PI generated initial inductive codes and grouped the codes into theme headings. Each code was a descriptive phrase indicating the theme of the content. This was revised and refined several times by the coders

independently and then collaboratively. The codes and themes were finalised during the group discussions to minimize bias [176]. The final codes were considered subthemes, which were then grouped under two major themes. Thematic analysis identified important insights into patient and carer experiences and their perspectives on appropriateness and acceptability of the care provided associated with the TLCRP.

Ethics

Ethics approval was obtained for the study from TUH HREC (HREC/2020/QTHS/58635). The study was reported according to COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines[177]. The trustworthiness of the study was enhanced using reflexivity, member checking, peer review and negative case analysis.[178]

Study 4: Clinicians' perspectives of TLCRP

Objective

The objective of this study was to explore the perspectives of GPs and lung cancer specialists about the effectiveness and acceptability of the TLCRP and identify perceived barriers and facilitators to using TLCRP.

Study design

The study used a qualitative exploratory framework.[169] A qualitative exploratory framework is an approach used to investigate a new phenomenon and gain a deeper understanding of the topic.[170, 179]

Research team and reflexivity

The research team included PI, AB and GK. PI and GK conducted the interviews. PI and AB did the analysis. The interviews took place during the COVID-19 pandemic in North Queensland. This made the recruitment of GPs very difficult, as many GP practices were closed, or GPs had other priorities like family commitments. Face-to-face interviews were not possible due to COVID-19 restrictions. Although all the GPs in THHS were invited through PHN newsletters, only a few of them consented. We had to call individual GPs and invite them. Finally, we were able to recruit an adequate number of GPs for data saturation.

Recruitment

Recruitment of participants followed two different but parallel pathways, GPs and specialists. GPs were identified via an address book located on the hospital intranet. All the GPs in the Townsville Hospital and Health Service (THHS) region were eligible to participate in the study. A purposive approach to recruitment of the sample was adopted by the PI and another member of research team (G K). Initially, an invitation to participate in the study was mailed to all the GP practices in the THHS. However, possibly due to the COVID-19 outbreak, only a few GPs responded to this invitation. The PI and GK then contacted GPs by telephone individually and invited them to participate. We purposively sampled the GPs to create maximum variability in the sample. All the GPs who agreed to participate were included in the study. The timeline for the recruitment of GPs was from October 2021 to May 2022. Although the final number in the maximum variation sample was decided by the number of GPs who agreed to participate, we aimed to recruit 15 GPs. GPs were emailed the Participant Information and Consent Form (PICF). They returned it to PI by email after signing.

All the hospital specialists who manage lung cancer: Respiratory physicians (N=4), Thoracic surgeons (N=2), Radiation oncologists (N=2) and Medical oncologists(N=3) were invited by PI to participate in the study. The timeline of the recruitment of specialists was from February 2022 to May 2022. Of the specialists who agreed to participate, the PI selected participants to include representation of all specialities. None of the Radiation oncologists agreed to participate. The specialists were then provided with the PICF. Once consent was obtained, PI contacted them to arrange a suitable time and place for the interview.

Data collection

After obtaining written informed consent from participants, semi-structured interviews were conducted by the principal investigator (ZO) and another member of the research team (GK). The data collection and analysis were done in parallel for both GP and specialist interviews. There were separate interview guides for GPs and specialists (Appendix C & D) . The investigators constructed the questions for the interview guide through multiple meetings, informed by knowledge of the relevant literature and the theoretical framework used. After revisions, piloting for content validity was conducted by interviewing a GP and a medical registrar. The questionnaires were modified after the pilot interviews. The interview guide contained questions on awareness of and use of TLCRP, barriers to its use and opinions on employing telehealth in the referral process.

The initial interview questions were open-ended, to facilitate an inductive approach to clinician experiences while not leading participants. Follow-up probing questions were used to elicit deeper responses. The interviews were conducted face-to-face or by telephone (as indicated by participant choice), at a time convenient to the participant. Once we were not obtaining any newer information from the GP interviews, recruitment was stopped. This

was the deciding point that informed saturation. Since there were only few lung cancer specialists in the hospital, the PI interviewed all the specialists who agreed to participate in the study. All the interviews were audio-recorded and transcribed verbatim, through an external transcribing service, to facilitate later qualitative analysis.

Analysis

An iterative inductive thematic analysis [180] of the transcripts was used to derive key codes, then grouped into themes regarding participant experiences and perceptions. Coding and thematic analysis were performed using NVivo12 software (QSR international, Melbourne, Australia), initially by the primary investigator (ZO). The process was repeated by another member of the research team (AB), to improve qualitative rigour through coder triangulation. Both investigators undertook a preliminary coding exercise, in which a code was applied to every comment made by the participants. Each code was a descriptive phrase indicating the theme of the content. The coders revised and refined this several times independently and then collaboratively. The results were then discussed in meetings with the other researchers. The final codes were considered subthemes, then grouped under two major themes. The COREQ (Consolidated Criteria for Reporting Qualitative Research) guideline was used to report the results[177] Reflexivity, member-checking, peer review, and negative case analysis enhanced the study's trustworthiness.

Ethics

Ethics approval was obtained for the study from the TUH HREC (HREC/2020/QTHS/58635). All participants provided written informed consent and transcripts were deidentified prior

to analysis by researchers. The study was conducted according to Good Clinical Practice and the Australian Code for the Responsible Conduct of Research.

Data integration

The studies have been reported separately throughout the thesis and have been published separately. However, these parts were inextricably linked. The third part of the SIF [95] (monitor, support and sustain), was used to integrate the findings from this thesis (Chapter 7). Integration of the studies occurred at the interpretation and reporting level through a narrative approach[181]. [181] The results of all four studies are connected thematically, and the quantitative and qualitative data weave back and forth around similar themes.[181]

Reflexivity

My role as a medical oncologist managing people with lung cancer has impacted this thesis , in both positive and negative ways. I used my insider knowledge about how people with lung cancer are diagnosed and managed to inform the co-design and implementation of the TLCRP. This knowledge has also helped me to formulate the research questions and interview guides. However, my role as an oncologist may have also affected how I interpret the study results. I have used various techniques to improve the rigour and trustworthiness of the study, including regular debriefing with supervisors, use of triangulation techniques (of data collection, methods and coding). and purposive sampling methods. Furthermore, in order to avoid any perception of coercion among participants, I did not conduct the interviews of patients and carers myself.

Effect of COVID 19 pandemic on the thesis

The COVID-19 pandemic, which was declared in April 2020 and lasted through to January 2022, had an impact on this study at different stages and may have affected the study results. During the pandemic, patients were encouraged to stay at home if they had respiratory symptoms and avoid consulting their GPs[182]. The GPs were also less inclined to see patients with respiratory symptoms or organise imaging studies for them. This likely resulted in a reduced number of suspected lung cancer patients being referred to the respiratory clinic and possibly caused increased delays in the referral pathway. There were also restrictions in specialist appointments and diagnostic tests. The COVID-19 pandemic also impacted recruitment of patients and their carers for the interviews. Whilst the initial plan was to conduct all the interviews face-to-face, few patients/carers consented. Once we amended the protocol to do telephone interviews, recruitment gained pace and adequate participants were recruited.

Chapter 4. Effect of TLCRP Implementation on Service Outcomes of People Suspected with Lung Cancer

Otty Z, Larkins S, Evans R, Brown A, Sabesan S. Improving timeliness of care for lung cancer patients through implementation of a web-based lung cancer referral pathway- a retrospective analysis. *Internal Medicine Journal 2025.* **DOI:** 10.1111/imj.70138	This chapter includes a modified version of the published manuscript.

Chapter overview

After the TLCRP was designed and implemented**,** it was important to analyse its service outcomes for the lung cancer patients in North Queensland. The scoping review of literature had informed the recommended timelines and quality indicators. This was an exploratory retrospective cohort study, where the exposure event was the use of TLCRP. Data were used from the medical record to observe changes in timelines and secondary variables of interest. The study compared the timelines and other Cancer Australia lung cancer OCP quality indicators for participants before and after implementation of TLCRP.

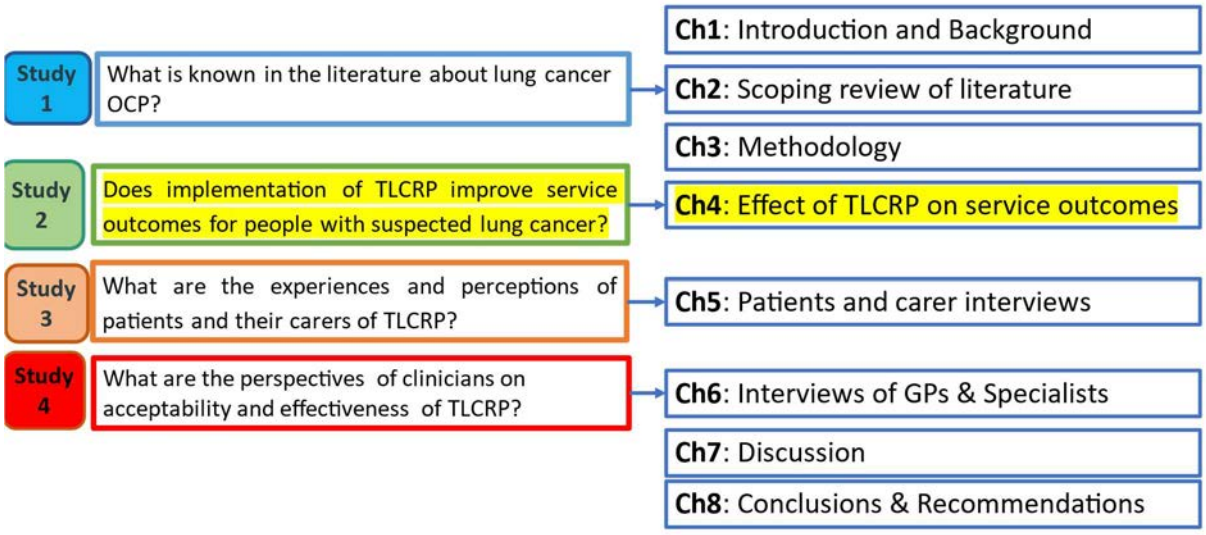


Figure 4.1 Schematic overview of thesis – chapter 4

Manuscript text

Otty Z, Larkins S, Evans R, Brown A, Sabesan S. Improving timeliness of care for lung cancer patients through implementation of a web-based lung cancer referral pathway- a retrospective analysis

Abstract

Background

The Townsville Lung Cancer Referral Pathway (TLCRP) was implemented in order to guide local General Practitioners in the referral process of people with suspected lung cancer. This study evaluates the effects of TLCRP on the timeliness of care and adherence to Cancer Australia lung cancer OCP Guidelines.

Methods

A retrospective cohort study of 316 participants was conducted and descriptive statistical analysis of the data was used to discern any difference in timelines and other clinical outcomes, in the pre-pathway implementation group (number=164) compared to post-pathway implementation group (number=152).

Interventions

Data was collected from patients' hospital-based electronic health records.

Results

The time interval from initial GP presentation to initial referral to specialist appointment was statistically significantly reduced in the post-pathway group (15 days) compared to the pre-pathway group (8 days) (p= 0.03). However, the time interval from GP referral to initial

appointment with a specialist statistically significantly increased in the post-pathway group (15 days compared to 20 days) (p = 0.03).

Implementation of TLCRP did not improve many of the lung cancer OCP quality indicators. Only 40% of the pre-pathway group and 34% of the post-pathway group were seen in the specialist clinic within two weeks of GP referral. Considerable proportions of participants in both groups did not have a chest X-ray done by the GP (62% and 57%) and the proportion of participants who was appropriately referred to the respiratory clinic did not improve after implementation of TLCRP (76% and 72%) . Nearly 30% of participants in both groups were diagnosed after emergency presentations.

Conclusions

Townsville lung cancer referral pathway improved the time interval from initial GP consultation to specialist referral, thus meeting its primary objective. However, better strategies are required to improve other timelines and meet the Cancer Australia lung cancer OCP quality indicators.

Introduction

Lung cancer remains a major public health problem and a leading cause of cancer-related mortality worldwide. [3] Around 80% of patients with lung cancer are already at an advanced stage at initial presentation, therefore excluding them from potentially curative surgical resection and radiation therapy[5]. There is concern that delays in diagnosis may be a contributing factor in the high frequency of advanced disease at presentation [183]. Studies suggest that timeliness may be particularly important for early-stage lung cancer that could

potentially be cured with surgery [33, 184]. Timeliness of care improves patient satisfaction and may also improve lung cancer survival. [9, 141, 185, 186]

In Australia, initial recognition by a general practitioner (GP) in primary health care settings and appropriate specialist referrals for definitive diagnosis and staging are critical steps in the care of people suspected of having lung cancer [29] and many studies have shown delays in these steps [36, 101, 187, 188]. Inappropriate specialist referrals can also lead to duplication of investigations, inappropriate management, all of which increases health care costs [37]. These delays are more pronounced for rural and regional Australians compared to their urban counterparts [22, 31, 32]. For example, a North Queensland study found that lung cancer patients who lived in rural and remote areas experienced delays in the time from onset of symptoms to treatment and the time from GP consultation to seeing a specialist [36]. It has been suggested that novel solutions like web-based care pathways are needed to reduce these delays [79].

HealthPathways (HPWs) is an international web-based information portal that provides health providers with over 550 condition-specific guidelines and referral pathways to specialists and services [76]. HealthPathways was developed by New Zealand's Canterbury District Health Board and subsequently adopted by health services throughout New Zealand, Australia and the UK. Each localised pathway becomes an agreement between regional primary and specialist services on how local patients with particular health conditions are to be managed in their region. There is emerging evidence that, in general, use of HPW is associated with improved referral quality from primary care, more timely access to secondary care, standardisation of clinical management decisions by GPs and

improved survival [57, 68, 71, 83]. Several authors have investigated the time taken to initiate diagnosis and treatment of patients with lung cancer [36, 101, 187, 188].

Published studies on other HPW have evaluated their usage, acceptance, satisfaction and economic benefits [38, 41, 67, 71, 72, 74, 80]. However, there is limited information on the impact of implementing HPWs on referral patterns of people with suspected lung cancer, particularly in rural and regional areas. Townsville Cancer Centre (TCC), a regional cancer centre in North Queensland, Australia (within Townsville Hospital and Health Service (THHS) serves a large rural and remote population [1]. In order to improve care of lung cancer patients in the region, TCC has started implementing an optimal care pathway for people with lung cancer [141], the initial phase being the implementation of a HPW to guide GPs on the referral process of people with suspected lung cancer. Implementation of TLCRP was publicized to all the GPs in THHS by the NQPHN through newsletters and flyers. The Townsville Hospital GPLO also organised in-person information sessions about TLCRP for selected GP clinics in the area.

Aim

The aim of the study was to compare the time interval from initial GP consultation of the person with suspected lung cancer to the first specialist referral and from the first specialist referral to initial specialist appointment, before and after implementation of TLCRP. Other service outcomes that were compared were the proportion of participants seen in lung cancer specialist clinics within two-weeks of GP referral, proportion of participants whose first GP referral was to respiratory clinic, proportion of participants diagnosed via emergency admission route, proportion of participants who had recommended imaging organised by the GP, and the median time interval from GP referral to first specialist clinic

appointment for rural participants compared to those living in regional areas. It is part of a broader project exploring the implementation of the TLCRP and its impact on lung cancer patient outcomes.

The research question for this study was, “Does implementation of TLCRP improve the timeliness and other system outcomes of people with suspected lung cancer?”

Materials and Methods

Design and setting

Pre and post-test evaluation employing a retrospective cohort study was conducted of lung cancer patients seen at the TCC between 2016 and 2023. Lung cancer services at TCC (within the Townsville University Hospital) are part of the government-funded public healthcare system and consist of respiratory medicine, cardio-thoracic surgery, radiation and medical oncology, palliative care, pathology and radiology and allied health. Patients with suspected lung cancer are referred to TCC by GPs in the community or other specialists or by the Emergency Department. TCC also accepts referral of patients outside the THHS region, as it is the tertiary referral centre for whole of North Queensland. The TLCRP was implemented and added to the Townsville HealthPathways website in August 2019. Information about the TLCRP was distributed to all the GPs and lung cancer specialists in the THHS region through the North Queensland Primary Health Network (NQPHN) and The TUH GP-Link team. GPs were informed about TLCRP through emails, flyers and updates on Townsville HealthPathways website. Advertising through NQPHN publications, particularly the monthly newsletters, was done to inform GPs about the pathway. Specialist clinicians and other health care workers who are involved in the management of people with lung cancer were also informed about TLCRP during the lung cancer MDTs and through emails. We

anticipated that 12 months post-implementation of TLCRP would provide enough time for all the GPs to become aware of the TLCRP and start using it, thus this was the start date for the post-implementation audit.

