

ORIGINAL ARTICLE

Patient and carer experiences of lung cancer referral pathway in a regional health service: a qualitative study

Zulfiqer Otty ^{1,2}, Amy Brown ¹, Sarah Larkins ², Rebecca Evans ² and Sabe Sabesan ^{1,2}¹Townsville Cancer Centre, Townsville University Hospital, and ²College of Medicine and Dentistry, James Cook University, Townsville, Queensland, Australia

Key words

lung cancer, referral pathway, patient experience, qualitative study, regional and rural health.

Correspondence

Zulfiqer Otty, Townsville Cancer Centre, Townsville University Hospital, 100, Angus Smith Drive, Townsville, Queensland 4814, Australia.
Email: zulfiqer.otty@health.qld.gov.au

Received 11 November 2022; accepted 26 January 2023.

Abstract

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

Aim: As part of implementing a lung cancer referral pathway at a regional Australian hospital, this study aimed to explore the experiences and perceptions of people with lung cancer and their carers.

Methods: In-depth interviews were used to elicit data for thematic analysis in this cross-sectional descriptive qualitative study. 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 audiorecorded, transcribed and qualitatively analysed. Descriptive phrases were used to generate initial inductive codes and themes.

Results: Nineteen participants approached agreed to take part in the study. Factors that 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: Understanding the experiences of rural and regional patients and carers with the lung cancer referral pathway is important to improve quality of care. Implementing changes to the referral pathway to improve patient and carer experiences needs to be an ongoing quality improvement exercise.

Introduction

Lung cancer is a significant cause of morbidity and a leading cause of cancer mortality in the world.¹ Studies performed internationally show significant variations in pathways to lung cancer diagnosis and treatment between countries and health services.^{2–5} In Australia, lung cancer care spans both hospital and community-based healthcare settings^{6,7} with most patients with lung cancer initially presenting to their general practitioner (GP) with symptoms.^{6,8}

Although most such patients are referred promptly for specialist assessment, some experience multiple prior medical consultations, which lead to delays in diagnosis and treatment. Delays often occur in the time interval between

the initial presentation to the GP and specialist referral.^{9–11} These challenges are magnified for clients from rural, remote and regional areas, where access to medical care and imaging might be difficult.^{12,13}

To reduce variations in management approaches and delays, many organisations have established evidence-based referral pathways for their regions, often known as health pathways.^{14–16} Locally, in north Queensland, HealthPathways is accessed via an online portal that provides tailored, locally relevant guidance to GPs on the management and specialist referral of various medical conditions.¹⁷

To improve the timeliness and referral patterns of people with suspected lung cancer by GPs, the Townsville Lung Cancer Referral Pathway (TLCRP) was added to the regional HealthPathways portal in 2019. Despite the disruption caused by coronavirus disease 2019 (COVID-19),

Conflict of interest: None.

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.^{18,19} 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 the implementation of such a pathway in a metropolitan area.^{20,21}

Although studies evaluating the implementation of HealthPathways have been published, only a few have been performed on patient and carer experiences of lung cancer referral,^{22–25} and none of these focused on the experiences of those from rural areas. Analysis of English patients with lung cancer suggested that patient characteristics and type of treatment influenced their expectations of care.²⁶ A mixed methods study explored the experiences of patients with lung cancer who presented to a UK emergency department and found high levels of support and palliative care needs in this population.²⁷ A qualitative study of patients with lung cancer 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 patients with lung cancer.²⁸

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 patients with lung cancer and their carers about their pathway experience from the 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 (Appendix 1). Aside from providing a better understanding of regional lung cancer patients' experiences, this study may highlight the broad needs of patients with lung cancer and their carers, which, if addressed, could improve quality of care.

Methods

Study design and setting

This manuscript presents findings from a project that is part of a broader evaluation of the TLCRP using the strategic implementation framework.^{29,30} The study was

conducted in a regional tertiary public hospital in northern Australia, which has a large catchment area of about 148 000 km, with a significant number of geographically dispersed rural and remote communities. A descriptive approach informed by phenomenology was undertaken to understand the experiences of patients with lung cancer and their carers. In this descriptive cross-sectional qualitative element of the study, we used semistructured interviews to elicit data for thematic analysis.

