CENTRE FOR COMMUNITY-DRIVEN RESEARCH

Personal Experience, Expectations and Knowledge (PEEK)

People diagnosed with:

Lung cancer

Volume 6 (2023), Issue 1

This study was generously sponsored by Gilead Australia.

Gilead Australia provided arm's length sponsorship for the Centre for Community-Driven Research to report on the PEEK protocol data for people who have been diagnosed with bladder cancer. The sponsor had no input into the methodology, data collection, data analysis or reporting.

Thank you to each and every person that participated in this PEEK study.

PEEK study process information

Volume	6
Issue	1
Reference	Centre for Community-Driven Research (CCDR). Personal Experience Expectations and Knowledge (PEEK) study: People who have experienced lung cancer. Volume 6, Issue 1 (2023)
CCDR research team	Kate Holliday, Anne Holliday, Viven Cheung, Victoria Koh, Fay Miller, Daniel Weber, Alannah Kearns, Aleysha Martin
Number of participants	32

Contents

Summary of results

Executive summary

There were 29 people diagnosed with lung cancer, 3 family members or carers to people with lung cancer throughout Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 55 and 74. About half of the participants had completed some university, and most were not in paid employment. The majority of the participants were not carers to family members or spouses.

Physical health and emotional problems interfered with work and other activities for participants in this study.

On average they had 3 symptoms before diagnosis, usually fatigue, shortness of breath, and coughing up blood which all contributed to poor quality of life.

This is a group that had health conditions other than lung cancer to deal with, most often sleep problems, anxiety, depression, and anxiety.

This is a patient population that experienced shortness of breath or a persistent cough that led to diagnosis which they recalled clearly. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist.

This is a cohort that on average, three diagnostic tests for lung cancer, they were diagnosed by a respiratory specialist in a hospital. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with non-small cell lung cancer and had stage 4 disease. This is a group that did not have enough emotional support at the time of diagnosis. This is a cohort that did not have conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a study cohort that had limited knowledge of lung cancer before they were diagnosed. This patient population were uncertain about their diagnosis or described that they had a terminal condition.

This is a patient population that had discussions about multiple treatment options, and about a third participated in the decision-making process.

This is a study cohort that took into account efficacy, and the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, similar numbers of participants had changed decision making over time and hadn't changed over time, for those that changed, this was linked to being more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to be cancer free, avoid recurrence and live longer.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a medical oncologist, but also had access to radiation oncologists and general practitioners to manage their lung cancer.

Almost 60% of this cohort had private health insurance and were most often treated as public patients. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. They did however have monthly expenses.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change employment status. The loss of family income was often in the 1000s per month.

More than half of the participants had immunotherapy, surgery, chemotherapy and radiotherapy was also common.

About a third had conversations about clinical trials, and the majority would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using specific examples such as aches and pain, or as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as being short of breath, they also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described adherence to treatments in terms of not giving up on any treatment. This is a study cohort that needed to see evidence of stable disease or no disease progression to know that treatment was working.

In this PEEK study, participants had very good knowledge about their condition and treatments, they were good at coping with their condition, were very good at recognising and managing symptoms, and were very good adhering to treatment.

Participants were given information about treatment options, disease cause, and physical activity from health care professionals, and searched for disease management, disease causes, and treatment options most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, their health charities or social media.

This is a study cohort that found information about other people's experience as being helpful.

Participants commonly found information from sources that were not credible, and worst-case scenarios as not helpful.

This is a group that preferred to get their information by talking to someone plus online information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis, or after they have results from their treatment or follow up scans.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive with one-way conversations.

The participants in this study experienced good quality of care, and moderate coordination of care. They had a moderate ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population that did not receive any formal support. When participants felt supported, most found support through charities, or peer support or other patients.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as physical exercise, and mindfulness and mediation, and noted the importance of family and friends in maintaining their mental health.

Within this patient population, participants described being physically active, and the understanding their limitations in order to maintain their general health.

Participants in this study had felt vulnerable especially when having sensitive discussions about their condition, and during or after treatments. To manage vulnerability, they relied on self-help, such as resilience, acceptance and staying positive.

This cohort most commonly felt there was an overall negative impact on their relationships, with the dynamics of relationships changing due to anxiety of difficult decisions.

Participants felt they were a burden on their family, due to the emotional strain.

Most participants felt there was some cost burden which was from needing to take time off work, and the costs of treatments.

Life was a little distressing for this group, due to having lung cancer.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more affordable, and for there to be more access to clinical trials and new treatments.

This is a study cohort that would like information to be easier to find, and will include to talk to a healthcare professional.

Participants in this study would like future communication to be more empathetic, and that will include a coordinated multidisciplinary approach.

Participants would like future care and support to include specialist clinics or services where they can talk to professionals.

This patient population was grateful for low cost or free treatments available through the government, and healthcare staff including specialists.

It was important for this cohort to control pain, nauseas and vomiting, and fatigue to improve quality of life. Participants in this study would consider taking a treatment for more than 1 to 5 years if quality of life is improved with no cure.

Participants' message to decision-makers was to help raise community awareness, provide new treatments or clinical trials for lung cancer, and to provide timely and equitable access to support, care and treatment.

This is a patient population that wished they had communicated and increased their understanding of their condition.

Many participants would not change any aspect of their treatment or care, though some would have accessed treatment or their specialist sooner.

Section 1

Introduction and methods

Section 1 Introduction and methodology

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 women[1], in 2015, it was the fourth most common cause of death and the most common cause of cancer deaths[2]. There were 13,078 new cases of lung cancer in 2018, with more men (7,168) than women (5,910) diagnosed[3]. In 2022, 8457 people in Australia died from lung cancer, 4,751 of these deaths were in men[4]. 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[4]. 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[5].

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[6].

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.

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 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, www.zoho.com/survey). 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 instructions[7-10]. 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 Statistics[11].

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 Statistics[11].

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-by-line 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 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 life[12-16], 5 studies focused on Side effects and symptoms[17-21], 4 studies focused on Treatment[22-25], 3 studies focused on Care and support[26-28], 2 studies focused on Communication[29,30], and one study each focused on Co-morbidities[31], Decision making[32], General experience[33], and Knowledge and understanding[34].

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 support[38], and Physical activity[39].

There were 80 studies that included surveys of between 13 and 640 participants. There were 21 studies focused on HRQOL[40-60], 17 studies focused on Treatment[61-77], 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 symptoms[97-102], 5 studies focused on Physical activity[103-107]
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-morbidities[114], and Diagnosis[115].

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.

Table 1.1: PEEK position

First Author (Year)	Location	Study focus	Interviews	Focus groups	Survey	PEEK SECTION							
						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						X	X	
Adorno, 2017[110]	USA	Care and support	0	0	30	X				X		X	
Sato, 2021[111]	Japan	Care and support	0	0	248 [232]	X	X			X	X	X	
Yi, 2018[114]	South Korea	Co-morbidities	0	0	337	X	X						
Hazell, 2020[112]	USA	Costs	0	0	143	X	X		X				
Ezeife, 2019[113]	Canada	Costs	0	0	200				X				
Trejo, 2020[90]	Australia	Decision making	0	0	111	X	X						
Sullivan, 2019[91]	USA	Decision making	0	0	114			X					
Mokhles, 2018[92]	Netherlands	Decision making	0	0	152	X		X				X	
Islam, 2019[93]	USA	Decision making	0	0	235			X				X	
Kameyama, 2022[94]	Japan	Decision making	0	0	248	X		X				X	
Schwartz, 2022[95]	USA	Decision making	0	0	543	X		X					
Sato, 2018[96]	Japan	Decision making	0	0	193 [167]	X	X	X				X	
Kidd, 2021[36], Cassim, 2021[116]	New Zealand	Diagnosis	0	109*	0		X		X		X	X	
Kuon, 2022[115]	Germany	Diagnosis	0	0	217	X	X					X	
Feliciano, 2018[35]	USA	Diagnosis	0	17	0		X	X				X	
Timmerman, 2018[40]	Netherlands	HRQOL	0	0	23	X	X						
Medysky, 2021[41]	USA	HRQOL	0	0	72	X							
Ha, 2022[42]	USA	HRQOL	0	0	75	X							
Ch'ng, 2022[43]	Australia	HRQOL	0	0	89	X			X				
Friis, 2021[44]	Denmark	HRQOL	0	0	94	X	X					X	
Martin, 2021[45]	USA	HRQOL	0	0	103	X	X					X	
Kyriazidou, 2022[46]	Greece	HRQOL	0	0	104	X					X		

First Author (Year)	Location	Study focus	Interviews	Focus groups	Survey	PEEK SECTION							
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Nugent, 2020[47]	USA	HRQOL	0	0	127	X	X					X	
Koch, 2022[48]	Germany	HRQOL	0	0	130	X							
van Montfort, 2020[49]	Netherlands	HRQOL	0	0	130	X	X						
Levinsen, 2022[50]	Denmark	HRQOL	0	0	137	X	X			X			
Torrente, 2022[51]	Portugal	HRQOL	0	0	140	X			X				
Cruz-Castellanos, 2022[52]	Spain	HRQOL	0	0	145	X						X	
Müller, 2022[53]	Multi-national	HRQOL	0	0	150	X		X					
Ichimura, 2021[54]	Japan	HRQOL	0	0	223	X	X						
Heiden, 2022[55]	USA	HRQOL	0	0	334	X							
Pompili, 2022[56]	UK	HRQOL	0	0	388	X							
Hechtner, 2019[57]	Germany	HRQOL	0	0	657	X	X						
Petrillo, 2022[58]	USA	HRQOL	0	0	856	X							
Pierzynski, 2018[59]	USA	HRQOL	0	0	6420	X	X						
Wood, 2019[60]	Multi-national	HRQOL	0	0	1030 [427]	X							
Lee, 2018[108]	South Korea	Knowledge and understanding	0	0	80	X				X			
Arai, 2021[109]	Japan	Knowledge and understanding	0	0	225	X	X	X					
Granger, 2019[39]	Australia	Physical activity	0	7	0				X		X		
Ha, 2020[103]	USA	Physical activity	0	0	35	X	X						
Bade, 2018[104]	USA	Physical activity	0	0	39	X	X						
Ha, 2018[105]	USA	Physical activity	0	0	62	X	X					X	
Yoo, 2020[106]	South Korea	Physical activity	0	0	92	X	X		X			X	
D'Silva, 2018[107]	Canada	Physical activity	0	0	127	X	X		X				
Looijmans, 2018[37]	Netherlands	Quality of life	0	26	0								
McDonnell, 2022[78]	USA	Quality of life	0	0	56	X						X	
Johnson, 2019[79]	USA	Quality of life	0	0	62	X	X					X	

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McFarland, 2022[80]	USA	Quality of life	0	0	98							X	
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							X	
Maguire, 2019[85]	UK	Quality of life	0	0	201	X	X						
Rigney, 2021[86]	USA	Quality of life	0	0	208								
Lee, 2019[87]	South Korea	Quality of life	0	0	212	X	X				X	X	
Aubin, 2022[88]	Canada	Quality of Life	0	0	206 [131]								
Tan, 2018[89]	UK	Quality of life	0	0	43 [43]	X	X					X	
de Mol, 2020[97]	Netherlands	Side effects and symptoms	0	0	151	X	X						
Choi, 2018[99]	South Korea	Side effects and symptoms	0	0	178	X	X						
Harle, 2020[100]	UK	Side effects and symptoms	0	0	202		X					X	
Kuon, 2019[101]	Germany	Side effects and symptoms	0	0	208	X	X					X	
Linares-Moya, 2022[98]	Spain	Side effects and symptoms	0	0	174	X	X						
Mendoza, 2019[102]	USA	Side effects and symptoms	0	0	460	X	X						
Walter, 2022[66]	Germany	Treatment	0	0	93	X						X	
Feld, 2019[67]	USA	Treatment	0	0	100			X	X	X	X		
Janssens, 2019[70], van de Wiel, 2021[117]	Belgium	Treatment	0	0	125	X	X	X		X		X	
Klein, 2019[61]	USA	Treatment	0	0	13	X	X		X				
Nguyen, 2019[62]	Belgium	Treatment	0	0	32	X	X						
Steffen McLouth, 2020[63]	Usa	Treatment	0	0	60	X	X						

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de, 2019[64]	Netherlands	Treatment	0	0	69	X	X						
Lavdaniti, 2021[65]	Greece	Treatment	0	0	76	X	X						
Asemota, 2022[68]	UK	Treatment	0	0	106	X	X					X	
Khullar, 2021[69]	USA	Treatment	0	0	123	X	X						
Hollen, 2021[71]	USA	Treatment	0	0	164	X	X					X	
Ryan, 2019[72]	USA	Treatment	0	0	167	X	X					X	
Oswald, 2018[74]	Uk	Treatment	0	0	292			X		X			
Rallis, 2019[75]	Greece	Treatment	0	0	300	X	X						
Saito, 2020[76]	Japan	Treatment	0	0	311	X							
Wilkie, 2022[77]	USA	Treatment	0	0	1361	X	X						
Souliotis, 2021[73]	Greece	Treatment	0	0	250				X	X			
Bédard, 2022[12]	Canada	Quality of life	8	4	53							X	
McMullen, 2019[32]	USA	Decision making	10	0	77			X				X	
Bossert, 2020[31]	Germany	Co-morbidities	15	0	0				X		X		
Mieras, 2021[34], Mieras, 2021[118]	Netherlands	Knowledge and understanding	15	0	266			X					X
Somayaji, 2022[29]	USA	Communication	16	0	0		X			X			
Stanze, 2019[13]	Germany	Quality of life	17	0	0						X		
Belqaid, 2018[17]	Sweden	Side effects and symptoms	17	0	0				X		X	X	
Bever, 2022[22]	Canada	Treatment	18	0	0							X	
Teteh, 2022[14]	USA	Quality of life	19	0	0							X	
Wong, 2022[15], Singhal, 2022[119]	USA	Quality of life	20	0	93	X							
Skurla, 2022[18]	USA	Side effects and symptoms	20	0	0		X		X		X	X	
Kutzleben, 2022[19]	Germany	Side effects and symptoms	21	0	0				X				
Dao, 2020[26]	USA	Care and support	23	0	0		X						

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Park, 2020[33]	Multi-national	General experience	24	0	0		X					X	
Brown, 2020[23]	USA	Treatment	25	0	0				X			X	
Taylor, 2022[16]	UK	Quality of life	30	0	0					X		X	
Martin, 2022[20]	Multi-national	Side effects and symptoms	42	0	0				X				
Edbrooke, 2020[24]	Australia	Treatment	45	0	0				X	X	X		
Nababan, 2020[27]	Australia	Care and support	47	0	0						X	X	
Martin, 2022[21]	USA	Side effects and symptoms	66	0	0				X				
Krug, 2021[28]	Germany	Care and support	13 [12]	0	0					X	X		
El-Turk, 2021[25]	Australia	Treatment	16 [1]	0	0				X	X	X	X	X
Petrillo, 2022[30], Petrillo, 2021[120]	USA	Communication	39 [16]	0	0		X	X		X	X		X

[Carer]

***Not specified if carer or person with lung cancer**

Abbreviations and terminology

ASGS	The Australian Statistical Geography Standard from the Australian Bureau of Statistics, defines remoteness and urban/rural definitions in Australia
CCDR	Centre for Community-Driven Research
dF	Degrees of Freedom. The number of values in the final calculation of a statistic that are free to vary.
f	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.
p	Probability value. A small *p*-value (typically ≤ 0.05) indicates strong. A large *p*-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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Section 2

Demographics

Section 2 Demographics

Participants

There were 29 people with lung cancer and 3 family members or carers who took part in this study. There were 4 participants (12.90%) with Stage 1, 3 participants (9.68%) with Stage 2, 4 participants (58.06%) with Stage 3, and 18 participants (58.06%) with Stage 4.

Demographics

Participants were aged from 35 to over 75 years of age, most were aged between 55 to 74 years (n=21, 65.63%). Participants were most commonly from Queensland (n=10, 31.25%), Victoria (n=10, 31.25%), and Western Australia (n=7, 21.88%). Most participants were from major cities (n=29, 90.63%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 20 participants (62.50%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 12 participants (37.50%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 15 participants (46.88%) that had completed university to at least an associate degree. There were 10 participants (34.48%) who were in paid employment. Less than half of the participants were carers to family members or spouses (n=13,40.63%), most commonly carers to Children (n=9, 28.13%).

Other health conditions

Almost all of the participants had at least one other condition that they had to manage (n=30, 96.77%), the maximum number reported was 7 other conditions, with a median of 2.00 other conditions (IQR = 2.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was sleep problems (n=11, 35.48%), followed by depression (n=9, 29.03%), anxiety (n=9, 29.03%), and arthritis (n=9, 29.03%).

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health almost always interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems often interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being scale** measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning scale** measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain scale** measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health scale** measures perception of health. On average, participants reported average health.

The **SF36 Health change scale** measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Demographics

There were 29 people with lung cancer and 3 family members or carers who took part in this study, 23 were females (71.88%). Participants were aged from 35 to over 75 years of age, most were aged between 55 to 74 years (n=21, 65.63%).

Participants were most commonly from Queensland (n=10, 31.25%), Victoria (n=10, 31.25%), and Western Australia (n=7, 21.88%). Most participants were from major cities (n=29, 90.63%), and they lived in all levels of advantage, defined by Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au) with 20 participants (62.50%) from an area with a high SEIFA score of 7 to 10 (more advantage), and 12 participants (37.50%) from an area of mid to low SEIFA scores of 1 to 6 (less advantaged).

There were 15 participants (46.88%) that had completed university to at least an associate degree. There were 10 participants (34.48%) who were in paid employment.

Less than half of the participants were carers to family members or spouses (n=13,40.63%), most commonly carers to Children (n=9, 28.13%). The demographics of participants are listed in Table 2.1.

Table 2.1: Demographics

Demographic	Definition	Number (n=32)	Percent
Gender	Female	23	71.88
	Male	9	28.13
Age	35-44	1	3.13
	45-54	8	25.00
	55-64	9	28.13
	65-74	12	37.50
	75+	2	6.25
Location	Major Cities of Australia	29	90.63
	Inner Regional Australia	3	9.38
	Outer Regional or remote Australia	0	0.00
	Remote Australia	0	0.00
State	Queensland	10	31.25
	Victoria	10	31.25
	Western Australia	7	21.88
	South Australia	3	9.38
	New South Wales	2	6.25
	Australian Capital Territory	0	0.00
	Northern Territory	0	0.00
	Tasmania	0	0.00
Socio-Economic Indexes for Areas (SEIFA)	1	1	3.13
	2	5	15.63
	3	1	3.13
	4	1	3.13
	5	2	6.25
	6	2	6.25
	7	4	12.50
	8	5	15.63
	9	6	18.75
	10	5	15.63
Race/ethnicity	Caucasian/White	28	87.50
	Other	4	12.50
Education	Less than high school degree	2	6.25
	High school degree or equivalent	5	15.63
	Some college but no degree	2	6.25
	Trade	2	6.25
	Associate degree	3	9.38
	Bachelor degree	11	34.38
	Graduate degree	7	21.88
Employment	Currently receiving Centrelink support	2	6.25
	Disabled not able to work	8	25.00
	Employed working full time	3	9.38
	Employed working part time	8	25.00
	Full/part time carer	2	6.25
	Full/part time study	0	0.00
	Not Employed looking for work	0	0.00
	Retired	12	37.50
Carer status	I am not a carer	19	59.38
	Children	9	28.13
	Grandchildren	3	9.38
	Parents	1	3.13

Participants

There were 29 people with lung cancer and 3 family members or carers who took part in this study. There were 4 participants (12.90%) with Stage 1, 3 participants (9.68%) with Stage 2, 4 participants (58.06%) with Stage 3, and 18 participants (58.06%) with Stage 4 (Table 2.2, Figure 2.1).

Table 2.2: Participants

Participants and diagnosis	Number (n=31)	Percent
Stage 1	4	12.90
Stage 2	3	9.68
Stage 3	4	12.90
Stage 4	18	58.06
Family member or carer	3	9.68

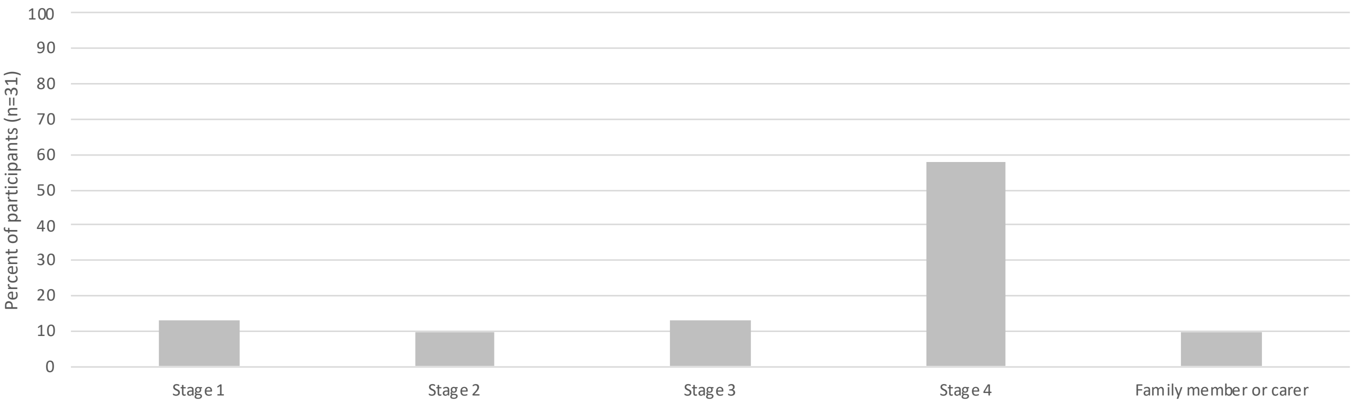


Figure 2.1: Participants

Other health conditions

Participants were asked about health conditions, other than lung cancer that they had to manage. Participants could choose from a list of common health conditions and could specify other conditions.

Almost all of the participants had at least one other condition that they had to manage (n=30, 96.77%), the maximum number reported was 7 other conditions, with a median of 2.00 other conditions (IQR = 2.00) (Table 2.3, Figure 2.2). The most commonly reported health condition was sleep problems (n=11, 35.48%), followed by depression (n=9, 29.03%), anxiety (n=9, 29.03%), and arthritis (n=9, 29.03%) (Table 2.4, Figure 2.3).

Table 2.3: Number of other health conditions

Number of other conditions	Number (n=31)	Percent
No other conditions	1	3.23
1 to 2	15	48.39
3 to 4	11	35.48
5 or more	4	12.90

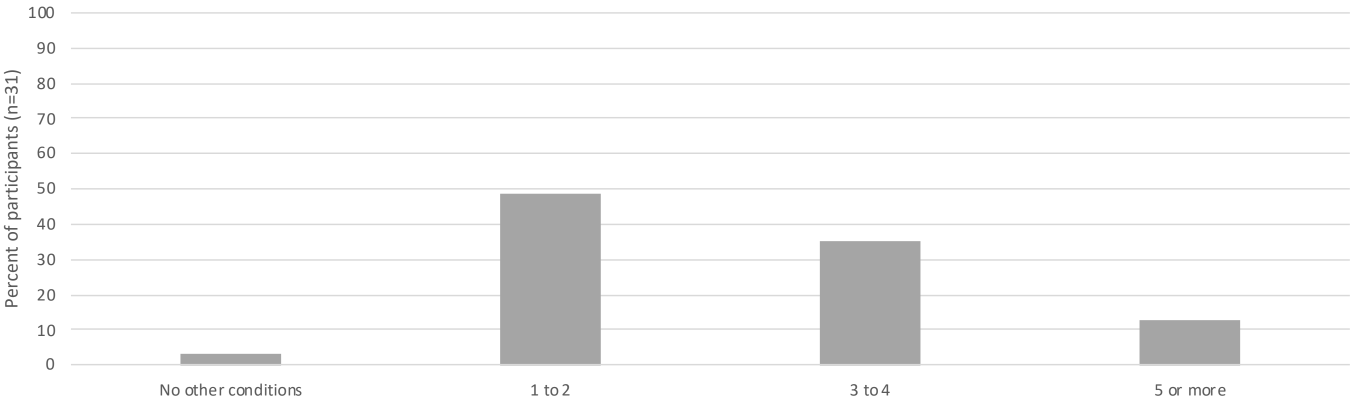


Figure 2.2: Number of other health conditions

Table 2.4: Other health conditions

Other conditions	Number (n=31)	Percent
Sleep problems	11	35.48
Depression	9	29.03
Anxiety	9	29.03
Arthritis	9	29.03
Hypertension	8	25.81
Asthma	6	19.35
Chronic pain	6	19.35
COPD	3	9.68
Chronic kidney disease	3	9.68
Arrhythmias	3	9.68
Chronic heart failure	1	3.23
Angina	1	3.23
Diabetes	1	3.23

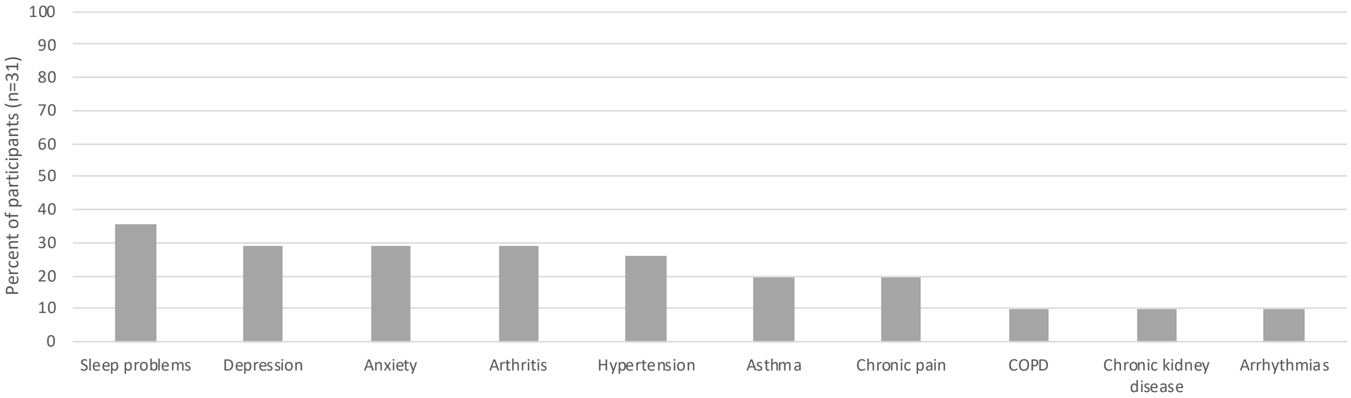


Figure 2.3: Other health conditions (% of all participants)

Subgroup analysis

Subgroup analysis are included throughout the study and the subgroups are listed in Table 2.5.

There were 29 participants (90.63%) that had been diagnosed with lung cancer, and 3 participants (9.38%) that were family members or carers to people with lung cancer. Comparisons by participant type were not made because there were too few family members and carers.

Comparisons were made by cancer stage, there were 11 participants (37.93%) with non-metastatic lung cancerand, 18 participants (62.07%) with metastatic lung cancer.

Comparisons were made by gender, there were 23 female participants (71.88%), and 9 male particpants (28.13%).

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=18, 56.25%), and participants aged 65 or older (n=14, 43.75%).

Comparisons were made by education status, between those with trade or high school qualifications (n=17, 53.13%), and those with a university qualification (n=15, 46.88%).

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 3 participants (9.38%) living in regional or remote areas and 29 participants (90.63%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas.

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=12, 37.50%) compared to those with a higher SEIFA score of 7-10, Higher status (n=20, 62.50%).

Table 2.5: Subgroups

Subgroup	Definition	Number (n=32)	Percent
Type	Person with	29	90.63
	Carer	3	9.38
Stage (n=29)	Non-metastatic	11	37.93
	Metastatic	18	62.07
Gender	Female	23	71.88
	Male	9	28.13
Age	Aged 35 to 64	18	56.25
	Aged 65 or older	14	43.75
Education	Trade or high school	17	53.13
	University	15	46.88
Location	Regional or remote	3	9.38
	Metropolitan	29	90.63
Economic status	Mid to low status	12	37.50
	Higher status	20	62.50

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function.

Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 2.6, for scales with a normal distribution, the mean and SD should be used as a central measure, and median and IQR for scales that do not have a normal distribution.

The overall scores for the cohort were in the second highest quintile for SF36 Physical functioning (median=70.00, IQR=55.00), SF36 Emotional well-being (mean=69.03, SD=20.03), SF36 Social functioning (median=62.50, IQR=56.25), SF36 Pain (mean=62.02, SD=24.74), indicating good physical functioning, good emotional well-being, good social functioning, and mild pain.

The overall scores for the cohort were in the middle quintile for SF36 Energy/Fatigue (mean=42.58, SD=24.52), SF36 General health (mean=44.52, SD=15.62), SF36 Health change (median=50.00, IQR=50.00), indicating moderate energy, moderate general health, and health that is about the same as a year ago

The overall scores for the cohort were in the second lowest quintile for SF36 Role functioning/emotional (median=33.33, IQR=100.00), indicating poor emotional role functioning.

The overall scores for the cohort were in the lowest quintile for FALSE, SF36 Role functioning/physical (median=0.00, IQR=75.00), indicating very poor physical role functioning.

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, physical activities were slightly limited for participants in this study.

SF36 Role functioning/physical scale measures how physical health interferes with work or other activities. On average, physical health almost always interfered with work or other activities for participants in this study.

SF36 Role functioning/emotional scale measures how emotional problems interfere with work or other activities. On average, emotional problems often interfered with work or other activities for participants in this study.

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants were sometimes fatigued.

The **SF36 Emotional well-being scale** measures how a person feels, for example happy, calm, depressed or anxious. On average, participants had good emotional well-being.

The **SF36 Social functioning scale** measures limitations on social activities due to physical or emotional problems. On average, social activities were slightly limited for participants in this study.

The **SF36 Pain scale** measures how much pain, and how pain interferes with work and other activities. On average, participants had mild pain.

The **SF36 General health scale** measures perception of health. On average, participants reported average health.

The **SF36 Health change scale** measures health compared to a year ago. On average, participants reported that their health is about the same as a year ago.

Table 2.6: SF36 summary statistics

SF36 scale (n=31)	Mean	SD	Median	IQR	Possible range	Quintile
Physical functioning	62.58	31.99	70.00	55.00	0 to 100	4
Role functioning/physical	34.68	44.10	0.00	75.00	0 to 100	1
Role functioning/emotional	47.31	47.74	33.33	100.00	0 to 100	2
Energy/Fatigue*	42.58	24.52	40.00	37.50	0 to 100	3
Emotional well-being*	69.03	20.03	68.00	28.00	0 to 100	4
Social functioning	59.27	30.61	62.50	56.25	0 to 100	4
Pain*	62.02	24.74	57.50	35.00	0 to 100	4
General health*	44.52	15.62	40.00	20.00	0 to 100	3
Health change	49.19	26.21	50.00	50.00	0 to 100	3

*Normal distribution, use mean and SD as central measure. Possible range 0-100

SF36 scales by participant type

There were 29 participants (93.55%) that had been diagnosed with lung cancer, and 2 participants (6.45%) that were family members or carers to people with lung cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 2.7.

Table 2.7: SF36 by participant type summary statistics

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	Median	IQR	Quintile
Physical functioning	Person with lung cancer	29	93.55	60.52	32.00	65.00	60.00	4
	Family member or carer	2	6.45	92.50	10.61	92.50	7.50	NA
Role functioning physical	Person with lung cancer	29	93.55	35.34	45.08	0.00	75.00	1
	Family member or carer	2	6.45	25.00	35.36	25.00	25.00	NA
Role functioning emotional	Person with lung cancer	29	93.55	50.57	47.66	33.33	100.00	2
	Family member or carer	2	6.45	0.00	0.00	0.00	0.00	NA
Energy/fatigue*	Person with lung cancer	29	93.55	43.28	24.79	40.00	35.00	3
	Family member or carer	2	6.45	32.50	24.75	32.50	17.50	NA
Emotional well-being*	Person with lung cancer	29	93.55	70.34	19.99	72.00	32.00	4
	Family member or carer	2	6.45	50.00	8.49	50.00	6.00	NA
Social functioning	Person with lung cancer	29	93.55	62.07	29.60	62.50	50.00	4
	Family member or carer	2	6.45	18.75	8.84	18.75	6.25	NA
Pain*	Person with lung cancer	29	93.55	61.29	24.36	57.50	35.00	4
	Family member or carer	2	6.45	72.50	38.89	72.50	27.50	NA
General health*	Person with lung cancer	29	93.55	44.48	16.11	40.00	20.00	3
	Family member or carer	2	6.45	45.00	7.07	45.00	5.00	NA
Health change	Person with lung cancer	29	93.55	50.86	26.29	50.00	50.00	3
	Family member or carer	2	6.45	25.00	0.00	25.00	0.00	NA

*Normal distribution, use mean and SD as central measure. Possible range 0-100

Comparisons of SF36 scales by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (37.93%) with non-metastatic lung cancerand, 18 participants (62.07%) with metastatic lung cancer.

Boxplots of each SF36 scale by **lung cancer stage** are displayed in Figures 2.4 to 2.12, summary statistics are displayed in Tables 2.8 and 2.9.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.8), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.9).

No significant differences were observed between participants by **lung cancer stage** for any of the SF36 scales.

Table 2.8: SF36 by lung cancer stage summary statistics and T-test

SF36 scale	Group	Number (n=29)	Percent	Mean	SD	T	dF	p-value
Energy/fatigue	Non-metastatic	11	37.93	42.73	24.33	-0.10	27	0.9244
	Metastatic	18	62.07	43.61	24.00			
Emotional well-being	Non-metastatic	11	37.93	73.82	19.30	1.09	27	0.2847
	Metastatic	18	62.07	65.78	19.22			
Social functioning	Non-metastatic	11	37.93	70.45	26.97	1.69	27	0.1027
	Metastatic	18	62.07	51.39	30.88			
Pain	Non-metastatic	11	37.93	55.91	24.96	-0.88	27	0.3887
	Metastatic	18	62.07	64.44	25.75			
General health	Non-metastatic	11	37.93	49.55	19.68	1.26	27	0.2187
	Metastatic	18	62.07	42.22	11.79			

Table 2.9: SF36 by lung cancer stage summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=29)	Percent	Median	IQR	W	p-value
Physical functioning	Non-metastatic	11	37.93	70.00	47.50	96.50	0.9281
	Metastatic	18	62.07	70.00	50.00		
Role functioning physical	Non-metastatic	11	37.93	0.00	100.00	113.00	0.4932
	Metastatic	18	62.07	0.00	68.75		
Role functioning emotional	Non-metastatic	11	37.93	66.67	83.33	119.50	0.3264
	Metastatic	18	62.07	0.00	100.00		
Health change	Non-metastatic	11	37.93	50.00	50.00	106.00	0.7564
	Metastatic	18	62.07	50.00	43.75		

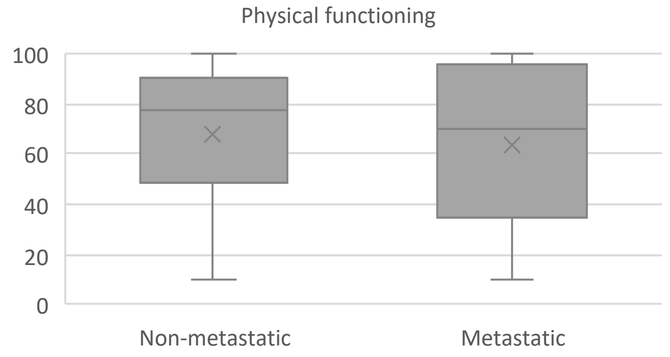


Figure 2.4: Boxplot of SF36 Physical functioning by lung cancer stage

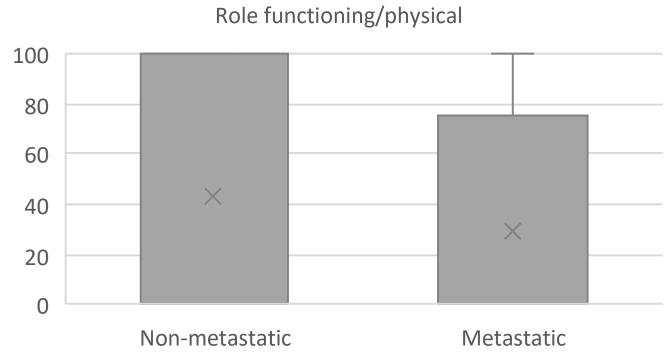


Figure 2.5: Boxplot of SF36 Role functioning/physical by lung cancer stage

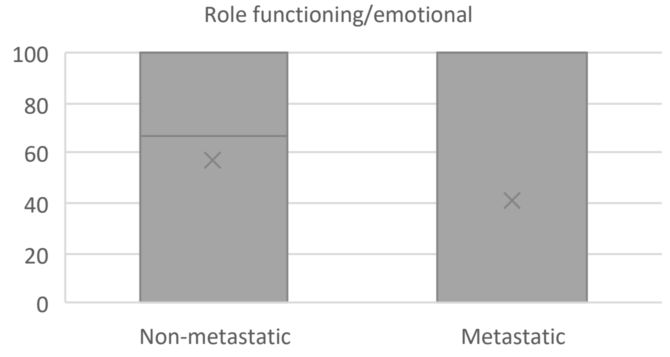


Figure 2.6: Boxplot of SF36 Role functioning/emotional by lung cancer stage

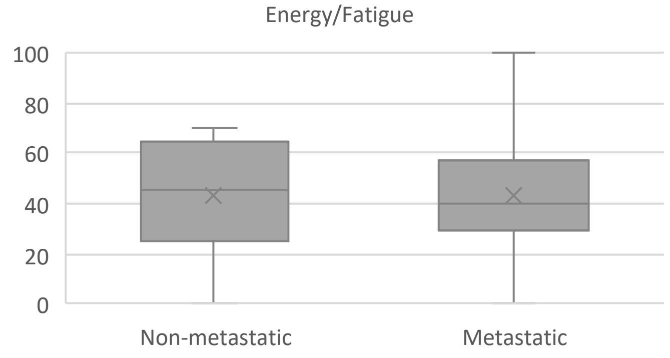


Figure 2.7: Boxplot of SF36 Energy/fatigue by lung cancer stage

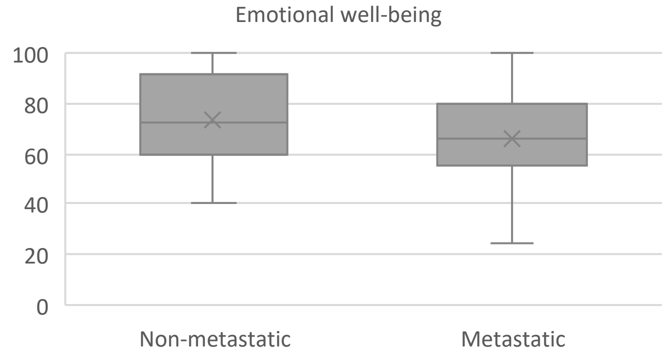


Figure 2.8: Boxplot of SF36 Emotional well-being by lung cancer stage

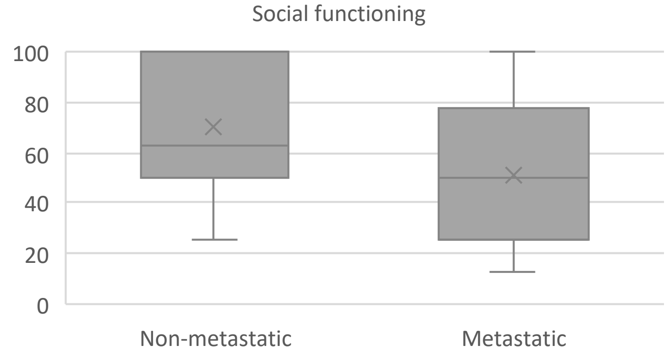


Figure 2.9: Boxplot of SF36 Social functioning by lung cancer stage

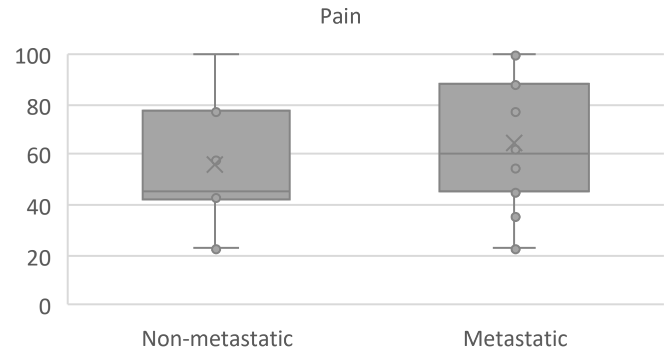


Figure 2.10: Boxplot of SF36 Pain by a lung cancer stage

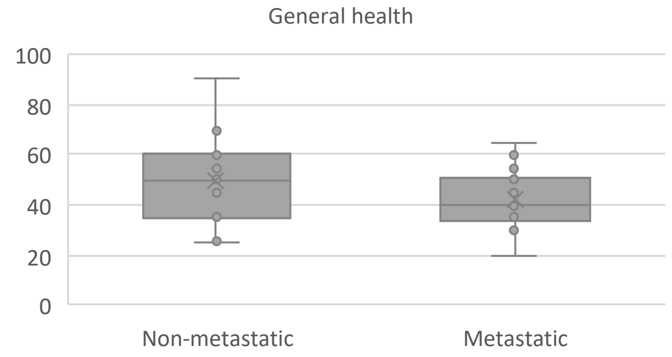


Figure 2.11: Boxplot of SF36 General health by lung cancer stage

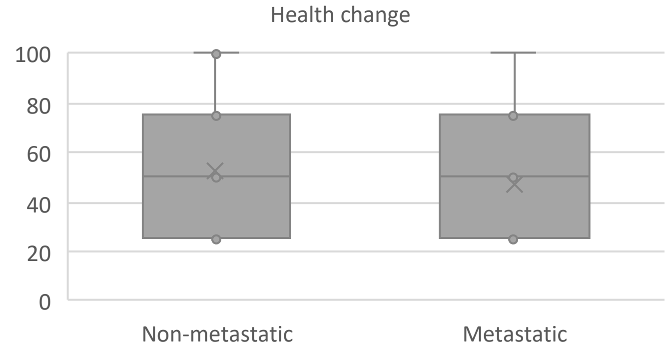


Figure 2.12: Boxplot of SF36 Health change by lung cancer stage

Comparisons of SF36 scales by gender

Comparisons were made by gender, there were 23 female participants (74.19%), and 8 male particpants (25.81%).

Boxplots of each SF36 scale by **gender** are displayed in Figures 2.13 to 2.21, summary statistics are displayed in Tables 2.10 and 2.11.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.10), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.11).

Wilcoxon rank sum tests with continuity correction indicated that the median score for the **SF36 Physical functioning scale** [W = 35.00, p = 0.0104] was significantly lower females (Median = 55.00, IQR = 65.00) compared males (Median = 87.50, IQR = 20.00).

A two sample t-test indicated that the mean score for the **SF36 Pain scale** [t(29) = -2.39 , p = 0.0237] was significantly lower females (Mean = 56.20, SD = 24.05) compared to males (Mean = 78.75, SD = 19.36.)

SF36 Physical functioning scale measures health limitations in physical activities such as walking, bending, climbing stairs, exercise, and housework. On average, males scored higher than females. This indicates that physical activities were not limited for males, and were slightly limited for females.

SF36 Pain scale measures how much pain, and how pain interferes with work and other activities. On average, males scored higher than females. This indicates males had mild pain, and females had moderate pain.

Table 2.10: SF36 by gender summary statistics and T-test

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Energy/fatigue	Female	23	74.19	39.35	25.91	-1.26	29	0.2190
	Male	8	25.81	51.88	18.31			
Emotional well-being	Female	23	74.19	67.83	20.63	-0.56	29	0.5784
	Male	8	25.81	72.50	19.06			
Social functioning	Female	23	74.19	57.61	29.37	-0.51	29	0.6158
	Male	8	25.81	64.06	35.63			
Pain	Female	23	74.19	56.20	24.05	-2.39	29	0.0237*
	Male	8	25.81	78.75	19.36			
General health	Female	23	74.19	42.39	16.71	-1.30	29	0.2042
	Male	8	25.81	50.63	10.50			

*Statistically significant at p<0.05

Table 2.11: SF36 by gender summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Physical functioning	Female	23	74.19	55.00	65.00	35.00	0.0104*
	Male	8	25.81	87.50	20.00		
Role functioning physical	Female	23	74.19	0.00	75.00	65.00	0.1787
	Male	8	25.81	62.50	100.00		
Role functioning emotional	Female	23	74.19	0.00	100.00	64.00	0.1740
	Male	8	25.81	100.00	75.00		
Health change	Female	23	74.19	50.00	50.00	92.00	1.0000
	Male	8	25.81	37.50	50.00		

*Statistically significant at p<0.05

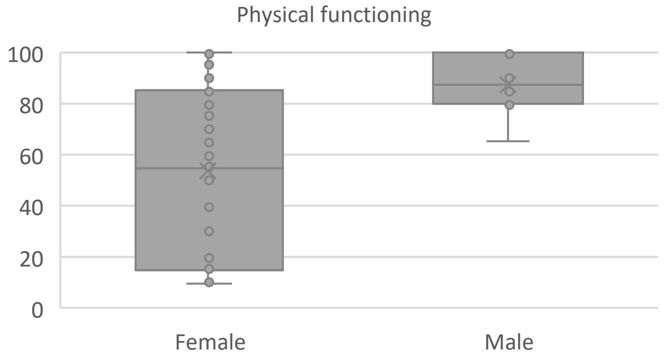


Figure 2.13: Boxplot of SF36 Physical functioning by gender

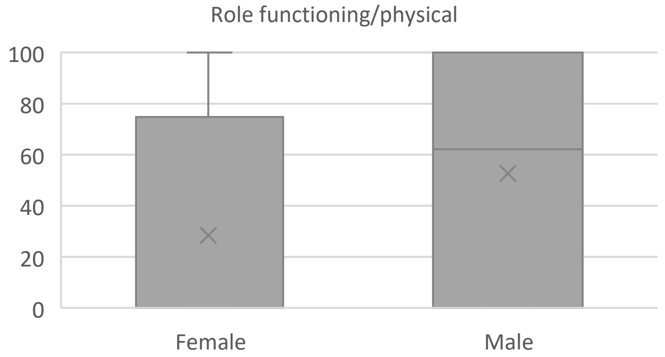


Figure 2.14: Boxplot of SF36 Role functioning/physical by gender

Figure 2.15: Boxplot of SF36 Role functioning/emotional by gender

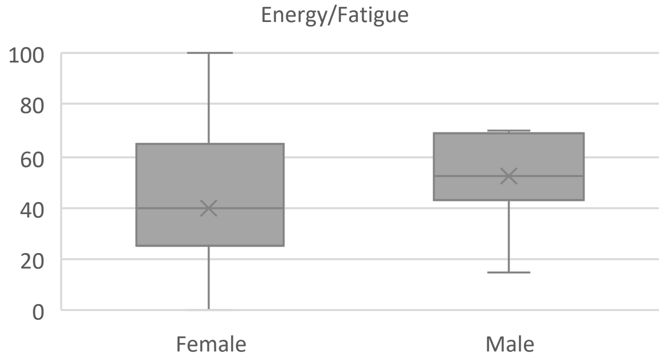
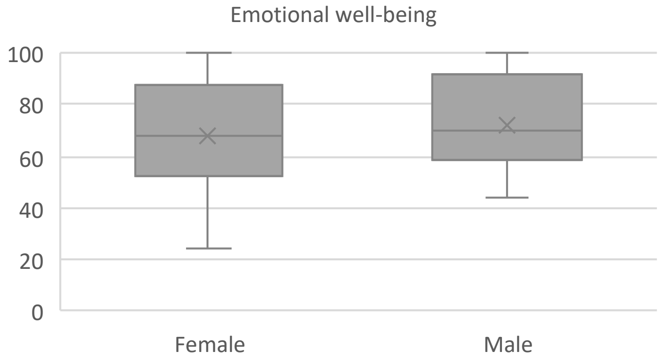


Figure 2.16: Boxplot of SF36 Energy/fatigue by gender



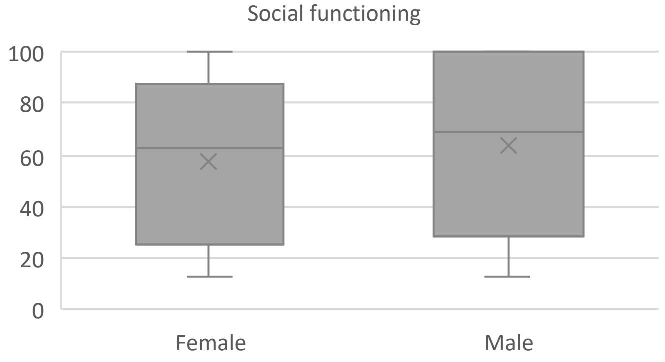


Figure 2.17: Boxplot of SF36 Emotional well-being by gender

Figure 2.18: Boxplot of SF36 Social functioning by gender

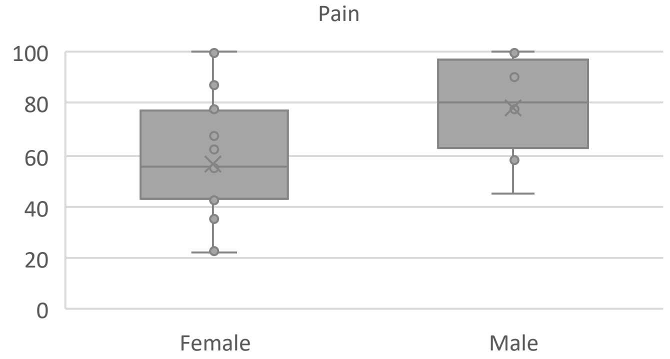


Figure 2.19: Boxplot of SF36 Pain by a gender

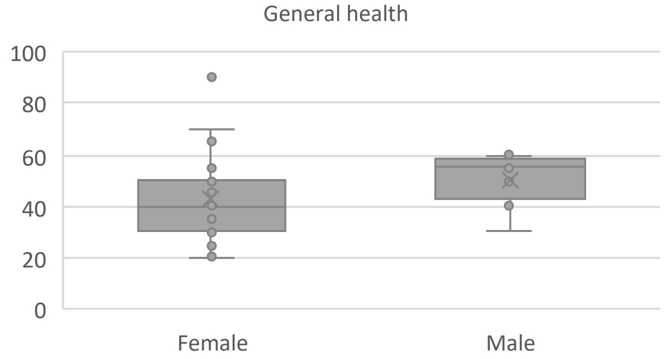


Figure 2.20: Boxplot of SF36 General health by gender

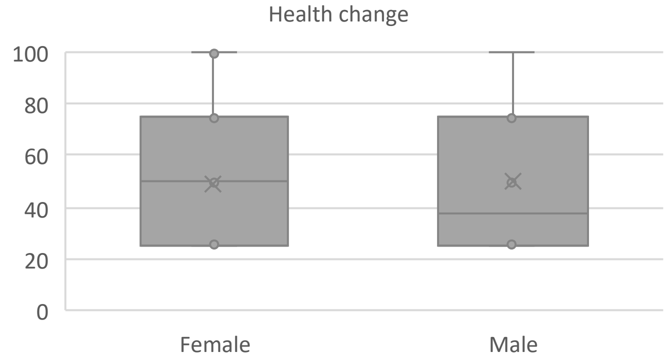


Figure 2.21: Boxplot of SF36 Health change by gender

Comparisons of SF36 scales by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=17, 54.84%), and participants aged 65 or older (n=14, 45.16%).

Boxplots of each SF36 scale by **age** are displayed in Figures 2.22 to 2.30, summary statistics are displayed in Tables 2.12 and 2.13.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.12), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.13).

No significant differences were observed between participants by **age** for any of the SF36 scales.

Table 2.12: SF36 by age summary statistics and T-test

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Energy/fatigue	Aged 35 to 64	17	54.84	40.88	28.95	-0.42	29	0.6783
	Aged 65 or older	14	45.16	44.64	18.65			
Social functioning	Aged 35 to 64	17	54.84	63.24	30.45	0.79	29	0.4366
	Aged 65 or older	14	45.16	54.46	31.24			
Pain	Aged 35 to 64	17	54.84	65.44	22.19	0.85	29	0.4049
	Aged 65 or older	14	45.16	57.86	27.80			
General health	Aged 35 to 64	17	54.84	41.76	15.30	-1.08	29	0.2873
	Aged 65 or older	14	45.16	47.86	15.90			

Table 2.13: SF36 by age summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Physical functioning	Aged 35 to 64	17	54.84	70.00	50.00	130.50	0.6610
	Aged 65 or older	14	45.16	70.00	55.00		
Role functioning/physical	Aged 35 to 64	17	54.84	0.00	100.00	140.00	0.3603
	Aged 65 or older	14	45.16	0.00	43.75		
Role functioning/emotional	Aged 35 to 64	17	54.84	66.67	100.00	133.50	0.5429
	Aged 65 or older	14	45.16	16.67	100.00		
Emotional well-being	Aged 35 to 64	17	54.84	72.00	24.00	126.00	0.7957
	Aged 65 or older	14	45.16	62.00	34.00		
Health change	Aged 35 to 64	17	54.84	50.00	50.00	124.50	0.8329
	Aged 65 or older	14	45.16	37.50	50.00		

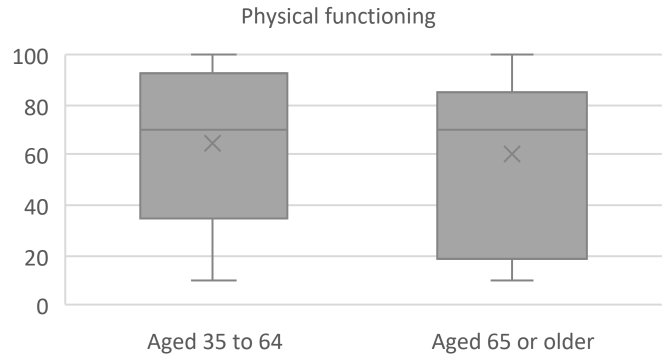


Figure 2.22: Boxplot of SF36 Physical functioning by age

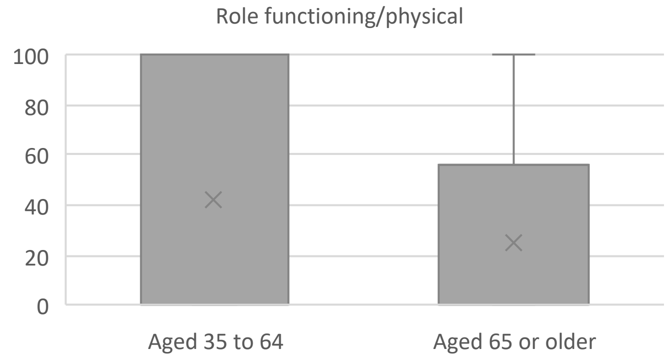


Figure 2.23: Boxplot of SF36 Role functioning/physical by age

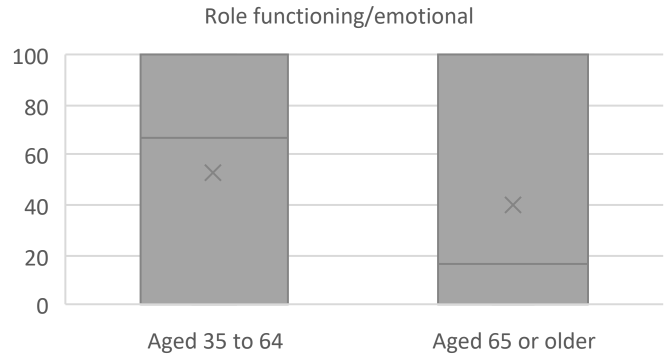


Figure 2.24: Boxplot of SF36 Role functioning/emotional by age

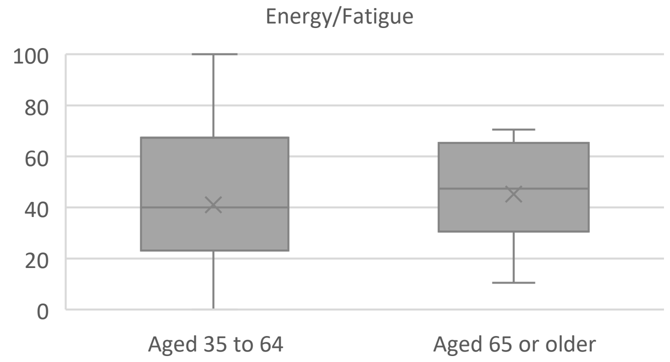


Figure 2.25: Boxplot of SF36 Energy/fatigue by age

Figure 2.26: Boxplot of SF36 Emotional well-being by age

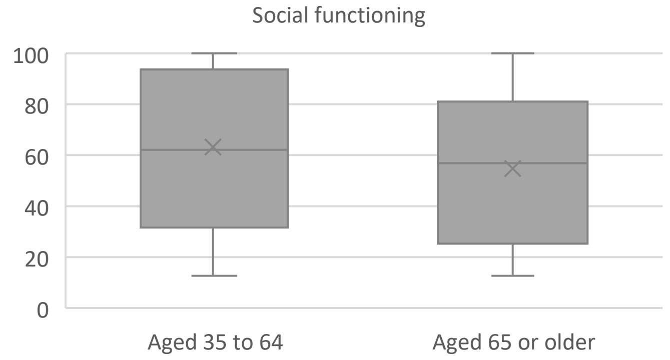


Figure 2.27: Boxplot of SF36 Social functioning by age

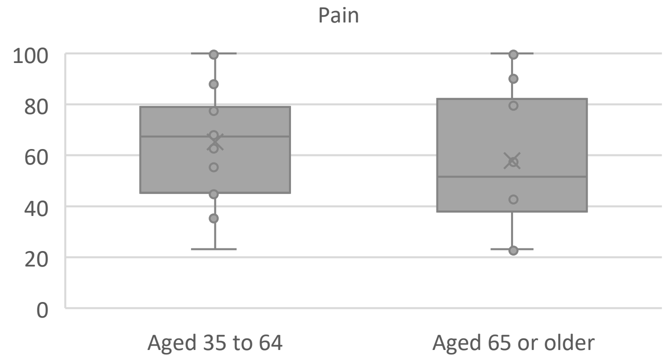


Figure 2.28: Boxplot of SF36 Pain by age

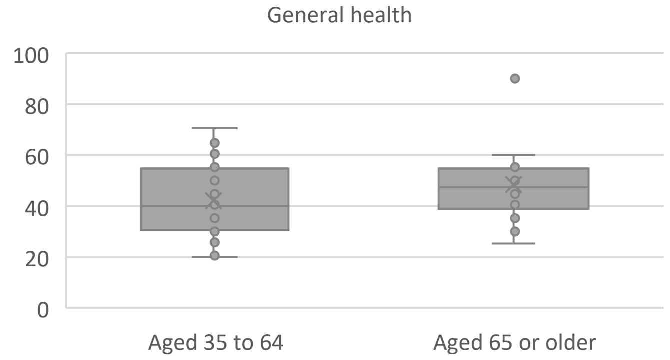


Figure 2.29: Boxplot of SF36 General health by age

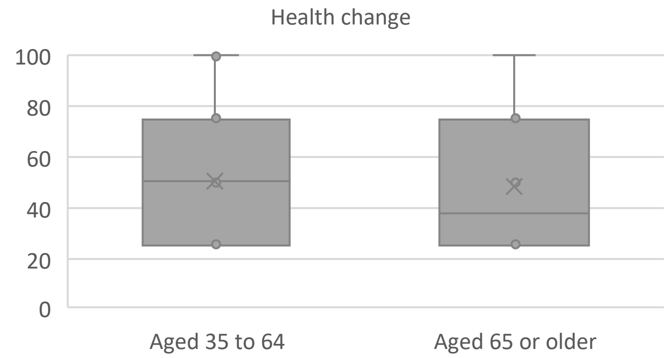


Figure 2.30: Boxplot of SF36 Health change by age

Comparisons of SF36 scales by education

Comparisons were made by education status, between those with trade or high school qualifications (n=17, 54.84%), and those with a university qualification (n=14, 45.16%).

Boxplots of each SF36 scale by **education** are displayed in Figures 2.31 to 2.39, summary statistics are displayed in Tables 2.14 and 2.15.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.14), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.15).

No significant differences were observed between participants by **education** for any of the SF36 scales.

Table 2.14: SF36 by education summary statistics and T-test

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Energy/fatigue	Trade or high school	17	54.84	42.94	25.98	0.09	29	0.9299
	University	14	45.16	42.14	23.59			
Emotional well-being	Trade or high school	17	54.84	68.24	22.56	-0.24	29	0.8118
	University	14	45.16	70.00	17.24			
Pain	Trade or high school	17	54.84	55.74	25.11	-1.60	29	0.1211
	University	14	45.16	69.64	22.87			

Table 2.15: SF36 by education summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Physical functioning	Trade or high school	17	54.84	65.00	65.00	104.50	0.5768
	University	14	45.16	77.50	47.50		
Role functioning/physical	Trade or high school	17	54.84	0.00	75.00	118.00	0.9822
	University	14	45.16	0.00	75.00		
Role functioning/emotional	Trade or high school	17	54.84	33.33	100.00	114.00	0.8449
	University	14	45.16	50.00	100.00		
Social functioning	Trade or high school	17	54.84	50.00	37.50	84.00	0.1660
	University	14	45.16	75.00	34.38		
General health	Trade or high school	17	54.84	40.00	20.00	133.00	0.5897
	University	14	45.16	42.50	23.75		
Health change	Trade or high school	17	54.84	50.00	50.00	149.00	0.2132
	University	14	45.16	25.00	25.00		

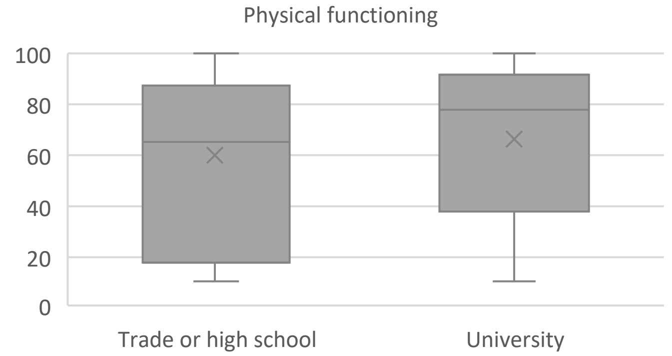


Figure 2.31: Boxplot of SF36 Physical functioning by education

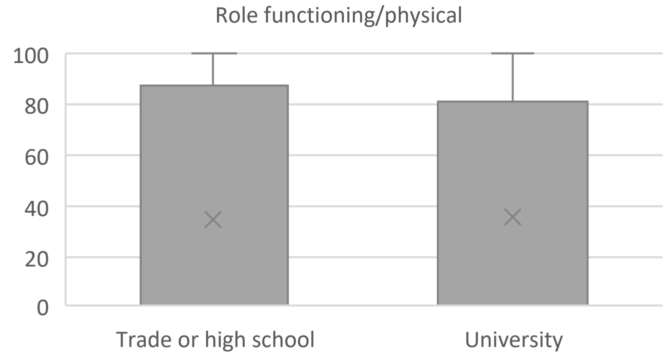


Figure 2.32: Boxplot of SF36 Role functioning/physical by education

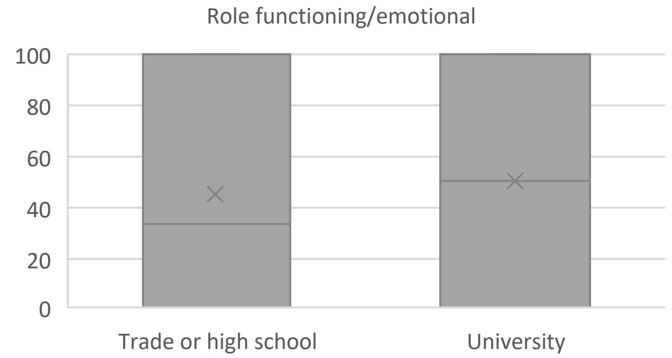


Figure 2.33: Boxplot of SF36 Role functioning/emotional by education

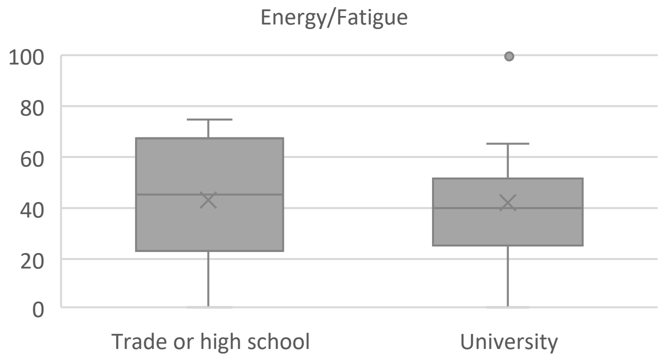


Figure 2.34: Boxplot of SF36 Energy/fatigue by education

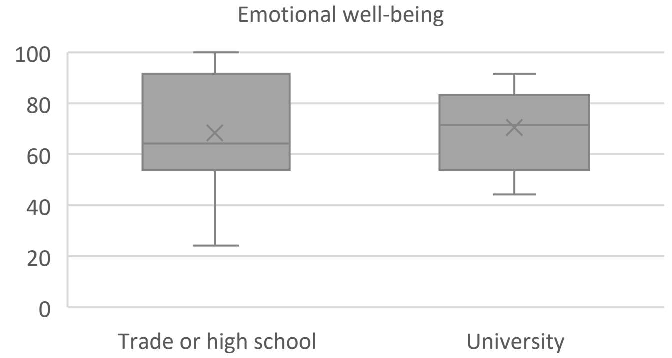


Figure 2.35: Boxplot of SF36 Emotional well-being by education

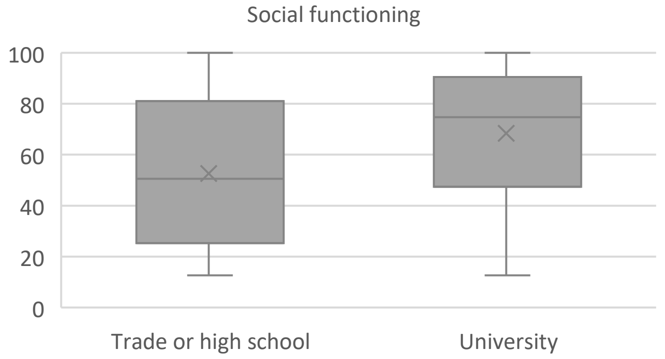


Figure 2.36: Boxplot of SF36 Social functioning by education

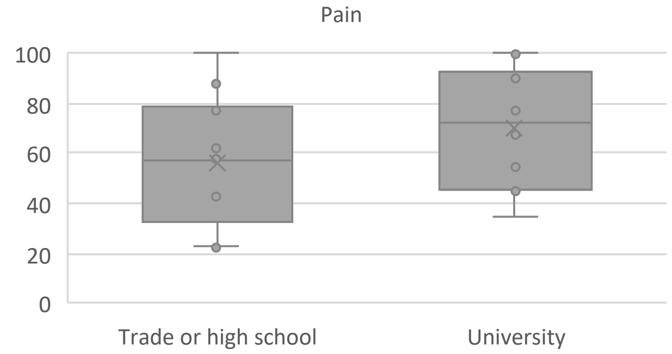


Figure 2.37: Boxplot of SF36 Pain by education

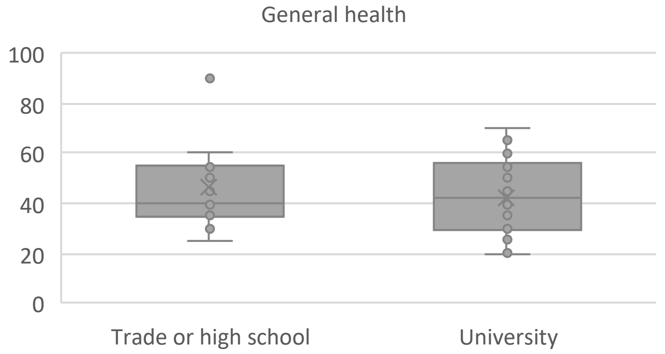


Figure 2.38: Boxplot of SF36 General health by education

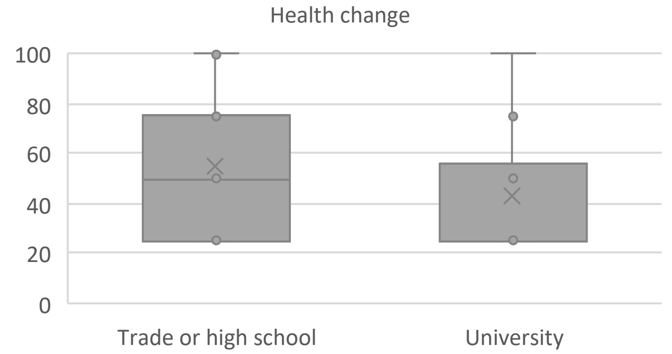


Figure 2.39: Boxplot of SF36 Health change by education

Comparisons of SF36 scales by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 2 participants (6.45%) living in regional or remote areas and 29 participants (93.55%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 2.16.