Data collection

Data was collected from patients' hospital-based electronic health records, PowerChart ® (Cerner Corporation, Kansas City, Missouri) and MOSAIQ ® (Elekta Inc., Sunnyvale, California, USA), by the first author and two medical registrars. Cerner PowerChart is an enterprise-wide, multi-facility, multi-entity, longitudinal electronic medical record. MOSAIQ is a certified health information system that manages the treatment of cancer patients in both medical oncology and radiation oncology healthcare settings. All data for patients referred to hospital specialists were entered into electronic medical records as part of standard practice, including the date of GP referral to a hospital specialist. If the date of initial consultation with GP was not available in the medical record or GP letters, the GP practice was telephoned to obtain the relevant dates. We could not obtain the correct date of initial GP presentation for 12 patients (6% of the total), who had to be excluded from the final analysis. Other data that were missing included route of diagnosis (three patients), investigations done by GP (17 patients), Indigenous status (25 patients), stage of lung cancer (22 patients) and treatment intent (18 patients).

Two junior doctors initially collected the data and entered them into the audit tool. Later, the PI and another investigator (AB) rechecked all the data by going back into the medical records. The variables collected included basic demographics (including rurality and Indigenous status), date of diagnosis, date of initial GP presentation, date of specialist

referral, date of first specialist appointment, pathway of diagnosis, and investigations done by the GP prior to referral.

Inclusion and exclusion criteria

All patients with lung cancer seen in TCC during the following time periods were included:

- Pre-Pathway implementation group from August 2016 to July 2019
- Post-Pathway implementation group from August 2020 to July 2023

Records were excluded if

1. Patients were referred by GPs outside the THHS as these GPs would not have access to TLCRP.
2. Patients were referred to private specialists, as we are not able access their data.
3. Patients without a histological confirmation of lung cancer.
4. Patients on treatment or follow-up for other cancers in the Oncology Department (no new referral required).

Primary outcome

The time interval (T1) from the date of initial presentation to GP to the date when the GP sent the referral to a lung cancer specialist (respiratory physician, oncologist or thoracic surgeon).

Secondary outcomes

- Time interval (T2) from the date of receipt of GP referral to the date of initial appointment with a lung cancer specialist.

- Median time interval from GP referral to first specialist clinic appointment for rural and remote patients compared to regional patients. Rurality was measured using Modified Monash Method 2019 version [165].
- Proportion of patients seen in the specialist clinic within two weeks of referral from the GP [141].
- Proportion of patients with suspected lung cancer referred by GP directly to the respiratory clinic.
- Proportion of patients who had chest X-ray and CT scan of chest organised by the GP.
- Proportion of lung cancer patients diagnosed via emergency admission rather than in the outpatient clinic.

Sample size and statistical power

Hypothesising an improvement of 20% in the time from initial GP consultation to specialist referral post-implementation of TLCRP, 182 cases in total were needed to determine the difference between the two groups with a power of 90% and type 1 error of 0.05 (two-tailed test). The sample size was calculated using OpenEpi version3 software [166].

Some of the variables that would likely impact the outcomes of this study were socio-demographic variables, availability of GPs, the cost impact of attending GP consultations and the COVID-19 outbreak. Other variables that would impact the outcomes were variation in the pathological type and stage of the lung cancer. About 15% of patients in both groups had small cell lung cancer, which progresses rapidly compared to non-small cell lung cancer. Different stages of lung cancer can vary in their clinical presentations, and we did not

separate different stages of lung cancer whilst evaluating time to care. There was uncertainty about the accuracy of some of the data collected.

Data analysis

Simple univariate descriptive statistics were used to compare outcomes pre- and post-pathway implementation. Chi-square tests with the calculations of odds ratios and 95% confidence intervals were used to compare proportions pre- and post-implementation. Fischer's exact tests were used to compare times pre- and post-pathway implementation. T-tests were used to compare parametric demographics . Only patients diagnosed via the GP referral pathway were included in time interval analyses. Participants who were diagnosed through ED admission or referred from other specialists were excluded from the analysis. We excluded participants diagnosed via ED admission, as they may not have seen their GP with symptoms of lung cancer and would not have followed the GP referral pathway.

Ethics approval was obtained for the study from the local Hospital and Health Service Human Research Ethics Committee (HREC/2020/QTHS/58635). All collected data was de-identified and stored in a secure computer and managed according to Australian Code for Responsible Conduct of Research.

Results

Out of 316 participants included, 164 were in the pre-pathway group and 152 were in the post-pathway group. Participant demographics are summarised in Table 4.1. The median age was 68 years and there were equal proportions of male and female patients in both groups (58% male and 42% female in both groups). Rurality, Aboriginal and Torres Strait islander status, type of lung cancer, stage of lung cancer and treatment intent in both

groups were statistically comparable. There was no statistically significant difference in the diagnostic pathways between the groups: 29.8 % of the pre-pathway group (49 participants) and 32.9 % of the post-pathway group (50 participants) were diagnosed after being admitted through the Emergency Department.

Table 4.1 Participant demographics

	Pre-Pathway N=164 n (%)	**Post-Pathway N=152 n (%)**	**p-value**
Median Age	68	68	0.96
Gender			1.0
Male	96 (58.5)	89 (58.5)	
Female	68 (41.5)	63 (41.5)	
Indigenous Status			0.44
Non-Indigenous	148 (90)	131 (86)	
Aboriginal &/or Torres Strait Islander	16 (10)	21 (14)	
Type of lung cancer			0.93
Non-small cell lung cancer	139 (84.7)	128 (84.2)	
Small cell lung cancer	23 (14)	23 (15)	
Others	2 (1)	1 (0.6)	
Lung cancer stage			0.93
1	6 (4)	4 (3)	
2	14 (9)	5 (3)	
3	37 (22)	35 (23)	
4	107 (65)	108 (71)	
Treatment Intent			0.95
Curative	42 (25.6)	38 (25)	
Palliative	122 (74.4)	114 (75)	
Diagnostic Pathway			0.56
GP	95 (57.9)	88 (57.9)	
Emergency	49 (29.8)	50 (32.9)	
Other specialists	20 (12.2)	14 (9.2)	

Locality MMM 2 (regional) MMM 3 -7 (rural & remote)	 115 46	 112 40	0.75

GP: General Practitioner; MMM Modified Monash Model

Table 4.2 Changes in time intervals for the pre-pathway and post-pathway groups. (Only participants who were directly referred by GP to a lung cancer specialist were included in the analysis).

Time interval	***Pre-Pathway*** *Median (Range) in days* ***n =95***	***Post-Pathway*** *Median (Range) in days* ***n =88***	**p-value**
Initial presentation to the GP to Initial referral to specialist (T1)	15 (1-160)	8 (1-70)	0.03
Initial referral from the GP to lung cancer specialist appointment (T2)	15 (1-90)	20 (1-76)	0.03
Initial presentation to GP to lung cancer specialist appointment (T1 + T2)	35 (2-183)	30 (6-90)	0.10

GP: General Practitioner; T1: Time interval 1; T2: Time interval

Table 4.3 Changes in time intervals for rural and remote participants compared to regional patients.

	Rural patients‡			**Regional patients†**		
Time interval	Pre-Pathway *Median in days n=46*	Post-Pathway *Median in days n=40*	p-value	Pre-pathway *Median in days n=115*	Post-Pathway *Median in days n=112*	p-value
***Initial presentation to initial referral* (T1)**	15	7	0.12	16	11	0.12
***Initial referral to Lung Specialist appointment* (T2)**	20	17	0.38	16	21	0.04

† Regional defined as MMM of 2; ‡ Rural/Remote defined as MMM of 3-7

Primary outcome

The time interval from initial GP presentation to initial specialist referral (T1) was statistically significantly reduced in the post-pathway group: eight days compared to 15 days (p= 0.03; Table 4.2).

Secondary outcomes

However, the time interval from GP referral to initial appointment with a lung cancer specialist (T2) statistically significantly increased after implementation of TLCRP: from 15 days in the pre-pathway group to 20 days in the post-pathway group (Table 4.2). The median duration from initial presentation to GP to initial appointment with a lung cancer

specialist was 35 days in the pre-pathway group and 30 days in post-pathway group, this difference was not statistically significant (Table 4.2).

Both rural/ remote and regional participants had apparent improvements in T1, although not sufficiently powered for statistical significance (Table 4.3). T2 also showed reduction for rural patients after implementation of TLCRP, although it increased in regional patients.

Table 4.4 Proportion of GP referrals meeting the quality indicators

Quality Indicator	**Pre-pathway** ***n (%)*** **n=95**	**Post-pathway** ***n (%)*** **n=88**	**P value**
Proportion of patients seen by a lung cancer specialist within 14 days of initial GP referral	38 (40)	30 (34)	0.43
Proportion of patients whose initial referral was to the respiratory clinic by GP	76 (83)	72 (81)	0.20
Proportion of patients who had a chest X-ray organised by the GP	57 (62.6)	51 (57.3)	0.54
Proportion of patients who had CT chest organised by the GP	85 (93.4)	83 (93.2)	0.98

Only 40% of the pre-pathway group and 34 % of the post-pathway group were seen in the specialist clinic within two weeks of referral from the GP, as recommended by Australian lung cancer OCP (Table 4.4) [141]. Although the majority of patients had a CT chest organised by their GPs, only 62.6% patients in pre-pathway group and 57.3% patients in post-pathway group had a chest X-ray. The proportion of patients whose initial specialist referral was to the respiratory clinic did not improve after implementation of TLCRP (81% versus 83%).

Discussion

The time interval from initial GP consultation to initial lung cancer specialist referral (T1) was statistically significantly reduced after the implementation of TLCRP. Since the aim of TLCRP was to help GPs in the diagnosis and referral of people with suspected lung cancer, the study met its primary objective. To our knowledge, this is the first study to show that a web-based referral pathway like TLCRP may help to optimise the timeliness of GP referral to specialists for people with suspected lung cancer. Both regional and rural cohorts showed improvements in T1 after implementation of TLCRP. Web-based referral pathways may help to improve referral times from GPs in other cancers as well, although this needs to be empirically tested.

However, despite meeting the primary goal, the time interval from GP referral to specialist appointment (T2) was increased in the post-implementation group. Furthermore, this study identified several gaps in adherence to the Australian Optimal Care Pathway Guidelines for people with lung cancer[141]. For example, only 30-40% of participants in this study met Australian lung cancer OCP recommendation of being seen by a specialist within two weeks of GP referral. [112, 141].There could be several potential reasons for these findings, and this finding indicates an area for future research. Some of the time delays during the post-TLCRP implementation period could be explained by the confounding impact of the COVID-19 pandemic and local workforce shortage during this period [189-192]. However, it is equally possible that these factors did not influence the findings. There was also a local shortage of respiratory physicians during this period as two of the consultants were on leave and there were restrictions on diagnostic procedures like bronchoscopy . This might indicate the sensitivity of patient flow and timeliness of care to workforce interruptions. The factors

causing delay in specialist appointments need to be addressed in the next phase of implementation of the Lung Cancer Optimal Care Pathway in TCC.

The guidelines also recommend that GPs organise a chest Xray for all patients with suspected lung cancer prior to specialist referral and computed tomography chest if the chest Xray is abnormal [141]. There was no improvement in the percentage of patients having either a chest Xray or CT chest after the implementation of TLCRP. The proportion of both time periods having a CT chest was considerably higher than those having a chest X-ray, the reasons for which should be further investigated. TLCRP will be revised according to the findings.

There was no change in the percentage of patients diagnosed via emergency admission after the implementation of TLCRP. The published literature shows that patients diagnosed with lung cancer after presenting to the emergency department with severe symptoms have worse outcomes than patients diagnosed by the GP [193]. Townsville lung cancer referral pathway sought to increase early detection of lung cancer by GPs, so that patients do not present to Emergency Department with advanced cancer. Also, the proportion of patients referred directly to a respiratory clinic by GPs did not change in the post-implementation group. When GPs refer suspected lung cancer patients to the oncologist or thoracic surgeon without histological diagnosis and staging, their diagnosis and treatment is often delayed [36].

Relatively few studies have evaluated the effect of referral pathways on the care of rural lung cancer patients [41, 72]. It was interesting to note in this study that T2 was reduced in the rural/remote cohort while it increased in the urban cohort. Although the cause was somewhat unclear, perhaps this finding could be explained by tele-health consultations not experiencing as much disruption as face-to-face consultations during the COVID-19

pandemic [194]. More rural and remote patients were seen by tele-health rather than in face to face consultations with specialists during the COVID 19 pandemic. [191]

TLCRP addresses the initial part of the lung cancer care optimal care pathway. The rest of the lung cancer optimal care pathway, including treatment and survivorship, is yet to be implemented, but the team hopes to improve overall care of lung cancer patients and compliance with the national guidelines. Lessons learned in implementing the TLCRP, including the need for better co-ordination of services, can be used to improve the referral pathways for other common cancers in THHS. Many national guidelines have been published to improve the care of people with lung cancer [141], but adherence to these guidelines is variable [195-197]. Many centres in Australia and a small number of developed countries have implemented referral pathways for common cancers[41, 119, 132]. Novel strategies have been successfully trialled in other health services to reduce the waiting time for specialist clinics, like rapid-access clinics [146, 198], increasing use of tele-medicine [64] or introducing a timed lung cancer diagnostic pathway.[109]

Strengths and Limitations

The study included an adequate number of patients to calculate the differences in timelines between both groups. Since THHS had implemented electronic medical records, all the referrals to specialist clinics were captured. There was good support from the local primary care network in educating all the GPs about TLCRP. The data collected by registrars was cross-checked by the PI. One of the components of the third part of the SIF is to monitor the usefulness of TLCRP. The cohort study has provided the baseline quality indicators that can be used to monitor TLCRP.

The study also has several limitations. The date of initial consultation with the GP could not be accurately captured for some patients. It was difficult to define the exact time when some patients initially presented to their GP with symptoms of possible lung cancer, as they also had symptoms from other chronic respiratory illnesses like chronic obstructive pulmonary disease documented in consultation records. Therefore, the study may have overestimated the time interval from initial presentation to GP with symptoms to specialist referral (T1). The study was done in a single health service and responses may have been affected by a range of local, contextual factors. The onset of the COVID-19 epidemic in Queensland occurred early 2020 and could have affected the documented timelines of care of lung cancer patients in the post-pathway period[191]. Since only bivariate comparisons were made, the complex interactions between multiple variables in the data could not be captured. Multivariate analysis could not be conducted in a meaningful way given collinearity in some of the variables.

About 15% of patients in both groups had small cell lung cancer, which progresses rapidly compared to non-small cell lung cancer. These patients often present with acute symptoms and TLCRP may be relatively less useful in managing these patients. Different stages of lung cancer can vary in their clinical presentations, and we did not separate different stages of lung cancer whilst evaluating time to care.

There was some uncertainty about some of the data such as the date of patients' first visit to the GP. The date of first visit to the GP for most patients was obtained from the GP letters. But sometimes, the patient would have been consulting the GP previously for other chronic medical conditions, and it was difficult to ascertain the exact date on which the person presented with symptoms of lung cancer. This data was unavailable in the medical

records for a few patients, and we had to obtain it by contacting the GP. We could not obtain the correct date of initial GP presentation for 12 patients (6% of the total), who had to be excluded from the final analysis. Other missing data included the route of diagnosis (three patients), investigations done by GP (17 patients), Indigenous status (25 patients), stage of lung cancer (22 patients) and treatment intent (18 patients).

Implications for future research

More research is needed to identify the degree of GP awareness about the TLCRP in the region and to address other potential barriers to the uptake of TLCRP. Then solutions can be found to eliminate these barriers. Work is underway in these areas. The initiative described in this manuscript is largely the effort of clinical champions, but adoption at system level is crucial for sustainability. This can be achieved through adequate resourcing, monitoring and quality improvement. Sustainability of TLCRP and other care pathways require adoption at a whole of health service level for adequate resourcing, monitoring and quality improvement.

Townsville lung cancer referral pathway addresses the initial part of an optimal care pathway for lung cancer patients, but implementing the rest of the optimal care pathway through to survivorship is needed. Even if people with suspected lung cancer are referred early to specialist clinics, there can be delays in specialist appointments and investigations which can adversely affect their outcomes. Strategies to reduce waiting times for respiratory clinic appointments and specialist investigations need to be implemented in order to improve the care of people with lung cancer and meet national Optimal Care Pathway Guidelines.

