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ORIGINAL ARTICLE

Patients' experience of lung cancer care coordination: a quantitative exploration

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Abstract

Purpose Improving the coordination of care for people with lung cancer is a health priority. This study aimed to tailor an existing care coordination survey for a lung cancer population, investigate coordination experiences for patients who had received hospital-based treatment and identify any factors that may be associated with poor care coordination.

Methods We conducted a cross-sectional survey of lung patients within two tertiary hospitals in Sydney, Australia. The Cancer Care Coordination Questionnaire for Patients (CCCQ-P) is a psychometrically valid and reliable survey originally developed for colorectal cancer. We pilot tested a survey adaptation with lung cancer patients, support group members and medical specialists ($n = 49$). A revised survey was mailed to eligible patients via their medical specialist.

Results Fifty-three of 118 eligible participants (45%) completed the CCCQ-P; most had early-stage disease and were about 70 years old. Overall, participants reported positive experiences of care coordination (mean total score 78.1), with high scores on communication and navigation subscales. The most problematic areas related to administrative aspects of care coordination and communication and information provision. Two patient groups (those residing in regional and rural areas, or no experience with the health system prior to diagnosis) reported significantly lower scores on the navigation subscale.

Conclusions This study found that lung cancer patients' experience of care coordination was positive, but highlighted the need for strategies to assist patients living in rural areas, and those with no experience of the health care system. The CCCQ-P survey instrument can be used in future lung cancer studies.

Keywords Lung neoplasms · Care coordination · Questionnaire · Australia · Navigation · Communication

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Introduction

Lung cancer is the leading cause of cancer death in Australia and many developed countries [1]. Treatment for lung cancer is complex, depending on the tumour histology and stage as well as the general health of the patient. Surgery, radiotherapy, chemotherapy and other agents are used either singly or in combination [2] with care provided by a range of health professionals within and across multiple health services (respiratory medicine, thoracic surgery, medical oncology, radiation oncology, palliative care and hospice settings) and sectors (public, private and community-based) and often for extended periods of time. People with lung cancer often have a high symptom burden, including breathlessness and fatigue, and are known to have high supportive care needs [3–6]. Supportive care is frequently provided by nurses, allied health professionals such as physiotherapists, occupational therapists, psychologists and social workers. Patients often need to navigate a complex system involving a diverse range of medical, nursing and allied health practitioners in both hospital and community settings. In such circumstances, patients may experience poorly coordinated and fragmented care [7, 8].

Internationally, improving cancer care coordination has been identified as an important component to streamline and optimise cancer care delivery to improve patients' care experiences and outcomes [9, 10]. The Agency for Healthcare Research and Quality defines cancer care coordination as:

> 'the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all Required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.' [11]

Quality care coordination requires effective and timely communication, and thorough planning and appropriate support for patients, and their families or carers, to navigate the health care system. Improving care coordination and outcomes for people with lung cancer is a priority at the policy level across many jurisdictions [9, 12–16]. Qualitative research with lung cancer patients has highlighted that there are coordination of care challenges in the lung cancer pathway, including during presentation of signs and symptoms [17], diagnosis and prior to treatment commencement [18], treatment [19] and palliative care [20]. However, few studies have undertaken quantitative assessment of the adequacy of cancer care coordination [8], which is essential if we are to identify priority groups that need additional support and to monitor health system performance over time [21]. Therefore, it is timely to investigate the use of quantitative measures of cancer care coordination for people with the disease.

Our group has previously developed and validated a self-report instrument, Cancer Care Coordination Questionnaire for Patients (CCCQ-P), that provides a quantitative assessment of patients' experience [22]. A population-based study of patients with colorectal cancer found that increasing comorbidity was associated with an increased risk of poor cancer care coordination [23], similar to findings among breast cancer patients [24]. Furthermore, aspects of the cancer system that were associated with better care coordination included contact with a care coordinator or specialist nurse, having a good understanding of the health system prior to diagnosis and the provision of a written treatment plan [23]. Other researchers have investigated cancer care coordination for people with pancreatic and colorectal cancers [25, 26]. However, there is a paucity of information about the experiences of patients with lung cancer.

Therefore, the aim of this study was to tailor the CCCQ-P for a lung cancer population and investigate the experience of cancer care coordination among a sample of patients who had received hospital-based treatment for lung cancer. We also aimed to identify any factors that may be associated with poor cancer care coordination.