Table 2.16: SF36 by location summary statistics

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	Median	IQR	Quintile
Physical functioning	Regional or remote	2	6.45	55.00	56.57	55.00	40.00	3
	Metropolitan	29	93.55	63.10	31.27	70.00	50.00	NA
Role functioning physical	Regional or remote	2	6.45	0.00	0.00	0.00	0.00	1
	Metropolitan	29	93.55	37.07	44.63	0.00	75.00	NA
Role functioning emotional	Regional or remote	2	6.45	50.00	70.71	50.00	50.00	3
	Metropolitan	29	93.55	47.13	47.57	33.33	100.00	NA
Energy/fatigue*	Regional or remote	2	6.45	20.00	28.28	20.00	20.00	1
	Metropolitan	29	93.55	44.14	24.02	45.00	35.00	NA
Emotional well-being*	Regional or remote	2	6.45	68.00	33.94	68.00	24.00	4
	Metropolitan	29	93.55	69.10	19.71	68.00	24.00	NA
Social functioning	Regional or remote	2	6.45	56.25	26.52	56.25	18.75	3
	Metropolitan	29	93.55	59.48	31.28	62.50	62.50	NA
Pain*	Regional or remote	2	6.45	62.50	7.07	62.50	5.00	4
	Metropolitan	29	93.55	61.98	25.58	57.50	35.00	NA
General health*	Regional or remote	2	6.45	42.50	31.82	42.50	22.50	3
	Metropolitan	29	93.55	44.66	15.00	40.00	20.00	NA
Health change	Regional or remote	2	6.45	50.00	35.36	50.00	25.00	3
	Metropolitan	29	93.55	49.14	26.29	50.00	50.00	NA

*Normal distribution, use mean and SD as central measure. Possible range 0-100

Comparisons of SF36 scales by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=12, 37.50%) compared to those with a higher SEIFA score of 7-10, Higher status (n=20, 62.50%).

Boxplots of each SF36 scale by **socioeconomic status** are displayed in Figures 2.40 to 2.48, summary statistics are displayed in Tables 2.17 and 2.18.

A two-sample t-test was used when assumptions for normality and variance were met (Table 2.17), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 2.18).

A two sample t-test indicated that the mean score for the SF36 Energy/fatigue scale [t(29) = -2.66 , p = 0.0127] was significantly lower for participants in the Mid to low status subgroup (Mean = 28.18, SD = 25.62) compared to participants in the Higher status subgroup (Mean = 50.50, SD = 20.45.)

SF36 Energy/fatigue scale measures the proportion of energy or fatigue experienced. On average, participants in the higher status subgroup scored higher than participants in the lower status subgroup. This indicates that participants in the higher status subgroup were sometimes fatigued, and participants in the lower status subgroup were often fatigued.

Table 2.17: SF36 by socioeconomic status summary statistics and T-test

SF36 scale	Group	Number (n=31)	Percent	Mean	SD	T	dF	p-value
Energy/Fatigue	Mid to low status	11	35.48	28.18	25.62	-2.66	29	0.0127*
	Higher status	20	64.52	50.50	20.45			
Emotional well-being	Mid to low status	11	35.48	64.36	23.22	-0.96	29	0.3443
	Higher status	20	64.52	71.60	18.16			
Pain	Mid to low status	11	35.48	52.95	25.64	-1.55	29	0.1327
	Higher status	20	64.52	67.00	23.39			
General health	Mid to low status	11	35.48	42.27	20.54	-0.59	29	0.5620
	Higher status	20	64.52	45.75	12.59			

Table 2.18: SF36 by socioeconomic status summary statistics and Wilcoxon test

SF36 scale	Group	Number (n=31)	Percent	Median	IQR	W	p-value
Physical functioning	Mid to low status	11	35.48	40.00	65.00	70.50	0.1059
	Higher status	20	64.52	77.50	33.75		
Role functioning/physical	Mid to low status	11	35.48	0.00	50.00	92.50	0.4301
	Higher status	20	64.52	0.00	100.00		
Role functioning/emotional	Mid to low status	11	35.48	0.00	100.00	95.00	0.5121
	Higher status	20	64.52	50.00	100.00		
Social functioning	Mid to low status	11	35.48	50.00	25.00	99.00	0.6610
	Higher status	20	64.52	62.50	75.00		
Health change	Mid to low status	11	35.48	50.00	37.50	140.50	0.1879
	Higher status	20	64.52	25.00	31.25		

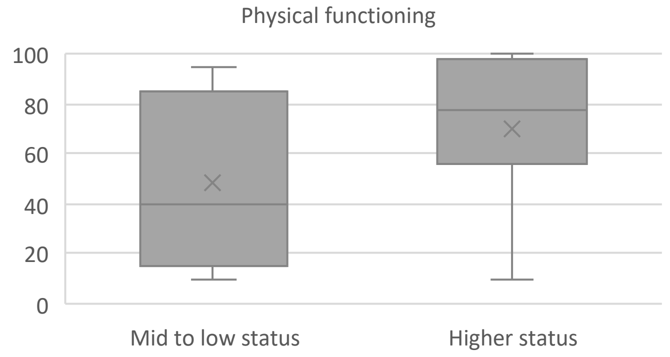


Figure 2.40: Boxplot of SF36 Physical functioning by socioeconomic status

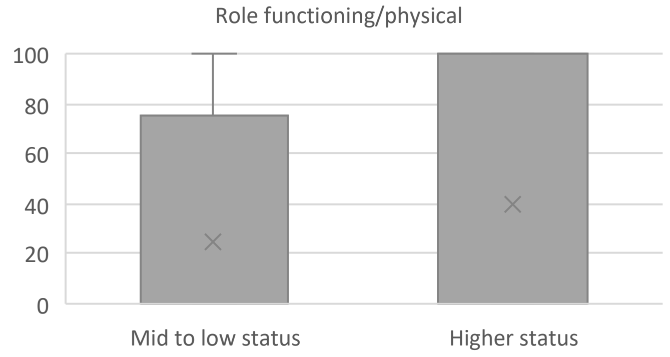


Figure 2.41: Boxplot of SF36 Role functioning/physical by socioeconomic status

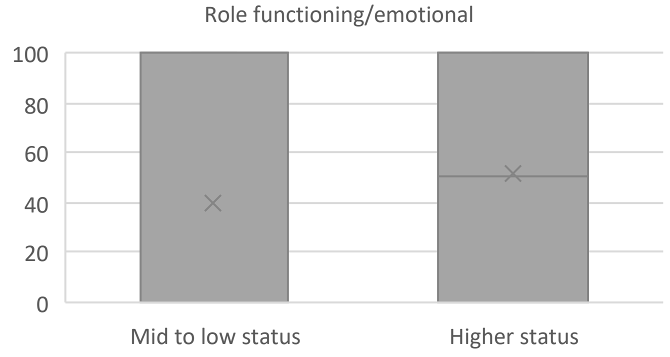


Figure 2.42: Boxplot of SF36 Role functioning/emotional by socioeconomic status

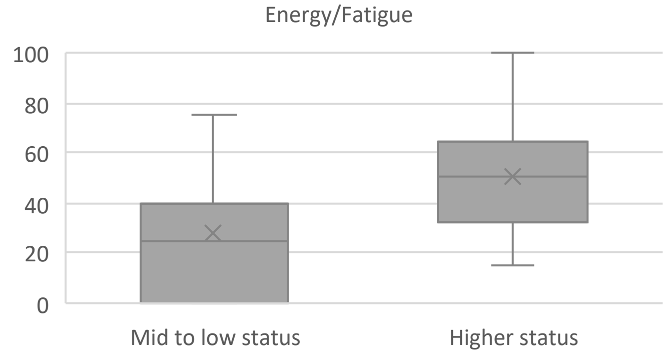


Figure 2.43: Boxplot of SF36 Energy/fatigue by socioeconomic status

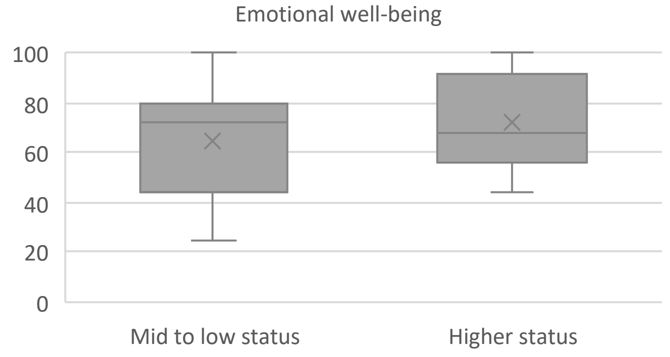


Figure 2.44: Boxplot of SF36 Emotional well-being by socioeconomic status

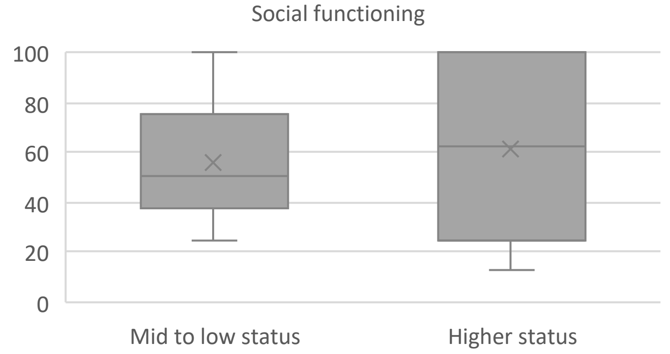


Figure 2.45: Boxplot of SF36 Social functioning by socioeconomic status

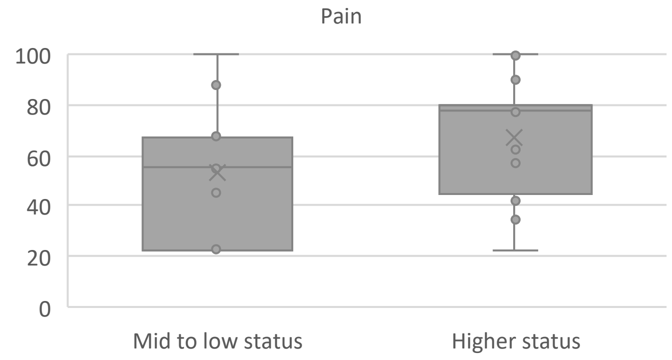


Figure 2.46: Boxplot of SF36 Pain by socioeconomic status

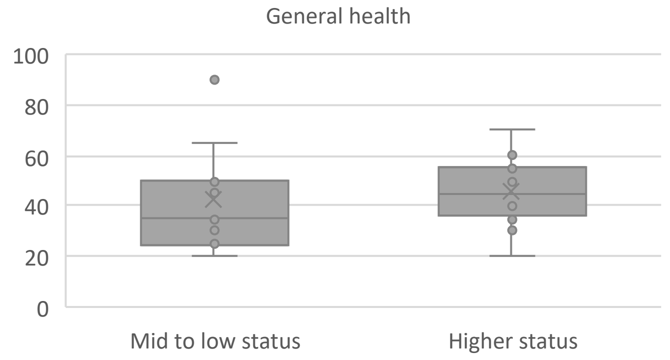


Figure 2.47: Boxplot of SF36 General health by socioeconomic status

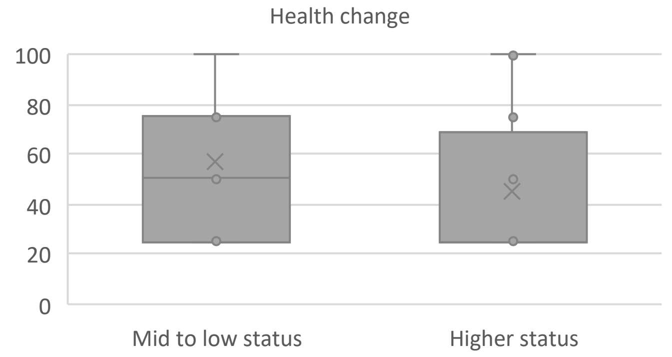


Figure 2.48: Boxplot of SF36 Health change by socioeconomic status

Section 3

Symptoms and diagnosis

Section 3: Symptoms and diagnosis

Symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed. There were 6 participants (20.69%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 3.00 (IQR=3.00)

The most common symptoms before diagnosis were feeling tired or having lower energy levels than usual (n=19, 65.52%), shortness of breath and wheezing (n=13, 44.83%), and coughing or spitting up blood (n=13, 44.83%). The median quality of life was between 2.00 and 5.00, for all of the symptoms listed in the questionnaire, this is in the "Life was very distressing" to "Life was good" range. The symptoms with the worst quality of life were feeling tired or having lower energy levels than usual, shortness of breath and wheezing, coughing or spitting up blood, and shoulder or back pain

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually led to their diagnosis. Almost all participants (92.31%) strongly recalled their symptoms or how they came to be diagnosed. The most common symptom leading to diagnosis was having shortness of breath (30.77%), persistent cough or chest infection (26.92%), and there were 5 participants (19.23%). who experienced no symptoms before diagnosis. Other symptoms included fatigue (15.38%), blood in phlegm (11.54%), flu-like symptoms (11.54%), and rib or lung pain (11.54%).

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were seeking medical attention relatively soon (53.85%), followed by not seeking medical attention initially (26.92%). There were 5 participants that described having no symptoms (19.23 %)

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common responses were that they were diagnosed by a specialist from their general practitioner (34.62%), and having multiple specialists needed before diagnosis (26.92%). Other pathways included being diagnosed in an emergency department (23.08%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.38%)

Timing of diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of lung cancer and the approximate date of diagnosis with lung cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated. Duration was calculated for 29 participants (9 participants had no symptoms before diagnosis), there were 7 participants (24.14%) that were diagnosed less than 1 month of noticing symptoms, 4 participants (13.79%) diagnosed between 2 and 3 months from noticing symptoms, 5 participants (17.24%) that were diagnosed between 6 months and 1 year of noticing symptoms, and 4 participants (13.79%) that were diagnosed more than 1 year of noticing symptoms.

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis. There were 7 participants (24.14%) that were diagnosed less than 1 week after testing, 8 participants (27.59%) diagnosed between 1 and 2 weeks after testing, 8 participants (27.59%) that were diagnosed between 2 and 3 weeks after testing, and 6 participants (20.69%) that were diagnosed 4 weeks or after testing.

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with lung cancer. They could choose from a set list of diagnostic tests and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 0 to 5 diagnostic tests (median=3.00 , IQR=1.00). The most common tests were PET scan (n=23, 79.31%), Biopsy (n=20, 68.97%), CT scan (n=25, 86.21%), and Chest x-ray (n=15, 51.72%).

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis. Almost half of the participants were given their diagnosis by a respiratory specialist (n=14, 48.28%), and there were 5 participants (17.24%) given the diagnosis by a general practitioner, 3 participants (10.34%) diagnosed by an oncologist, and 3 participants (10.34%) by an emergency doctor or ambulance paramedic. Participants were most commonly given their diagnosis in the hospital (n=15, 51.72%), this was followed by the specialist clinic (n=6, 20.69%), and the general practice.

Year of diagnosis

Participants were diagnosed between 2012 to 2022. There were 24 participants (82.76%) that were diagnosed in the last five years.

Lung cancer diagnosis, stage and spread

The majority of participants were diagnosed with Non-small cell lung cancer. There were 4 participants (12.50%), with Stage 1 lung cancer, 3 participants (9.38%) with Stage 2, 4 participants (12.50%) with Stage 3, and 18 participants (56.25%), with Stage 4 lung cancer. . There were 13 participants (44.83%) that noted that the cancer had spread. The most common sites of spread were the brain (n=6, 20.69%), lymph nodes (n=4, 13.79%) and bones (n=4, 13.79%). There were 8 participants (27.59%) that reported having had a lung cancer recurrence.

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were having no or little knowledge at diagnosis(61.54%), having knowledge because of family history of the condition or knowing someone who has the condition (15.38%), and having knowledge from a professional background (11.54 %).

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis. There were 6 participants (20.69%) who had enough support, 3 participants (10.34%) that had some support but it wasn't enough, and 20 participants (68.97%) had no support.

Costs at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests. There were 16 participants (55.17%) who had no out of pocket expenses, and 3 participants (10.34%) who did not know or could not recall. There were 5 participants (17.24%) that spent between \$400 and \$800, and 5 participants (17.24%) that spent more than \$1000

For 22 participants (75.86%) the cost was slightly or not at all significant. For 5 participants (17.24%) the out-of-pocket expenses were somewhat significant, and for 2 participants (6.90%), the burden of out-of-pocket expenses were moderately or extremely significant.

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did. Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=16, 55.17%). There were 3 participants (10.34%) who brought up the topic with their doctor, and 10 participants (34.48%) whose doctor brought up the topic with them

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test. Participants most commonly did not have any genetic or biomarker tests but would like to (n=13, 44.83%). There were 2 participants (6.90%) who did not have these tests and were not interested in them, and a total of 14 participants (48.28%) that had biomarker tests.

More than half status for at least one biomarker (n=16, 55.17%). Most commonly, participants knew their EGFR status (n=9, 31.03%), followed by ALK status (n=7, 24.14%)

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were uncertainty around prognosis (61.54%), and that they had a poor prognosis or a terminal condition (15.38%). Other themes included having no evidence of disease or that they are in remission (11.54%), and describing a specific timeframe that they are expected to live (7.69%).

Experience of symptoms before diagnosis

Participants were asked in the questionnaire which symptoms they had before diagnosis, they could choose from a set list of symptoms and could then specify other symptoms not listed.

There were 6 participants (20.69%) that had no symptoms before diagnosis. Participants had a maximum of 8 symptoms, and a median of 3.00 (IQR=3.00) (Table 3.1, Figure 3.1).

Table 3.1: Number of symptoms per participant

Number of symptoms per participant	Number (n=29)	Percent
No symptoms	6	20.69
1 to 2	7	24.14
3 to 4	10	34.48
5 to 6	3	10.34
7 to 8	3	10.34

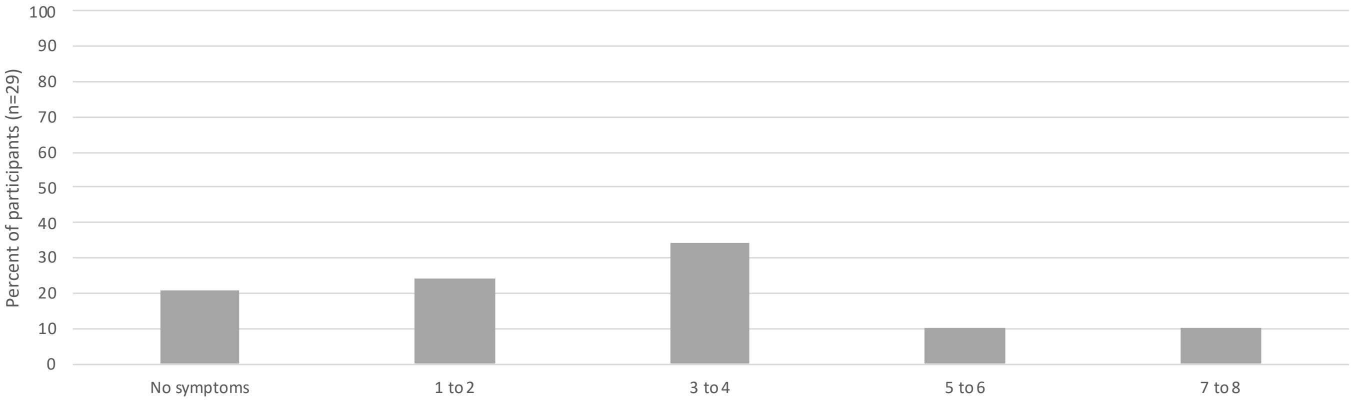


Figure 3.1: Number of symptoms per participant

Symptoms before diagnosis

The most common symptoms before diagnosis were feeling tired or having lower energy levels than usual (n=19, 65.52%), shortness of breath and wheezing (n=13, 44.83%), and coughing or spitting up blood (n=13, 44.83%) (Table 3.2, Figure 3.2).

Participants were asked a follow up question about their quality of life while experiencing these symptoms. Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Median quality of life is presented where five or more participants reported the symptom.

The median quality of life was between 2.00 and 5.00, for all of the symptoms listed in the questionnaire, this is in the “Life was very distressing” to “Life was good” range. The symptoms with the worst quality of life were feeling tired or having lower energy levels than usual, shortness of breath and wheezing, coughing or spitting up blood, and shoulder or back pain (Table 3.2, Figure 3.3).

Table 3.2: Symptoms before diagnosis

Symptom	Number (n=29)	Percent	Quality of life	
			Median	IQR
Feel tired/lower energy levels than usual	19	65.52	3.00	3.50
Shortness of breath and wheezing	13	44.83	3.00	2.00
Coughing or spitting up blood	13	44.83	3.00	3.00
Shoulder or back pain	11	37.93	3.00	1.50
A new persistant cough	11	37.93	5.00	2.50
Chest pain	5	17.24	2.00	4.00
Recurring bronchitis or pneumonia	4	13.79	NA	NA
Hoarseness (scratchy voice)	3	10.34	NA	NA
Loss of appetite	2	6.90	NA	NA
Unexplained weight loss	2	6.90	NA	NA
No symptoms	6	20.69	NA	NA

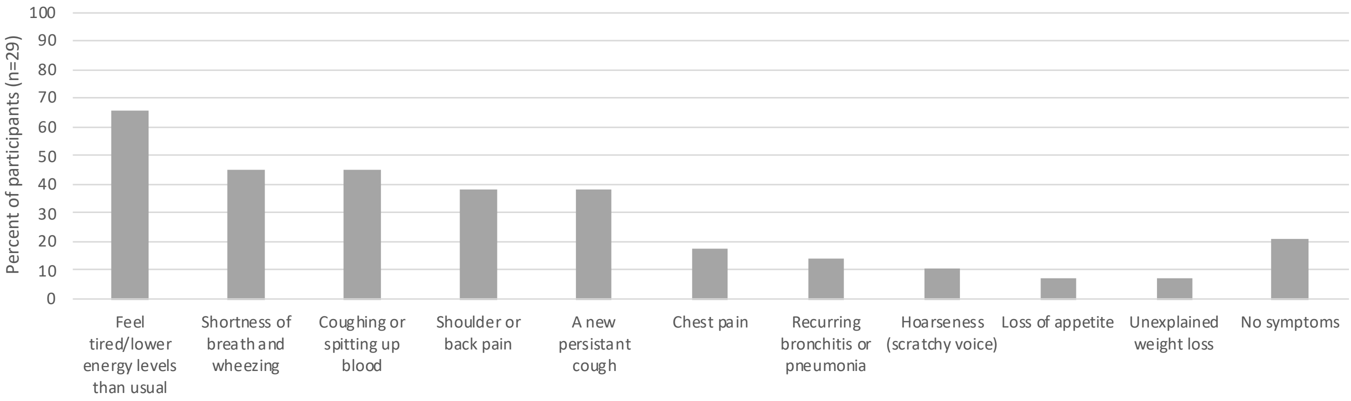


Figure 3.2: Symptoms before diagnosis

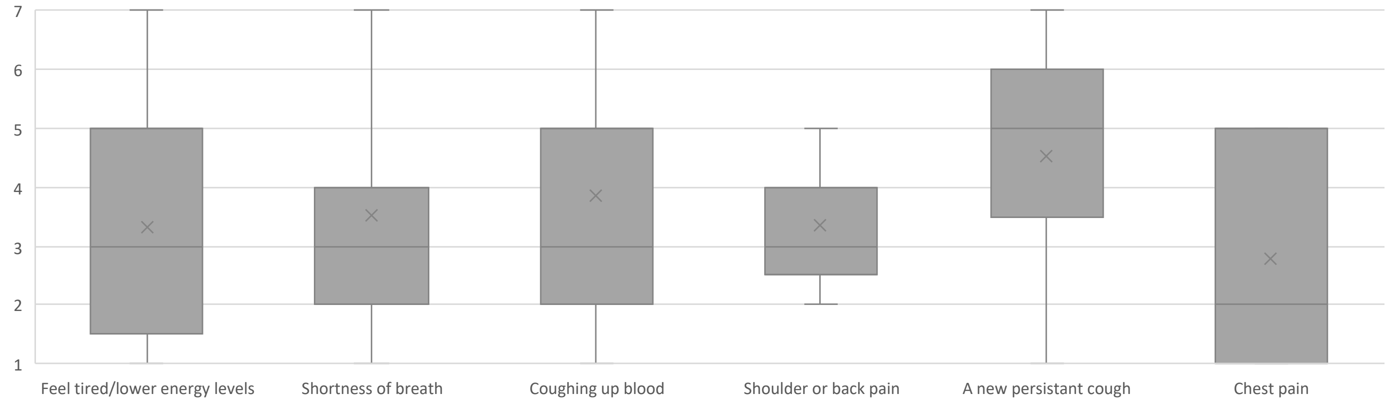


Figure 3.3: Quality of life from symptoms before diagnosis

Symptoms leading to diagnosis

In the online questionnaire, participants were asked to select every symptom that they had at diagnosis. In the structured interview, participants were asked to describe the symptoms that actually *led* to their diagnosis.

Almost all participants (92.31%) strongly recalled their symptoms or how they came to be diagnosed.

The most common symptom leading to diagnosis was having shortness of breath (30.77%), persistent cough or chest infection (26.92%), and there were 5 participants (19.23%). who experienced no symptoms before diagnosis. Other symptoms included fatigue (15.38%), blood in phlegm (11.54%), flu-like symptoms (11.54%), and rib or lung pain (11.54%).

Participant describes having shortness of breath which led to their diagnosis

Yes. I was away during COVID. We were up north with friends. We were in LOCATION, but there was no COVID. Every day, we used to walk about 10 kilometers which I didn't have a problem with. Then on this walk, there was one part of it where we had to climb over a big hill to get to the other side. I just couldn't climb up a hill. My friends were older than me said, "That's not right." I just thought, well, perhaps that's just normal for me. I'm fine on the flat, but I can't do hills. Anyway, and then I got home, say in late September, early October. I always walk every day and I started going for walks and I was getting more and more short of breath. Went to my local doctor and told them and he listened.
Participant 001_2023AULUC

Yes. At work, it was becoming extremely difficult to breathe while I was working. I was becoming more and more short of breath, and that probably happened six months before they found the nodule in my lung.
Participant 003_2023AULUC

Yes. I had only one symptom and that was what I thought was getting progressively and significantly unfit. What I realized now was that I was getting restless because of a significant pleural effusion. I was aware of this through December and January. December 2020 to January 2021, thinking my fitness was going backwards very, very fast. Then I decided now there's something seriously going wrong here, maybe I have a lung infection or something, I thought.

Shall I go into this detail? Is this appropriate? It would have been something like the 27th or 28th of January 2021 and I thought, there's seriously wrong here. I've got to find out what's going on so I called a telehealth number and I opted to speak to a nurse and she asked me typical sorts of questions and I reported really severe breathlessness on exertion and she, I think, had the view that it was likely I had some heart condition. Anyway, it ended in her saying, "Well, on the basis of everything you've told me, I think this is a medical emergency, would you like me to call an ambulance?" I was completely shocked by that response, but I said, "Well, no, no need to call an ambulance, I'll get my wife to take me up to the hospital." 022_2023AULUC

Participant describes having persistent cough or chest infection which led to their diagnosis

Probably had a bit of a cough for ages. [crosstalk] Yes, maybe a year or so. I had a chest infection that I'd been on some antibiotics, and then I went back to the doctor because I still had the cough and they sent me for a CT. Participant 026_2023AULUC

I think the most prominent one is I had a cough, but then a few people around me in my friendship group had this same cough. I almost felt like I was getting a cold because I just felt very fatigued and like I was coming down with a virus or something. I ended up going to the doctor just to get antibiotics for the cough. Just on the off chance he happened to say, "Well, you're 50 years old. I think we'll do a CT scan just to be--" the famous last words, "it'll probably be nothing but just do the CT scan." That's when it came back as, yes, lung cancer stage 4, kind of thing.
Participant 004_2023AULUC

Participant describes having not experiencing symptoms before diagnosis

No, I didn't have any symptoms at all, INTERVIEWER. It was found by mistake
14_2023AULUC

Yes. I actually had no symptoms to offer because it was incidentally found at a very early stage, so I was extremely fortunate.
21_2023AULUC

Participant describes having fatigue which led to their diagnosis

Yes. For five years prior to diagnosis, I presented to the GP with extreme fatigue, cough, a lot of cough, breathlessness. 023_2023AULUC

There was definitely shortness of breath, fatigue and then a wheeze on exertion that then progressively developed and all those symptoms got worse until eventually I coughed up blood.
Participant 015_2023AULUC

Participant describes having blood in phlegm which led to their diagnosis

Yes. I had a persistent cough and chest infections for two and a half years. Yes, before I was diagnosed. I kept going back to the doctor and he kept doing x-rays and sputum tests and nothing shows as wrong with me until then I started getting pain up under my rib. I started coughing just a tiny little bit of blood in my phlegm. Then he sent me for a nose and throat specialist and they did a CT.
Participant 007_2023AULUC

Participant describes having flu-like symptoms which led to their diagnosis

I didn't know any symptoms. I wasn't aware of what lung cancer looks like or any of the symptoms, but thinking back now, dad had said that he had the flu, he had something on his chest. He thought it was a chest infection so he kept visiting GPs in the area because we'd only just moved to the area. Participant 030_2023AULUC

Participant describes having pain (Ribs/lungs) which led to their diagnosis

Yes. I had fatigue. I found it difficult to walk up the stairs without having a rest halfway up, which was just not like me. That's probably the biggest problem I had. I didn't have anything else up until I got pain. I had pain under my right arm in my ribcage. It was quite bad. I couldn't sleep on that side. That's when I went to the doctor.
Participant 002_2023AULUC

Table 3.3: Symptom recall

Symptom recall	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Symptom recall strong	24	92.31	23	92.00	1	100.00	9	90.00	15	93.75	18	112.50	6	60.00
No Symptoms	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	0	0.00	1	10.00

Symptom recall	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Symptom recall strong	24	92.31	15	88.24	9	100.00	12	92.31	12	92.31	2	100.00	22	91.67	9	100.00	15	88.24
No Symptoms	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

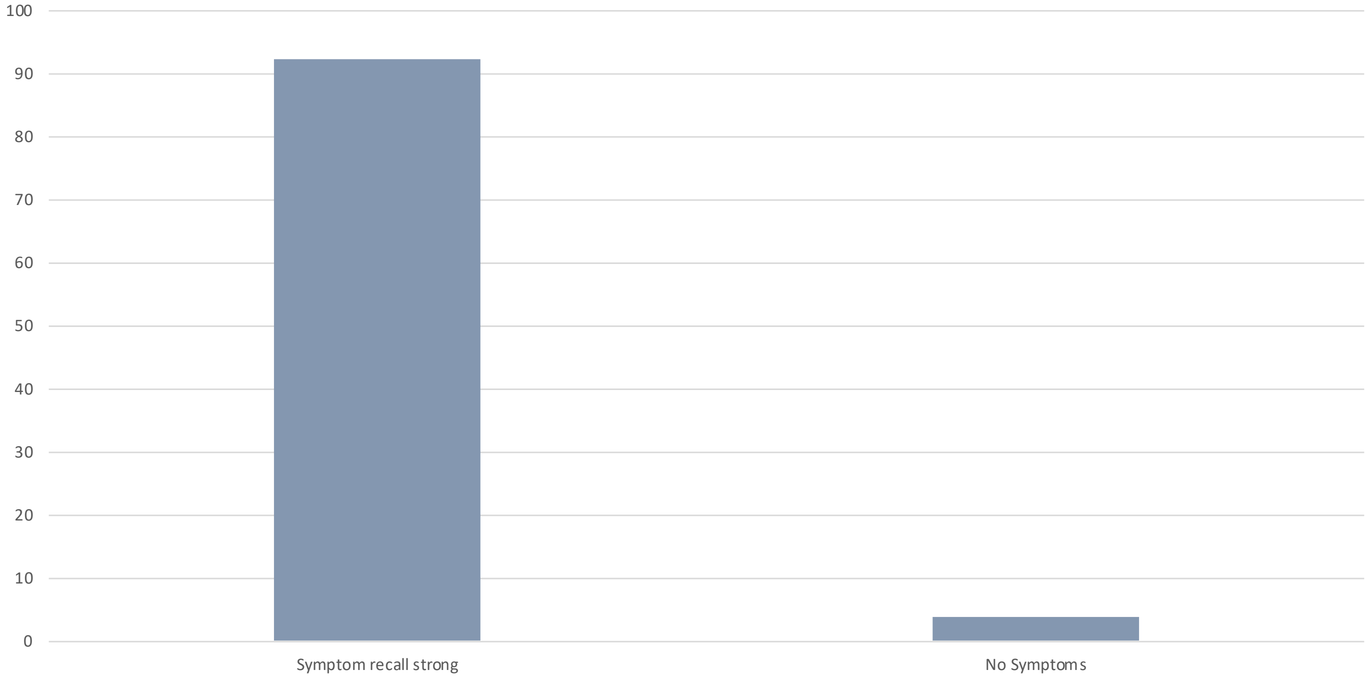


Figure 3.4: Symptom recall

Table 3.4: Symptoms leading to diagnosis

Symptoms leading to diagnosis	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes having shortness of breath which led to their diagnosis	8	30.77	8	32.00	0	0.00	1	10.00	7	43.75	7	43.75	1	10.00
Participant describes having persistent cough or chest infection which led to their diagnosis	7	26.92	6	24.00	1	100.00	3	30.00	4	25.00	5	31.25	2	20.00
Participant describes having not experiencing symptoms before diagnosis	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00
Participant describes having fatigue which led to their diagnosis	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes having blood in phlegm which led to their diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes having flu-like symptoms which led to their diagnosis	3	11.54	2	8.00	1	100.00	0	0.00	3	18.75	2	12.50	1	10.00
Participant describes having pain (Ribs/lungs) which led to their diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Symptoms leading to diagnosis	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes having shortness of breath which led to their diagnosis	8	30.77	5	29.41	3	33.33	3	23.08	5	38.46	1	50.00	7	29.17	3	33.33	5	29.41
Participant describes having persistent cough or chest infection which led to their diagnosis	7	26.92	4	23.53	3	33.33	4	30.77	3	23.08	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes having not experiencing symptoms before diagnosis	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes having fatigue which led to their diagnosis	4	15.38	3	17.65	1	11.11	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes having blood in phlegm which led to their diagnosis	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes having flu-like symptoms which led to their diagnosis	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes having pain (Ribs/lungs) which led to their diagnosis	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

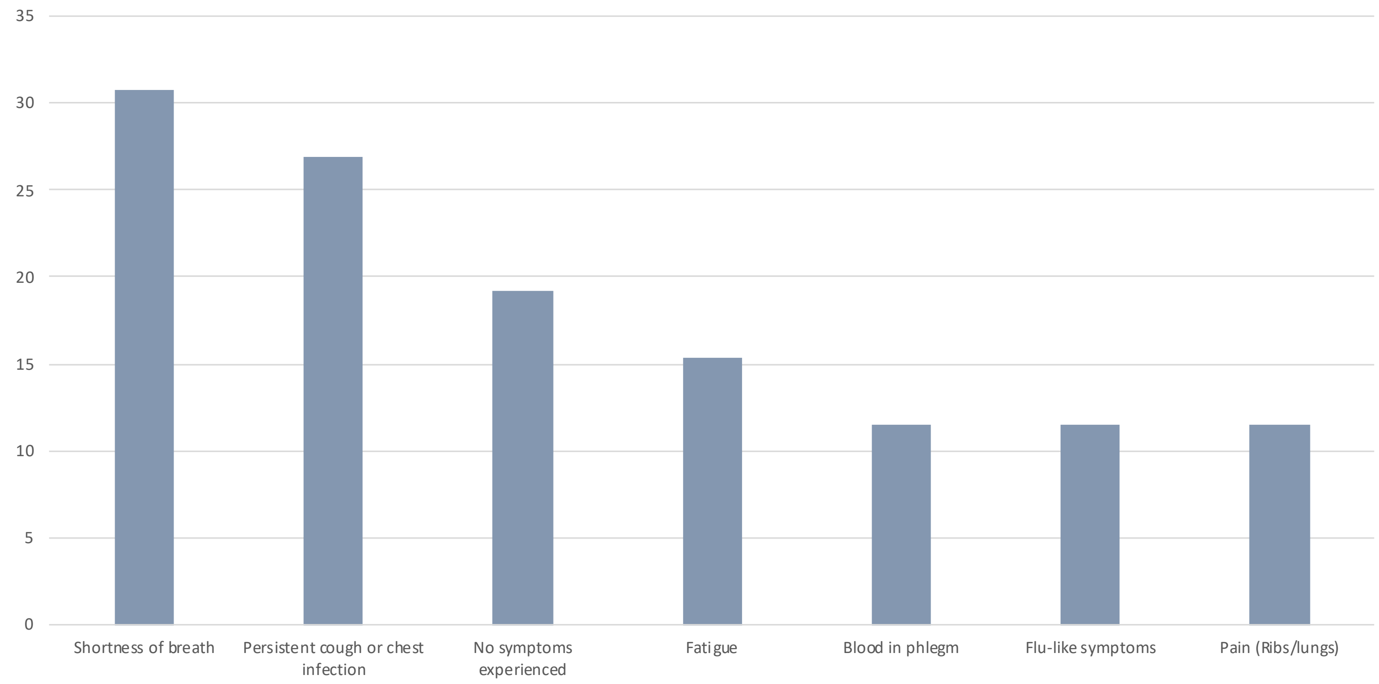


Figure 3.5: Symptoms leading to diagnosis

Table 3.5: Symptoms leading to diagnosis – subgroup variations

Symptoms leading to diagnosis	Less frequently	More frequently
Participant describes having shortness of breath which led to their diagnosis	Non-metastatic Male	Metastatic Female
Participant describes having not experiencing symptoms before diagnosis	-	Non-metastatic Aged 65 or older
Participant describes having fatigue which led to their diagnosis	Non-metastatic Male	-
Participant describes having blood in phlegm which led to their diagnosis	Mid to low status	-
Participant describes having flu-like symptoms which led to their diagnosis	Non-metastatic	-
Participant describes having pain (Ribs/lungs) which led to their diagnosis	Male	-

Symptoms leading to diagnosis: Seeking medical attention

Participants described when they sought medical attention after noticing symptoms. The most common responses were seeking medical attention relatively soon (53.85%), followed by not seeking medical attention initially (26.92%). There were 5 participants that described having no symptoms (19.23 %)

Having symptoms and seeking medical attention relatively soon

Yes. I had fatigue. I found it difficult to walk up the stairs without having a rest halfway up, which was just not like me. That's probably the biggest problem I had. I didn't have anything else up until I got pain. I had pain under my right arm in my ribcage. It was quite bad. I couldn't sleep on that side. That's when I went to the doctor. No, there was no surveillance. I'd been going to my doctor for about six months saying, "I'm really tired." He just kept checking my blood and saying, "Your blood work's fine." He didn't know what else to do. I lost a lot of weight. I thought maybe it was because I was overweight. I got down to 60 kilos, and I still didn't feel any better. When I had this pain, I actually didn't go to my doctor. I went to another just a random doctor. I said, "I think I've broken my rib." That's what it felt like. She sent me for a chest x-ray to check my ribs.
Participant 001_2023AULUC

I think the most prominent one is I had a cough, but then a few people around me in my friendship group had this same cough. I almost felt like I was getting a cold because I just felt very fatigued and like I was coming down with a virus or something. I ended up going to the doctor just to get antibiotics for the cough. Just on the off chance he happened to say, "Well, you're 50 years old. I think we'll do a CT scan just to be--" the famous last words, "it'll probably be nothing but just do the CT scan." That's when it came back as, yes, lung cancer stage 4, kind of thing.
Participant 004_2023AULUC

Yes. I had a persistent cough and chest infections for two and a half years. Yes, before I was diagnosed. I kept going back to the doctor and he kept doing x-rays and sputum tests and nothing shows as wrong with me until then I started getting pain up under my rib. I started coughing just a tiny little bit of blood in my phlegm. Then he sent me for a nose and throat specialist and they did a CT.
Participant 007_2023AULUC

Yes. For five years prior to diagnosis, I presented to the GP with extreme fatigue, cough, a lot of cough, breathlessness. They did some X-rays, and some lung function tests, and said that I was suffering from asthma, while in fact, I've never had asthma. That's it.
Participant 023_2023AULUC

He thought it was a chest infection so he kept visiting GPs in the area because we'd only just moved to the area. Through that, that's when they misdiagnosed, basically sitting home with Panadol. Then it got to the point that dad, he was doing some gardening work and I said, "Look, I think it's time we go to the hospital." The hospital's done the scan and found a mast in his lungs. Participant 030_2023AULUC

Having symptoms and not seeking medical attention initially

Yes. It started with a sore back and I just thought it was a muscular problem, I guess. It was probably a good six months before I went to a doctor. [chuckles] I went to massage, went to physios, did all that and it didn't work, and then went to a GP. Looking back, I probably also had some other symptoms. I'm a OCCUPATION, so lots of things I ignored, but had a bit of tachycardia, night sweats that I thought were maybe menopausal, maybe not. A few things that probably could have been signs.
Participant 006_2023AULUC

Probably had a bit of a cough for ages. [crosstalk] Yes, maybe a year or so. I had a chest infection that I'd been on some antibiotics, and then I went back to the doctor because I still had the cough and they sent me for a CT.
Participant 026_2023AULUC

I think I noticed, because I've got INFORMATION REMOVED background, I would notice that I had more of a restricted capacity. I would put it down to aging too because I know that changes as you get a go along. I didn't really think much more of it. Then probably the month before I noticed I was getting headaches a lot more frequently and would take, excuse me, I've got hiccups, take a few bouts of Panadol, but I was also going through menopause. I would get to treatment at my physio thinking that maybe it was also tension in my shoulders and neck, and they seemed to relieve it for a bit. Even two weeks before, we had a wedding and we were dancing and I felt like I was very puffed out. Again, I just put it down to getting older and didn't really think much more of it. Then it all came to head when I had a seizure. I collapsed at home and from the seizure, they determined that I had secondary brain tumors and the primary tumor was in my lungs. That's when it all happened.
Participant 005_2023AULUC

Having no symptoms or not noticing any symptoms before diagnosis

I didn't have symptoms. My diagnosis was picked up by a CT calcium score.
Participant 010_2023AULUC

PARTICIPANT: No.
INTERVIEWER: No? Didn't have anything?
PARTICIPANT: None.
Participant 027_2023AULUC

Table 3.6: Seeking medical attention

Seeking medical attention	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Having symptoms and seeking medical attention relatively soon	14	53.85	13	52.00	1	100.00	4	40.00	10	62.50	9	56.25	5	50.00
Having symptoms and not seeking medical attention initially	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	7	43.75	0	0.00
Having no symptoms or not noticing any symptoms before diagnosis	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00

Seeking medical attention	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Having symptoms and seeking medical attention relatively soon	14	53.85	8	47.06	6	66.67	7	53.85	7	53.85	0	0.00	14	58.33	2	22.22	12	70.59
Having symptoms and not seeking medical attention initially	7	26.92	6	35.29	1	11.11	3	23.08	4	30.77	2	100.00	5	20.83	5	55.56	2	11.76
Having no symptoms or not noticing any symptoms before diagnosis	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65

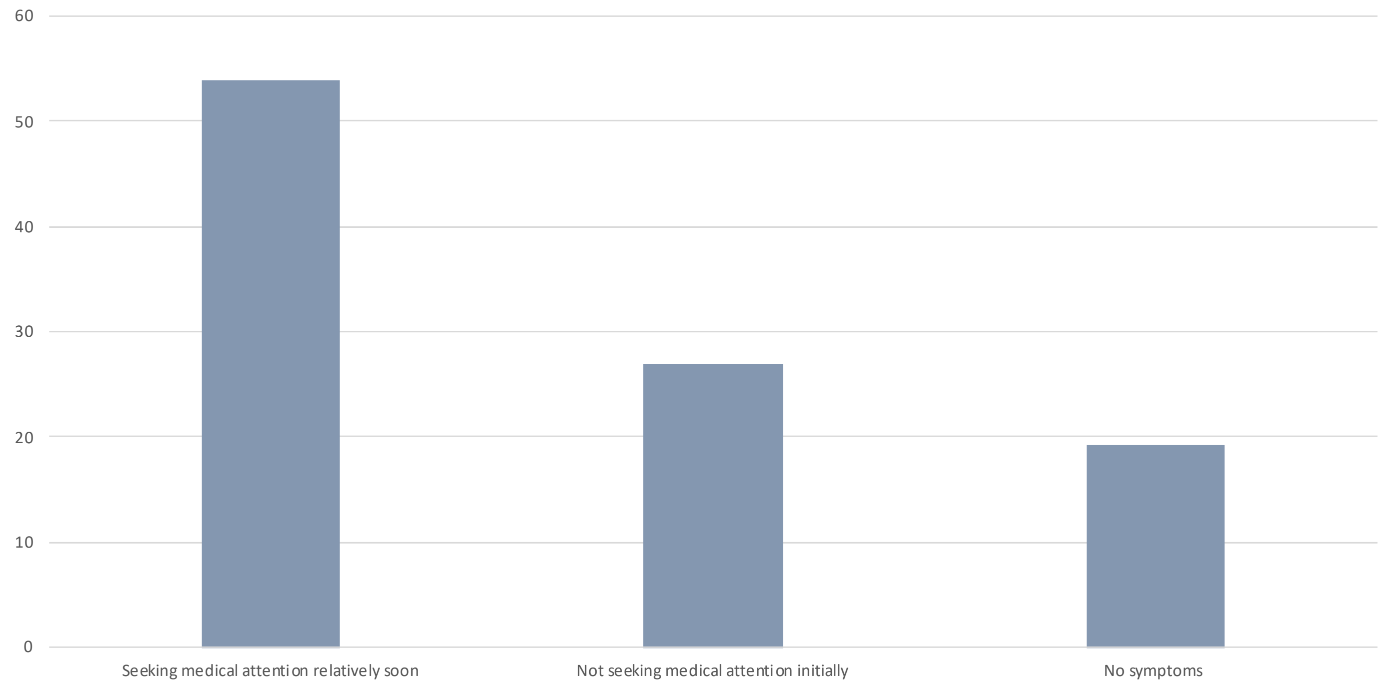


Figure 3.6: Seeking medical attention

Table 3.7: Seeking medical attention – subgroup variations

Seeking medical attention	Less frequently	More frequently
Having symptoms and seeking medical attention relatively soon	Non-metastatic Mid to low status	Aged 65 or older Higher status
Having symptoms and not seeking medical attention initially	Male Aged 65 or older Higher status	Female Mid to low status
Having no symptoms or not noticing any symptoms before diagnosis	-	Non-metastatic Aged 65 or older

Symptoms leading to diagnosis: Description of diagnostic pathway

In the structured interview, participants described their diagnostic pathway in the healthcare system. The most common responses were that they were diagnosed by a specialist from their general practioner (34.62%), and having multiple specialists needed before diagnosis (26.92%). Other pathways included being diagnosed in an emergency department (23.08%), and being diagnosed by their general practitioner during a routine check-up that was not related to symptoms (15.38%)

Specialist from their general practitioner (Linear)

I'd been going to my doctor for about six months saying, "I'm really tired." He just kept checking my blood and saying, "Your blood work's fine." He didn't know what else to do. I lost a lot of weight. I thought maybe it was because I was overweight. I got down to 60 kilos, and I still didn't feel any better. When I had this pain, I actually didn't go to my doctor. I went to another just a random doctor. I said, "I think I've broken my rib." That's what it felt like. She sent me for a chest x-ray to check my ribs. I got the results back before she did. I could see what was there. It was pretty obvious from there what was going on. When I walked in there, I knew. Then she said, "There's a mass in the right lung which just looked like a golf ball on the x-ray." She sent me for a CT, which I had the next day. Then the day after that, I went back to her and she hadn't read it. I watched her read it, and I could see by her face that it wasn't good. She did not hide. [laughs] She said, "This blood." Then she just kept shaking her head and saying, "This is very, very bad." I said, "Can I read it?" I had a read of it and I said, "Okay."
Participant 002_2023AULUC

Yes. At work, it was becoming extremely difficult to breathe while I was working. I was becoming more and more short of breath, and that probably happened six months before they found the nodule in my lung.
Participant 003_2023AULUC

One day I think I blew my nose and there may have been blood in it or something. I went back down to my GP for something completely-- I think it was the iron, and I said, "Oh, actually, also, I did cough up and there was a bit of blood, but I've got a cold, so I'm not worried about it." She said, "Oh, okay." She said, "Can you just go next door to the X-ray people, the radiologist, and just have a chest X-ray?"I went straight next door and got straight in, and the radiologist said to me, "Go straight back to your doctor."
Participant 019_2023AULUC

Multiple specialists needed before diagnosis (Complex)

She said it's an infection, so she put me on a double course of Rulide and Augmentin. I did that. I had a pre-chest x-ray as well, to see if the antibiotics has changed, then went back and had a post-x-ray. There was no change. She said to me, "I think you need a bronchoscopy." I'll give you a timeline. I saw her on 1st of September. By the 25th of October, I had a bronchoscopy, which I was really worried about. She came out and said, "No. All clear. You've just got garden variety pneumonia." I think I said to her, "What the hell's garden variety pneumonia?" But anyway. She then put me on three months of long-term antibiotics. Which I took for three months. I think I finished them in the end of January. Went back for a CT. I work in a hospital so the CT-- I could feel something is in my back by then, in my upper chest. The radiologist said to me-- I said to him, "It's still there." and he went, "Yes, it's still there." Anyway, I didn't have an appointment with her for a couple of weeks, so I didn't see her for a while. Then she rang me. I couldn't go in because there was a lot of COVID. I don't know if I had COVID going on or whatever. She said, "It's still there." At that point, I hadn't seen the results. She was still going down the line of, "Oh, have you been in contact with TB? It could be a fungal. Blah, blah, blah." Which is completely different to what the CT said. The CT said quite clear it was a cancer. Anyway, I had to wait another nine days or so for the lung biopsy. Had that. She got the results on the day. Still had to wait another nine or ten days to see her, which I actually brought forward because I was so stressed. I walked in and she said, "Oh, you've got an adenocarcinoma." That's how my diagnosis came about. She said stage 1B. Turned out to be 2A.
Participant 025_2023AULUC

The first week of August, I went in and I said, "I want a scan. This is ridiculous. There is something else going on." I booked in for a CT. On August 8th, I was told that my wrists were fine, but there was something in my lung, but not to worry. Then I went to the doctors and they said, "Oh, don't worry." I've not been a smoker before. "You're fit and healthy." The GP said, "Oh, we'll send you to our-- I think you should go for a PET scan." "What do you mean? I haven't been diagnosed at this stage. All right? So I get sent to a respiratory specialist. He tells me, "It can't be lung cancer." I'm a little bit stressed. It's probably me seeing-- when you have to have medications [inaudible]. You have to go into a nuclear scan which can only be done at the HOSPITAL. We've got to be there. So that...I have to wait two weeks. I have the assessment. I've got to wait another appointment to go see the respiratory specialist. The respiratory specialist said, "Oh, yes. It's come back. It doesn't look like it's a carcinoid, but there's other thing that it could be. I think we should just wait and see."
Participant 027_2023AULUC

Diagnosed in emergency department

Then it all came to head when I had a seizure. I collapsed at home and from the seizure, they determined that I had secondary brain tumors and the primary tumor was in my lungs. That's when it all happened.
Participant 005_2023AULUC

Right, now I went to the hospital because I had been puffy, like out of breath, and I had swollen legs so they put me into hospital. [crosstalk] Actually, they did a lung x-ray, is in the casualty department, and that's when they must have seen some spots, but didn't tell me.
Participant 013_2023AULUC

Diagnosed by their general practitioner during a routine check-up (not related to symptoms)

I didn't have symptoms. My diagnosis was picked up by a CT calcium score. My GP sent me off for the CT calcium score I think it was November last year because she wanted to check for plaque in my arteries and the lesions showed up then. After that, she sent me for another CT scan just specifically for the lungs. They reconfirmed what the CT calcium score had said. No symptoms. Participant 010_2023AULUC

Table 3.8: Diagnostic pathway

Diagnostic pathway	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Specialist from their general practitioner (Linear)	9	34.62	9	36.00	0	0.00	3	30.00	6	37.50	7	43.75	**2**	**20.00**
Multiple specialists needed before diagnosis (Complex)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	**6**	**37.50**	**1**	**10.00**
Diagnosed in emergency department	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	3	18.75	3	30.00
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	4	15.38	4	16.00	0	0.00	**3**	**30.00**	1	6.25	3	18.75	1	10.00

Diagnostic pathway	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Specialist from their general practitioner (Linear)	9	34.62	7	41.18	**2**	**22.22**	**3**	**23.08**	**6**	**46.15**	2	100.00	7	29.17	4	44.44	5	29.41
Multiple specialists needed before diagnosis (Complex)	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	2	22.22	5	29.41
Diagnosed in emergency department	6	23.08	**2**	**11.76**	**4**	**44.44**	**6**	**46.15**	**0**	**0.00**	0	0.00	6	25.00	2	22.22	4	23.53
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65

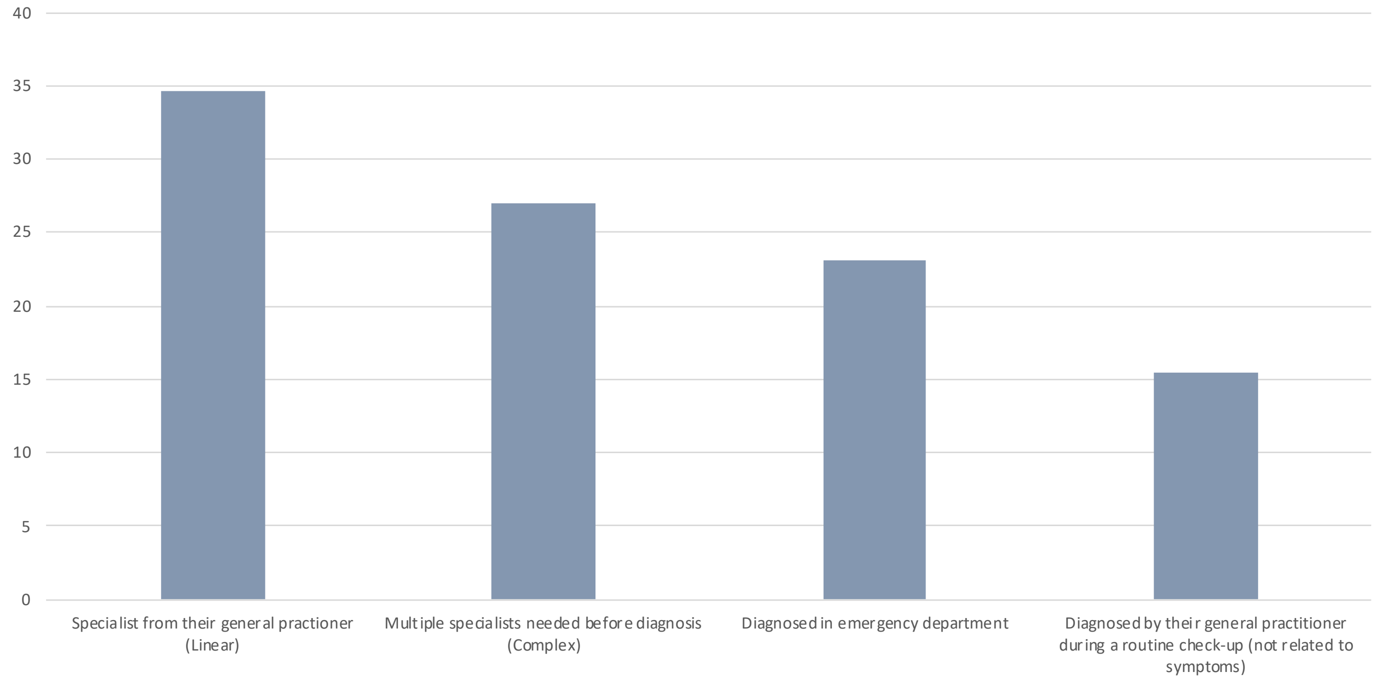


Figure 3.7: Diagnostic pathway

Table 3.9: Diagnostic pathway – subgroup variations

Diagnostic pathway	Less frequently	More frequently
Specialist from their general practitioner (Linear)	Male Aged 65 or older Trade or high school	University
Multiple specialists needed before diagnosis (Complex)	Male	Female
Diagnosed in emergency department	Aged 35 to 64 University	Aged 65 or older Trade or high school
Diagnosed by their general practitioner during a routine check-up (not related to symptoms)	-	Non-metastatic

Timing of diagnosis

Time from symptoms to diagnosis

Participants were asked to give the approximate date of when they first noticed symptoms of lung cancer and the approximate date of diagnosis with lung cancer. Where enough information was given, an approximate duration from first noticing symptoms to diagnosis was calculated.

Duration was calculated for 29 participants (9 participants had no symptoms before diagnosis), there were 7 participants (24.14%) that were diagnosed less than 1 month of noticing symptoms, 4 participants (13.79%) diagnosed between 2 and 3 months from noticing symptoms, 5 participants (17.24%) that were diagnosed between 6 months and 1 year of noticing symptoms, and 4 participants (13.79%) that were diagnosed more than 1 year of noticing symptoms (Table 3.10, Figure 3.8).

Time from diagnostic test to receiving a diagnosis

Participants were asked in the online questionnaire how long they waited between diagnostic tests and getting a diagnosis.

There were 7 participants (24.14%) that were diagnosed less than 1 week after testing, 8 participants

(27.59%) diagnosed between 1 and 2 weeks after testing, 8 participants (27.59%) that were diagnosed between 2 and 3 weeks after testing, and 6 participants (20.69%) that were diagnosed 4 weeks or after testing (Table 3.11, Figure 3.9).

Table 3.10: Time from symptoms to diagnosis

Time from symptoms to diagnosis	Number (n=29)	Percent
Less than 1 month	7	24.14
Between 2 and 3 months	4	13.79
Between 6 months and 1 year	5	17.24
More than 1 year	4	13.79
No symptoms	9	31.03

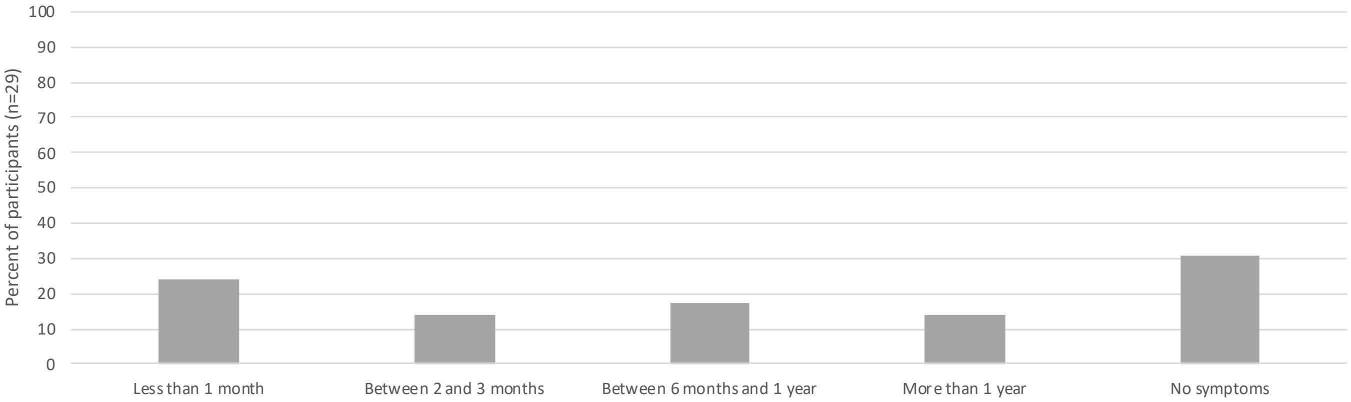


Figure 3.8: Time from symptoms to diagnosis

Table 3.11: Time from diagnostic test to diagnosis

Time from diagnosis test to diagnosis	Number (n=29)	Percent
Less than 1 week	7	24.14
Between 1 and 2 weeks	8	27.59
Between 2 and 3 weeks	8	27.59
4 weeks or more	6	20.69

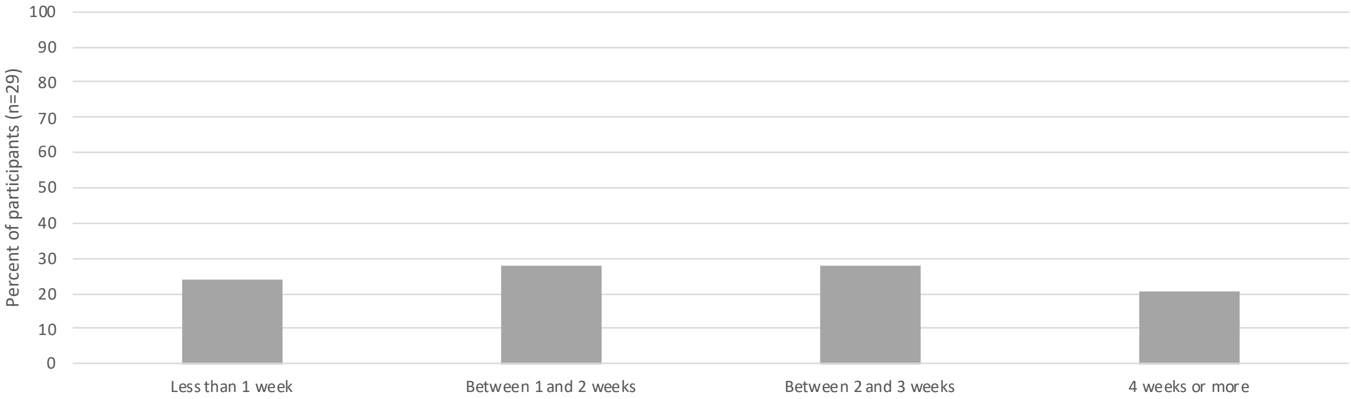


Figure 3.9: Time from diagnostic test to diagnosis

Diagnostic tests

Participants were asked in the questionnaire which diagnostic tests they had for their diagnosis with lung cancer. They could choose from a set list of diagnostic tests, and could then specify other tests not listed. The number of tests per participant were counted using both tests from the set list and other tests specified.

Participants reported between 0 to 5 diagnostic tests (median=3.00 , IQR=1.00) (Table 3.12, Figure 3.10). The most common tests were PET scan (n=23, 79.31%), Biopsy (n=20, 68.97%), CT scan (n=25, 86.21%), and Chest x-ray (n=15, 51.72%) (Table 3.13, Figure 3.11).

Table 3.12: Number of diagnostic tests

Number of diagnostic tests per participant	Number (n=29)	Percent
0	1	3.45
1	2	6.90
2	3	10.34
3	13	44.83
4	9	31.03
5	1	3.45

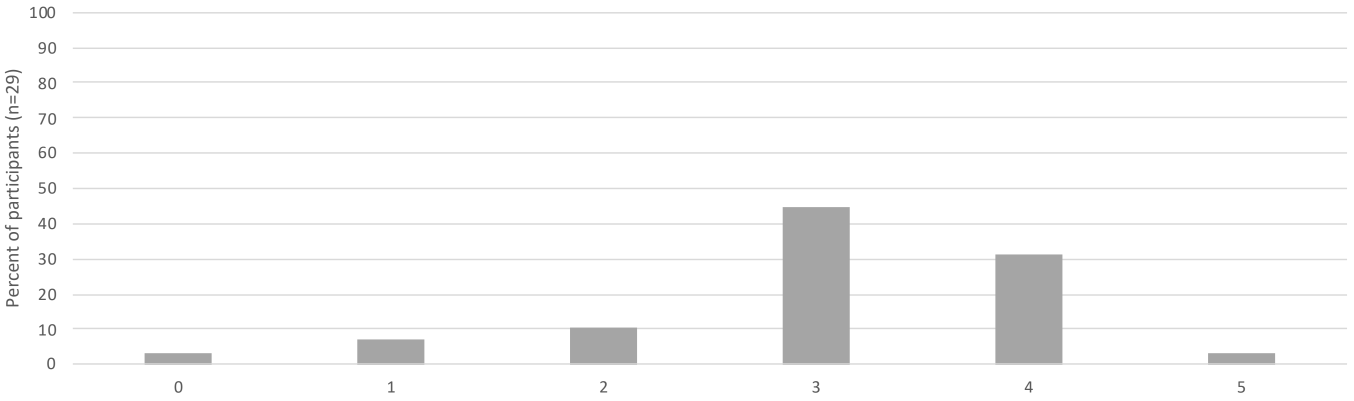


Figure 3.10: Number of diagnostic tests

Table 3.13: Diagnostic tests

Diagnostic tests	Number (n=29)	Percent
PET scan	23	79.31
Biopsy	20	68.97
CT scan	25	86.21
Chest x-ray	15	51.72
Sputum cytology (mucus from your lungs examined under a microscope)	2	6.90
Other	3	10.34
None	1	3.45

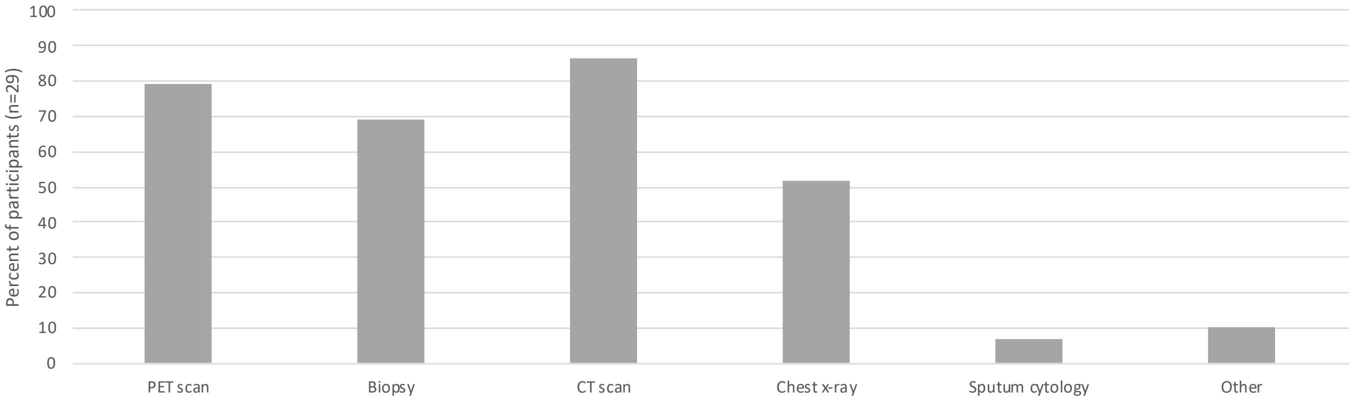


Figure 3.11: Diagnostic tests

Diagnosis provider and location

Participants were asked in the online questionnaire, which healthcare professional gave them their diagnosis, and where they were given the diagnosis.

Almost half of the participants were given their diagnosis by a respiratory specialist (n=14, 48.28%), and there were 5 participants (17.24%) given the diagnosis by a general practitioner, 3 participants (10.34%) diagnosed by an oncologist, and 3 participants (10.34%) by an emergency doctor or ambulance paramedic (Table 3.14, Figure 3.12).

Participants were most commonly given their diagnosis in the hospital (n=15, 51.72%), this was followed by the specialist clinic (n=6, 20.69%), and the general practice (n=4, 13.79%) (Table 3.15, Figure 3.13).