Conclusions

Implementation of the TLCRP reduced the time interval from initial GP consultation to specialist referral for people with suspected lung cancer in North Queensland. However, more comprehensive strategies are required to address delays in specialist clinic appointments and to meet the national Optimal Care Pathway Guidelines. Refining TLCRP and implementing the rest of the lung cancer optimal care pathway may help to improve outcomes of lung cancer patients in the region.

The next part of the thesis reports the study that explored the experiences of lung cancer patients and their carers about TLCRP. This was a qualitative study that employed semi-structured interviews.

Chapter 5. Patient and carer experiences of the Townsville lung cancer referral pathway

This study was published in *Internal Medicine Journal*.

Otty Z, Brown A, Evans R, Larkins S, Sabesan S. Patient and carer experiences of lung cancer referral pathway in a regional health service, a qualitative study. Internal Medicine Journal (2023), 1-12. DOI: 10.1111/imj.16022	This chapter is an edited version of the published manuscript.

Chapter overview

The retrospective cohort study (Chapter 4) analysed some of the important service outcomes of TLCRP implementation. However, future quality improvement activities need to include patients' and/or their carers' experiences and perspectives to ensure that services are delivered to acceptable standards. Since TLCRP was a novel intervention, patient and carer experiences could be employed to identify the deficiencies in pathway design and enable us to further improve TLCRP.

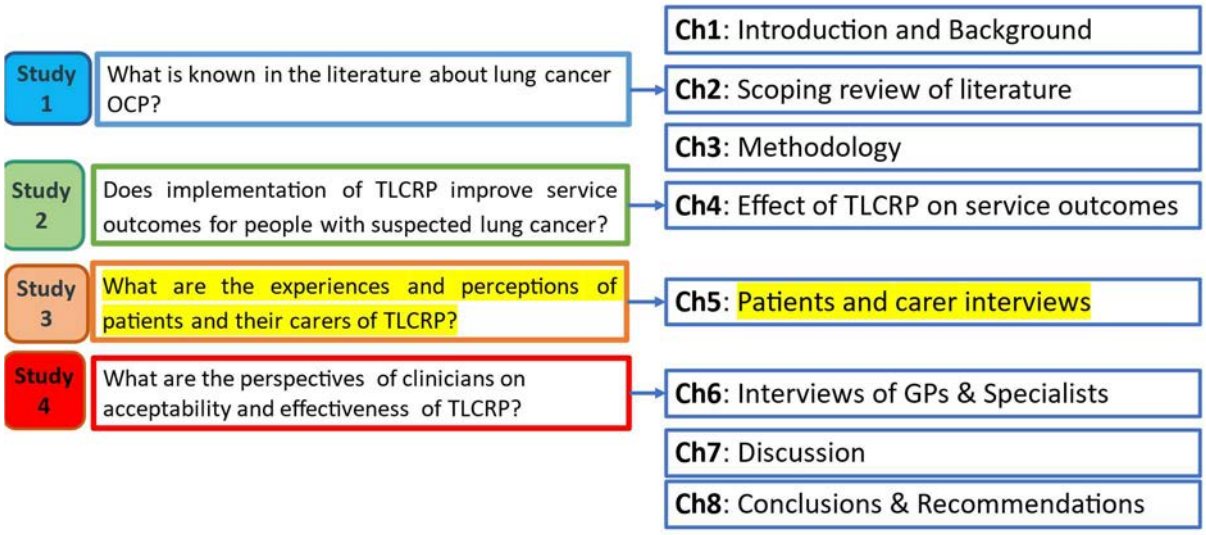


Figure 5.1 Schematic overview of thesis – chapter 5

Abstract

Background: Lung cancer referral pathways aim to reduce delays and improve referral patterns of people with suspected lung cancer.

Aim: As part of evaluating TLCRP, this study aims to explore the experiences and perceptions of people with lung cancer and carers of people with lung cancer.

Methods: The study used a qualitative exploratory framework[169] to understand the experiences of lung cancer patients and their carers. Semi-structured interviews were used to elicit data for thematic analysis. Patients with newly diagnosed lung cancer and their carers at a regional academic cancer centre were invited to participate in interviews. Five interviews were conducted face-to-face, and 14 interviews were conducted by telephone (as per interviewee preference). Interviews were audio recorded, transcribed and

qualitatively analysed. Descriptive phrases were used to generate initial inductive codes and themes.

Results: Out of the 36 participants approached, 19 agreed to take part in the study. Factors that were found to have positively impacted the care experience were good communication, timeliness and patient advocacy and support. Improper communication, long waiting times for investigations and appointments, uncertainty about the process and inconsistent advice from providers negatively impacted the care experience. Participants preferred face-to-face or video-linked consultations over telephone consultations.

Conclusions: To improve the quality of care, it is important to understand the experiences of rural and regional patients and carers while they are participating in the lung cancer referral pathway . Implementing changes to the referral pathway in order to improve patient and carer experiences needs to be an ongoing quality improvement exercise.

Introduction

To reduce variations in management approaches and delays, many health care organisations have established evidence-based referral pathways for their regions, which are often known as Health Pathways. [71, 76, 80] Locally, in North Queensland, HPWs are accessed via an online portal. This portal provides tailored, locally relevant guidance to GPs on the management and specialist referral of various medical conditions. [68]

To improve the timeliness and improve referral patterns for people with suspected lung cancer by GPs, TLCRP was added to the HPWs Townsville portal in 2019. Despite the general disruption caused by COVID-19, there was minimal impact on the structure of the TLCRP, with the main contextual change being the widespread use of telehealth for consultations.

With any health system intervention, a planned evaluation of implementation, outcomes and impact is necessary to inform improvements in service delivery. Patient and carer perspectives are a very important component of such an evaluation [199, 200]. The setting of this study is regional and rural North Queensland, servicing rural and remote locations. This might raise additional issues in terms of access, timeliness and patient preferences compared with implementation of such a pathway in a metropolitan area [32, 201].

Although studies evaluating the implementation of HPWs have been published, only a few studies have been carried out on patient and carer experiences of lung cancer referral[41, 67, 74, 202], and none of these has focused on the experiences of participants from rural areas. Analysis of English lung cancer patients suggested that patient characteristics and type of treatment influenced their expectations of care[203]. A mixed methods study exploring the experiences of lung cancer patients who presented to a UK Emergency Department found high levels of support and palliative care needs in this population [204]. A qualitative study of lung cancer patients in another Australian state suggested that early involvement of GPs and two-way communication between hospital and primary care clinicians during the disease continuum is required for improving the experiences of lung cancer patients[205].

As part of a comprehensive evaluation using an implementation science framework on the outcomes and impact of the TLCRP, we conducted a qualitative study with the aim of exploring the experiences and perceptions of lung cancer patients and their carers about their pathway experience from the point of initial presentation with symptoms to lung cancer diagnosis. This current study is part of a broader project analysing the impact of TLCRP on patient outcomes, including timeliness of care. As well as providing a better understanding of regional lung cancer patients' experiences, this study may highlight the

broad needs of lung cancer patients and their carers which, if addressed, could improve quality of care.

Methods

Objective

This study aims to explore the experiences and perceptions of people with lung cancer and their carers.

Study design and setting

The study was conducted in a regional tertiary public hospital in northern Australia, which has a catchment area of about 148,000 kilometers^2, with a significant number of geographically dispersed rural and remote communities.

The study used a qualitative exploratory framework[169] to understand the experiences of lung cancer patients and their carers. A qualitative exploratory framework is an approach used to investigate a new phenomenon and gain a deeper understanding of the topic[170]. Exploratory approaches were used as our intent was to explore and describe people's experiences to understand what worked and what did not work for them, how this affected their feelings and the consequences of their care. In this study, semi-structured interviews were conducted to elicit data, which subsequently underwent thematic analysis. This manuscript presents findings from a project that is part of a broader evaluation of the TLCRP using the strategic implementation framework[95, 206]. We developed a semi-structured qualitative interview guide, focusing on patients' and carers' experiences of the lung cancer referral pathway and their perspectives on the acceptability and appropriateness of the care provided (Appendix B). The initial interview questions were open-ended, in order to

facilitate an inductive approach to patient experiences that did not unnecessarily "lead" participants. Follow-up probing questions were used to elicit deeper responses. Interview questions were piloted with two volunteers (a lung cancer patient and a junior doctor), with two members of the research team present (ZO and AB). Relevant changes were made prior to use to ensure appropriateness and clarity of the questions.

Patient recruitment

Newly diagnosed lung cancer patients and/or their carers, attending the Townsville university hospital oncology clinic from 1st October 2020 to 30th March 2021 were eligible to participate if they were aged over 18 years, able to provide informed consent and participate in an English language interview. Patients were purposively sampled (for gender, rurality, different stages of lung cancer and treatment modalities) in order to ensure that a range of perspectives and experiences were captured. Identification of eligible potential participants was undertaken by the principal researcher (ZO), in conjunction with a co-investigator (AB) and the research assistant to ensure purposive sampling. The principal researcher (ZO), an oncologist, did not recruit participants nor conduct the interviews, in order to avoid any perception of coercion amongst participants. Instead, recruitment was undertaken by a co-investigator (AB) or the research assistant, neither of whom were involved in the patient's clinical care. Potential participants were approached while attending an oncology appointment at the hospital and the study explained to them at this time. They were given at least 24 hours to consider the study, after which time the researcher/assistant followed up with them. Recruitment was iterative to obtain variance in patient characteristics, and the interview process continued until thematic saturation was reached.

Data collection

After obtaining written consent, a research assistant trained in oncology nursing conducted semi-structured interviews with patients and/or their carers. The interviews were conducted face-to-face or by telephone, (as indicated by participant choice), at a time convenient to the patient/carer. All the interviews were audio-recorded and transcribed verbatim through an external transcribing service. The research assistant also took field notes during the interviews.

Analysis

An iterative inductive thematic analysis[175] was undertaken after the data was collected, in order to derive key codes and themes regarding participant experiences. Concurrent analysis was done by three authors (ZO, AB and RE), including the principal investigator, who separately read through a proportion of transcripts to familiarise themselves with the data. NVivo 12 software (QSR International, Melbourne, Australia) was used to facilitate data analysis. The principal researcher (ZO) generated initial inductive codes and grouped the codes into theme headings. The codes and themes were finalised during the group discussions. This process was employed to minimise intrusion of biases from any one author in interpreting data sources and generating coding and themes. The consolidated criteria for reporting qualitative research (COREQ) checklist was used as a guide to report the study findings [177].

Ethics approval was obtained for the study from the local Hospital and Health Service Ethics Committee (HREC/2020/QTHS/58635). All participants provided written informed consent. The study was conducted according to Good Clinical Practice

(https://www.australianclinicaltrials.gov.au/researchers/good-clinical-practice#australian-guidelines) and the Australian Code for the Responsible conduct of Research (https://www.nhmrc.gov.au/file/14384).

Results

After approaching 36 eligible patients and their carers, 19 participated in the study. Out of this, 14 were interviewed by telephone and five participated in a face-to-face interview. Participant characteristics are provided in Table 6.1. Data was not routinely collected regarding reasons for non-participation, though two patients indicated they felt too unwell to participate. There was one participant who identified as an Indigenous Australian. We did not collect data on Culturally and Linguistically Diverse (CALD) status.

Data analysis identified four major themes and several sub-themes. The themes were inter-connected (Figure 5.1), and the sub-themes assist in further describing important elements of the larger themes. Relevant quotations from patients and carers along with themes and sub-themes are provided in Table 5.2.

Table 5.1 Semi-structured interview participant characteristics (N=19)

Characteristic	**Number N=19**
Median age in years (range)	64 (52 – 82)
Gender	
Male	10
Female	9
Residence	
Regional	12
Rural & remote	7
Stage of cancer	
Early stage	9
Late stage	10
Type of lung cancer	
Non-small cell lung ca	16
Small cell lung ca	3
Present for Interview	
Patient only	12
Carer only	2
Patient and carer together	5
Initial presentation	
GP	8
Emergency dept	8
Other specialties	3
Indigenous Australian	1
Non-indigenous Australian	18

Figure 5.2 Themes are interconnected.

1. Quality of communication from HCPs affects patient and carer satisfaction.

'It has been quick; it has been easy, Communication has been great. Every doctor we've ever had has always been willing to answer anything I've wanted to know, like even if it's just the tiniest little question…"(58, female, urban).

2. Delays cause significant anxiety to patients and their carers.

"In [regional town], you wait six to eight weeks as an emergency to be seen, that's the point. Especially public, it's just horrendous. They have trouble with doctors staying there or whatever, I don't know but you just don't." (72, female, regional town)

3. The importance of patient advocacy, support and coordination during the referral process .

"It wasn't severe, just in the back of my mind being a nurse, I thought no let's clarify that. And it was me that persevered with our GP to say look he needs a chest x-ray. The second time I went with him and insisted. And he had chest x-ray and obviously I'm very glad he did." (carer, female, urban).

Overall patient satisfaction depends on having all these elements of care present.

Table 5.2 Themes, sub-themes and relevant quotations from patients and carers

Theme	Sub-themes	Quotations
Quality of communication fro m HCPs affects patient and carer satisfaction.	Information needs vary between patients.	*"I suppose because I don't know anything medical, don't want to see pictures, I just want to get on with it. I just want to get told what I have to do to get this over and done with."* (Patient, 55, female, regional)
		" lived on Dr Google for two weeks, trying to learn everything. One thing we did find very confusing was the staging. Trying to understand how that worked, but I did find a very good video on YouTube."(67, male, urban)
		"I think we received quite enough information. Like I think the only thing I wanted to know is, how much time have I got?" (Patient, 65, male, regional)
	Both content and type of information from HCPs are important.	"*He was upfront, he said it me that it was that they had found a mass. He said a picture paints a thousand words, so he showed me my x-rays, and showed me how one third of my left lung had collapsed and showed me the mass that was on my lung."* (Patient,52, female, regional)

	Sub-optimal communication causes distress.	*"But in very broken English over a very bad phone line, I heard that – 1) I had lung cancer, 2) it had spread to my bones, hips, spine, lymph system; with treatment would be 12 months and I would be dead. Basically, the phone call was over in 15 minutes. Suddenly it went from I'm getting no information; I'm getting information that is unexpected, uncontextualized and not given in a format where I have the opportunity to understand or ask questions."* (Patient, 61, male, regional)
	Taking patient concerns seriously during initial consultations is important.	"*It was just the coughing up blood. Because I've got COPD anyway. I do have a little bit of breathlessness all the time. The doctor told me it was pneumonia."* (Patient, 70, female, regional)
	Video-linked or face to face consultations are preferred over telephone consultations.	*"Unless it's like remote telemedicine, do it on a video link, do not do it just on a mobile phone."* (Patient, 60, male, regional).
Delays cause anxiety to patients and their carers.	Variation occurs in presentations, referral pathways and timeliness.	*"My GP practice had all different doctors, and I think in the beginning I think that they should have investigated it further."* (Patient, 75, female, rural).

		"I mean my tumour was 6cm when it was eventually diagnosed at the [metropolitan hospital] a week later. It couldn't grow just in a minute, it had to have been there for a least a long time…". (Patient,72, female, rural).
	Perceptions of causes and impacts of delays can seem	*"To me waiting 30 days to see someone to have that [the diagnosis] verified, just seems senseless to me. He said I may as well not get the treatment, sick of all this mucking around".* (Carer, female, regional).
	Uncertainty about the process is a cause of anxiety.	*"And it was just near the end that I felt like oh my God, please can we get something going, because I was really well aware of the fact there was really something there then, and I just wanted something to start".* (Patient,63, female, rural).
The importance of patient advocacy, support and coordination during the referral process cannot be overestimated.	Patient advocacy is conducted by HCPs, family and friends.	*"The specialist said, 'From now on I'm going to hand you to oncology because they are the experts in that area, and I'm just going to be your advocate. So, if you need anything from me, just ring me and I'll be your advocate for that'".* (Patient, female, 63, remote).
	Psychosocial support is important for patients and carers.	*"I'm his carer, but we do have a support worker that started in the last few years, because things were getting a bit much for me in the way of heavy work and things. I'll go to the doctors' meetings in the morning,*

		and then I go and do what I need to do while [name] stays with him." (Carer, female, regional).
	Co-ordination of care between clinicians can be poor.	*"Then I got handed over to a number of other doctors. And so come November when it all finished, there was no indication of appointment follow-ups or scan or anything. And that's where they fell down there a little bit."* (Patient,62, male, regional).

The quality of communication from health care providers (HCPs) affects patient and carer satisfaction.

When participants were asked about the quality of communication, they commented on various aspects like the clarity of information, willingness to answer any questions, being knowledgeable, and using pictures and diagrams. Having other family members accompanying them during medical consultations generally improved patients' feelings about comprehension. One elderly Indigenous patient did not understand English very well and had help from family in translating all the information.