Methods

Study design and setting

We conducted a cross-sectional survey of patients receiving follow-up care within Sydney Local Health District, which includes two hospitals where lung cancer treatment is administered. This study was conducted under the auspices of Cancer Australia's Lung Cancer Demonstration Project which aimed to develop an evidence-based framework to support national uptake of the *Principles for best practice management of lung cancer in Australia* [27, 28]. Specifically, Principle 4 relates to the coordination, communication and continuity of care and specifies that all relevant health professionals, including GPs, provide coordinated delivery of care across the lung cancer continuum of care.

Questionnaire development and pilot testing

The CCCQ-P is a 20-item self-report questionnaire that generates a total score (possible range 20–100) and two subscales 'communication' (possible range 13–65) and 'navigation' (possible range 7–35) with higher scores indicating better cancer care coordination. The instrument has good psychometric properties but has been used most extensively for people with gastrointestinal tumours [21–23]. To ensure that the questionnaire was appropriate for people with lung cancer, we conducted a pilot test to confirm face validity, to obtain feedback on the clarity and relevance of questionnaire items and to identify any additional aspects of lung cancer care coordination that should be included. Pilot testing was undertaken with three groups: (i) patients in follow-up for lung cancer ($n = 4$), (ii) lung cancer support group members from the Lung Foundation Australia (LFA) ($n = 13$) and (iii) clinicians in the lung multidisciplinary teams (MDT) at the study hospitals ($n = 32$). The questionnaire was found to be acceptable and comprehensive for people with lung cancer, and only very minor word changes were made to improve the clarity of questionnaire items.

Demographic questions (age, sex, marital status, country of birth, language spoken at home, employment status, education level, prior experience with health system and treatments received) were also included in the questionnaire.

Clinical information

Clinical details regarding date of diagnosis, stage of disease, ECOG performance status, hospital location, reason for attendance, multidisciplinary case review and referral to palliative care were collected from patient's medical records. Geographic remoteness was classified using the Accessibility/Remoteness Index of Australia Plus (ARIA+) [29] system based on patients' postcode of residence.

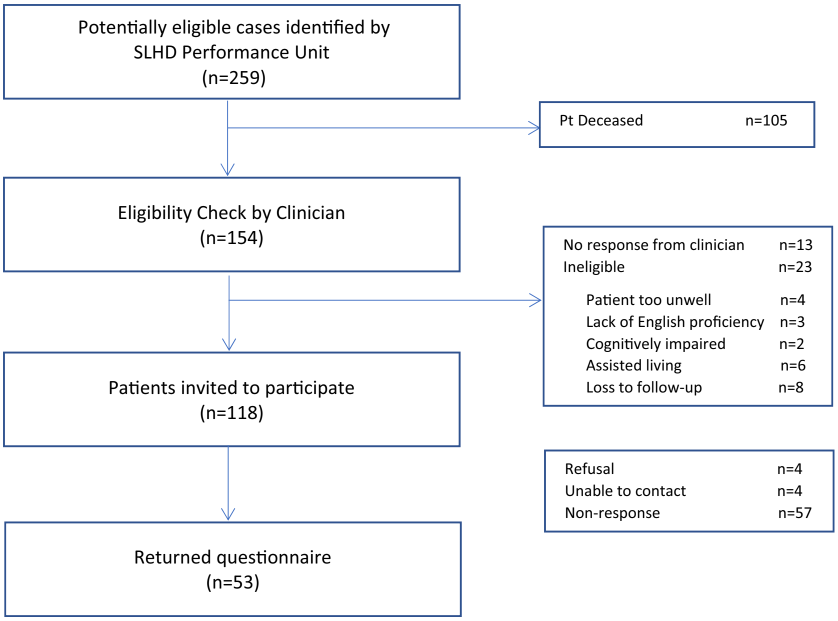
Patient recruitment

A consecutive sample of patients aged 18 years or older with a primary lung cancer diagnosed between 1 July 2014 and 30 April 2016 was identified from administrative hospital separations records by the Performance Monitoring, Systems Improvement and Innovation Unit of Sydney Local Health District (SLHD). The patients' treating clinicians were contacted to confirm eligibility. Patients were considered ineligible if they had died, were receiving end-of-life care or were considered by their treating doctor to be too unwell to participate, did not have sufficient English language skills, resided in assisted-living facilities, were not aware of their cancer diagnosis or were not cognitively able to participate. The vital status of patients who had not attended a study hospital within the previous month was confirmed by the NSW Registry of Births, Deaths & Marriages (RBDM) [30]. Eligible patients were then mailed a letter of introduction from their medical specialist, a study information sheet and consent form, and a copy of the questionnaire to complete and return in a reply-paid envelope. Patients were contacted between 2 and 12 months after their diagnosis. Non-responders were mailed a reminder 2 weeks later.

