Section 1

Introduction and methods

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Background

Lung cancer is the fourth most diagnosed cancer in Australia for both men and women, in 2015, it was the fourth most common cause of death and the most common cause of cancer deaths. There were 13,078 new cases of lung cancer in 2018, with more men (7,168) than women (5,910) diagnosed. In 2022, 8457 people in Australia died from lung cancer, 4,751 of these deaths were in men. The survival rates from lung cancer are low, with less than half (48.4%) of those diagnosed surviving for one-year, and 21.6% surviving for five years. The survival rates are higher in women compared to men, younger people compared to older people, non-indigenous compared to indigenous, major cities compared to very remote locations, and those in the highest socioeconomic group compared to those in the lowest.

Lung cancer has the greatest cancer burden, and it is the second most common reason for radiotherapy for both men and women (after prostate and breast cancers respectively), and it is the second most common type of cancer for palliative care (14%) after secondary site.

Personal Experience, Expectations and Knowledge (PEEK)

Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients and their families with treatments, information and care.

Position of this study

A search was conducted in Pubmed (January 8, 2023) to identify studies of lung cancer with patient reported outcomes, or patient experience conducted in the past five years in World wide (Table 1.1). Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 104 studies identified of between 7 and 6420 lung cancer participants.

In this PEEK study, 29 people diagnosed with lung cancer, and 3 carers to people diagnosed with lung cancer throughout Australia participated in the study that included 26 qualitative structured interviews and quantitative questionnaire. This study in lung cancer has the largest number of interviews conducted with people with lung cancer in an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Introduction

Background

Lung cancer is the fourth most diagnosed cancer in Australia for both men and women¹, in 2015, it was the fourth most common cause of death and the most common cause of cancer deaths². There were 13,078 new cases of lung cancer in 2018, with more men (7,168) than women (5,910) diagnosed³. In 2022, 8457 people in Australia died from lung cancer, 4,751 of these deaths were in men⁴. The survival rates from lung cancer are low, with less than half (48.4%) of those diagnosed surviving for one-year, and 21.6% surviving for five years⁴. The survival rates are higher in women compared to men, younger people compared to older people, non-indigenous compared to indigenous, major cities compared to very remote locations, and those in the highest socioeconomic group compared to those in the lowest⁵.

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The research protocol used in PEEK studies is independently driven by CCDR. PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in

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relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform policy, research, care, information, supportive care services and advocacy efforts.

Participants

To be eligible for the study, participants needed to have been diagnosed with lung cancer, have experienced the healthcare system in Australia, be 18 years of age or older, be able to speak English, and be able to give consent to participate in the study. Recruitment commenced 1 April 2021 and was completed by 15 June 2021.

Ethics

Ethics approval for this study was granted (as a low or negligible risk research study) by the Centre for Community-Driven Research Ethics Committee (Reference CS_Q4_03).

Data collection

Data for the online questionnaire was collected using Zoho Survey (Zoho Corporation Pvt. Ltd. Pleasanton, California, USA, <u>www.zoho.com/survey</u>). Participants completed the survey from 1 April 2022 to 30 June 2022.

There were five researchers who conducted telephone interviews and used standardised prompts throughout the interview. The interviews were recorded and transcribed verbatim. Identifying names and locations were not included in the transcript. All transcripts were checked against the original recording for quality assurance.

Interview data was collected from 1 April 2022 to 30 June 2022.

Online questionnaire (quantitative)

The online questionnaire consisted of the 36-Item Short Form Health Survey (SF36) (RAND Health)⁷, a modified Cancer Care Coordination Questionnaire for Patients (CCCQ)⁸, the Short Fear of Progression Questionnaire (FOP12)⁹, and the Partners in Health version 2 (PIH)¹⁰. In addition, investigator derived questions about demographics, diagnosis, treatment received and future treatment decisions making were included.

Structured Interview (qualitative)

Interviews were conducted via telephone by registered nurses who were trained in qualitative research. The first set of interview questions guided the patient through their whole experience from when symptoms were noticed up to the present day.