Table 3.14: Diagnosis provider

Health professional gave diagnosis	Number (n=29)	Percent
Respiratory specialist	14	48.28
General practitioner	5	17.24
Oncologist	3	10.34
Emergency department or ambulance	3	10.34
Surgeon	2	6.90
Other	2	6.90

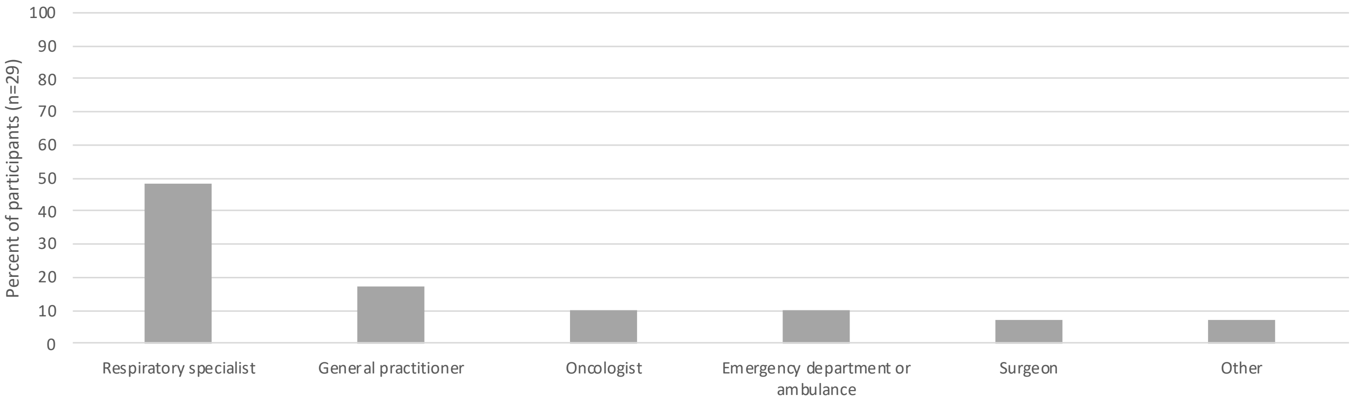


Figure 3.12: Diagnosis provider

Table 3.15: Diagnosis location

Location of diagnosis	Number (n=29)	Percent
Hospital	15	51.72
Specialist clinic	6	20.69
General practice	4	13.79
Over the phone	3	10.34
Other	1	3.45

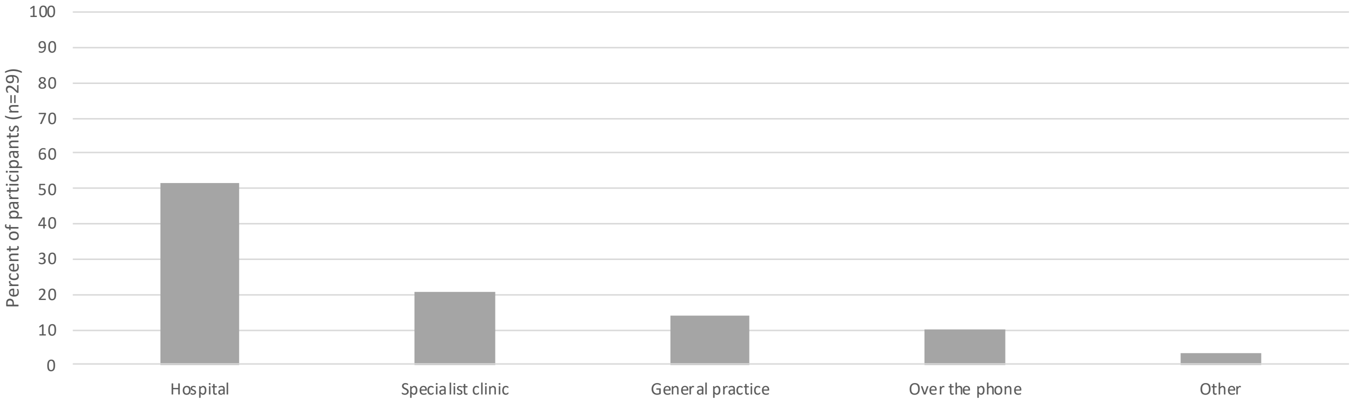


Figure 3.13: Diagnosis location

Year of diagnosis

In the online questionnaire, participants noted the approximate date of diagnosis, the year of diagnosis is presented in Table 3.16, Figure 3.14.

Participants were diagnosed between 2012 to 2022. There were 24 participants (82.76%) that were diagnosed in the last five years.

Table 3.16: Year of diagnosis

Year of diagnosis	Number (n=29)	Percent
2014 or before	3	10.34
2015 to 2019	5	17.24
2020 to 2022	21	72.41

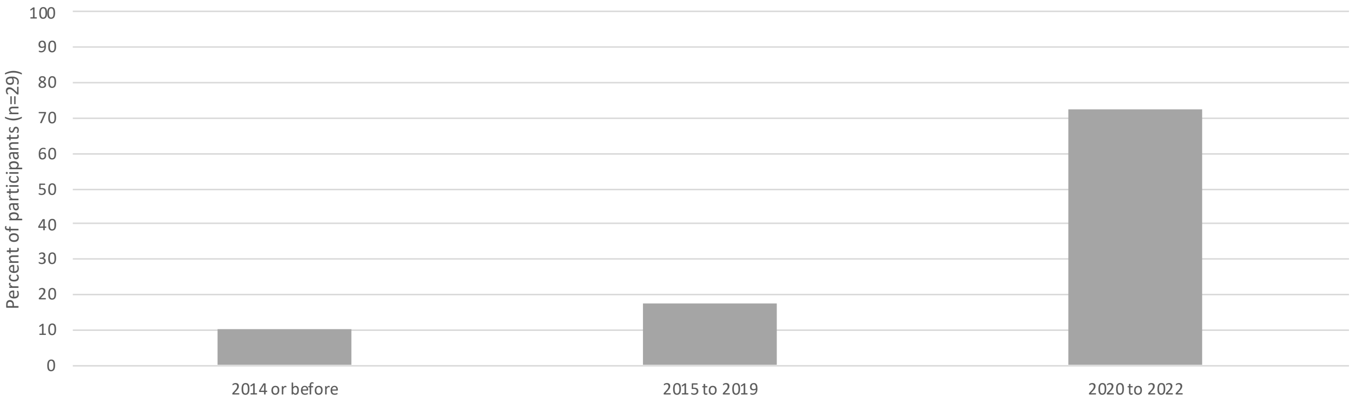


Figure 3.14: Year of diagnosis

Lung cancer diagnosis, stage and spread

Lung cancer diagnosis

The majority of participants were diagnosed with Non-small cell lung cancer (n=29, 90.63%) (Table 3.17, Figure 3.15).

Lung cancer stage

There were 4 participants (12.50%), with Stage 1 lung cancer, 3 participants (9.38%) with Stage 2, 4 participants (12.50%) with Stage 3, and 18 participants (56.25%), with Stage 4 lung cancer.
(Table 3.18, Figure 3.16).

Lung cancer spread

Participants noted in the online questionnaire if the cancer had spread, and where it had spread to. There were 13 participants (44.83%) that noted that the cancer had spread. The most common sites of spread were the brain (n=6, 20.69%), lymph nodes (n=4, 13.79%) and bones (n=4, 13.79%) (Table 3.19, Figure 3.17).

Lung cancer recurrence

There were 8 participants (27.59%) that reported having had a lung cancer recurrence.

Table 3.17: Type of lung cancer

Diagnosis	Number (n=32)	Percent
Non-small cell lung cancer	29	90.63
Other/not sure	3	9.38

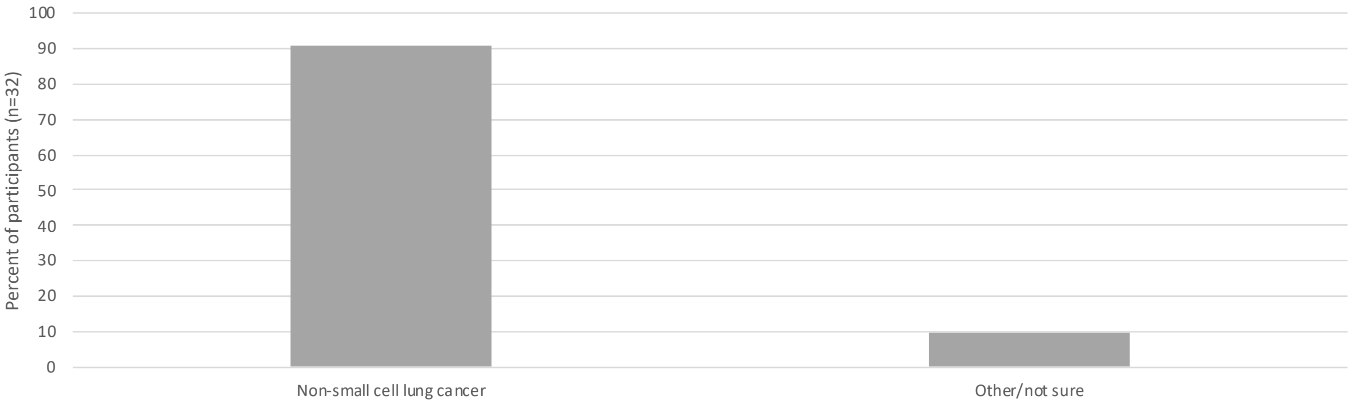


Figure 3.15: Type of lung cancer

Table 3.18: Lung cancer stage

Lung cancer stage	Number (n=32)	Percent
Stage 1	4	12.50
Stage 2	3	9.38
Stage 3	4	12.50
Stage 4	18	56.25
Not known	3	9.38

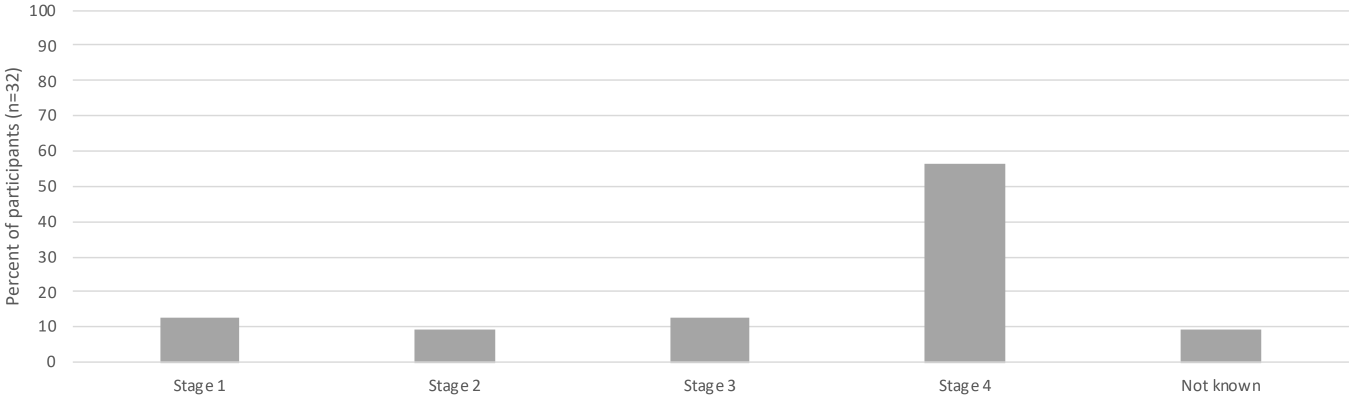


Figure 3.16: Lung cancer stage

Table 3.19: Lung cancer spread

Cancer spread	Number (n=29)	Percent
Brain	6	20.69
Lymph nodes	4	13.79
Bone	4	13.79
Lymph nodes	4	13.79
Liver	3	10.34
Esophagus	1	3.45
Adrenal glands	1	3.45
No spread/not sure	16	55.17

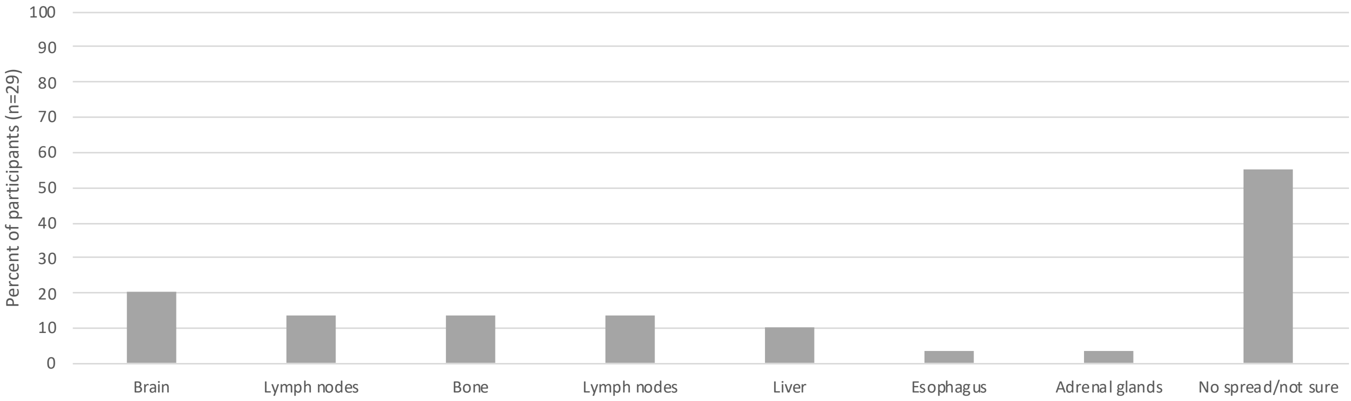


Figure 3.17: Lung cancer spread

Table 3. 20: Lung cancer recurrence

Lung cancer recurrence	Number (n=29)	Percent
No	21	72.41
Yes	8	27.59

Figure 3.18: Lung cancer recurrence

Understanding of disease at diagnosis

Participants were asked in the structured interview how much they knew about their condition at diagnosis. The most common responses were having no or little knowledge at diagnosis(61.54%), having knowledge because of family history of the condition or knowing someone who has the condition (15.38%), and having knowledge from a professional background (11.54 %).

Knowing nothing or very little about the condition at diagnosis

Not a lot, to be honest. There is a public perception that is related to smoking and I've never been a smoker. I know non-smokers would get it too. I really didn't have much information about lung cancer and would've never considered that that was a possibility for me. I couldn't understand how it could be at my age with my level of fitness at the time. It wouldn't have been comprehensible to consider lung cancer as a diagnosis.
Participant 005_2023AULUC

Nothing. Absolutely nothing at all. Participant 007_2023AULUC

Not a lot really. To be honest, I was in denial because a couple of years ago I'd had a very bad chest infection and I thought, "Oh, it's probably just scarring from that because that's not unusual." Of course, I follow all this up. I didn't not do anything about it, but until the respiratory specialist said it was lung cancer, I didn't think much of it. As I said, I had no symptoms. I felt well.
Participant 010_2023AULUC

Not a lot at all. I didn't even know your lungs started underneath your collarbone. I knew very, very little. I guess I was as ignorant as most of the public are thinking that I'm going to die, because you just hear that everyone who gets lung cancer dies. I had been a previous smoker, so I figured it was my own fault. That was basically all I knew.
Participant 018_2023AULUC

Very little, really. Of course, I jumped onto Google and freaked myself out completely about if it was a-- I was told that it was a spiculated nodule. Then having looked up to see what a spiculated module was and what the likelihood that that was cancerous, I was obviously extremely concerned at that point in time. 021_2023AULUC

Relatively little. I would say no specialist knowledge. Participant 022_2023AULUC

All I knew is that it was a bad cancer to have. Participant 023_2023AULUC

Very little. We've not got cancer in the family. Look, I smoked a tiny bit when I was way young, like 40 years earlier. I'm a HEALTH PROFESSIONAL but not in the area, oncology, and lung cancers as such is not an area I've ever worked in. I probably knew enough, but not enough, if that makes sense. 025_2023AULUC

Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition

I knew that it had killed my father. I knew that it was in most cases fairly dire diagnosis. I didn't think it was a good diagnosis. I thought it was a terminal diagnosis. 014_2023AULUC

Oh gosh. My only real knowledge of lung cancer is I knew through my work that it metastasizes to the brain and the eye. That was part of what I knew. I knew it went to bones. The only experience I'd had is that my father died of it about 20 years ago. That was pretty horrific because, of course, I came with that preconceived idea of I've really only got about six months to go.
Participant 020_2023AULUC

Knowing about the condition due to professional background

I'm a HEALTH PROFESSION. I probably have a little bit more knowledge about it than the average person, but I'm also a smoker. Yes. I'm not a professional in that field, but may be a little bit more than the average person. Participant 003_2023AULUC

Only what I'd learned at uni, because I have a health background, so I expected it to happen to smokers. I knew that lung cancer wasn't a great cancer to get, but I wasn't quite sure of the exact statistics until after I was diagnosed. That was about-- I knew there were different types of lung cancer. I knew there was non-small cell and small cell, but again, I didn't know specific details, certainly didn't know there was any mutations because of the [unintelligible 00:08:02] study that I had done was 8 or 9 or 10 years prior, even longer actually, maybe. Participant 015_2023AULUC

Table 3.21: Understanding of disease at diagnosis

Understanding of disease at diagnosis	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Knowing nothing or very little about the condition at diagnosis	16	61.54	15	60.00	1	100.00	5	50.00	11	68.75	11	68.75	5	50.00
Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Knowing about the condition due to professional background	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Understanding of disease at diagnosis	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Knowing nothing or very little about the condition at diagnosis	16	61.54	8	47.06	8	88.89	10	76.92	6	46.15	1	50.00	15	62.50	5	55.56	11	64.71
Knowing about the condition at diagnosis because they have a family history of the condition/know someone who has the condition	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65
Knowing about the condition due to professional background	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76

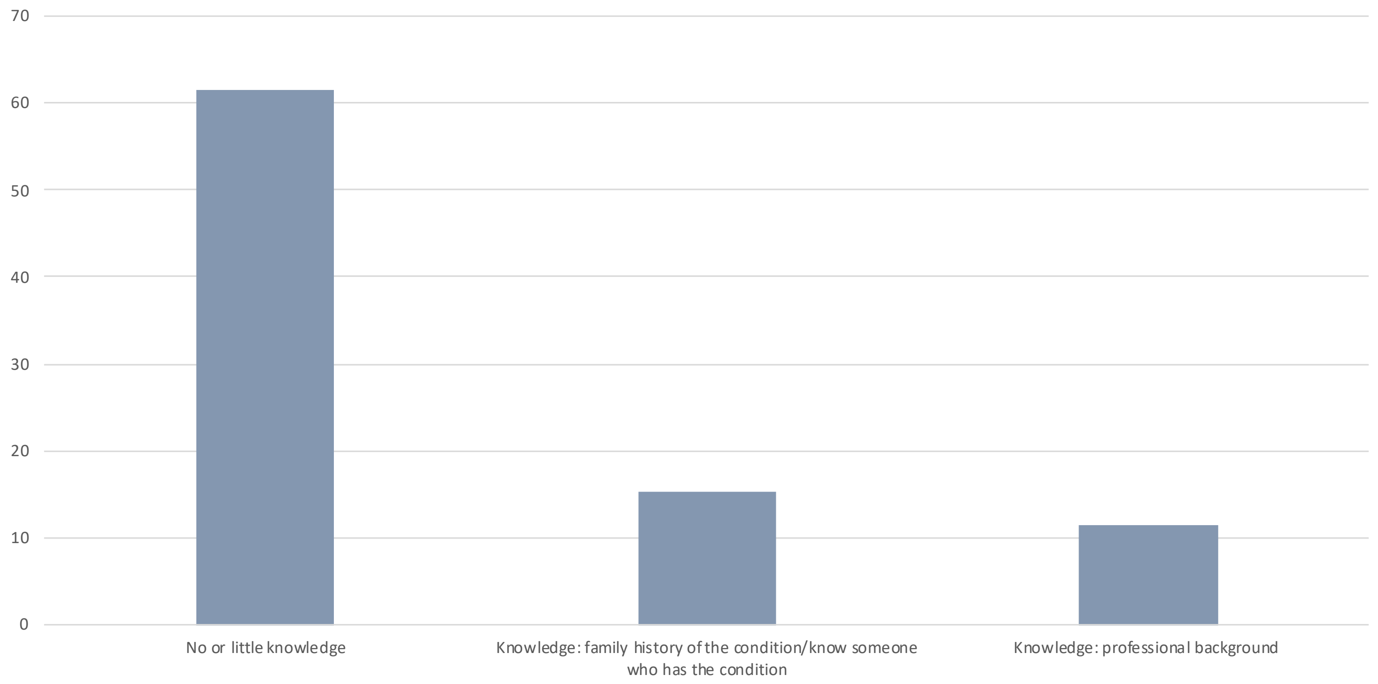


Figure 3.19 Understanding of disease at diagnosis

Table 3.22: Understanding of disease at diagnosis – subgroup variations

Understanding of disease at diagnosis	Less frequently	More frequently
Knowing nothing or very little about the condition at diagnosis	Non-metastatic Male Aged 35 to 64 University	Aged 65 or older Trade or high school
Knowing about the condition due to professional background	Male Aged 65 or older	-

Emotional support at diagnosis

Participants were asked in the online questionnaire how much emotional support they or their family received between diagnostic testing and diagnosis.

There were 6 participants (20.69%) who had enough support, 3 participants (10.34%) that had some support but it wasn't enough, and 20 participants (68.97%) had no support (Table 3.23, Figure 3.20).

Table 3.23: Emotional support at diagnosis

Emotional support at diagnosis	n=29	%
Enough support	6	20.69
Some support but it wasn't enough	3	10.34
No support	20	68.97

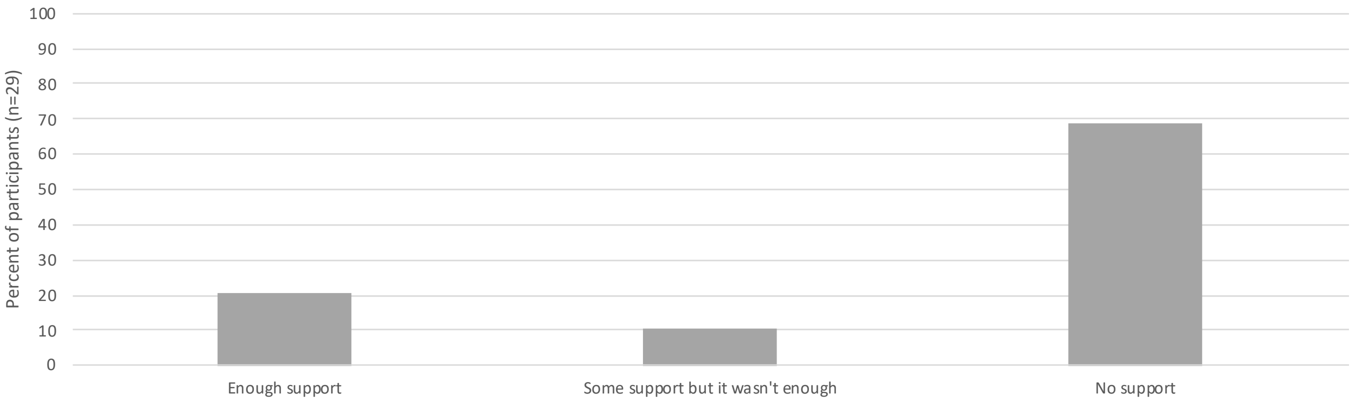


Figure 3.20: Emotional support at diagnosis

Costs at diagnosis

Out of pocket expenses at diagnosis

Participants noted in the online questionnaire the amount of out-of-pocket expenses they had at diagnosis, for example doctors' fees, and diagnostic tests.

There were 16 participants (55.17%) who had no out of pocket expenses, and 3 participants (10.34%) who did not know or could not recall. There were 5 participants (17.24%) that spent between $400 and $800, and 5 participants (17.24%) that spent more than $1000 (Table 3.24, Figure 3.21).

Burden of diagnostic costs

For 22 participants (75.86%) the cost was slightly or not at all significant. For 5 participants (17.24%) the out-of-pocket expenses were somewhat significant, and for 2 participants (6.90%), the burden of out-of-pocket expenses were moderately or extremely significant (Table 3.25, Figure 3.22)

Table 3.24: Out of pocket expenses at diagnosis

Out of pocket expenses for diagnostic tests	Number (n=29)	Percent
$0	16	55.17
$400 to 800	5	17.24
>$1000	5	17.24
Not sure	3	10.34

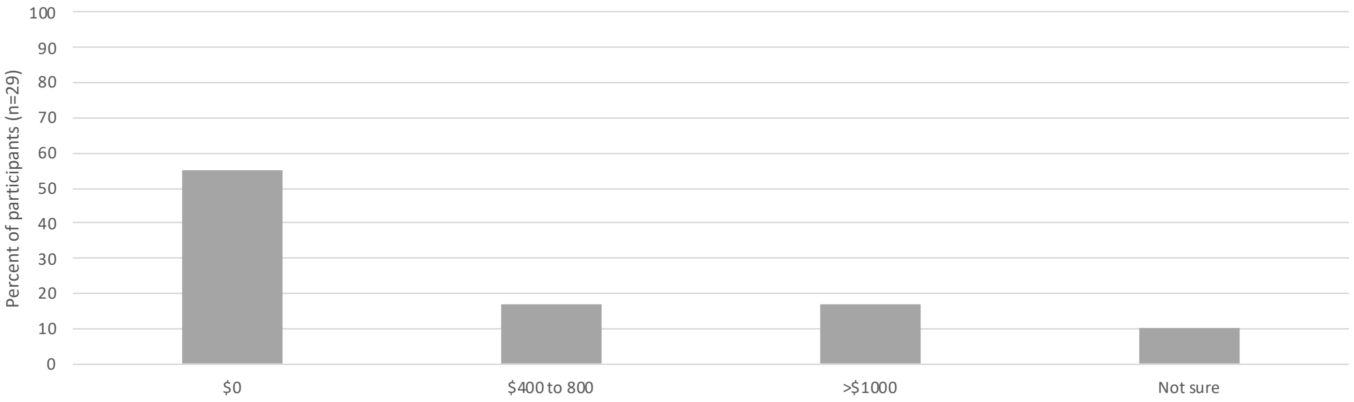


Figure 3.21: Out of pocket expenses at diagnosis

Table 3.25: Burden of diagnostic costs

Burden of diagnostic costs	Number (n=29)	Percent
Not at all significant	15	51.72
Slightly significant	7	24.14
Somewhat significant	5	17.24
Moderately significant	0	0.00
Extremely significant	2	6.90

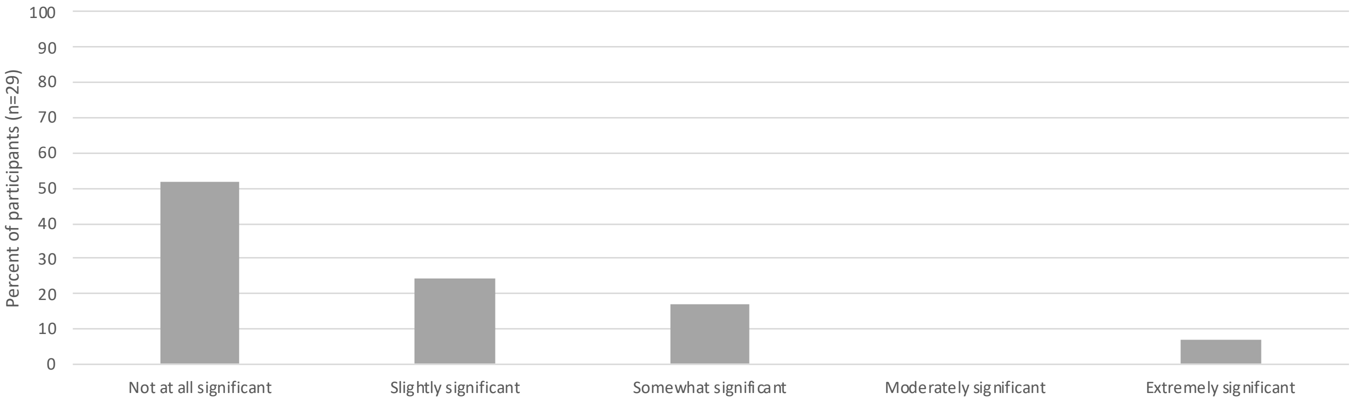


Figure 3.22: Burden of diagnostic costs

Genetic tests and biomarkers

Participants answered questions in the online questionnaire about if they had any discussions with their doctor about biomarkers, genomic and gene testing that might be relevant to treatment. If they did have a discussion, they were asked if they brought up the topic or if their doctor did.

Most commonly, participants had never had a conversation about biomarkers, genomic, or gene testing that might be relevant to treatment, (n=16, 55.17%). There were 3 participants (10.34%) who brought up the topic with their doctor, and 10 participants (34.48%) whose doctor brought up the topic with them (Table 3.26, Figure 3.23).

Participants were then asked if they had had any biomarker, genomic or gene testing. If they had testing, they were asked if they had it as part of a clinical trial, paid for it themselves or if they did not have to pay for it. Those that did not have the test were asked if they were interested in this type of test.

Participants most commonly did not have any genetic or biomarker tests but would like to (n=13, 44.83%). There were 2 participants (6.90%) who did not have these tests and were not interested in them, and a total of 14 participants (48.28%) that had biomarker tests (Table 3.27, Figure 3.24).

Table 3.26: Discussions about biomarkers

Discussions about biomarkers	Number (n=29)	Percent
Participant brought up the topic with doctor for discussion	3	10.34
Doctor brought up the topic with participant for discussion	10	34.48
Participant had no discussion about this type of test	16	55.17

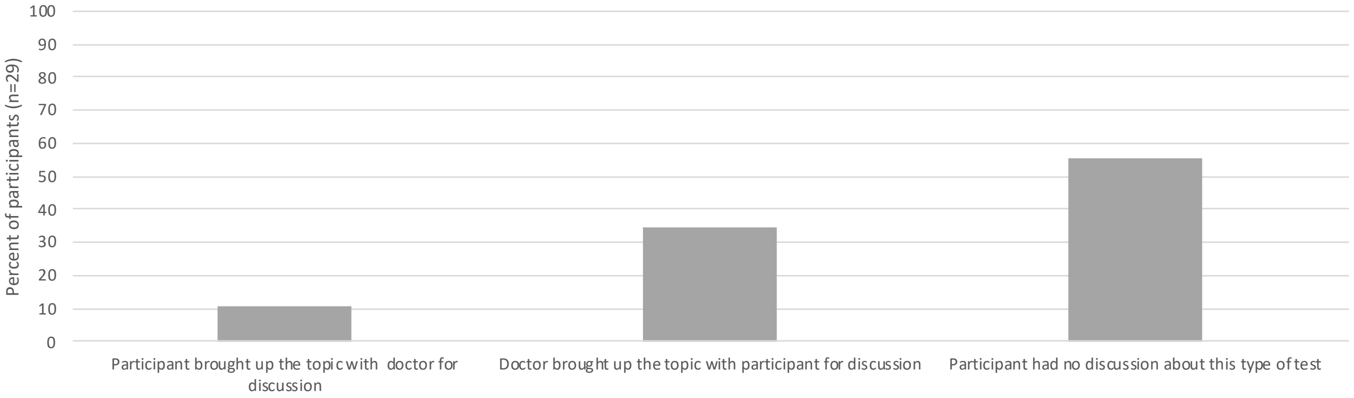


Figure 3.23: Discussions about biomarkers

Table 3.27: Experience of genetic tests and biomarkers

Experience of genetic tests and biomarkers	Number (n=29)	Percent
Participant had this test and did not have to pay out of pocket for it	9	31.03
Participant had this test athrough a clinical trial	0	0.00
Participant had this type of test and paid for it	5	17.24
Participant did not have this test and is not interested in it	2	6.90
Participant did not have this test but would like to	13	44.83

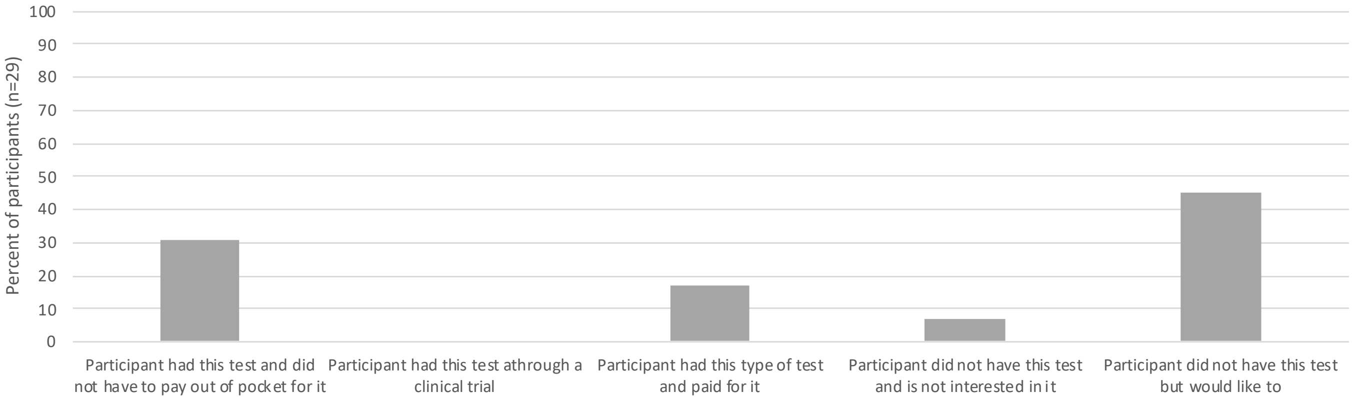


Figure 3.24: Experience of genetic tests and biomarkers

Biomarker status

More than half status for at least one biomarker (n=16, 55.17%). Most commonly, participants knew their EGFR status (n=9, 31.03%), followed by ALK status (n=7, 24.14%) (Table 3.28, Figure 3.25).

Table 3. 28: Biomarker status

Biomarkers	Number (n=29)	Percent
EGFR	9	31.03
ALK	7	24.14
TP53	1	3.45
Not sure	13	44.83

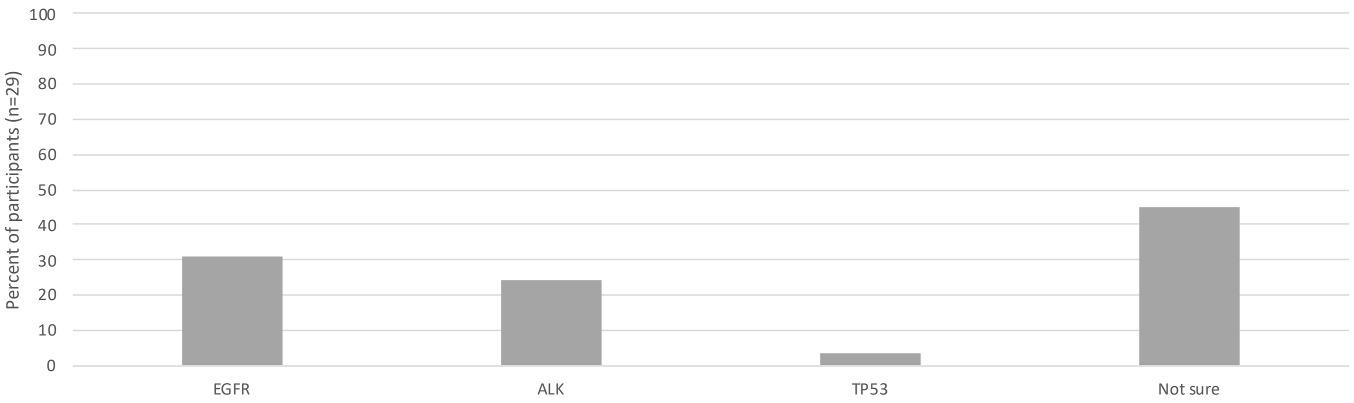


Figure 3.25: Biomarker status

Understanding of prognosis

Participants were asked in the structured interview to describe what their current understanding of their prognosis was. The most common responses were uncertainty around prognosis (61.54%), and that they had a poor prognois or a terminal condition (15.38%). Other themes included having no evidence of disease or that they are in remission (11.54%), and describing a specific timeframe that they are expected to live (7.69%).

Participant describes prognosis in relation to uncertainty around prognosis

I don't have one. Participant 003_2023AULUC

It's a stage 4. They don't really give you a timeline. My oncologist said, "You can live the years and hopefully, there'll be new drugs coming out all the time." I think the prognosis there was a bit overhyped because I don't think there's that many clinical trials or good tablets for EGFR at the moment, but he didn't give me any timeframe. He just said, Years; I can keep you well for years." Participant 004_2023AULUC

No, I don't know what it is. Participant 007_2023AULUC

Well, I don't know. I was diagnosed in August, not last year, the year before. Participant 013_2023AULUC

At the time they did, but certainly not since because nobody knows how long anyone has to live at this point. I've had a lot of ups and downs in my treatment and I'm still alive. Participant 015_2023AULUC

Participant describes prognosis in relation to poor outcomes, or terminal condition

There's no cure for what I've got. Participant 001_2023AULUC

I don't like talking about survivors of lung cancer because there aren't many. For three and a half years, it's been, "You're going to die, you're not going to die, you're going--" to living with lung cancer. I look at it now and I hope that this is where it's going. It is like having blood pressure. We're taking a tablet each day, but we know the tablets stop working. We're just hoping that they come up with more tablets to stop the cancer developing. Participant 019_2023AULUC

For me, I'm realistic that this is a terminal disease. I am doing really well on my treatment and feeling like I don't have anything wrong with me. The side effects from my treatment are manageable. I tend to go, I don't want to think about them because I'm enjoying life as I did before and I will keep going that way until this stops working, and then we'll face the next thing. I'm cautiously optimistic. I know I can't live a long life, but what I'm living is a very good life. Participant 020_2023AULUC

Yes, it's good. It has progressed. Basically, they just don't talk about prognosis, really. They said, from the time when I was diagnosed, it was not curable, so I knew that as well. It's just-- For every day that you have, every week, every month, you're grateful, and that's it. It's just prolonging it, and making the best of it. 023_2023AULUC

Yes. Well, I'm considered terminal at the moment. Participant 024_2023AULUC

Participant describes prognosis in relation to there being no evidence of disease or that they are in remission

Well, I'm sort of in between scans. I'm halfway through before my next scan. I have been no evidence of disease within four weeks of taking the pills. That's continued, knock on wood, till my next scan. I'm in a lot of pain, but the chemo tablets are just horrific. I have a lot of problems, my joints, my muscles hurt. It's hard. It's affected my heart...No, it's poison in the end. Participant 002_2023AULUC

The surgeon said that they got all the cancer-- I had a lobectomy in the right lung, and he said that they got all the cancer that was there. There is no chemotherapy or radiotherapy. At the moment, I think I'm diagnosed as NED, no evidence of disease. I have to have a CT scan every six months and see the surgeon for the next five years. Participant 010_2023AULUC

I've just had my last scan about a month ago, and I'm cancer free. That was my 12-month scan. I've been 12 months since treatment. I've had 12 months and 3 monthly scans, and I'm clear at this stage. Participant 018_2023AULUC

At the moment, I'm officially cancer free. Participant 021_2023AULUC

Participant describes prognosis in relation to specific timeframe that they are expected to live

Yes. When I was diagnosed it was 2020, so what's that? Two years? That's pretty good. The prognosis was about seven months, I think, but I'm on targeted therapy, which has been working. I've just changed over to the new Osimertinib, but that will last less time than the first one did. I think my guess is end of the year would be a good-- If I can make it to the end of the year, so what's that? Another 6, 7 months maybe? Participant 006_2023AULUC

I got a 2 to 10-year prognosis. Participant 026_2023AULUC

No one will tell me that, but by the research, the progression pre-survival is between, they say it's up to seven years now, but there's some other people that it really depends on its targeted treatment. Participant 027_2023AULUC

Table 3. 29: Understanding of prognosis

Understanding of prognosis	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes prognosis in relation to uncertainty around prognosis	9	34.62	9	36.00	0	0.00	2	20.00	7	43.75	8	50.00	1	10.00
Participant describes prognosis in relation to poor outcomes, or terminal condition	7	26.92	6	24.00	1	100.00	0	0.00	7	43.75	5	31.25	2	20.00
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	5	19.23	5	20.00	0	0.00	4	40.00	1	6.25	3	18.75	2	20.00
Participant describes prognosis in relation to specific timeframe that they are expected to live	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Understanding of prognosis	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes prognosis in relation to uncertainty around prognosis	9	34.62	6	35.29	3	33.33	6	46.15	3	23.08	1	50.00	8	33.33	6	66.67	3	17.65
Participant describes prognosis in relation to poor outcomes, or terminal condition	7	26.92	3	17.65	4	44.44	3	23.08	4	30.77	1	50.00	6	25.00	1	11.11	6	35.29
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes prognosis in relation to specific timeframe that they are expected to live	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	3	33.33	0	0.00

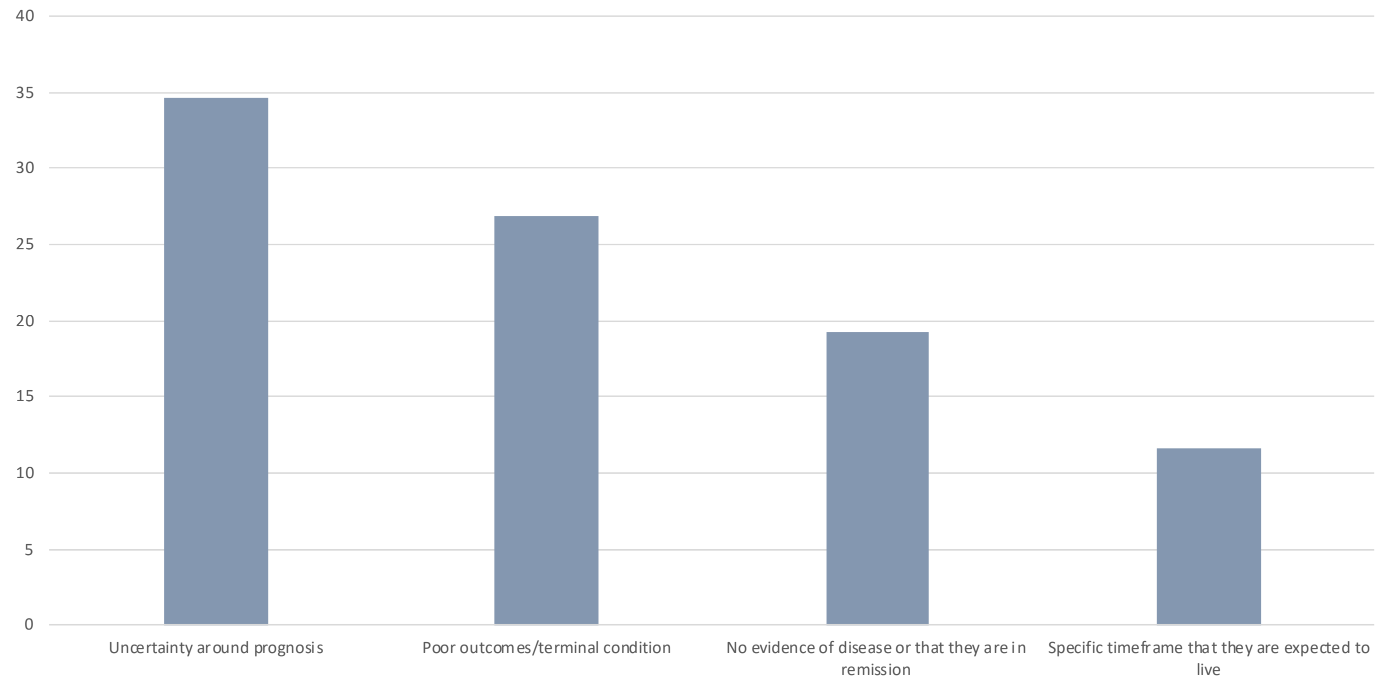


Figure 3.29: Understanding of prognosis

Table 3.26: Understanding of prognosis – subgroup variations

Understanding of prognosis	Less frequently	More frequently
Participant describes prognosis in relation to uncertainty around prognosis	Non-metastatic Male University Higher status	Female Trade or high school Mid to low status
Participant describes prognosis in relation to poor outcomes, or terminal condition	Non-metastatic Mid to low status	Metastatic Aged 65 or older
Participant describes prognosis in relation to there being no evidence of disease or that they are in remission	Metastatic Mid to low status	Non-metastatic Higher status
Participant describes prognosis in relation to specific timeframe that they are expected to live	Male Aged 65 or older Higher status	Mid to low status

Section 4

Decision-making

Section 4 summary

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (61.54%), followed by one treatment option (34.62%).

Discussions about treatment (Participation in discussions)

Participants described their participation in discussions about treatments. The most common responses were participants presented with multiple options were that they participated in the decision-making process (34.62%), they were told what to do without discussion (19.23 %), and that they were presented with multiple option but did not give a reason or a description of participation in discussions (19.23%). For those with a single treatment option, most commonly they were told what to do without discussion (11.54%).

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were efficacy (50.00%), advice of their clinician (26.92%), and side effects (23.08 %). Other considerations included their own research (19.23%), quality of life (15.38%), cost (11.54%), and that they were not given options so considerations not taken into account (11.54%).

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they made decisions (42.31%), followed by not changing the way they made decisions (38.46%).

Where participants had changed the way they make decisions, the most common reason was that they had become more informed and/or more assertive (30.77%). Where participants had not changed the way they make decisions, the most common reason was that they had always taken advice of clinicians (11.54%).

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to be cancer free, to avoid recurrence, or increase longevity (38.46%).

Other themes treatment goals included minimising or avoiding side effects (26.92%), quality of life, or return to normality (23.08%), and some wanted improvements in the communication and information about treatment they received from their doctor (15.38%)

Discussions about treatment

Participants were asked to recall what treatment options they were presented with and how they felt about the options. Participants most commonly were presented with multiple options (61.54%), followed by one treatment option (34.62%).

Participants described their participation in discussions about treatments. The most common responses were participants presented with multiple options were that they participated in the decision-making process (34.62%), they were told what to do without discussion (19.23 %), and that they were presented with multiple option but did not give a reason or a description of participation in discussions (19.23%). For those with a single treatment option, most commonly they were told what to do without discussion (11.54%).

Participant describes multiple options being presented and participating in the decision-making process

Before they found out it was ALK, they said they'd get me started on chemo. Then from chemo, they would go to immunotherapy and possibly radiate too. After I was diagnosed ALK, obviously, I'm going to go on these tablets and at the end of the tablets, when they stop working, then we'll go through chemo. That took immunotherapy, but that won't be happening because it doesn't work on ALK. I think the biggest problem we've got in Australia is the oncologists really don't know a lot about ALK. Immuno just speeds it up and makes it more aggressive. He and I had an argument about that one day. [chuckles] I've run out of the target therapy. I'll just be on chemo until that stops working. Then that'll be it.
Participant 002_2023AULUC

Look, the respiratory specialist recommended that I have surgery because it was quite small the lesion but it was growing. He did say that obviously, I didn't have to have it done. If opted to, I could just have regular scans to monitor it for a while, but that wasn't his recommendation.
Participant 010_2023AULUC

Well, he initially, the specialist, said that-- Well, I asked him, as I said, what the prognosis was and he said, well, it's 20%. Then I said, well, I don't know if it's worth going ahead with those odds and he said, "There a lot of people are still around, that were diagnosed the same as you, and they're still around a few years later," but he said, "What happens is, at the hospital, all the specialists get together, I think there's about five of them, every Tuesday and they discuss all the new cases for the week and decide what their best course of action is for each patient." He said that to me, and then he said, "I'll ring you when we've decided, and then it's up to you whether you want to proceed or not."He rang me back and told me on a Tuesday that they had decided to go ahead with both radium and chemo consecutively for a six-week period and did I want to proceed, and I had been arrested by everybody by then and said, "Yes, I suppose so."
Participant 017_2023AULUC

Basically, of course, they held off, except I have a lot of brain metastasis. On the cards is eventually whole brain radiation. At the moment, as soon as we got the EGFR diagnosis, I was started on the tablet. When they stop working, they have talked about the types of chemo and immunotherapy. One question that's come up is they're cautious about immunotherapy with me because I have had some major autoimmune disease. That will be a discussion we have when we get there. What I can see on the cards is when this drug stops working optimally, that I am looking at some brain radiation and looking down a path of some chemo question immunotherapy.
Participant 020_2023AULUC

Participant describes multiple options being presented and being told what to do without discussion

Well, he didn't give me any option. He just said, "We're giving you chemo and immunotherapy." I went right on, that was it.
Participant 001_2023AULUC

I've had one appointment with the respiratory specialist on the 4th of March at my local base hospital. I was told that I would probably have to go to LOCATION for resection, for surgery to remove the nodule. I've also been back to my GP every Friday for the last month, and that's it. They can't give me any answers. They're not communicating with him. He's requested my information and he hasn't gotten anything. That's it.
Participant 003_2023AULUC

Initially, I suppose I have to say I was first diagnosed over the phone. They told me the news that I had lung cancer via a telehealth, which I didn't necessarily agree with, but anyway, that's what happened to me. They said, "We'll be choosing your team of doctors for you." Then he said, "I want you to go and speak to the

radiation oncologist. I want you to speak to a medical oncologist. I want you to speak to the surgeon. Then we'll come back and discuss from there." I hurried around and tried to make those appointments to go and speak to these people. The medical oncologist said, "We're going to do one more bronchoscopy, and if all your lymph nodes are clear, then we'll start you on chemo." I wasn't asked or even told these are your options. It was just like, this is what we're going to do. We're going to do this, we're going to do that, we're going to do this. I was a private patient. I'd never been diagnosed with lung cancer. I just figured that was what happened. You just went, "Okay, righto." You went with it, basically.
Participant 018_2023AULUC

No, I don't know. They haven't told me much at all. They said there's a few types of treatment, but they did not elaborate. It was more a chemo treatment. They said if a chemo fails, they'll do the radio type. Participant 029_2023AULUC

Participant describes one option being presented and being told what to do without discussion

When I was in respiratory, I was seeing a doctor in respiratory, this is the early stages of diagnosis, and a surgeon, I think a lady surgeon came in and she sat in. She went away, and she's coming back and she said, "Are you free to stay for an extra hour?" I said, "Yes, of course, I am." Immediately, when I was finished with the respiratory doctor, she said, "Come with me." Immediately, took me to radiation.
Participant 012_2023AULUC

I'm racking my brains. I think it was pretty much presented to me that there was really only one course of action which was surgery to remove it, which was probably-- No. Yes, I think the facts of the matter of that without my interpretation of the facts were just that, yes, that was the only course of action, was to take a lobectomy, undertake a lobectomy, and remove the associated lymph nodes as well. Participant 021_2023AULUC

Nobody ever spoke to me about what the treatment would be post. There was talk about seeing an oncologist but, at that point in time nothing had been discussed or decided. That all came post-surgery. Participant 025_2023AULUC

Table 4.1: Discussions about treatment

Discussions about treatment	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes multiple treatment options being discussed	16	61.54	15	60.00	1	100.00	**4**	**40.00**	**12**	**75.00**	**13**	**81.25**	**3**	**30.00**
Participant describes one treatment option being discussed	9	34.62	9	36.00	0	0.00	**5**	**50.00**	4	25.00	5	31.25	4	40.00
No particular comment (Other/no response)	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	1	6.25	0	0.00

Discussions about treatment	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes multiple treatment options being discussed	16	61.54	9	52.94	**7**	**77.78**	9	69.23	7	53.85	1	50.00	15	62.50	5	55.56	11	64.71
Participant describes one treatment option being discussed	9	34.62	6	35.29	3	33.33	4	30.77	5	38.46	1	50.00	8	33.33	4	44.44	5	29.41
No particular comment (Other/no response)	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	0	0.00	1	4.17	0	0.00	1	5.88

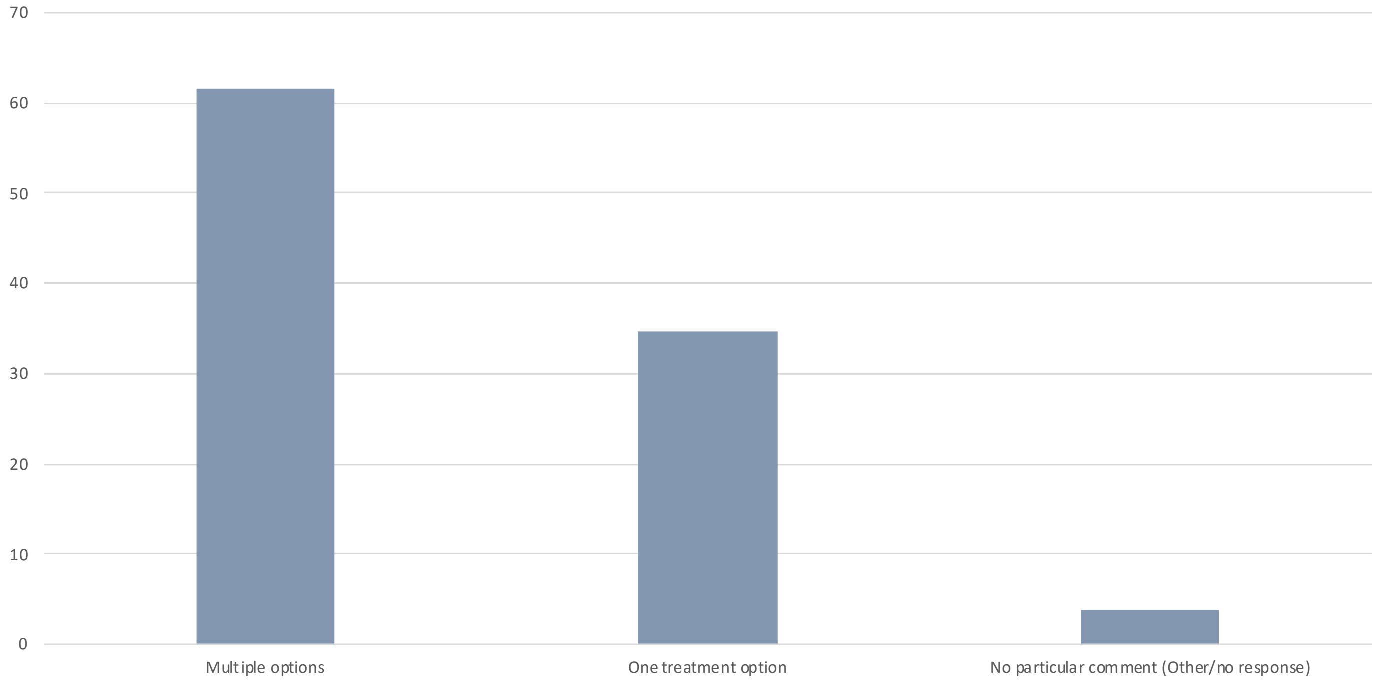


Figure 4.1: Discussions about treatment

Table 4.2: Discussions about treatment – subgroup variations

Theme	Less frequently	More frequently
Participant describes multiple treatment options being discussed	Non-metastatic Male	Metastatic Female Aged 65 or older
Participant describes one treatment option being discussed	-	Non-metastatic

Table 4.3: Discussions about treatment (Participation in discussions)

Participation in decision making	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes multiple options being presented and participating in the decision-making process	9	34.62	9	36.00	0	0.00	4	40.00	5	31.25	8	50.00	1	10.00
Participant describes multiple options being presented and there is no particular reason noted	5	19.23	4	16.00	1	100.00	0	0.00	5	31.25	4	25.00	1	10.00
Participant describes multiple options being presented and being told what to do without discussion	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes one option being presented and being told what to do without discussion	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	1	6.25	2	20.00

Participation in decision making	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes multiple options being presented and participating in the decision-making process	9	34.62	5	29.41	4	44.44	6	46.15	3	23.08	0	0.00	9	37.50	2	22.22	7	41.18
Participant describes multiple options being presented and there is no particular reason noted	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	3	33.33	2	11.76
Participant describes multiple options being presented and being told what to do without discussion	5	19.23	2	11.76	3	33.33	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes one option being presented and being told what to do without discussion	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65

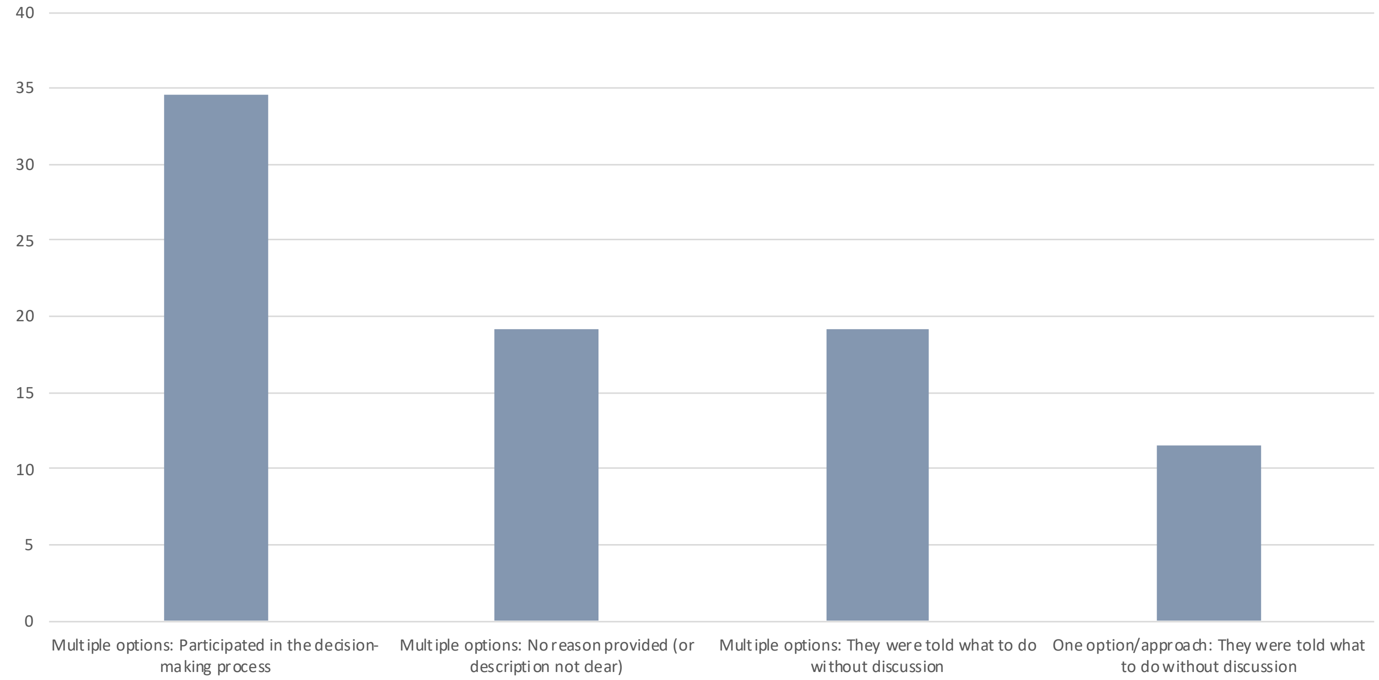


Figure 4.2: Discussions about treatment (Participation in discussions)

Table 4.4: Discussions about treatment (Participation in discussions) – subgroup variations

Theme	Less frequently	More frequently
Participant describes multiple options being presented and participating in the decision-making process	Male University Mid to low status	Female Trade or high school
Participant describes multiple options being presented and there is no particular reason noted	Non-metastatic	Metastatic Mid to low status
Participant describes multiple options being presented and being told what to do without discussion	-	Aged 65 or older
Participant describes one option being presented and being told what to do without discussion	Metastatic Mid to low status	Non-metastatic

Considerations when making decisions

Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were efficacy (50.00%), advice of their clinician (26.92%), and side effects (23.08 %). Other considerations included their own research (19.23%), quality of life (15.38%), cost (11.54%), and that they were not given options so considerations not taken into account (11.54%).

Participant describes taking efficacy into account when making decisions about treatment

I suppose the effectiveness, the side effects, and I suppose this time around because I really didn't have any other choice, I had to go with the chemotherapy. There was no other choice in terms of targeted therapy. This was my next option and immunotherapy.
Participant 005__2023AULUC

How effective they're going to be, and the side effects I'm going to have.
Participant 024__2023AULUC

The main thing I take into consideration is living as long as physically possible because I've got a child, but I guess, I like to maintain well as long as possible, and I just do whatever's necessary at the time, while this medication works. [crosstalk] but when it stops working, I'll look at something else.
Participant 026__2023AULUC

Participant describes taking the advice of their clinician into account when making decisions about treatment

I took whatever they offered me.
Participant 019_2023AULUC

To be honest, we haven't been involved in those decisions. The oncologist makes those decisions and just says what you're going to do. Dad's been happy to follow with that but as a daughter, I've been there every step of the way, every appointment. We'll chat about it later on and dad's put his trust in this oncologist, so he just trusts what they've actually said and what they've laid out. There really hasn't been

any options or given options. It's been dictated what your treatment route's going to be.
Participant 030_2023AULUC

Well, right from the beginning we were sold the osimertinib, the targeted therapy. The oncologist at the beginning was very big on pushing that. When I spoke just privately to the cardiothoracic surgeon, he backed it. I just wanted to check with him and make sure or see what he thought and he thought it was a worthwhile path to go down.
Participant 025_2023AULUC

Participant describes taking side effects into account when making decisions about treatment

I look at how long is it while it has to be administered. I look at the results of the trial and I want to have an idea of the demographics on which the drugs have been tested. That's quite a complex thing because I basically now look at research papers and how long it's been conducted, and then I decide if the treatment is going to be worse then than the cancer itself. More destructive. If the treatment is going to do more harm than the cancer.
Participant 023_2023AULUC

How effective they're going to be, and the side effects I'm going to have.
Participant 024_2023AULUC

I suppose the effectiveness, the side effects, and I suppose this time around because I really didn't have any other choice, I had to go with the chemotherapy. There was no other choice in terms of targeted therapy. This was my next option and immunotherapy.
Participant 005_2023AULUC

Participant describes taking their own research into account when making decisions about treatment

That I was put on a second generation, not a first generation when I started. I've been doing a lot of research on when the third generation, which is the last one runs out, can I go back and get on the first generation one? I've been doing a bit of study on that sort of thing so that I can present it to my oncologist. Also, my second generation, there were two of them in the second generation. Can I go up sideways once this one stops working? Can I go to its-- I don't know if they're exactly the same. If they're exactly the same, it's not going to work. My oncologist is given me free-range. He said if I pick something, he'll just do it. As long as it's on the PBS, he'll just do it. That's what we are going to do.
Participant 002_2023AULUC

Well, right from the beginning we were sold the osimertinib, the targeted therapy. The oncologist at the beginning was very big on pushing that. When I spoke just privately to the cardiothoracic surgeon, he backed it. I just wanted to check with him and make sure or see what he thought and he thought it was a worthwhile path to go down. Fortunately, we are in a position where we can afford it, albeit being a little bit difficult, but [inaudible] afford it. I'm taking that for three years. I haven't really been given a lot of information about it. I've researched it all myself because there is a lot about it online, of course, as there is with everything. I've pretty much done most of the research about the drug myself and decided myself that I would pursue this for a while, providing I didn't have too many adverse side effects. To date, I haven't.
Participant 025_2023AULUC

Participant describes taking quality of life into account when making decisions about treatment

Look, I do a bit of research, but I just want quality of life. That's my big thing. I know I'm never going to get better, but I want a good quality of life for as long as I can. I guess that would be my main decision-maker. My darling sister does a lot of research stuff. She's currently doing a thesis on—Anyway, but she does a lot of research for me into things. Family are good support and look, I've got a lot of friends in the medical field, so often I'll run things by them as well.
Participant 006_2023AULUC

At the beginning, I needed the best possible treatment so that my kids had a mum. I needed a treatment that was going to keep me alive. I didn't care what the side effects were, if it meant I could live another day, to live and breathe and touch my child, my newborn baby, that was my priority. I actually was willing to take and tolerate a lot in that first three years, even though that treatment was so harsh, I was willing to do that, that sort of considerations for me then. Then, as we've moved along, it's been more about quality of life, how can I maximize my quality of life so that I can be a mom, so that I can kick a football with my son, so that I can watch a movie with my daughter and take her out for a milkshake, on a ride on their bike [unintelligible] Being able to do things and have a good quality of life that enabled me to not only live but to live well.
Participant 015_2023AULUC

Look, there's a few. Very much my relationship, the impact it's going to have on the adult, but my adult children and my partner. It's got to be manageable for them and not distressing for them what I do as well. Very much my cognitive functioning. That is one thing I'm very scared of losing, and quality of life. Quality of life is to me more important to be enjoying life and participating in a way that I want to, even if it's limited, but in a way that I find comfortable rather than just being alive for being alive sake.
Participant 020_2023AULUC

Participant describes taking cost into account when making decisions about treatment

Quality of life, how long the treatment will last, how much the treatment will cost and whether I can have it locally or if I have to travel. Those type of decisions.
Participant 007_2023AULUC

It's a little bit hypothetical because I've only had one treatment, but I have talked about future treatments. I look at, in particular the updated website, which PROFESSOR is a co-contributor to, and that gathers all of the latest information on, in my case ALK. I would look at what performances had, what clinical trials have tested for, what the limitations of their conclusions might be, and what the cost of the treatment might be because we're very fortunate in Australia that in the tyrosine kinase inhibitor area, the key drugs that are already covered by PBS. It's a serious concern to me that I could end up thinking, "Well, the next treatment for me is something that's not on the PBS, and it's going to cost me and my family a huge amount." Just have my fingers crossed, that that doesn't occur. That's why being actively involved in sources of clinical trial information, that's TOGA especially, and connected to other things, it is useful to make me as fit a patient as I can be, for those discussions.
Participant 022_2023AULUC

Participant described that they were not given options and that their considerations not taken into account

I think the easiest way to answer that is I wasn't really given a decision about treatment. It was do you want surgery or do you not want surgery, so it's not really a decision is it? Do you want surgery? Do you want it out? [chuckles] There wasn't a choice between--
Participant 021_2023AULUC

Well, as I said, with this one I've got, my treatment options have been limited, so my choices have also been limited, but I guess for this drug side effects, but then if I don't take it, then I die, if I take it, I get a little bit sick. I guess––
Participant 006_2023AULUC

Table 4.5 Considerations when making decisions

Considerations when making decisions about treatment	**All participants**		**Person with lung cancer**		**Family member or carer**		**Non-metastatic**		**Metastatic**		**Female**		**Male**	
	n=26	**%**	**n=25**	**%**	**n=1**	**%**	**n=10**	**%**	**n=16**	**%**	**n=16**	**%**	**n=10**	**%**
Participant describes taking efficacy into account when making decisions about treatment (Total)	13	50.00	13	52.00	0	0.00	4	40.00	9	56.25	9	56.25	4	40.00
Participant describes taking efficacy into account as part of multiple aspects when making decisions about treatment	11	42.31	11	44.00	0	0.00	**3**	**30.00**	8	50.00	8	50.00	**3**	**30.00**
Participant describes taking efficacy into account as the only consideration when making treatment decisions	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	1	6.25	1	10.00
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	7	26.92	6	24.00	1	100.00	**4**	**40.00**	3	18.75	5	31.25	2	20.00
Participant describes taking the advice of their clinician into account as part of multiple aspects when making decisions about treatment	3	11.54	3	12.00	0	0.00	**3**	**30.00**	**0**	**0.00**	2	12.50	1	10.00
Participant describes taking the advice of their clinician into account as the only consideration when making treatment decisions	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes taking side effects into account when making decisions about treatment (Total)	6	23.08	6	24.00	0	0.00	**1**	**10.00**	5	31.25	4	25.00	2	20.00
Participant describes taking side effects into account as part of multiple aspects when making decisions about treatment	6	23.08	6	24.00	0	0.00	**1**	**10.00**	5	31.25	4	25.00	2	20.00
Participant describes taking side effects into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account when making decisions about treatment (Total)	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes taking their own research into account as part of multiple aspects when making decisions about treatment	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Participant describes taking their own research into account as the only consideration when making treatment decisions	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	1	6.25	0	0.00
Participant describes taking quality of life into account when making decisions about treatment (Total)	4	15.38	4	16.00	0	0.00	**0**	**0.00**	4	25.00	4	25.00	**0**	**0.00**
Participant describes taking quality of life into account as part of multiple aspects when making decisions about treatment	4	15.38	4	16.00	0	0.00	**0**	**0.00**	4	25.00	4	25.00	**0**	**0.00**
Participant describes taking quality of life into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes taking cost into account as part of multiple aspects when making decisions about treatment	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes taking cost into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options and that their considerations not taken into account (Total)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes that they were not given options and that their considerations not taken into account, but described other considerations that were important to them when making decisions about treatment	2	7.69	2	8.00	0	0.00	0	0.00	2	12.50	2	12.50	0	0.00
Participant describes that they were not given options and that their considerations not taken into account	1	3.85	1	4.00	0	0.00	1	10.00	0	0.00	0	0.00	1	10.00

Considerations when making decisions about treatment	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes taking efficacy into account when making decisions about treatment (Total)	13	50.00	8	47.06	5	55.56	5	38.46	8	61.54	2	100.00	11	45.83	4	44.44	9	52.94
Participant describes taking efficacy into account as part of multiple aspects when making decisions about treatment	11	42.31	7	41.18	4	44.44	4	30.77	7	53.85	2	100.00	9	37.50	4	44.44	7	41.18
Participant describes taking efficacy into account as the only consideration when making treatment decisions	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	7	26.92	3	17.65	4	44.44	4	30.77	3	23.08	1	50.00	6	25.00	2	22.22	5	29.41
Participant describes taking the advice of their clinician into account as part of multiple aspects when making decisions about treatment	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76
Participant describes taking the advice of their clinician into account as the only consideration when making treatment decisions	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes taking side effects into account when making decisions about treatment (Total)	6	23.08	3	17.65	3	33.33	4	30.77	2	15.38	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes taking side effects into account as part of multiple aspects when making decisions about treatment	6	23.08	3	17.65	3	33.33	4	30.77	2	15.38	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes taking side effects into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking their own research into account when making decisions about treatment (Total)	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes taking their own research into account as part of multiple aspects when making decisions about treatment	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes taking their own research into account as the only consideration when making treatment decisions	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	0	0.00	1	4.17	0	0.00	1	5.88
Participant describes taking quality of life into account when making decisions about treatment (Total)	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes taking quality of life into account as part of multiple aspects when making decisions about treatment	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes taking quality of life into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes taking cost into account when making decisions about treatment (Total)	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes taking cost into account as part of multiple aspects when making decisions about treatment	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes taking cost into account as the only consideration when making treatment decisions	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00	0	0.00
Participant describes that they were not given options and that their considerations not taken into account (Total)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes that they were not given options and that their considerations not taken into account, but described other considerations that were important to them when making decisions about treatment	2	7.69	2	11.76	0	0.00	1	7.69	1	7.69	1	50.00	1	4.17	2	22.22	0	0.00
Participant describes that they were not given options and that their considerations not taken into account	1	3.85	1	5.88	0	0.00	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

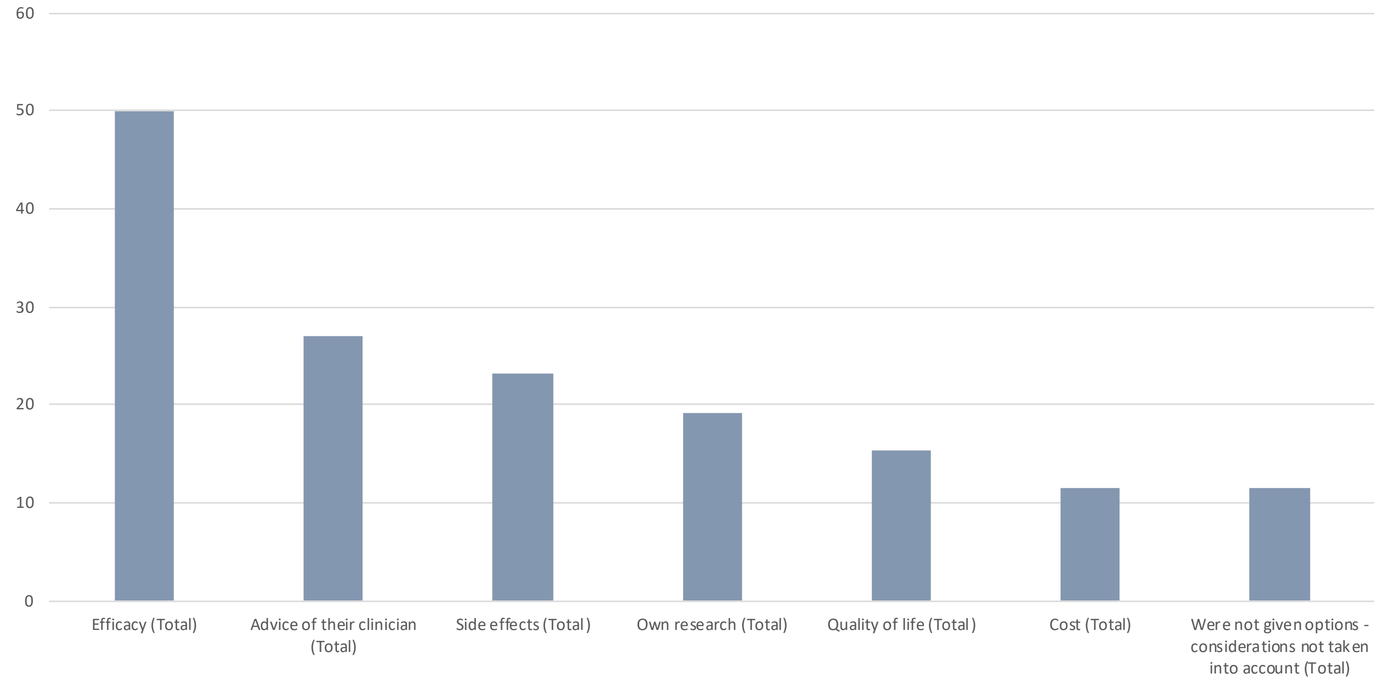


Figure 4.3 Considerations when making decisions

Table 4.6: Considerations when making decisions – subgroup variations

Theme	Less frequently	More frequently
Participant describes taking efficacy into account when making decisions about treatment (Total)	Trade or high school	University
Participant describes taking the advice of their clinician into account when making decisions about treatment (Total)	-	Non-metastatic Aged 65 or older
Participant describes taking side effects into account when making decisions about treatment (Total)	Non-metastatic	Aged 65 or older
Participant describes taking quality of life into account when making decisions about treatment (Total)	Non-metastatic Male Aged 65 or older	-
Participant describes taking cost into account when making decisions about treatment (Total)	Aged 65 or older Mid to low status	
Participant describes that they were not given options and that their considerations not taken into account (Total)	Aged 65 or older	Mid to low status

Decision-making over time

Participants were asked if the way they made decisions had changed over time. The most common responses were that they had not changed the way they made decisions (42.31%), followed by not changing the way they made decisions (38.46%).