Statistical analyses

Statistical analysis was carried out using Stata 13 software [31]. Study participants and non-responders were compared with respect to age, sex, language spoken at home, stage of disease, treating hospital and geographic remoteness (ARIA+) using chi-square tests [29]. Data were summarised using simple descriptive statistics (mean scores, standard deviations, percentages). Separate analyses were performed for overall perceived experience of care coordination, and the two subscales communication and navigation. Associations between patient factors and care coordination scores were assessed

Fig. 1 Flow chart of participant recruitment



using Student's *t* tests and univariate regression analysis. Multivariate linear regression analyses were performed to identify independent predictors of poor care coordination, using a manual backward elimination method. A *p* value of less than 0.05 was considered significant for all analyses.

Ethical approvals

We were granted ethics approval to conduct this study by the Sydney Local Health District Human Research Ethics Committee, RPAH zone (Reference No. LNR/15/RPAH/508).

Results

Overall, 259 patients with primary lung cancer diagnosed during the study period were identified from the hospital database. Of these, 141 were ineligible for the study (105 (42%) had died and 36 (14%) were deemed ineligible by their clinician), leaving 118 eligible patients. Completed questionnaires were returned by 53 participants (45% response rate) (see Fig. 1). As illustrated in Table 1, there were no statistically significant differences in the personal characteristics of survey responders and non-responders. On average, responders were 69.5 years (range 41–92 years) and 58% were male. The majority (61%) had early-stage disease.

Care coordination experience

Overall, participants reported positive experiences of care coordination with a mean total score of 78.1 SD 10.6 (highest possible score 100), communication subscale 51.0 SD 7.7 (highest possible score 65) and navigation subscale 27.1 SD 3.9 (highest possible score 35). Table 2 summarises individual item responses within the care coordination measure in rank order of problems experienced. More than 85% of patients reported positive experiences (see items 9, 14–18 and 20) with regard to communication about treatments, tests and appointments.

The most problematic areas of cancer care coordination related to administrative aspects as well as communication and provision of information (see items 1–7). One in five patients reported confusion about the roles of different health professionals involved in their care (item 1) and that these professionals were not always fully informed about their history or progress (item 7). Similarly, 19% of participants reported difficulties in meeting the financial costs of their health care (item 2), and 15% reported that they received insufficient information about potential financial entitlements such as Medicare and private health fund claims or travel allowances (item 5). Additionally, 15% did not know who to call out of business hours if they had a problem (item 6) or had difficulty getting an appointment with their general practitioner (item 4).

Table 1 Characteristics of survey responders and non-responders

Characteristic	Responders		Non-responders		
	n	%	*n*	%	*p*
Age					
Mean (SD)	69.5 (10.8)		69.2 (14.6)		0.9
Sex					
Male	31	58	43	66	0.4
Female	22	42	22	34	
Language spoken at home					
English	43	81	52	85	0.5
Other	10	19	9	15	
Stage of disease					
IA–IIB	28	61	35	65	0.7
IIIA–IV	18	39	19	35	
Reason hospital attendance					
Admission	11	21	17	26	0.3
Clinic	42	79	46	71	
Palliative care referral					
Yes	5	9	8	13	0.4
No	48	91	55	87	
Hospital location					
RPAH	34	64	44	68	0.7
Concord	19	38	21	32	
ARIA					
Major city	36	68	45	70	0.8
IR/OR/R	17	32	19	30	
Employment status					
Employed	7	13	–	–	
Not employed	46	87	–	–	
Highest education					
Post-secondary	22	42	–	–	
High school	31	58	–	–	
Co-morbidities					
< 3	43	81	–	–	
≥ 3	10	19	–	–	
Previous experience with health system					
Yes	36	68	–	–	
No	17	32	–	–	
Marital status					
Partnered/married	32	60	–	–	
Single/divorced/widowed	21	40	–	–	
Treatment received					
Surgery	35	66	–	–	
Chemotherapy	30	57	–	–	
Radiotherapy	24	45	–	–	