Questionnaire analysis

Statistical analysis was conducted using R included in the packages "car", "dplyr" and "ggplot2" (R 3.3.3 GUI 1.69 Mavericks build (7328). The aim of the statistical analysis of the SF36, CCCQ, FOP12, and PIH responses was to identify variations by disease stage, gender, age, education status and socio-economic status. Scales and subscales were calculated according to reported instructions⁷⁻¹⁰. Data is presented by participant type (person with cancer, and carer or family member to person with lung cancer), and location (metropolitan and regional or remote), however due to small numbers in carer or family group, and regional or remote group, no comparisons are made.

The Location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics¹¹.

The level of socio-economic status of participants was evaluated by postcode using the Socio-economic Indexes for Areas (SEIFA) accessed from the Australian Bureau of Statistics¹¹.

For subgroup comparisons a two-sample t-test was used when assumptions for normality and variance were met, or when assumptions were not met, a Wilcoxon rank sum test with continuity correction was used. Questions where participants were asked to rank preferences were analysed using weighted averages. Weights were applied in reverse, the most preferred option was given the largest weight equal to the number of options, the least preferred option was given the lowest weight of 1.

Structured interviews analysis

A content analysis was conducted using conventional analysis to identify major themes from structured interviews. Text from the interviews were read line-byline by the lead researcher and then imported into CCDR's custom-made database. Each question within the interview was individually analysed. Initial categories and definitions were identified and

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registered in CCDR's custom-made database. The minimum coded unit was a sentence with paragraphs and phrases coded as a unit.

A second researcher verified the codes and definitions, and the text was coded until full agreement was reached using the process of consensual validation. Where a theme occurred less than 5 times it was not included in the study results, unless this result demonstrated a significant gap or unexpected result.

Data analysis and final reporting was completed in March 2023.

Position of this study

A search was conducted in Pubmed (January 8, 2023) to identify studies of lung cancer with patient reported outcomes, or patient experience conducted in the past five years worldwide (Table 1.1). Interventional studies, meta-analysis studies, studies with children, studies conducted in developing countries, and studies of less than five participants were excluded. There were 104 studies identified of between 7 and 6420 lung cancer participants.

There were 19 studies that included interviews of between 15 and 66 participants. There were 5 studies focused on Quality of life¹²⁻¹⁶, 5 studies focused on Side effects and symptoms¹⁷⁻²¹, 4 studies focused on Treatment²²⁻²⁵, 3 studies focused on Care and support²⁶⁻²⁸, 2 studies focused on Communication^{29,30}, and one study each focused on Co-morbidities³¹, Decision making³², General experience³³, and Knowledge and understanding³⁴.

There were 5 studies that collected data by focus group of between 7 and 109 participants. There were 2 studies focused on Diagnosis^{35,36}, 2 studies focused on Quality of life^{12,37}, and one study each focused on Care and support³⁸, and Physical activity³⁹.

There were 80 studies that included surveys of between 13 and 640 participants. There were 21 studies focused on HRQOL⁴⁰⁻⁶⁰, 17 studies focused on Treatment⁶¹⁻⁷⁷, 14 studies focused on Quality of life^{12,15,78-89}, 8 studies focused on Decision making^{32,90-96}, 6 studies focused on Side effects and symptoms⁹⁷⁻¹⁰², 5 studies focused on Physical activity¹⁰³⁻¹⁰⁷

3 studies focused on Knowledge and understanding^{34,108,109}, 2 studies focused on Care and support^{110,111}, 2 studies focused on Costs^{112,113}

and one study each focused on Co-morbidities¹¹⁴, and Diagnosis¹¹⁵.

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people with lung cancer in an Australian population. In addition, PEEK is a comprehensive study covering all aspects of disease experience from symptoms, diagnosis, treatment, healthcare communication, information provision, care and support, quality of life, and future treatment and care expectations.