Where participants had changed the way they make decisions, the most common reason was that they had become more informed and/or more assertive (30.77%). Where participants had not changed the way they make decisions, the most common reason was that they had always taken advice of clinicians (11.54%).

Participant describes decision-making changing over time as they are more informed and/or more assertive

I'm more of an advocate. Like, I won't take, "No, nothing's wrong." I kind of go, "No, I will go to somebody who I can see immediately." I have changed. I'm a bit more determined to get answers.
Participant 004_2023AULUC

No, it's totally changed. The more [crosstalk] you have and the more knowledge you have, the more informed your decisions are.
Participant 007_2023AULUC

I've got more information now. I can ask more questions.
Participant 010_2023AULUC

Basically, I was a bit in a state of panic where I didn't think very clearly. Plus, I have never dealt with health providers previously and I had this naive approach that they know best. I was not able to drive my care. I didn't have enough knowledge. Now I can.
Participant 023_2023AULUC

Participant describes no change in decision-making over time as they have always taken advice of clinicians

Oh no, I approach it the same way. Like he picked the first one for me and I'm happy with that. That's going to change at some point. At some point, we're going to have to sit down and say, "Right, what's next?" We'll just wait and then we'll make those decisions.
Participant 002_2023AULUC

Not really. I've put my trust in my oncologist and I've had good results up until now. I've followed through what he suggested.
Participant 005_2023AULUC

Table 4.7: Decision-making over time

Decision making over time	All participants n=26	%	Person with lung cancer n=25	%	Family member or carer n=1	%	Non-metastatic n=10	%	Metastatic n=16	%	Female n=16	%	Male n=10	%
Participant describes the way they make decisions not changing over time	11	42.31	11	44.00	0	0.00	5	50.00	6	37.50	8	50.00	3	30.00
Participant describes no change in decision-making over time as they have always taken advice of clinicians	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes no change in decision-making but does not mention any reason	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Participant describes the way they make decisions changing over time	10	38.46	9	36.00	1	100.00	2	20.00	8	50.00	8	50.00	2	20.00
Participant describes decision-making changing over time as they are more informed and/or more assertive	8	30.77	8	32.00	0	0.00	2	20.00	6	37.50	7	43.75	1	10.00
No particular comment (Other/no response)	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00

Decision making over time	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes the way they make decisions not changing over time	11	42.31	7	41.18	4	44.44	**7**	**53.85**	**4**	**30.77**	1	50.00	10	41.67	**5**	**55.56**	6	35.29
Participant describes no change in decision-making over time as they have always taken advice of clinicians	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes no change in decision-making but does not mention any reason	3	11.54	1	5.88	**2**	**22.22**	**3**	**23.08**	**0**	**0.00**	0	0.00	3	12.50	**2**	**22.22**	1	5.88
Participant describes the way they make decisions changing over time	10	38.46	5	29.41	**5**	**55.56**	5	38.46	5	38.46	0	0.00	10	41.67	**2**	**22.22**	8	47.06
Participant describes decision-making changing over time as they are more informed and/or more assertive	8	30.77	4	23.53	**4**	**44.44**	4	30.77	4	30.77	0	0.00	8	33.33	2	22.22	6	35.29
No particular comment (Other/no response)	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	1	50.00	4	16.67	2	22.22	3	17.65

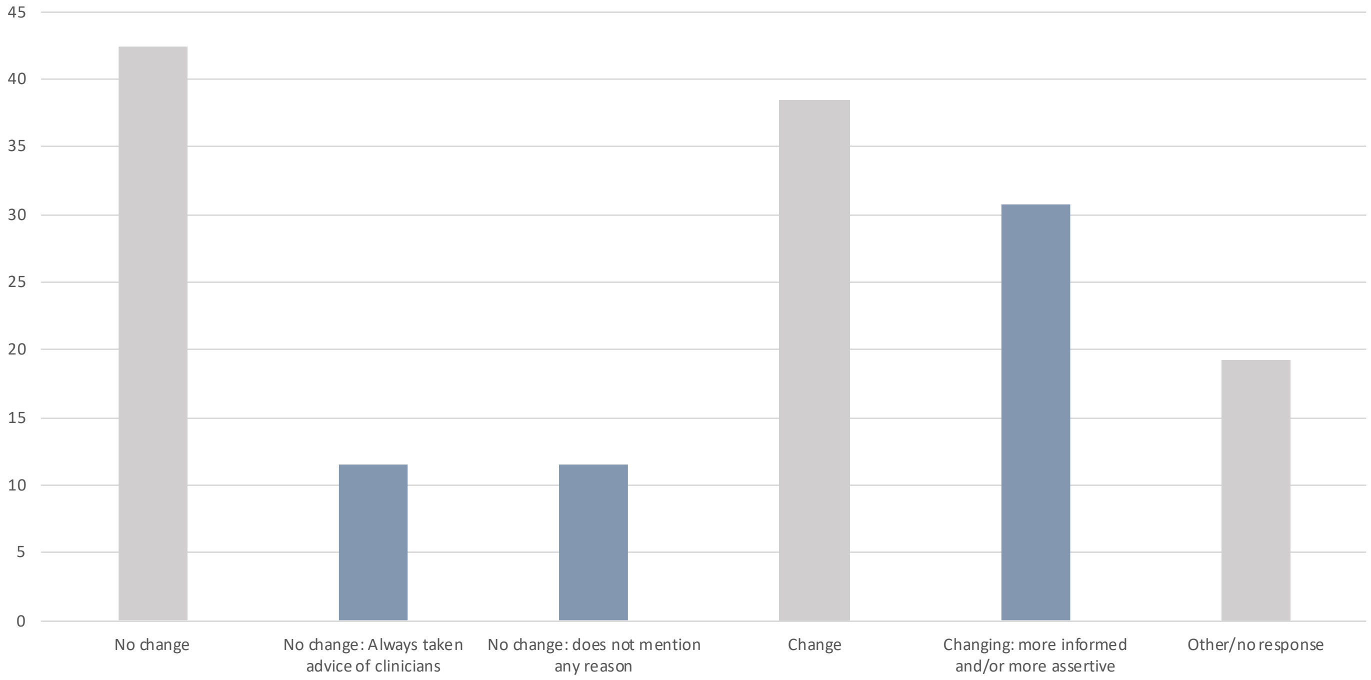


Figure 4.4: Decision-making over time

Table 4.8: Decision-making over time – subgroup variations

Theme	Less frequently	More frequently
Participant describes the way they make decisions not changing over time	Male University	Trade or high school Mid to low status
Participant describes the way they make decisions changing over time	Non-metastatic Male Mid to low status	Metastatic Female Aged 65 or older

Personal goals of treatment or care

Participants were asked what their own personal goals of treatment or care were. The most common response was to be cancer free, to avoid recurrence, or increase longevity (38.46%).

Other themes treatment goals included minimising or avoiding side effects (26.92%), quality of life, or return to normality (23.08%), and some wanted improvements in the communication and information about treatment they received from their doctor (15.38%)

Participants describe wanting to be cancer free, avoid recurrence or increase longevity

I want to stay alive. I want the best treatment that would keep me alive.
Participant 007_2023AULUC

Yes, definitely-- Obviously, I want to live longer. I want to live as long as I possibly can and that was one of the treatment decisions that we made. We switched for that reason, that would then also help to promote better quality of life, potentially. When I say potentially, it's a bit of a convoluted way of answering because I was on a targeted therapy, and was starting to show signs of progression over a 12-month period. We treated a lesion and I continued on the treatment, we treated another lesion, and I wanted to continue

on that treatment. My doctor said to me, I would rather switch treatments now and give you the best possible coverage we can versus you stay on this treatment, potentially progress again, that we don't know what physical limitations it may then lead to long term. So it's living long with a good quality of life. The side effects were also a plus to this type of treatment, so I was initially not keen to it but we've switched because of that.
Participant 015_2023AULUC

My own goal? To get better. To be cancer free. To do everything I could within my power to improve how I was living my life. If there was any steps I could take to change things and to end up with a cancer-free diagnosis. I viewed every stage of my treatment, as hard as it was, I just went, "I'm one step closer to being cancer-free." That's all I kept saying in my head. I'm one step closer to cancer free. I worked in small increment but incremental goals of getting myself cancer free.
Participant 018_2023AULUC

Participant describes wanting to minimise or avoid side effects of treatment for their condition

For me to be pain-free. That's one of the goals and to try and avoid progression in the central nervous system. That's the second goal. Pain-free is one, and then central nervous system is the second goal.
Participant 023_2023AULUC

PARTICIPANT: Oh, yes. I have, yes. I had to avoid, especially during the chemo, I had to avoid the nausea because I used to get terrible nausea with [crosstalk]. I really don't like chemo. I don't think I'd ever have it again. Nausea, and also sent me into a mental spiral where I got very depressed. I lost a lot of weight. I lost the will to live especially.
Participant 024_2023AULUC

PARTICIPANT: I don't mind, I can tell you. My first thing is I try and reduce the side effects of the medication I'm on. I try to start-- The situation is that my oncologist has not ever treated anyone with my cancer and the medication is new. It's new medication and he doesn't really understand it. He's like, "If the side effects are too much, I'll put you on a lower dose." I don't want to go on a lower dose, but as he says to me, "I'm here for your cancer. Anything else that's going on, you have to see your GP." I go to my GP and my GP is like, "I've never even heard of this treatment, it's all very new and I don't know what you can do."
Participant 027_2023AULUC

Participant describes wanting to improve their quality of life or return to normality

I don't know. Look, I'm just living. I'm not thinking about it too much. In the first, probably, year because I'm only 15 months, 16 months in. First-year, you wake up every morning it's the first thing you'd think about and it was the last thing you thought about when you went to bed. That's not happening now. It's a part of me and it's part of our life, so we're just getting on with it.
Participant 002_2023AULUC

PARTICIPANT: It's hard to say because I don't know if it's realistic to want to be back to normal because I don't know anybody in this situation. I don't know if that is a realistic goal. At the moment, I'm post eight weeks up. Whilst the operation was good and so was the post-recovery, I have had quite a bit of soreness. It's made me reluctant to do certain things like picking up my grandkids. The surgeon said to me at the postoperative interview, don't lift anything over five kilos. He intimated that was for six to eight weeks after the op. I'm only just now starting to feel confident that I could maybe do that and maybe get back into some gardening and maybe pull my weight in around the house with the housework. Is that the sort of things you meant? The one thing that I did do straight away, we always walked for exercise. When I got back home from the hospital, we got back into that straight away. Obviously, it was slower to start with, but I do think that helped me with my recovery that I was active and moving.
Participant 010_2023AULUC

My own personal goal is to maximize my quality of life, not the quantity. I'm not a person who will go for any treatment just for the sake of a few more weeks or months if it's going to mean those weeks and months don't give me quality of life. For me, that is maintaining relationships with my family. I'm willing to lose a little bit of independence. Absolutely autonomous at the moment, but they will become-- Cognitively, it's very important that I'm cognitively okay. I wouldn't do treatment if I thought it meant a huge cognitive decline and that would affect my relationships. I don't want to do treatment which means my family are seeing me so incapacitated that it's distressing to them even though I'm alive because that's not life for me.
Participant 020_2023AULUC

Participant describes wanting better communication and information from their doctor about their treatment and disease status

I just want something done. I'd be happy if I knew what their plan was, if they had a plan. I want to get back to work. I can't work at the moment because of the symptoms. I would just be happy if I knew what was happening.
Participant 003_2023AULUC

Long-term is to be given information which I think is very hard to extract from people. Approachability, to be able to actually have access to-- I went private, which I'm not too sure is such the best thing to do. To have access to somebody when you need them when things are going pear-shaped. I'm on targeted therapy now, which I'm having to pay for myself, which is I don't know if you know how much it costs, but it's a freaking arm and a leg. I think there should be some campaign or some interest in having the treatment put on the PBS. I don't understand why people who don't have the metastases are not able to access the treatment that will prevent me from getting metastases. I don't get that, and I don't understand why there isn't any campaigning for it.
Participant 025_2023AULUC

It's not a goal, but I found that the oncologist that he sees is way too brief, does not explain things. I find myself looking to Google, which is not a good thing, to try and research what things mean, but apparently, that's a common occurrence with certain oncologists and dad doesn't want to change.
Participant 030_2023AULUC

Table 4.9: Personal goals of treatment or care

Personal goals of treatment	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	10	38.46	10	40.00	0	0.00	6	60.00	4	25.00	7	43.75	3	30.00
Participant describes wanting to minimise or avoid side effects of treatment for their condition	7	26.92	7	28.00	0	0.00	1	10.00	6	37.50	4	25.00	3	30.00
Participant describes wanting to improve their quality of life or return to normality	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	1	10.00
Participant describes wanting better communication and information from their doctor about their treatment and disease status	4	15.38	3	12.00	1	100.00	2	20.00	2	12.50	2	12.50	2	20.00

Personal goals of treatment	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	10	38.46	9	52.94	1	11.11	3	23.08	7	53.85	0	0.00	10	41.67	2	22.22	8	47.06
Participant describes wanting to minimise or avoid side effects of treatment for their condition	7	26.92	3	17.65	4	44.44	5	38.46	2	15.38	0	0.00	7	29.17	1	11.11	6	35.29
Participant describes wanting to improve their quality of life or return to normality	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	0	0.00	6	25.00	0	0.00	6	35.29
Participant describes wanting better communication and information from their doctor about their treatment and disease status	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	1	50.00	3	12.50	1	11.11	3	17.65

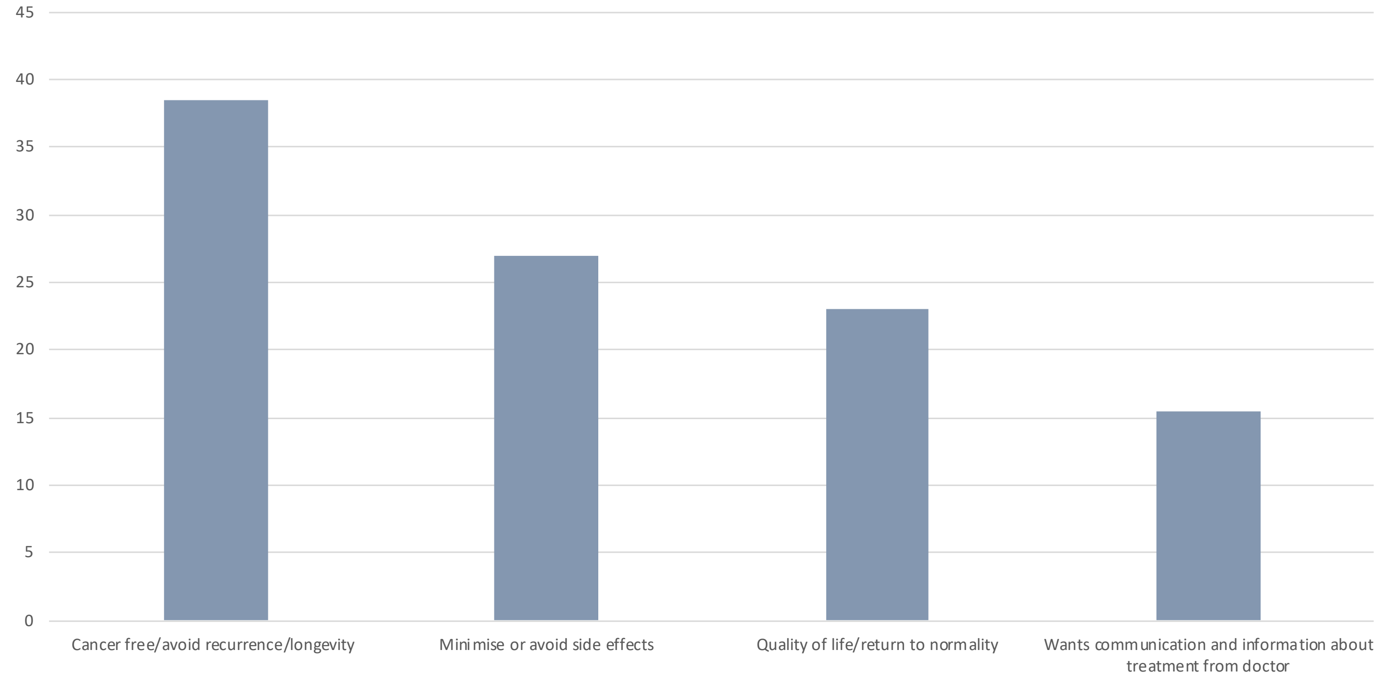


Figure 4.5: Personal goals of treatment or care

Table 4.10: Personal goals of treatment or care – subgroup variations

Theme	Less frequently	More frequently
Participants describe wanting to be cancer free, avoid recurrence or increase longevity	Metastatic Aged 65 or older Trade or high school Mid to low status	Non-metastatic Aged 35 to 64 University
Participant describes wanting to minimise or avoid side effects of treatment for their condition	Non-metastatic University Mid to low status	Metastatic Aged 65 or older Trade or high school
Participant describes wanting to improve their quality of life or return to normality	Male Mid to low status	Higher status

Section 5

Treatment

Section 5: Experience of treatment

Main provider of treatment

The most common provider of treatment and care were medical oncologists (n=21, 72.41 %), followed by radiation oncologists (n=4, 13.79%) (

Access to healthcare professionals

The majority of participants had access to a medical Oncologist (n=23, 85.19%), a respiratory physician (n=21, 77.78%) and a General Practitioner (n=22, 81.48%). Less than a third (n=8, 29.63%) had access to a lung cancer nurse. A third of participants (n=9, 33.33%) had counselling or psychological support.

Respect shown

There were 14 participants (51.85%) that indicated that they had been treated with respect throughout their experience, and 9 participants (33.33%) that were treated with respect with the exception of one or two occasions. There were 4 participants (14.81%) that felt they had not been treated respectfully (Table 5.3, Figure 5.3).

Health care system

The majority of participants had private health insurance (n=16, 59.26%). Throughout their treatment, there were 11 participants (40.74%) that were treated as a private patient, 14 participants (51.85%) were mostly treated as a public patient, and there were 2 participants (7.41%) that were equally treated as a private and public patient.

Throughout their treatment, there were 10 participants (37.04%) that were treated mostly in the private hospital system, 12 participants (44.44%) were mostly treated in the public system, and there were 5 participants (18.52%) that were equally treated in the private and public systems.

Affordability of healthcare

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 22, 81.48%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=25, 92.59%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 22 participants (81.48%) that never or rarely had trouble paying for essentials, and 2 participants (7.41%) that sometimes found it difficult, and 3 participants (11.11%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 4 participants (14.81%) that paid for additional carers due to their condition.

Cost of condition

Participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. The most common amount was between $1 to 100 (n=7, 25.93%), followed by between $251 to 500 (n=5, 18.52%). There were 3 participants (11.11%), that spent More than $1000 a month.

Changes to employment status

Work status for 3 participants (11.11%) had not changed since diagnosis, and 5 participants (18.52%) were retired or did not have a job. There were 8 participants (29.63%) had to quit their job, 9 participants (33.33%) reduced the number of hours they worked, and 3 participants (11.11%) that accessed their superannuation early. There were 2 participants (7.41%) that took leave from work without pay, and 5 participants (18.52%) that took leave from work with pay.

Changes to carer/partner employment status

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=14, 51.85%), and there were 8 partners (29.63%) or carers that were retired or did not have a job. There were 4 participants (14.81%) whose partners reduced the numbers of hours they worked, and 1 partner (3.70%) that quit their job. The partners of 2 participants (7.41%) took leave without pay, and there were 4 partners (14.81%) that took leave with pay.

Reduced income due to condition

More than half of the participants (n=13, 48.15%) indicated in the online questionnaire that they had a reduced family income due to their condition. Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 29.41%), or reduced by between More than $5000 per month (n=5, 29.41%).

Summary of treatments

There were 12 participants (41.38%) that had surgery, 12 participants (44.44%) that had chemotherapy, 15 participants (55.56%) that had immunotherapy, 10 participants (37.04%) that had radiotherapy, 2 participants (7.41%) that had taken part in clinical trials, and 2 participants (7.41%) that had no treatment. There were 12 participants (41.38%) that had surgery for their condition (excluding biopsies). There were 9 participants (31.03%) that had one operation, 3 participants (10.34%) that had two operations

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Quality of life ranged between 2.00 and 5.00 for all treatments, in the life was distressing to life was good range. Quality of life was in the life was distressing range for surgery to remove lymph nodes, and for cisplatin (Median =2.00). Quality of life was in the life was distressing to a little distressing range for radiotherapy, and was in the life was a little distressing (Median =3.00) range for lobectomy and Wedge resection, Segmentectomy or Sleeve resection. Quality of life for both immunological treatments, Tagrisso and Alectinib was in the life was good range (median=5.0).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Participants on average found all types of surgery (lobectomy, Wedge resection, Segmentectomy or Sleeve resection, and lymph node resection) to be very effective (median =5.00), and all types of immunotherapy (Tagrisso and Alectinib) to be very effective (median = 5.00). Cisplatin was found to be moderately effective (median =3.00), and radiotherapy somewhat to moderately effective (median = 2.75).

Clinical trials discussions

There was a total of 11 participants (40.74%) that had discussions about clinical trials, 5 participants (18.52%) had brought up the topic with their doctor, and the doctor of 6 participants (22.22%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=16, 59.26%).

Clinical trial participation

There were 2 participants (7.41%) that had taken part in a clinical trial, 22 participants (81.48%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (11.11%).

Description of mild side effects

In the structured interview, participants were asked how they would describe the term ‘mild side effects’. The most common response was using a specific example to describe mild side effects (69.23%). Other descriptions of mild side effects were those that do not interfere with life(46.15%), and those that can be managed with self-medication or self-management (Over-the-counter) (30.77 %).

When a specific side effect was described, the most common responses were aches/pain (general) (23.08%), skin rash or itch (23.08%), and gastrointestinal distress (19.23 %). Other examples included fatigue/lethargy (11.54%), and being short of breath (11.54%)

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’.
The most common response was using a specific example to describe severe side effects (61.54%), followed by side effects that impact everyday life/ability to conduct activities of daily living (38.46%).

When a specific side effect was described, the most
The most common examples were being short of breath (15.38%), having general aches and pains (11.54%), and the emotional or mental impact (11.54 %).

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime. The most common responses were that they did not give up on any treatment (34.62%), and as long as side effects are tolerable (23.08%). Other themes included the advice of their specialist, or as long as prescribed (19.23%), adhering to treatment for a specific amount of time (19.23%), and being unable to answer as they had not had treatment or cannot answer hypothetical question (11.54%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months.

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were seeing evidence of stable disease or no disease progression (57.69%), and seeing reduction of physical signs and symptoms (19.23%).

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described. The most common responses were allowing them to do everyday activities and return to normal life (23.08%), leading to a reduction in symptoms orside effects (19.23%), and allowing them to engage more with social activities and family life (15.38 %). Other themes included allowing them to return to work (11.54%), allowing them to do domestic tasks (11.54%), allowing them to do more exercise (11.54%), and that it would have a positive impact on their mental health (11.54%).

Main provider of treatment

Participants were asked in the online questionnaire who was the main healthcare professional that provided treatment and management of their condition.

The most common provider of treatment and care were medical oncologists (n=21, 72.41 %), followed by radiation oncologists (n=4, 13.79%) (Table 5.1, Figure 5.1).

Table 5.1: Main provider of treatment

Main provider of treatment	Number (n=29)	Percent
Medical oncologist	21	72.41
Radiation oncologist	4	13.79
Respiratory specialist	2	6.90
Surgeon	2	6.90
General practitioner	1	3.45

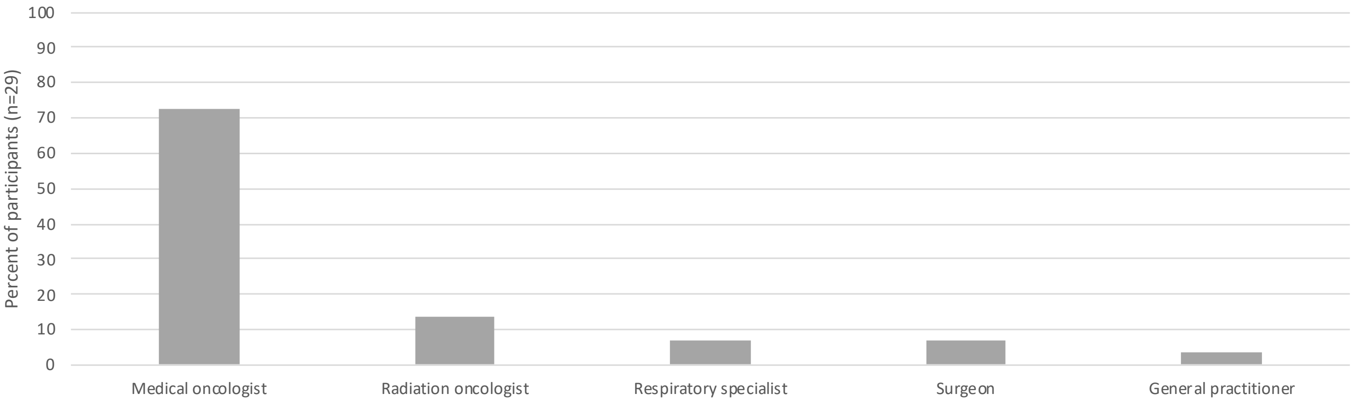


Figure 5.1: Main provider of treatment

Access to healthcare professionals

Participants noted in the online questionnaire the healthcare professionals they had access to for the treatment and management of their condition.

The majority of participants had access to a medical Oncologist (n=23, 85.19%), a respiratory physician (n=21, 77.78%) and a General Practitioner (n=22, 81.48%). Less than a third (n=8, 29.63%) had access to a lung cancer nurse. A third of participants (n=9, 33.33%) had counselling or psychological support. (Table 5.2, Figure 5.2)

Table 5.2: Access to healthcare professionals

Healthcare professional	Number (n=27)	Percent
Medical Oncologist	23	85.19
Respiratory physician	21	77.78
Surgeon	15	55.56
Radiation oncologist	10	37.04
Psychiatrist	1	3.70
General Practitioner	22	81.48
Lung cancer nurse	8	29.63
Registered Nurse	8	29.63
Counselling or psychological support	9	33.33
Dietitian	6	22.22
Physiotherapy	6	22.22
Podiatrist	1	3.70
Genetic counsellor	1	3.70
Occupational therapy	1	3.70
Other	4	14.81

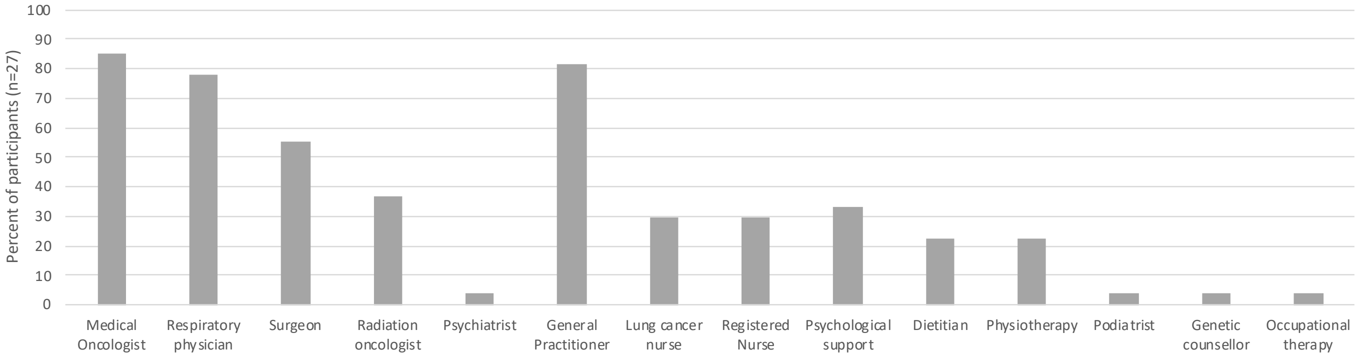


Figure 5.2: Access to healthcare professionals

Respect shown

Participants were asked to think about how respectfully they were treated throughout their experience, this question was asked in the online questionnaire.

There were 14 participants (51.85%) that indicated that they had been treated with respect throughout their experience, and 9 participants (33.33%) that were treated with respect with the exception of one or two occasions. There were 4 participants (14.81%) that felt they had not been treated respectfully (Table 5.3, Figure 5.3).

Table 5.3: Respect shown

Respect shown	Number (n=27)	Percent
Respect shown	14	51.85
Respect shown, with the exception of one or two occasions	9	33.33
Respect not shown	4	14.81

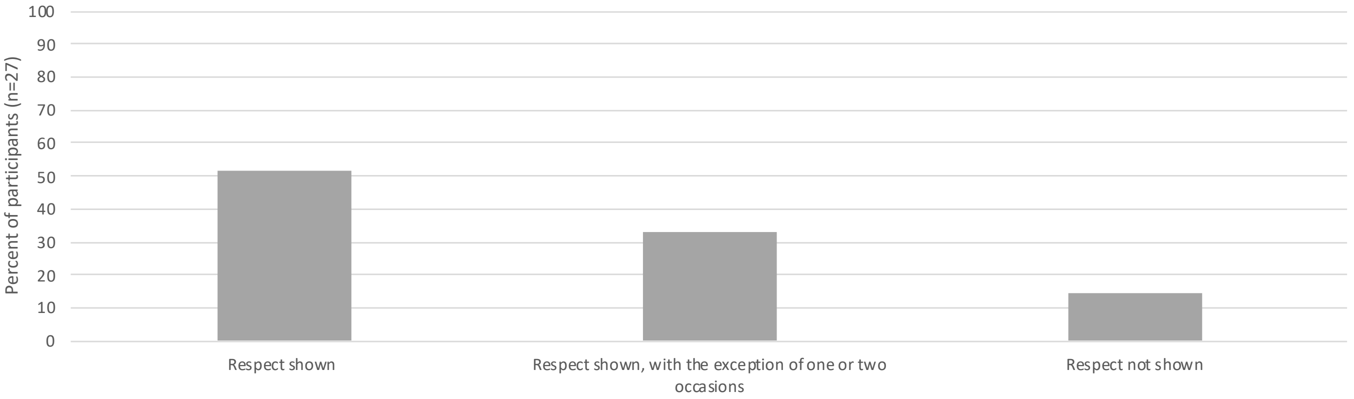


Figure 5.3: Respect shown

Health care system

In the online questionnaire, participants were asked questions about the healthcare system they used, about private insurance and about whether they were treated as a public or private patient (Table 5.4, Figures 5.4 and 5.5).

The majority of participants had private health insurance (n=16, 59.26%). Throughout their treatment, there were 11 participants (40.74%) that were treated as a private patient, 14 participants (51.85%) were mostly treated as a public patient, and there were 2 participants (7.41%) that were equally treated as a private and public patient.

Throughout their treatment, there were 10 participants (37.04%) that were treated mostly in the private hospital system, 12 participants (44.44%) were mostly treated in the public system, and there were 5 participants (18.52%) that were equally treated in the private and public systems.

Table 5.4: Health care system

Health care services	Response	Number (n=27)	Percent
Private health insurance	No	11	40.74
	Yes	16	59.26
Throughout your treatment in hospital, have you most been treated as a public or a private patient	Equally as a public and private patient	2	7.41
	Private patient	11	40.74
	Public patient	14	51.85
Which hospital system have you primarily been treated in	Both public and private	5	18.52
	Private	10	37.04
	Public	12	44.44

Figure 5.4: Health insurance

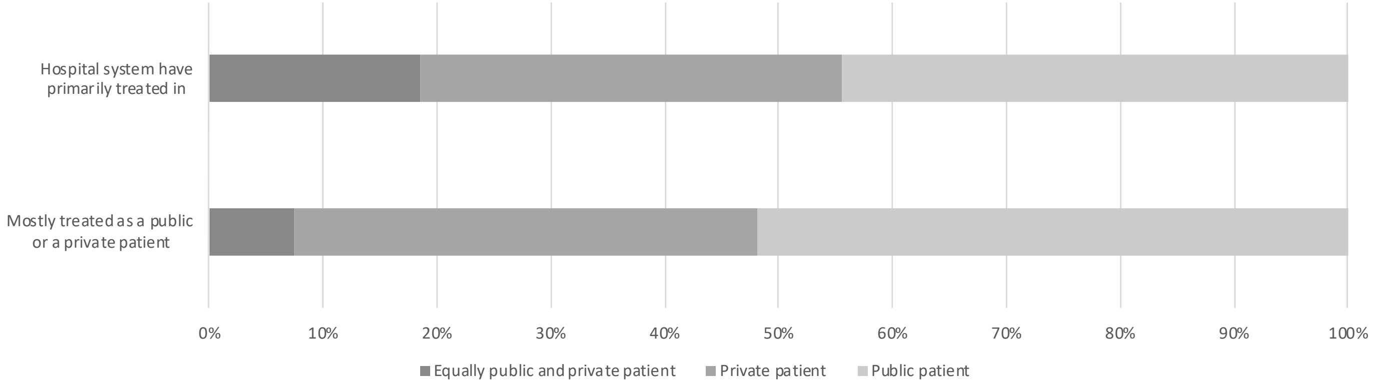


Figure 5.5: Hospital system

Affordability of healthcare

Participants were asked a series of questions about affordability of healthcare in the online questionnaire (Table 5.5, Figure 5.6).

The first question was about having to delay or cancer healthcare appointments because they were unable to afford them. Almost all the participants never or rarely had to delay or cancel appointments due to affordability (n = 22, 81.48%).

The next question was about the ability to fill prescriptions. Almost all of the participants never or rarely were unable to fill prescriptions (n=25, 92.59%).

The third question was about the affordability of basic essentials such as such as food, housing and power. There were 22 participants (81.48%) that never or rarely had trouble paying for essentials, and 2 participants (7.41%) that sometimes found it difficult, and 3 participants (11.11%) often or very often found it difficult to pay for basic essentials.

The final question was about paying for additional carers for themselves or for their family, there were 4 participants (14.81%) that paid for additional carers due to their condition.

Table 5.5: Affordability of healthcare

Health services and insurance	Response	Number (n=27)	Percent
Delay or cancel healthcare appointments due to affordability	Never	20	74.07
	Rarely	2	7.41
	Sometimes	4	14.81
	Often	1	3.70
	Very often	0	0.00
Did not fill prescriptions due to cost	Never	25	92.59
	Rarely	0	0.00
	Sometimes	1	3.70
	Often	1	3.70
	Very often	0	0.00
Difficult to pay for basic essentials	Never	15	55.56
	Rarely	7	25.93
	Sometimes	2	7.41
	Often	1	3.70
	Very often	2	7.41
Pay for additional carers for self or family	Yes	4	14.81
	No	23	85.19

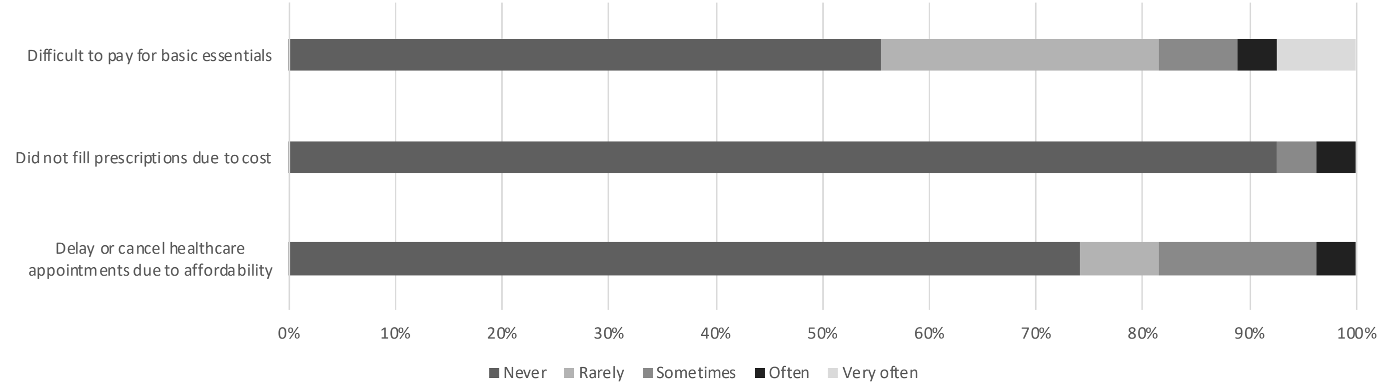


Figure 5.6: Affordability of healthcare

Cost of condition

In the online questionnaire, participants estimated the amount they spend per month due to their condition, including doctors' fees, transport, carers, health insurance gaps and complementary therapies. Where the response was given in a dollar amount, it is listed below (Table 5.6, Figure 5.7).

The most common amount was between $1 to 100 (n=7, 25.93%), followed by between $251 to 500 (n=5, 18.52%). There were 3 participants (11.11%), that spent More than $1000 a month.

Table 5.6: Estimated monthly out of pocket expenses due to condition

Estimated monthly out of pocket expenses	Number (n=27)	Percent
$0	4	14.81
$1 to 100	7	25.93
$101 to 250	3	11.11
$251 to 500	5	18.52
$501 to 1000	3	11.11
More than $1000	3	11.11
Not sure	2	7.41

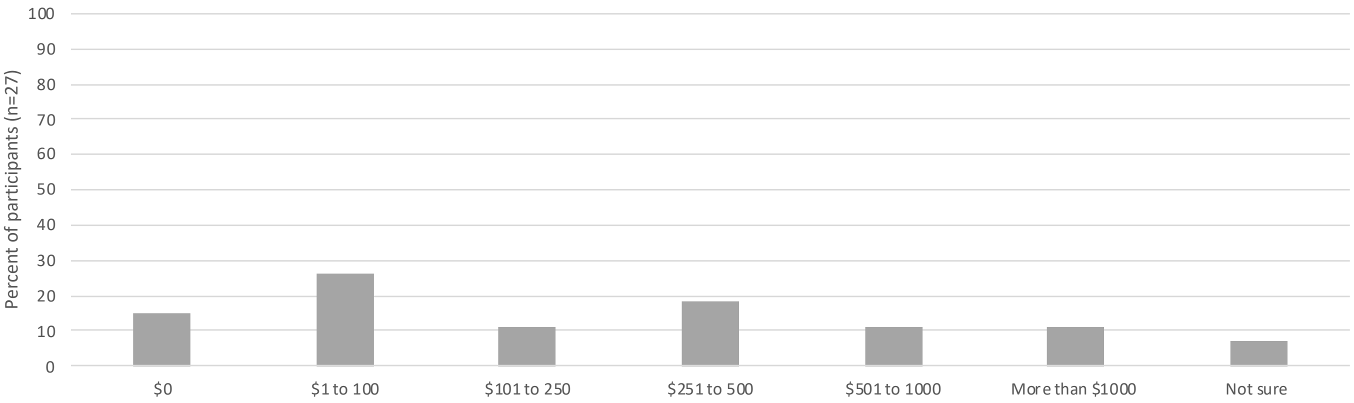


Figure 5.7: Estimated monthly out of pocket expenses due to condition

Changes to employment status

Participants were asked, in the online questionnaire, if they had any changes to their employment status due to their condition. Participants were able to choose multiple changes to employment (Table 5.7, Figure 5.8).

Work status for 3 participants (11.11%) had not changed since diagnosis, and 5 participants (18.52%) were retired or did not have a job. There were 8 participants (29.63%) had to quit their job, 9 participants (33.33%) reduced the number of hours they worked, and 3 participants (11.11%) that accessed their superannuation early. There were 2 participants (7.41%) that took leave from work without pay, and 5 participants (18.52%) that took leave from work with pay.

Changes to carer/partner employment status

Participants were asked, in the online questionnaire, if they had any changes to the employment status of their care or partner due to their condition. Participants were able to choose multiple changes to employment. (Table 5.8, Figure 5.9).

Most commonly, participants had partners or carers that did not change their work status due to their condition (n=14, 51.85%), and there were 8 partners (29.63%) or carers that were retired or did not have a job. There were 4 participants (14.81%) whose partners reduced the numbers of hours they worked, and 1 partner (3.70%) that quit their job. The partners of 2 participants (7.41%) took leave without pay, and there were 4 partners (14.81%) that took leave with pay.

Table 5.7: Changes to employment status

Changes in work status due to condition	Number (n=27)	Percent
Work status has not changed	3	11.11
Retired or did not have a job	5	18.52
Had to quit job	8	29.63
Reduced number of hours worked	9	33.33
Leave from work without pay	2	7.41
Leave from work with pay	5	18.52
Accessed Superannuation early due to condition	3	11.11

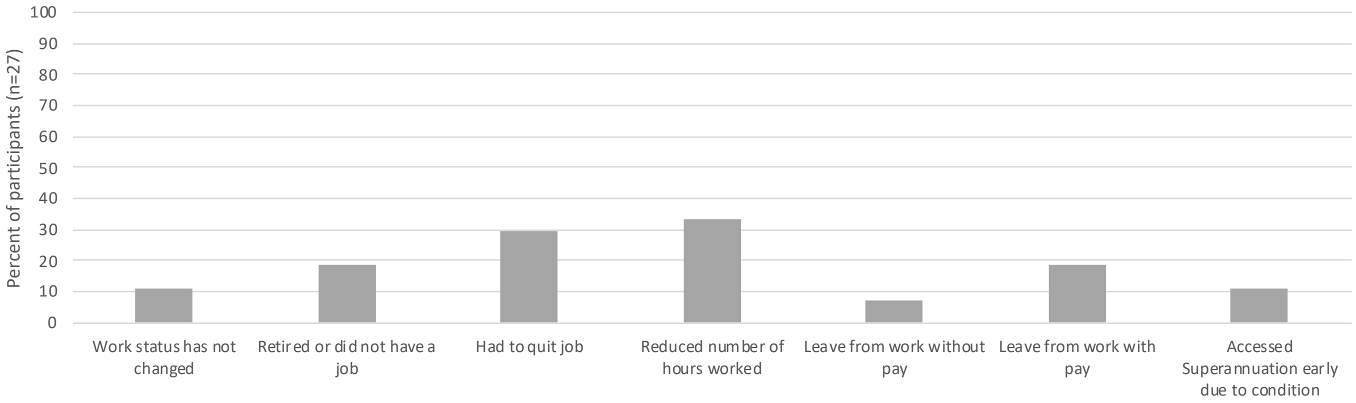


Figure 5.8: Changes to employment status

Table 5.8: Changes to care/partner employment status

Changes to care/partner employment status	Number (n=27)	Percent
Work status has not changed	14	51.85
Retired or did not have a job	8	29.63
Had to quit job	1	3.70
Reduced number of hours worked	4	14.81
Leave from work without pay	2	7.41
Leave from work with pay	4	14.81

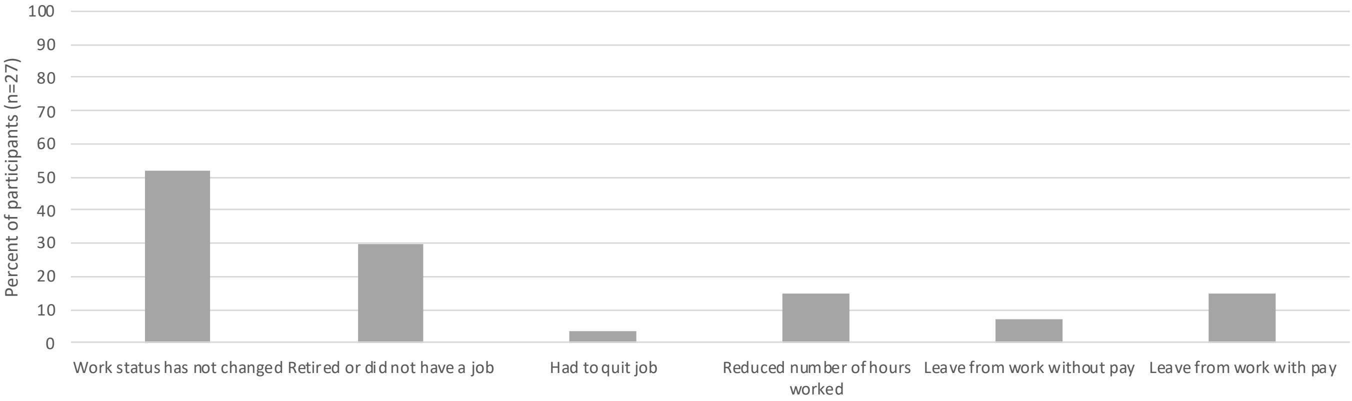


Figure 5.9: Changes to care/partner employment status

Reduced income due to condition

More than half of the participants (n=13, 48.15%) indicated in the online questionnaire that they had a reduced family income due to their condition.

Estimated reduction monthly income

As a follow up question, participants were asked if their family or household income had reduced due to their condition. Where a dollar amount was given, it is listed below (Table 5.9, Figure 5.10).

Most commonly, participants were not sure about the amount their monthly income was reduced by (n=5, 29.41%), or reduced by between More than $5000 per month (n=5, 29.41%).

Table 5.9: Estimated monthly loss of income

Estimated monthly loss of income	Number (n=17)	Percent
$0	4	23.53
$3000 to 5000	3	17.65
More than $5000	5	29.41
Not sure	5	29.41

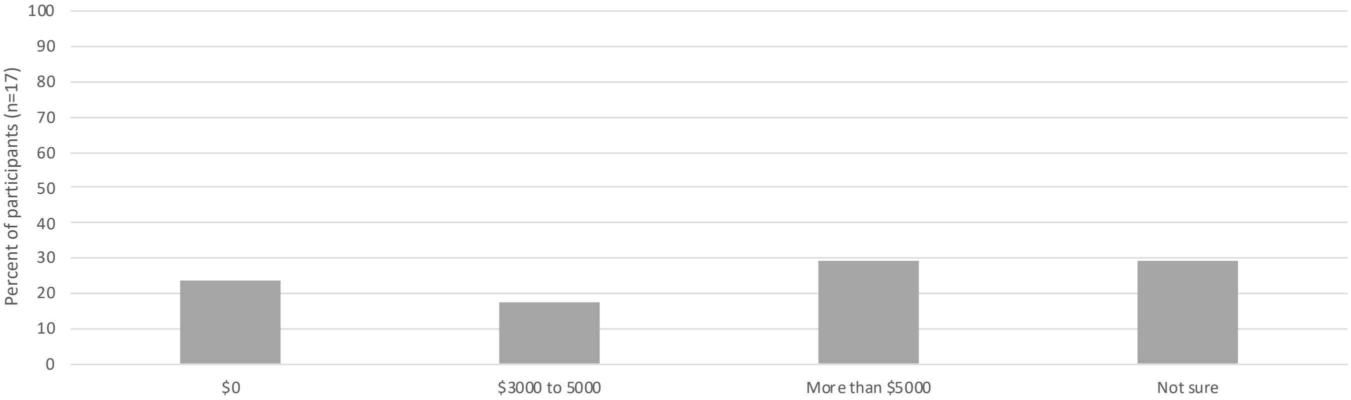


Figure 5.10: Estimated monthly loss of income

Summary of treatments

In the online questionnaire, participants noted the types of treatment they had for lung cancer, the side effects, their quality of life during treatment and rated how effective they found the treatments. All of the treatments noted in the online questionnaire are listed in Table 5.10 and Figure 5.11) Additional details about side effects, quality of life, and effectiveness are listed for treatments were more than 5 participants had used the treatment (Tables 5.10 to 5.14, Figures 5.12 and 5.13)

There were 12 participants (41.38%) that had surgery, 12 participants (44.44%) that had chemotherapy, 15 participants (55.56%) that had immunotherapy, 10 participants (37.04%) that had radiotherapy, 2 participants (7.41%) that had taken part in clinical trials, and 2 participants (7.41%) that had no treatment.

There were 12 participants (41.38%) that had surgery for their condition (excluding biopsies). There were 9 participants (31.03%) that had one operation, 3 participants (10.34%) that had two operations (Table 5.11, Figure 5.14).

Quality of life was rated on a Likert scale from one to seven, where one is “Life was very distressing” and seven is “Life was great”. Quality of life ranged between 2.00 and 5.00 for all treatments, in the life was distressing to life was good range.
Quality of life was in the life was distressing range for surgery to remove lymph nodes, and for cisplatin (Median =2.00). Quality of life was in the life was distressing to a little distressing range for radiotherapy, and was in the life was a little distressing (Median =3.00) range for lobectomy and Wedge resection, Segmentectomy or Sleeve resection. Quality of life for both immunological treatments, Tagrisso and Alectinib was in the life was good range (median=5.0).

Effectiveness of treatment was rated on a five-point scale where one is ineffective, and five is very effective. Participants on average found all types of surgery (lobectomy, Wedge resection, Segmentectomy or Sleeve resection, and lymph node resection) to be very effective (median =5.00), and all types of immunotherapy (Tagrisso and Alectinib) to be very effective (median = 5.00). Cisplatin was found to be moderately effective (median =3.00), and radiotherapy somewhat to moderately effective (median = 2.75).

Side effects from treatments are listed in Tables 5.12. to 5.14.

Table 5.10: Summary of treatments

Treatments overview	Number	Percent	Type of treatment	Number	Percent	Quality of life		Effectiveness	
						Median	IQR	Median	IQR
No treatment (n=27)	2	7.41	-	-	-	-	-	-	-
Surgery (n=29)	12	41.38	Lobectomy	10	34.48	3.00	1.00	5.00	0.75
			Wedge resection, Segmentectomy or Sleeve resection	5	17.24	3.00	1.00	5.00	2.00
			Surgery to remove lymph nodes	5	17.24	2.00	1.00	5.00	2.00
Chemotherapy (n=27)	12	44.44	Cisplatin	8	29.63	2.00	0.75	3.00	2.00
			Carboplatin	4	14.81	-	-	-	-
			Vinorelbine	3	11.11	-	-	-	-
			Paclitaxel	3	11.11	-	-	-	-
			Pemetrexed	3	11.11	-	-	-	-
			Etoposide and cisplatin	2	7.41	-	-	-	-
			Carboplatin and etoposide	2	7.41	-	-	-	-
			Pemetrexed and cisplatin	2	7.41	-	-	-	-
			Gemcitabine	1	3.70	-	-	-	-
Immunotherapy (n=27)	15	55.56	Tagrisso	7	25.93	5.00	0.50	5.00	0.25
			Alectinib	6	22.22	5.00	1.50	5.00	0.00
			Tarceva	3	11.11	-	-	-	-
			Crizotinib	2	7.41	-	-	-	-
			Certinib	1	3.70	-	-	-	-
			Lorlatinib	1	3.70	-	-	-	-
Radiotherapy (n=27)	10	37.04	-	-	-	2.50	2.00	2.75	3.00
Clinical trials (n=27)	2	7.41	-	-	-	-	-	-	-

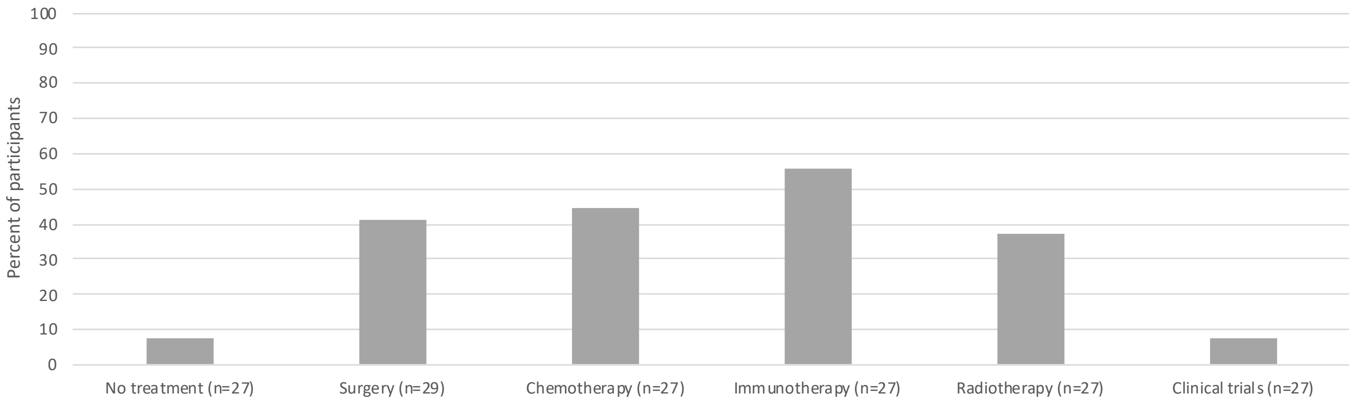


Figure 5.11: Summary of treatments

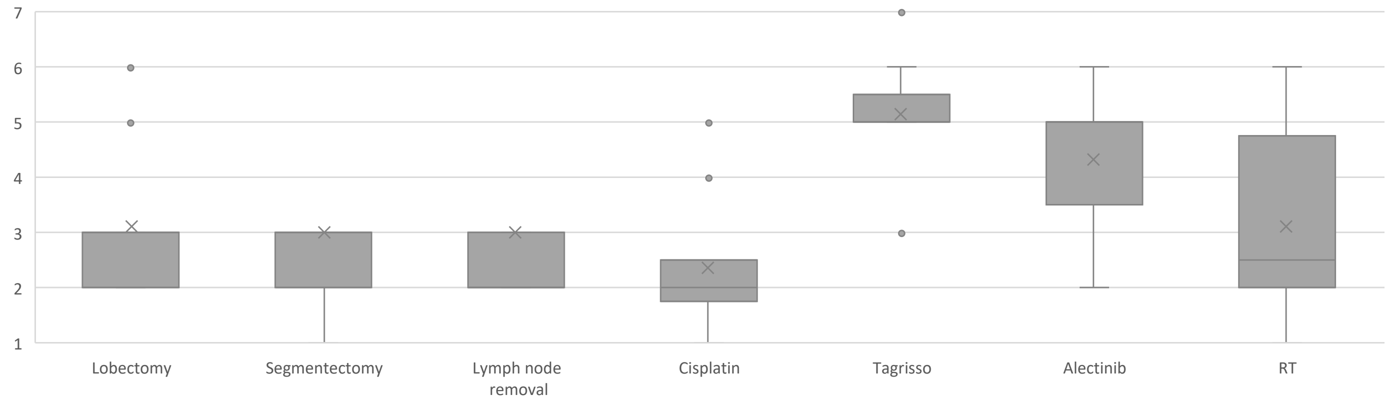


Figure 5.12: Quality of life from treatments

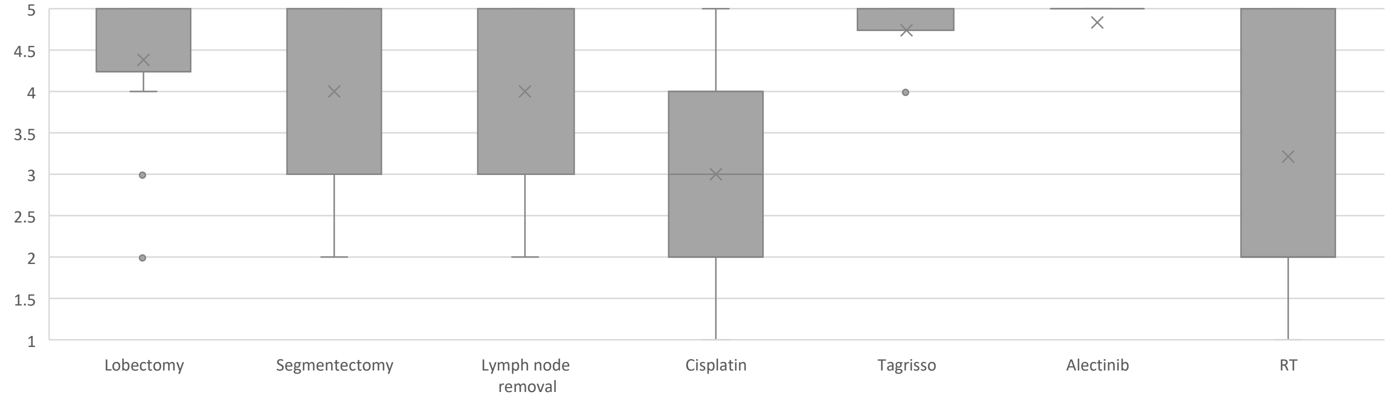


Figure 5.13: Effectiveness of treatments

Table 5.11: Number of surgeries

Number of operations (excluding biopsy)	Number (n=29)	Percent
0	17	58.62
1	9	31.03
2	3	10.34

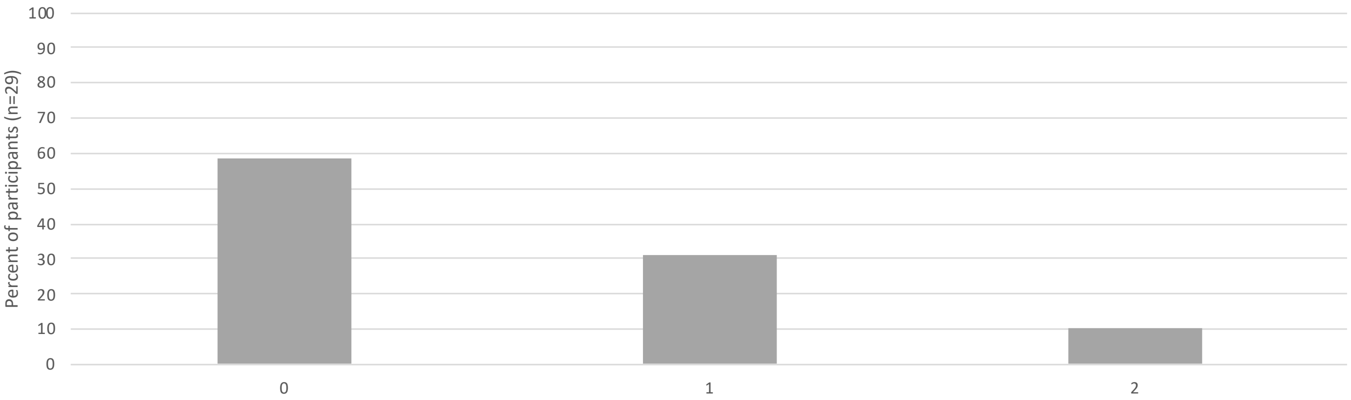


Figure 5.14: Number of surgeries

Table 5.12: Side effects from surgery

Side effects from surgery	Lobectomy		Wedge resection, Segmentectomy or Sleeve resection		Surgery to remove lymph nodes	
	n=10	Percent	n=5	Percent	n=5	Percent
No side effects	0	0.00	0		0	0.00
Pain	9	90.00	5	100.00	4	80.00
Breathlessness	5	50.00	2	40.00	3	60.00
Fatigue	5	50.00	3	60.00	3	60.00
Feeling generally unwell	2	20.00	1	20.00	0	0.00
Long term side effects	2	20.00	1	20.00	2	40.00
Swelling or redness around wound	2	20.00	2	40.00	3	60.00
Cough	1	10.00	0	0.00	1	20.00

Table 5.13: Side effects from drug treatments

Side effects from drug treatments	Cisplatin		Count of Tagrisso		Count of Alectinib	
	n=8		n=7		n=6	
No side effects	0	0.00	0	0.00	0	0.00
Anemia (low red blood cell counts)	4	50.00	0	0.00	1	16.67
Appetite changes	4	50.00	1	14.29	2	33.33
Changes in libido and sexual function	6	75.00	0	0.00	5	83.33
Chemo brain	5	62.50	2	28.57	4	66.67
Constipation	5	62.50	1	14.29	5	83.33
Diarrhoea	3	37.50	3	42.86	2	33.33
Easy bruising and bleeding	1	12.50	0	0.00	1	16.67
Fatigue	7	87.50	6	85.71	6	100.00
Hair loss	4	50.00	0	0.00	2	33.33
Infection	1	12.50	1	14.29	0	0.00
Mood changes	4	50.00	0	0.00	2	33.33
Mouth, tongue and throat problems	6	75.00	0	0.00	2	33.33
Nausea and vomiting	4	50.00	1	14.29	0	0.00
Nerve and muscle problems	4	50.00	2	28.57	4	66.67
Skin and nail changes	2	25.00	5	71.43	3	50.00
Urine and bladder changes and kidney problems	2	25.00	1	14.29	3	50.00
Weight changes	6	75.00	1	14.29	3	50.00

Table 5.14: Side effects from radiotherapy

Side effects from radiotherapy	Number (n=10)	Percent
No side effects	1	10.00
A type of swelling called lymphedema	1	10.00
Cough, fever and fullness of the chest	2	20.00
Dental probelms	1	10.00
Difficulty swallowing	3	30.00
Dry mouth	2	20.00
Fatigue	7	70.00
Mouth and gum sores	2	20.00
Nausea and vomiting	1	10.00
Radiation fibrosis which is permanent scarring of the lungs	1	10.00
Shortness of breath	3	30.00
Shoulder stiffness	1	10.00
Skin blistering or peeling	3	30.00
Skin dryness or itching	3	30.00

Clinical trials

Clinical trials discussions

In the online questionnaire, participants were asked if they had discussions with their doctor about clinical trials, and if they did, who initiated the discussion (Table 5.15, Figure 5.15).

There was a total of 11 participants (40.74%) that had discussions about clinical trials, 5 participants (18.52%) had brought up the topic with their doctor, and the doctor of 6 participants (22.22%) brought up the topic. The majority of participants had not spoken to anyone about clinical trials (n=16, 59.26%).

Clinical trial participation

As a follow up question, participants were asked if they had taken part in a clinical trial, and if they had not taken part if they were interested in taking part (Table 5.16, Figure 5.16).

There were 2 participants (7.41%) that had taken part in a clinical trial, 22 participants (81.48%) that would like to take part in a clinical trial if there was a suitable one, and 3 participants, that have not participated in a clinical trial and do not want to (11.11%).