We developed a semistructured qualitative interview guide, focusing on patients' and carers' experiences of the lung cancer referral pathway and their perspectives on appropriateness and acceptability of the care provided (Appendix 2). The initial interview questions were open-ended, 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 (one patient with lung cancer and the other a junior doctor), with two members of the research team present (ZO and AB), and relevant changes were made prior to use to ensure appropriateness and clarity of the questions.

Patient recruitment

Patients with newly diagnosed lung cancer and/or their carers, attending the university hospital oncology clinic from 1 October 2020 to 30 March 2021 were eligible to participate if they were older than 18 years, able to provide informed consent and participate in an English language interview. Patients were purposively sampled (for sex, rurality, different stages of lung cancer and treatment modalities) 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 coinvestigator (AB) and the research assistant, to ensure purposive sampling. The principal researcher (ZO), an oncologist, did not recruit participants nor conduct the interviews, to avoid any perception of coercion among patients and participants. Instead, recruitment was undertaken by a coinvestigator (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 was explained to them at this time. They were given at least 24 h to consider the study, after which time the researcher/assistant followed up with them. Recruitment was iterative to obtain variance in patient characteristics, and interviewing continued until thematic saturation was reached.

Data collection

A trained research assistant with oncology nursing training conducted semistructured interviews with patients and/or their carers, after obtaining written consent. The interviews were conducted face-to-face or by telephone (as indicated by participant choice), at a time convenient to the patient/carer. All of 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 was undertaken after the data were collected, to inductively derive key codes and themes regarding participant experiences. Concurrent analysis was performed 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 biases of any one author in interpreting data sources and generating coding and themes. A consolidated criteria for reporting qualitative research (COREQ) checklist was used as a guide to report the study findings.³¹

Ethics approval was obtained for the study from the local Hospital and Health Service ethics committee (HREC/2020/QTHS/58635) and University ethics committee (H8189). All participants provided written informed consent. The study was conducted according to Good Clinical Practice and the Australian Code for the Responsible Conduct of Research.

Results

Nineteen participants took part in the study: 14 were phone interviews and five were conducted face-to-face. Participant characteristics are provided in Table 1. In total, 36 patients and/or their carers were approached to participate in this study. Data were not routinely collected regarding reasons for nonparticipation, though two patients indicated they felt too unwell to participate.

Data analysis identified four major themes and several subthemes. The themes were interconnected (Fig. 1), and the subthemes assist in further describing important elements of the larger themes. Relevant quotations from patients and carers along with themes and subthemes are provided in Table 2.

Table 1 Patient characteristics

Characteristic	Number (%), N = 19
Median age in years (range)	64 (52–82)
Sex	
Male	10 (52)
Female	9 (48)
Residence	
Regional (MMA 2 and 3)	12 (64)
Rural (MMA 4 and 5)	4 (21)
Remote (MMA 6 and 7)	3 (15)
Stage of cancer	
Early stage	9 (48)
Late stage	10 (52)
Type of lung cancer	
Nonsmall cell lung	16 (84)
Small cell lung	3 (15)
Present for interview	
Patient only	12 (63)
Carer only	2 (10)
Patient and carer	5 (26)
Initial presentation	
GP	8 (42)
Emergency department	8 (42)
Other specialties	3 (15)

Modified Monash model (MMA) to classify rurality in Australia. GP, general practitioner.

Quality of communication from healthcare providers affects patient and carer satisfaction

When participants were asked about the quality of communication, they commented on various aspects such as 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



Figure 1 Relationships between themes.

Table 2 Themes, subthemes and relevant quotations from patients and carers

Theme	Subthemes	Quotations
Quality of communication from HCPs affects patient and carer satisfaction	Information needs vary between patients	<p><i>'I suppose because I do not know anything medical, do not 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)</i></p> <p><i>'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)</i></p>
	Both content and type of information from HCPs are important	<p><i>'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)</i></p>
	Improper communication causes significant distress	<p><i>'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 min. 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)</i></p>
	Taking patient concerns seriously during initial consultations	<p><i>'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)</i></p>
	Video-linked or face-to-face consultations are preferred over telephone consultations	<p><i>'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)</i></p>
	Importance of timeliness: Delays cause significant anxiety to patients and their carers	Variation in presentations, referral pathways and timeliness
Perceptions of causes and impacts of delays		<p><i>'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)</i></p>
Uncertainty about the process is a cause of anxiety		<p><i>'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)</i></p>