Table 1.1: PEEK position

First Author (Year)	Location	Study focus	Interviews	Focus	Survey	PEEK SECTION								
				groups		2: Health status, co- morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication and self- management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages	
McDonnell. 2020 ³⁸	USA	Care and support	0	26 [26]	0						х	х		
Adorno, 2017 ¹¹⁰	USA	Care and support	0	0	30	х				х		Х		
Sato, 2021 ¹¹¹	Japan	Care and support	0	0	248 [232]	х	х			Х	Х	Х		
Yi, 2018 ¹¹⁴	South Korea	Co-morbidities	0	0	337	Х	Х							
Hazell, 2020 ¹¹²	USA	Costs	0	0	143	Х	Х		Х					
Ezeife, 2019 ¹¹³	Canada	Costs	0	0	200				Х					
Trejo, 2020 ⁹⁰	Australia	Decision making	0	0	111	Х	Х							
Sullivan, 2019 ⁹¹	USA	Decision making	0	0	114			Х						
Mokhles, 2018 ⁹²	Netherlands	Decision making	0	0	152	Х		Х				Х		
Islam, 2019 ⁹³	USA	Decision making	0	0	235			Х				Х		
Kameyama, 2022 ⁹⁴	Japan	Decision making	0	0	248	Х		Х				Х		
Schwartz, 2022 ⁹⁵	USA	Decision making	0	0	543	Х		Х						
Sato, 201896	Japan	Decision making	0	0	193 [167]	X	х	Х				Х		
Kidd, 2021 ³⁶ , Cassim,	New Zealand	Diagnosis	0	109*	0		Х		X		Х	Х		
Kuon 2022 ¹¹⁵	Germany	Diagnosis	0	0	217	х	Х					Х		
Feliciano 2018 ³⁵	USA	Diagnosis	0	17	0		Х	Х				Х		
Timmerman, 2018 ⁴⁰	Netherlands	HRQOL	0	0	23	х	Х							
Medysky, 2021 ⁴¹	USA	HRQOL	0	0	72	Х								
Ha, 2022 ⁴²	USA	HRQOL	0	0	75	Х								
Ch'ng, 2022 ⁴³	Australia	HRQOL	0	0	89	Х			Х					
Friis, 2021 ⁴⁴	Denmark	HRQOL	0	0	94	Х	Х					Х		
Martin, 2021 ⁴⁵	USA	HRQOL	0	0	103	Х	Х					Х		
Kyriazidou, 2022 ⁴⁶	Greece	HRQOL	0	0	104	Х					Х			

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Nugent, 202047	USA	HRQOL	0	0	127	Х	Х					Х			
Koch, 2022 ⁴⁸	Germany	HRQOL	0	0	130	Х									
van Montfort, 202049	Netherlands	HRQOL	0	0	130	Х	Х								
Levinsen, 2022 ⁵⁰	Denmark	HRQOL	0	0	137	Х	Х			x					
Torrente, 2022 ⁵¹	Portugal	HRQOL	0	0	140	Х			Х						
Cruz-Castellanos,			0	0	145	Х						Х			
2022 ⁵²	Spain Multi-	HRQOL	0	0	150	Х		х							
Ichimura 202154	lanan	HROOL	0	0	223	Х	Х								
Holdon 20225	заран	HROOL	0	0	334	Х									
Bempili 202256	USA	HRQOL	0	0	388	Х									
Pompin, 2022 ³³	OK		0	0	657	Х	Х								
Detrille 202258	Germany	HRQOL	0	0	856	Х									
Petrillo, 2022		HRQOL	0	0	6420	Х	х								
Wood, 2019 ⁶⁰	Multi- national	HRQOL	0	0	1030 [427]	Х									
Lee, 2018 ¹⁰⁸	South Korea	Knowledge and understanding	0	0	80	Х				х					
Arai, 2021 ¹⁰⁹	Japan	Knowledge and understanding	0	0	225	Х	Х	Х							
Granger, 2019 ³⁹	Australia	Physical activity	0	7	0				X		Х				
Ha, 2020 ¹⁰³	USA	Physical activity	0	0	35	Х	Х								
Bade, 2018 ¹⁰⁴	USA	Physical activity	0	0	39	Х	Х								
Ha, 2018 ¹⁰⁵	USA	Physical activity	0	0	62	Х	Х					х			
Yoo, 2020 ¹⁰⁶	South Korea	Physical activity	0	0	92	Х	Х		Х			Х			
D'Silva, 2018 ¹⁰⁷	Canada	Physical activity	0	0	127	Х	Х		X						
Looijmans, 201837	Netherlands	Quality of life	0	26	0										
McDonnell, 2022 ⁷⁸	USA	Quality of life	0	0	56	Х						Х			
Johnson, 2019 ⁷⁹	USA	Quality of life	0	0	62	Х	Х					Х			