Table 5.15: Clinical trial discussions

Clinical trial discussions	Number (n=27)	Percent
Participant brought up the topic of clinical trials doctor for discussion	5	18.52
Doctor brought up the topic of clinical trials for discussion	6	22.22
Participant has ever spoken to me about clinical trials	16	59.26

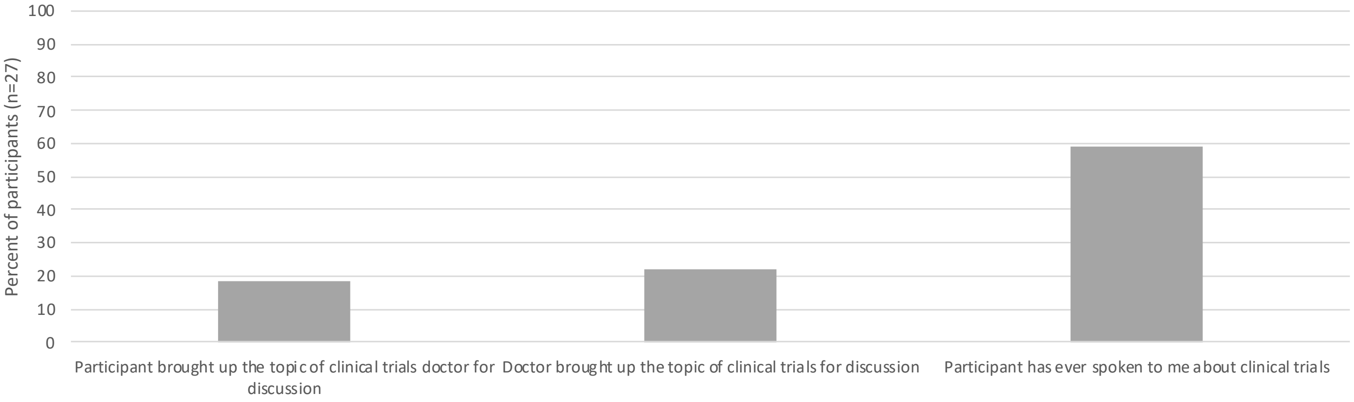


Figure 5.15: Clinical trial discussions

Table 5.16: Clinical trial participation

Clinical trial participation	Number (n=27)	Percent
Has not participated in a clinical trial and does not want to	3	11.11
Has not participated in a clinical trial but would like to if there is one	22	81.48
Has participated in a clinical trial	2	7.41

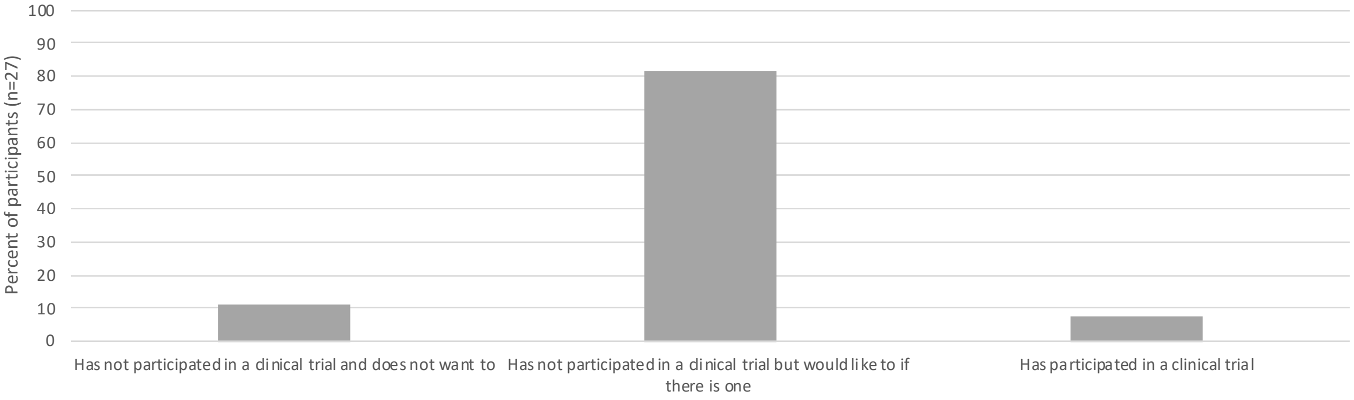


Figure 5.16: Clinical trial participation

Description of mild side effects

In the structured interview, participants were asked how they would describe the term 'mild side effects'. The most common response was using a specific example to describe mild side effects (69.23%). Other descriptions of mild side effects were those that do not interfere with life(46.15%), and those that can be managed with self-medication or self-management (Over-the-counter) (30.77 %).

When a specific side effect was described, the most common responses were aches/pain (general) (23.08%), skin rash or itch (23.08%), and gastrointestinal distress (19.23 %). Other examples included fatigue/lethargy (11.54%), and being short of breath (11.54%)

Participant describes mild side effects as those that do not interfere with daily life

I think the mild side effects still allow you to have that quality of life and do things, where you're not lying in bed feeling bad and stuff like that.
Participant 004_2023AULUC

Mild side effect is something you can go about your daily life with and it doesn't have an impact, doesn't have too much of an impact on your quality of life. You can still dress yourself, you can still get to move yourself around. You don't actually need a carer.
Particpant 007_2023AULUC

I think mild side effects are things that might cause some pain or some annoyance, general annoyance, but don't prevent you from doing anything in your normal day.
Participant 026_2023AULUC

Participant describes mild side effects as those that can be self-managed

They weren't mild. A mild side effect is having to take a Panadol. Actually, I'll tell you what, the Tagrisso I'm on, that had my, well, mildish side effects.
Participant 019_2023AULUC

Cope with? The rashes he can cope with usually we medicate for that. Breathing is a major side effect. Like I said, that's a huge impact on his life. The coughing up of blood is a mild side effect. The reflux is a mild one. The major one is the breathing.
Participant 030_2023AULUC

If it's skin eruptions, you can put cream on it. Participant 024__2023AULUC

Participant describes mild side effects giving the specific example of Aches/pain (general)

Just some discomfort and limited movement. Not sleeping well, but they're all mild side effects. I don't think I had significant side effects.
Particpant 010_2023AULUC

Oh, most of them aren't that mild really. They're probably a bit more significant than that. Pain, I suppose. If I breathe in deeply now I can still feel pain in my chest. When I lay on my side in bed, it's still sore, when I lean back on one side in my chair, it's very uncomfortable where one of the surgical insertions was. I suppose it's probably the mild things would be pain. Moving towards the more moderate stuff, it's probably really my-- the side effects are really just in terms of my breathing, my aerobic capacity, which is understandable
Participant 021_2023AULUC

Participant describes mild side effects giving the specific example of a skin rash or an itch

From my point of view my mild side effects are things that don't impact my daily life so much. They don't impact me doing my daily life. At the moment, I have skin rashes from the medication, that's become a mild side effect. It's when they negatively impact my function and how I perform in the day.
Participant 027_2023AULUC

Mild side effects would be tiredness, a rash from the radiation. That's mild. You can expect that. That's about mild as you can get.
Participant 014_2023AULUC

Participant describes mild side effects giving the specific example of Gastrointestinal distress

Mild side effects I would say nausea or diarrhea and loss of appetite. Yes, that's just mild.
Participant 023_2023AULUC

PARTICIPANT: Side effects that are noticeable but don't have a significant impact on my daily life.
INTERVIEWER: Could you list a few examples?
PARTICIPANT: Like the constipation. It's annoying but it doesn't stop me doing anything. It's just unpleasant. That's all. It's just unpleasant. I don't think it's causing me any effects beyond what I'm observing.
Participant 022_2023AULUC

Participant describes mild side effects giving the specific example of Fatigue/lethargy

Just feeling a little bit sick. Feeling tired. It was okay. All my side effects are mild I'd say. I wasn't really sick or anything.
Participant 001_2023AULUC

Fatigue. I have that every day. I go to bed early. I sleep like [unintelligible] and what else? That's probably the only mild one I have, but the major one.
Participant 002_2023AULUC

Participant describes mild side effects giving the specific example of shortness of breath

Okay, so I've probably got mild side effects now because I know it's just going to get worse. Mild side effects would be shortness of breath. I don't know. There's a lot to take into account with that. I have a lot of inflammation in my lungs. I cough up blood. I get dizzy when I cough. I have nausea. I get headaches. That sort of thing.
Participant 003_2023AULUC

Maybe just a slight shortness of breath, that I can cope with. What else? I don't know.
Particpant 013_2023AULUC

Table 5.17: Description of mild side effects

Description of mild side effects	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant provides a specific side effect as an example	18	69.23	17	68.00	1	100.00	7	70.00	11	68.75	12	75.00	6	60.00
Participant describes mild side effects as those that do not interfere with daily life	12	46.15	12	48.00	0	0.00	4	40.00	8	50.00	10	62.50	2	20.00
Participant describes mild side effects as those that can be self-managed	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	5	31.25	3	30.00

Description of mild side effects	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant provides a specific side effect as an example	18	69.23	10	58.82	8	88.89	10	76.92	8	61.54	2	100.00	16	66.67	6	66.67	12	70.59
Participant describes mild side effects as those that do not interfere with daily life	12	46.15	9	52.94	3	33.33	5	38.46	7	53.85	0	0.00	12	50.00	5	55.56	7	41.18
Participant describes mild side effects as those that can be self-managed	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	0	0.00	8	33.33	1	11.11	7	41.18

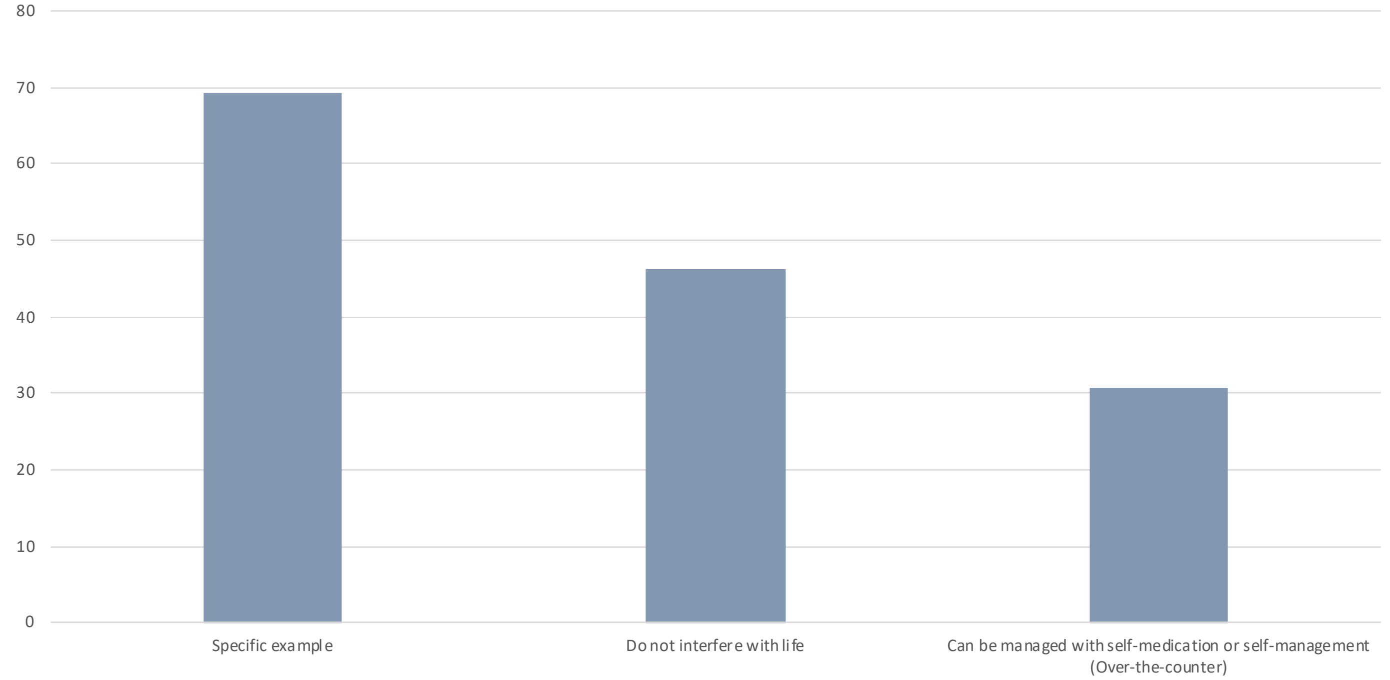


Figure 5.17: Description of mild side effects

Table 5.18: Description of mild side effects – subgroup variations

Theme	Less frequently	More frequently
Participant provides a specific side effect as an example	Aged 35 to 64	Aged 65 or older
Participant describes mild side effects as those that do not interfere with daily life	Male Aged 65 or older	Female
Participant describes mild side effects as those that can be self-managed	Mid to low status	Higher status

Table 5.19: Description of mild side effects (Specific side effects)

Description of mild side effects (specific example)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes mild side effects giving the specific example of Aches/pain (general)	6	23.08	6	24.00	0	0.00	4	40.00	2	12.50	4	25.00	2	20.00
Participant describes mild side effects giving the specific example of a skin rash or an itch	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	4	25.00	2	20.00
Participant describes mild side effects giving the specific example of Gastrointestinal distress	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	2	12.50	3	30.00
Participant describes mild side effects giving the specific example of Fatigue/lethargy	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes mild side effects giving the specific example of shortness of breath	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Description of mild side effects (specific example)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes mild side effects giving the specific example of Aches/pain (general)	6	23.08	4	23.53	2	22.22	5	38.46	1	7.69	0	0.00	6	25.00	1	11.11	5	29.41
Participant describes mild side effects giving the specific example of a skin rash or an itch	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	1	50.00	5	20.83	4	44.44	2	11.76
Participant describes mild side effects giving the specific example of Gastrointestinal distress	5	19.23	2	11.76	3	33.33	4	30.77	1	7.69	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes mild side effects giving the specific example of Fatigue/lethargy	3	11.54	2	11.76	1	11.11	0	0.00	3	23.08	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes mild side effects giving the specific example of shortness of breath	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88

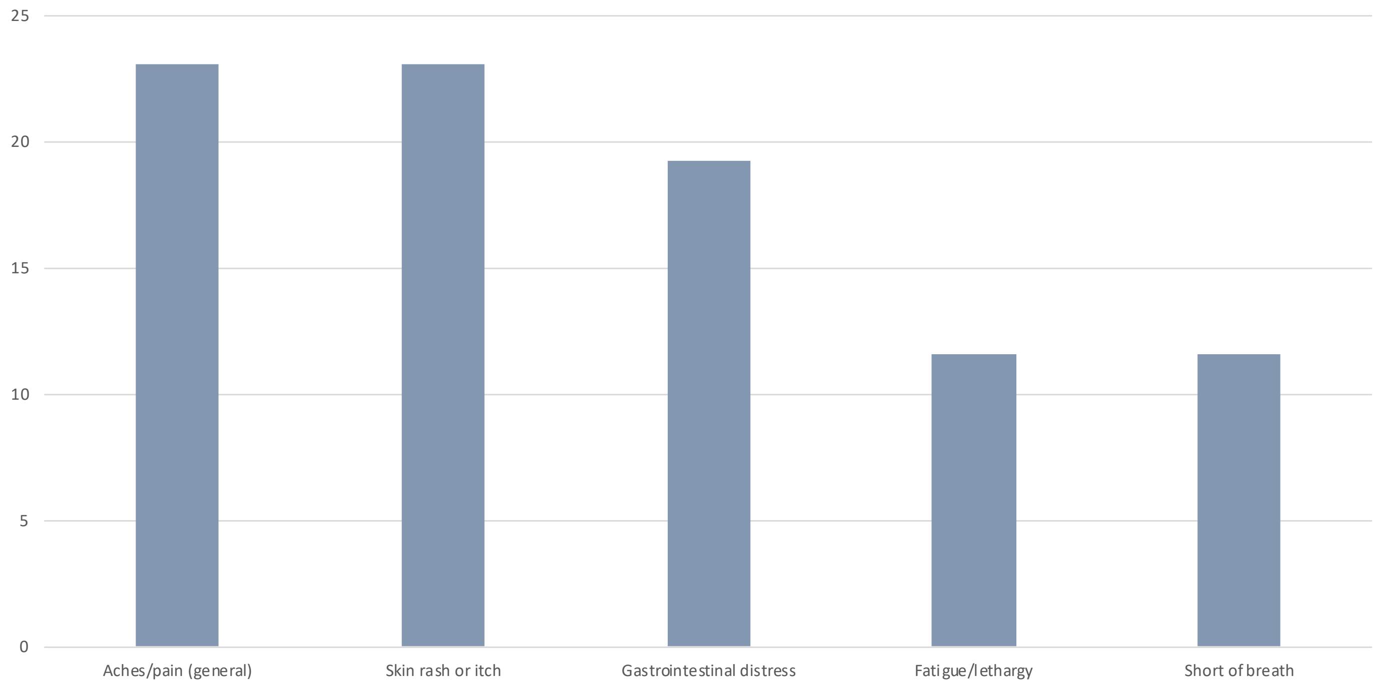


Figure 5.18: Description of mild side effects (Specific side effects)

Table 5.20: Description of mild side effects (Specific side effects) – subgroup variations

Theme	Less frequently	More frequently
Participant describes mild side effects giving the specific example of Aches/pain (general)	Metastatic University Mid to low status	Non-metastatic Trade or high school
Participant describes mild side effects giving the specific example of a skin rash or an itch	Higher status	Mid to low status
Participant describes mild side effects giving the specific example of Gastrointestinal distress	University Mid to low status	Male Aged 65 or older Trade or high school Higher status
Participant describes mild side effects giving the specific example of Fatigue/lethargy	Male Trade or high school	University
Participant describes mild side effects giving the specific example of shortness of breath	-	Mid to low status

Description of severe side effects

In the structured interview, participants were asked how they would describe the term ‘severe side effects’. The most common response was using a specific example to describe severe side effects (61.54%), followed by side effects that impact everyday life/ability to conduct activities of daily living (38.46%)

The most common examples were being short of breath (15.38%), having general aches and pains (11.54%), and the emotional or mental impact (11.54 %).

Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living

A severe side effect. Wow, probably when you can't breathe or pain that stops me from just generally moving freely and doing things.
Participant 006_2023AULUC

Where it's just so debilitating you can't actually function.
Participant 020_2023AULUC

Severe is when you can't get out of bed, or when you have a shower and you have to lay on the floor for 30 minutes before you can get up. That's severe. Participant 025_2023AULUC

Participant describes severe side effects giving the specific example of shortness of breath

Vomiting, nausea, I heard of those, and not being able to breathe properly, maybe being put on oxygen. Participant 014_2023AULUC

Cope with? The rashes he can cope with usually we medicate for that. Breathing is a major side effect. Like I said, that's a huge impact on his life. The coughing up of blood is a mild side effect. The reflux is a mild one. The major one is the breathing.
Participant 030_2023AULUC

Participant describes severe side effects giving the specific example of Aches/pain (general)

You know what, I am coping so just my hip joints, they're extremely painful. My back, I have a lot of problems with my back now. Just my spine and my ribcage. Everything hurts but you just get on with it.
Participant 002_2023AULUC

Severe vomiting, severe nausea, severe diarrhea, all-over body rash, and just uncontrollable pain. Particpant 005_2023AULUC

Participant describes severe side effects giving the specific example of Emotion/mental impact

Those were extremely severe. Post all of that, I don't really think there were any severe. I would say there were moderate effects, probably because I'm pretty physically fit, as I said. I think my aerobic capacity has been affected moderately, I don't think it's been affected severely. Mentally, I would say, it's probably quite severe in terms of the overall effect it's had on me. Even saying that I'm feeling a bit emotional now.
Participant 021_2023AULUC

PARTICIPANT: Oh, I think depression and severe nausea and weight loss. Yes. I had anxiety, overeating. Severe. Other than that, the mental side of it. Yes.
Participant 024__2023AULUC

Severe is fatigue where I can't even lift my arms up. Or I'm on the couch and I fall asleep, that's severe for me. Things like, I have insomnia and you could put this down to stress, or I think it's got something to do-- like weight gain with the medication, that can impact-- That's there and it's bad that obviously impacts my daily function because my self-esteem but the fatigue and the cognition, that's impacting how I function every day.
Participant 027_2023AULUC

Table 5. 21: Description of severe side effects

Description of severe side effects	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant provides a specific side effect as an example	16	61.54	15	60.00	1	100.00	5	50.00	11	68.75	10	62.50	6	60.00
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	10	38.46	9	36.00	1	100.00	4	40.00	6	37.50	8	50.00	2	20.00

Description of severe side effects	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant provides a specific side effect as an example	16	61.54	8	47.06	8	88.89	9	69.23	7	53.85	0	0.00	16	66.67	5	55.56	11	64.71
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	10	38.46	8	47.06	2	22.22	4	30.77	6	46.15	1	50.00	9	37.50	4	44.44	6	35.29

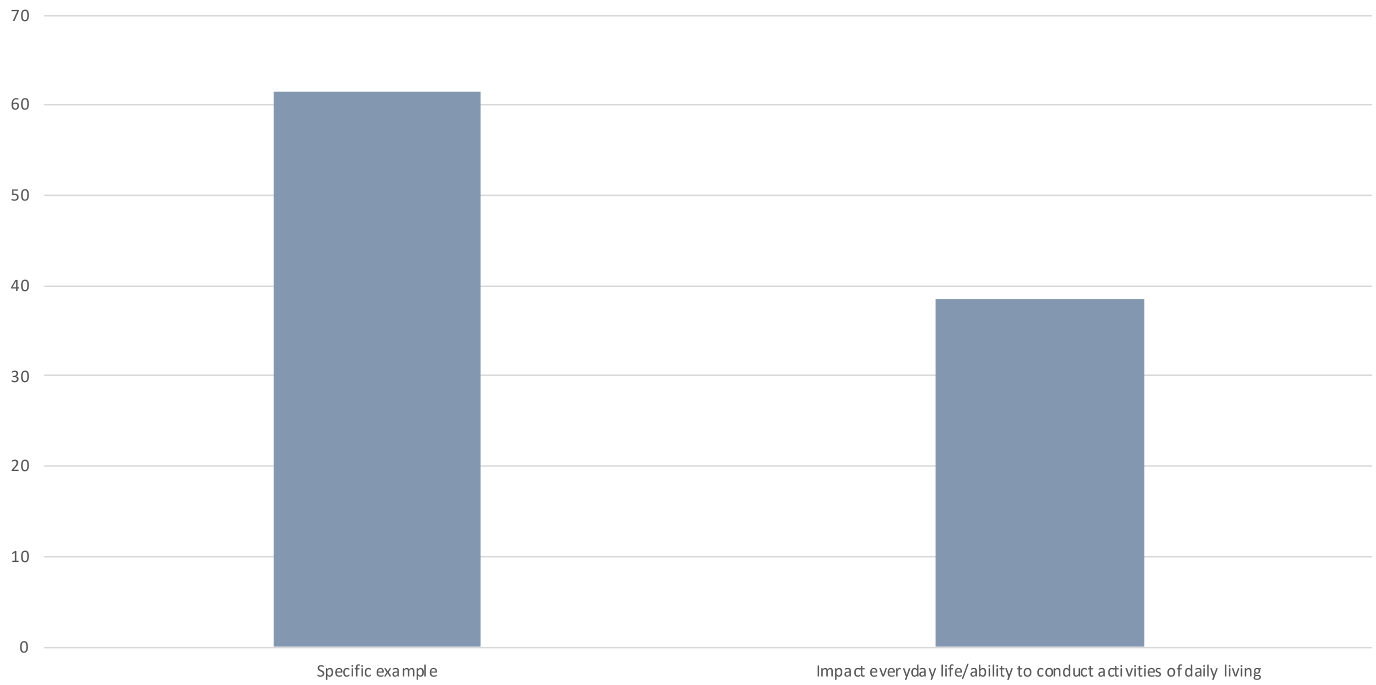


Figure 5.19: Description of severe side effects

Table 5. 22: Description of severe side effects – subgroup variations

Theme	Less frequently	More frequently
Participant provides a specific side effect as an example	Non-metastatic Aged 35 to 64	Aged 65 or older
Participant describes severe side effects as those that impact everyday life/ability to conduct activities of daily living	Male Aged 65 or older	Female

Table 5. 23: Description of severe side effects (Specific example)

Description of severe side effects (specific examples)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes severe side effects giving the specific example of shortness of breath	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes severe side effects giving the specific example of Aches/pain (general)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes severe side effects giving the specific example of Emotion/mental impact	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	1	6.25	2	20.00

Description of severe side effects (specific examples)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes severe side effects giving the specific example of shortness of breath	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	1	50.00	3	12.50	3	33.33	1	5.88
Participant describes severe side effects giving the specific example of Aches/pain (general)	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes severe side effects giving the specific example of Emotion/mental impact	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

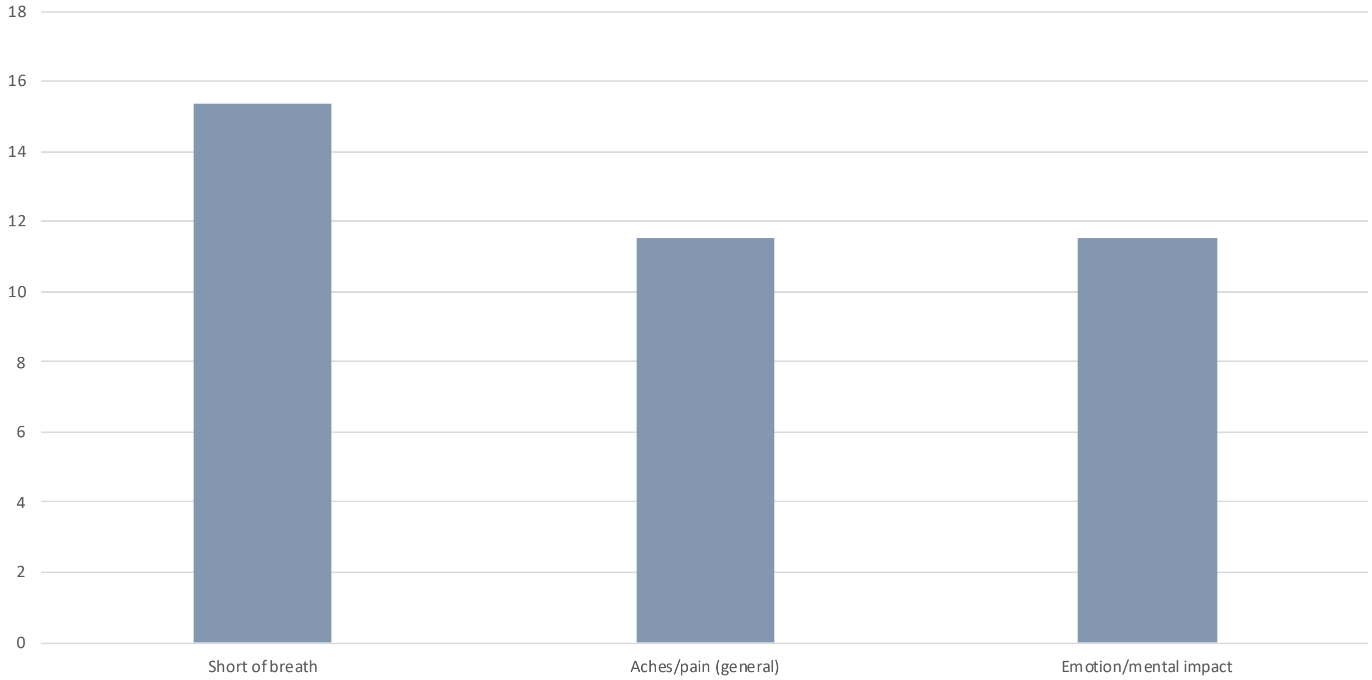


Figure 5.20: Description of severe side effects (Specific example)

Table 5. 24: Description of severe side effects (Specific side effects)– subgroup variations

Theme	Less frequently	More frequently
Participant describes severe side effects giving the specific example of shortness of breath		Mid to low status
Participant describes severe side effects giving the specific example of Aches/pain (general)	Non-metastatic Male Aged 65 or older	Mid to low status

Adherence to treatment

Participants were asked in the structured interview what influences their decision to continue with a treatment regime.

The most common responses were that they did not give up on any treatment (34.62%), and as long as side effects are tolerable (23.08%). Other themes included the advice of their specialist, or as long as prescribed (19.23%), adhering to treatment for a specific amount of time (19.23%), and being unable to answer as they had not had treatment or cannot answer hypothetical question (11.54%).

When participants stated a specific amount of time to adhere to a treatment, the most common amount of time was two to three months.

Participant describes not giving up on any treatment

I'd keep going with it just, hopefully it works. They did give me dexamethasone to stop me being sick while I was having chemo. That was something different they gave me and that did a good job.
Participant 001_2023AULUC

I think with this EGFR lung cancer you just put up with anything because the alternative is you're going to die. You just go, "Well, that's the tablet that I'm on," and that's the way it is.
Participant 004_2023AULUC

I've never given up a treatment.
Particpant 007_2023AULUC

PARTICIPANT: I think that's probably not applicable in my case because I haven't had any other treatments post-surgery.
INTERVIEWER: Understand, yes. We can skip it.
PARTICIPANT: Yes, if I did have one I would stick to absolutely because it's just too important not to.
Participant 021_2023AULUC

Participant describes adhering to treatment as long as side effects are tolerable

That's a good question. You're saying if I'm having chemotherapy now and I don't think it's working, I suppose again, I would rely on my doctor's advice because I want to persevere with it to obviously get a positive outcome. At the same time, how much pain and severe side further effects can you deal with as well? The hair loss doesn't bother me. I lost a fair bit of hair when I had the radiotherapy. Something like that doesn't bother me because you can deal with that. It's just dealing with, say, vomiting, which I didn't experience at all this time. I suppose pain more than anything. Particpant 005_2023AULUC

I would say about two months. If I've got the mild side effects of diarrhea or of the skin rash, but it's not with high temperature and no pus, what I do is I reduce what they give me. I just do it because I think, well, I'll have to manage it myself, and then when I have the appointment, I say, "I've taken half of what you gave me because I can't live like that." That's all.
Participant 023_2023AULUC

Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed

It's a bit of a hypothetical, but my approach would be to discuss that very point with my treatment team and say, "How often are you expecting to see me and what should I do if I have some concerns between those sessions?" That's the discussion I had with my first treatment. I'll start this, what should I expect and what do I do if something unexpected happens? That's part of why I like the team.
Participant 022_2023AULUC

I would not give up on anything until a doctor said that it doesn't work.
Participant 026_2023AULUC

Participant describes adhering to treatment for a specific amount of time

Probably a couple of months.
Participant 014_2023AULUC

Really when it comes to these sort of medications, it would be getting back test results that really show you having no impact. If you're talking generally about other medications I've been on, I would give them several weeks because things can take a long time to click in and work, but with the Osimertinib, it was really that scan results showed a change.
Participant 020_2023AULUC

PARTICIPANT: Well, I can tell you that because they've put me on Lyrica for some pain. I'd ask for three days and I went, "You can dump this one. I'm not doing it." Two to three days, and I would just get it out of my system. I wouldn't take it. I had severe nightmares and sweats. It was like honestly like I was having some sort of hallucinogenic drug. It was just awful. I just refused to take it. I said, "Find me something else. That's not working."
Participant 018_2023AULUC

Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question

Well, that's a hard question because with the problem that I've got, how do you know if it's working? You don't know. It's not as if you've got an ulcer or something on your leg and you take something for it and you can watch it heal or not heal. You can't see this. I find it quite a difficult question to answer.
Participant 017_2023AULUC

I haven't really been in that situation.
Participant 024__2023AULUC

Table 5. 25: Adherence to treatment

Adherence to treatment	**All participants**		**Person with lung cancer**		**Family member or carer**		**Non-metastatic**		**Metastatic**		**Female**		**Male**	
	n=26	**%**	**n=25**	**%**	**n=1**	**%**	**n=10**	**%**	**n=16**	**%**	**n=16**	**%**	**n=10**	**%**
Participant describes not giving up on any treatment	9	34.62	9	36.00	0	0.00	**2**	**20.00**	7	43.75	7	43.75	**2**	**20.00**
Participant describes adhering to treatment as long as side effects are tolerable	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	5	31.25	**1**	**10.00**
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes adhering to treatment for a specific amount of time	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	**5**	**31.25**	**0**	**0.00**
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Adherence to treatment	**All participants**		**Aged 35 to 64**		**Aged 65 or older**		**Trade or high school**		**University**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=26	**%**	**n=17**	**%**	**n=9**	**%**	**n=13**	**%**	**n=13**	**%**	**n=2**	**%**	**n=24**	**%**	**n=9**	**%**	**n=17**	**%**
Participant describes not giving up on any treatment	9	34.62	6	35.29	3	33.33	4	30.77	5	38.46	1	50.00	8	33.33	3	33.33	6	35.29
Participant describes adhering to treatment as long as side effects are tolerable	6	23.08	4	23.53	2	22.22	4	30.77	2	15.38	0	0.00	6	25.00	2	22.22	4	23.53
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	5	19.23	**5**	**29.41**	**0**	**0.00**	**1**	**7.69**	**4**	**30.77**	1	50.00	4	16.67	**3**	**33.33**	2	11.76
Participant describes adhering to treatment for a specific amount of time	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	3	11.54	**0**	**0.00**	**3**	**33.33**	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

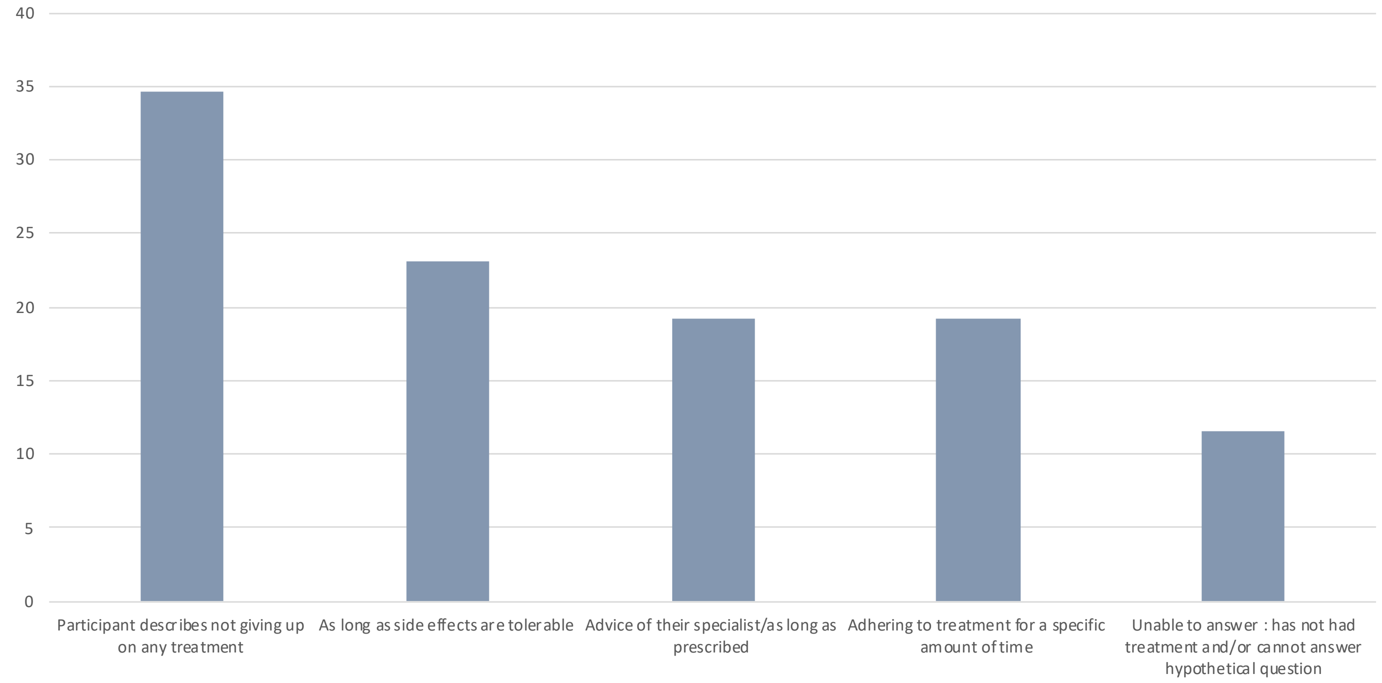


Figure 5.21: Adherence to treatment

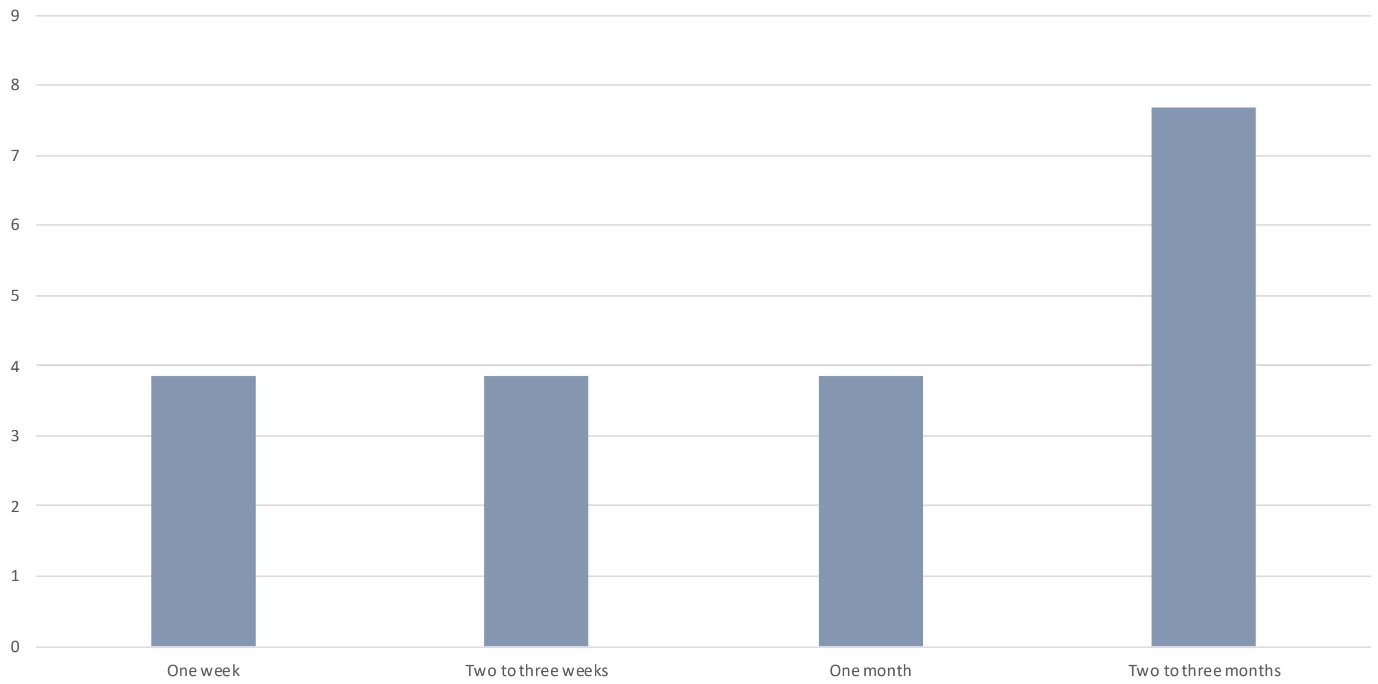


Figure 5.22: Adherence to treatment: specific time

Table 5. 27: Adherence to treatment – subgroup variations

Theme	Less frequently	More frequently
Participant describes not giving up on any treatment	Non-metastatic Male	-
Participant describes adhering to treatment as long as side effects are tolerable	Male	-
Participant describes adhering to treatment as per the advice of their specialist/as long as prescribed	Aged 65 or older Trade or high school	Aged 35 to 64 University Mid to low status
Participant describes adhering to treatment for a specific amount of time	Male	Female
Participant describes being unable to answer as they have not had treatment and/or cannot answer hypothetical question	Aged 35 to 64	Aged 65 or older

What needs to change to feel like treatment is working

Participants were asked to describe what needs to change to feel like treatment is effective. The most common responses were seeing evidence of stable disease or no disease progression (57.69%), and seeing reduction of physical signs and symptoms (19.23%).

Participants reported needing to experience evidence of stable disease/no disease progression

Oh, it means it's keeping it at bay, or reducing the tumors.
Participant 004_2023AULUC

What needs to improve, I suppose just getting accurate scan results, test results once the treatment's finished, evidence that it has done something.
Particpant 005_2023AULUC

Oh, seeing the data. I see that the blood tests aren't showing any out-of-control blood features. The CT scan shows that the main tumor is reduced and stable and that there's no evidence and that there's no evidence of any other metastatic activities. That's everything. That's I guess the triumvirate there of no pathology, no metastasis, and no progression. That's it.
Participant 022_2023AULUC

Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects

It comes back to that quality of daily living, doesn't it? If I have improved symptom management, if the symptom control is better than the side effects if that makes sense.
Particpant 006_2023AULUC

I actually need to feel or see some improvement. I need to feel that my symptoms are slightly better than what they were. Not worse. Does that make sense?
Participant 018_2023AULUC

When I started the Osimertinib, it was a few weeks in and I actually did get relief from some symptoms that I hadn't realized were lung cancer, like a really minor cough that I hadn't even thought about until I got the diagnosis and went, "Oh, that does come." It totally went and I actually thought then it was working a few weeks in. Physical things, I think that was it. I didn't have many physical symptoms really, so I wasn't expecting to feel much, I was more expecting to see it on a scan.
Participant 020_2023AULUC

What would it mean if treatment worked

As a follow up question, participants were asked what it would mean to them if the treatment worked in the way they described.

The most common responses were allowing them to do everyday activities and return to normal life (23.08%), leading to a reduction in symptoms orside effects (19.23%), and allowing them to engage more with social activities and family life (15.38 %). Other themes included allowing them to return to work (11.54%), allowing them to do domestic tasks (11.54%), allowing them to do more exercise (11.54%), and that it would have a positive impact on their mental health (11.54%).

Participant describes treatment allowing them to do everyday activities/ return to normal life

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.
Participant 004_2023AULUC

I guess with the first drug, the side effects were that bad that I couldn't work. Sometimes I couldn't leave the house. Even shaving was an issue because my skin would fall off, so that was terrible. This new drug means I was able to go back to work for a short amount of time once the side effect is still down. With this new drug, no, I feel great. I can go out, I can do things. I don't even know that I'm taking it.
Particpant 006_2023AULUC

Participant describes treatment leading to a reduction in symptoms/side effects

Oh, it would be bliss. It's like this drug I'm taking at the moment for my neuropathy. This is week three, week four. It is making a mild difference, which I've been able to stand up longer and I'm not as pins and needly and that sort of thing. That to me, it's showing some signs of success. That's what it needs to be. If I'm not seeing that, then I'm not putting another foreign thing into my body just for the sake of it.
Participant 018_2023AULUC

Like now, well, they usually make you very tired. You don't have as much energy. The tablets are, yes, they're fatiguing and just like my appetite's gone. I've lost weight.
Participant 019_2023AULUC

Participant described treatment allowing them to engage more with social activities and family life

Well, the treatment I got for the nausea never worked for me. Yes, and because of that, your whole life was changed. I didn't go out much. We got very insulated.
Participant 024__2023AULUC

Participant describes treatment allowing them to return to work

Huge. I would be able to get back to work, I'm hoping, and continue on with a reasonably functional life. Right now, I can't.
Participant 003_2023AULUC

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.
Participant 004_2023AULUC

Participant describes treatment allowing them to do domestic tasks

It means I could probably live 80% like a normal person, and just do normal things like go shopping and just do normal things, basically. Maybe even have a job, I don't know.
Participant 004_2023AULUC

Participant describes treatment allowing them to do more exercise

I could take the dog for a walk and I could get to do some exercise and lose some weight. I wouldn't be washing the dishes and then I do half of them because I'm too tired to do the other half.
Participant 002_2023AULUC

Okay. All right. I feel like I would be able to engage more socially within my community, with family and friends. I would be able to exercise and have a regular exercise routine that would be inclusive within the *community. Right now, I don't know if I'm too scared or not confident enough to, but exercising in the community is something I'm not able to do. What else would I be able to do? I'd probably be more productive around the house.*

Participant 015__2023AULUC

Participant describes treatment working as having a positive impact on their mental health

I think it just gave me the fact that I yes, once I knew that treatment was working, it stopped me dwelling on death and made me dwell on life and go, "Now you've got an opportunity to keep moving forward." It took that weight of preparing to die off my shoulders and I went, "No, you're living for a while longer." It made me get up and go again, rather than sitting in that little mire of despair. I think psychologically it was huge and we don't know how long it's going to last, no one does, but it gave me that thing of get up and make the most of what you've got.

Participant 020_2023AULUC

Table 5. 28: What needs to change to feel like treatment is working

What needs to change to feel like treatment is working	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participants reported needing to experience evidence of stable disease/no disease progression	15	57.69	14	56.00	1	100.00	5	50.00	10	62.50	12	75.00	3	30.00
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00

What needs to change to feel like treatment is working	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participants reported needing to experience evidence of stable disease/no disease progression	15	57.69	10	58.82	5	55.56	6	46.15	9	69.23	0	0.00	15	62.50	5	55.56	10	58.82
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	5	19.23	5	29.41	0	0.00	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65

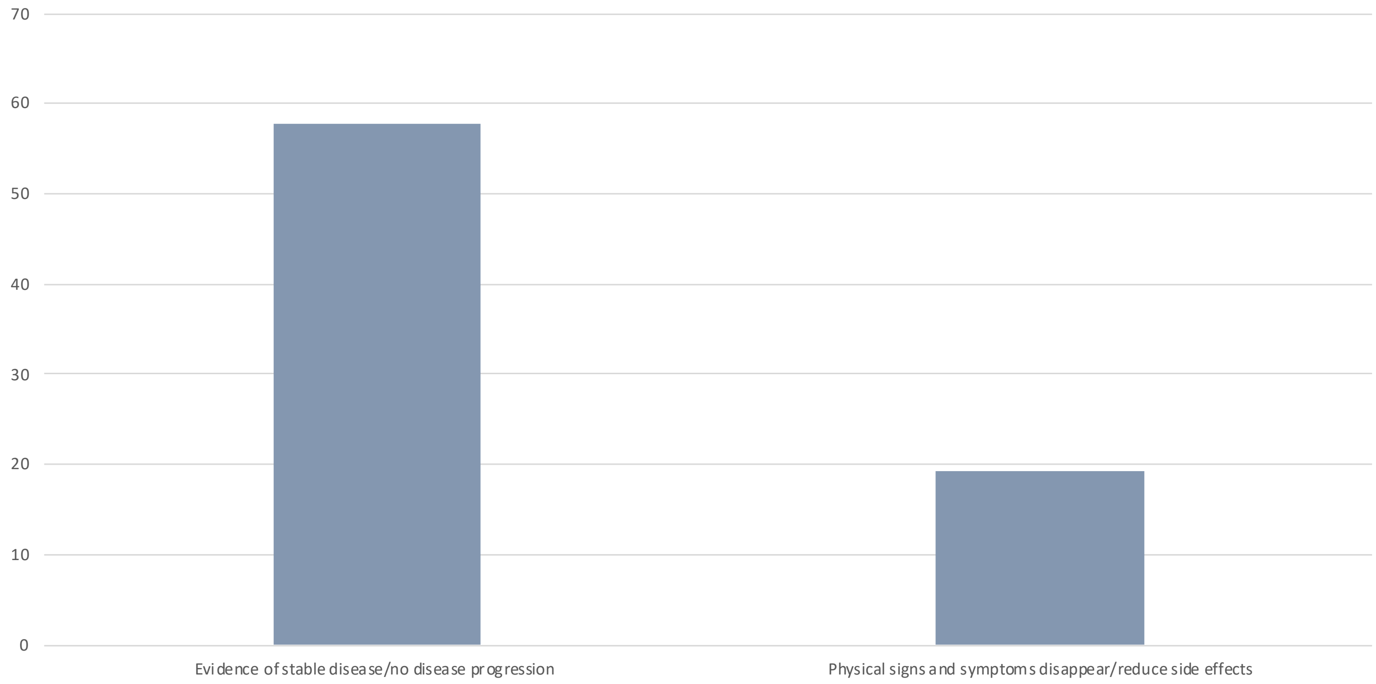


Figure 5.23: What needs to change to feel like treatment is working

Table 5. 29: What needs to change to feel like treatment is working – subgroup variations

Theme	Less frequently	More frequently
Participants reported needing to experience evidence of stable disease/no disease progression	Male Trade or high school	Female University
Participants reported needing to experience a reduction in physical signs and symptoms disappear/reduce side effects	Male Aged 65 or older	Female Aged 35 to 64

Table 5.30: What would it mean if treatment worked

What it would mean if treatment worked	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	6	23.08	5	20.00	1	100.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes treatment leading to a reduction in symptoms/side effects	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	5	31.25	0	0.00
Participant described treatment allowing them to engage more with social activities and family life	4	15.38	3	12.00	1	100.00	0	0.00	4	25.00	2	12.50	2	20.00
Participant describes treatment allowing them to return to work	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes treatment allowing them to do domestic tasks	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes treatment allowing them to do more exercise	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes treatment working as having a positive impact on their mental health	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00

What it would mean if treatment worked	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes treatment allowing them to do everyday activities/ return to normal life	6	23.08	5	29.41	1	11.11	2	15.38	4	30.77	2	100.00	4	16.67	4	44.44	2	11.76
Participant describes treatment leading to a reduction in symptoms/side effects	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	0	0.00	5	20.83	2	22.22	3	17.65
Participant described treatment allowing them to engage more with social activities and family life	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	1	50.00	3	12.50	1	11.11	3	17.65
Participant describes treatment allowing them to return to work	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	2	100.00	1	4.17	3	33.33	0	0.00
Participant describes treatment allowing them to do domestic tasks	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes treatment allowing them to do more exercise	3	11.54	2	11.76	1	11.11	0	0.00	3	23.08	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes treatment working as having a positive impact on their mental health	3	11.54	3	17.65	0	0.00	3	23.08	0	0.00	0	0.00	3	12.50	1	11.11	2	11.76

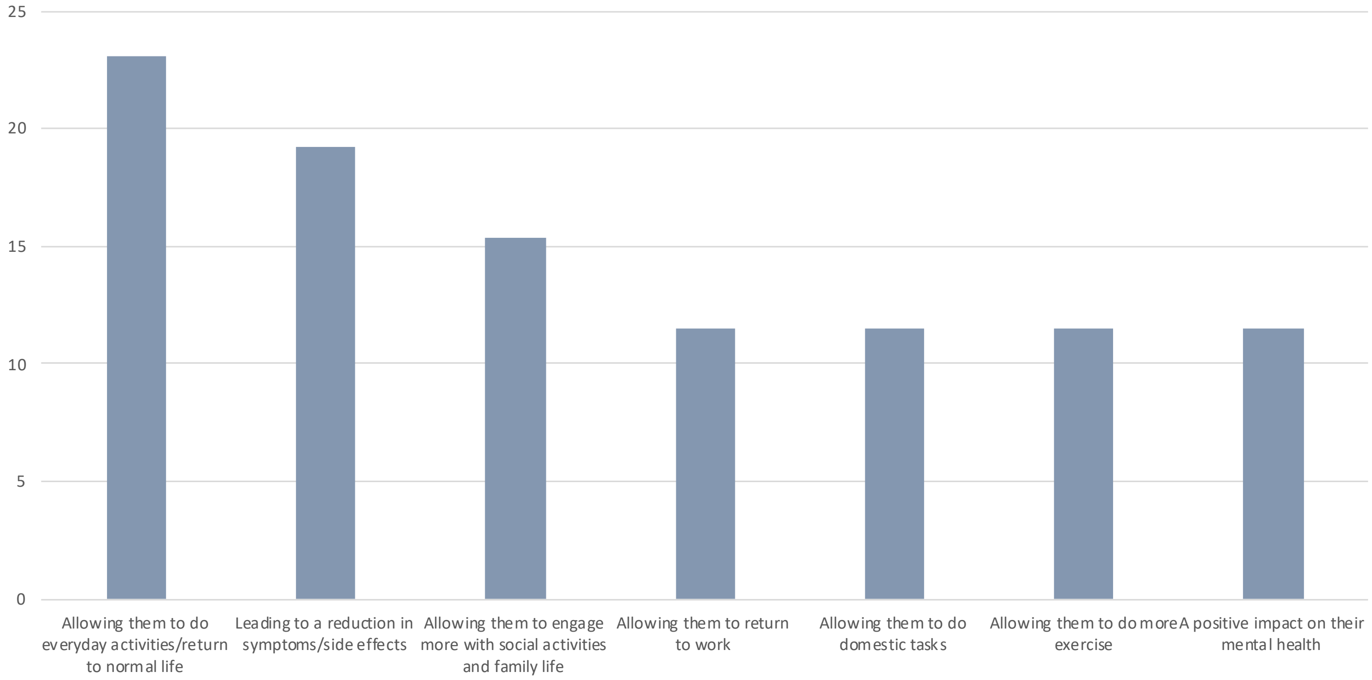


Figure 5.24: What would it mean if treatment worked

Table 5.31: What would it mean if treatment worked– subgroup variations

Theme	Less frequently	More frequently
Participant describes treatment allowing them to do everyday activities/ return to normal life	Aged 65 or older Higher status	Mid to low status
Participant describes treatment leading to a reduction in symptoms/side effects	Male Trade or high school	Female University
Participant described treatment allowing them to engage more with social activities and family life	Non-metastatic	-
Participant describes treatment allowing them to return to work	Male Aged 65 or older Trade or high school Higher status	University Mid to low status
Participant describes treatment allowing them to do domestic tasks	Non-metastatic Male Aged 65 or older Trade or high school	University
Participant describes treatment allowing them to do more exercise	Non-metastatic Male Trade or high school Mid to low status	University
Participant describes treatment working as having a positive impact on their mental health	Non-metastatic Male Aged 65 or older University	Trade or high school

Section 6

Information and communication

Section 6: Information and communication

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (57.69%), specific health charities (57.69%), and Facebook and\or social media (42.31 %). Other information sources included other patient's experience (including support groups) (19.23%), journals (research articles) (15.38%), books, pamphlets and newsletters (11.54%), and conferences or webinars (11.54%).

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common response was other people’s experiences (peer-to-peer) (42.31%). Other helpful information included talking to a doctor or specialist or healthcare team (19.23%), hearing what to expect (e.g. from disease, side effects, treatment) (19.23 %), medical journals and scientific information (19.23%), and health charities (11.54%)

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were sources that are not credible (not evidence-based) (26.92%), worse case scenarios (23.08 %), and some information given by their GP or specialist (15.38%) were not helpful. Other participants described that no information was not helpful (23.08%), or that they were confident in deciding themselves (11.54%)

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone plus online information (38.46%), online information (30.77%), and written information (23.08 %). Other preferences included talking to someone (11.54%), and all forms (11.54%).

The main reasons for a preference for online information were accessibility (38.46%), and being able to digest information at their own pace (19.23%). The main reason for talking to someone as a preference was being able to ask questions, get clarifications, and feeling supported (23.08 %). Participants described that written information, online information and talking to someone was preferred because it was relevant or personalised (30.77%).

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (26.92%), and after results from treatment, follow up scans, or when disease progressed (26.92%). Other times included after treatment (19.23%), continuously (19.23%), and after the shock of diagnosis (11.54%).

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=26, 52.00%). The most common responses that they had overall positive communication (38.46%), and overall negative communication (30.77%). Other participants described that communication was overall positive, with the exception of one or two occasions (19.23%).

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (19.23%). The main reason for negative communication was that it was dismissive, that they had one way conversations (15.38 %).

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had were good at coping with their condition.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in this study had very good recognition and management of symptoms.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average, participants in this study had very good treatment adherence.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in this study had very good overall knowledge, coping and confidence for managing their own health.

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=15, 60.00%), and 10 participants (40.00%) responded that they took medicines as prescribed most of the time.

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=17, 62.96%), disease cause (n=8, 29.63%), physical activity (n=8, 29.63%) and, disease management (n=7, 25.93%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=3, 11.11%), how to interpret test results (n=2, 7.41%) and, hereditary considerations (n=2, 7.41%) were given least often.

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease management (n=22, 81.48%), disease cause (n=19, 70.37%), treatment options (n=19, 70.37%) and, interpret test results (n=16, 59.26%) were most frequently searched for independently by participants, and, information about physical activity (n=13, 48.15%), diet (n=11, 40.74%) and, psychological/ social support (n=11, 40.74%) were searched for least often.

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=13, 48.15%) and diet (n=12, 44.44%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=6, 22.22%) and physical activity (n=6, 22.22%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=11, 40.74%) and disease management (n=6, 22.22%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease management (n=16, 59.26%) and interpret test results (n=16, 59.26%).

Most accessed information

Participants were asked to rank which information source that they accessed most often. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Pharmaceutical companies and from were least accessed.

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 11 participants (35.48%) had accessed My Health Record, 20 participants (64.52%) had not.

Of those that had accessed My Health Record, there were 5 participants (45.45%) who found it to be poor or very poor, 2 participants (18.18%) who found it acceptable, and 4 participants (36.36%) who found it to be good or very good.

Access to information

In the structured interview, participants were asked what information they had been able to access since they were diagnosed. The most common responses were the internet (Including health charities) (57.69%), specific health charities (57.69%), and Facebook and\or social media (42.31 %). Other information sources included other patient's experience (including support groups) (19.23%), journals (research articles) (15.38%), books, pamphlets and newsletters (11.54%), and conferences or webinars (11.54%).

Participant describes accessing information through the internet in general

*Everything on the internet that I can read. Everything. I'll probably read too much.
Participant 003_2023AULUC*

PARTICIPANT: Well, I would say one word, Google. I went there straight away soon as I came home from the hospital and I was diagnosed, I Googled it. Even all my family Googled it. Participant 013_2023AULUC

Well, the hospital's given me far more than I don't even need and the rest of it I just googled. Participant 017_2023AULUC

Participant describes accessing information from a specific health charity

Well, I've Googled online and they say never Google, but I have. I've looked up medical things because I've got a medical background. None of it is good news. I've looked at the Cancer Council of Victoria and then I got onto the Lung Cancer Society in Queensland. I've been looking at all that stuff, reading up on it. Participant 001_2023AULUC

Since I was diagnosed there was nothing available in Australia. There was like one lung cancer foundation nurse in Brisbane. That's the only kind of information that was available. Since then it's improved slightly. I just went to all the American support websites and the Lung Cancer Foundation of America just to seek out-- just to have that hope. Just to have that hope that people can actually live with this. I think the American sites were really quite positive and hopeful. Participant 004_2023AULUC

*Internet obviously, a cancer council, with their information guides and facts, but Dr. Google with everything else, any questions I've had actually, I would Google. Any research or everything.
Participant 026_2023AULUC*

Participant describes accessing information primarily through Facebook and/or social media

*In I went and there's all the trials that are going on around the world and all different. I've just got in my saved area of my Facebook, I've got hundreds and hundreds and hundreds and hundreds of studies and all the information I need. If something happens, then I just go into that and I can look it up and say, okay, this is what you do, because, in the end, the oncologists here do not know how to deal with my type of lung cancer. Because it's so rare, they just don't have the capacity to do it, and I understand that, and I know they don't have time to read all the stuff that I'm reading, so I'm doing that job for them. Anyway, this page has been fantastic. There's so many doctors in there. The people that have ALK lung cancer, there's, [inaudible] and they're all really smart people. Really, really smart people.
Participant 002_2023AULUC*

Yes, Dr. Google and I joined a couple of Facebook pages that talk about lung cancer. One is exclusively Australian. Another one isn't so it's a bit different and I like to look for-- A lot of the people on the Facebook pages, a lot of them are going through horrendous times with radiotherapy and chemotherapy so it's not applicable to me. I seek out those who've had something similar to me to see what sort of experience it was for them and their recovery periods. Participant 010_2023AULUC

*Most of mine has been via a Facebook group, which is an ALK-positive, so it's specific to my genetic mutation that I have, and it's a global group, and it's extremely good. It is within the group or a number of health professionals globally who specialize in this particular type of cancer. Plus, also there's a wealth of people globally who are suffering from it currently, and there's so much information that comes after that unbelievably useful. It primarily comes from there, and also just from searching around on the internet, but I haven't really had anything that was relevant from my medical team.
Participant 021_2023AULUC*

Participant describes primarily accessing information through other patient's experience

Yes, and connecting with other people. That is the way you find your information and navigate your care because people have that knowledge, they've been through it before. You can always learn from someone who's gone ahead of you. That was my biggest thing, we've got to have more people to connect with, so that we can learn from the people in front of us. That's one thing. That was a face-to-face support group. Then I came across an online support group specifically for ALK-positive lung cancer, that was amazing. They were trying to advocate and do all those things which was fantastic. I learnt heaps from them. Then we all build off each other. Through connecting with each other, we had so much to share, so much we could do. I learnt about Gamma Knife radiation so I knew how to navigate that.
Participant 015_2023AULUC

Oh gosh. Did lots of Googling, until I actually stopped myself, because you go down a rabbit hole of looking at statistics and [unintelligible] accumulation, not a person. The other thing I've done is got in touch with the Lung Foundation Australia and I guess sought support as in becoming a peer connect member. I've joined a group through our Peter MacCallum Hospital that meet monthly and those connections. You get to talk about the things that perhaps you want an answer to and that's easy there because you don't need a specialist to tell you. I've joined the Facebook EGRF cancer group and they're all good. They're all good avenues to ask simple things such as my toes playing up with this drug, anyone got any ideas, the best way to tackle it and it's great. The little things where I don't want to go running off to a medical specialist. If I think it's serious, I will see a doctor. If it's these minor things, they're often a great source.
Participant 020_2023AULUC

Participant describes accessing information primarily through journals (research articles)

I've purposely avoided lung organizations, patient organizations, and I've gone straight to reading the papers of people who presented at conferences. I started with the World Conference in Barcelona, which I think was four years ago. I read absolutely all the papers of the different people who presented at this conference. For each person who presented at the World Conference on lung cancer, often get published 50 papers each or more, so I read. I only go to that. I've looked up some journals on some of the studies that are done. In fact, I found one that looked at brain radiation, let's say in Spain and on metastases in the brain, and it found that this compound had a favorable overall survival advantage over not having it.
Participant 024_2023AULUC

Participant describes receiving information from books, pamphlets and newsletters

Everywhere I can find it. I actually … I look at research articles on a weekly basis. I get a lot of newsletters from different lung cancer organizations and foundations. They inform me of trials and new treatments and patients stories and all that type of thing. Much of my information I get through lung cancer foundations.
Participant 007_2023AULUC

As soon as the diagnosis came through, they give you a large package that has everything from what lung cancer is right through the treatments, et cetera. It's a bit of heavy reading.
Participant 012_2023AULUC

Participant describes accessing information from conferences and webinars

Through the Lung Foundation and I actually speak regularly to one of the lung cancer nurses there. I remember calling the Cancer Council, speaking to one of the nurses there. Then just various articles that come through email, social media. I'm aware that there's-- Is it in Melbourne? They had a conference in May. The Thoracic Surgeon's Association.
Participant 005_2023AULUC

PARTICIPANT: I've tried to, every single bit of information about how positive, I've tried to research. I've been fortunate that website-- there's an American group and that's on a website and they've got oncologists that really specialize in [unintelligible], they do webinars. I've watched them and I join-- They do two days of speaking about the different drugs. I make sure I'm familiar with everything. I know there's a new trial in America, [crosstalk] Australia at the moment. I follow all of that. I feel it's good and bad because I feel like I'm very knowledgeable about everything to do without. I don't know other stuff but I feel like I've looked at everything, even complicated threads. What people do with vitamins and things like that. Not that I've done a lot of that. I take my medication.
Participant 027_2023AULUC

Table 6.1: Access to information.