Table 2 Continued

Theme	Subthemes	Quotations
Importance of patient advocacy, support and coordination during the referral process	Patient advocacy by HCPs, family and friends	<i>'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)</i>
	Psychosocial support for patients and carers	<i>'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)</i>
	Coordination of care between clinicians	<i>'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)</i>

COPD, chronic obstructive pulmonary disease; GP, general practitioner; HCP, healthcare provider.

and had help from family in translating all of 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 have left to live.

Improper 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.

Importance of timeliness: Delays in care cause significant 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

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 since there was frequent turnover of GPs in their area. Another concern voiced by some patients was that the delays may have caused their tumours to grow while they were waiting, which led to worse outcomes. In contrast to those with perceived delays, one participant 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 significant distress. Many patients reported that they lived in fear while waiting for their diagnosis. 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 coordination during the referral process

Although most participants were content with the management advised by their GPs, some demanded

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 where they perceived that their healthcare providers advocated for them to access a needed resource or to connect them with another healthcare professional.

Although most patients did not have access to cancer care coordinators, one patient reflected that her appointments were made more quickly with the help of a care coordinator. Sometimes, a breach in 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 healthcare. Although we did not explicitly ask the participants about referral for psychosocial services, one carer mentioned receiving help from a support worker in taking the patient to appointments.

Discussion

Patients and their carers in this study indicated high satisfaction with care if they had every step of the lung cancer referral pathway clearly explained to them. Our study also suggests that avoiding delays in investigations and informing them about test results as soon as available can reduce patient anxiety and distress. More resources are needed in our region to provide adequate psychosocial support and improved care coordination for lung cancer patients. Unlike most other similar studies on lung cancer referral pathway, we were able to obtain the experiences and perceptions of caregivers.^{32,33} Few studies have considered the significance of communication from healthcare practitioners during the lung cancer referral process and the psychological impact of delays.^{32,34,35}

The data and themes identified in this study also align with literature about unmet needs of patients with cancer.^{36,37} Unmet needs in the *psychological domain* included ‘uncertainty about diagnosis and treatment’, emotional support, ‘worry that the results of treatment are beyond your control’ and ‘fears about the cancer growing’. Unmet needs in the *social domain* included support from healthcare services. There was significant 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 showed 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 talk to always’ and ‘being informed of the test results as soon as possible’.

A similar qualitative study in patients with lung cancer in New Zealand found that there were significant barriers for GPs to refer to specialists and these delayed treatments.³² Most of the participants in this study complained of delays occurring in primary care, which is similar to the results of other studies performed in similar health systems.³⁸ Previous studies on lung cancer referral pathways have shown that lack of established trust between patients and GPs leads to delays in taking the patient’s concerns seriously and GPs providing inadequate information to patients.^{32,34,39} These clinician-patient communication barriers were often exacerbated by a lack of GP continuity.^{32,40} Rural areas can have problems with retaining GPs, which can result in poor relationships with patients.⁴¹ Our study findings are consistent with this observation.

We also found that many participants preferred face-to-face or video-linked consultations over telephone consultations. Dissatisfaction with phone consults was attributable to a lack of communication skills of doctors over the phone, diagnosis and prognosis given by unfamiliar doctors and lack of adequate time to ask questions. Many studies have established the advantages of telehealth in delivery of cancer care in regional and rural areas.^{42–44} In a systematic review comparing videoconferencing with telephone consultations in healthcare delivery, there was no difference in patient satisfaction between the two modalities.⁴⁵ The contradictory result in our study could be the result of differences in study population.