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McFarland, 2022 ⁸⁰	USA	Quality of life	0	0	98							х			
Williamson, 2018 ⁸¹	USA	Quality of life	0	0	101										
Hyland, 2019 ⁸²	USA	Quality of life	0	0	105										
Perloff, 2019 ⁸³	USA	Quality of life	0	0	108										
Bodd. 2022 ⁸⁴	USA	Quality of life	0	0	152							х			
Maguire, 2019 ⁸⁵	UK	Quality of life	0	0	201	Х	Х								
Rigney 2021 ⁸⁶	USA	Quality of life	0	0	208										
1 60 2019 ⁸⁷	South Korea	Quality of life	0	0	212	Х	х				Х	х			
Aubin, 2022 ⁸⁸	Canada	Quality of Life	0	0	206 [131]										
Tan, 2018 ⁸⁹	UK	Quality of life	0	0	43 [43]	х	Х					Х			
do Mal 202097	Nothorlanda	Side effects and	0	0	151	X	X								
Choi, 2018 ⁹⁹	South Korea	Side effects and symptoms	0	0	178	Х	х								
Harle, 2020 ¹⁰⁰	ик	Side effects and symptoms	0	0	202		X					X			
Kuon, 2019 ¹⁰¹	Germany	Side effects and symptoms	0	0	208	х	х					х			
Linares-Moya, 202298	Spain	Side effects and symptoms	0	0	174	Х	Х								
Mendoza, 2019 ¹⁰²	USA	Side effects and symptoms	0	0	460	X	X								
Walter, 2022 ⁶⁶	Germany	Treatment	0	0	93	Х						Х			
Feld, 2019 ⁶⁷	USA	Treatment	0	0	100			Х	X	Х	Х				
Janssens, 2019 ⁷⁰ , van de Wiel, 2021 ¹¹⁷	Belgium	Treatment	0	0	125	X	X	Х		Х		Х			
Klein, 2019 ⁶¹	USA	Treatment	0	0	13	Х	Х		Х						
Nguyen, 2019 ⁶²	Belgium	Treatment	0	0	32	Х	Х								
Steffen McLouth, 2020 ⁶³	Usa	Treatment	0	0	60	X	X								

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de, 2019 ⁶⁴	Netherlands	Treatment	0	0	69	Х	Х								
Lavdaniti, 202165	Greece	Treatment	0	0	76	X	Х								
Asemota, 202268	UK	Treatment	0	0	106	Х	Х					Х			
Khullar, 2021 ⁶⁹	USA	Treatment	0	0	123	Х	Х								
Hollen, 2021 ⁷¹	USA	Treatment	0	0	164	Х	Х					Х			
Ryan, 2019 ⁷²	USA	Treatment	0	0	167	Х	Х					х			
Oswald, 2018 ⁷⁴	Uk	Treatment	0	0	292			Х		Х					
Rallis, 2019 ⁷⁵	Greece	Treatment	0	0	300	Х	Х								
Saito, 2020 ⁷⁶	Japan	Treatment	0	0	311	х									
Wilkie, 2022 ⁷⁷	USA	Treatment	0	0	1361	Х	Х								
Souliotis, 2021 ⁷³	Greece	Treatment	0	0	250				х	Х					
Bédard, 2022 ¹²	Canada	Quality of life	8	4	53							Х			
McMullen, 2019 ³²	USA	Decision making	10	0	77			Х				Х			
Bossert, 2020 ³¹	Germany	Co-morbidities	15	0	0				Х		Х				
Mieras, 2021 ³⁴ , Mieras, 2021 ¹¹⁸	Netherlands	Knowledge and understanding	15	0	266			х					Х		
Somavaii. 2022 ²⁹	USA	Communication	16	0	0		Х			Х					
Stanze, 2019 ¹³	Germany	Ouality of life	17	0	0						Х				
Belgaid, 2018 ¹⁷	Sweden	Side effects and symptoms	17	0	0				x		Х	Х			
Bever, 2022 ²²	Canada	Treatment	18	0	0							Х			
Teteh, 2022 ¹⁴	USA	Quality of life	19	0	0							Х			
Wong, 2022 ¹⁵ , Singhal, 2022 ¹¹⁹	USA	Quality of life	20	0	93	х									
Skurla, 2022 ¹⁸	USA	Side effects and symptoms	20	0	0		Х		Х		Х	Х			
Kutzleben, 2022 ¹⁹	Germany	Side effects and symptoms	21	0	0				x						
Dao, 2020 ²⁶	USA	Care and support	23	0	0		Х								