Information needs varied among the participants, with some of them expecting detailed information, while others were satisfied with minimal information. Some patients used the internet to learn more about the cancer and treatments. Many patients and their carers were happy with whatever decisions their GP or specialist recommended to them, as they felt that the professionals knew what they were doing. The main concern expressed by many patients was about knowing their prognosis and how long they potentially had left to live.

Sub-optimal communication from clinicians caused distress to some participants. A few patients were informed of the lung cancer diagnosis and prognosis over the phone by specialists. One of them had not seen the patient previously, had a difficult accent and did not offer any time for the patient or his wife to ask any questions. Another patient felt that the specialist was not aware of all the results before the consultation.

Delays in care cause anxiety and distress to patients and their carers

Although many patients reported that all stages of their referral pathways took place in a timely manner, some patients expressed that it took too long for the GP to acknowledge their condition and arrange for necessary investigations. Many patients felt that since their GPs did not take their symptoms seriously during initial consultations, their diagnosis and treatment were delayed.

Some patients who lived in rural areas reported that their diagnosis was delayed due to frequent turnover of GPs in their area. Another concern voiced by some patients was that the delays may have caused their tumors to grow while they were waiting, which led to worse outcomes. In contrast to those with perceived delays, others reported that everything was too rushed, and they did not have time to comprehend what was going on. Participants expressed that the experience of uncertainty was hard to handle and caused considerable distress. One patient reported contemplating not having any further investigations as he was frustrated with the perceived delays.

Importance of patient advocacy, psychosocial support, and care co-ordination during the referral process

Although most participants were satisfied with the management plan advised by their GPs, some of them demanded more investigations and specialist referrals. One of the carers, who was a retired nurse, requested an urgent chest X-ray for her husband, who was being treated for pneumonia. Participants also spoke positively about experiences during which they felt that their health care providers advocated for them in accessing a needed resource or to by connecting them with another health care professional.

Although most patients did not have access to cancer care coordinators, one patient reported that her appointments were made more quickly with the help of a care coordinator. Sometimes a break in the continuity of care happened when a patient was transferred from one hospital to another. Many patients and carers received valuable emotional, financial, and practical support from family and friends while accessing health care.

Discussion

Patients and their carers in this study indicated a high level of satisfaction if they have every step of the referral pathway clearly explained to them. Our study also suggested that avoiding delays in investigations and informing patients about test results as soon as they become available can reduce patient anxiety and distress. More resources are needed in our region to provide adequate psycho-social support and improved care co-ordination for lung cancer patients. Unlike most other similar researchers considering the lung cancer referral pathway, we were able to obtain the experiences and perceptions of caregivers[193, 207]. Few studies have considered the significance of communication from health care practitioners during the lung cancer referral process and the psychological impact of delays[207-209].

The data and themes identified in this study also align with the published literature about unmet needs of cancer patients[210, 211]. Unmet needs in the *psychological domain* included 'uncertainty about diagnosis and treatment', 'emotional support', 'worry about having little control over the treatment and 'fears about the cancer growing'. Unmet needs in the *social domain* focused on support from health care services. There was notable unmet need in the *communication domain*, especially in the type and content of communication from GPs and specialists. Unmet needs in the *patient's care and support domain* included acknowledgement and showing of sensitivity to patient's feelings and emotional needs. There were multiple unmet needs identified in the *healthcare service and information domain*. These included 'being provided proper information', 'having one member of the hospital staff with whom you can always talk' and 'being informed of the test results as soon as possible.'

A similar qualitative study concerning lung cancer patients in New Zealand found that there were considerable barriers for GPs to refer patients to specialists and that these delayed treatment[207]. Similarly to results reported elsewhere, most of the patients and carers in this study complained of delays occurring in primary care [212]. Previous studies on lung cancer referral pathways have shown that failing to establish trust between patients and GPs led to delays in taking the patient's concerns seriously and thus to the GP providing inadequate information to patients[207, 208, 213]. These clinician-patient communication barriers were often exacerbated by a lack of GP continuity[207, 214], especially in the rural areas which often have difficulty in retaining GPs, which can result in poor relationships with patients[215]. Our study results are consistent with this finding.

We also found that many participants preferred face-to-face or video-linked consultations to telephone consultations. Dissatisfaction with phone consults were due to doctors' lack of communication skills over the telephone, diagnosis and prognosis given by unfamiliar doctors and lack of adequate time to ask questions. Many studies have established the advantages of telehealth in the delivery of cancer care in regional and rural areas [64, 216, 217]. In a systematic review comparing videoconferencing to telephone communication in healthcare delivery, there was no difference in patient satisfaction between the two modalities[218]. The contradictory findings in our study could be due to differences in study populations.

These findings may help to inform us about how to improve the referral process for people with suspected lung cancer. Informing the patients and their carers about the results of investigations and what to expect next will improve their satisfaction with care. THHS may need to employ more clinical staff to fulfil the unmet needs for people with lung cancer.

Strengths and limitations of the study

This study highlights many issues discovered for regional and rural patients and their carers while they are on the lung cancer referral pathway. Resolving these issues will improve the care pathway. As far as we are aware, this is the only study conducted during the COVID-19 pandemic on patient and carer experiences of the use of a lung cancer referral pathway, particularly in a rural/regional area. As the region where this study was conducted only experienced limited COVID-19 outbreaks, we expect similar results if there had not been a pandemic. The study included seven participants who live in rural and remote areas, and some of the specific problems faced by this population were captured. Given that the lung cancer diagnosis affects the life of patients as well as their carers, this study can help

researchers better understand the experiences of rural Australian patients newly diagnosed with lung cancer and their carers.

This study has some limitations. Telehealth using video-linked consultations was already in place in rural areas prior to the pandemic, but there was increased adoption of telephone consultations during this period[219]. Increased use of telephone and tele-health consultations would have impacted upon the quality of patient-clinician communication during the study period. During the COVID-19 pandemic, patients were discouraged from attending GP practices if they had respiratory symptoms[220, 221]. These changes may have contributed to delays in diagnosis of lung cancer for many patients[222], and thereby influenced their experience. This study was done in a single regional hospital and therefore only the experiences of those patients attending this hospital were captured. We may have missed patients with lung cancer who never attend oncology clinics, such as early-stage lung cancer patients who are cured after surgery. Almost all participants in this study were Caucasian and only one Aboriginal or Torres Strait Islander patient was included in the study. It is also possible that patients may not be able to recall all the details of their symptoms and investigations as described in other studies[223].

Implications for future research and practice

Given the barriers to care in the rural and remote context of Australia, understanding the experiences of regional, rural and remote users of lung cancer referral pathways is important for quality improvement efforts[26, 104]. The barriers identified in this study included perceived delays in diagnosis and specialist appointments, frequent turnover and lack of clinician time, improper communication and use of telephone consultations and lack of adequate psycho-social support. Addressing these barriers is likely to improve the patient

and carer experience of TLCRP. Some of the enablers of optimal experience of TLCRP as reported by patients included proper and adequate information provided by clinicians, supportive care and patient advocacy. The data obtained will inform ongoing quality improvement of TLCRP. Since this study is part of a broader project to evaluate the pathway, the findings will be used to prioritise improvements in TLCRP and patient/carer experiences. Further, it is important to consider the ongoing role of tele-health in the TLCRP, given it is an important part of clinical care for rural and remote patients who must otherwise travel long travel distances. Since patients and carers in this study indicated a preference for video-linked consultations over telephone consultations, general practice clinics will require access to video-conferencing facilities.

Conclusion

Understanding the experiences of rural and regional patients and carers with the TLCRP is important in improving quality of care. Factors which positively impacted the care experience were good communication, timeliness and patient advocacy and support. Sub-optimal communication, long waiting times for investigations and appointments, uncertainty about the process and inconsistent advice from providers negatively impacted the care experience. Implementing changes to Townsville Lung Cancer Referral Pathway to improve patient and carer experiences needs to be an ongoing quality improvement exercise.

The next part of the thesis explores clinicians' perspectives of TLCRP. Since the GPs and lung cancer specialists in THHS are the end-users of TLCRP, it was important to interview them and understand their thoughts and suggestions about TLCRP. The next chapter, Chapter 6, discusses clinicians' perspectives about the efficacy and acceptability of the TLCRP.

Chapter 6. Clinicians' perspectives of Townsville lung cancer referral pathway

This study has been published in the *International Journal of Integrated Care*.

Otty Z, Larkins S, Evans R, Brown A, Sabesan S. Clinicians' Experiences and Perspectives about a New Lung Cancer Referral Pathway in a Regional Health Service. *International Journal of Integrated Care,* 2024; 24(Article 3). https://ijic.org/articles/10.5334/ijic.7627, DOI: 10.5334/ijic.7627	This chapter is an edited version of the published manuscript.

Chapter overview

This study was developed to answer the research question:

What are the perspectives of GPs and lung cancer specialists regarding the efficacy and acceptability of TLCRP?

Like the previous study analysing patient and carer experiences, exploring clinicians' perspectives will help to improve service delivery. This qualitative study used semi-structured interviews with GPs and lung cancer specialists.

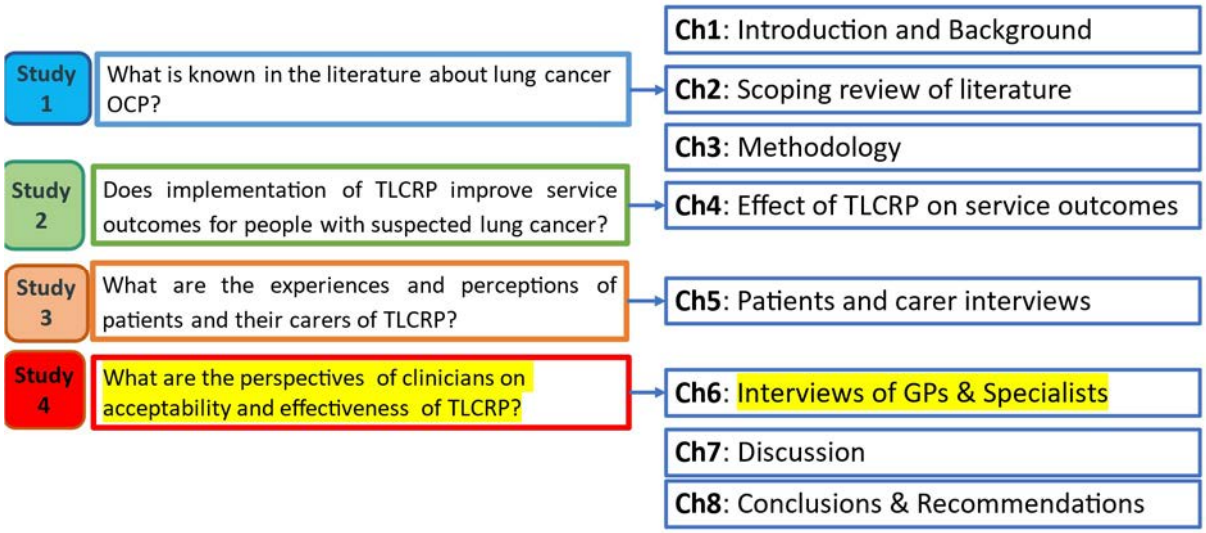


Figure 6.1 Schematic overview of thesis – Chapter 6 position

Abstract

Introduction

Development and implementation of the Townsville Lung Cancer Referral Pathway (TLCRP) aims to reduce delays and improve referral patterns of people with suspected lung cancer in North Queensland, Australia. This chapter reports the experiences and perspectives of general practitioners (GPs) and specialists of the TLCRP.

Methods

This was an exploratory descriptive qualitative study nested within a larger project evaluating TLCRP, utilising a broader implementation science framework. In-depth, semi-structured interviews with GPs and specialists were conducted. An iterative, inductive thematic analysis of interview transcripts was used to derive key codes, which were then grouped into themes regarding participant experiences and perceptions.

Results

Data analysis identified two major themes and several sub-themes. The major themes were: Variation in the uptake of TLCRP, and enhancing coordinated care and communication.

Discussion

Several enablers and barriers to implementing TLCRP were identified. Barriers to adaptation of TLCRP included lack of clinical time, resistance to changing referral patterns, lack of familiarity or experience with HPWs and technology issues.

Conclusion

Emerging themes from this study may be used to reduce the barriers and improve uptake of TLCRP and other health care pathways in the local health service and may have wider relevance in other settings.

Keywords: Referral pathways, lung cancer, clinicians' experiences, qualitative study

Introduction

Lung cancer is a leading cause of mortality and morbidity worldwide [3]. Regional, rural, and remote patients as well as Aboriginal and Torres Strait Islander patients have worse outcomes from lung cancer [25, 31, 224]. There are frequently considerable delays in diagnosis and management of lung cancer in rural patients[36, 208]. Delays in the care of people with suspected lung cancer often occur at the interface between primary care and the hospital[102]. Structured and streamlined referral of patients with suspected lung cancer is an integral part of providing optimal care for these patients [49]. There is emerging evidence that the use of online care pathways-- such as HPWs, is associated with improved referral quality from primary care, more timely access to secondary care and standardisation of clinical

management decisions by general practitioners (GPs). [38, 70, 85] This is in line with the development of integrated care pathways as best practice as is reported in the literature.[57, 86, 87]

In Queensland, Australia, HPWs are used as the point-of-care clinical practice guideline for guiding GPs on the management, and specialist referral, of various medical conditions [72, 90]. *HPWs Townsville* is the locally agreed, evidence-based clinical pathway portal used in THHS, which serves a considerable number of geographically dispersed, rural, remote and Aboriginal and Torres Strait Islander populations. Implementation of HPWs in Townsville aims to reduce delays and improve quality of care for these patients. The clinical pathways are available to local clinicians via a password-protected web-based portal. TLCRP was developed by the primary author, in consultation with local GPs and lung cancer specialists, and went online in 2019.

General practices in the health service region use an electronic referral system called Smart Referrals to refer patients to specialist clinics in the public hospital. The HPWs Townsville web portal is partly integrated within the Smart Referrals platform. Whenever a GP makes an electronic referral for a person with suspected lung cancer for specialist care, the TLCRP site can be opened, which prompts the GP to do recommended investigations prior to making the referral. The GPLO at the TUH supervised the implementation of TLCRP as they would with other HPWs.

Given the barriers to health care in the rural and remote areas of Australia, understanding the experiences of regional, rural and remote users of lung cancer referral pathways is important for quality improvement efforts [26, 27, 104, 225]. As with any newly implemented health program, it is important that periodic evaluations are conducted to assess

intervention effectiveness and inform iterative improvement efforts [67, 71, 74, 226]. Qualitative studies evaluating implementation of various care pathways have been published from Australia, New Zealand, and the United Kingdom [38, 41, 67, 71, 72, 74, 80]. However, none of these studies specifically considered a referral pathway for people with suspected lung cancer in a regional or rural setting.

This study is part of a broader project exploring the implementation of the TLCRP and its impact on patient outcomes, including timeliness of care (Table 7.1). Evaluation of patient and carer experience of TLCRP has been published[37]. This paper reports on clinicians' experiences and perspectives about the TLCRP, providing an important user perspective about its sustainability.

Methods

Objective:

The objective of this study was to explore the perspectives of GPs and lung cancer specialists about the acceptability, uptake and awareness of the TLCRP and identify perceived barriers and facilitators to using TLCRP.

Study design and setting

This study was nested within a larger evaluation project of TLCRP and employed an exploratory descriptive approach[227]. Participant groups included GPs in the health service region and specialists working at the local tertiary referral hospital. Qualitative exploratory approaches were used as our intent was to explore the clinicians' perspectives of the newly implemented TLCRP and elicit suggestions for improvement, if relevant.

The overarching implementation science framework [95, 206] for the project was the SIF, which arranges implementation strategies along the continuum of change. Various stages of this framework are interconnected and cyclical, so that the Active Implementation phase may occur alongside the Monitoring phase [95].

Recruitment

Recruitment of participants followed two different but parallel pathways, GPs and specialists. GPs were identified via an address book located on the hospital intranet. All the GPs in the Townsville Hospital and Health Service (THHS) region were eligible to participate in the study. A purposive approach to recruitment of the sample was adopted by the PI and another member of research team (G K). Initially, an invitation to participate in the study was mailed to all the GP practices in the THHS. However, possibly due to the COVID-19 outbreak, only a few GPs responded to this invitation. The PI and GK then contacted GPs by telephone individually and invited them to participate. We purposively sampled the GPs in order to create maximum variability in the sample. All the GPs who agreed to participate were included in the study. We were aiming to recruit about 15 GPs and stopped recruitment once we had interviewed 14 GPs. The timeline for recruitment of GPs was from October 2021 to May 2022. Although the final number in the maximum variation sample was decided by the number of GPs who agreed to participate, we aimed to recruit total of 15 GPs. GPs were emailed the Participant Information and Consent Form (PICF). They returned it to PI by email after signing.