Strengths and limitations of the study

This study highlights many significant issues for regional and rural patients and their carers while on the lung cancer referral pathway, which will be used to improve the care pathway. As far as we are aware, this is the only study performed 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. Our region experienced only limited outbreaks of COVID-19 during the study period. So, we expect that most of the findings in this study are generalisable for nonpandemic situations as well. The study included seven participants who lived in rural and remote areas, and some of the specific problems faced by this population were captured. Given that the diagnosis of lung cancer affects the life of patients as well as their carers, these data help to understand the experiences of both patients and 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.⁴⁶ Increased use of telephone and telehealth consultations would have impacted 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.^{47,48} These changes may have contributed to delays in diagnosis of lung cancer in many patients⁴⁹ and influenced their experience. This study was performed in a single referral hospital and therefore only the experiences of those patients attending this hospital were captured. We may have missed patients with lung cancer who never attended the oncology clinics, such as patients with early-stage lung cancer 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 possible that patients may not be able to recall all of the details of their symptoms and investigations as described in other studies.⁵⁰

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.^{51,52} 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 psychosocial 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

results will be used to prioritise improvements in TLCRP and patient/carer experiences. Further, it is important to consider the ongoing role of telehealth in the TLCRP, given it is an important part of clinical care for rural and remote patients who must otherwise travel long distances. Since patients and carers in this study indicated a preference for video-linked consultations over telephone consultations, general practice clinics should have access to videoconferencing facilities.

Conclusion

Understanding the experiences of rural and regional patients and carers with the TLCRP is important to improve quality of care. Factors that 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. Implementing changes to TLCRP to improve patient and carer experiences needs to be an ongoing quality improvement exercise.

Acknowledgements

Kareela Campbell assisted in conducting interviews. This work was funded by the Townsville Hospital and Health Service Study, Education and Research Trust and Administration (SERTA) grant (Reference: 14_2020). Open access publishing facilitated by James Cook University, as part of the Wiley - James Cook University agreement via the Council of Australian University Librarians.

Data Availability Statement

Deidentified data can be provided upon reasonable request to the corresponding author.

References

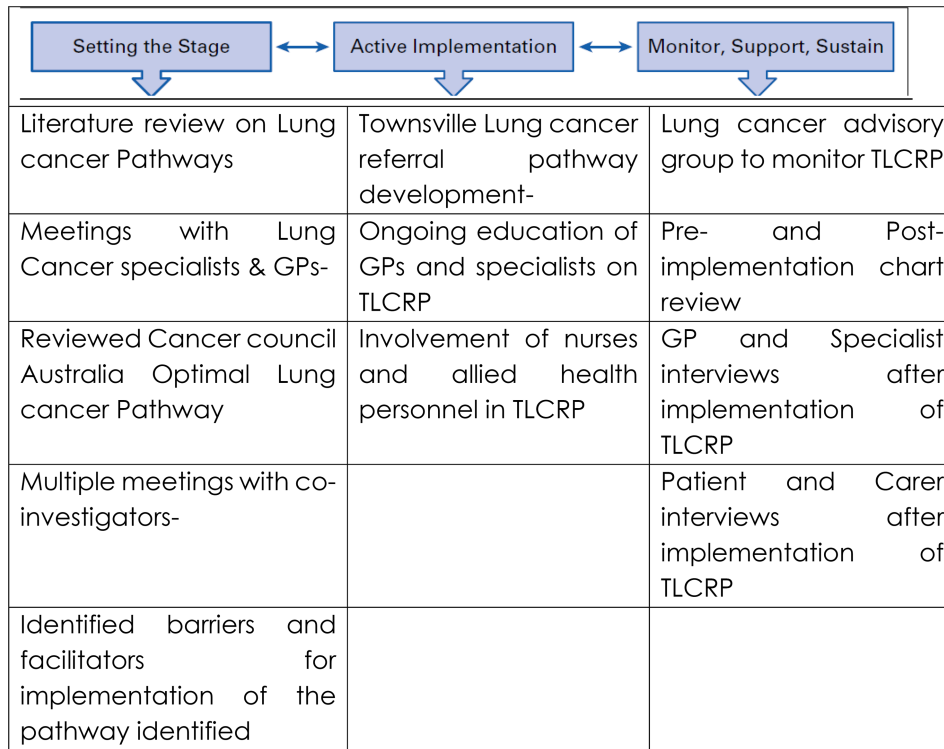
- 1 Ferlay J, Soerjomataram I, Dikshit R, Eser S, Mathers C, Rebelo M *et al.* Cancer incidence and mortality worldwide: sources, methods and major patterns in GLOBOCAN 2012. *Int J Cancer* 2015; **136**: E359–86.
- 2 Hansen RP, Vedsted P, Sokolowski I, Søndergaard J, Olesen F. Time intervals from first symptom to treatment of cancer: a cohort study of 2,212 newly diagnosed cancer patients. *BMC Health Serv Res* 2011; **11**: 284.
- 3 Evans SM, Earnest A, Bower W, Senthuren M, McLaughlin P, Stirling R. Timeliness of lung cancer care in Victoria: a retrospective cohort study. *Med J Aust* 2016; **204**: 75.
- 4 Liberman M, Liberman D, Sampalis JS, Mulder DS. Delays to surgery in non-small-cell lung cancer. *Can J Surg* 2006; **49**: 31–6.
- 5 Dransfield MT, Lock BJ, Garver RI Jr. Improving the lung cancer resection rate in the US Department of