Access to information	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes accessing information through the internet in general	15	57.69	14	56.00	1	100.00	**7**	**70.00**	8	50.00	**11**	**68.75**	**4**	**40.00**
Participant describes accessing information from a specific health charity	15	57.69	14	56.00	1	100.00	**4**	**40.00**	**11**	**68.75**	**12**	**75.00**	**3**	**30.00**
Participant describes accessing information primarily through Facebook and/or social media	11	42.31	11	44.00	0	0.00	5	50.00	6	37.50	**9**	**56.25**	**2**	**20.00**
Participant describes primarily accessing information through other patient's experience	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	4	25.00	1	10.00
Participant describes accessing information primarily through journals (research articles)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	2	12.50	2	20.00
Participant describes receiving information from books, pamphlets and newsletters	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00
Participant describes accessing information from conferences and webinars	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	**0**	**0.00**

Access to information	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes accessing information through the internet in general	15	57.69	9	52.94	6	66.67	8	61.54	7	53.85	2	100.00	13	54.17	**8**	**88.89**	**7**	**41.18**
Participant describes accessing information from a specific health charity	15	57.69	**12**	**70.59**	**3**	**33.33**	**5**	**38.46**	**10**	**76.92**	1	50.00	14	58.33	**4**	**44.44**	11	64.71
Participant describes accessing information primarily through Facebook and/or social media	11	42.31	**10**	**58.82**	**1**	**11.11**	**3**	**23.08**	**8**	**61.54**	1	50.00	10	41.67	**2**	**22.22**	**9**	**52.94**
Participant describes primarily accessing information through other patient's experience	5	19.23	**5**	**29.41**	**0**	**0.00**	**1**	**7.69**	**4**	**30.77**	0	0.00	5	20.83	**0**	**0.00**	**5**	**29.41**
Participant describes accessing information primarily through journals (research articles)	4	15.38	1	5.88	**3**	**33.33**	3	23.08	1	7.69	0	0.00	4	16.67	**0**	**0.00**	4	23.53
Participant describes receiving information from books, pamphlets and newsletters	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	**0**	**0.00**	3	17.65
Participant describes accessing information from conferences and webinars	3	11.54	3	17.65	**0**	**0.00**	2	15.38	1	7.69	0	0.00	3	12.50	**2**	**22.22**	1	5.88

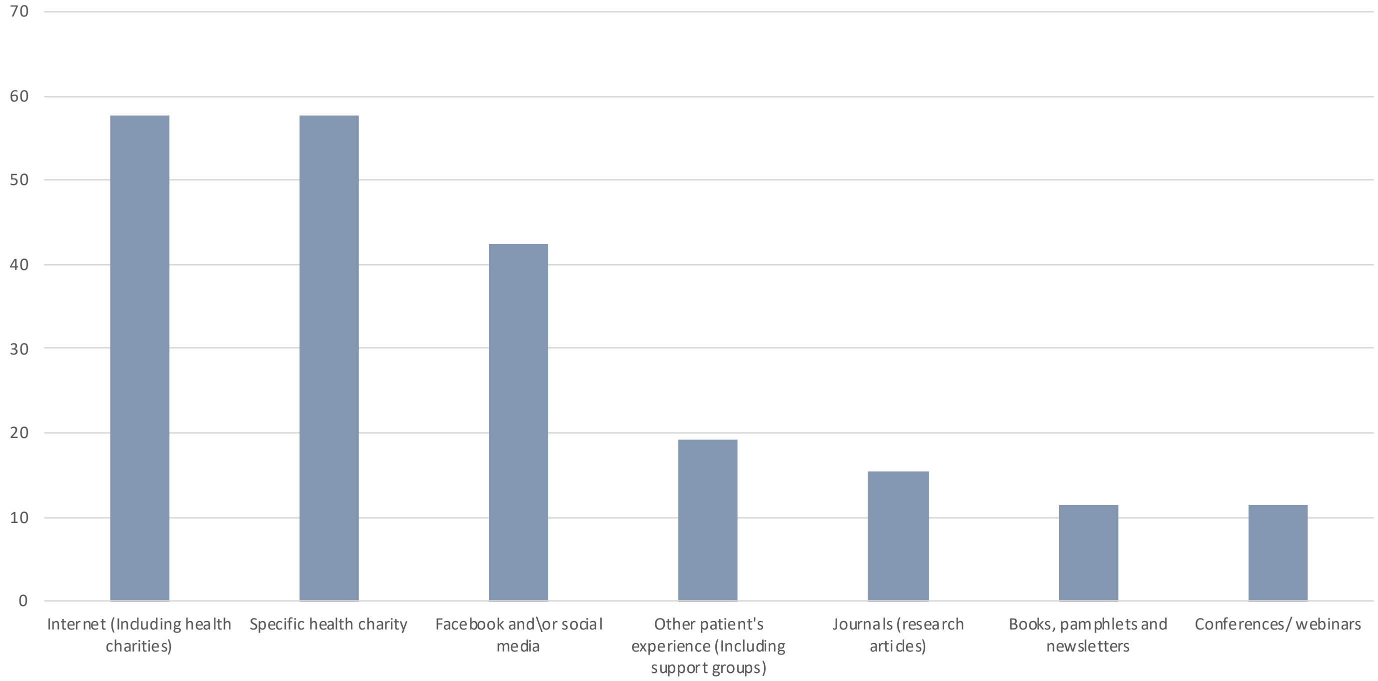


Figure 6.1: Access to information

Table 6.2: Access to information – subgroup variations

Theme	Less frequently	More frequently
Participant describes accessing information through the internet in general	Male Higher status	Non-metastatic Female Mid to low status
Participant describes accessing information from a specific health charity	Non-metastatic Male Aged 65 or older Trade or high school Mid to low status	Metastatic Female Aged 35 to 64 University
Participant describes accessing information primarily through Facebook and/or social media	Male Aged 65 or older Trade or high school Mid to low status	Female Aged 35 to 64 University Higher status
Participant describes primarily accessing information through other patient's experience	Aged 65 or older Trade or high school Mid to low status	Aged 35 to 64 University Higher status
Participant describes accessing information primarily through journals (research articles)	Mid to low status	Aged 65 or older
Participant describes receiving information from books, pamphlets and newsletters	Mid to low status	-
Participant describes accessing information from conferences and webinars	Male Aged 65 or older	Mid to low status

Information that was helpful

In the structured interview, participants were asked to describe what information they had found to be *most* helpful. The most common response was other people's experiences (peer-to-peer) (42.31%). Other helpful information included talking to a doctor or specialist or healthcare team (19.23%), hearing what to expect (e.g. from disease, side effects, treatment) (19.23 %), medical journals and scientific information (19.23%), and health charities (11.54%)

Participant describes other people's experiences as helpful (Peer-to-peer)

I think from a psychological perspective-- when you get diagnosed you're not going, "Okay, let me see what this treatment will do," and that. You're kind of more going-- you google it, says you'll be dead within a year, and you're literally trying to find information that says, "No, you won't be dead in a year." That's the information when you've got lung cancer stage 4, you're looking for that kind of information, the information that will give you hope, "That these people here, they've lived for X number of years," and that gets you back on a normal track of feeling like, "Well, I've got this thing, but I can actually maybe live with it." Participant 004_2023AULUC

With the social media pages, I guess other people who are on exactly the same drug with exactly the same type of cancer is nice because it's a fairly rare one, so people say you'll get better and there'll be a new drug, but I know there's not going to be. It's nice to have other people who are just happy to be symptom-free, I guess. Participant 006_2023AULUC

***What I've just said the Facebook page, the Australian Lung Cancer Support Group it's called. I just found that they don't talk in medical terms, they talk in lay terms. People ask questions that sometimes they don't want to ask their doctors or whatever.
Participant 010_2023AULUC***

***I think the most helpful because it's also a lot to do with getting the head around it all has been the Facebook group. I just, oh, both and the HOSPITAL, the actual group, Oh God, we're not consumers. I hate that word. People with lived experience. Meeting up with other people with lived experience has been the biggest help to me in getting my head around having this diagnosis, which has been very important to do.
Participant 020_2023AULUC***

Participant describes talking to their doctor or specialist as helpful

The most helpful information was Doctors NAME and NAME, the information that they imparted to me, my specialists. Just the information they imparted. Once again, it goes back to you've got a problem, they're going to try and help you and fix you. Participant 012_2023AULUC

I think the initial beautiful diagram I got from the first oncologist, it was fantastic. I remember going to her initially and then she did tests, and then she couldn't see me. I think it was 10 days later, and I just rang her up on day seven, and I said, "I'm really sorry." I said, "I cannot wait another day." She said, "Come in and see me tomorrow." She saw me and wrote down the results, and then she said, "Look, I haven't got all the tests back, however, this is where we're going." Participant 019_2023AULUC

The most helpful information obviously, comes from the oncologist because it's factual and based on [crosstalk] It's just basically about, the prognosis for a start, but also about the treatment.
Participant 026_2023AULUC

Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful

Given that I've gone on this one treatment that's been very effective, knowing what to expect from this drug treatment, observing that I'm consistent with the good end of that, that's all very encouraging. I have a friend who's a doctor. My GP is very approachable. My lung cancer nurse answers any questions I have or tells me who to go to. Just no lack of information about anything I want to know about.
Participant 022_2023AULUC

Treatments available, prognosis, general outcomes. Different options because when you do initially hear the word cancer let alone lung cancer, initially have just one thought in mind, that there's only one path that you can go down. Then you realize there's new treatments, like the targeted therapy. I've told people along the way when I-- You've talked about it. I always think that had this happened 10 years ago, I might not be here today, but because we've made advancements in this new type of treatment, we're able to live with it a lot longer.
Participant 005_2023AULUC

Participant describes information from research journals or scientific sources

PARTICIPANT: Journal articles. They're up-to-date information and they are normally cutting-edge information. Participant 007_2023AULUC

It depends because it changes according to where I am in the journey and what kind of information I seek. For instance, what has been the most helpful recently to me has been on YouTube looking at surgery of lymph nodes on people who had previously received immunotherapy and how it actually impacts on the texture of the tissues of the lymph node. That's quite interesting. That was useful for me because I had received no information on the impact of immunotherapy on the tissue of lymph nodes. Receiving images of surgery of ablation of lymph nodes after immunotherapy or before and the difference in the tissue of the body and the lymph nodes, which is part of the immune system, that was helpful. Because for me, what is helpful is knowledge. Anything which increases my scientific knowledge is helpful. Because it will help me manage and drive my care if I try and gain as much knowledge as possible. It's scientific knowledge.
Participant 023_2023AULUC

I'm following the trials on the targeted therapy. I find that really interesting because I suspect that's where I'm heading. If I do get a recurrence and I perhaps can't take the [unintelligible] biomarkers [unintelligible] change, then the targeted therapy is what's going to help me because I don't know if I could go down a chemo line again.
Participant 025_2023AULUC

Participant describes health charities information as helpful

For me, it's verbal, not written. I'm more of a verbal person. Them just going through with me, like the Lung Foundation just chatting over the phone going this is what usually happens or whatever, and then we can follow that. I'm more of a verbal person. Participant 030_2023AULUC

The most helpful I think is I joined a Facebook group, Lung Cancer Australia. I can't quite remember the name of it. I read their stories. The people who belong to that group, I read their stories, the posts they put up. I read what they go through, what they've been through. I think that I'm quite lucky compared to what some other people are going through. Honestly, that's been the most helpful because that just makes me feel grateful that I'm not as unwell as what they are, or some of those people that have been battling this disease for years.
Participant 003_2023AULUC

Table 6.3: Information that was helpful

Information that has been helpful	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes other people's experiences as helpful (Peer-to-peer)	11	42.31	11	44.00	0	0.00	6	60.00	5	31.25	8	50.00	3	30.00
Participant describes talking to their doctor or specialist as helpful	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes information from research journals or scientific sources	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00
Participant describes health charities information as helpful	3	11.54	2	8.00	1	100.00	2	20.00	1	6.25	2	12.50	1	10.00

Information that has been helpful	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes other people's experiences as helpful (Peer-to-peer)	11	42.31	8	47.06	3	33.33	4	30.77	7	53.85	2	100.00	9	37.50	4	44.44	7	41.18
Participant describes talking to their doctor or specialist as helpful	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes hearing what to expect (e.g. from disease, side effects, treatment) as being helpful	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes information from research journals or scientific sources	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes health charities information as helpful	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76

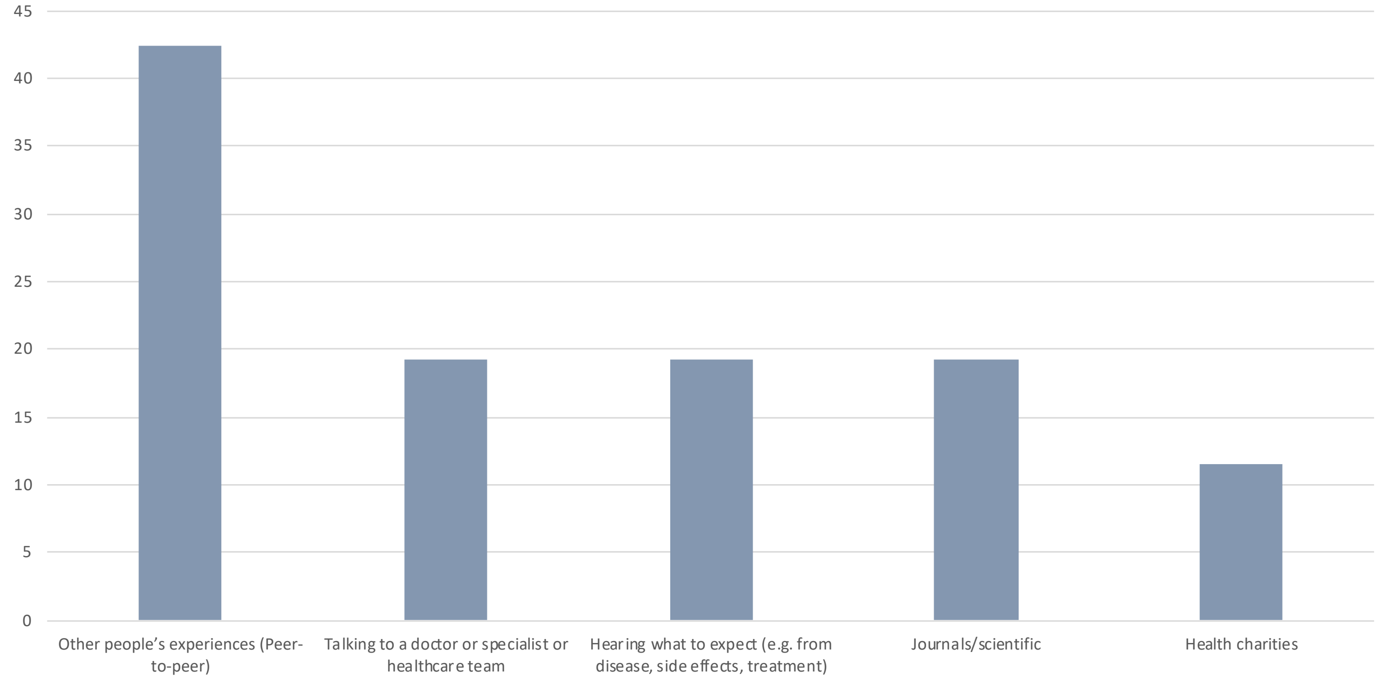


Figure 6.2: Information that was helpful

Table 6.4: Information that was helpful – subgroup variations

Theme	Less frequently	More frequently
Participant describes other people's experiences as helpful (Peer-to-peer)	Metastatic Male Trade or high school	Non-metastatic University
Participant describes information from research journals or scientific sources	Male	Female

Information that was not helpful

In the structured interview, participants were asked if there had been any information that they did not find to be helpful. The most common responses were sources that are not credible (not evidence-based) (26.92%), worse case scenarios (23.08 %), and some information given by their GP or specialist (15.38%) were not helpful. Other participants described that no information was not helpful (23.08%), or that they were confident in deciding themselves (11.54%)

Participant describes information from sources that are not credible as not helpful (Not evidence-based)

Yes. As I said, lots of pages that are telling me that if I pray, [laughs] enough that everything will be fine. Probably more of that just social media stuff.Participant 006_2023AULUC

Mostly social media posts from uneducated people who thinks they have some weird and wacky thing they think you should do to cure your cancer. Mainly social media is very unhelpful in my opinion. Sometimes there are helpful, but that's [unintelligible] unhelpful information. Participant 007_2023AULUC

No, only from listening to other people who don't know what they're talking about. Participant 017_2023AULUC

Yes, it's all the crap about if don't eat sugar or if you don't eat that. Friendly advice from every single person. I don't even tell them now. I feel comfortable not listening to it. I also sometimes feel comfortable ignoring my GP. I have really worked out that they have no clue. This sounds bad, I suppose, [unintelligible] but I wish I could speak with people that know what I'm going through, the medical people that actually get it in a way. Participant 027_2023AULUC

Participant describes no information being not helpful

No, I don't think there's a-- Knowledge is power. Participant 019_2023AULUC

No, every bit of information is useful. I've tried to go on sites that's Mayo Clinic or proper medical sites, not crazy crackpot sort of science, and also just listening to what people who've gone through cancer. A few of the people commented on my condition. One of the things I came to a conclusion that everyone's cancer is slightly different so we can't necessarily draw solid conclusions. Participant 028_2023AULUC

No, I can't think of anything. Participant 010_2023AULUC

Participant describes information about worse case scenarios and negative information as being not helpful

Just from Google Search, just soon as you type "lung cancer prognosis stage 4," it says that 3% or something of people will be alive in 5 years and most people will be getting a year. That's not helpful information.Participant 004_2023AULUC

Absolutely. Every time I saw a statistic, every time I saw something about smoking or non-smoking, it was really not helpful. The stigma, [crosstalk], the statistics, especially early on, are really confronting for someone newly diagnosed. It was like your death sentence. Every research article you read started with, "Lung cancer is the leading cause cancer, morbidity, and mortality in Australia." Participant 015_2023AULUC

I'm very selective about what I read on the internet because I know I'll only read peer-reviewed stuff. I guess some of the internet delving I did was unhelpful because the statistics are so miserable for metastatic lung cancer that I had myself dead in no time anyway. Then you start meeting people who are on the same drug as you, who are actually living longer than the statistics say they should. I think some of the internet stuff, even if it's peer-reviewed, et cetera, it can be unhelpful for your mental state. Participant 020_2023AULUC

Participant describes the GP/specialist as being not helpful

No, nothing. I've not found anything unhelpful, apart from my GP, he's unhelpful. Participant 003_2023AULUC

Just the lack of conversation from the oncologist, to be honest, as a carer it's really frustrating. You turn up there for your regular three-weekly or six-weekly appointment and she goes, "How's everything going? Good. See you later. I'll see you in six weeks." There's no discussion around the ins and outs. She won't dig a bit further for dad and dad doesn't [inaudible] Participant 030_2023AULUC

Participant describes feeling confident in deciding if something is not helpful (or not credible)

I'd say no. I determine what I think is helpful to know. There's information out there which is, in my view, very unregulated. I just don't choose to explore that. I'm aware of source of information that I would regard with some skepticism, but I don't feel affected by that because I just choose what I want to pay attention to. Participant 022_2023AULUC

I'm very selective about what I read on the internet because I know I'll only read peer-reviewed stuff. I guess some of the internet delving I did was unhelpful because the statistics are so miserable for metastatic lung cancer that I had myself dead in no time anyway. Then you start meeting people who are on the same drug as you, who are actually living longer than the statistics say they should. I think some of the internet stuff, even if it's peer-reviewed, et cetera, it can be unhelpful for your mental state. Participant 020_2023AULUC

Table 6.5: Information that was not helpful

Information that has not been helpful	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	6	37.50	1	10.0
Participant describes no information being not helpful	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	4	25.00	2	20.0
Participant describes information about worse case scenarios and negative information as being not helpful	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	1	10.0
Participant describes the GP/specialist as being not helpful	4	15.38	3	12.00	1	100.00	2	20.00	2	12.50	3	18.75	1	10.0
Participant describes feeling confident in deciding if something is not helpful (or not credible)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	2	12.50	1	10.0

Information that has not been helpful	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	1	50.00	6	25.00	3	33.33	4	23.5
Participant describes no information being not helpful	6	23.08	2	11.76	4	44.44	2	15.38	4	30.77	1	50.00	5	20.83	1	11.11	5	29.4
Participant describes information about worse case scenarios and negative information as being not helpful	6	23.08	6	35.29	0	0.00	3	23.08	3	23.08	0	0.00	6	25.00	3	33.33	3	17.6
Participant describes the GP/specialist as being not helpful	4	15.38	3	17.65	1	11.11	2	15.38	2	15.38	1	50.00	3	12.50	3	33.33	1	5.88
Participant describes feeling confident in deciding if something is not helpful (or not credible)	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.7

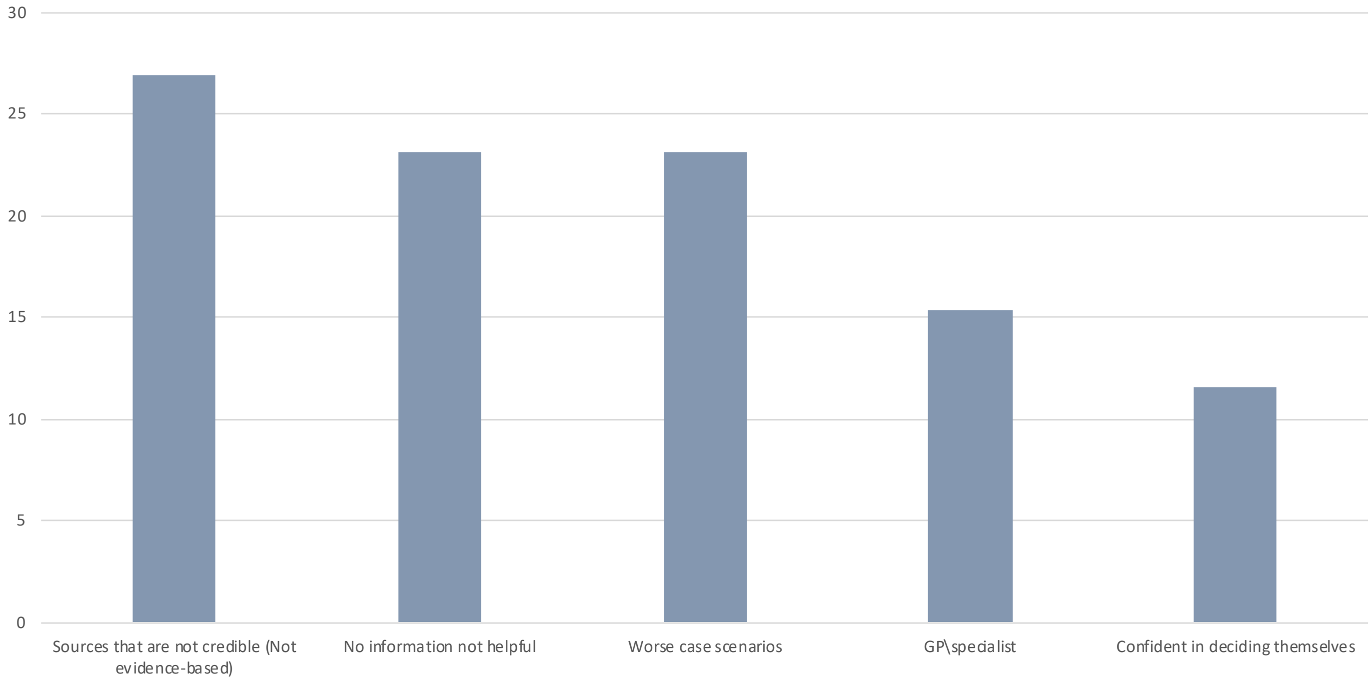


Figure 6.3: Information that was not helpful

Table 6.6: Information that was not helpful – subgroup variations

Theme	Less frequently	More frequently
Participant describes information from sources that are not credible as not helpful (Not evidence-based)	Male	Female
Participant describes no information being not helpful	Aged 35 to 64 Mid to low status	Aged 65 or older
Participant describes information about worse case scenarios and negative information as being not helpful	Male Aged 65 or older	Aged 35 to 64 Mid to low status
Participant describes the GP/specialist as being not helpful	-	Mid to low status
Participant describes feeling confident in deciding if something is not helpful (or not credible)	Non-metastatic	-

Information preferences

Participants were asked whether they had a preference for information online, talking to someone, in written (booklet) form or through a phone App. The most common responses were talking to someone plus online information (38.46%), online information (30.77%), and written information (23.08 %). Other preferences included talking to someone (11.54%), and all forms (11.54%).

The main reasons for a preference for online information were accessibility (38.46%), and being able to digest information at their own pace (19.23%). The main reason for talking to someone as a preference was being able to ask questions, get clarifications, and feeling supported (23.08 %). Participants described that written information, online information and talking to someone was preferred because it was relevant or personalised (30.77%).

Talking to someone plus online information as main preference

Probably a bit of a mixture, but online, via email or the Alpha Group, which is the lung cancer group with the Lung Foundation, that's an online forum. That's all good. That kind of stuff is good, but having online where I'm able to print something if I want to read through it at my own pace would be ideal. Person to person. I think there should be a little bit more person-to-person if possible. Sometimes you need to feel like someone actually has some compassion and care. Participant 018_2023AULUC

I actually like to talk to the oncologist to get a general overview and then I love being referred to something online because it's always there. I don't want to find that bit of paper that they handed me with it on and I can always refer back to it because you don't take everything in at a consultation. It's great to have a reliable source that they will say, go and get this information here that I can refer back to. Online for me is really handy.
Participant 020_2023AULUC

I spend a lot of my time online so I'm quite comfortable with-- I've been using computers for more than 40 years or whatever, so I'm not like some my people of my age who don't know how to use a computer, so I'm fairly comfortable. I've got a research background, so I know how to do research properly, but it was interesting to talk to some of the doctors and nurses who have got current and day-to-day experience.
Participant 028_2023AULUC

Online information as main preference

Definitely online because I can read it over and over again until I get it right and I can save, that in the end, that's all I need. I don't go on the internet, but when I'm reading a proper studies that have been done on real patients and so on.
Participant 002_2023AULUC

Probably online just because it's easier. As I said, I'm from a fairly smaller country town. It's not like I have big groups or people to talk about it with. Of course, COVID has prevented any type of groups. I'm happy with online information.
Participant 006_2023AULUC

Only online information because I can come and go to that point and I can read it at my leisure and I can critique at my leisure and actually try and work out how viable and accurate the information is. Participant 007_2023AULUC

Look, it is easier just to look online and the information is readily available. Sorry, I've just remembered something else. I have been looking at the Cancer Council as well online and that's been quite good as well.
Participant 010_2023AULUC

Written information as main preference

PARTICIPANT: I would've loved it if Australia had like breast cancer, but had pamphlets. You just go and grab the pamphlet from your doctor's surgery and there you have it. It tells you about the new types of treatment, and that it's not all doom and gloom anymore. That's what I would love. They didn't have anything, it's so underfunded in lung cancer. There's literally nothing out there. All your oncologist says to you is, "Don't google it," but you've got to get your information from somewhere…I think when it happens and you get the CT scan results and you go to your GP and they go, oh, they think they found the lung cancer. At that point, you need to have that booklet so that you can have knowing the facts of the matter, sort of thing. You go through so much mental turmoil going, "I didn't smoke, how did I get this thing?" You go through a lot. It would be nice to have that booklet that explains everything and that they've got these new treatments, et cetera.
Participant 004_2023AULUC

PARTICIPANT: Look, if I can access it online, great. I'm still not opposed to written. I have lots of books and lots of things here.
Participant 015_2023AULUC

Talking to someone as main preference

I don't think you can-- You need to speak to your oncologist. Your oncologist is the only one that really knows. You can't compare your journey with someone else's journey. You've just got to hope that you've got a good oncologist, whether they're-- I did an interview the other day with someone and I think they were talking about the lack of information. It's funny, that's the one thing I will say is, you know how the Cancer Council have all the books on all the different cancers? When you go to a Guard Chemo, they'll have every cancer and those yellow books, and they're very good. However, I could not bring myself to go and get the lung cancer one because I was so mortified that I had it, and because of the general attitude, no one's survived.I couldn't even go and get the book, I was just

not ready to face it. I'll just deal with the oncologist and the nurse, the fantastic nurse I had for the trial. They were positive. Not positive, positive, but they told you what-- Just their communication was brilliant. The people who can't deal with not having a yes or a no, they're not going to find the journey good, because no one really knows. A lot of people-- One of my friends has rung me up because her mother was diagnosed with it last year, and she didn't want to have any treatment. He said, "Could you speak to her?" I did. I did manage to talk her into having the treatment. However, she's going to die. You're dealing with all that as well. It's just everyone is individually on this journey next to each other. It's not like other cancers.
Participant 019_2023AULUC

I like to get information from a mixed range of sources. My preference is to get the factual information from the specialist, and then, to have material to take away that you can read that he's given all his referred to because then, you know it's accurate information but, I do like to read it later because obviously the appointments are quite quick and you forget stuff when you get bombarded.
Participant 026_2023AULUC

All forms

No. You can ring me. You can email me. You can fax me. You can do whatever you want.
Participant 014_2023AULUC

No, it doesn't matter.
Participant 017_2023AULUC

Table 6.7: Information preferences

Information preferences	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Talking to someone plus online information as main preference	10	38.46	9	36.00	1	100.00	4	40.00	6	37.50	6	37.50	4	40.00
Online information as main preference	8	30.77	8	32.00	0	0.00	**2**	**20.00**	6	37.50	**7**	**43.75**	**1**	**10.00**
Written information as main preference	6	23.08	6	24.00	0	0.00	**1**	**10.00**	5	31.25	5	31.25	**1**	**10.00**
Talking to someone as main preference	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
All forms	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	**0**	**0.00**

Information preferences	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Talking to someone plus online information as main preference	10	38.46	7	41.18	3	33.33	5	38.46	5	38.46	0	0.00	10	41.67	**1**	**11.11**	**9**	**52.94**
Online information as main preference	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	2	100.00	6	25.00	3	33.33	5	29.41
Written information as main preference	6	23.08	3	17.65	**3**	**33.33**	**1**	**7.69**	**5**	**38.46**	0	0.00	6	25.00	2	22.22	4	23.53
Talking to someone as main preference	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
All forms	3	11.54	1	5.88	**2**	**22.22**	2	15.38	1	7.69	0	0.00	3	12.50	**3**	**33.33**	**0**	**0.00**

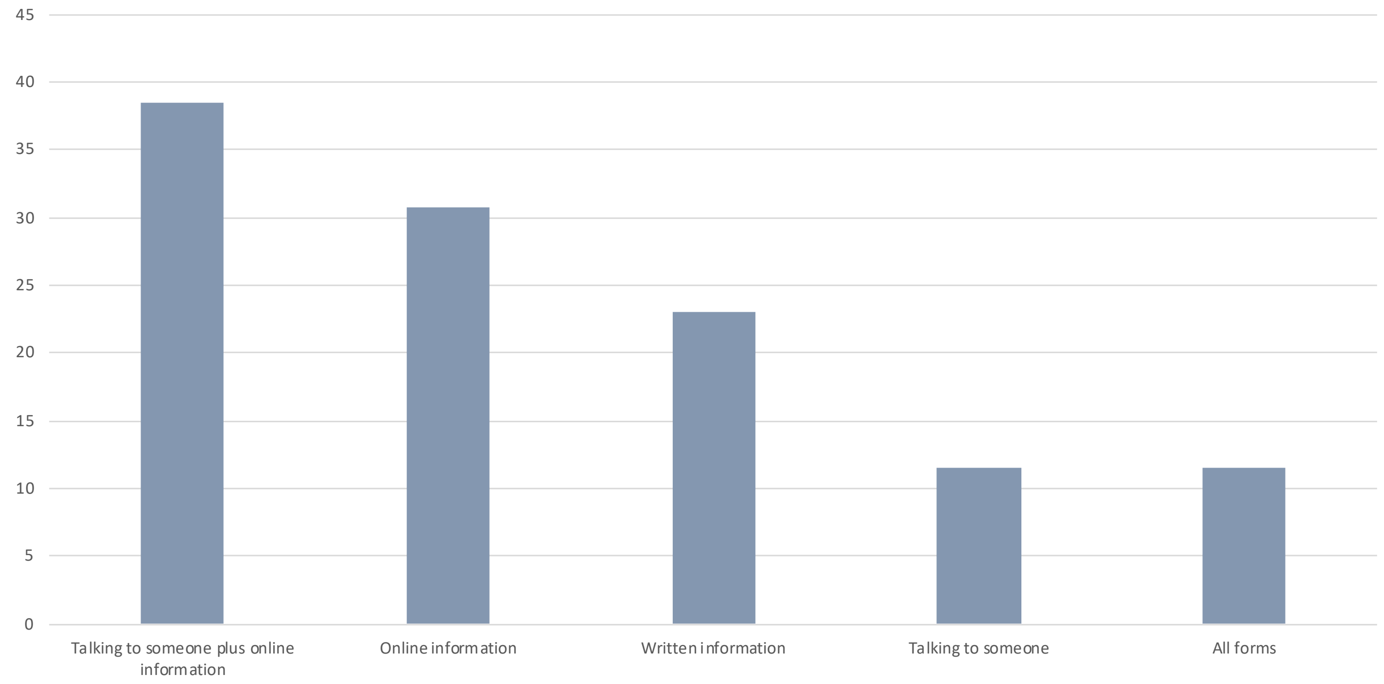


Figure 6.4: Information preferences

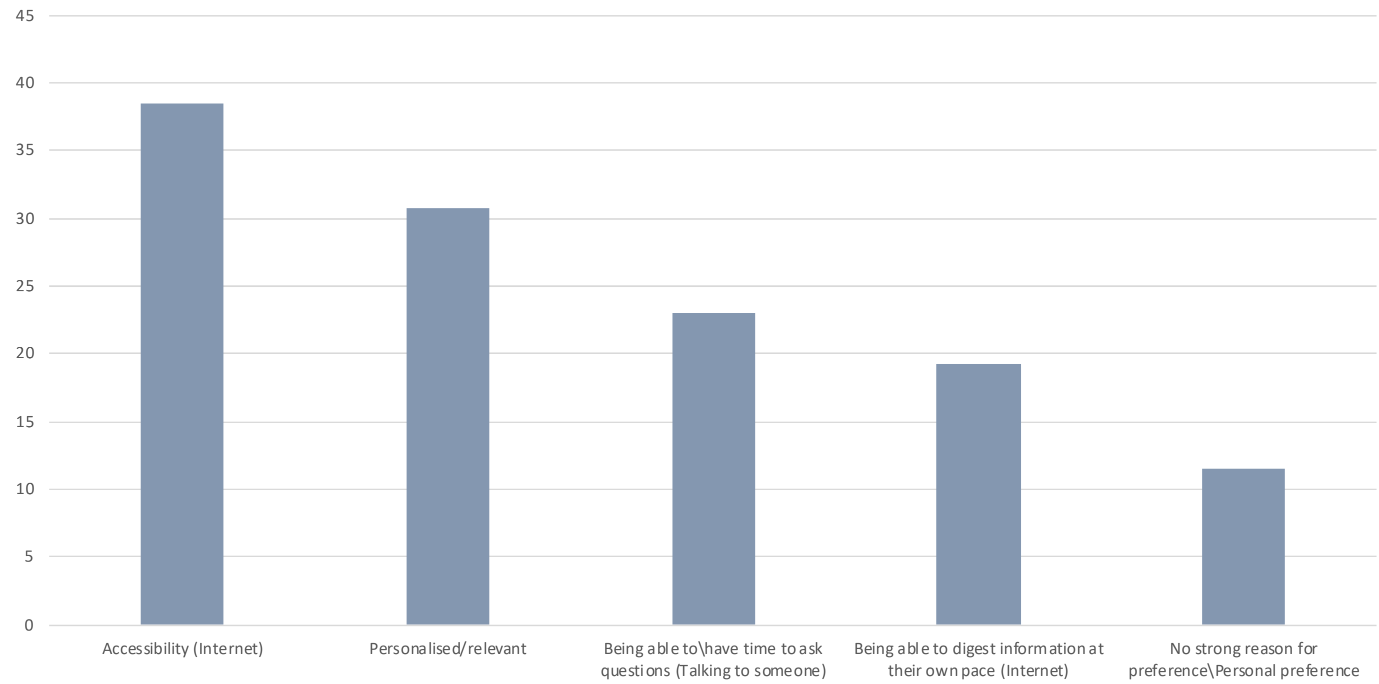


Figure 6.5: Reasons for information preferences by format

Table 6.8: Information preferences – subgroup variations

Theme	Less frequently	More frequently
Talking to someone plus online information as main preference	Mid to low status	Higher status
Online information as main preference	Non-metastatic Male	Female
Written information as main preference	Non-metastatic Male Trade or high school	Aged 65 or older University
All forms	Male Higher status	Aged 65 or older Mid to low status

Timing of information

Participants in the structured interview were asked to reflect on their experience and to describe when they felt they were most receptive to receiving information. The most common times were at the beginning (diagnosis) (26.92%), and after results from treatment, follow up scans, or when disease progressed (26.92%). Other times included after treatment (19.23%), continuously (19.23%), and after the shock of diagnosis (11.54%).

Participant describes being receptive from the beginning (diagnosis)

Definitely, in the beginning. In the beginning, you've got your adrenaline going through the roof and you're just inputting. Inputting, inputting the whole time, trying to find a way out of this. I know that sounds really silly, but it's like you're in a hole and you're trying to dig your way out. Definitely in the beginning. Then the adrenaline drops off after about six months, you can feel it dropping off, and you relax to this. Participant 002_2023AULUC

Immediately once I was sent to the two specialists, they sat me down and they told me what going to occur, what was the problem, and the procedures were going to happen. Of course, I had to give my consent. That should do. I had to give my consent, but they were like, "There's a diagnosis, and this is what we can do, this is what we can't do, and this is how we're going to approach it." I think that's the greatest information you can get to make [crosstalk]. Participant 012_2023AULUC

I wish I had met someone that could have explained cancer to me when I was originally diagnosed. I still can't believe no one spoke to me about it or talked to me about it. All that they said to me was, "You're 1B," and it was something like the cancer was smaller or [inaudible] one. It's a B because-- I can't even remember it. Then, when I went on [unintelligible] my oncologist didn't even tell me that I was stage 4. I heard it on the phone. He rang up and had to get my prescription. I said to him, "Am I now stage 4 cancer?" He said, "Yes.". If I hadn't overheard his conversation when he rang up requesting my medication I wouldn't have known.
Participant 027_2023AULUC

Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans

Probably once I had my very first scan after my initial treatment and I saw positive results, then I was probably more receptive to all that information because I could see that the treatment was actually working. Since my latest diagnosis, I haven't really done much research. I think I've just been overwhelmed with taking in what I have to go through this time around. To be honest, the third time that you hear that the disease has progressed is the hardest compared to the first time. For a while, I was almost cruising along, living with this disease is stable to the point where the doctors could hardly see any tumour. Not that I was in remission, but it was very stable. Then to find that we've gone backwards quite a bit with this latest diagnosis and it's really been confronting mentally.
INTERVIEWER: Yes, that would be hard.
PARTICIPANT: We thought that's stable that we even bought a river cruise in Europe for May next year. We haven't cancelled that. We've got up to a month before if we need to. That's how confident we were. I was actually having issues getting travel insurance. That's why we hadn't been able to book the whole trip because my cancer wasn't going to be covered but we thought, we can work around that. Even my doctor given me a letter of recommendation stating that my disease was stable to help support my application for travel insurance.
Participant 005_2023AULUC

Probably after I've kept getting good results. Participant 013_2023AULUC

Yes. I think in the period after the major improvements from my drug treatment, that was when I was most available because prior to that, there was a degree of desperation, of desperately hoping that the direction I was going was going to lead to my recovery. Once the signs of that recovery were there, that was very reassuring and enabled me to access that information in a much more relaxed manner. That's how it is now. I just think about the time when my drug treatment ceases to be effective and that there's a very major likelihood that that will be the case. I won't be on this drug treatment forever or for the rest of my life. That's an anxiety in waiting. My preparation for that is to be well informed, to have my connections active, and to give it my attention and talk with relevant people about what my needs are. Participant 022_2023AULUC

Participant describes being receptive to information after treatment

I think probably post-treatment once because in terms of emergency, your brain is not, actually it's a flight or fight. It's this survival thing where you have this tunnel vision and the tunnel vision is, okay, you are the specialist. I've got that. What do I need? If you frame it into the perspective that I was trusting the medical system and the health system, which I've lost total trust in now, so at the time the last thing I wanted, it was just throw me a hand, save me from that, and do whatever you think. Once you do the first treatment, you finish the first treatment. After I think you've done something, at least it's action. Then in the time where you finished the treatment that you've been given, then the emergency has passed because you've done whatever you had to do at the time. That's when you start accumulating information and integrating information. I certainly don't need it at the beginning.
Participant 024_2023AULUC

Probably post-op but pre-op it was just such a shock because of my anxiety and catastrophizer as well. Post-op it's better to get information about the future, what happens now, what's the prognosis, what your outlook going to be.
Participant 010_2023AULUC

Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible

Okay, I'm going to give you an example here, you're probably going to [crosstalk]. Here's a great example of when not to give information, when a person has a-- what it bronchoscopy or myelination? No, bronchoscopy. When a person has just had a bronchoscopy being put under sedation and I've come out and I said to the nurse, "Am I okay?" I was still waking up, she said, "Yes, yes, they got lots of blood clots out." I went, "Oh, great." I go in and been put in my room, and I think, "Great, it's a blood clot." Then a doctor comes into my room and starts wanting to talk to me and says, "Do you know why you're here?" I say, "Yes, I have a blood clot." He says, "No, you have lung cancer." "What do you mean? No, I have a blood clot." He said, "Doctor, blah, blah, blah, came in and spoke to you about you having lung cancer." I do not recall a single word that he-- Never tell someone who has just come out from sedation bad news, because it's bad enough that you're coming out from sedation, let alone being hit by the words. You know what? He

probably did tell me but do I remember a single word of it? No. Was my [crosstalk] my first experience, someone [crosstalk] me saying, "No, you do not have a blood clot, you have lung cancer." I think that little bits over time, for someone like me, I was in hospital for two weeks. There was no reason for anybody to not keep communicating with me along the way. To be honest, it did happen slowly over time, but it could have been better. I think that even over a course of a day, someone could have come in and started speaking to me about some things and assess the situation. I don't think anyone ever assesses the situation about where you're at, if I'm in hospital, someone needed to have assessed, "When is the right time to tell her?" I don't feel anyone did.
Participant 015_2023AULUC

PARTICIPANT: No because when they give you the diagnosis, they also give you-- I've got three big booklets and a whole heap of paper stuff and a whole heap of information to bring home and read. Then when you go up for treatment for the first time, they show you videos and all sorts of things. It's just incredible. I was just blown away by it all.
Participant 017_2023AULUC

Participant describes being receptive to information after the shock of diagnosis

I don't know about that. At the start, there was a lot going on. I took a nurse with me to the original appointment who took lots of notes so I could read through them later. I did put my head in the sand for a while. I guess I'm probably more receptive now, but only maybe because I've come to terms [laughs] a bit better.
Participant 006_2023AULUC

Yes and I remember the first couple of visits where you're getting told this is and I got told it was lung cancer from my breasts oncologist because we were all going down that path and then she got the results and she said to me, "I'm really sorry to tell you." That was like a big body blow. The first visit to the medical oncologist for my lung cancer was just a blur. I would say a couple of months in was when I had my head around enough that I could actually start to ask questions that were more relevant. I consider myself pretty good medically and understand a lot but I really think it takes a couple of months before you can go, oh my head's clear enough to ask some more pertinent questions, not to be just in this whirlwind of panic. Does that make sense?
Participant 020_2023AULUC

Table 6.9: Timing of information

Timing of information	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes being receptive from the beginning (diagnosis)	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	5	31.25	2	20.00
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	**6**	**37.50**	**1**	**10.00**
Participant describes being receptive to information after treatment	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	**5**	**31.25**	**0**	**0.00**
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes being receptive to information after the shock of diagnosis	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	**0**	**0.00**

Timing of information	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes being receptive from the beginning (diagnosis)	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	0	0.00	7	29.17	3	33.33	4	23.53
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	7	26.92	5	29.41	2	22.22	**5**	**38.46**	**2**	**15.38**	1	50.00	6	25.00	**4**	**44.44**	3	17.65
Participant describes being receptive to information after treatment	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	5	19.23	4	23.53	1	11.11	**0**	**0.00**	**5**	**38.46**	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes being receptive to information after the shock of diagnosis	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	1	50.00	2	8.33	1	11.11	2	11.76

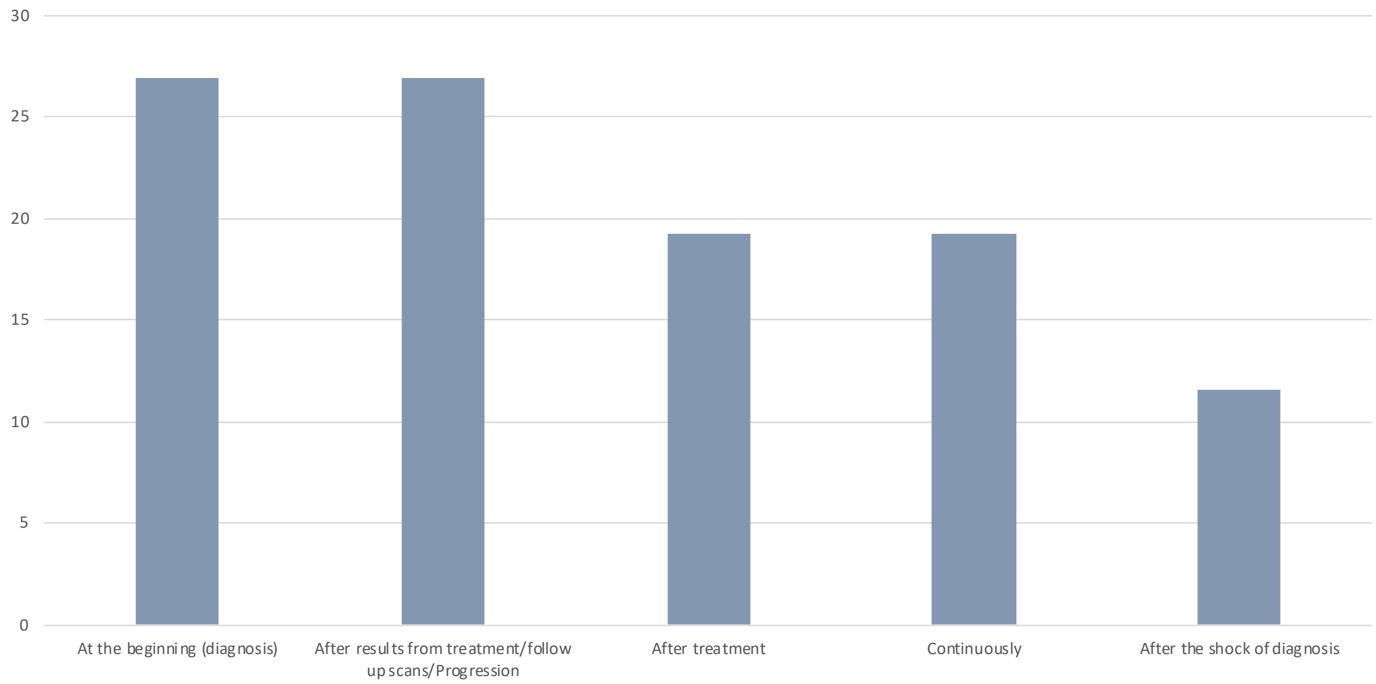


Figure 6.6: Timing of information

Table 6.10: Timing of information – subgroup variations

Theme	Less frequently	More frequently
Participant describes being receptive from the beginning (diagnosis)	-	-
Participant describes being receptive to information after results from treatment are known, or when getting results of follow up scans	Male University	Female Trade or high school Mid to low status
Participant describes being receptive to information after treatment	Male	Female
Participant describes being receptive to information continuously throughout their experience or bit-by-bit so that it is digestible	Trade or high school	University
Participant describes being receptive to information after the shock of diagnosis	Male	-

Healthcare professional communication

Participants were asked to describe the communication that they had had with health professionals throughout their experience. The most common theme was that participants described having an overall positive experience (n=26, 52.00%). The most common responses that they had overall positive communication (38.46%), and overall negative communication (30.77%). Other participants described that communication was overall positive, with the exception of one or two occasions (19.23%).

Participants describes health professional communication as being overall positive

It's been good, especially with my oncologist because he seems to have a lot of empathy and I can tell when things are going well and when things aren't going well. I never actually asked him for a prognosis at the beginning and I don't think he believes in giving a prognosis either because everyone's different. Everyone's situation is different in how they deal with treatment, that sort of thing. We never discussed prognosis and another lung cancer patient said to me, "No other human being should tell you how many months you've got left." I agree with that, just go with what you've got but this time around, when I had this latest diagnosis, I did ask him and he gave me a timeframe, I think maybe reluctantly, but I think I pressed it a bit more this time. He said, "You can go way past that.
Participant 005_2023AULUC

It's been good since I've been referred from the oncologist, the first part, I guess where they're trying to determine what stage you're at and because the PET showed up a few different hotspots, and unfortunately in CITY, different hospitals have different specialists, so I got referred to four different hospitals all around CITY for different treatment at different body parts, whereas it's easier just to be managed by one

hospital. Good, yet coordination could be better. Participant 026_2023AULUC

Yes, it's been awesome. Top-notch.
Participant 006_2023AULUC

Participants describes health professional communication as being overall negative

DOCTOR said, "You've got lung cancer, you're going to die. This is what we can do now. That's it." They really don't know much enough about it. They put all lung cancers into the same box, I guess, too because that's what most people do. I share to people a lot about lung cancer. They, "Oh, did you smoke?" "No. It's nothing to do with smoking. It's a gene, but anyway." I think they're a bit the same, too. They know that if you've got stage 4 lung cancer, that you're going to be dead within 12 months. They don't tell me anything I don't already know. [crosstalk].
Participant 002_2023AULUC

Between 0 and 10, I would say 2.
Participant 023_2023AULUC

I'd say pretty woeful. It's been shocking. I thought I was going a bit nuts. [unintelligible] talked one night to my husband, and he said, "I was wondering when you're going to say something about this." because he's been coming to the appointments with the oncologist and he said, he can't believe how poor it is. I'm not nuts. It has been really-- It's just like a process and it's almost like they've got their hand on the door the minute you sit down to open up and chuck you out again. They're nice enough people. Whether they're just so busy, or whether because I'm 2A and they're dealing with much sicker people. I don't know what it is but anyway, still a paying client.
Participant 025_2023AULUC

Participants describes health professional communication as being overall positive, with the exception of one or two occasions

Good. Mostly good. Sometimes, it's really good when you've got an appointment, and you're sitting in front of the person or you're on the phone with them. It's really hard to get that appointment sometimes. If you want information outside of your allotted appointment time that might really difficult.
Participant 007_2023AULUC

I think the communication has been-- Okay. Look I think it'd be unfair to paint that brush, the negative brush to the clinician to have provided really superior care and support and communication. I think communication in general has been really good but there have been particular individuals where it has been horrible. I don't want to give an average score and go, "Oh, yes, this generally has been okay." Because it has either been really good or I've had really bad. I've had a clinician walk in again and say, "Do you why you're here today?" Because they all want to ask you why you're here today. You say, "Yes, I have lung cancer." He says, "Well, I have your results." I say, "Well, I don't want them." He said, "I'm sorry?" I said, "Well, have you got my pathology report?" He said, "No." I said, "Well, until you've got my report and you know exactly what you're going to do with me, don't give me anything. Don't come and talk to me." He said, "Well, that's not how we do things here." I said, "That's how we're going to do things here." I think, again, no understanding or consideration of where I was at. I said, "I feel like I've been bashed to the floor, and now they want to beat me over and over and over again." I was sick of people walking into my room, wanting to give me more information when I'm, "Enough already." I think communication when I-- Communication has been poor, because they hadn't recognized where I was at at the earlier stage. Then I did have one oncologist where his communication was horrible, and I hated that 12 months. The stress that that created for me was incredible. He was one of the reasons I wanted to leave and come off the trial. Then, I've had others where it's amazing.
Participant 015_2023AULUC

I've either had really good communication or I've had awful communication. Awful. In some respects, the awful people have actually accessed me and made it so I ended up with a better outcome, if that makes any sense. You don't get any more from doctors unless you ask. You don't get anymore unless you have it written down and you go in there and ask for it. Otherwise, you don't necessarily get told it. Then with different receptionists, some of them can be quite awful. One of them, who was booking my surgery, was just appalling, but, had she not been so appalling, I probably wouldn't have had -- Well, we had words and then [chuckles] I said, "Move me to another doctor," and she did, and I think I ended up with a better surgeon and a better outcome. As awful as it was, it probably gave me a better outcome, truth be known. My actual care of looking after me, I think, seemed quite

good, but some of the communication, like the finance person, in Genesis care for my radiation because, of course, that's not covered under your private healthcare and you had to pay for it. She was completely rude and obnoxious. Anyway, you get through that.
Participant 018_2023AULUC

Table 6.11: Healthcare professional communication.

Healthcare professional communication	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participants describes health professional communication as being overall positive	10	38.46	10	40.00	0	0.00	6	60.00	4	25.00	6	37.50	4	40.0
Participants describes health professional communication as being overall negative	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	7	43.75	1	10.0
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	4	25.00	1	10.0
No particular comment (Other/no response)	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	2	12.50	1	10.0

Healthcare professional communication	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participants describes health professional communication as being overall positive	10	38.46	6	35.29	4	44.44	7	53.85	3	23.08	1	50.00	9	37.50	4	44.44	6	35.2
Participants describes health professional communication as being overall negative	8	30.77	5	29.41	3	33.33	2	15.38	6	46.15	1	50.00	7	29.17	2	22.22	6	35.2
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	0	0.00	5	20.83	1	11.11	4	23.5
No particular comment (Other/no response)	3	11.54	1	5.88	2	22.22	3	23.08	0	0.00	0	0.00	3	12.50	2	22.22	1	5.88

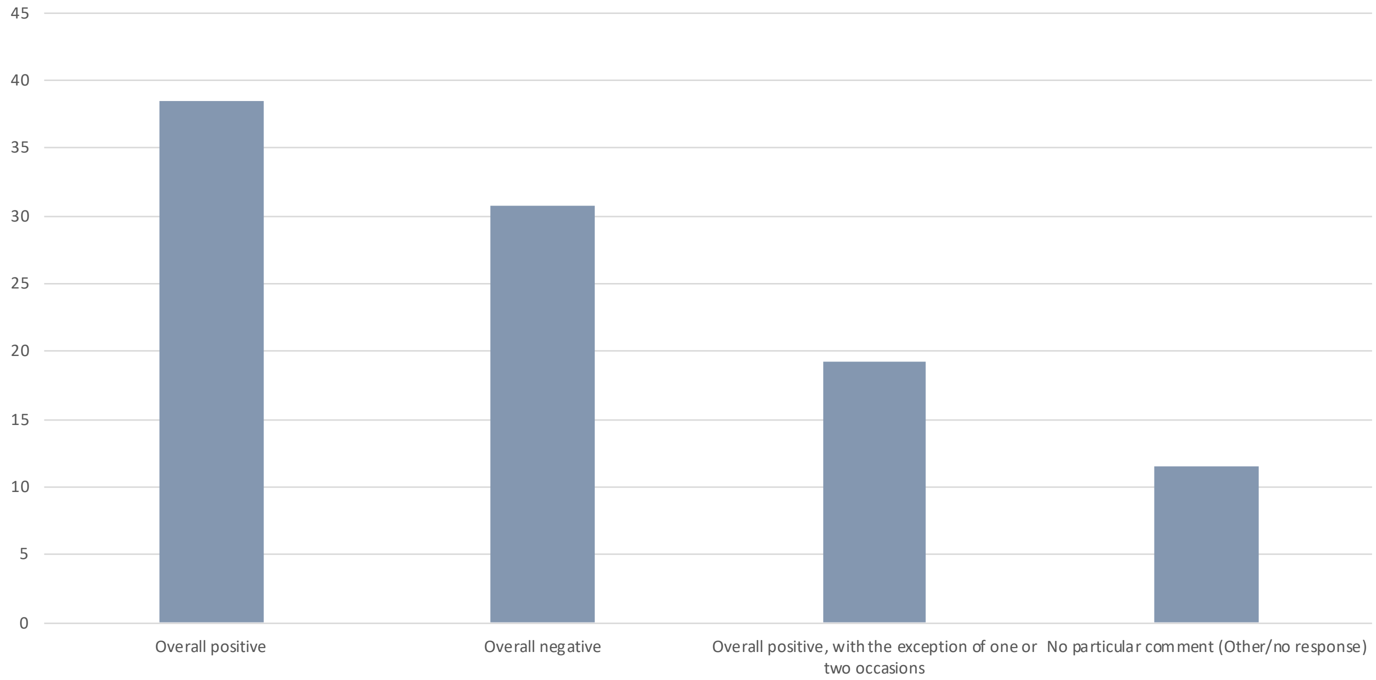


Figure 6.7: Healthcare professional communication

Table 6.12: Healthcare professional communication – subgroup variations

Theme	Less frequently	More frequently
Participants describes health professional communication as being overall positive	Metastatic University	Non-metastatic Trade or high school
Participants describes health professional communication as being overall negative	Male Trade or high school	Female University
Participants describes health professional communication as being overall positive, with the exception of one or two occasions	Trade or high school	University
No particular comment (Other/no response)	Non-metastatic University	Aged 65 or older Trade or high school Mid to low status

Healthcare professional communication (Rationale for response)

Participants described reasons for positive or negative communication with healthcare professionals. Participants that had positive communication, described the reason for this was because of holistic, two-way, supportive and comprehensive conversations (19.23%). The main reason for negative communication was that it was dismissive, that they had one way conversations (15.38 %).

Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)

Care coordination scale (n=27)	*Mean*	*SD*	*Median*
*Communication**	*34.30*	*11.06*	*32.00*
*Navigation**	*23.37*	*6.52*	*25.00*
*Total score**	*57.67*	*15.82*	*56.00*
Care coordination global measure	*5.96*	*3.31*	*6.00*
Quality of care global measure	*6.81*	*3.00*	*8.00*

I think the communication has been-- Okay. Look I think it'd be unfair to paint that brush, the negative brush to the clinician to have provided really superior care and support and communication. I think communication in general has been really good but there have been particular individuals where it has been horrible. I don't want to give an average score and go, "Oh, yes, this generally has been okay." Because it has either been really good or I've had really bad. Participant 015_2023AULUC

Participant describes health professional communication as being dismissive (One way conversation)

I think been pretty good. Although 18 years ago when I went off the trial and the trial nurse went away, I think she's a general cancer nurse who works over two hospitals, it's diminished. She was the one who also said, "Oh, it's in your head. It's like, "How dare you?" You just shouldn't say that as a nurse. There are other ways to approach things like that. Anyway, it is what it is, isn't it? I think nursing's changed a lot as well in the last 20 years. There's not as much care over there. When they moved me from ICU to the ward, they knocked the tube that I had for my pain relief. It was an odd PSA button that you press. All night, I was calling the nurse and I kept on saying, I'm in pain. He said, just keep on clicking it. You can't overdose on it. I'm thinking, why? I've been clicking all night. I was in so much pain and I couldn't move. I had a drain coming out of the side. The day nurse came on and she took off the tube. It had been dismantled and there was a big lump and a bruise all over my arm from where it had just drained and hadn't gone into my blood. You're just thinking, oh my gosh. Like just shit, whose fault is it? Who is in the wrong here? NAME has it, it was the one who shut it down. Do I blame him or do I blame the nurse who wheels me from ICU into the ward, or do I blame the nurse who I kept on buzzing and he did nothing about it? You just think, well, thank God I'm still alive and I can walk out of here. It shouldn't have happened. Participant 019_2023AULUC

Table 6.13: Healthcare professional communication (Rationale for response)

Healthcare professional communication (rationale for response)	**All participants**		**Person with lung cancer**		**Family member or carer**		**Non-metastatic**		**Metastatic**		**Female**		**Male**	
	n=26	**%**	**n=25**	**%**	**n=1**	**%**	**n=10**	**%**	**n=16**	**%**	**n=16**	**%**	**n=10**	**%**
Participant describes healthcare communication as good, with no particular reason given	6	23.08	6	24.00	**0**	**0.00**	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	19.23	5	20.00	**0**	**0.00**	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes health professional communication as being dismissive (One way conversation)	4	15.38	4	16.00	**0**	**0.00**	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes healthcare communication as limited, with no particular reason given	4	15.38	3	12.00	**1**	**100.00**	1	10.00	3	18.75	3	18.75	1	10.00

Healthcare professional communication (rationale for response)	**All participants**		**Aged 35 to 64**		**Aged 65 or older**		**Trade or high school**		**University**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=26	**%**	**n=17**	**%**	**n=9**	**%**	**n=13**	**%**	**n=13**	**%**	**n=2**	**%**	**n=24**	**%**	**n=9**	**%**	**n=17**	**%**
Participant describes healthcare communication as good, with no particular reason given	6	23.08	3	17.65	3	33.33	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes health professional communication as holistic (Two way, supportive and comprehensive conversations)	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Participant describes health professional communication as being dismissive (One way conversation)	4	15.38	3	17.65	1	11.11	0	0.00	4	30.77	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes healthcare communication as limited, with no particular reason given	4	15.38	1	5.88	3	33.33	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65

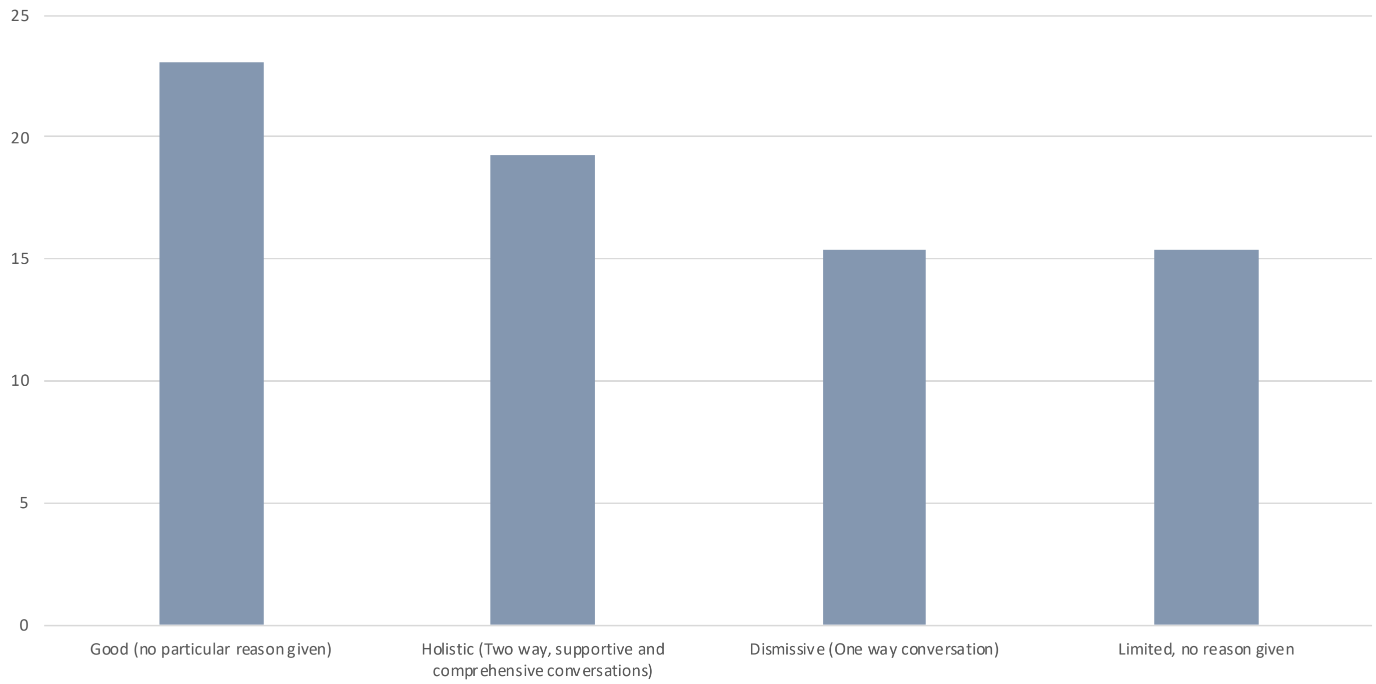


Figure 6.8: Healthcare professional communication (Rationale for response)

Table 6.14: Healthcare professional communication (Rationale for response) – subgroup variations

Theme	Less frequently	More frequently
Participant describes healthcare communication as good, with no particular reason given	-	Aged 65 or older
Participant describes health professional communication as being dismissive (One way conversation)	Trade or high school Mid to low status	University
Participant describes healthcare communication as limited, with no particular reason given	-	Aged 65 or older

Partners in health

The Partners in Health questionnaire (PIH) measures an individual's knowledge and confidence for managing their own health. The Partners in Health comprises a global score, 4 scales; knowledge, coping, recognition and treatment of symptoms, adherence to treatment and total score. A higher score denotes a better understanding and knowledge of disease. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 6.15.

The overall scores for the cohort were in the highest quintile for **Partners in health: Knowledge** (median=28.00, IQR=7.50), **Partners in health: Recognition and management of symptoms** (mean=19.89, SD=3.39), **Partners in health: Adherence to treatment** (median=15.00, IQR=4.00), **Partners in health: Total score** (median=78.00, IQR=26.50) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health

The overall scores for the cohort were in the second highest quintile for **Partners in health: Coping** (mean=15.89, SD=5.96), indicating good coping.

The **Partners in health: knowledge** scale measures the participants knowledge of their health condition, treatments, their participation in decision making and taking action when they get symptoms. On average, participants in this study had very good knowledge about their condition and treatments.

The **Partners in health: coping** scale measures the participants ability to manage the effect of their health condition on their emotional well-being, social life and living a healthy life (diet, exercise, moderate alcohol and no smoking). On average, participants in this study had were good at coping with their condition.

The **Partners in health: recognition and management of symptoms** scale measures how well the participant attends all healthcare appointments, keeps track of signs and symptoms, and physical activities. On average, participants in this study had very good recognition and management of symptoms.

The **Partners in health: treatment** scale measures the participants ability to take medications and complete treatments as prescribed and communicate with healthcare professionals to get the services that are needed and that are appropriate. On average, participants in this study had very good treatment adherence.

The **Partners in health: total score** measures the overall knowledge, coping and confidence for managing their own health. On average, participants in this study had very good overall knowledge, coping and confidence for managing their own health.

Table 6.15: Partners in health summary statistics

Partners in health scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Knowledge	25.15	6.70	28.00	7.50	0 to 32	5
Coping*	15.89	5.96	16.00	7.50	0 to 24	4
Recognition and management of symptoms*	19.89	3.39	20.00	4.50	0 to 24	5
Adherence to treatment	13.41	3.72	15.00	4.00	0 to 16	5
Total score	74.33	18.45	78.00	26.50	0 to 96	5

*Normal distribution use mean and SD as measure of central tendency

Partners in health by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 6.16.

Table 6.16: Partners in health by participant type summary

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Knowledge	Person with lung cancer	25	92.59	25.40	6.76	28.00	7.00	5
	Family member or carer	2	7.41	22.00	7.07	22.00	5.00	-
Coping*	Person with lung cancer	25	92.59	16.08	6.14	16.00	7.00	4
	Family member or carer	2	7.41	13.50	2.12	13.50	1.50	-
Recognition and management of symptoms*	Person with lung cancer	25	92.59	19.88	3.53	20.00	5.00	5
	Family member or carer	2	7.41	20.00	0.00	20.00	0.00	-
Adherence to treatment	Person with lung cancer	25	92.59	13.44	3.86	16.00	4.00	5
	Family member or carer	2	7.41	13.00	1.41	13.00	1.00	-
Total score	Person with lung cancer	25	92.59	74.80	19.00	79.00	27.00	5
	Family member or carer	2	7.41	68.50	10.61	68.50	7.50	-

*Normal distribution use mean and SD as measure of central tendency

Partners in health by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancerand, 14 participants (56.00%) with metastatic lung cancer.

Assumptions for normality and variance for a two-sample t-test were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.17).

No significant differences were observed between participants by **lung cancer stage** for any of the Partners in health scales.

Table 6.17: Partners in health by lung cancer stage summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Non-metastatic	11	44.00	24.00	12.00	42.00	0.0576
	Metastatic	14	56.00	28.50	3.75		
Coping	Non-metastatic	11	44.00	15.00	8.50	66.00	0.5632
	Metastatic	14	56.00	16.00	4.50		
Recognition and management of symptoms	Non-metastatic	11	44.00	18.00	6.50	51.50	0.1658
	Metastatic	14	56.00	20.00	2.00		
Adherence to treatment	Non-metastatic	11	44.00	13.00	6.50	50.50	0.1303
	Metastatic	14	56.00	16.00	2.75		
Total score	Non-metastatic	11	44.00	77.00	31.00	54.50	0.2281
	Metastatic	14	56.00	80.50	11.50		

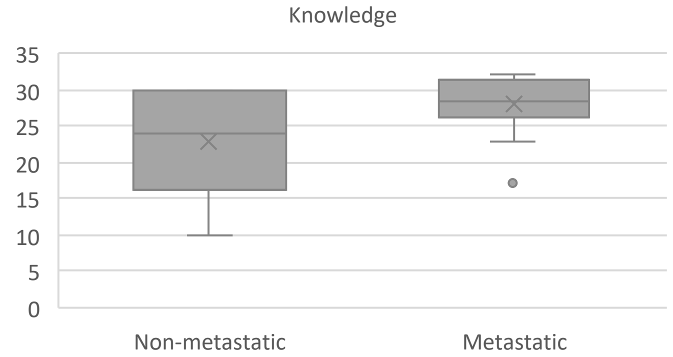


Figure 6.9: Boxplot of Partners in health: knowledge by lung cancer stage

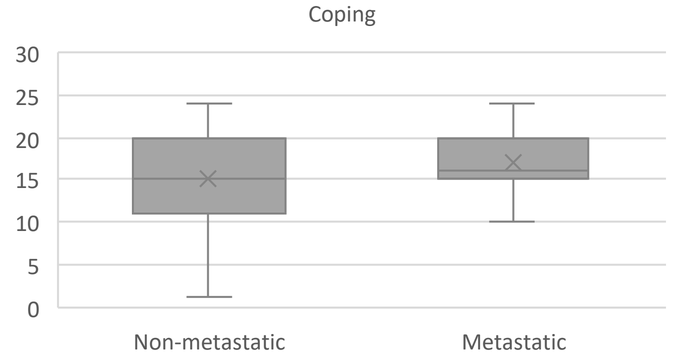


Figure 6.10: Boxplot of Partners in health: coping by lung cancer stage

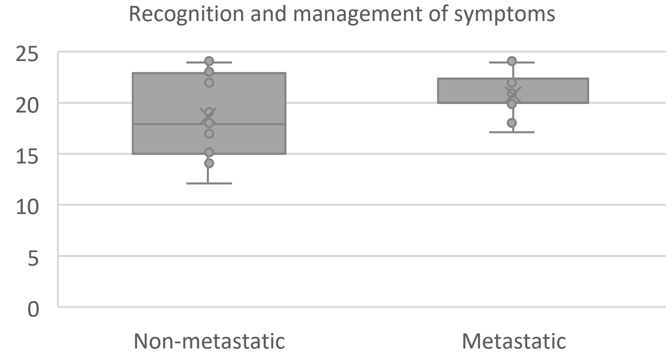


Figure 6.11: Boxplot of Partners in health: recognition and management of symptoms by lung cancer stage

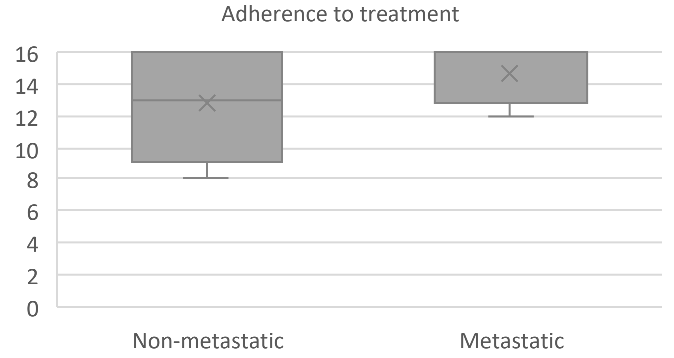


Figure 6.12: Boxplot of Partners in health: adherence to treatment by lung cancer stage

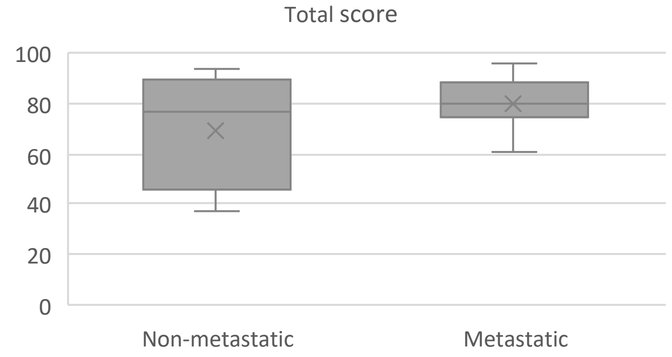


Figure 6.13: Boxplot of Partners in health Total score by lung cancer stage

Partners in health by gender

Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.18), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.19).

No significant differences were observed between participants by **gender** for any of the Partners in health scales.