All the hospital specialists who manage lung cancer: Respiratory physicians (N=4), Thoracic surgeons (N=2), Radiation oncologists (N=2) and Medical oncologists(N=3) were invited by PI to participate in the study. The timeline of recruitment of specialists was from February

2022 to May 2022. Of the specialists who agreed to participate, the PI selected participants to include representation of all specialities. None of the Radiation oncologists agreed to participate. The specialists were then provided with the PICF. Once the consent was obtained PI contacted them to arrange a suitable time and place for the interview.

Data collection

After obtaining written informed consent from participants, semi-structured interviews were conducted by the principal investigator (ZO) and another member of the research team (GK). The data collection and analysis were done in parallel for both GP and specialist interviews. There were separate interview guides for GPs and specialists (Appendix C & D). The questions for the interview guide were constructed by the investigators through multiple meetings, informed by knowledge of the relevant literature and the theoretical framework used. After revisions, piloting for content validity was conducted by interviewing a GP and a medical registrar. The questionnaires were modified after the pilot interviews. The interview guide contained questions on awareness of and use of TLCRP, barriers to its use and opinions on employing telehealth in the referral process. The initial interview questions were open-ended, to facilitate an inductive approach to clinician experiences while not leading participants. Follow-up probing questions were used to elicit deeper responses. The interviews were conducted face-to-face or by telephone (as indicated by participant choice), at a time convenient to the participant. Once we had not obtained any new information from the GP interviews, recruitment was stopped. This was the deciding point that informed data saturation, as a concept used to guide when to cease ongoing recruitment in qualitative studies.[228]

Since there were only few lung cancer specialists in the hospital, the PI interviewed all the specialists who agreed to participate in the study. All the interviews were audio-recorded and transcribed verbatim, through an external transcribing service, to facilitate later qualitative analysis.

Analysis

An iterative inductive thematic analysis [180] of the transcripts was used to derive key codes and themes regarding participant experiences and perceptions. Coding and thematic analysis were performed using NVivo12 software (QSR international, Melbourne, Australia), initially by the primary investigator (ZO). The process was repeated by another member of the research team (AB), to improve qualitative rigour. Both investigators undertook a preliminary coding exercise, in which a code was applied to every comment made by the participants. Each code was a descriptive phrase indicating the theme of the content. This was revised and refined several times by the coders independently and then collaboratively. The results were then discussed in meetings with the other researchers. The final codes were considered subthemes, which were then grouped together under two major themes (Table 7.4). The COREQ (Consolidated Criteria for Reporting Qualitative Research) checklist was used to report the results.[177]

Ethics approval

Ethics approval for this study was obtained from the Hospital Human Research Ethics Committee (HREC/2020/QTHS/58635).

Results

Descriptive findings

Twenty interviews were conducted, 14 with GPs and six with specialists, across the disciplines of respiratory medicine, oncology, and cardiothoracic surgery. All the specialists practiced in the public hospital. Of the GPs, 11 were practicing in the regional locality of Townsville and three practiced in surrounding rural areas (GP characteristics can be found in Table 7.2). The years of general practice experience varied from one to 31 years. The reported average number of people seen per year with suspected lung cancer by each GP ranged from one to 10. The average duration of the GP interviews was about 30 minutes, and the average duration of specialist interviews was about 20 minutes. Of the 14 GPs, 12 were aware of the TLCRP and seven had used it. Twelve GPs reported that they will use the TLCRP if they see a person with suspected lung cancer.

Table 6.1 GP characteristics

GP (N=14)	Years as GP	Regional (MMM 2&3) , Rural &remote (MMM 4-7)	Aware of TLCRP Y= yes, N=no	Used TLCRP Y= yes N=no	Will use TLCRP in the future. Y= yes, N=no
1	7	Regional	Y	Y	Y
2	31	Rural	N	N	N
3	12	Regional	Y	N	Y
4	15	Regional	Y	N	Y
5	5	Rural	Y	Y	Y
6	11	Regional	Y	Y	Y
7	8	Regional	N	Y	Y
8	20	Rural	Y	N	Y
9	14	Regional	Y	N	Y
10	11	Regional	Y	Y	Y
11	3	Regional	Y	Y	Y
12	12	Regional	Y	N	Y

13	5	Regional	Y	N	N
14	1	Regional	Y	Y	Y

* MMM (Modified Monash Model) to classify rurality in Australia.

Table 6.2 Specialist characteristics

Total number = 6	Medical speciality	Years of experience in Australia	Improvement in referral process after implementation of TLCRP
1	Respiratory medicine	17	yes
2	Respiratory medicine	4	yes
3	Respiratory medicine	2	yes
4	Medical oncology	11	yes
5	Medical oncology	10	yes
6	Cardiothoracic surgeon	6	yes

Thematic findings

The implementation outcomes evaluated by this study were acceptability, uptake and awareness of TLCRP. Interview analysis identified two major themes and several sub-themes, as follows (Table 6.3).

Table 6.3 Themes

Major themes	Sub-themes
Variation in uptake of TLCRP	• Awareness and use of TLCRP • Benefits of TLCRP • Barriers to implementation of TLCRP
Enhancing coordinated care and communication	• Co-ordination of patient care between GPs and specialists • Integration of telehealth in TLCRP • Support for use of TLCRP

Awareness and use of TLCRP

Most GPs were aware of Townsville HPWs and used them as part of the electronic referral system, 'Smart Referrals'.

> *We're using the HPWs more as part of the Smart Referral. It is incorporating the pathway in that Smart Referral anyway.*
>
> (Male GP, regional, 20 yrs. experience)

However, some GPs were unaware that there was a specific lung cancer referral pathway (TLCRP). Since some GPs see only a few people with suspected lung cancer annually, they did not see a need to use the TLCRP. Use of the TLCRP was more common among more junior GPs and GP trainees. Some GPs did not refer to the pathway unless they had a specific question about management of a patient. Hospital specialists had become aware of TLCRP during the focus group meetings for implementing TLCRP. GPs found TLCRP to be

user-friendly and easily accessible, but one GP mentioned that the follow-up section was superfluous.

> *"But the follow-up section is a bit long. Just talking about alcohol and exercise, nutrition. So, that might be superfluous."*
>
> (Female GP, regional, 4 yrs. experience)

Benefits of TLCRP

Many GPs mentioned that TLCRP streamlined the referral process of a person with suspected lung cancer and encouraged appropriate use of resources. They used TLCRP as a step-by-step guide to do appropriate investigations and referrals for people with suspected lung cancer. GPs also used the information provided in the TLCRP on primary prevention of lung cancer, accessing the asbestos exposure registry and educating patients. Once a patient was diagnosed with lung cancer, GPs used the TLCRP HPWs information for supportive care advice and to guide their patient education.

> *"I use it [TLCRP] more as a reference. It's very thorough when looking at early signs and symptoms, looking at risk factors. It just walks you through all the investigations to do, besides the CT scan.*
>
> *It is very handy from that respect, just to print out information about lung cancer."*
>
> (Female GP, regional, 4 yrs. experience)

GPs reported that once they started using the referral pathway and did all the necessary investigations, fewer of their referrals were rejected, resulting in earlier specialist

appointments for their patients. They felt their patients benefited via more rapid assessment by specialists and fewer duplicated investigations.

> *"It [following the TLCRP] will avoid rejections. That's the main part. Like, we usually get a lot of rejections asking us to do this investigation and re-refer again. So, it avoids that rejection of referrals a lot, because we know what to do before we send [the patient] to the specialist."*
>
> (Female GP, regional, 2 yrs. experience).

Hospital specialists felt that there had been an improvement in the quality of referrals from GPs, after the implementation of the TLCRP. Oncologists and surgeons reported seeing fewer undiagnosed lung cancer patients. These clinicians felt that, prior to TLCRP implementation, more patients used to be directly referred to oncology and surgical clinics by GPs, leading to duplication of investigations and unnecessary delays in patient care.

> *"I don't have to see unnecessarily undiagnosed patients. Patients also have a certainty of where they're heading, what they're doing, if all the providers are confident of the next step of care and everybody is talking the same thing. So, it all sort of helps them build that trust in the system, and that they feel that all the doctors are communicating with each other."*
>
> (Oncologist).

GPs were more confident in monitoring lung nodules as per the guidelines in TLCRP rather than referring all of them to the respiratory clinic.

"I don't send in the nodules if they just need to be followed up, we can do CTs every three months to follow them up, and they only get sent in if they're progressing."

(Male GP, rural, 3 yrs. experience)

GPs also reported updating their knowledge and teaching junior doctors or medical students using Townsville HPWs, including TLCRP. The TLCRP was felt to be particularly beneficial for new GPs and GP trainees as it provided them with the information required to manage and refer a person with suspected lung cancer.

Barriers to implementing TLCRP

Reasons cited by GPs in this study for not using TLCRP included:

- Lack of time to use it. Many GPs stated that they do not have enough time in consultation to use the HPWs website.

"I don't have time to go through the HPWs, even if I want to use it."

(Male GP, rural, 11 yrs. experience)

- Lack of willingness to change referral patterns.

"Having a pathway for a specific disease is very hard for me to navigate. If I only use it once a year, it'll be forgotten. I am happy with my current referral process and don't think this pathway is going to make it better."

- (Male GP, rural, 30 yrs. experience) Problems with the online referral system.

"So, I think a lot of GPs have stopped doing Smart Referrals, which kind of takes you out of the HealthPathway, because they're all linked together on the same program."

(Female GP, regional, 22 yrs. Experience)

GPs in some rural and remote locations reported unstable internet connections were problematic for using online resources such as TLCRP and some general practices did not have electronic referral systems. In addition, existing referral habits of clinicians were found to be a barrier to adoption of HPWs. Many senior GPs appeared to have entrenched referral habits and did not feel that using TLCRP would improve patient care, especially if they saw people with suspected lung cancer infrequently.

The specialists did not mention any specific barriers to using TLCRP, but they did not routinely use it.

Co-ordination of patient care between GPs and specialists

When discussing the TLCRP, clinicians expressed a need for greater integration of GP and specialist care for people suspected of having lung cancer. While the focus of this project was on TLCRP, GPs still found difficulties in accessing care for their patients with lung cancer after specialist referral was completed. There were sometimes considerable delays in respiratory clinic appointments and investigative procedures.

> *"I guess the barriers are still the interface between GPs and the hospital. Shortages in staffing. Sometimes patients can't afford to pay for the scans privately, and certainly we don't do lung biopsies privately. So, that's all got to come from the hospital. So, that's where the hold-up sometimes is".*
>
> (Female GP, regional, 22 yrs. experience)

Respiratory physicians attributed delay in specialist appointments to shortage of doctors in the department and lack of adequate investigative facilities and lack of care co-ordinator.

"I think the manpower is a big problem where there's a delay in seeing cancer patients, from a respiratory point of view."

(Respiratory physician)

"I'm just wondering whether MDT coordinators can actually have a designated job plan to say what their roles are and that'll be actually helpful". (Respiratory physician)

GPs mentioned they get frustrated by delayed feedback from specialists about their patients. The lack of a dedicated lung cancer co-ordinator in Townsville University Hospital was mentioned as one of the causes for delays in patient appointments.

Integrating tele-health into TLCRP

Telehealth was recommended by many GPs and specialists as a strategy to speed up care under the TLCRP. Clinicians used telehealth to consult with people with suspected lung cancer, to discuss results and their management.

"Since COVID has started, we have done more telehealth. When they have symptoms, we just tell them, "Hey, look, you need to go and get an X-ray or a CT scan straight away," and then organise investigations based on that.

(Male GP, rural,7 yrs. experience)

Only a few GP practices had facilities for video-linked consultations and most of them used telephone consultations. All the specialists interviewed had access to good quality video-link facilities. There were varying opinions regarding use of telehealth in the lung cancer referral pathway (TLCRP), but most clinicians agreed that telehealth helps to reduce patient travel

and improve their care. Most of the clinicians felt that telephone consultations were not appropriate to break bad news or discuss treatment options.

> *"Yeah. I find video-linked consultations are better [than phone consultations], because the patient and the treating physician or surgeon can see each other, and the understanding is better -- rather than talking over the phone. Minimise unnecessary travels and unnecessary hospital visits, et cetera".*
>
> (Thoracic surgeon)

Support for the use of TLCRP

Most GPs felt that they received good support and training for using Townsville HPWs from the GP Liaison team at the hospital and the local Primary Health Network. It was also reported that the GP liaison team regularly updated the HPWs and that this is one of the reasons for increased uptake of TLCRP.

> *"I think Primary Health Network has made that part very easy. They gave us IDs and passwords [for Townsville HPWs] and then they also have, like, merchandise and things like that. For example, they have given me a mousepad with ID and password, which is there in front of the computer all the time."*
>
> (Male GP, rural, 7 yrs. experience)

Discussion

This qualitative study provides important insights into barriers to and enablers of lung cancer referral pathway adoption in a regional Australian health service. Barriers to the adoption of TLCRP included practical and technology issues, lack of time and lack of

familiarity and experience with HPWs. Enablers to the adoption of TLCRP were the timely education and training of GPs, the usefulness of TLCRP in patient management and presence of technical support to use TLCRP.

The setting of this study is North Queensland, servicing regional, rural and remote locations. This setting might raise different issues in terms of access, timeliness and patient preferences compared to the implementation of such a pathway in a metropolitan area [201, 208]. Few studies have been done on referral pathways in rural and regional areas. As in other studies, we found that implementation of TLCRP has had a positive impact on how GPs refer lung cancer patients [41, 67, 74, 229]. Most clinicians who participated in this study felt that TLCRP streamlined and improved the quality of GP referrals, resulting in better care for people suspected with lung cancer.

Increased awareness among clinicians was identified as essential for improving the uptake of health pathways in other Australian studies [67, 79]. Lack of awareness among some participants in this study about TLCRP and its usefulness was found to be a barrier to uptake. This indicates a need to consider alternative methods of reaching primary health care clinicians in order to raise awareness (in addition to those successfully employed to date). Among those GPs that did not routinely use TLCRP, this was most often due to difficulty in accepting change to their workplace routines. Entrenched routines as barriers to adopting the use of health pathways has been previously identified [31, 230]. Further exploration of reluctance to use TLCRP and other HPWs is required.

We found that lack of integration with existing GP referral systems, inability to create electronic referrals directly from within HPWs and the busy, time-pressured nature of general practice were all barriers to using TLCRP; results that were mirrored in a region of

New South Wales, Australia. [85] A robust and secure electronic-referral system alongside HPWs is key to communication at the interface between GPs and specialists [68]. In Canterbury, New Zealand, the health pathways are integrated with the local e-referral system and this may have facilitated uptake in that community [69]. Many GPs who were interviewed reported not using the TLCRP and other HPWs if there were problems with the Smart Referrals portal or poor internet connection. The findings of the present study suggest that mechanisms to better incorporate HPWs into GPs' existing routine practice may be helpful. In particular, better integration of HPWs with Smart Referrals may improve the uptake of TLCRP and other HPWs [231].

A unique finding of this study is that junior GPs (with experience less than five years) more commonly use the TLCRP compared to senior GPs. There are several potential explanations for this. One is that new GPs are more eager to learn about navigating the health care system and are more comfortable to use novel software [232, 233]. Conversely, more experienced GPs, accustomed to a certain referral pattern for lung cancer for many years, did not feel the need to change routine practice. This difference in uptake may suggest that different implementation strategies may be required for senior GPs compared to junior GPs.

Few, if any studies have evaluated clinicians' experience of using telehealth in a lung cancer referral pathway. Telehealth became part of routine clinical practice for most clinicians during the COVID-19 pandemic, [219] during which this project was conducted. Most of the GPs and specialists were using telehealth to consult with patients with suspected lung cancer and arrange the necessary investigations required for TLCRP. We found that, quite appropriately, clinicians were not comfortable to discuss a new cancer diagnosis or break

bad news using telehealth. But, if face to face consultation were not possible, they would use telehealth, but preferred video consultation over telephone consultation.

Implications for future research and practice

This study identified several enablers and barriers to using TLCRP by the clinicians working in a regional and rural health service. Many GPs reported not using TLCRP and other HPWs due to lack of time. Time pressure is one of the common barriers to adherence to guidelines by GPs [230]. A shortage of GPs in regional and rural areas in Australia could be one of the reasons why GPs feel time pressures. Another problem faced by regional health services is the rapid turnover of GPs, [36, 215] hence many new GPs may lack awareness of *HPWs Townsville* or TLCRP. Health administrators must continue to work to overcome these deficiencies by increasing incentives for GPs to work in regional and rural areas and providing thorough orientation to the systems and supports available for new workforce arrivals. GPs also need to have more funded time for consultations to adequately evaluate patients with suspected lung cancer and appropriately use TLCRP.