With regard to clinical communication and information provision (items 3 and 7), 17% felt they did not know which warning signs and symptoms they needed to monitor their health,

Table 2 Care coordination survey item responses

Item no.	Subscale	Item description	Problem experienced*		Neutral		Positive experience†	
			n	%	*n*	%	*n*	%
1	Nav*	I was confused about the roles of the different health professionals involved in my care	10	19	13	25	30	57
2	Nav*	It was difficult to meet the financial costs associated with my health care	10	19	13	25	30	57
3	Comm	I knew the warning signs and symptoms I should watch for to monitor my health	9	17	9	17	35	66
4	Nav	I never had any difficulty getting an appointment with my GP	8	15	3	6	42	79
5	Comm	I was fully informed by health professionals about my financial entitlements (e.g. Medicare and health fund claims, travel allowances)	8	15	9	17	36	68
6	Nav	I always knew who to call out of business hours if I had a problem	8	15	10	19	35	66
7	Nav*	The health professionals looking after me were not always fully informed about my history and progress	8	15	11	21	34	64
8	Comm	The health professionals looking after me always picked up on whether I was feeling anxious or down	6	11	17	32	30	57
9	Comm	I always knew what tests, treatments and follow up were planned for me	5	9	3	6	45	85
10	Comm	I had access to all the additional services that I needed (e.g. physiotherapy, counselling, cancer support groups, social worker support, pain management, palliative care, nutritional advice)	5	9	10	19	38	72
11	Comm	I had sufficient help from health professionals with dealing with the emotional impact of my cancer	5	9	15	28	33	62
12	Comm	My Doctors always asked how well my family and I were coping	4	8	19	36	30	57
13	Comm	I had sufficient help from health professionals with practical arrangements such as organising transport, accommodation and appointments	4	8	20	38	29	55
14	Nav	I never had to wait too long to get the first available appointment for a test or treatment	3	6	2	4	48	91
15	Comm	I knew which therapies were suitable for me (e.g. surgery, chemotherapy, radiotherapy)	3	6	3	6	47	89
16	Nav	I always knew who to contact if I had concerns about my health or treatment plan	3	6	4	8	46	87
17	Comm	I was fully informed about the benefits and harms of any treatments	2	4	3	6	48	91
18	Comm	I always knew the reason why I was having a test or treatment	1	2	5	9	47	89
19	Comm	My Doctors always asked how my visits with other health professionals were going	1	2	19	36	33	62
20	Comm	I had a good understanding of what I was responsible for to help my treatment plan run smoothly	0	0	5	9	48	91

*Negatively worded items

†Positive experience comprises: 'strongly agree' and 'agree' for positively worded items or the inverse for negatively worded items

‡Problem experienced comprises: 'strongly disagree' and 'disagree' for positively worded items or the inverse for negatively worded items

Nav, navigation; *Comm*, communication

and 15% felt their health professionals were not always fully informed about their medical history and clinical progress.

There were no statistically significant univariate associations between patient factors and the total score or the communication subscale score, as shown in Table 3. For the navigation subscale, previous experience with the health care system was significantly associated in univariate analysis. Multivariate regression modelling demonstrated that two factors, namely previous experience with the health care system and remoteness of residence, were independently and statistically significantly associated with navigation scores. Patients who resided in regional or rural areas had navigation scores on average 2.37 points lower than those in major cities ($\beta = -2.37$, SE = 1.1, $p = 0.04$) after adjusting for experience with the health care system. Patients with no experience of the health care system had navigation scores on average 3.15 points lower than experienced patients ($\beta = -3.05$, SE = 1.1, $p = 0.006$), after adjusting for remoteness of residence.