Table 6.18: Partners in health by gender summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Knowledge	Female	20	74.07	24.25	7.11	-1.19	25	0.2466
	Male	7	25.93	27.71	4.89			
Adherence to treatment	Female	20	74.07	12.80	4.09	-1.46	25	0.1557
	Male	7	25.93	15.14	1.57			

Table 6.19: Partners in health by gender summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Coping	Female	20	74.07	16.00	8.25	60.50	0.6169
	Male	7	25.93	16.00	6.00		
Recognition and management of symptoms	Female	20	74.07	20.00	4.50	50.50	0.2872
	Male	7	25.93	21.00	3.00		
Total score	Female	20	74.07	77.50	25.00	51.50	0.3189
	Male	7	25.93	83.00	14.00		

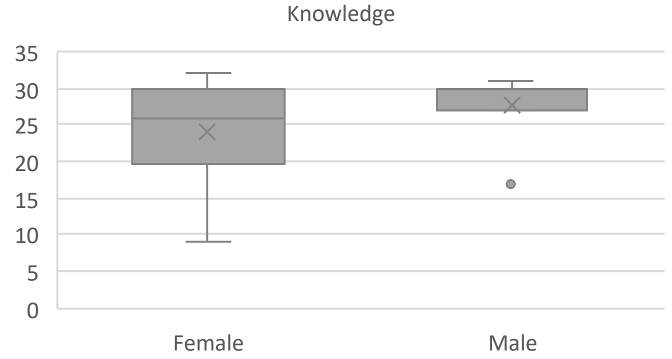


Figure 6.14: Boxplot of Partners in health: knowledge by gender

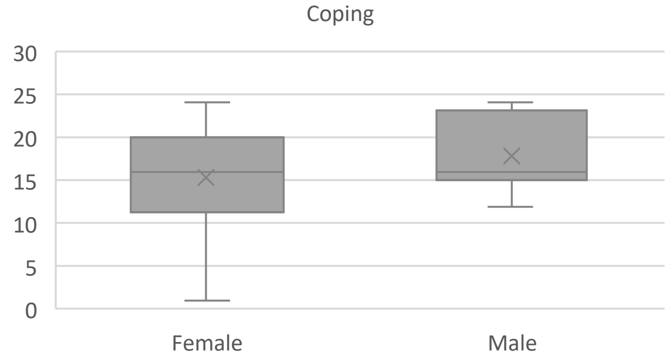


Figure 6.15: Boxplot of Partners in health: coping by gender

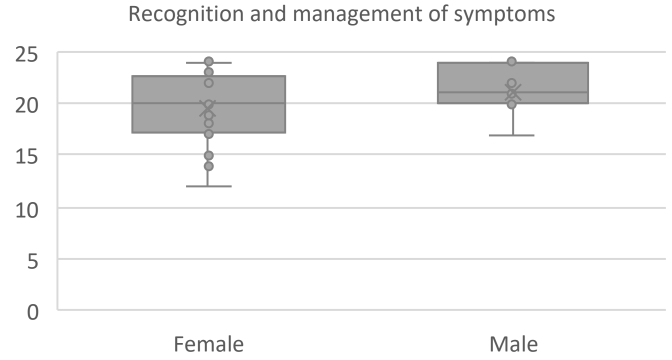


Figure 6.16: Boxplot of Partners in health: recognition and management of symptoms by gender

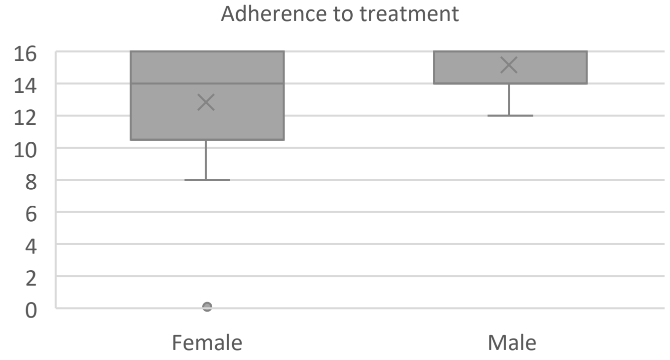


Figure 6.17: Boxplot of Partners in health: adherence to treatment by gender

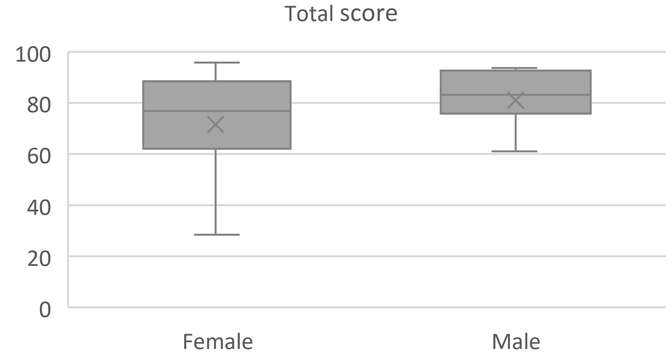


Figure 6.18: Boxplot of Partners in health Total score by gender

Partners in health by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.**20**), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.**21**).

No significant differences were observed between participants by **age** for any of the Partners in health scales.

Table 6.20: Partners in health by age summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Coping	Aged 35 to 64	15	55.56	15.87	5.79	-0.02	25	0.9832
	Aged 65 or older	12	44.44	15.92	6.42			
Total score	Aged 35 to 64	15	55.56	73.20	19.93	-0.35	25	0.7286
	Aged 65 or older	12	44.44	75.75	17.17			

Table 6.21: Partners in health by age summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Aged 35 to 64	15	55.56	28.00	6.00	85.50	0.8442
	Aged 65 or older	12	44.44	28.50	8.75		
Recognition and management of symptoms	Aged 35 to 64	15	55.56	20.00	6.50	81.00	0.6745
	Aged 65 or older	12	44.44	20.00	2.25		
Adherence to treatment	Aged 35 to 64	15	55.56	15.00	4.00	77.00	0.5167
	Aged 65 or older	12	44.44	16.00	4.00		

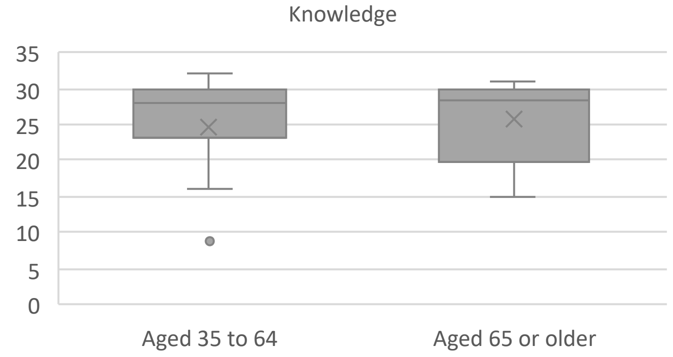


Figure 6.19: Boxplot of Partners in health: knowledge by age

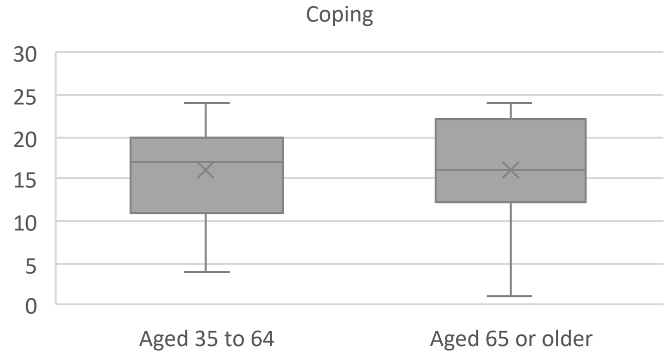


Figure 6.20: Boxplot of Partners in health: coping by age

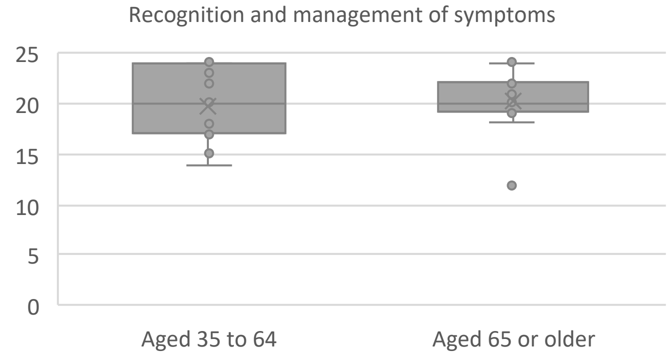


Figure 6.21: Boxplot of Partners in health: recognition and management of symptoms by age

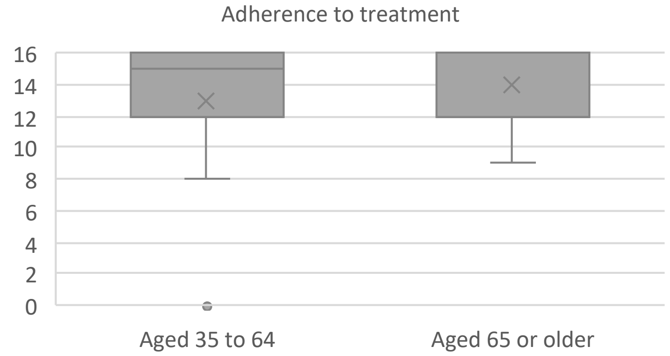


Figure 6.22: Boxplot of Partners in health: adherence to treatment by age

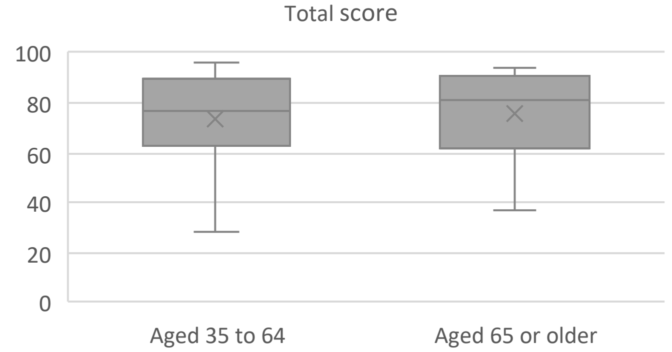


Figure 6.23: Boxplot of Partners in health Total score by age

Partners in health by education

Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.22), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6. 23).

No significant differences were observed between participants by **education** for any of the Partners in health scales.

Table 6.22: Partners in health by education summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Coping	Trade or high school	15	55.56	15.13	6.51	-0.73	25	0.4721
	University	12	44.44	16.83	5.31			
Recognition and management of symptoms	Trade or high school	15	55.56	19.40	3.40	-0.83	25	0.4127
	University	12	44.44	20.50	3.42			

Table 6.23: Partners in health by education summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Trade or high school	15	55.56	28.00	9.50	80.50	0.6584
	University	12	44.44	27.50	6.75		
Adherence to treatment	Trade or high school	15	55.56	15.00	4.00	79.50	0.6040
	University	12	44.44	15.50	3.00		
Total score	Trade or high school	15	55.56	77.00	25.00	78.00	0.5744
	University	12	44.44	79.00	15.50		

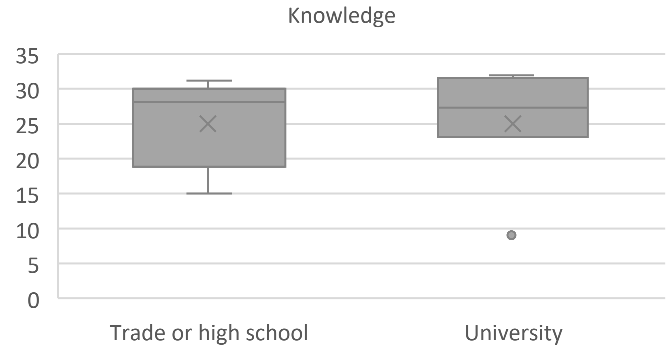


Figure 6.24: Boxplot of Partners in health: knowledge by education

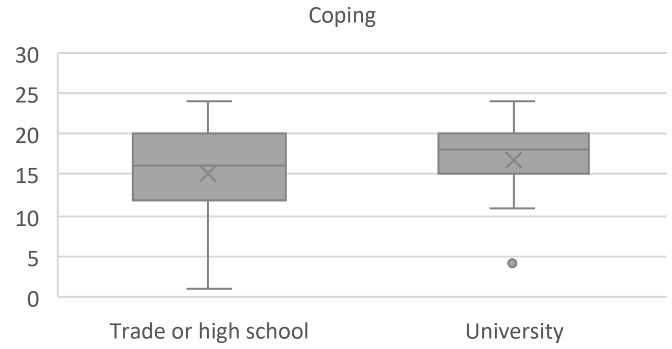


Figure 6.25: Boxplot of Partners in health: coping by education

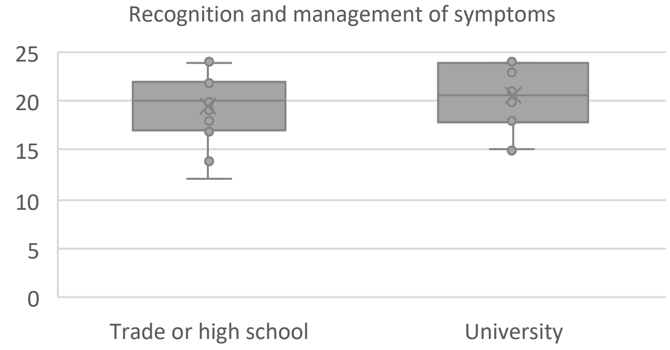


Figure 6.26: Boxplot of Partners in health: recognition and management of symptoms by education

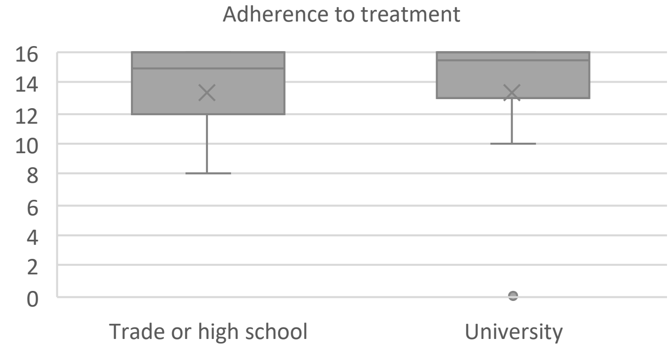


Figure 6.27: Boxplot of Partners in health: adherence to treatment by education

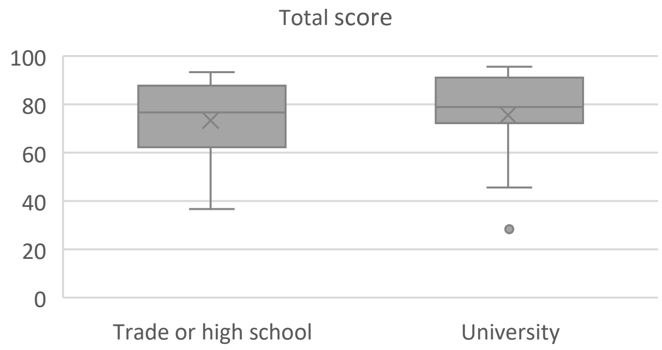


Figure 6.28: Boxplot of Partners in health Total score by education

Partners in health by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 2 participants (7.41%) living in regional or remote areas and 25 participants (92.59%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 6.24.

Table 6.24: Partners in health by location summary statistics

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Knowledge	Regional or remote	2	7.41	20.50	16.26	20.50	11.50	5
	Metropolitan	25	92.59	25.52	5.97	28.00	7.00	-
Coping	Regional or remote	2	7.41	14.00	14.14	14.00	10.00	4
	Metropolitan	25	92.59	16.04	5.46	16.00	7.00	-
Recognition and management of symptoms	Regional or remote	2	7.41	19.50	6.36	19.50	4.50	5
	Metropolitan	25	92.59	19.92	3.28	20.00	4.00	-
Adherence to treatment	Regional or remote	2	7.41	8.00	11.31	8.00	8.00	5
	Metropolitan	25	92.59	13.84	2.66	15.00	4.00	-
Total score	Regional or remote	2	7.41	62.00	48.08	62.00	34.00	5
	Metropolitan	25	92.59	75.32	16.08	78.00	25.00	-

*Normal distribution use mean and SD as measure of central tendency

Partners in health by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 6.25), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 6.26).

No significant differences were observed between participants by **socioeconomic status** for any of the Partners in health scales.

Table 6.25: Partners in health by socioeconomic status summary statistics and T-test

Partners in health scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Recognition and management of symptoms	Mid to low status	10	37.04	17.70	3.80	-0.04	25	0.9675
	Higher status	17	62.96	21.18	2.40			

Table 6.26: Partners in health by socioeconomic status summary statistics and Wilcoxon test

Partners in health scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Knowledge	Mid to low status	10	37.04	24.50	12.50	74.50	0.6150
	Higher status	17	62.96	29.00	6.00		
Coping	Mid to low status	10	37.04	13.50	11.50	83.00	0.9399
	Higher status	17	62.96	16.00	5.00		
Adherence to treatment	Mid to low status	10	37.04	12.50	6.50	60.50	0.2238
	Higher status	17	62.96	16.00	3.00		
Total score	Mid to low status	10	37.04	70.00	34.25	57.50	0.1706
	Higher status	17	62.96	82.00	14.00		

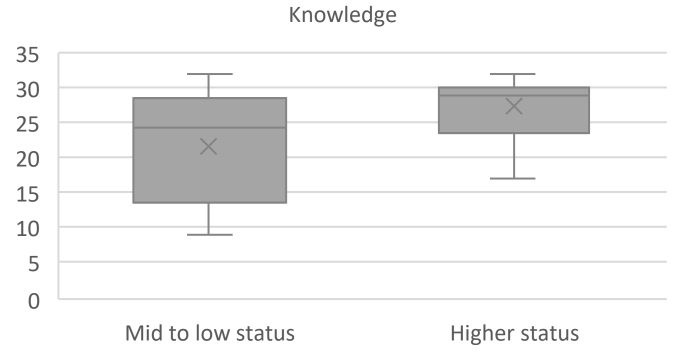


Figure 6.29: Boxplot of Partners in health: knowledge by socioeconomic status

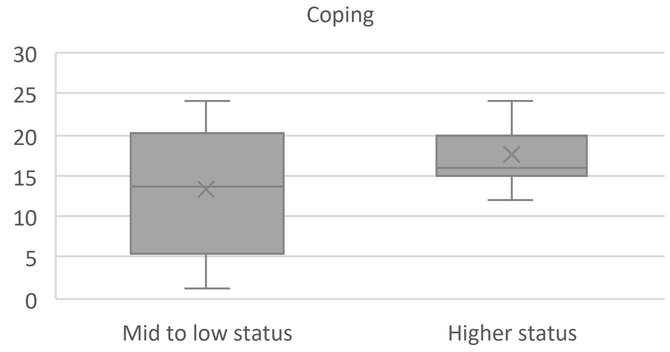


Figure 6.30: Boxplot of Partners in health: coping by socioeconomic status

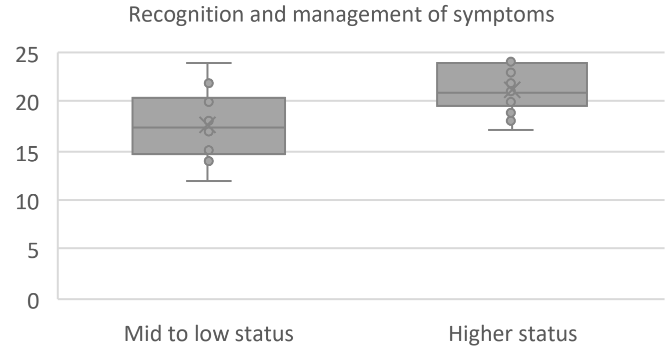


Figure 6.31: Boxplot of Partners in health: recognition and management of symptoms by socioeconomic status

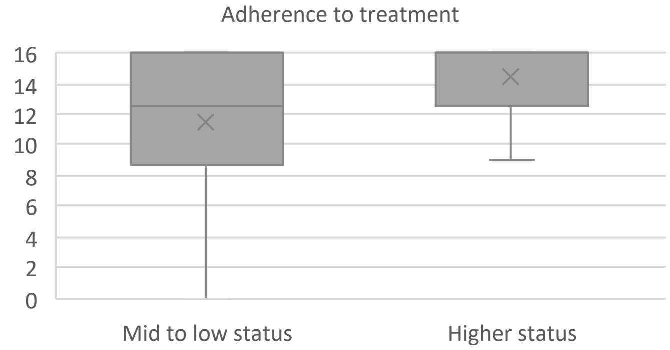


Figure 6.32: Boxplot of Partners in health: adherence to treatment by socioeconomic status

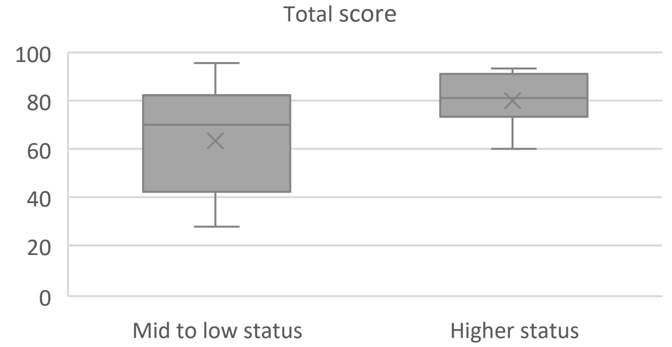


Figure 6.33: Boxplot of Partners in health Total score by socioeconomic status

Ability to take medicine as prescribed

Participants were asked about their ability to take medicines as prescribed. The majority of the participants responded that they took medicine as prescribed all the time (n=15, 60.00%), and 10 participants (40.00%) responded that they took medicines as prescribed most of the time. (Table 6.27, Figure 6.34).

Table 6.27: Ability to take medicine as prescribed

Ability to take medicine and stick to prescription	Number (n=25)	Percent
All of the time	15	60.00
Most of the time	10	40.00
Sometimes	0	0.00
Rarely	0	0.00

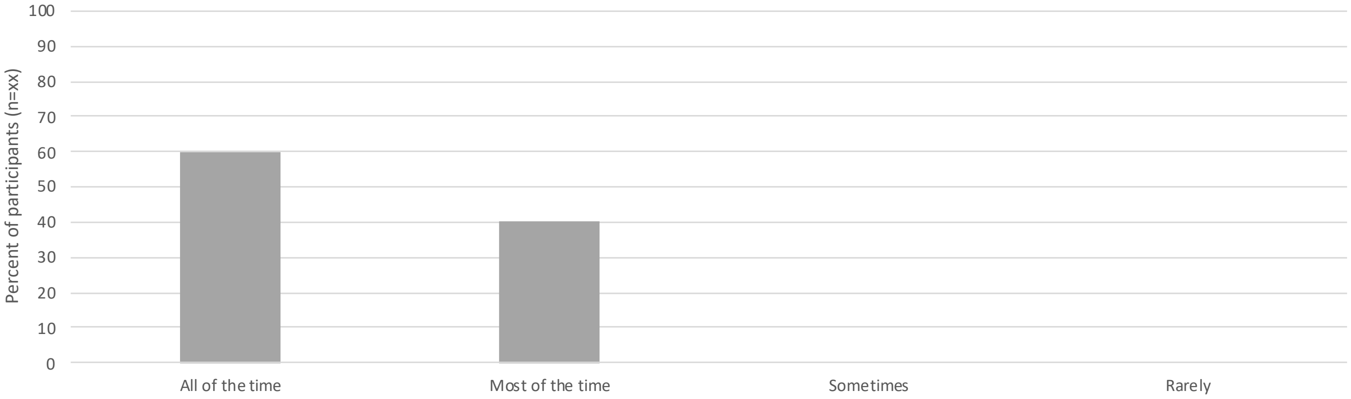


Figure 6.34: Ability to take medicine as prescribed

Information given by health professionals

Participants were asked about what type of information they were given by healthcare professionals, information about treatment options (n=17, 62.96%), disease cause (n=8, 29.63%), physical activity (n=8, 29.63%) and, disease management (n=7, 25.93%) were most frequently given to participants by healthcare professionals, and, information about clinical trials (n=3, 11.11%), how to interpret test results (n=2, 7.41%) and, hereditary considerations (n=2, 7.41%) were given least often (Table 6.28, Figure 6.35).

Table 6.28: Information given by health professionals

Accessed "My health record"	Number (n=27)	Percent
Disease cause	8	29.63
Treatment options	17	62.96
Disease management	7	25.93
Complementary therapies	3	11.11
How to interpret test results	2	7.41
Clinical trials	3	11.11
Dietary	5	18.52
Physical activity	8	29.63
Psychological/social support	5	18.52
Hereditary considerations	2	7.41
No information	5	18.52

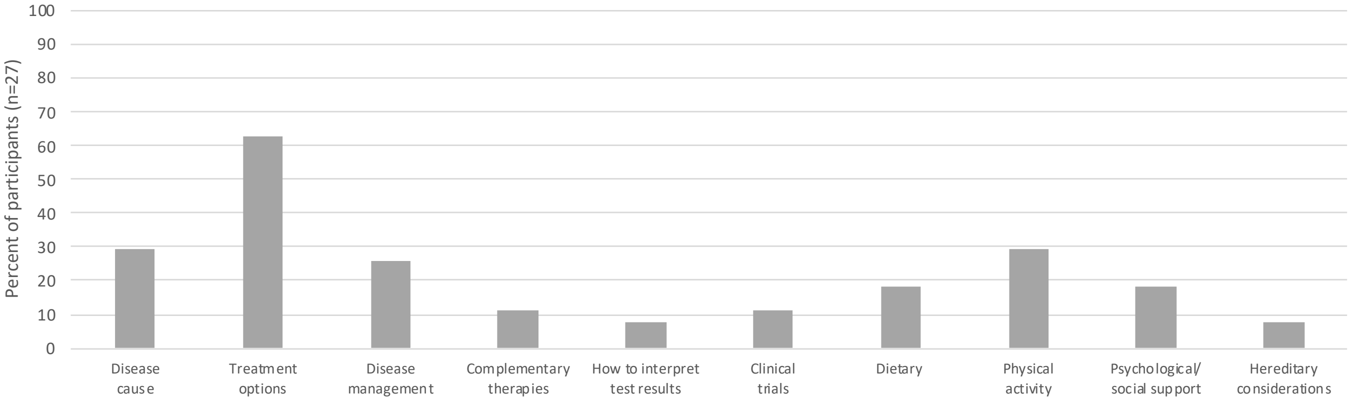


Figure 6.35: Information given by health professionals

Information searched independently

Participants were then asked after receiving information from healthcare professionals, what information did they need to search for independently. The topics participants most often searched for were disease management (n=22, 81.48%), disease cause (n=19, 70.37%), treatment options (n=19, 70.37%) and, interpret test results (n=16, 59.26%) were most frequently searched for independently by participants, and, information about physical activity (n=13, 48.15%), diet (n=11, 40.74%) and, psychological/ social support (n=11, 40.74%) were searched for least often (Table 6.29, Figure 6.36).

Table 6.29: Information searched for independently

Accessed “My health record”	Number (n=27)	Percent
Disease cause	19	70.37
Treatment options	19	70.37
Disease management	22	81.48
Complementary therapies	15	55.56
How to interpret test results	16	59.26
Clinical trials	13	48.15
Dietary	11	40.74
Physical activity	13	48.15
Psychological/social support	11	40.74
Hereditary considerations	15	55.56
No information	0	0.00

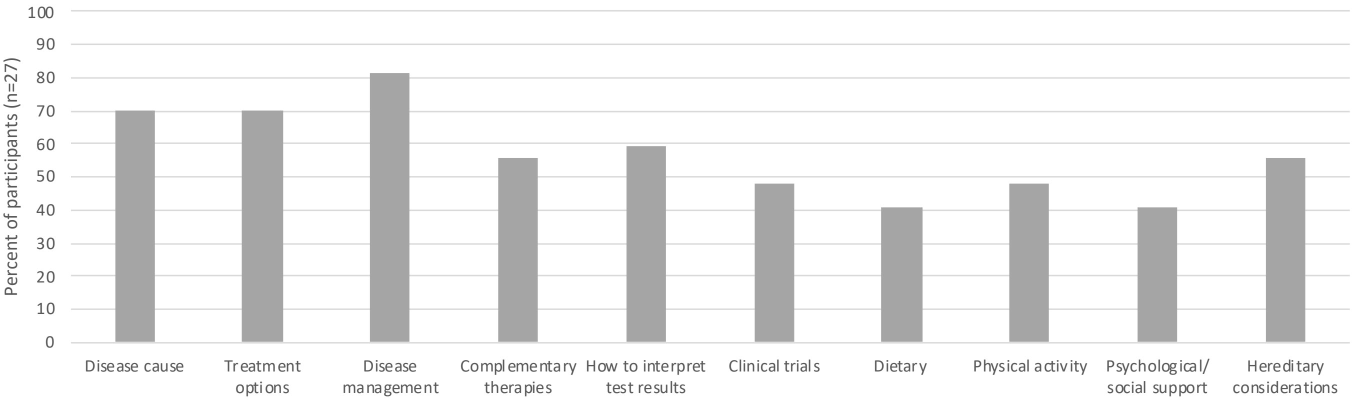


Figure 6.36: Information searched for independently

Information gaps

The largest gaps in information, where information was neither given to patients nor searched for independently were clinical trials (n=13, 48.15%) and diet(n=12, 44.44%).

The topics that participants did not search for independently after not receiving information from healthcare professionals were treatment options (n=6, 22.22%) and physical activity (n=6, 22.22%).

The topics that participants were given most information from both healthcare professionals and searching independently for were treatment options (n=11, 40.74%) and disease management (n=6, 22.22%).

The topics that participants searched for independently after not receiving information from healthcare professionals were disease management (n=16, 59.26%) and interpret test results (n=16, 59.26%) (Table 6.30, Figure 6.37).

Table 6.30: Information gaps

Information topic	Not given by health professional, not searched for independently		Given by health professional only		Given by health professional, searched for independently		Searched for independently only	
	n=27	%	n=27	%	n=27	%	n=27	%
Disease Cause	5	18.52	3	11.11	5	18.52	14	51.85
Treatment options	2	7.41	6	22.22	11	40.74	8	29.63
Disease management	4	14.81	1	3.70	6	22.22	16	59.26
Complementary therapies	10	37.04	2	7.41	1	3.70	14	51.85
How to interpret test results	9	33.33	2	7.41	0	0.00	16	59.26
Clinical trials	13	48.15	1	3.70	2	7.41	11	40.74
Dietary information	12	44.44	4	14.81	1	3.70	10	37.04
Physical activity	8	29.63	6	22.22	2	7.41	11	40.74
Psychological/social support	12	44.44	4	14.81	1	3.70	10	37.04
Hereditary considerations	12	44.44	0	0.00	2	7.41	13	48.15

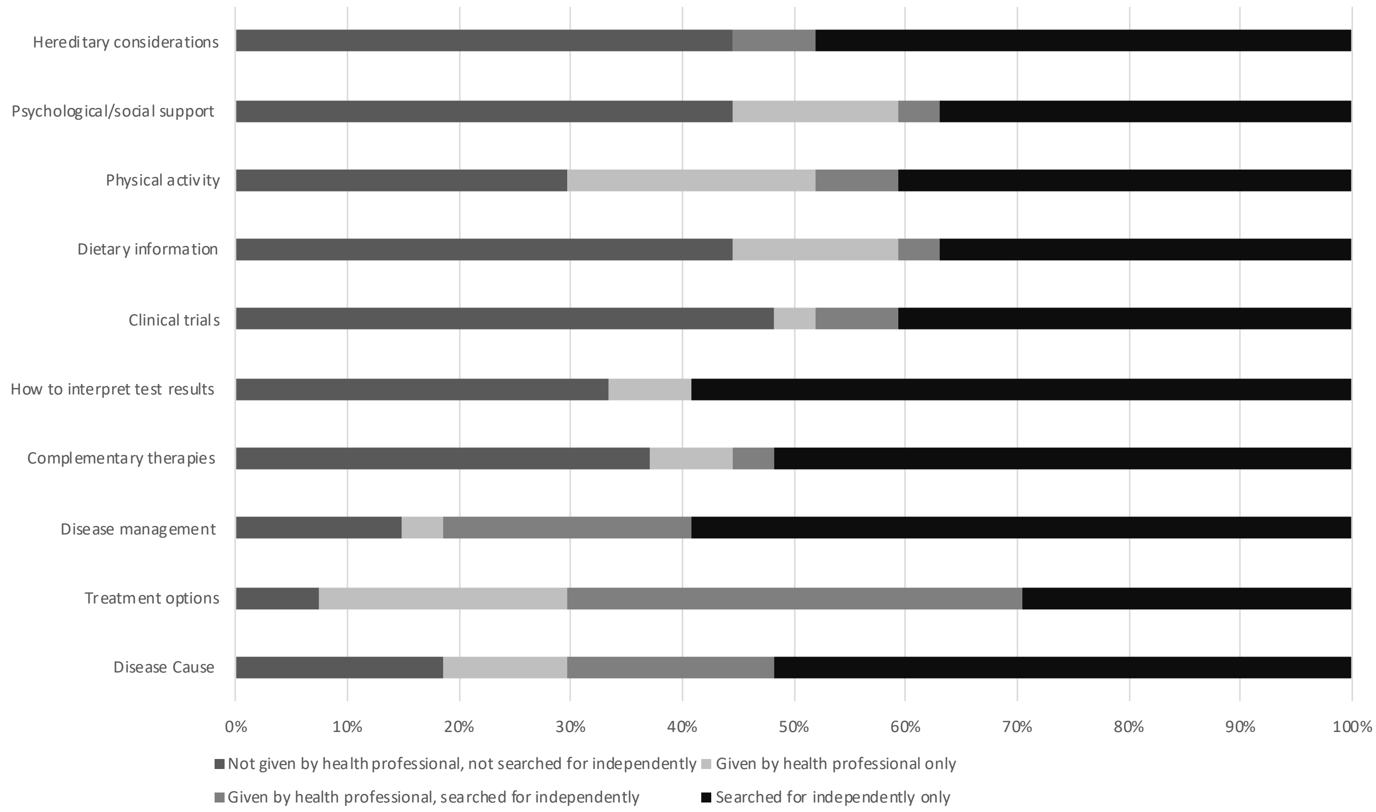


Figure 6.37: Information gaps

Most accessed information

Participants were asked to rank which information source that they accessed most often, where 1 is the most trusted and 4 is the least trusted. A weighted average is presented in Table 6.31 and Figure 6.38. With a weighted ranking, the higher the score, the more accessed the source of information. Across all participants, information from Non-profit organisations, charity or patient organisations was most accessed followed by information from the Government. Information from Pharmaceutical companies and from were least accessed.

Table 6.31: Most accessed information

Information source	Weighted average (n=27)
Non-profit organisations, charity or patient organisations	3.04
Government	2.74
Hospital or clinic I am being treated in	2.59
Pharmaceutical companies	1.63

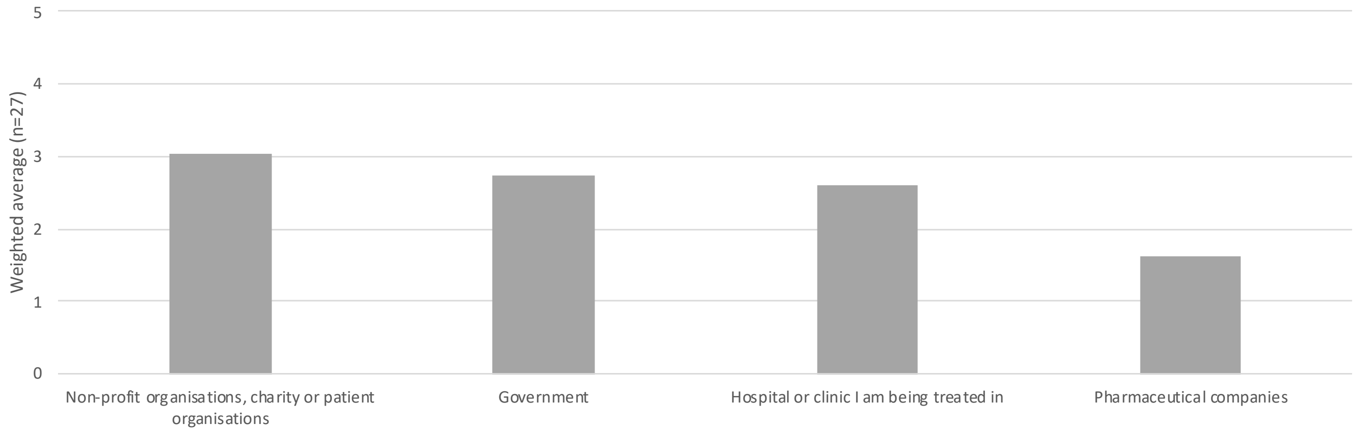


Figure 6.38: Most accessed information

My Health Record

My Health Record is an online summary of key health information, an initiative of the Australian Government. There were 11 participants (35.48%) had accessed My Health Record, 20 participants (64.52%) had not (Table 6.32. Figure 6.39).

Of those that had accessed My Health Record, there were 5 participants (45.45%) who found it to be poor or very poor, 2 participants (18.18%) who found it acceptable, and 4 participants (36.36%) who found it to be good or very good (Table 6.33, Figure 6.40).

Table 6.32: Accessed My Health Record

Accessed "My health record"	Number (n=31)	Percent
Yes	11	35.48
No	16	51.61
Not sure	1	3.23
Doesn't know what 'My Health Record' is	3	9.68

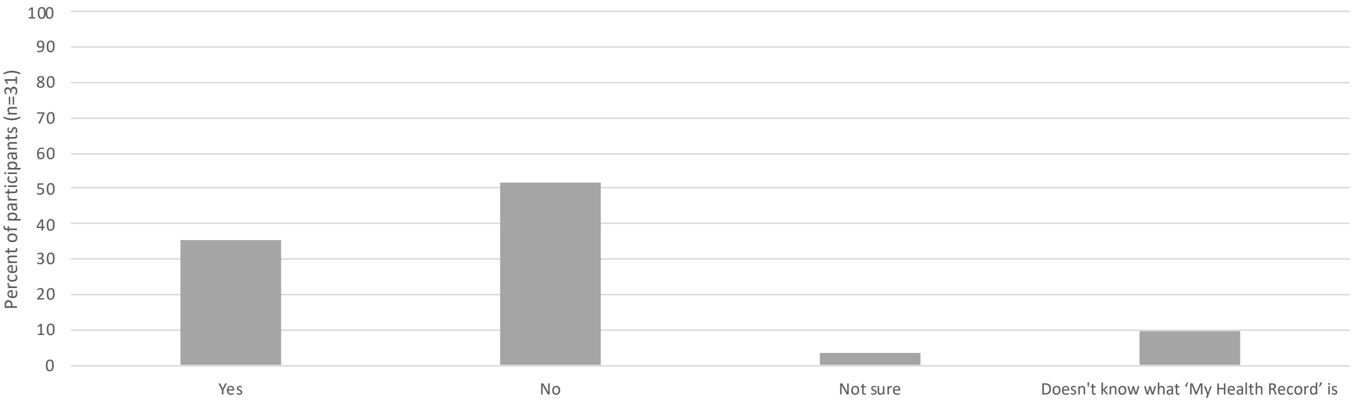


Figure 6.39: Accessed My Health Record

Table 6.33: How useful was My Health Record

How useful was "My health record"	Number (n=11)	Percent
Very poor	1	9.09
Poor	4	36.36
Acceptable	2	18.18
Good	4	36.36
Very good	0	0.00

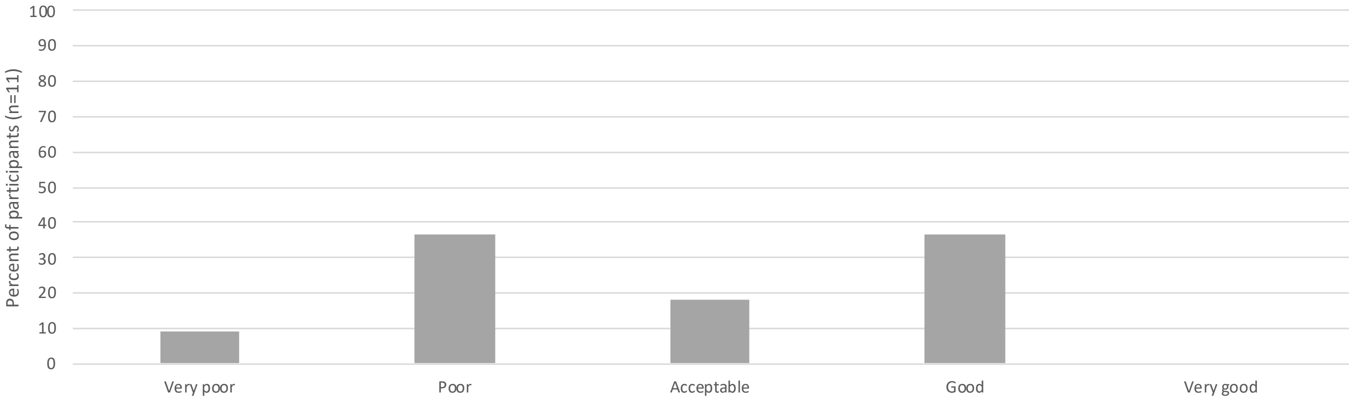


Figure 6.40: How useful was My Health Record

Section 7

Care and support

Section 7: Experience of care and support

Care coordination

The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome.

The **Care coordination: communication scale** measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in this study had average communication with healthcare professionals.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in this study had average navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had average communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in this study rated their care coordination as average.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their rated their quality of care as good.

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common response was that they did not receive any formal support (30.77%), and some participants described that they did not need or seek help or support (19.23%). When participants got support, they most commonly received support from charities (30.77%) and from peer support or other patients (15.38%).

Care coordination

A Care Coordination questionnaire was completed by participants within the online questionnaire. The Care Coordination questionnaire comprises a total score, two scales (communication and navigation), and a single question for each relating to care-coordination and care received. A higher score denotes better care outcome. Summary statistics for the entire cohort are displayed alongside the possible range of each scale in Table 7.1.

The overall scores for the cohort were in the second highest quintile for **Care coordination: Quality of care global measure** (median=8.00, IQR=4.50) indicating good quality of care

The overall scores for the cohort were in the middle quintile for **Care coordination: Communication** (mean=34.30, SD=11.06), **Care coordination: Navigation** (mean=23.37, SD=6.52), **Care coordination: Total** score (mean=57.67, SD=15.82), **Care coordination: Care coordination global measure** (median=6.00, IQR=6.00) indicating moderate communication, moderate communication, moderate care coordination, moderate care coordination.

The **Care coordination: communication scale** measures communication with healthcare professionals, measuring knowledge about all aspects of care including treatment, services available for their condition, emotional aspects, practical considerations, and financial entitlements. On average, participants in this study had average communication with healthcare professionals.

The **Care coordination: navigation** scale measures the ability of a patient to navigate the healthcare system including knowing important contacts for management of condition, role of healthcare professional in management of condition, healthcare professional knowledge of patient history, ability to get appointments and financial aspects of treatments. On average, participants in this study had average navigation of the healthcare system.

The **Care coordination: total score** scale measures communication, navigation and overall experience of care coordination. On average, participants in this study had average communication, navigation and overall experience of care coordination.

The **Care coordination: care coordination global measure** scale measures the participants overall rating of the coordination of their care. On average, participants in this study rated their care coordination as average.

The **Care coordination: Quality of care global measure** scale measures the participants overall rating of the quality of their care. On average, participants in this study rated their rated their quality of care as good.

Table 7.1: Care coordination summary statistics

Care coordination scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	34.30	11.06	32.00	13.50	13 to 65	3
Navigation*	23.37	6.52	25.00	11.50	7 to 35	3
Total score*	57.67	15.82	56.00	22.50	20 to 100	3
Care coordination global measure	5.96	3.31	6.00	6.00	1 to 10	3
Quality of care global measure	6.81	3.00	8.00	4.50	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 7.x

Table 7.2: Care coordination by participant type summary statistics

Care coordination scale (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Communication*	34.30	11.06	32.00	13.50	13 to 65	3
Navigation*	23.37	6.52	25.00	11.50	7 to 35	3
Total score*	57.67	15.82	56.00	22.50	20 to 100	3
Care coordination global measure	5.96	3.31	6.00	6.00	1 to 10	3
Quality of care global measure	6.81	3.00	8.00	4.50	1 to 10	4

*Normal distribution use mean and SD as measure of central tendency

Care coordination by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancerand, 14 participants (56.00%) with metastatic lung cancer.

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.1).

No significant differences were observed between participants by **lung cancer stage** for any of the Care coordination scales.

Table 7.3: Care coordination by lung cancer stage summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Communication	Non-metastatic	11	44.00	35.55	11.50	0.39	23	0.6984
	Metastatic	14	56.00	33.79	10.84			
Navigation	Non-metastatic	11	44.00	24.09	6.16	0.61	23	0.5486
	Metastatic	14	56.00	22.43	7.22			
Total score	Non-metastatic	11	44.00	59.64	16.33	0.53	23	0.6036
	Metastatic	14	56.00	56.21	15.98			
Care coordination global measure	Non-metastatic	11	44.00	6.00	3.07	-0.05	23	0.9577
	Metastatic	14	56.00	6.07	3.47			
Quality of care global measure	Non-metastatic	11	44.00	6.36	3.35	-0.92	23	0.3648
	Metastatic	14	56.00	7.43	2.41			

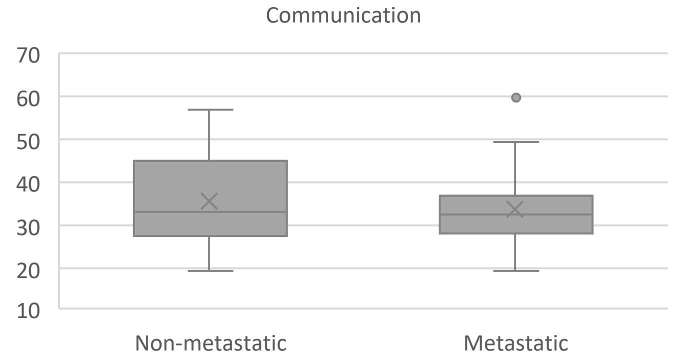


Figure 7.1: Boxplot of Care coordination: Communication by lung cancer stage

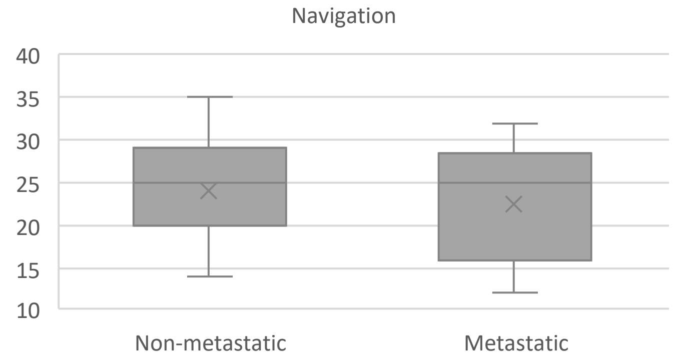


Figure 7.2: Boxplot of Care coordination: Navigation by lung cancer stage

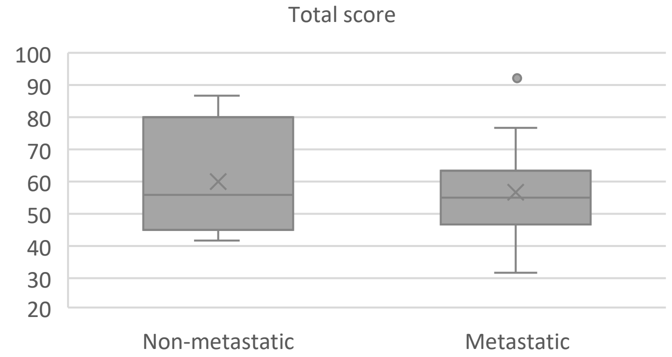


Figure 7.3: Boxplot of Care coordination: Total score by lung cancer stage

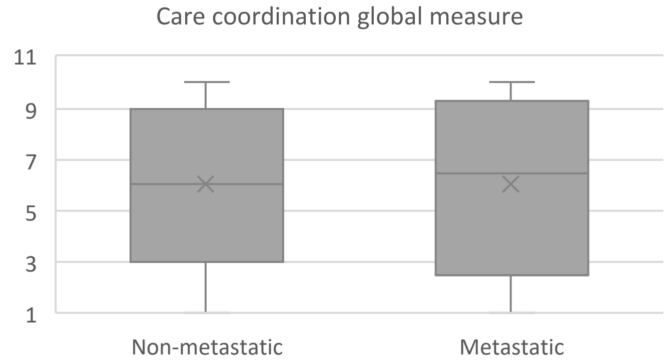


Figure 7.4: Boxplot of Care coordination: Care coordination global measure by lung cancer stage

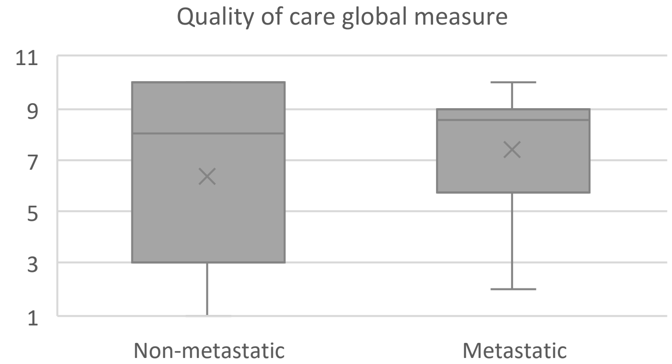


Figure 7.5: Boxplot of Care coordination: Quality of care global measure by lung cancer stage

Care coordination by gender

Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.2), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.3).

No significant differences were observed between participants by **gender** for any of the Care coordination scales.

Table 7.4: Care coordination by gender summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Female	20	74.07	23.30	6.30	-0.09	25	0.9267
	Male	7	25.93	23.57	7.66			
Total score	Female	20	74.07	56.80	16.07	-0.47	25	0.6397
	Male	7	25.93	60.14	16.06			

Table 7.5: Care coordination by gender summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Female	20	74.07	31.50	7.25	53.50	0.3751
	Male	7	25.93	39.00	13.00		
Care coordination global measure	Female	20	74.07	5.50	6.00	63.00	0.7166
	Male	7	25.93	7.00	4.50		
Quality of care global measure	Female	20	74.07	7.50	5.00	62.00	0.6749
	Male	7	25.93	8.00	2.00		

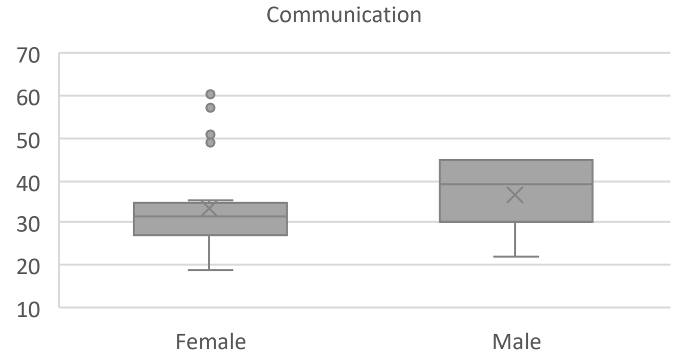


Figure 7.6: Boxplot of Care coordination: Communication by gender

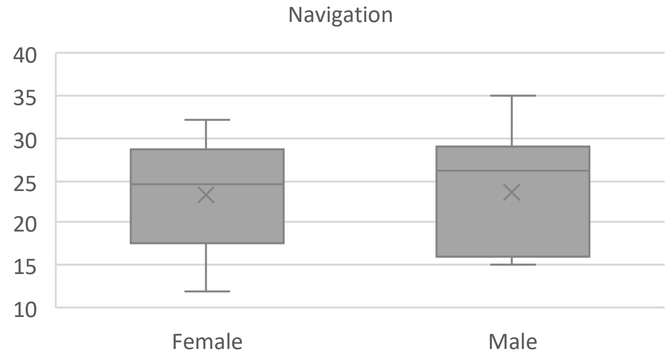


Figure 7.7: Boxplot of Care coordination: Navigation by gender

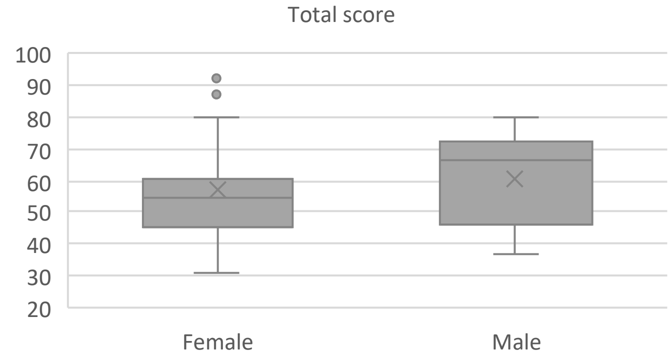


Figure 7.8: Boxplot of Care coordination: Total score by gender

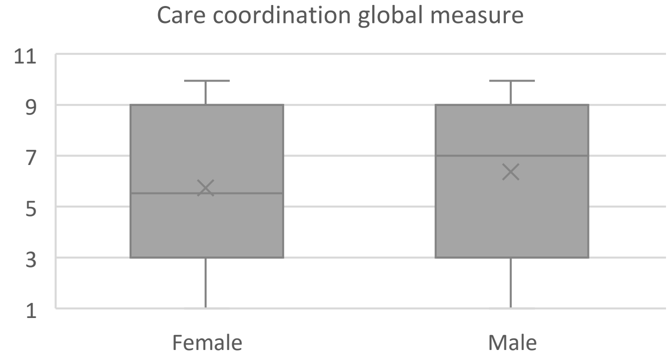


Figure 7.9: Boxplot of Care coordination: Care coordination global measure by gender

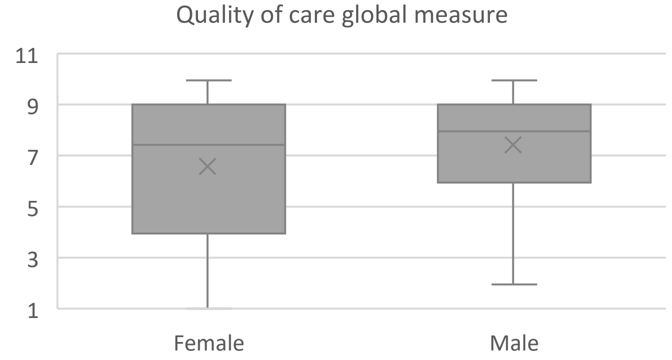


Figure 7.10: Boxplot of Care coordination: Quality of care global measure by gender

Care coordination by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.4), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.5).

No significant differences were observed between participants by **age** for any of the Care coordination scales.

Table 7.6: Care coordination by age summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Aged 35 to 64	15	55.56	23.20	6.70	-0.15	25	0.8829
	Aged 65 or older	12	44.44	23.58	6.58			
Total score	Aged 35 to 64	15	55.56	55.07	15.57	-0.95	25	0.3498
	Aged 65 or older	12	44.44	60.92	16.21			

Table 7.7: Care coordination by age summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Aged 35 to 64	15	55.56	29.00	6.50	61.50	0.1711
	Aged 65 or older	12	44.44	34.00	14.25		
Care coordination global measure	Aged 35 to 64	15	55.56	7.00	6.50	76.00	0.5061
	Aged 65 or older	12	44.44	6.00	4.75		
Quality of care global measure	Aged 35 to 64	15	55.56	8.00	5.00	79.50	0.6218
	Aged 65 or older	12	44.44	8.00	3.50		

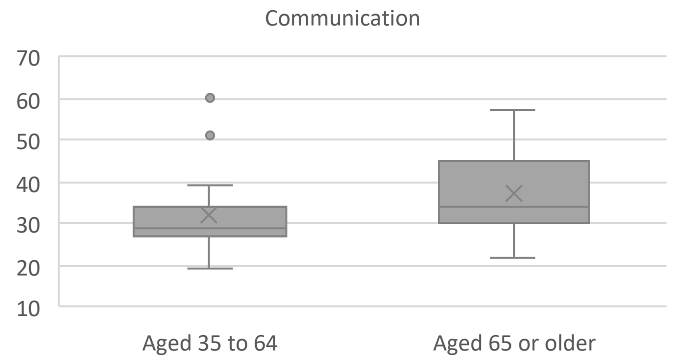


Figure 7.11: Boxplot of Care coordination: Communication by age

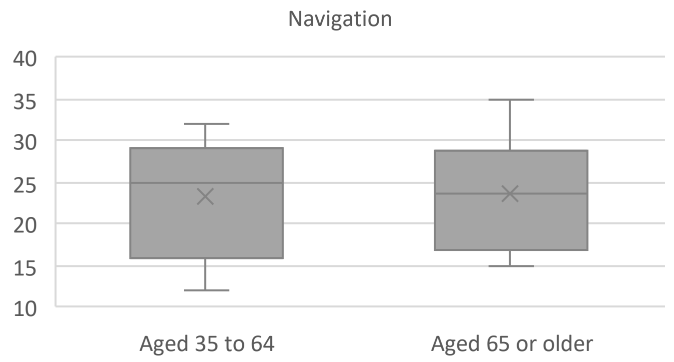


Figure 7.12: Boxplot of Care coordination: Navigation by age

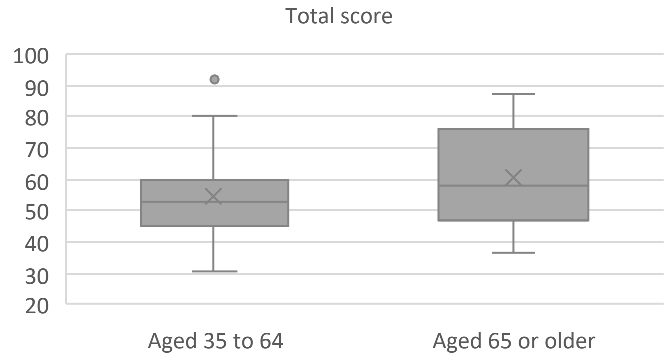


Figure 7.13: Boxplot of Care coordination: Total score by age

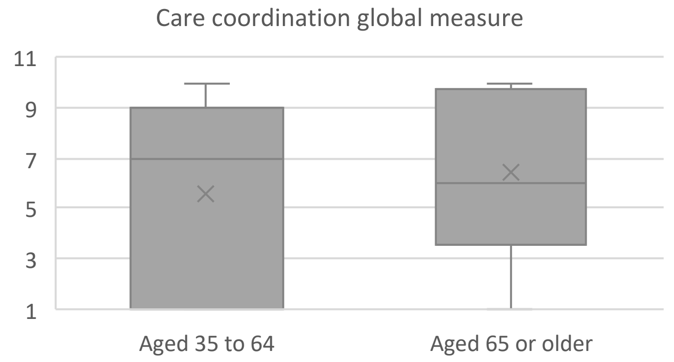


Figure 7.14: Boxplot of Care coordination: Care coordination global measure by age

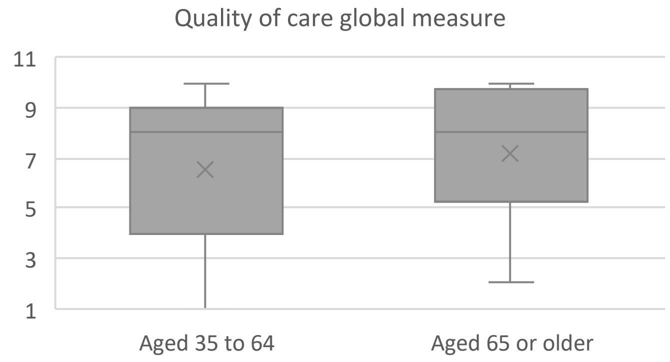


Figure 7.15: Boxplot of Care coordination: Quality of care global measure by age

Care coordination by education

Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.6), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.7).

No significant differences were observed between participants by **education** for any of the Care coordination scales.

Table 7.8: Care coordination by education summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Communication	Trade or high school	15	55.56	34.53	10.40	0.12	25	0.9038
	University	12	44.44	34.00	12.30			
Navigation	Trade or high school	15	55.56	23.07	6.90	-0.27	25	0.7927
	University	12	44.44	23.75	6.30			
Total score	Trade or high school	15	55.56	57.60	16.19	-0.02	25	0.9810
	University	12	44.44	57.75	16.07			

Table 7.9: Care coordination by education summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Care coordination global measure	Trade or high school	15	55.56	5.00	5.00	72.00	0.3887
	University	12	44.44	8.00	4.25		
Quality of care global measure	Trade or high school	15	55.56	8.00	4.50	90.00	1.0000
	University	12	44.44	8.00	3.50		

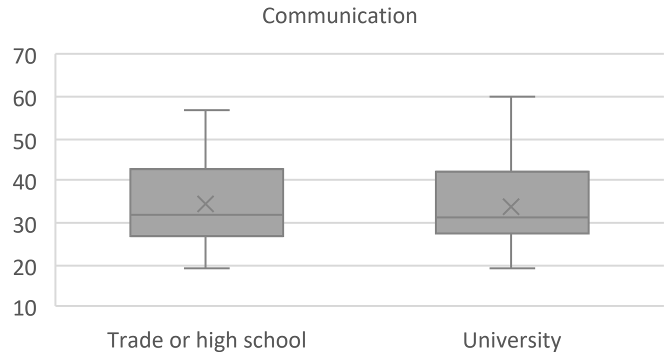


Figure 7.16: Boxplot of Care coordination: Communication by education

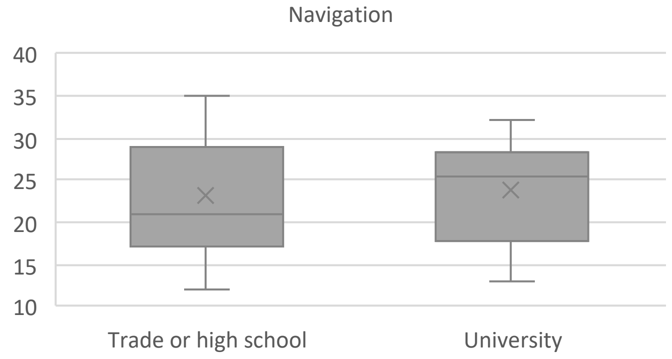


Figure 7.17: Boxplot of Care coordination: Navigation by education

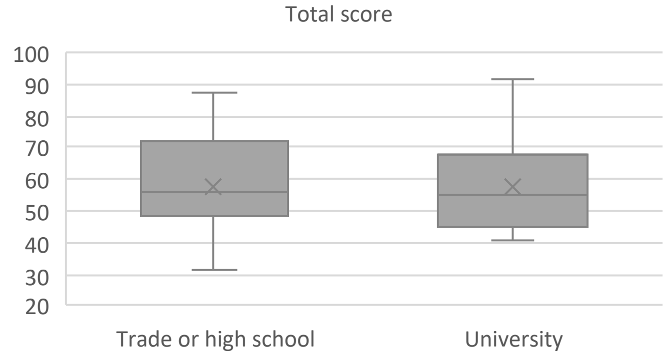


Figure 7.18: Boxplot of Care coordination: Total score by education

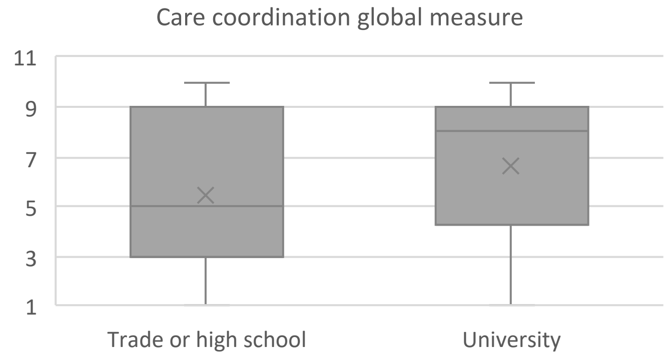


Figure 7.19: Boxplot of Care coordination: Care coordination global measure by education

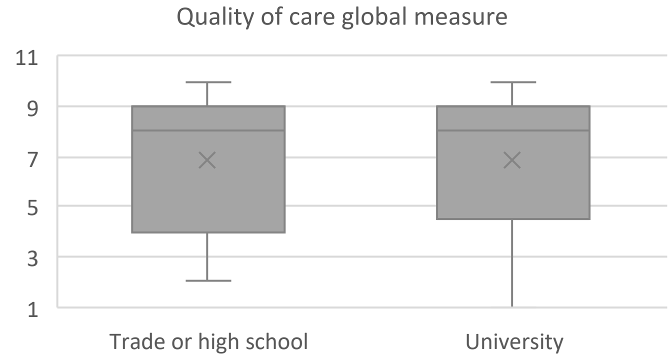


Figure 7.20: Boxplot of Care coordination: Quality of care global measure by education

Care coordination by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 2 participants (7.41%) living in regional or remote areas and 25 participants (92.59%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 7.10.

Table 7.10: Care coordination by location summary statistics

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Communication*	Regional or remote	2	7.41	39.50	28.99	39.50	20.50	3
	Metropolitan	25	92.59	33.88	9.75	32.00	11.00	-
Navigation*	Regional or remote	2	7.41	27.50	6.36	27.50	4.50	3
	Metropolitan	25	92.59	23.04	6.55	25.00	11.00	-
Total score*	Regional or remote	2	7.41	67.00	35.36	67.00	25.00	3
	Metropolitan	25	92.59	56.92	14.54	56.00	20.00	-
Care coordination global measure	Regional or remote	2	7.41	5.50	6.36	5.50	4.50	3
	Metropolitan	25	92.59	6.00	3.19	6.00	6.00	-
Quality of care global measure	Regional or remote	2	7.41	5.50	6.36	5.50	4.50	4
	Metropolitan	25	92.59	6.92	2.81	8.00	4.00	-

*Normal distribution use mean and SD as measure of central tendency

Care coordination by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

A two-sample t-test was used when assumptions for normality and variance were met (Table 7.11), or when assumptions for normality and variance were not met, a Wilcoxon rank sum test with continuity correction was used (Table 7.12).

No significant differences were observed between participants by **socioeconomic status** for any of the Care coordination scales.

Table 7.11: Care coordination by socioeconomic status summary statistics and T-test

Care coordination scale	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Navigation	Mid to low status	10	37.04	23.00	7.20	-0.22	25	0.8260
	Higher status	17	62.96	23.59	6.32			
Total score	Mid to low status	10	37.04	57.50	21.37	-0.04	25	0.9675
	Higher status	17	62.96	57.76	12.25			
Care coordination global measure	Mid to low status	10	37.04	4.80	3.68	-1.43	25	0.1658
	Higher status	17	62.96	6.65	2.98			

Table 7.12: Care coordination by socioeconomic status summary statistics and Wilcoxon test

Care coordination scale	Group	Number (n=27)	Percent	Median	IQR	W	p-value
Communication	Mid to low status	10	37.04	30.50	25.75	74.50	0.6150
	Higher status	17	62.96	32.00	10.00		
Quality of care global measure	Mid to low status	10	37.04	4.50	7.00	57.50	0.1706
	Higher status	17	62.96	8.00	2.00		

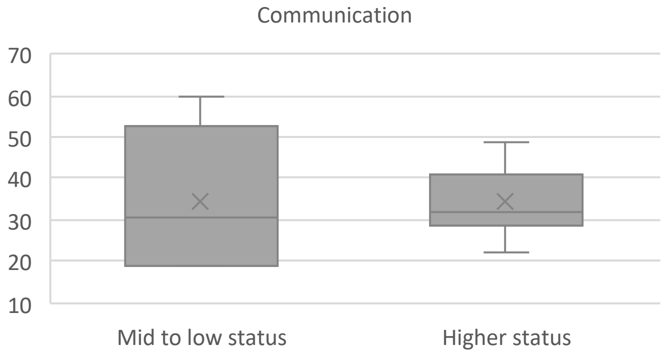


Figure 7.21: Boxplot of Care coordination: Communication by socioeconomic

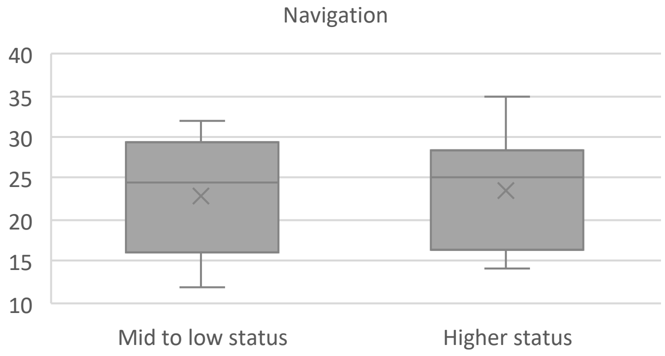


Figure 7.22: Boxplot of Care coordination: Navigation by socioeconomic

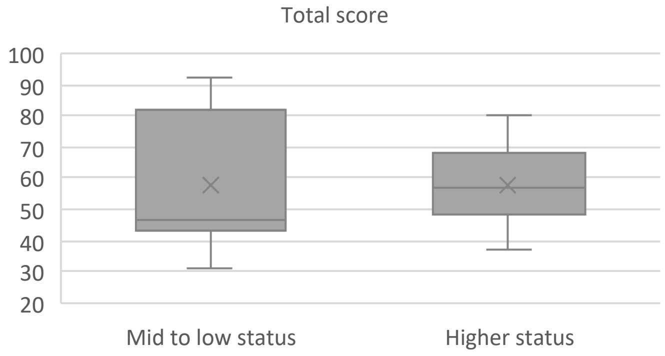


Figure 7.23: Boxplot of Care coordination: Total score by socioeconomic

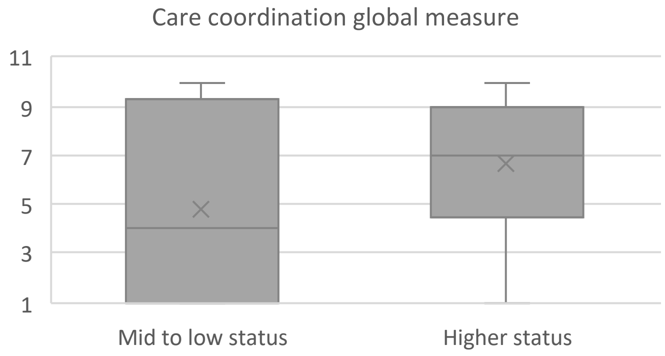


Figure 7.24: Boxplot of Care coordination: Care coordination global measure by socioeconomic

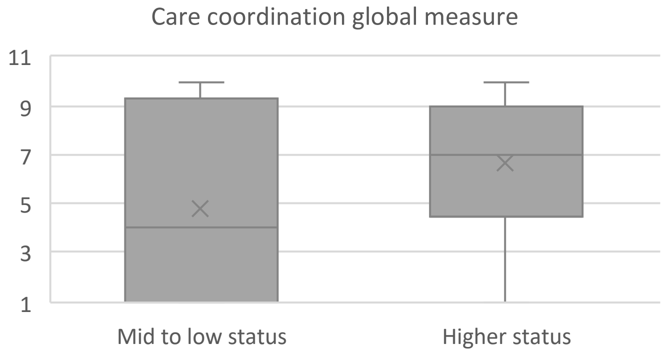


Figure 7.25: Boxplot of Care coordination: Quality of care global measure by socioeconomic

Experience of care and support

In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common response was that they did not receive any formal support (30.77%), and some participants described that they did not need or seek help or support (19.23%). When participants got support, they most commonly received support from charities (30.77%) and from peer support or other patients (15.38%).