Although this study concerned perceptions and experiences of the TLCRP, clinicians still discussed delays in care that were more related to the specialist workforce. Even if an appropriate referral has been completed by the GP, there can be delays in appointments to respiratory clinic due to shortages in staffing, inadequate resourcing for infrastructure such as investigative facilities, or lack of co-ordination between various specialists. Increasing the number of respiratory specialists, providing more radiology and pathology facilities and employing specialist lung cancer nurses and lung cancer care coordinators may help to reduce these delays.

Many clinicians in this study proposed the increased use of telehealth to reduce the delays in the process as prescribed by the TLCRP. People residing in rural and remote regions can be quickly reviewed by GPs and specialists through telehealth, and appropriate investigations can be quickly arranged [64]. Improving tele-health facilities and internet connections in rural and remote clinics can reduce delays and improve the uptake of TLCRP. However, GPs also need adequate resourcing, training and exposure in delivering patient care via the various telehealth options. One of reasons for increased awareness of TLCRP is the dedicated GP-liaison team, who support the GPs and update them regularly about the HPWs. A dedicated GP liaison team requires ongoing funding to increase and sustain the uptake of pathways.

Limitations of the study

This study evaluates only one health pathway, in a single regional Australian health service area, and the results may not be comparable to other types of care pathways in other locations. The responses from clinicians were sometimes on *HPWs Townsville* in general and not specifically on TLCRP. Many of the clinicians knew that the principal investigator was involved in managing lung cancer and this may have influenced some of their responses. Bias was minimised by adhering to the interview guide and assuring participants that their views and perceptions were important to the improvement of services. Another limitation of this study was that specialist nurses or allied health staff were not included in the study. The scoping review had identified the roles of specialist nurses and care coordinators in enabling lung cancer OCP implementation[52]. Radiation oncology specialists, who are an important part of lung cancer management team, did not participate in the interviews.

Conclusion

This study provides important information on experiences of lung cancer referral pathway for clinicians in a regional and rural area. Emerging themes from this study may be used to reduce the barriers and improve uptake of TLCRP and other local health pathways. Improving the uptake of TLCRP may mean that more patients in our region experience a streamlined journey to more timely specialist lung cancer care and improved health outcomes.

Chapter 7. Discussion

Introduction

This chapter integrates the findings from all the four studies using the third part of the SIF.[95] The overarching aim of this thesis was to evaluate TLCRP after its implementation. The project described in this thesis employed an implementation science approach and utilised multimethods design to analyse the impacts of pathway implementation on the timeliness of care and the clinician and patient experiences. The initial phase of the thesis was to review and synthesise international literature on lung cancer OCPs. The next phase of the thesis was to evaluate the TLCRP, using quantitative and qualitative studies to explore the experiences of patients and carers, perceptions of clinicians, and the service outcomes following implementation and to explore barriers and facilitators to the implementation. Identifying barriers and facilitators to TLCRP implementation helped us to refine the pathway and contribute to a greater likelihood of sustainability. The studies have been reported separately throughout the thesis. However, these parts were inextricably linked.

The thesis found that the TLCRP improved the timeliness of care, particularly in reducing the interval between the initial GP presentation by the patient and the initial specialist referral. However, TLCRP had minimal impact on other lung cancer OCP quality indicators. Quality indicators like the two-week timeframe for an initial specialist appointment, initial chest X-ray assessment by GP for all patients and percentage of patients referred to the respiratory clinic did not improve after implementation of TLCRP, although these results were possibly confounded by the impact of the COVID-19 pandemic. The perceptions of clinicians were positive, and the experiences of patients and carers suggested some areas of improvement as a result of the TLCRP, particularly in the areas of communication and timeliness. Similar

studies have also reported positive impacts of HPWs on patient outcomes and clinicians' experience. [38, 41, 74, 79, 81] However, there are no published studies evaluating the implementation and outcomes of lung cancer referral pathways in regional or rural health services.

Integration of studies

The third part of the Strategic Implementation Framework [95] (monitor, support and sustain), was used to integrate the findings from the four studies. The Strategic Implementation Framework was the conceptual framework that guided the project and its sub-studies and has been discussed in detail in Chapter 3 . The framework arranges implementation stages along the continuum of change, beginning with setting the stage and moving through to active implementation and then to monitoring, supporting and sustaining change(Figure 7.1).[91]

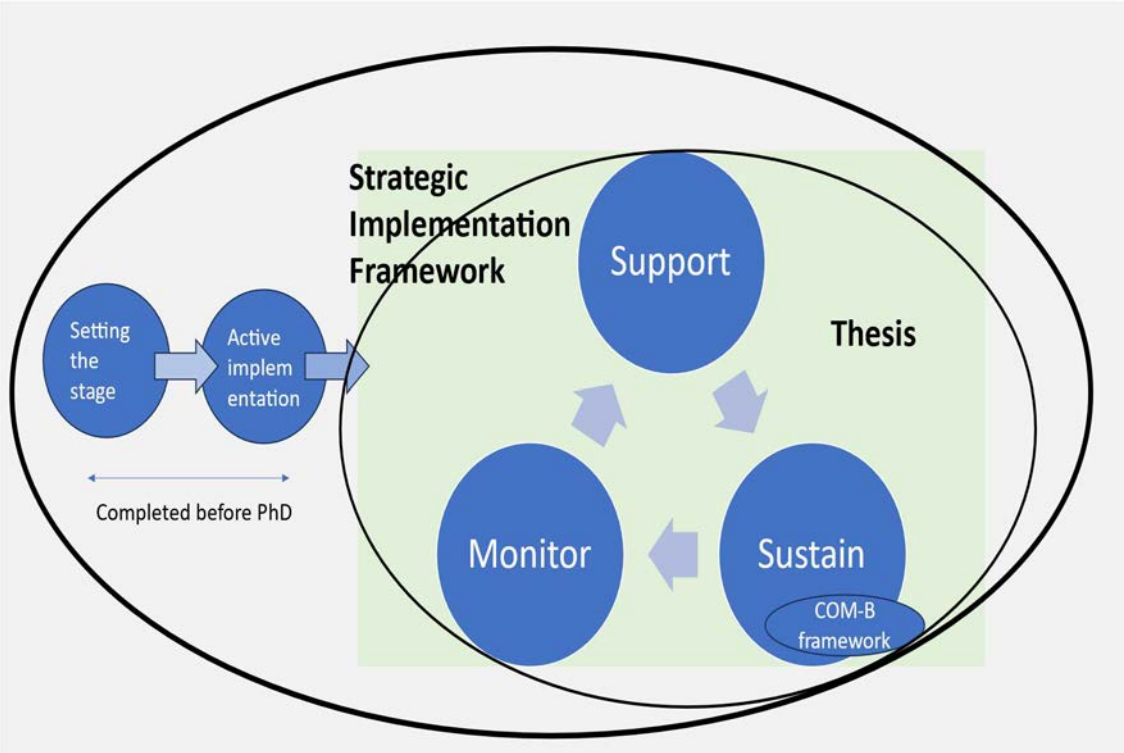


Figure 7.1 Third part of SIF used for the integration of studies.[95]

A. Monitor

With any newly implemented health programme, periodic evaluations must be conducted to assess its effectiveness to inform improvement efforts. [67, 74] Regular monitoring of TLCRP can be conducted using the quality indicators employed in this project, as well as those identified in the scoping review of the literature.[52] In the cohort study (Chapter 4), we found that many of the service outcomes proposed by Cancer Australia lung cancer OCP did not improve after implementing the TLCRP. These service outcomes, including the proportion of people with suspected lung cancer seen by a specialist within the recommended two weeks,the proportion of patients whose initial specialist referral was to the respiratory clinic and the proportion of people with lung cancer who are diagnosed through the emergency department (ED). Implementing TLCRP did not improve the time interval from GP referral to specialist appointment (Chapter 4). One reason for this may have been the shortage of respiratory physicians and diagnostic facilities like bronchoscopy at Townsville University Hospital. As discussed previously, the COVID-19 pandemic, which occurred from April 2020 to January 2022, would also have played a role in this delay.

Another quality indicator which needs to be monitored is the proportion of people with lung cancer diagnosed after ED admission. One of the aims of implementing TLCRP was to diagnose patients before their clinical condition deteriorates to the point at which they have to present to the Emergency Department for urgent assessment and care. However, the cohort study (Chapter 4) found that implementing TLCRP did not reduce the proportion of patients who had lung cancer diagnosed after presenting to the ED. There may be various reasons why the proportion of patients diagnosed through emergency admission did not improve after the implementation of TLCRP. Several other studies have shown a similar

prevalence of the emergency route diagnoses of lung cancer, as was documented by the current study. [101, 234, 235] A qualitative study in the UK found that GPs required high levels of certainty to refer patients to respiratory clinics. Concerns about system overload were widespread, so patients were referred to respiratory clinics relatively late.[236] Unsurprisingly, patient-related factors such as age, high comorbidity index score, gender, and socio-economic deprivation increase the likelihood of lung cancer being diagnosed via ED admission.[234, 235]

The delay in specialist appointments and subsequent delays in diagnosis and treatment would also have negatively impacted the patient' and carer's experience of TLCRP.[37] Delays in appointments can cause considerable anxiety for cancer patients[237, 238], and unsurprisingly, some of the participants in the qualitative study reported improved satisfaction with their care if waiting times were reduced.[37] Since the TLCRP reduces the timeline from initial consultation with the GP to specialist referral, it may help to improve the experiences of people with suspected lung cancer. One of the limitations of this project is that a measure of patient satisfaction before and after implementation was not collected.

Another finding was that only 34% of patients were seen by a specialist within the recommended two weeks. Nearly 86% of patients in southwest Victoria (Barwon Health) were seen within this timeframe after implementing a lung cancer optimal care pathway.[239] THHS has implemented only the initial phase of lung cancer OCP[24], while cancer services in Barwon Health have implemented all the phases of the lung cancer OCP since 2018. One of the reasons why the majority of lung cancer patients in Barwon Health were seen within two weeks could be that they had implemented lung cancer OCP for an extended period. Better results with Barwon Health's lung cancer pathway could also be related to geography

and the more plentiful generalist and specialist health workforce per capita in these southern regions. THHS may have to implement all the parts of the lung cancer OCP to meet all the recommended timeframes, including the initial specialist consultation within two weeks.

This thesis has reported barriers to implementation of TLCRP, similar to those reported in previous studies, including a lack of integration with existing GP referral systems, a general lack of awareness about the usefulness of the HPWs, an inability to make electronic referrals within the system and struggles to find time for TLCRP in their demanding work schedules.[41, 79, 80] Other barriers to HPW uptake were increased consultation time and deeply ingrained clinical routines.[67, 88] Recent studies reported general scepticism about care pathways and the general perception that they are inaccurate.[83, 229] In several studies, time constraints and heavy workloads of GPs (also experienced by most GPs in the THHS) are barriers to implementing any clinical practice guideline in primary care.[230, 240, 241] Another study found variation in cancer referral patterns between health services due to inflexibility of referral pathways, lack of managed routes for non-specific symptoms, primary care practitioner decision-making autonomy, and direct access to investigations by GPs.[242]

The existing referral habits of clinicians were a barrier to adopting the TLCRP. Many senior GPs appeared to have entrenched referral habits and did not feel that using TLCRP would improve patient care, especially if they infrequently saw people with suspected lung cancer. Entrenched routines as barriers to adopting healthcare pathways have also been previously identified in the literature[31]. Other reported HCP-related barriers to the implementation of clinical pathways include a lack of relevant knowledge, negative beliefs about the consequences of the pathway, and low motivation to change.[241, 243, 244]

We found that patients and carers had worse experiences of the lung cancer pathway if clinicians did not communicate with them properly.

The content of the TLCRP has to be updated regularly to keep it relevant. Majority of clinicians who were interviewed in the qualitative study approved of the content of TLCRP.[99] As with other HPWs, the GP-link team at TUH updates TLCRP periodically and informs all THHS clinicians about the changes. After the implementation of TLCRP, referral letters from GPs for people suspected with lung cancer were reported to be more thorough in the perception of hospital specialists.[99] However, this thesis did not conduct a formal assessment of the quality of GP referrals. The quality of GP referrals needs to be monitored regularly as an indicator of the usefulness of TLCRP.

The use of TLCRP by clinicians can be monitored using Google Analytics or online and telephone surveys.[41, 89] During the clinician interviews, we captured awareness and perceived usage of TLCRP by GPs. Two out of 14 GPs (14%) who were interviewed were not aware of the TLCRP.[99]

A system for ongoing feedback from GPs, specialists, and patients about TLCRP and regular auditing of the pathway would help improve TLCRP, as would more overtly incorporating the views of other health professionals and consumers/ patients.

B. Support

The clinicians who participated in the interviews felt that TLCRP and other Townsville HPWs are well-supported by Queensland Health, the local Primary Health Network, THHS, and the Townsville University Hospital GP-link team.[99] The future success of TLCRP will depend on ongoing financial and material support from these entities. Townsville Hospital and Health

Service covers a large geographical area, and the turnover of GPs in rural and remote areas is high. New GPs, especially those who recently migrated to North Queensland, may not have adequate knowledge of TLCRP and other Townsville HealthPathways. Increased awareness among clinicians was identified as essential for improving the uptake of health pathways in other Australian studies.[67, 79]

Healthcare provider-related barriers, which were identified in this thesis, can be addressed through adequate education and training. Regular education and training on TLCRP can be incorporated into existing educational programmes for GPs, medical students and other clinical staff. The TUH GP-link team conducts workshops and seminars for all the new GPs on TLCRP and other HPWs.

A robust and secure electronic referral system supporting the HPW is crucial to communication at the interface between GPs and specialists.[68] Software problems with Smart Referrals and HPWs websites or internet connectivity issues can prevent a GP from using TLCRP. Other studies have also identified unfriendly software systems and a lack of technical support as barriers to implementing clinical practice guidelines in primary care.[245, 246] Townsville HPW is linked to the Smart Referrals platform. Most GP practices have installed software compatible with Smart Referrals and HPWs Townsville. However, several practices in remote areas do not have software compatible with these websites and cannot use electronic referrals. GPs who routinely use Smart Referrals to refer patients can easily access the HPWs website and TLCRP and tend to use them more often. The Smart Referrals portal will prompt the GP to use TLCRP when initiating a referral for suspected lung cancer. Some GPs who still fax referrals rather than use electronic referrals tend not to use the HPWs, as it is an extra step for them to access it online.[99]

Successful implementation of a quality improvement project like TLCRP requires several enablers, including innovation, effective performance management, partnerships between the organisations, adequate communication between various team members, good technical support and effective political commitment to obtaining resources [247]. Several enablers for uptake of TLCRP were identified in this project, which included increased professional incentives for GPs to use HPWs like Continuous Professional Development (CPD) points from the Royal College of General Practitioners (RACGP)[99]. Other enablers were the involvement of local clinicians in updating TLCRP, positive feedback from specialists and administrators, precise clarification of the role of GPs in managing a person suspected of lung cancer. and good compatibility with most current practice software.

Patients and carers reported increased satisfaction with care if their GP kept them updated about the results of investigations progress along the pathway.[37] TLCRP recommends the GPs to inform their patients about the results of the investigations within one week. In the clinicians' interviews study, many GPs mentioned that they do not get regular communication from specialists regarding the progress of their patients, which needs to be addressed as part of improving TLCRP. [99]

Implementing any health pathway requires participation of a wide network of engaged GPs.[74] Although the benefits of using TLCRP was publicised among THHS GPs , many GPs were not using TLCRP. In Canterbury, New Zealand, the HPWs team built their credibility by delivering results within short timeframes and supporting change with extensive communication and education.[75] More targeted strategies focusing on the GPs and practices who are not currently using TLCRP and providing incentives for the use of the portal may help to increase the uptake of the pathway.[71] Alternatively, perhaps exploring different

practice workflows to facilitate TLCRP, such as focussing on the role of practice nurses in using TLCRP , could be worthwhile.

Communication in a clinical context is a core skill essential for safe and effective healthcare.[248, 249] Communication skills are especially important in telehealth and many patients and carers in this study felt that face-to-face or video-linked consultations rather than telephone-based consultations should be used to discuss sensitive and important patient management matters.[37] Although communication skills upskilling is outside the TLCRP domain, clinicians can use one of the several communication skills training programmes available.