- Veterans Affairs Health system. *Clin Lung Cancer* 2006; **7**: 268–72.
- 6 Guldbrandt LM, Fenger-Grøn M, Rasmussen TR, Jensen H, Vedsted P. The role of general practice in routes to diagnosis of lung cancer in Denmark: a population-based study of general practice involvement, diagnostic activity and diagnostic intervals. *BMC Health Serv Res* 2015; **15**: 21.
 - 7 Lamb BW, Brown KF, Nagpal K, Vincent C, Green JS, Sevdalis N. Quality of care management decisions by multidisciplinary cancer teams: a systematic review. *Ann Surg Oncol* 2011; **18**: 2116–25.
 - 8 Elliss-Brookes L, McPhail S, Ives A, Greenslade M, Shelton J, Hiom S et al. Routes to diagnosis for cancer – determining the patient journey using multiple routine data sets. *Br J Cancer* 2012; **107**: 1220–6.
 - 9 Verma R, Pathmanathan S, Otty Z, Binder J, Vangaveti V, Buttner P et al. Delays in lung cancer referral pathways between rural and urban patients in North Queensland: a mixed methods study. *Intern Med J* 2018; **48**: 1228–33.
 - 10 Olsson JK, Schultz EM, Gould MK. Timeliness of care in patients with lung cancer: a systematic review. *Thorax* 2009; **64**: 749–56.
 - 11 Bjerager M, Palshof T, Dahl R, Vedsted P, Olesen F. Delay in diagnosis of lung cancer in general practice. *Br J Gen Pract* 2006; **56**: 863–8.
 - 12 Heathcote KE, Armstrong BK. Disparities in cancer outcomes in regional and rural Australia. *Cancer Forum* 2007; **31**: 70–74.
 - 13 George M, Ngo P, Prawira A. Rural oncology: overcoming the tyranny of distance for improved cancer care. *J Oncol Pract* 2014; **10**: e146–e9.
 - 14 Senanayake S, Abell B, Novick M, Exley H, Dolejs W, Hutchinson K et al. Impact and outcome evaluation of HealthPathways: a scoping review of published methodologies. *J Prim Health Care* 2021; **13**: 260–73.
 - 15 McGeoch G, Anderson I, Gibson J, Gullery C, Kerr D, Shand B. Consensus pathways: evidence into practice. *N Z Med J* 2015; **128**: 86–96.
 - 16 Stokes T, Tumilty E, Doolan-Noble F, Gauld R. HealthPathways implementation in a New Zealand health region: a qualitative study using the consolidated framework for implementation research. *BMJ Open* 2018; **8**: e025094.
 - 17 McGonigle L, McGeoch G. The Canterbury pathway to integrated care, warts and all. *Int J Integr Care* 2017; **17**: 449.
 - 18 Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S et al. Engaging patients to improve quality of care: a systematic review. *Implement Sci* 2018; **13**: 98.
 - 19 Long Roche K, Angarita AM, Cristello A, Lippitt M, Haider AH, Bowie JV et al. "Little big things": a qualitative study of ovarian cancer survivors and their experiences with the health care system. *J Oncol Pract* 2016; **12**: e974–e80.
 - 20 Hall SE, Holman CD, Sheiner H. The influence of socio-economic and locational disadvantage on patterns of surgical care for lung cancer in Western Australia 1982-2001. *Aust Health Rev* 2004; **27**: 68–79.
 - 21 Emery JD, Walter FM, Gray V, Sinclair C, Howting D, Bulsara M et al. Diagnosing cancer in the bush: a mixed methods study of GP and specialist diagnostic intervals in rural Western Australia. *Fam Pract* 2013; **30**: 541–50.