Discussion

People with lung cancer experience high symptom burden and require care across a diverse range of multidisciplinary medical, nursing and supportive care services. This is one of the first quantitative studies to report on lung cancer patients' experiences regarding their coordination of care. Overall, patients reported positive experiences of cancer care coordination. The results indicate that lung cancer patients were satisfied with information provision and communication about their treatment, tests and appointment waiting times. However, participants reported issues with particular elements of care coordination related to administrative processes

Table 3 Factors associated with care coordination experience (CCCQ-P): univariate analysis

	Total care coordination		Communication		Navigation	
	Mean (SD)	*p* value	Mean (SD)	*p* value	Mean (SD)	*p* value
Sex						
Male	79.5 (9.7)	0.24	52 (7.0)	0.22	27 (3.8)	0.44
Female	76 (11.8)		49 (8.5)		26 (4.3)	
Country of birth						
Australia	78 (9.9)	0.88	50.7 (7.1)	0.75	27 (3.7)	0.83
Other	78 (11.8)		51 (8.5)		27 (4.3)	
Language spoken at home						
English	77 (10.5)	0.35	50 (7.6)	0.25	27 (3.7)	0.79
Other	81 (11.5)		54 (7.8)		27 (5.1)	
Education						
High school	77 (10.6)	0.21	50 (7.5)	0.33	27 (4.1)	0.13
Post-secondary	81 (10.4)		53 (8.1)		28 (3.2)	
ARIA						
MC	79 (11.2)	0.17	52 (8.0)	0.25	28 (4.20)	0.15
IR/OR/R	75 (8.9)		49 (6.8)		26 (3.15)	
Experience with health system						
Yes	79 (11.5)	0.25	51 (8.2)	0.67	28 (4.0)	0.02
No	76 (8.2)		50 (6.6)		25 (3.2)	
Comorbidities						
None	80 (14.5)	0.45	52 (10.2)	0.59	28 (4.8)	0.30
Any	77 (9.4)		50 (7.0)		27 (3.5)	
COPD						
Yes	80 (9.6)	0.50	52 (7.2)	0.51	28 (4.0)	0.52
No	77 (11.0)		51 (7.9)		27 (4.0)	
Stage of disease						
IA–IIB	80 (9.7)	0.89	51 (6.9)	0.82	27 (4.0)	0.42
IIIA–IV	78 (12.3)		51 (8.7)		28 (4.1)	
Surgery						
Yes	76 (10.1)	0.15	50 (7.3)	0.15	27 (3.8)	0.30
No	81 (11.3)		53 (8.1)		28 (4.2)	
Chemotherapy						
Yes	80 (10.9)	0.26	52 (8.1)	0.33	28 (3.9)	0.26
No	76 (10.2)		50 (7.1)		26 (4.0)	
Radiotherapy						
Yes	79 (11.2)	0.43	52 (8.1)	0.40	27 (4.0)	0.64
No	77 (10.3)		50 (7.3)		27 (3.9)	
Clinical trial enrolment						
Yes	85 (9.4)	0.08	56 (6.9)	0.05	28 (3.6)	0.34
No	77 (10.6)		50 (7.5)		27 (4.0)	
Health professionals seen						
< 3	76 (9.6)	0.12	49 (6.7)	0.07	27 (3.8)	0.50
> =4+	81 (11.7)		53 (8.5)		28 (4.3)	
Saw a cancer care coordinator						
Yes	81 (12.8)	0.32	53 (9.4)	0.24	28 (4.8)	0.69
No	77 (9.9)		50 (7.1)		27 (3.7)	
Hospital attendance						
Admission	79 (8.78)	0.87	52 (6.8)	0.78	27 (3.49)	

Table 3 (continued)

	Total care coordination		Communication		Navigation	
	Mean (SD)	*p* value	Mean (SD)	*p* value	Mean (SD)	*p* value
Clinic appointment	78 (11.16)		51 (8.0)		27 (4.09)	0.93
MDT review						
Yes	79 (11.2)	0.61	51 (8.1)	0.98	28 (4.1)	0.15
No	77 (9.8)		51 (7.0)		26 (3.4)	
Time since diagnosis	Coeff. (SD)		Coeff. (SD)		Coeff. (SD)	
2–6 months	Ref	0.37	Ref	0.42	Ref	0.41
7–12 months	6.23 (4.42)		4.22 (3.19)		2.06 (1.60)	
+ 12 months	3.69 (4.23)		2.76 (3.06)		0.93 (1.53)	
Age	0.15 (0.13)	0.28	0.09(0.05)	0.34	0.05 (0.05)	0.28

CCCQ-P Cancer Care Coordination Questionnaire for Patients

(including financial costs and difficulty getting appointments with health professionals) and communication and information provision. These findings can serve as a baseline against which to monitor improvements in the provision of care coordination or for comparison across different institutions.