C. Sustain

Several changes in clinical practice at THHS have been initiated by this research, which will help to sustain TLCRP in the long term. The Rapid Access Lung Cancer Clinic started this year at TUH, will be structured so that all the relevant specialists can review patients on the same day and plan their treatment. This will help to implement lung cancer OCP guidelines, which recommend that the treatment of a person diagnosed with lung cancer should begin within six weeks of the first specialist appointment.[141]

Another significant change in clinical practice at TUH has been the appointment of a specialist lung cancer nurse. In the qualitative interviews,[37, 99] we found that one of the barriers to optimal care was the lack of lung cancer nurse and care co-ordinator. Better care coordination has been shown to improve the timeliness of care, improve patient satisfaction, and reduce disparities in the care of rural cancer patients.[185, 250-252]

One of the concerns expressed by patients, carers and GPs who participated in the semi-structured interviews was the delay in initial appointment with the respiratory medicine specialist and subsequent investigations.[37, 99] Several changes have been made to reduce delays in respiratory clinic appointments at TUH. The respiratory department at TUH started a dedicated lung cancer tissue clinic in 2022 to review patients as soon as biopsy results are available. The interventional radiology team at TUH has started prioritising biopsies of suspected lung cancer, and more respiratory physicians who are trained in endobronchial ultrasound (EBUS) were recruited in 2023.

One of the most common barriers cited during the GP interviews was the lack of time to use HPWs between patient consultations.[99] This lack of time was especially pertinent for GPs who work in busy bulk-billing clinics. Time constraints make it challenging to implement any clinical guideline, especially if the GPs appear to be facing an information overload.[253, 254] Employing more GPs in THHS and empowering other clinical staff like nurses to use TLCRP may help to reduce this barrier and increase uptake of TLCRP. Better communication from GPs, specialists and other clinical staff will improve patient satisfaction and help to sustain TLCRP in the long term.

COM-B behavioural change framework

COM-B behavioural change framework[164] was introduced post-study as an explanatory framework to conceptualise how quality improvement solutions can be implemented to sustain TLCRP. The COM-B framework was a component of the third part of SIF (Sustain).

Although all the local GPs have access to TLCRP, many GPs who participated in this study did not have the capability to use it, due to a lack of time. This study also found that some GPs

lack the motivation to use TLCRP, due to various reasons.[99] Uptake of TLCRP could be increased if interventions are created that facilitate these three behavioural factors, using models like the behavioural change wheel.[164]

Table 7.1: Examples of interventions to sustain TLCRP, based on the COM-B framework.

Interventions	**Examples**
Education	Providing information on TLCRP through regular updates by GP-link team and PHN newsletters.
Persuasion	More frequent engagement of the GP-link team with GPs who don't use TLCRP.
Incentivisation	RACGP CPD points for using TLCRP.
Training	Regular training for GPs to use TLCRP.
Restriction	Accepting only the referrals containing adequate information as per TLCRP.
Environmental restructuring	Providing on-screen prompts for clinicians to use TLCRP.
Modelling	Using examples of GPs who use TLCRP regularly in CPD events or discussions.
Enablement	Reduce barriers to using TLCRP like providing more time for consultations.

Table 7.2: Examples of policy categories to sustain TLCRP, based on the COM-B

Policies	**Examples**
Communication/ marketing	Better communication between lung cancer specialists and GPs in patient management.

Guidelines	Implementing the rest of the lung cancer OCP in THHS. Disseminating the Cancer Australia lung cancer management protocols for GPs.
Fiscal	Providing monetary benefit for appropriate consultation and specialist referral.
Regulation	Establishing agreements on specialist referrals.
Legislation	Queensland Government policy to mandate the use of HealthPathways.
Environmental/ social planning	Employing adequate number of clinicians in the health service.
Service provision	Providing diagnostic facilities like CT scans and pathology in rural and remote areas.

Strengths of the thesis

Other chapters have described in detail several strengths and limitations of each part of this thesis. As far as we know, this thesis is the first to evaluate a lung cancer referral pathway in a regional and rural Australian health service. This thesis evaluated a health service intervention to reduce delays in referring people with suspected lung cancer. The thesis evaluated several aspects of TLCRP implementation, and the result has practical implications for caring for people with lung cancer.

As described in the methodology section, a multi-methods study approach was adopted for this thesis. Using multiple methods allowed for a greater understanding of the focus areas of patient and clinician perspectives, clinical outcomes, and integration of research context. Multi-methods, i.e. using quantitative methods complemented by qualitative methods, helped to evaluate the development and implementation effects of HPWs. [80, 229] Qualitative research methods are also best placed to gather the in-depth insights required to

understand the barriers and facilitators to the use of HPWs, as this information is currently not well understood by other means.[255] For example, the quantitative findings from the cohort study were further explained by using qualitative data, especially that from the clinician interviews.

The thesis used semi-structured interviews, which are better than online surveys for getting more detailed information from participants. Poor response to online surveys is common among GPs, potentially introducing non-response bias and leading to erroneous conclusions. Furthermore, GPs more engaged with HPWs could respond more often to these surveys, introducing selection bias.[38]

Limitations of the thesis

The thesis was done in a single health service, and responses may have been affected by various local contextual factors. The COVID-19 outbreak occurred in North Queensland during the study period and caused disruptions in all aspects of healthcare, including restrictions on GP consultations, diagnostic tests and specialist appointments. COVID-19 restrictions affected the timeliness of appointments and caused delays, impacting the study results. Restrictions due to the COVID-19 outbreak also affected the recruitment of interview participants.

Another limitation of this thesis is that it did not evaluate several vital outcomes of TLCRP implementation, including 1) quality of GP referrals for people suspected of lung cancer;[41, 73] 2) review of website utilisation by GPs and specialists; and 3) use by other clinical staff and students. The specialist interviews contained a few questions on improvement in quality and completeness of lung cancer referrals, but this was not assessed formally. The cost-effectiveness of implementing TLCRP was not studied.

Lack of patient or consumer involvement in the study design was another limitation. There was also a lack of specific Indigenous participation in developing the program of research for the thesis, despite the fact that about 12% of those diagnosed with lung cancer at TUH identify as Aboriginal or Torres Strait Islander. There was only one Aboriginal or Torres Strait Islander participant in the patient and carer interviews. Patient and public involvement is important in facilitating the implementation of research evidence into clinical practice and thus maximising potential benefit. [256, 257] Another limitation of this study included the possibility of self-selection bias, in that engaged users may have been more likely to respond, as was noted previously by McGeoch *et al*[38]. Some important health service outcomes like cost and sustainability of TLCRP have not been evaluated [258], as well as actual survival outcomes. Another limitation of the thesis was not including nurses and allied health staff in the clinician interview study.

However, despite these limitations, the thesis contributes to the growing literature on HPWs by providing unique new information on lung cancer referral pathways in a regional health service in Australia.

Chapter 8. Conclusions and Recommendations

This final chapter describes the impact of the program of research reported in the thesis, identifies future research opportunities in research, policy, and clinical practice, and concludes this thesis.

Impact of the thesis

There has been more support for TLCRP from clinicians and administrators, and increased momentum to implement the subsequent phase of the Lung Cancer OCP. Recent changes in the management of people with suspected lung cancer at TUH will help to strengthen and sustain the TLCRP.

A Rapid Access lung cancer clinic is one of the strategies to improve care coordination and reduce delays.[131, 146, 198] Many health services in Australia, Canada, New Zealand and the UK have developed Rapid Access lung cancer clinics to reduce diagnostic delays for people suspected of lung cancer.[198, 259, 260] The Rapid Access lung cancer clinic at TUH will be especially useful for people living far from Townsville and patients who cannot afford to travel multiple times to TUH.

There has been increasing appreciation among the GPs in the THHS about the usefulness of TLCRP in optimising the management of people with suspected lung cancer.[76] One of the respiratory physicians who participated in the interviews commented that after implementing TLCRP, GPs have become more confident in managing benign lung nodules and that fewer referrals for benign lung nodules are being made to respiratory clinics.[76] This outcome is particularly relevant as the Australian Lung Cancer Screening programme will start in July 2025, resulting in increased detection of benign lung nodules[2.52]

As mentioned in previous chapters, the work within this thesis has been disseminated widely by publications in international and national journals [37, 52, 99] and conference presentations. The study on patients' and carers' experiences was presented at the Clinical Oncology Society of Australia (COSA) annual scientific meeting in 2022, the results of the chart audit were presented at the European Lung Cancer Conference 2024, and the clinician interviews study was presented at the American Society of Clinical Oncology (ASCO) annual meeting 2024. All the studies were also presented as posters in the Townsville Hospital Research Symposium. Based on the publications, an interview was conducted by the Lung Cancer Policy Network and published in 'Care Pathways for Lung Cancer: Building a Foundation for Optimal Care.[261]

Future directions for clinical practice

To improve clinical practice and continue the lung cancer pathway across primary and secondary care, changes must be made at multiple levels: patient, provider, organisational and system. [95] The journey of a person with suspected lung cancer from initial symptoms to diagnosis, treatment and follow-up consists of multiple interconnected pathways.[262] Primary and secondary care are two distinct elements of health care; both must be addressed while developing a lung cancer pathway.[263] The overall patient outcomes will be improved only if optimal timelines for specialist appointments, diagnostic tests and treatment can be achieved. The TLCRP addresses only the initial part of the lung cancer OCP. In order to have a significant impact on the outcomes of our lung cancer patients, the rest of the lung cancer OCP also has to be implemented.[141] Knowledge gathered from this study will help us implement the rest of the lung cancer OCP, as we have identified the stakeholders (learning from our earlier omissions including consumers), informed the hospital administration

about the necessity for implementing the OCP and identified some potential barriers to implementing OCP.

Since the lung cancer screening programme using low-dose CT scans will be implemented in Australia next year, updated screening guidelines and pulmonary nodule evaluation protocols will be added to TLCRP. Symptom-based detection and diagnosis of lung cancer could be improved by training health professionals and implementing rapid referral pathways to reduce delays in assessing specialist diagnostics.[264, 265] Providing GPs and other practice staff such as nurses with lung cancer-specific information, resources, and guidelines can improve symptom recognition.[266] The free e-learning resource from Lung Foundation Australia for GPs on management of a person suspected with lung cancer, also focuses on providing safe and culturally appropriate care for Indigenous Australians.[267] GPs and specialists also need regular updates and education sessions on TLCRP. Increased incentives for GPs to use HPWs, effective communication channels between GPs and specialists, more time for GPs to review patients, and increased technical support may increase TLCRP uptake. The increased use of telehealth can reduce appointment delays for rural and remote patients [64] and there may be options to explore the involvement of other health professionals (particularly practice nurses) in the implementation of lung cancer pathway. Rural and remote areas also need more radiology and pathology services to enable early testing before referral, so TLCRP can be appropriately implemented.

Future directions for policy

This thesis has shown that health systems can be improved by clinicians empowered to do so, teamed with managers and funders who support them. This aligns with the Australian

Cancer Plan, proposed by The Australian Government in 2023. The Australian Cancer Plan is a national framework launched by Cancer Australia to improve cancer care for all Australians.[268] One of the main components of the plan is implementing Optimal Care Pathways, which outline best care recommendations across seven steps in the cancer continuum.

Several changes in health care policy for the region may be needed to address the challenges in diagnosing and treating lung cancer care in THHS. Increased investments in the prevention of lung cancer, such as the promotion of smoking cessation, can yield better results in the long term. Public awareness campaigns can communicate key information about lung cancer to many people.[269] Another critical health service issue in THHS is the lack of clinicians across both primary and specialist care. Training nursing staff and practice nurses and involving them directly in the referral process along with other healthcare providers may also reduce delays in the lung cancer patient's journey.

Since lung cancer affects people of lower socio-economic status and those of Indigenous background disproportionately[1, 270, 271], implementing care pathways alone may not be sufficient to achieve equity in their care. Extra resources must be allocated to improve care pathways for rural, remote and Indigenous people with suspected lung cancer. Healthcare services must be proactive and provide all the support needed to ensure that these people get proper investigations and appointments without delay. Employing more Indigenous clinical staff, cancer care coordinators, and social workers in rural and remote clinics may be one of the ways to achieve this, such as through better coordination of appointments and investigations. Cancer Australia has published an Optimal Cancer Care Pathway for Indigenous people with cancer, which addresses some of the specific problems faced by

Indigenous patients. [272] Implementing TLCRP and lung cancer OCP should ideally be based on a solid understanding of social, cultural and community contexts to ensure success.

Future directions for research

More research is needed on improving TLCRP and increasing its uptake among clinicians. Improving the implementation of evidence-based practice depends on successful behavioural change interventions.[96] Further research on using these behavioural change focussed frameworks [164] and interventions for continued sustainability of TLCRP is needed. More research is also needed on effect of TLCRP on implementation outcomes like cost, survival and sustainability of TLCRP.[258, 273] Since TLCRP and other HPWs are linked to the 'Smart Referrals' portal, better digital technologies and improved system interoperability may assist with information management and maximise pathway efficacy. More research is also needed to address the specific challenges faced by lung cancer patients who live in rural and remote areas, like travel and accommodation, out-of-pocket expenses and lack of care coordination. Since the COVID-19 pandemic may have affected the results of the timeliness study, repeating the audit of the post-implementation cohort when there is no pandemic will provide us with a more accurate analysis of clinical and service outcomes of TLCRP.

Conclusions

This PhD thesis addresses a knowledge gap in the evaluation of a lung cancer referral pathway within a regional health service in Australia. Implementing TLCRP reduced the time interval from initial GP presentation to specialist referral. Clinicians' experiences with using TLCRP were largely positive, but patient and caregiver interviews suggested areas for improvement in the TLCRP. Knowledge gained from this project has the potential to help

implement remaining components of a lung cancer OCP (steps 3 to 7 of the OCP), and thereby, further improve outcomes for lung cancer patients.

The findings of this thesis have been directly translated into local clinical practice changes to inform patient-centred care and ultimately improve the lives of people with suspected lung cancer. However, several challenges remain for the sustainability of TLCRP, like optimising resource allocations, facilitating education and technical support, and prompt implementation of the rest of the lung cancer OCP in THHS. Integrating TLCRP and other HPWs into routine practice requires adopting these models as programs at all state and national health systems layers through enabling policies, procedures, infrastructure, and monitoring mechanisms. The sustainability of TLCRP and other HPWs in THHS requires ownership and oversight by system leadership and clinical governance involving all end-users.

Post-script

My PhD journey

I have always been interested in clinical research, which is one of the main reasons for my specialisation in medical oncology. Patients with cancer face many challenges including challenges in simply accessing treatment, which are exacerbated for rural and remote residents. In order to improve outcomes for cancer patients I have participated in numerous clinical and translational research projects in the Oncology Department.

While doing my fellowship in medical oncology, I had published in peer-reviewed journals and presented at conferences. However, publishing my PhD projects in peer-reviewed journals was a very valuable experience. I learned a lot about writing for academic

publications while revising the articles with my supervisors and from the feedback from journal reviewers/ editors.

Like most other candidates, my PhD journey has been challenging but exciting. Although I completed this PhD part-time, it was difficult to find time to complete the projects between my professional responsibilities and family activities. Nonetheless, I was able to complete the projects on time and continue with the course only because I had excellent support from my supervisors. All my previous experience in research had been using quantitative methodology. During my training as a physician and medical oncologist, I have had only minimal exposure to qualitative research. I started my PhD with little knowledge about qualitative studies or mixed methods research. Now, after completing two qualitative studies and one quantitative study, I am more confident about this mode of clinical research. Attending the JCU Cohort Doctoral Studies Program sessions helped me significantly in understanding qualitative methodology. I also completed the JCU postgraduate course on qualitative research methodology.

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Appendix A: TLCRP

Lung Cancer

Red flags

- Massive or persistent haemoptysis (>100 ml blood)
- Stridor
- Respiratory distress
- Signs of superior vena cava obstruction e.g. dyspnoea, facial plethora

Background

About lung cancer

About lung cancer

- Lung cancer is the leading cause of cancer death in Australia. It is the fourth most commonly diagnosed cancer. [1]
- About 90% of cases in males and 65% in females are associated with smoking (though the women may well have been exposed to secondary smoke). [2]
- Survival after lung cancer diagnosis at any stage is improved by quitting smoking. [1]
- Early detection leads to better survival rates. Best rates are in early, fully resectable disease, otherwise survival is only about 15% at 5 years. [3]

Assessment

Practice point

Have high index of suspicion

Normal chest X-ray does not exclude lung cancer. [2]

1. If symptomatic, screen for lung cancer.
2. Consider lung cancer if:
   - unexplained ⌄ symptoms and signs for > 3 weeks duration, or

Symptoms and signs [2]

Multiple symptoms and signs compound the risk:

- New or changed cough, especially in smoker or patient with a high-risk occupation
- ⌄ Signs of superior vena cava obstruction
- Persistent or non-resolving cough
- Haemoptysis
- Stridor
- Persistent localised wheeze
- Chest and/or shoulder pain
- Shortness of breath
- Hoarseness
- Weight loss or loss of appetite
- Unresolved chest infection
- Abnormal chest signs
- Finger clubbing
- Cervical and/or supraclavicular lymphadenopathy
- Signs of pleural effusion

   - ⌄ risk factors .