 - 22 McGeoch G, McGeoch P, Shand B. Is HealthPathways effective? An online survey of hospital clinicians, general practitioners and practice nurses. *N Z Med J* 2015; **128**: 36–46.
 - 23 Gray JS, Swan JR, Lynch MA, Tay TM, Mackenzie MJ, Wiggers JH et al. Hunter and New England HealthPathways: a 4-year journey of integrated care. *Aust Health Rev* 2018; **42**: 66–71.
 - 24 Goddard-Nash A, Makate M, Varhol R, Quirk F, Larsen R, McGeoch G et al. Evaluation of HealthPathways: an appraisal of usage, experiences and opinions of healthcare professionals in Australia and New Zealand. *Aust Health Rev* 2020; **44**: 590–600.
 - 25 Mansfield SJ, Quirk F, von Treuer K, Gill G. On the right path? Exploring the experiences and opinions of clinicians involved in developing and implementing HealthPathways Barwon. *Aust Health Rev* 2016; **40**: 129–35.
 - 26 Nartey Y, Tata LJ, Khakwani A, Beattie V, Beckett P, Hubbard RB et al. Using patient experiences to evaluate care and expectations in lung cancer: analysis of the English Cancer Patient Experience Survey linked with the national cancer registry. *Support Care Cancer* 2022; **30**: 4417–28.
 - 27 Wilcock A, Crosby V, Freer S, Freemantle A, Caswell G, Seymour J. Lung cancer diagnosed following emergency admission: a mixed methods study protocol to improve understanding of patients' characteristics, needs, experiences and outcomes. *BMC Palliat Care* 2013; **12**: 24.
 - 28 Nababan T, Hoskins A, Watters E, Leong J, Saunders C, Slavova-Azmanova N. 'I had to tell my GP I had lung cancer': patient perspectives of hospital- and community-based lung cancer care. *Aust J Prim Health* 2020; **26**: 147–52.
 - 29 Aarons GA, Hurlburt M, Horwitz SM. Advancing a conceptual model of evidence-based practice implementation in public service sectors. *Adm Policy Ment Health* 2011; **38**: 4–23.
 - 30 Mitchell SA, Chambers DA. Leveraging implementation science to improve cancer care delivery and patient outcomes. *J Oncol Pract* 2017; **13**: 523–9.
 - 31 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International J Qual Health Care* 2007; **19**: 349–57.
 - 32 Walton L, McNeill R, Stevens W, Murray M, Lewis C, Aitken D et al. Patient perceptions of barriers to the early diagnosis of lung cancer and advice for health service improvement. *Fam Pract* 2013; **30**: 436–44.
 - 33 Caswell G, Seymour J, Crosby V, Hussain A, Manderson C, Farnan S et al. Lung cancer diagnosed following an emergency admission: exploring patient and carer perspectives on delay in seeking help. *Support Care Cancer* 2017; **25**: 2259–66.
 - 34 Hall SE, Holman CD, Threlfall T, Sheiner H, Phillips M, Katriss P et al. Lung cancer: an exploration of patient and general practitioner perspectives on the realities of care in rural Western Australia. *Aust J Rural Health* 2008; **16**: 355–62.
 - 35 Rankin NM, York S, Stone E, Barnes D, McGregor D, Lai M et al. Pathways to lung cancer diagnosis: a qualitative study of patients and general practitioners about diagnostic and pretreatment intervals. *Ann Am Thorac Soc* 2017; **14**: 742–53.