We identified two patient groups who reported significantly worse experiences on the navigation subscale. The first group were patients residing in regional and rural areas (representing 32% of the sample), who had navigation scores that were on average 2.4 points lower than those patients residing in major cities. This finding is consistent with our previous research among colorectal cancer patients [23]. These results suggest that regional and rural patients need greater assistance with the logistical aspects of coordinating care across multiple sites. The second patient group were those with no experience of the health care system prior to their cancer diagnosis. This group reported navigation scores on average 3 points lower than those patients with previous experience. These results highlight a need for additional support at the time of diagnosis and throughout their treatment journey. Support strategies could include patient education materials, including those that document available services, or care plans that are tailored for people who are new to the health system. This is of particular relevance for lung cancer patients given with the complexity of patient care pathways and treatment options [32, 33].

The strengths of this study include that it presents a unique view of cancer care coordination from the patients' perspective. To our knowledge, there are few studies that have specifically explored these elements of lung cancer care. Another strength is that the survey has been previously validated in a colorectal cancer population making it possible to compare experiences across tumour groups. The mean total care coordination score for the lung cancer patient sample (78.1) was similar to the mean reported in a population-based sample of people with colorectal cancer [23], and the distribution of responses was also similar. Treatment modalities for colorectal and lung cancer (surgery, radiotherapy, chemotherapy) are similar and our results suggest that patients with these solid tumours have similar experiences of cancer care coordination. A further strength is that the findings provide initial evidence to conduct further research with the priority groups of patients living in regional and rural areas and those people who are new to the health system.

The study has a number of limitations. The sample size was relatively small, with a modest response rate and was underpowered to perform further adjusted multivariate analyses. However, this study provides the necessary first steps of adapting the questionnaire for a lung cancer population and has demonstrated survey validity with this patient group. The study was conducted across two hospitals within the one local health district and may not be representative of the experiences of the broader lung cancer population receiving treatment. The comparison between survey responders and non-responders found no differences; however, there could have been other factors (such as education, comorbidities, marital status or treatments received) that we could not identify or account for. We acknowledge that our sample represents those who are receiving tertiary referral hospital care and the findings may not be applicable to people with lung cancer first referred to community-based services such as palliative care. We did attempt to gain a broad sample of participants via treating clinicians including respiratory physicians, surgeons, radiation and medical oncologists. We made numerous approaches to clinicians to contact patients in order to maximise the response rates. Finally, we recruited only those patients who were well enough to participate (via their clinician) and this reflects a broader challenge of recruiting patients with lung cancer into research studies when there is high morbidity and mortality associated with the disease, including that many people are diagnosed at an advanced stage or have rapidly declining health. Human ethics requirements did not enable a third approach to contact patients out of concerns of possible failing health.

This study presents useful findings for clinical care, policy development and future research directions. Strategies to enhance care coordination for patients residing in regional or rural areas and those with no experience of the health care system are a priority to improve the patient experience and support coordinated best-practice care for people with lung cancer. Principle 4 of the Cancer Australia *Principles for best practice management of lung cancer in Australia* suggests that a care plan should be developed for every lung cancer patient and includes a nominated key contact person [27]. Our findings support this suggestion. Future research should test the survey instrument in other settings and in larger populations of lung cancer patients. Interventions that address coordination of care require further investigation and include the use of lay patient navigators [34, 35], telephone-based support systems [21, 36] and access to a nurse care coordinator in hospital [37].

In conclusion, this study found that, overall, patients reported positive experiences of cancer care coordination. We found that care coordination was significantly worse for two groups: patients living in rural and regional areas, and those with no experience of the health care system. These priority groups may need additional support. The CCCQ-P survey instrument can be used in future lung cancer studies.

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Author contributions This study was proposed by JY. GKC wrote the first draft of the manuscript and significant contributions were made by ID and NMR. Project management was overseen by NMR. GKC undertook all project coordination tasks, including ethics and governance approvals and data collection. Data analysis was undertaken by ID with advice from JY. DJB and PB are clinical leaders at the participating sites. All authors contributed to manuscript drafts and approved the final draft of the manuscript for submission.

Compliance with ethical standards

Competing interests The authors declare that they have no competing interests.

Ethics Ethics approval for this project was obtained from the Sydney Local Health District Human Research Ethics Committee (LNR/15/RPAH/508) and site-specific local governance approvals were granted prior to project commencement.

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