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				groups		2: Health status, co- morbidities	3: Diagnosis experience	4: Decision making	5: Treatment, healthcare system use	6: Information, communication and self- management	7: Care, support and navigating healthcare system	8: Quality of life, mental health, relationships	9 Expectations, preferences and messages
Park, 2020 ³³	Multi- national	General experience	24	0	0		X					Х	
Brown, 2020 ²³	USA	Treatment	25	0	0				Х			Х	
Taylor, 2022 ¹⁶	UK	Quality of life	30	0	0					Х		Х	
Martin, 2022 ²⁰	Multi- national	Side effects and symptoms	42	0	0				x				
Edbrooke, 2020 ²⁴	Australia	Treatment	45	0	0				Х	Х	Х		
Nababan, 2020 ²⁷	Australia	Care and support	47	0	0						Х	Х	
Martin, 2022 ²¹	USA	Side effects and symptoms	66	0	0				x				
Krug, 2021 ²⁸	Germany	Care and support	13 [12]	0	0					х	Х		
El-Turk, 2021 ²⁵	Australia	Treatment	16 [1]	0	0				Х	х	Х	Х	Х
Petrillo, 2022 ³⁰ , Petrillo, 2021 ¹²⁰	USA	Communication	39 [16]	0	0		X	X		Х	х		Х

[Carer]

*Not specified if carer or person with lung cancer

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of
CCDR	Statistics, defines remoteness and diban/rural definitions in Australia
de	Degrees of Freedom. The number of values in the final calculation of
ur	a statistic that are free to yary
£	a statistic that are need to vary.
T	The F ratio is the ratio of two mean square values, used in an ANOVA
	comparison. A large F ratio means that the variation among group means is
	more than you'd expect to see by chance.
FOP	Fear of Progression. Tool to measure anxiety related to progression
IQR	Interquartile range. A measure of statistical dispersion, being equal to the
	difference between 75th and 25th percentiles, or between upper and
	lower quartiles.
р	Probability value. A small <i>p</i> -value (typically \leq 0.05) indicates strong. A large <i>p</i> -
	value (> 0.05) indicates weak evidence.
PEEK	Patient Experience, Expectations and Knowledge
PIH	Partners in Health
SD	Standard deviation. A quantity expressing by how much the members of a
	group digger from the mean value for the group/
SEIFA	Socio-Economic Indexes for Areas (SEIFA) ranks areas in Australia according to
	relative socio-economic advantage and disadvantage. This is developed by the
	Australian Bureau of Statistics.
SF36	Short Form Health Survey 36
t	t-Statistic. Size of the difference relative to the variation in your sample data.
Tukey HSD	Tukey's honestly significant difference test. It is used in this study to find
-	9significantly different means following an ANOVA test.
W	The W statistic is the test value from the Wilcoxon Rank sum test. The
	theoretical range of W is between 0 and (number in group one) x (number in
	group 2). When W=0, the two groups are exactly the same.
X ²	Chi-squared. Kruskal-Wallis test statistic approximates a chi-square
	distribution. The Chi-square test is intended to test how likely it is that an
	observed distribution is due to chance

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