- 36 Wang T, Molassiotis A, Chung BPM, Tan J-Y. Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliat Care* 2018; **17**: 96.
- 37 Harrison JD, Young JM, Price MA, Butow PN, Solomon MJ. What are the unmet supportive care needs of people with cancer? A systematic review. *Support Care Cancer* 2009; **17**: 1117–28.
- 38 Ellis PM, Vandermeer R. Delays in the diagnosis of lung cancer. *J Thorac Dis* 2011; **3**: 183–8.
- 39 Murray SR, Kutzer Y, Habgood E, Murchie P, Walter FM, Mazza D *et al*. Reducing barriers to consulting a general practitioner in patients at increased risk of lung cancer: a qualitative evaluation of the CHEST Australia intervention. *Fam Pract* 2017; **34**: 740–6.
- 40 Sharf BF, Stelljes LA, Gordon HS. 'A little bitty spot and I'm a big man': patients' perspectives on refusing diagnosis or treatment for lung cancer. *Psychooncology* 2005; **14**: 636–46.
- 41 Russell DJ, Wakerman J, Humphreys JS. What is a reasonable length of employment for health workers in Australian rural and remote primary healthcare services? *Aust Health Rev* 2013; **37**: 256–61.
- 42 Sabesan S, Larkins S, Evans R, Varma S, Andrews A, Beuttner P *et al*. Telemedicine for rural cancer care in North Queensland: bringing cancer care home. *Aust J Rural Health* 2012; **20**: 259–64.
- 43 Patt DA, Wilfong L, Toth S, Broussard S, Kanipe K, Hammonds J *et al*. Telemedicine in community cancer care: how technology helps patients with cancer navigate a pandemic. *JCO Oncol Pract* 2021; **17**: e11–e5.
- 44 Gondal H, Abbas T, Choquette H, Le D, Chalchal HI, Iqbal N *et al*. Patient and physician satisfaction with telemedicine in cancer care in Saskatchewan: a cross-sectional study. *Curr Oncol* 2022; **29**: 3870–80.
- 45 Rush KL, Howlett L, Munro A, Burton L. Videoconference compared to telephone in healthcare delivery: a systematic review. *Int J Med Inform* 2018; **118**: 44–53.
- 46 Chazan G, Franchini F, Alexander M, Banerjee S, Mileskin L, Blinman P *et al*. Impact of COVID-19 on cancer service delivery: results from an international survey of oncology clinicians. *ESMO Open* 2020; **5**: e001090.
- 47 Sharafeldin N, Bates B, Song Q, Madhira V, Yan Y, Dong S *et al*. Outcomes of COVID-19 in patients with cancer: report from the national COVID cohort collaborative (N3C). *J Clin Oncol* 2021; **39**: 2232–46.
- 48 Riera R, Bagattini ÂM, Pacheco RL, Pachito DV, Roitberg F, Ilbawi A. Delays and disruptions in cancer health care due to COVID-19 pandemic: systematic review. *JCO Glob Oncol* 2021; **7**: 311–23.
- 49 Gurney JK, Millar E, Dunn A, Pirie R, Mako M, Manderson J, Hardie C, Jackson CGCA, North R, Ruka M, Scott N, Sarfati D. The impact of the COVID-19 pandemic on cancer diagnosis and service access in New Zealand – a country pursuing COVID-19 elimination. *Lancet Reg Health West Pac* 2021; **10**: 100127.
- 50 Corner J, Hopkinson J, Fitzsimmons D, Barclay S, Muers M. Is late diagnosis of lung cancer inevitable? Interview study of patients' recollections of symptoms before diagnosis. *Thorax* 2005; **60**: 314–9.
- 51 Underhill C, Bartel R, Goldstein D, Snodgrass H, Begbie S, Yates P *et al*. Mapping oncology services in regional and rural Australia. *Aust J Rural Health* 2009; **17**: 321–9.
- 52 Australian Institute of Health and Welfare. Cancer in Australia In brief 2019. 2019.

Appendix 1

Overall project diagram (strategic implementation framework for the project)



Appendix 2

Interview Guide

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 (X-rays, CT scans, biopsy) were organized 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?

Did you have to attend the emergency department with severe symptoms?

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

2. Were you provided with enough information about your cancer and tests done prior to specialist appointment?

When were you told this information?

Who gave you the information?

- 2b. Did you understand the information given along the way before you saw the specialist?

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. Do you feel the process of being diagnosed and referred moved quickly enough for you?

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. Did you experience any difficulties in the lead up to your first specialist appointment? (Where there aspects of the pathway that was challenging?)

If yes, please explain further:

Prompts:

- Travel
- Work / other commitments
- Unwell
- not received appointment time.

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?

Thank you.