Risk factors

- Tobacco smoking
- COPD
- Heavy marijuana use
- Passive smoking
- Radon exposure
- Occupational exposure e.g., asbestos, diesel exhaust, industrial pollution, mining
- Air pollution
- Age over 55 years
- Family history of lung cancer
- Previous lung diseases, including previous lung cancer

- Previous smoking-related cancer e.g., head and neck cancer
- Geographical area – Southwest Asia
- Socioeconomic status.
- Ethnicity – Aboriginal and Torres Strait Islander, Middle Eastern and South-East Asian communities

3. Investigations:

- If any ✓ red flags , organise urgent CT chest with contrast if it doesn't delay request for acute respiratory assessment.

Red flags

- Massive or persistent haemoptysis (>100 ml blood)
- Stridor
- Respiratory distress
- Signs of superior vena cava obstruction e.g. dyspnoea, facial plethora

- If risk factors or possible signs of lung cancer, arrange ✓ chest X-ray .

Chest X-ray

- Incidental finding of a lung nodule is common. The patient is usually asymptomatic.
- Not all solitary lung nodules on X-ray are malignant. Differentials include hamartoma and post-infection granuloma.
- Comparison with previous chest X-rays is helpful. If there are no previous X-rays, repeat in 6 months.
- A normal chest X-ray does not exclude lung cancer. [2]
- If the nodule has not changed in size for the past two years, it is nearly always benign.
- Calcification of the nodule can suggest a benign lesion.
- A primary malignant nodule typically has a shaggy, speculated or lobulated margin, however a smooth margin cannot exclude malignancy.

  - If abnormal chest X-ray or ✓ other indications , organise CT chest with contrast (not high resolution).

Indications for a CT chest with contrast

- Chest X-ray suggesting lung cancer.
- High clinical suspicion with multiple risk factors for lung cancer (despite normal chest X-ray).
- Pleural effusion.

- Persistent consolidation (> 6 weeks).
- Persistent symptoms (despite normal chest X-ray).
- Any solid nodule < 6 mm in a smoker

  - If any indication of the non-lung primary cancer, where possible, organise a CT brain, thorax, abdomen with or without bone scan.
  - Have a high level of suspicion, a normal chest X-ray does not exclude lung cancer. [2]

- Consider blood tests – FBC, E/LFT, calcium

Management

1. If any ✓ red flags , request acute respiratory assessment (with CT chest with contrast arranged if it doesn't delay referral).

Red flags

- Massive or persistent haemoptysis (>100 ml blood)
- Stridor
- Respiratory distress
- Signs of superior vena cava obstruction e.g. dyspnoea, facial plethora

2. If a likely primary pulmonary nodule is visible on chest X-ray or CT scan, request non-acute respiratory assessment (mark as urgent) for tissue diagnosis and staging.
3. Request non-acute respiratory assessment if imaging shows:
   - a nodule > 6 mm in diameter.
   - multiple ground glass and/or part solid nodules < 6 mm.
   - any nodule in patients with history of cancer.
   - any increase in nodule size on repeat imaging.
4. If a tissue biopsy confirms lung cancer and CT chest shows a lung mass, request non-acute cardiothoracic surgery assessment if not already organised.
5. If consolidation seen on chest X-ray, treat as pneumonia and repeat imaging in 4 weeks.
6. If any solid nodule < 6 mm present in patient with ✓ risk factors  , repeat CT chest with contrast in 12 months.
7. If a patient has concerns about asbestos exposure:
   - inform the patient that having lived in a house with loose-fill asbestos (e.g., Mr Fluffy) does not put them in the high risk category by itself.
   - offer a baseline chest X-ray.
   - recommend registration with the National Asbestos Exposure Register .

Follow-up

A treatment summary and follow-up care plan will be provided after initial treatment (request if not provided).

1. Ensure appropriate follow-up, including monitoring of the status of the disease, detection of any metastatic disease, and management of symptoms that arise following the initial treatment.

> **Metastatic disease**
>
> Lung cancer is most likely to metastasise to liver, bone, and brain, which may cause a wide range of metastatic complications, including:
>
> - Superior vena cava obstruction
> - Spinal cord compression
> - Hypercalcaemia of malignancy

   - The care plan should avoid excessive follow-up by multiple specialists.
   - The general practitioner has a role in the management of any underlying respiratory disease, and in coordination of follow-up.
2. At each consultation, consider symptoms of possible recurrence or metastases.
3. Ensure the patient is making healthy lifestyle choices regarding:
   - alcohol intake.
   - exercise.
   - nutrition.
   - smoking cessation.
4. Provide ongoing support of patient and family and psychosocial management throughout the course of cancer treatment and after.

> **Psychosocial management**
>
> - Ask the patient how they are feeling emotionally at every visit.
> - Ask the patient how they are feeling about treatment.
> - Listen to fears and concerns about treatment and prognosis.
> - Provide the patient with information about counselling and arrange a referral, if needed.

> **Support for the patient and family**
>
> Ask the patient:
>
> - about their support network and the level of support provided.
> - how their family and partner are dealing with their cancer.

- if they have others with whom they can openly discuss their thoughts and feelings about their situation.
- who assists them with practical matters e.g., transport, work, childcare.

5. Consider Cancer Support Services, addressing:
   - psychological needs.
   - financial and legal needs.
   - practical and transport needs.
   - support groups and referral services.
6. Offer patient information about:
   - Lung Foundation resources .
   - referral to a lung cancer support nurse for patient and family support.
7. Consider Advanced Care Planning (ACP).
8. If required, arrange palliative care.

Request

- If any ✓ red flags , request acute respiratory assessment (with CT chest with contrast arranged if possible).

Red flags

- Massive or persistent haemoptysis (>100 ml blood)
- Stridor
- Respiratory distress
- Signs of superior vena cava obstruction e.g. dyspnoea, facial plethora

- If a likely primary pulmonary nodule is visible on chest X-ray or CT scan, request non-acute respiratory assessment (mark as urgent) for tissue diagnosis and staging.
- Request non-acute respiratory assessment if imaging shows:
  - a nodule > 6 mm in diameter.
  - multiple ground glass and/or part solid nodules < 6 mm.
  - any nodule in patients with history of cancer.
  - any increase in nodule size on repeat imaging.
- If a tissue biopsy confirms lung cancer and CT chest shows a lung mass, request non-acute cardiothoracic surgery assessment if not already organised.
- If required, refer to a lung cancer support nurse for patient and family support.
- Consider Cancer Support Services, addressing:

- psychological needs.
- financial and legal needs.
- practical and transport needs.
- support groups and referral services.

- If required, arrange palliative care.

Information

For health professionals

For patients

SOURCES

References

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Appendix B: Patients/ Carers Interview Guide

Semi-structured interview guide for people with lung cancer/carers

Patient journey-I would like to first talk about your experience of being diagnosed with Lung Cancer.

1. Could you please tell us about the process of being diagnosed with lung cancer? *[Get as much detail about their journey to diagnosis. Go through any of the following which are not covered initially by the participant.]*
   - What were your initial symptoms?
   - What investigations (Xrays, CT scans, biopsy) were organised by your GP when you presented with these symptoms?
     - If symptoms: Did you feel your symptoms were addressed by your GP?
   - What specialist/doctor did you see first (after your GP)? What investigations were done before you saw a specialist?
   -

Patient information- It is important for us to understand how much- and what- information is helpful to patients in their lung cancer journey.

2. What were you told about your cancer before seeing the specialist?
   - When were you told this information?
   - Which doctors gave you this information?

2b. Did you understand the information given, and was a plan discussed?
   - If yes - what information do you feel was important at various points in your journey? E.g. results of investigations, next steps in the referral pathway, management plans…
   - If no – what more information would you have liked to receive?

Timeliness of care-I would like to know whether your care took place in a timely manner.

3. How do you feel about the timeliness of your lung cancer management so far?
   - getting appointments quickly
   - referrals done for investigations
   - referrals to specialists

4 Do you think the waiting time from seeing the GP about your symptoms to your first appointment with a specialist was acceptable?
   - If no: Why is that so? (*teasing out delays, particularly if not medical*)

   - Overall, do you feel that you saw the doctors as quickly as you would have liked?

If no: where do you think there was potential for improvement?
(i.e. for which appointments/tests)

5. Do you feel that all your tests were done as quickly as you would have liked?

Referral pathway-next , I would like to get your perspective on the overall performance of your referral pathway to the specialist.

6. What has worked well with your lung cancer management?
   - If yes, can you tell me more about these?

7. Were there any (specific) difficulties in the referral pathway to your first specialist appointment? (Where there aspects of the pathway that was challenging?)
   - If yes, please explain further:

Closing thoughts

8. Can you suggest some improvements that could have been made to make your diagnosis and specialist referral easier for you and your family?

9. Is there anything else that you'd further like to add?

Demographics: (checklist for the interviewer)

Age group:
- < 40 years
- 41-70 years
- >70 years

Male/female:
- Female
- Male

Place of residence and post code_____

Patient or carer:
- Patient
- Carer

Clinic location:

Stage of cancer: _____

Treatment intent
- curative
- palliative

Appendix C: Semi-Structured Interview guide for GPs

Introduction: The purpose of this interview is to gather your thoughts on the Townsville Lung cancer Referral Pathway. This interview will take about 20 minutes. The interview will be audiotaped and transcribed to assist with later data analysis. All names will be removed from typing and your opinions will remain anonymous. Are you ready to start the interview now?

Demographics:

- Do you practice in a rural area? Which town (Postcode)?
- How many patients with suspected lung cancer do you see in a year, on average? _____
- How long have you been practicing in Australia _____(years)__ and in THHS_____(years)?

1. Are you aware of the Lung Cancer Referral Pathway available in the 'Townsville HPWs' website? Yes / No

And have you used it? Yes / No

- **If no**-

What is your current referral pattern for patients with suspected Lung cancer?

Prompts-

- *what investigations do you do prior to referring them to a specialist? ?CXR/CT scan*
- *Which specialist do you refer the patients to and why?*
- *How long does it take to get the patient to specialist appointment-in public & in private*?
- What is the reason for not using the referral pathway?

(Go to Q7)

- **If yes**- How did you become aware of the pathway? (note all that are relevant)
  - THHS newsletter
  - Primary Health Network (PHN)
  - Colleagues
  - During GP training

2. What has been your experience of using the Lung Cancer Referral Pathway?
   - Has anything changed in your practice to allow you to follow the Lung Cancer Referral Pathway?
- No
- Yes, please describe changes required: _____

Prompts –
How quickly can you refer a patient suspected lung cancer to respiratory clinic?
Do you send an urgent referral or call the specialist/ registrar?

3. In your opinion, are there benefits to using the Townsville Lung Cancer Referral Pathway?
If yes:
3a. What are the benefits of using the referral pathway for yourself as a clinician?

_____
_____

Prompts:

- *Better assistance with patient navigation, getting all necessary investigations prior to specialist appointment*
- *earlier appoints for their patients with specialist,*
- *better feedback from specialists-how prompt is it?*

3b. Are there benefits for patients by using the referral pathway?
Prompts only- -timely appointments, earlier diagnosis, more information about their condition, less anxiety about their lung cancer journey.

_____
_____
_____

4. What are the barriers to following the Townsville Lung Cancer Referral Pathway? (Clarification, if needed: what makes it difficult to follow the TLCRP?)
(Prompts)

- *Needs to login using a password*
- *difficulty in getting imaging prior to referral,*
- *difficulty in appointment with specialists,*
- *patients finding it difficult to travel*
- *Any difference between public and private patients?*

5. Do you have any suggestions to improve the Townsville Lung Cancer Referral Pathway?
prompts

- *Suggestions to provide better and tailored information.*
- *Suggestions to improve co-ordination between GPs and specialists- e.g., use of lung cancer care co-ordinators / nurse navigators.*
- *Prompt communication from specialists*
- *Electronic referral*

6. We are also interested in including tele-health consultations in the lung cancer referral pathway. What is your experience of using tele-health to communicate with people being investigated for lung cancer?

_____
_____
_____
_____

6a. What is your opinion about using video-linked consultations or telephone consultations to communicate with people with possible lung cancer or their carers?

_____
_____
_____
_____
_____

Prompts:
What is your opinion about use of video-linked consultations to discuss sensitive issues or break bad news?
What is your opinion about use of telephone consultations to discuss sensitive issues or break bad news?

7. Do you have any other comments you would like to add about the Townsville Lung Cancer Pathway before we conclude this interview?

_____
_____
_____
_____
_____

Appendix D: Semi-structured Interview Guide for Specialists

Introduction: The purpose of this interview is to gather your thoughts on the Townsville Lung Cancer Referral Pathway. This interview will take about 20 minutes. The interview will be audiotaped and transcribed to assist with later data analysis. All names will be removed from typing and your opinions will remain anonymous. Are you ready to start the interview now?

Demographics:

- *Hospital-based specialist. Speciality: _____*

How long you have been practicing:

in Australia? _____

inTHHS? _____

1. What is your opinion about Townsville lung cancer referral pathway?

In your opinion, are there benefits to using the referral pathway for people suspected with lung cancer?

Yes / No

If yes:

What are the benefits of using the referral pathway for yourself as a clinician?

_____

_____

_____

_____

Discipline specific prompts below (for those having difficulty to answer)

For oncologists and thoracic surgeons*-*

- *seeing less of undiagnosed cases and benign cases,*
- *fewer advanced cancers*

patients and family have been explained why they are seeing the oncologist

For respiratory physicians-

- *GPs referring patients promptly, without delay*
- *more appropriate workup for patients prior to referral.*
- *Less number of patients with benign conditions referred for urgent review.*
- *Fewer patients diagnosed via ED route*
-

2. What about benefits for patients and their carers by using the referral pathway?

Prompts only- -timely appointments, earlier diagnosis, more information about their condition, less anxiety, more satisfied.

_____

_____

_____

_____

_____

_____

3. In your opinion, has introduction of the Townsville Lung Cancer Referral Pathway led to improved referral patterns from GPs directly to respiratory clinics?

_____

_____

_____

_____

_____

4. What type of feedback do you give to the referring GPs about the results of investigations and plan of management?

Please prompt for explanation.

_____

_____

_____

_____

_____

_____

5. Do you have any suggestions to improve the referral patterns of people suspected with lung cancer?

_____

_____

_____

_____*prompts*

- *Suggestions to provide better and tailored information.*
- *lung cancer care co-ordinators/ lung cancer specialist nurses .*
- *Electronic referral*

6. We are also interested in including tele-health consultations in the lung cancer referral pathway. What is your experience of using tele-health to communicate with people being investigated for lung cancer?

_____

_____

_____

_____

_____

_____

6a. What is your opinion about using video-linked consultations or telephone consultations to communicate with people with possible lung cancer or their carers?

_____

_____

_____

_____

_____

Prompts:

What is your opinion about use of video-linked consultations to discuss sensitive issues or break bad news?

What is your opinion about use of telephone consultations to discuss sensitive issues or break bad news?

7. Do you have any other comments you would like to add about the Townsville Lung Cancer Pathway before we conclude this interview?

_____

_____

_____

_____

Appendix E: Data collection sheet for the cohort study.

	ata Collection Sheet V1.3 DAT			Reference number: HREC/2019/QTHS/5					: Implementation and Evaluation of referral pathway for people with Lung cancer in Townsville Health Ser								
	Demographics								Dates								
Audit ID	Pathway Status	Suburb	Postcode	Age	Gender	Indigenous Status	Type of Lung Ca	Stage	Diagnosis Pathway	Initial Presentation Date	Chest x-ray (GP organised)	CT scan (GP organised)	Biopsy (GP organised)	First referral to specialist	First appt with specialist	First specialist clinic attended	First Lung MDT
	1:Pre 2:Post	*Input*	*Input*	*Input*	1: Female 2: Male	1: Non-Indigenous 2: Aboriginal 3: Torres Strait 4: Aboriginal & TS	1: NSCLC 2: SCLC 3: Other	1/2/3/4 5: Recurrent 6:Unknown	1: GP 2: ED	*DD/MM/YY*	*DD/MM/YY (if not organised: NA)*	*DD/MM/YY (if not organised: NA)*	*DD/MM/YY (if not organised: NA)*	*DD/MM/YY*	*DD/MM/YY*	*DD/MM/YY*	*DD/MM/YY*