Participant describes that they did not receive any formal support

INTERVIEWER: My question is, have you received any support from Health and Community Services to help you manage the impact of your condition?
PARTICIPANT: No.
INTERVIEWER: Not at all.
PARTICIPANT: Australia are not very good at that.
Participant 002_2023AULUC

No, there's nothing there. I was never offered anything.
Participant 019_2023AULUC

Participant describes getting support from charities

Only the Lung Cancer Foundation, the nurse rings me every now and then to have a chat and she's lovely. I haven't got any home help, nothing like that.
Participant 001_2023AULUC

PARTICIPANT: Help that I've asked for, I did receive some help from an organization. There was Mummy's Wish. I reached out to them to get some comfort bears for my children where I could pre-record a message. I got that from them. There was another foundation, but I have a feeling both the people have passed away who had it. They provided a one-off financial support for when I was going to fly to CITY for Gamma Knife. They were called-- I could tell you, but I can't remember.
Participant 015_2023AULUC

Participant describes that they did not need or seek help or support

Yes, but I haven't wanted to either. They're available, but I haven't needed them.
Participant 006_2023AULUC

I was given the opportunity through the Cancer Care Services at the hospital, but no, I didn't take advantage of any of them. I didn't need them, and even with the counseling, I didn't need that either, but I was offered everything, offered all those.
Participant 017_2023AULUC

I'd say, no, because I haven't sorted. I'm not feeling it, in any way, under cared for.
Participant 022_2023AULUC

No, but then I've probably haven't really needed it.
Participant 025_2023AULUC

Participant describes having peer support, or getting support from other patients

Yes. Definitely I feel supported by the people in the groups, the online, the Facebook one, and the HOSPITAL group. People will reach out if they think you're not doing well. Yes, definitely supported there. The Peer Connect program through Lung Foundation Australia. I am a primary peer there, so I will contact people, but it works both ways, even though I do the primary calling and it works both ways. That back and forth with someone who's got the same lived experience is supportive.
Participant 020_2023AULUC

When I was first diagnosed, through the Cancer Council, yes, and then outside of that I'm on a couple of Facebook groups also.
Participant 026_2023AULUC

My lung cancer coffee club we actually created, we're called The Grateful. I thought that would be a good title for us. It's all because of this smoking, smoking, smoking narrative. There's a lot of people that are getting diagnosed with this at younger ages that have never smoked because not that many people in Australia do actually smoke, or smoke a lot. Who would? and it's expensive.
Participant 004_2023AULUC

Table 7.13: Experience of care and support

Care and support received	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes that they did not receive any formal support	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	5	31.25	3	30.00
Participant describes getting support from charities	8	30.77	7	28.00	1	100.00	2	20.00	6	37.50	6	37.50	2	20.00
Participant describes that they did not need or seek help or support	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	3	18.75	2	20.00
Participant describes having peer support, or getting support from other patients	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00

Care and support received	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes that they did not receive any formal support	8	30.77	3	17.65	5	55.56	7	53.85	1	7.69	1	50.00	7	29.17	3	33.33	5	29.41
Participant describes getting support from charities	8	30.77	4	23.53	4	44.44	7	53.85	1	7.69	0	0.00	8	33.33	2	22.22	6	35.29
Participant describes that they did not need or seek help or support	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes having peer support, or getting support from other patients	4	15.38	1	5.88	3	33.33	4	30.77	0	0.00	0	0.00	4	16.67	2	22.22	2	11.76

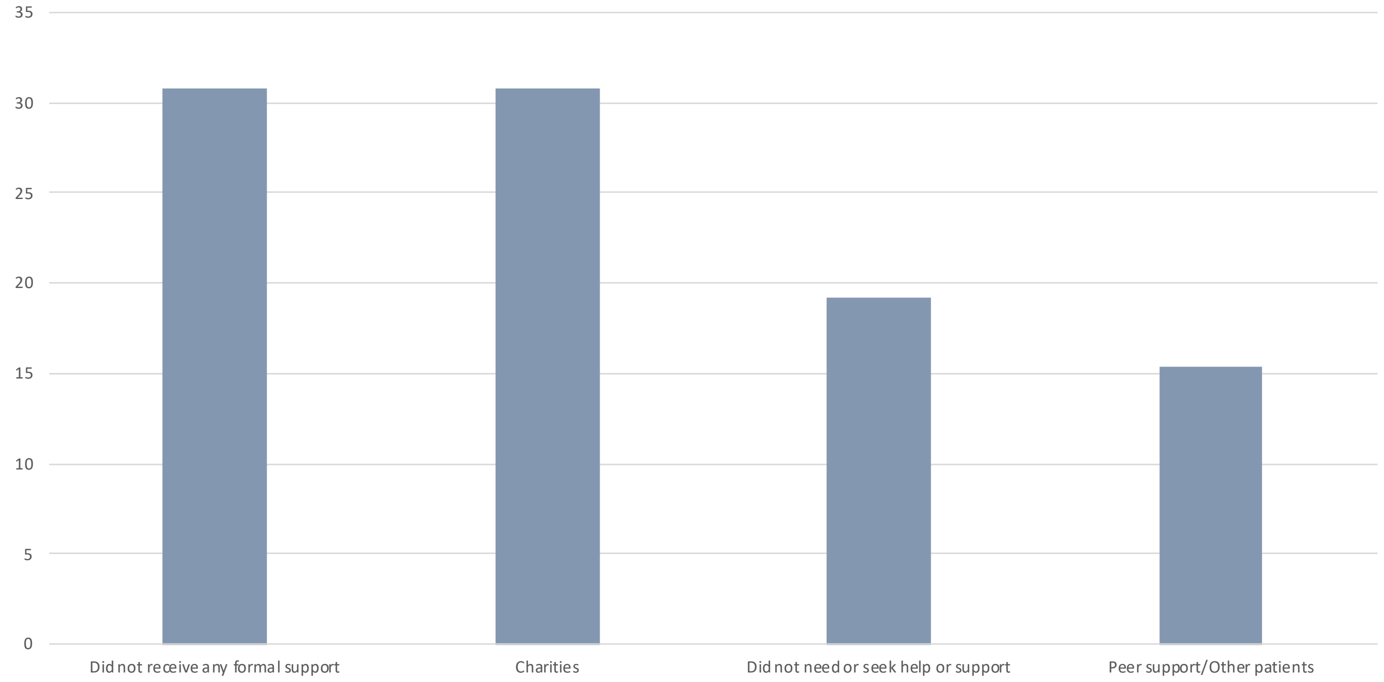


Figure 7.6: Experience of care and support

Table 7.14: Experience of care and support – subgroup variations

Theme	Less frequently	More frequently
Did not receive any formal support	Aged 35 to 64 University	Aged 65 or older Trade or high school
Charities	Non-metastatic Male University	Aged 65 or older Trade or high school
Did not need or seek help or support	-	Non-metastatic Aged 65 or older
Peer support/Other patients	Male University	Aged 65 or older Trade or high school

Section 8

Quality of life

Section 8: Quality of life

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (53.85%). Other participants descriptions suggested that there was a mix of positive and negative impact on quality of life (19.23%), that there was overall a minimal impact on quality of life (11.54 %). that there was overall no impact on quality of life (7.69%), and that there was an overall positive impact on quality of life (3.85%).

The most common themes in relation to a negative impact on quality of life were the emotional strain (including family/change in relationship dynamics) (57.69%), emotional strain on themself (42.31%), reduced capacity for physical activity/needing to slow down (26.92 %), the financial strain (11.54%), and reduced having social interactions (11.54%)

The most common theme in relation to a positive impact on quality of life was that it brings people together and highlights supportive relationships (23.08%).

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (65.38%), other participants descriptions suggested that overall, there was no impact on mental health (23.08%).

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was highlighting the importance of family and friends in maintaining their mental health (26.92%). Other activities to maintain mental health included physical exercise (19.23%), mindfulness and/or meditation (19.23%), and remaining social and engaging in hobbies (19.23%). Some described no activities to maintain mental health (11.54%).

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were physical exercise or being physically active (50.00%), and understanding their limitations (34.62%). Other activities included complying with treatment/ management (15.38%), maintaining a healthy diet (15.38%), maintaining a normal routine (15.38%), self care e.g. more rest, accepting help, pacing (15.38%), socialising with friends and family (15.38%), being organised and planning ahead (11.54%), and mindfulness and/ or meditation (11.54%).

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable when having sensitive discussions (diagnosis, treatment decision) (30.77%), and vulnerable during/after treatments (19.23%). Other times when participants felt vulnerable included when feeling sick or unwell (11.54%), vulnerable because of interactions with the medical team (11.54%), and vulnerable in general (11.54%). Some participants described that they did not feel vulnerable (11.54%).

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common response was self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability (30.77%). This was followed by support from family and friends to manage the feeling of vulnerability (7.69 %), and being supported by nurse or treatment team (7.69%).

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (30.77%). Other participants descriptions suggested that overall, there was an impact on relationships that was both positive and negative (23.08%), there was a positive impact on relationships (19.23 %), there no impact on relationships (15.38%), and that, there was an impact on relationships that was neither positive nor negative (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (34.62%), and that the dynamics of relationships changed due to anxiety, exacerbations and/or physical limitations of condition (23.08 %).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened (30.77%), and from people being well-meaning and supportive) (19.23%).

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (76.92%). Other participants descriptions suggested that overall, there was not a burden on their family (15.38%). The main reason that participant described their condition being a burden was from the mental and emotional strain placed on their family (38.46%).

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (61.54%), and that overall, there was no cost burden (34.62%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (38.46%), and the cost of treatments (26.92%). Other costs included diagnostic tests and scans (15.38%), cost of parking and travel to attend appointments (including accommodation) (15.38%), the cost of specialist appointments (15.38%), and public or private gap payments (11.54%). Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the health system (26.92%)

Overall impact of condition on quality of life

Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great. The average score was in the Life was a little distressing range (median=3.00, IQR=3.50).

Fear of progression

The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Impact on quality of life

In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (53.85%). Other participants descriptions suggested that there was a mix of positive and negative impact on quality of life (19.23%), that there was overall a minimal impact on quality of life (11.54 %). that there was overall no impact on quality of life (7.69%), and that there was an overall positive impact on quality of life (3.85%).

The most common themes in relation to a negative impact on quality of life were the emotional strain (including family/change in relationship dynamics) (57.69%), emotional strain on themself (42.31%), reduced capacity for physical activity/needing to slow down (26.92 %), the financial strain (11.54%), and reduced having social interactions (11.54%)

The most common theme in relation to a positive impact on quality of life was that it brings people together and highlights supportive relationships (23.08%).

Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics

Probably the quality, maybe the part of a little bit of happiness has gone from the family.
Participant 013_2023AULUC

At the moment, it's not having a huge direct impact. It has an underlying impact in that everyone carries a little bit of grief knowing that it's not forever. I'm not going to do 88 years like my mother. That's it at the back of everyone's mind so it has a little bit of an impact but my quality of life is pretty good. My relationships are very good.
Participant 020_2023AULUC

It's affected my family. It's affected my children because my children live with my dad. My children have seen my dad really, really sick and sometimes his mental health's not so great trying to process all that stuff that he's not going to be around. It's really impacted-- I have a daughter with autism as well so for her to understand things is quite difficult so we've had to go through that. It's impacted on me because my whole life's changed but I wouldn't change it.
Participant 030_2023AULUC

Participant describes negative impact on quality of life as a result of emotional strain on themeselves

PARTICIPANT: Not for the kids. The kids are okay. The kids just take things on and just go with it. My husband, he said, "I don't think about it until you say something and then I remember, then I get sad." To me, it's like walking around with a gun pointed at my head all the time constantly…Are they going to pull the trigger? When is the trigger going to be pulled? Yes, it does affect it. I suppose I don't talk to my friends as much now. I let them come to me and of course, they've stopped doing that. I don't think I was a Debbie Downer, but I think they didn't want to hear about it. I am a talker and I need to talk about it. People don't want to hear. I understand that. My relationship with my mother is non-existent now. She didn't even care. [chuckles] She just went, "Oh." I don't think she understood. I don't know. I said to her, "I have terminal lung cancer, mom." "Oh, that's because you smoked when you were a teenager." "No. Mum, I didn't smoke when I was a teenager. You smoked when I was a teenager." She just didn't seem to care. I thought, "Okay, I'll see how long it takes her to ring me." Because if your kids said kid said, "Mum, I have got a terminal illness," you'd be ringing them pretty much every day just to say are you okay? Is everything okay? Anything I can do? 28 days [unintelligible] before I gave up.
Participant 002_2023AULUC

Yes, sure has. It affects everything. People can say like, "Oh yes, but you're not your cancer," but it's pretty much your full-time job because it's always in the back of your mind like, "How long have I got to live? How long is this tablet going to last?" I think until they have tablets that last for years and years, I think it's just an ongoing issue, the quality of life, from a psychological perspective.
Participant 004_2023AULUC

No and yes. [chuckles] It hasn't really affected quality of life or probably added a layer of stress. It's just me and my son, so it probably added a layer of stress, obviously for him and me in terms of caring for him, but I think main relationships with everyone else has been reasonable. I think, there's that concept with people when people find you've got a terminal illness and then all of a sudden you haven't died within 12 months, it's quite a surprise for people.
Participant 026_2023AULUC

Participant describes negative impact on quality of life due to a reduced capacity for physical activity/needing to slow down

During treatment, it's affected my life. I can't do what I would normally do. We've got a grandson and we were hoping to look after him once my daughter went back to work. I can't really do much of that at all at the moment, but my daughter had already prepared to get him into childcare. The timing was right because as soon as I start treatment, he got a place. He goes to childcare now and he's at the age where he benefit from it anyway. I'm just being able to do basic domestic stuff, which I was taking for granted for quite a while. At the moment, I can only do one little task at a time and just hope to achieve that one little task for the day because I just get [unintelligible]. Even just planning outings, I can't plan too much for the day. For example, we had a family celebration on Sunday, we had a christening and I wasn't sure if I could get there because I had a fear of actually going out and being with a crowd, but I was reassured. I spoke to my lung cancer nurse about it and she said, "The mental health too, you need to continue on, just be careful, wear a mask, et cetera." We managed to do that on Sunday, but just getting ready in the morning just took a lot out of me. I have to accept that that's what's going to happen for a while until the effects of this treatment wear off. It makes you more determined to get to the next one when you know you can get to one…You still want to be part of all of that. You don't want to just give up and hide away at home.
Participant 005_2023AULUC

Yes, mainly about the limitations post-op which we heard that would be shortlived. We regularly look after grandchildren and couldn't push the pram up the hill, couldn't push somebody on a swing, couldn't lift somebody up. We're quite busy, playful and I'm used to pulling my own weight around the house and in the garden, and [unintelligible] is limiting. It's just a matter of taking my time and I'm just not used to that. That's all.
Participant 010_2023AULUC

PARTICIPANT: Like I said before, I was very fit, very active, physically out and about, and a hard-paced, fast-paced job. That's all slowed down. I'm managing to do things and I think I'm just learning to come to terms with the new me but that's all been pretty at times, quite confronting but I'm rolling with it. Just remind me the question again, how it affects.
INTERVIEWER: How it's affected your quality of life and that of your family?
PARTICIPANT: I think it's been a tough year for everyone. I'm just starting to come out of a bit of this haze, I think, and I'm realizing just how much it's impacted on my children and my husband but at the same time, we've all managed and we've all coped and we're all now the sun is starting to shine at last. I think we're all feeling a bit better. I wouldn't say minimally. It has impacted on my life and my relationships, but not in an horribly negative way. Let's say different, everything's different.
Participant 025_2023AULUC

Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships

I guess, as I said, when I first started taking the medication, my quality of life was very affected. Probably the last year, it's been a great quality of life. I've been good. As far as family, some of them struggle, and most of them are quite good. It's brought us closer together. I think it did. It's been a good thing
Participant 006_2023AULUC

PARTICIPANT: Of course, it has because, now, I've now only got one-and-a-half lungs. I get more fatigued more regularly and maybe that will change as it progresses. Because it's only been 18 months, or not even that, since I finished treatment. My libido's gone out the window, so I'm now trying to see a counselor, with my husband, to try and sort that part of things out. He's been very, very supportive, which I'm very grateful and very fortunate for. There are some people I haven't told that I've had lung cancer because of the stigma that surrounds it and how people treat you to say, "Oh, smoker, were you?", and give you grief. It's changed things, but it's actually probably helped me work out who's for real and who isn't, if that makes any sense. I'm extremely grateful to be alive, and I figure I'm here for a reason and, given a second chance, it's changed it a bit. Look, I don't look at it in a super bad way. I think it is the reason I'm alive.
Participant 018_2023AULUC

Yes, definitely. We were staring potential death in the face. It was pretty confronting. I'd like to think that there have been positives that have come out of that in terms of appreciating each other and probably stronger relationships as a result of it, which is obviously a great outcome. It's certainly been a tough time for everyone in the family. More extended family as well, like my mother and sister back in COUNTRY.

It's been tough for everyone, particularly because it was COVID as well.
Participant 021_2023AULUC

Participant describes negative impact on quality of life as a result of financial strain

My marriage has now failed and my children have been impacted because they have to watch me get scans every four months and go through the stress of has mum got cancer this time? Has it come back? has it grown more? Is it still there? It's something that they shouldn't have to deal with either. Yes, it's just changed. Because we don't have that financially stable, we don't go on holidays like we used to. It's a big impact on the family.
Participant 007_2023AULUC

That goes back mainly because one, you're not always tired. You have chronic side effects, and also you've lost one income, correct?
PARTICIPANT: Yes. Exactly.
INTERVIEWER: Anything else to add to that?
PARTICIPANT: Just emotionally, I think because I have no support.
Participant 027_2023AULUC

Participant describes negative impact on quality of life due to reduced social interaction

I struggle to do the grocery shopping now. I struggle to do housework now. My 29-year-old son lives with me. He is experiencing mental health issues. I don't like to go out because I'm afraid that I will get COVID or catch the flu or something stupid like that. I don't go out unless I have to.
Participant 003_2023AULUC

You know, there's a lot. Then just the emotional rollercoaster that we have to go on every three months. The quality of life is reasonable, we make the most of what we have, not what we don't have. If you're looking at what we don't have, [laughs] it would be significantly different in terms of, we would just be able to go and live a normal life. We'd be able to go out with friends more, and go out and have a late night, whereas now I can't because I get to have sensitive eyes at night, so we try not to go out at night. When I'm driving, and the reflection of the lights from the other cars—
Participant 015_2023AULUC

Table 8.1: Impact on quality of life

Impact on quality of life	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Experience described suggests that there was an overall negative impact on quality of life	14	53.85	13	52.00	**1**	**100.00**	**3**	**30.00**	**11**	**68.75**	**13**	**81.25**	**1**	**10.00**
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	5	19.23	5	20.00	**0**	**0.00**	**3**	**30.00**	2	12.50	3	18.75	2	20.00
Experience described suggests that there was overall a minimal impact on quality of life	3	11.54	3	12.00	**0**	**0.00**	2	20.00	1	6.25	1	6.25	2	20.00
Experience described suggests that there was overall no impact on quality of life	2	7.69	2	8.00	0	0.00	**2**	**20.00**	0	0.00	1	6.25	1	10.00
Experience described suggests that there was an overall positive impact on quality of life	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	1	6.25	0	0.00
No particular comment	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Impact on quality of life	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Experience described suggests that there was an overall negative impact on quality of life	14	53.85	10	58.82	4	44.44	6	46.15	8	61.54	1	50.00	13	54.17	**6**	**66.67**	8	47.06
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	**0**	**0.00**	5	20.83	1	11.11	4	23.53
Experience described suggests that there was overall a minimal impact on quality of life	3	11.54	1	5.88	**2**	**22.22**	2	15.38	1	7.69	**0**	**0.00**	3	12.50	**0**	**0.00**	3	17.65
Experience described suggests that there was overall no impact on quality of life	2	7.69	0	0.00	**2**	**22.22**	2	15.38	0	0.00	0	0.00	2	8.33	1	11.11	1	5.88
Experience described suggests that there was an overall positive impact on quality of life	1	3.85	1	5.88	0	0.00	0	0.00	1	7.69	**1**	**50.00**	0	0.00	1	11.11	0	0.00
No particular comment	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

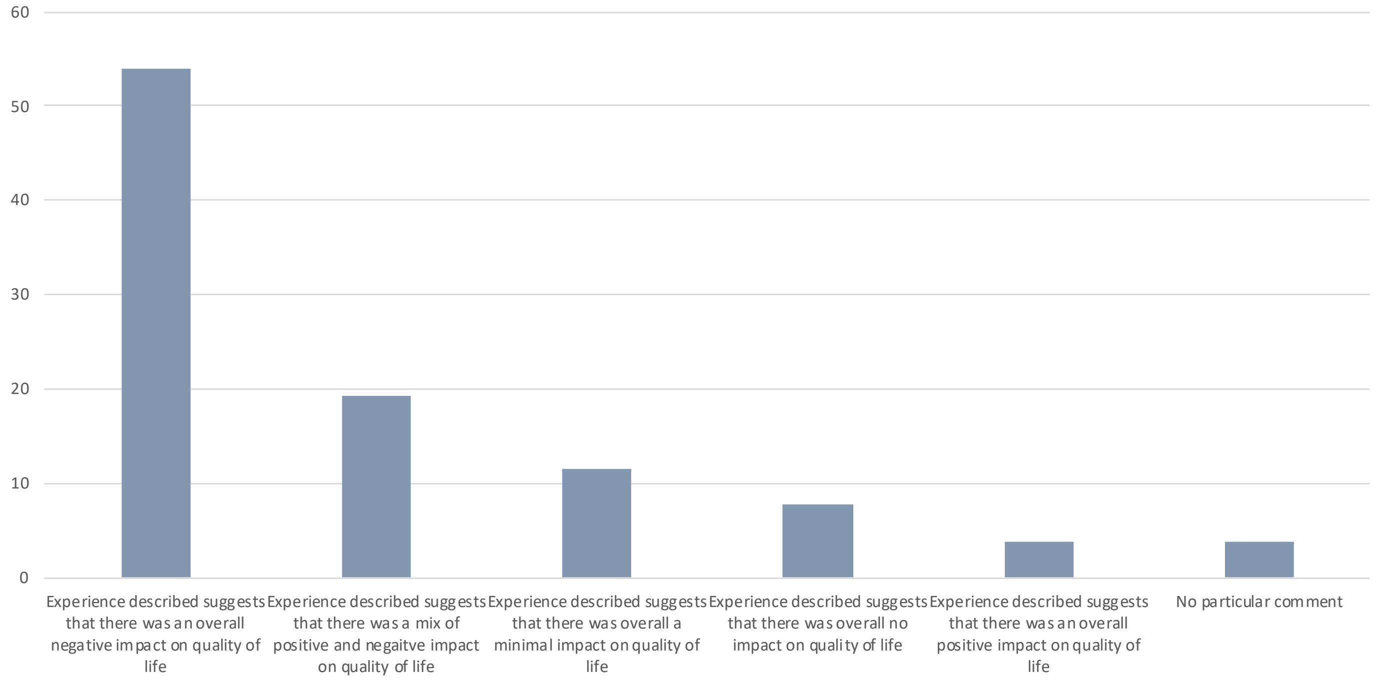


Figure 8.1: Impact on quality of life

Table 8.2: Impact quality of life – subgroup variations

Theme	Less frequently	More frequently
Experience described suggests that there was an overall negative impact on quality of life	Non-metastatic Male	Metastatic Female Mid to low status
Experience described suggests that there was a mix of positive and negaitve impact on quality of life	-	Non-metastatic
Experience described suggests that there was overall a minimal impact on quality of life	Mid to low status	Aged 65 or older
Experience described suggests that there was overall no impact on quality of life	-	Non-metastatic Aged 65 or older

Table 8.3: Impact on quality of life (Reasons)

Impact on quality of life (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	15	57.69	14	56.00	1	100.00	5	50.00	10	62.50	12	75.00	3	30.00
Participant describes negative impact on quality of life as a result of emotional strain on themselves	11	42.31	10	40.00	1	100.00	3	30.00	8	50.00	8	50.00	3	30.00
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/needing to slow down	7	26.92	7	28.00	0	0.00	4	40.00	3	18.75	5	31.25	2	20.00
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	4	25.00	2	20.00
Participant describes negative impact on quality of life as a result of financial strain	3	11.54	3	12.00	0	0.00	0	0.00	3	18.75	3	18.75	0	0.00
Participant describes negative impact on quality of life due to reduced social interaction	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Impact on quality of life (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	15	57.69	11	64.71	4	44.44	7	53.85	8	61.54	1	50.00	14	58.33	5	55.56	10	58.82
Participant describes negative impact on quality of life as a result of emotional strain on themselves	11	42.31	9	52.94	2	22.22	5	38.46	6	46.15	0	0.00	11	45.83	4	44.44	7	41.18
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/needing to slow down	7	26.92	5	29.41	2	22.22	4	30.77	3	23.08	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	6	23.08	5	29.41	1	11.11	2	15.38	4	30.77	1	50.00	5	20.83	2	22.22	4	23.53
Participant describes negative impact on quality of life as a result of financial strain	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes negative impact on quality of life due to reduced social interaction	3	11.54	3	17.65	0	0.00	0	0.00	3	23.08	1	50.00	2	8.33	1	11.11	2	11.76

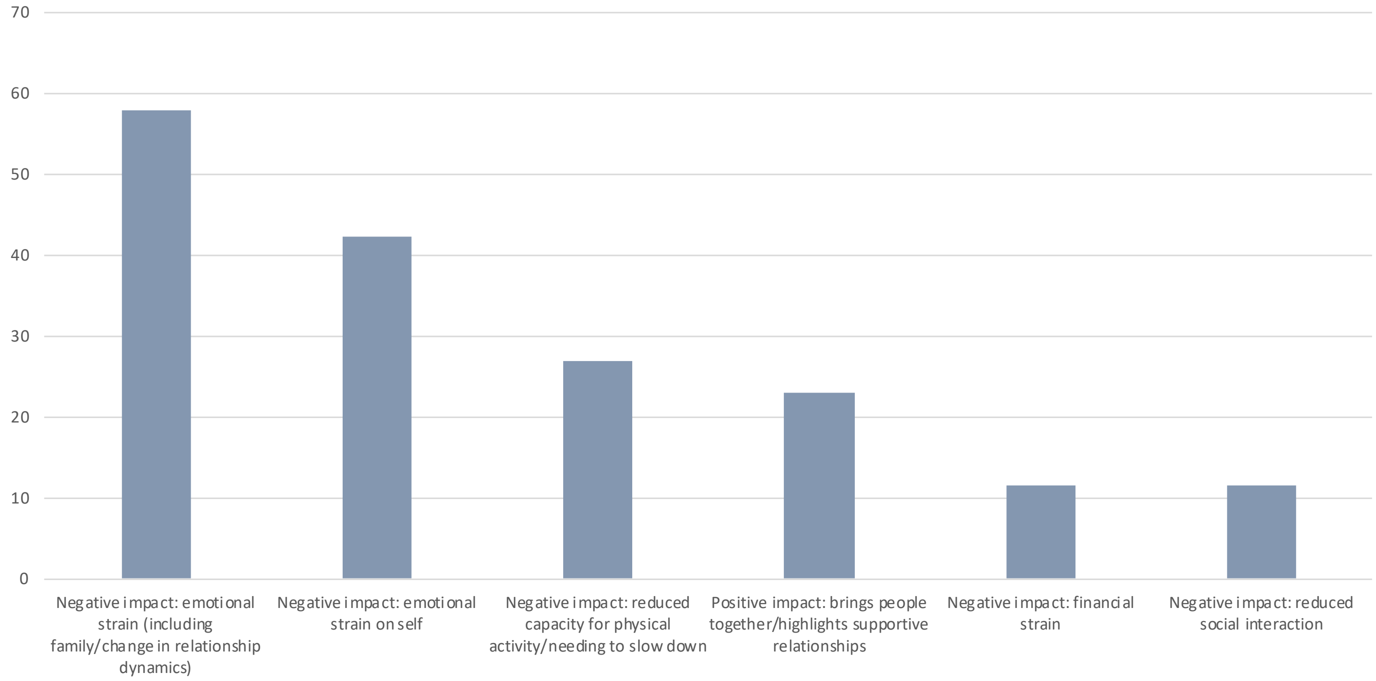


Figure 8.2: Impact on quality of life (Reasons)

Table 8.4: Impact on quality of life (Reasons)– subgroup variations

Theme	Less frequently	More frequently
Participant describes negative impact on quality of life as a result of emotional strain on family/change in relationship dynamics	Male Aged 65 or older	Female
Participant describes negative impact on quality of life as a result of emotional strain on themselves	Non-metastatic Male Aged 65 or older	Aged 35 to 64
Participant describes negative impact on quality of life due to a reduced capacity for physical activity/needing to slow down	-	Non-metastatic
Participant describes a positive impact on quality of life as it brings people together and highlights supportive relationships	Aged 65 or older	-
Participant describes negative impact on quality of life as a result of financial strain	Non-metastatic Male Aged 65 or older	-
Participant describes negative impact on quality of life due to reduced social interaction	Male Aged 65 or older Trade or high school	University

Impact on mental health

In the structured interview, participants were asked if there had been an impact on their mental health. Most commonly, the descriptions suggested that overall, there was at least some impact on mental health (65.38%), other participants descriptions suggested that overall, there was no impact on mental health (23.08%).

Experience described suggests that overall, there was at least some impact on mental health

Like I said, The first two months, I was a wreck. I wanted to cry. I was crying every other day and then I'd wake up in the night and think about it and just felt terrible, terrible down. Well, it's like they'll give you a death sentence, but now I have got myself out of it and I'm not thinking that way anymore. I've just changed my own way of thinking really. I'm just trying to think the best. Miracles do happen. [crosstalk] Participant 001_2023AULUC

PARTICIPANT: Oh yes, definitely. I'm a lot stronger now. I think with something like lung cancer, people are not supportive and that affects-- some people are not supportive, either friends or family or whatever because they just assume you've brought it on yourself, and that does affect your mental state. Or people that say the wrong things, it does affect your psychology when people are like that.
INTERVIEWER: Have you done anything to look after your mental and emotional health in these times?
PARTICIPANT: Yes, I joined a number of lung cancer forums with patients who've also got the stage 4. It's just been a marvelous source of support, it's just been

amazing. There's just so much kindness and support in these forums, it's incredible.
Participant 004_2023AULUC

PARTICIPANT: Yes, it has. This time around especially because it's a lot more confronting this time not knowing where this treatment will take you. I was hoping that I would have lasted a lot longer on [unintelligible] because I would read stories about some people even lasting 10 years. I always had that hope, but I only lasted the 18 months or 20 months. That was a shock because I was just cruising along and scans were looking good. I wasn't really having any symptoms until I started having the visual issues.
Participant 005_2023AULUC

Experience described suggests that overall, there was no impact on mental health

No, I'm fine. I'm all good. This is the card I've been dealt. I'm good. I'm putting practical things in place. It is what it is. Now, I'm fine
Participant 006_2023AULUC

I'm probably more emotional than I used to be. I tell people, more, how I feel or what I think, and not in a bad way. [laughs] How I feel about things and what have you, which I think we always say, "Oh, we should have told them we love them," or "we should have said this," I just to do that now. I just do that now. Things are certainly a little bit more emotional. I'm ever so much more grateful and I practice different, I suppose, practices, every day, of being grateful and seeing the joy in small things. I don't tolerate rules. I never really did, previous to this, anyway, but now it's even less. I stand my ground. I speak my mind. I advocate for myself because I know that nobody else will.
Participant 018_2023AULUC

No, well, see, I'm quite surprised that I haven't had any major breakdowns. I think that's my nursing. It is what it is and I just carry on. I'm probably a lot luckier than most in that I haven't gotten metastasis. It could have been better but does that make sense? I feel luckier than most. My mental health I think is doing okay. I think if I was falling apart, I would have sought help from somewhere but I haven't needed to. I've got great friends around me despite the fact I haven't been working. Whilst I'm getting a bit bored now, I've not been bored. I've had so many people call in and so many people have been there for me and my family are excellent. I've got a beautiful family.
Participant 025_2023AULUC

Table 8.5: Impact on mental health

Impact on mental health	**All participants**		**Person with lung cancer**		**Family member or carer**		**Non-metastatic**		**Metastatic**		**Female**		**Male**	
	n=26	**%**	**n=25**	**%**	**n=1**	**%**	**n=10**	**%**	**n=16**	**%**	**n=16**	**%**	**n=10**	**%**
Experience described suggests that overall, there was at least some impact on mental health	17	65.38	16	64.00	1	100.00	**5**	**50.00**	12	75.00	**13**	**81.25**	**4**	**40.00**
Experience described suggests that overall, there was no impact on mental health	6	23.08	6	24.00	0	0.00	**4**	**40.00**	**2**	**12.50**	5	31.25	**1**	**10.00**
Other or mixed experience	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	1	6.25	2	20.00

Impact on mental health	**All participants**		**Aged 35 to 64**		**Aged 65 or older**		**Trade or high school**		**University**		**Regional or remote**		**Metropolitan**		**Mid to low status**		**Higher status**	
	n=26	**%**	**n=17**	**%**	**n=9**	**%**	**n=13**	**%**	**n=13**	**%**	**n=2**	**%**	**n=24**	**%**	**n=9**	**%**	**n=17**	**%**
Experience described suggests that overall, there was at least some impact on mental health	17	65.38	12	70.59	5	55.56	8	61.54	9	69.23	1	50.00	16	66.67	**7**	**77.78**	10	58.82
Experience described suggests that overall, there was no impact on mental health	6	23.08	3	17.65	**3**	**33.33**	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Other or mixed experience	3	11.54	1	5.88	**2**	**22.22**	2	15.38	1	7.69	0	0.00	3	12.50	**0**	**0.00**	3	17.65

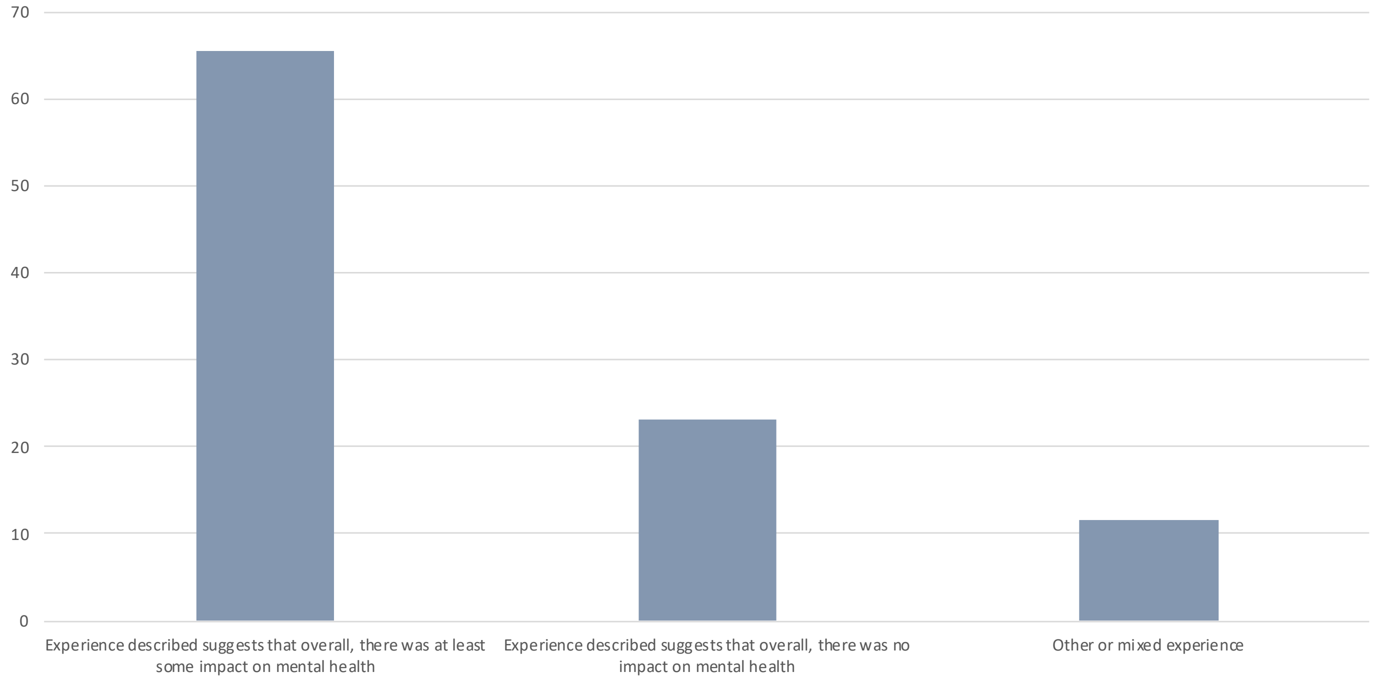


Figure 8.3: Impact on mental health

Table 8.6: Impact on mental health – subgroup variations

Theme	Less frequently	More frequently
Experience described suggests that overall, there was at least some impact on mental health	Non-metastatic Male	Female Mid to low status
Experience described suggests that overall, there was no impact on mental health	Metastatic Male	Non-metastatic Aged 65 or older

Regular activities to maintain mental health

In the structured interview, participants were asked what they needed to do to maintain their emotional and mental health. The most common response was highlighting the importance of family and friends in maintaining their mental health (26.92%). Other activities to maintain mental health included physical exercise (19.23%), mindfulness and/or meditation (19.23%), and remaining social and engaging in hobbies (19.23%). Some described no activities to maintain mental health (11.54%).

Participant describes the importance of family and friends in maintaining their mental health

I told you that I had anxiety catastrophizer so my poor husband co-opted a lot. Before I often talked about being dead and I'm going to die so I don't care about doing this anymore but I've since I've got over that. I think that it was good for my mental health to be able to talk that sort of shit. To say, "Oh, well [inaudible] and I'm going to be dead soon anyway." My husband, he's a great foil for that if you know what I mean. He can [unintelligible] back to me without sounding flippant or that he doesn't care. I wouldn't really say that my mental health has suffered because of it.
Participant 010_2023AULUC

I'm probably more emotional than I used to be. I tell people, more, how I feel or what I think, and not in a bad way. [laughs] How I feel about things and what have you, which I think we always say, "Oh, we should have told them we love them," or "we should have said this," I just to do that now. I just do that now. Things are certainly a little bit more emotional. I'm ever so much more grateful and I practice different, I suppose, practices, every day, of being grateful and seeing the joy in small things. I don't tolerate rules. I never really did, previous to this, anyway, but now it's even less. I stand my ground. I speak my mind. I advocate for myself because I know that nobody else will.
Participant 018_2023AULUC

No, well, see, I'm quite surprised that I haven't had any major breakdowns. I think that's my PROFESSION. It is what it is and I just carry on. I'm probably a lot luckier than most in that I haven't gotten metastasis. It could have been better but does that make sense? I feel luckier than most. My mental health I think is doing okay. I think if I was falling apart, I would have sought help from somewhere but I haven't needed to. I've got great friends around me despite the fact I

haven't been working. Whilst I'm getting a bit bored now, I've not been bored. I've had so many people call in and so many people have been there for me and my family are excellent. I've got a beautiful family.
Participant 025_2023AULUC

Participant describes the importance of physical exercise

PARTICIPANT: Yes, I do. I go for that walk every day and have a moment to try going to the carers group. I've got someone that comes to the house to look after the girls. My girls are still very young, they're 11 and 12, [crosstalk] 13 now. Then I started trying to-- you just caught me, I'll go to hydro…I use the girls' NDIS so I can leave the house. Now my husband works from home on Friday, so I can go off and do shopping…I can grab a coffee or something on a Friday
Participant 027_2023AULUC

PARTICIPANT: I was going to hydrotherapy, but I had to stop that after this latest diagnosis and I won't be able to go back till next year because I've got to be careful too about being in the water. I'm taking anesthesia, but also, just being aware of exposure to bacteria. I was doing that, going to Pilates, which I think in the next few weeks, I can start looking at going back to that. Now I was considering doing some yoga, going back to yoga because I'd worked at a fitness routine for a while, so I was going to at least once a week. I was going to Zumba Gold, hydrotherapy, Pilate. I was trying to do something, some sort of a routine exercise. I just do it once a week.
INTERVIEWER: It definitely sounds like staying active is helping for you.
PARTICIPANT: Yes, it does. Even I started going back to Lift last week, and this week, I've been for the second time today and I'm booking for tomorrow. There's days where you wake up and you're feeling a bit flat, but I know that as soon as I finish the session, I feel so much better. I know there's real advantages in continuing with that. I remember a friend of mine, she went through breast cancer treatment about seven years ago and I told her how I was exercising and she goes, "Oh, really?" She said, "I slept through my chemo." I found that really surprising. She said she just slept through that. Obviously, she wasn't getting any encouragement to do some exercise program to help her through it.
Participant 005_2023AULUC

PARTICIPANT: I have treatment and I'm trying to exercise because I had about four months where I didn't do any
and exercise was always important to me. We actually got a higher spin bike and put it in our room.
INTERVIEWER: Excellent
PARTICIPANT: That's been great through winter. It's been a really cold winter here. I've got a normal bike which I
ride.
INTERVIEWER: Road bike?
PARTICIPANT: I haven't been able to. I jump on the bike and get some sessions in.
INTERVIEWER: Excellent. Do you listen to music field or is there a program that you watch?
PARTICIPANT: When I'm writing, I listen to music. Music is really important to me.
INTERVIEWER: Excellent. All right.
PARTICIPANT: I love music.
INTERVIEWER: [inaudible 00:54:53].
PARTICIPANT: Actually, yes. Now planning a few holidays has really helped my outlook
Participant 024_2023AULUC

Participant describes using mindfulness and/or meditation

Like I said, The first two months, I was a wreck. I wanted to cry. I was crying every other day and then I'd wake up in the night and think about it and just felt terrible, terrible down. Well, it's like they'll give you a death sentence, but now I have got myself out of it and I'm not thinking that way anymore. I've just changed my own way of thinking really. I'm just trying to think the best. Miracles do happen.
Participant 001_2023AULUC

It definitely impacts it in a major way. I seek help from the Cancer Council of Queensland and do a mindfulness meditation course with [unintelligible], and then I do yoga retreats whenever I can. Hopefully mostly twice a year, once or twice a year. Or I do meditation as well. I try to keep physically active and, and meditate to counteract stress and anxiety.
Participant 007_2023AULUC

PARTICIPANT: Oh, absolutely. It's probably the biggest impact for me. That's bigger than physical for me. Mental and emotional health, especially now in this new treatment, this new treatment makes all that work. That basically is the biggest side effect. I obviously try and exercise again. I do yoga once a week.

INTERVIEWER: Talk to your psychologist regularly? PARTICIPANT: Yes, correct. I try and meditate when I need to. What else do I do? I call people, I talk to people, and I'm involved in support groups.
Participant 015_2023AULUC

Participant describes the importance of remaining social and taking part in their hobbies

I make soap. I'm starting a cosmetic formulation course in July. That's about it. I tend to isolate myself from people because I don't feel like I can talk to them without bringing them down, so to speak. I just do my thing really. I don't take on board anything that I don't have to. I only talk to friends that I know that I can trust and who understand where I'm coming from. That's about it.
Participant 003_2023AULUC

Yes, I've probably already answered that. I think about it every day and I deal with it through looking after my own mental health and all the things I discussed; physical activity and appreciating people and places and nature and all that stuff.
Participant 021_2023AULUC

Table 8.7: Regular activities to maintain mental health

Regular activities to maintain mental health	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes the importance of family and friends in maintaining their mental health	7	26.92	7	28.00	0	0.00	5	50.00	2	12.50	6	37.50	1	10.00
Participant describes the importance of physical exercise	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes using mindfulness and/or meditation	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	5	31.25	0	0.00
Participant describes the importance of remaining social and taking part in their hobbies	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Participant describes no activities to maintain mental health	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00

Regular activities to maintain mental health	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes the importance of family and friends in maintaining their mental health	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	1	50.00	6	25.00	2	22.22	5	29.41
Participant describes the importance of physical exercise	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes using mindfulness and/or meditation	5	19.23	4	23.53	1	11.11	1	7.69	4	30.77	1	50.00	4	16.67	1	11.11	4	23.53
Participant describes the importance of remaining social and taking part in their hobbies	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
Participant describes no activities to maintain mental health	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	2	22.22	1	5.88

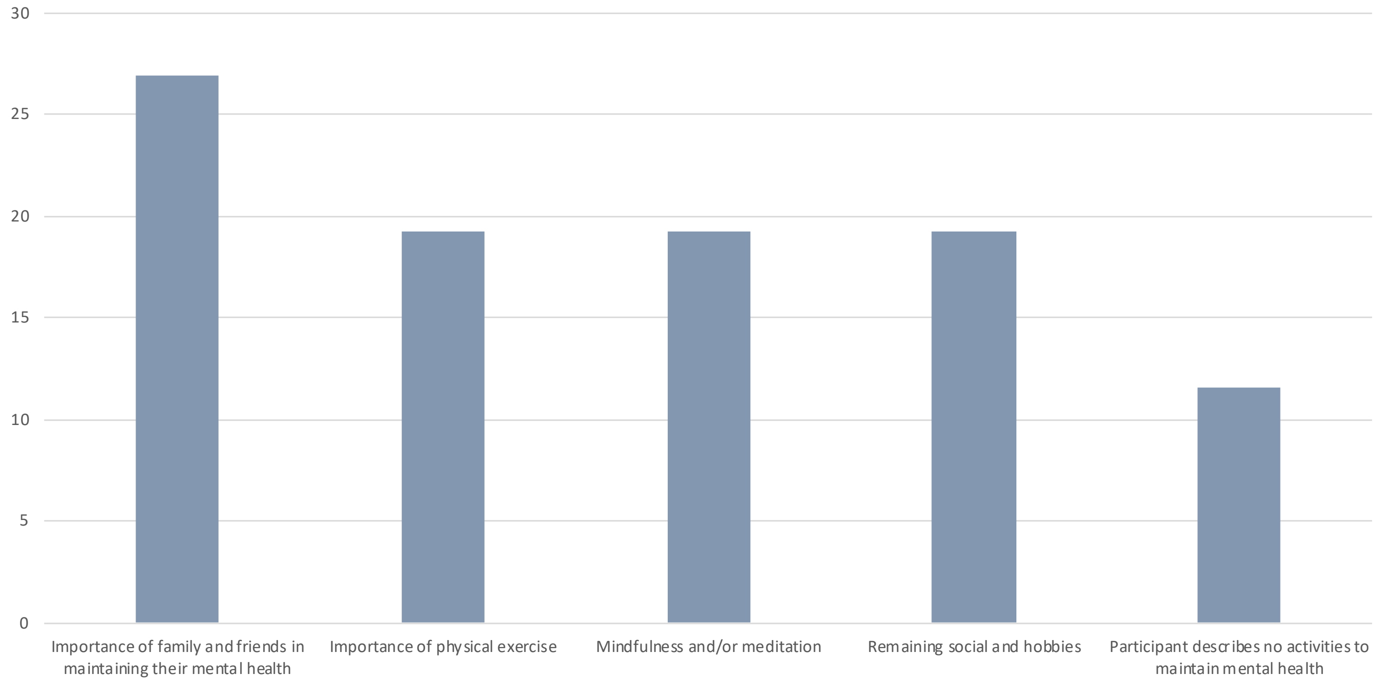


Figure 8.4: Regular activities to maintain mental health

Table 8.8: Regular activities to maintain mental health – subgroup variations

Theme	Less frequently	More frequently
Participant describes the importance of family and friends in maintaining their mental health	Metastatic Male	Non-metastatic Female
Participant describes using mindfulness and/or meditation	Male Trade or high school	Female University
Participant describes no activities to maintain mental health	Metastatic	Non-metastatic Aged 65 or older Mid to low status

Regular activities to maintain health

In the structured interview, participants were asked what were some of the things they needed to do everyday to maintain their health? The most common activities for general health were physical exercise or being physically active (50.00%), and understanding their limitations (34.62%). Other activities included complying with treatment/ management (15.38%), maintaining a healthy diet (15.38%), maintaining a normal routine (15.38%), self care e.g. more rest, accepting help, pacing (15.38%), socialising with friends and family (15.38%), being organised and planning ahead (11.54%), and mindfulness and/ or meditation (11.54%).

Participant describes being physically active

I need to keep fit, and I do yoga each week to keep my body moving and [unintelligible] twice a week. I get, like I said before, weekly massages and acupuncture. All of those things keep my body functioning and my lungs clear so that I don't get chest infections again.
Participant 007_2023AULUC

I probably just maintain, which is actually probably the hardest bit when you're feeling tired, but maintaining physical fitness, keeping busy, walking and exercises, stuff like that. I would do a lot more of that stuff like yoga and stuff like that if I wasn't working full-time and it didn't come with the cost.
Participant 026_2023AULUC

I'm a baby boomer, so we all think we'll live forever and we stay young forever. I'm a fairly positive person. I've had prostate cancer, I've had eye surgery, and I had another surgery on my bladder, and I've had bypass surgery, I had hernia surgeries. I've had quite a few surgeries over the years and I'm still here, which is good. At the moment I'm doing a fitness program through Deakin University, and I'm probably fitter now than I was 20 years ago. The only problem, I suffer from chronic fatigue, which is at the moment, this week, it's affecting me. I haven't been doing strenuous work around the house and exercise. I'm a bit going backwards as far as my fitness because of this chronic fatigue thing, but then I'll hopefully recover in the next few days. Sometimes it lasts a day, sometimes a few days, sometimes a few weeks. I never know. I just roll with it.
Participant 028_2023AULUC

Participant describes the importance of understanding their limitations

As I say, it's going to be a gradual reintroduction of some of the things that up to now I haven't been able to do. Getting back into the gardening, being more physical with the grandkids, getting back into the housework that my husband's taken over. Is that the sort of thing you mean?
Participant 010_2023AULUC

No, there's no great adjustment. Just at my age, it comes with it too because the lung cancer has slowed me down a bit. That's about all.
Participant 012_2023AULUC

Yes, at this point, it's not really stopping me from doing much on a day-to-day basis. I mean, it's slowed me down definitely, but yes, it's not really affecting me day-to-day.
Participant 014_2023AULUC

Participant describes the importance of complying with treatment

I go to yoga. I go on big long walks with my friends, and obviously, I take your sleeping tablet and the antidepressant. I'd really love to get off the antidepressants because you don't have the highs and the lows and you just flat line at okay and that's just not me. You lose a little bit of empathy. Maybe that's a good thing because it stops you from crying. Obviously, psychologists. Just help with everyday things like grocery shopping. I do order online and then go and pick it up. You just trying to continually conserve your energy because it's tiring. It's just debilitating. Whether it's the cancer or the medication, it is exhausting. Walking through the essential, I know there are walking clubs out there for people with lung cancer but I'd rather leave them to

the older people at this stage because I'm a young 50-year-old but I was 47 when I was diagnosed. My kids had gone from being told and growing to living with it.
Participant 019_2023AULUC

I have reduced things that I do on a day-to-day basis, but I can sort of do the things. I just monitor my temperature and just taking my vitamins, and sometimes Panadol and sometimes Nurofen, that's how I deal with it.
Participant 004_2023AULUC

Participant describes maintaining a healthy diet

I've got to try and keep myself as fit as possible, which I try. Make sure I try and walk every day. Well, my naturopath said Infrared Sauna's really good. I'm doing that. I'm just trying to keep myself and I'm trying to eat as healthy as I can
Participant 001_2023AULUC

Well, that's the only thing because I always eat well anyway. I probably just made it a little bit more refined by making vegetable and fruit pieces every day, instead of drinking a lot of coffee like I used to. I now drink more healthier food and juice, which the body needs right now to help it through this, but other than, nothing. I'm hanging out for my first read, I'm waiting.
Participant 017_2023AULUC

Participant describes the importance of maintaining a normal routine

As I say, it's going to be a gradual reintroduction of some of the things that up to now I haven't been able to do. Getting back into the gardening, being more physical with the grandkids, getting back into the housework that my husband's taken over. Is that the sort of thing you mean?
Participant 010_2023AULUC

We had really good systems in place. As soon as dad got cancer, as a carer, we changed the way that he took his medications. We now pack them in a blister pack. There's-- Oh, I don't know, I'm lost for words. Sorry. We've started a routine where he has a shower in the morning, not the evening because his breathing's a little bit better. It's just about planning as a carer. I've had to plan a little bit more than what I probably did with dad but I guess respecting him as a person and him as an adult as well and as my dad.
Participant 030_2023AULUC

Participant describes the importance of self care e.g. more rest, support for housework etc.

I need to get more sleep. I probably used to get by on six hours sleep and I find now I need minimum of eight, some days nine hours sleep. I am walking and-- I finally got walking go to gym regularly. I think that helps my mental health more than anything, but it does help my breathing a bit. I'm trying everything. I don't know how I'll go back at work, going up a flight of stairs if I have to rush around. That's when I get into trouble. If I pace myself with everything, I can do everything but I have to slow everything down.
Participant 025_2023AULUC

I'm a baby boomer, so we all think we'll live forever and we stay young forever. I'm a fairly positive person. I've had prostate cancer, I've had eye surgery, and I had another surgery on my bladder, and I've had bypass surgery, I had hernia surgeries. I've had quite a few surgeries over the years and I'm still here, which is good. At the moment I'm doing a fitness program through Deakin University, and I'm probably fitter now than I was 20 years ago. The only problem, I suffer from chronic fatigue, which is at the moment, this week, it's affecting me. I haven't been doing strenuous work around the house and exercise. I'm a bit going backwards as far as my fitness because of this chronic fatigue thing, but then I'll hopefully recover in the next few days. Sometimes it lasts a day, sometimes a few days, sometimes a few weeks. I never know. I just roll with it.
Participant 028_2023AULUC

Participant describes socialising with friends and/or family

As I said, I've now quit work, I've sold out my house, I've sorted out all my affairs and I live on a farm. I do a lot of gardening. I do a lot of knitting, I do some painting. I do a lot of relaxing, traveling, spend time with the family.
Participant 006_2023AULUC

I go to yoga. I go on big long walks with my friends, and obviously, I take your sleeping tablet and the antidepressant
Participant 019_2023AULUC

The both what I do is I exercise regularly. Soon after my diagnosis, we got a dog because we used to have dogs, and I thought this was great. This gives a reason that you get up and go each day because she's not going to let you lie in bed and be miserable. It's

keeping up my social relationships, making sure I keep in contact with friends, family, and meet up with them. That's very important to me, too. I love my cycling, and getting back on the bike after I had my brain surgery was so important and I do that socially, as well. I love it. I love exercise, so getting up and keeping up exercise it has been very important mentally and physically great for me and helps me manage a whole lot of things. I haven't really changed life to work around the minor side effects of the drugs. The one thing I did change was obviously working because physically I'm more tired. At times, I will be kind to myself and let myself have an [unintelligible 00:36:52] if I need it, and not push myself when I really, really feel tired.
Participant 020_2023AULUC

Participant describes the importance of being organised and planning ahead

I think I just need to fulfill my duty towards the kids, and that's it. You see, again, for me, it's also the collective. I pace myself, I organize myself. I think the thing I have to do every day is to focus on the care of the kids, and if I focus on the care of the kids, I will survive longer.
Participant 023_2023AULUC

We had really good systems in place. As soon as dad got cancer, as a carer, we changed the way that he took his medications. We now pack them in a blister pack. There's-- Oh, I don't know, I'm lost for words. Sorry. We've started a routine where he has a shower in the morning, not the evening because his breathing's a little bit better. It's just about planning as a carer. I've had to plan a little bit more than what I probably did with dad but I guess respecting him as a person and him as an adult as well and as my dad.
Participant 030_2023AULUC

Participant describes using mindfulness and or meditation to maintain their health

I have a heap of vitamins that I take every day. I exercise nearly every day, either walking or at the gym or whatever because HIIT exercises have been proven to be the best form of exercises to prevent re-occurrence. I ate pretty well, previously, but I now try to eat as organically as possible. I drink filtered water. I don't drink any of the council waters whatsoever. Just stuff like that, I try to do. I have a mantra or a meditation that I go through every day because I believe the mind is very powerful and makes a difference. I still and will continue seeing my Reiki healer and my massage person because I still have a lot of tension that builds up in my muscles from worrying about, "Is it coming back?" Especially leading up to scans and things like that. I take a lot of vitamins. I have to take these tablets at night for my neuropathy and deal with the fatigue that comes with that and manage that sort of thing. I have to sleep with white noise because of the ringing in my ear. Because I can't get to sleep otherwise. If I get five hours sleep, that's a bonus. I've just adjusted to "This is how things are with me. This is how much I can do and how much I can't do, and then I have to stop because I know that I'll be too tired," so bits and pieces like that every day.
Participant 018_2023AULUC

Well, mindset stuff, again, physical health stuff. Trying to keep myself as active as I can, which I do in any cases. That's me. Yes, I think that probably covers it.
Participant 021_2023AULUC

Table 8.9: Regular activities to maintain health

Regular activities to maintain general health	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes being physically active	13	50.00	13	52.00	0	0.00	6	60.00	7	43.75	10	62.50	3	30.00
Participant describes the importance of understanding their limitations	9	34.62	9	36.00	0	0.00	5	50.00	4	25.00	8	50.00	1	10.00
Participant describes the importance of complying with treatment	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00
Participant describes maintaining a healthy diet	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	0	0.00
Participant describes the importance of maintaining a normal routine	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00
Participant describes the importance of self care e.g. more rest, support for housework etc.	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00
Participant describes socialising with friends and/or family	4	15.38	4	16.00	0	0.00	0	0.00	4	25.00	4	25.00	0	0.00
Participant describes the importance of being organised and planning ahead	3	11.54	2	8.00	1	100.00	0	0.00	3	18.75	2	12.50	1	10.00
Participant describes using mindfulness and or meditation to maintain their health	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00

Regular activities to maintain general health	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes being physically active	13	50.00	9	52.94	4	44.44	6	46.15	7	53.85	1	50.00	12	50.00	3	33.33	10	58.82
Participant describes the importance of understanding their limitations	9	34.62	7	41.18	2	22.22	3	23.08	6	46.15	1	50.00	8	33.33	3	33.33	6	35.29
Participant describes the importance of complying with treatment	4	15.38	4	23.53	0	0.00	0	0.00	4	30.77	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes maintaining a healthy diet	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	0	0.00	4	16.67	2	22.22	2	11.76
Participant describes the importance of maintaining a normal routine	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes the importance of self care e.g. more rest, support for housework etc.	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes socialising with friends and/or family	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	1	50.00	3	12.50	2	22.22	2	11.76
Participant describes the importance of being organised and planning ahead	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	1	11.11	2	11.76
Participant describes using mindfulness and or meditation to maintain their health	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65

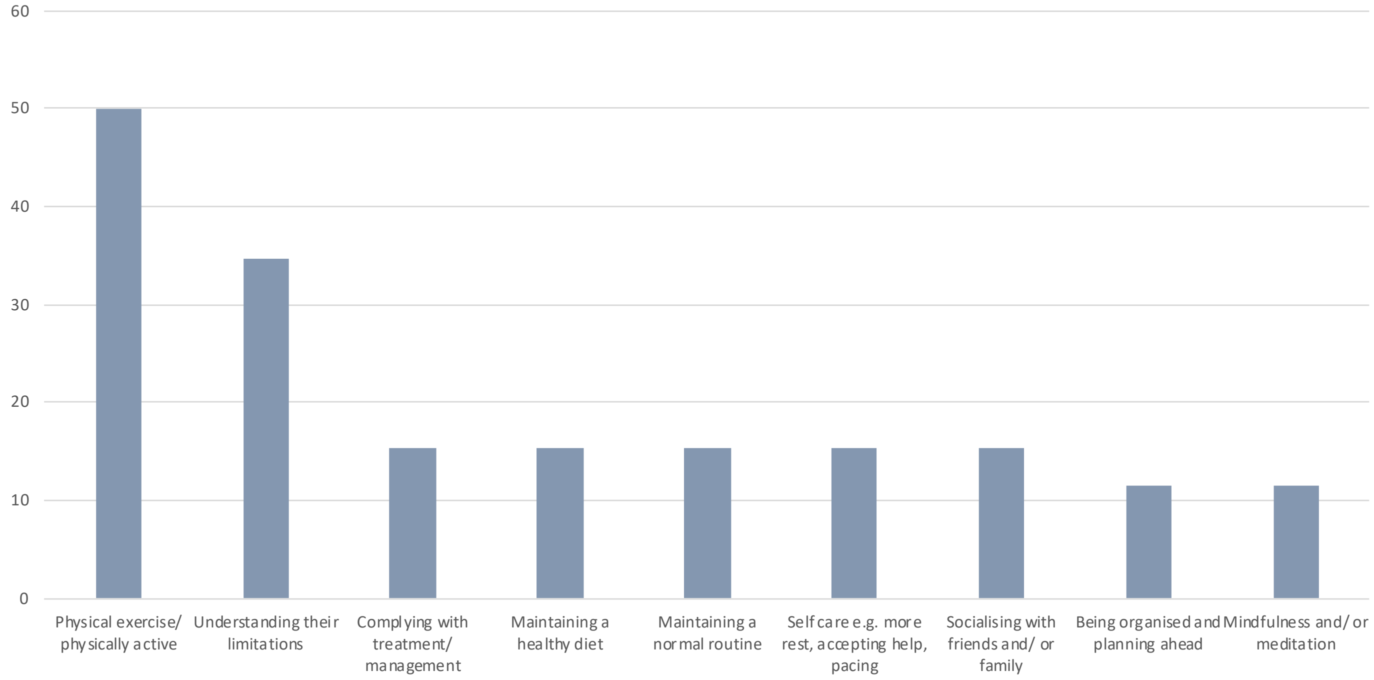


Figure 8.5: Regular activities to maintain health

Table 8.10: Regular activities to maintain health – subgroup variations

Theme	Less frequently	More frequently
Participant describes being physically active	Male Mid to low status	Female
Participant describes the importance of understanding their limitations	Male Aged 65 or older Trade or high school	Non-metastatic Female University
Participant describes the importance of complying with treatment	Male Aged 65 or older Trade or high school	University
Participant describes maintaining a healthy diet	Male	
Participant describes the importance of maintaining a normal routine	Mid to low status	Aged 65 or older
Participant describes the importance of self care e.g. more rest, support for housework etc.	Mid to low status	
Participant describes socialising with friends and/or family	Non-metastatic Male Aged 65 or older	
Participant describes the importance of being organised and planning ahead	Non-metastatic	Aged 65 or older
Participant describes using mindfulness and or meditation to maintain their health	Mid to low status	

Experience of vulnerability

In the structured interview, participants were asked if there had been times that they felt vulnerable. The most common responses were that they felt vulnerable when having sensitive discussions (diagnosis, treatment decision) (30.77%), and vulnerable during/after treatments (19.23%). Other times when participants felt vulnerable included when feeling sick or unwell (11.54%), vulnerable because of interactions with the medical team (11.54%), and vulnerable in general (11.54%). Some participants described that they did not feel vulnerable (11.54%).

Participant describes feeling vulnerable when having sensitive discussion, for eaxmple at diagnosis or when making treatment decisions

Now. As soon as they find that mass or nodule in your lung, that's when you become vulnerable
Participant 003_2023AULUC

Every time there's a progression, apart from when you first get diagnosed and then every time there's a progression, or there's like a wait-and-see or you've got symptoms, that's when you feel vulnerable.
Participant 004_2023AULUC

Probably right at the beginning because I didn't know what was going to happen.
Participant 013_2023AULUC

Probably just at the start before the doctors even know how bad it is.
Participant 026_2023AULUC

Participant describes feeling vulnerable while having treatments or the period following treatments

Yes, quite often. In particular, I felt vulnerable when somebody's doing brain radiation to your head. That's the most vulnerable I felt. Very scary.
Participant 007_2023AULUC

This time I ended up in hospital. My biggest concern, these days they're trying to get you out of hospital as fast as possible, which some ways it's good. In my experience, I don't mind being in hospitals. I'm in no rush to go home. I live alone. My son lives virtually next door to me, so I'm alone but not alone. I've always asked to stay a bit longer. If I could, I've always tried to get an extra day or two in hospital. This time around because of the complications with my lung draining or whatever, not draining properly, they kept me there. Instead of five days I ended up being there for nine days. That was good.
Participant 028_2023AULUC

Participant describes feeling vulnerable when feeling sick or unwell

Well, basically, there was a few times-- Most of the time I was on, what do you call drugs-- High dosage drugs. It was only a few weeks ago that my wife and I were talking and she said sometimes she'd visit me and I didn't even know where I was because I was allowed to have this drug every four hours because of the pain. Oh, I can't remember the name of it. I was getting two types of pain relief, both drugs, and one I can have every four hours, and trust me, I was having it every four hours. It was because of my esophagus. It wasn't my lung, it was my esophagus was the main problem. After the chemotherapy and radiation, the tumor was shrinking, and everything was happy. The problem with my case was the esophagus, the burn, and that led to loss of weight, loss of appetite, and having to take barbiturates or whatever they are on high dosage.
Participant 012_2023AULUC

I was very vulnerable when I was really sick with the chemo, really vulnerable. I really felt dreadful because they do give you a list of "Let us know when this happens, that happens." I'd ring-- I rang twice and said, "Well this is happening," and both times the response was you need to go to an emergency department and that was my multidisciplinary team providing assistance. I knew that was COVID and I'm neutropenic. You're not going to go and sit in an emergency department, are you?
Participant 025_2023AULUC

Participant describes feeling vulnerable because of interactions with the medical team

PARTICIPANT: Yes, totally. When you don't know what's going on or you sit there and like for an example, one of the radiation oncologists, we had to meet them on [unintelligible 00:33:16], and it wasn't my regular. It was with another guy, and he said, "How you feeling?" I said, "I'm still pretty short on breath." Because radiation does make you very short on breath. I kept having this goal in my head of "I'm moving myself forward to being cancer free. I'm moving myself forward. He was like, "That could be as good as it gets. You may not get you better. You could just be like this for the rest of your natural life." Then I got a bit teary and, bang, the next thing, he was talking to the nurse and saying, "We want NAME to see a psychologist." It's like as soon as you get emotional, they just, "Oh, how's your mental health?" You think, "My mental health is not too bad, all things considered. You, be given all this news and go through everything I've gone through and see how your mental health is." I thought it was okay, but they just brush you straight off to a psychologist, instead of just having a conversation with you.
Participant 018_2023AULUC

In the hospital? Yes, definitely. Even there's no toothbrushes in the hospital. This is just disgusting, but I was in theater roads and had my period and I was bleeding everywhere. That was the last line, but it was like, what is going on here? Just little things like that. It was a very bad hospital thing. If it wasn't that bad, I may have been a lot more better when I left the hospital, but I was an absolute mess when I left the hospital.

Participant 019_2023AULUC

Table 8.11: Experience of vulnerability

Experience of vulnerability	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	6	37.50	2	20.00
Participant describes feeling vulnerable while having treatments or the period following treatments	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant describes feeling vulnerable when feeling sick or unwell	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00
Participant describes feeling vulnerable because of interactions with the medical team	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant describes that they did not feel vulnerable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	0	0.00
Participant describes feeling vulnerable in general without giving a description	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00

Experience of vulnerability	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	8	30.77	7	41.18	1	11.11	3	23.08	5	38.46	1	50.00	7	29.17	4	44.44	4	23.53
Participant describes feeling vulnerable while having treatments or the period following treatments	5	19.23	3	17.65	2	22.22	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Participant describes feeling vulnerable when feeling sick or unwell	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65
Participant describes feeling vulnerable because of interactions with the medical team	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Participant describes that they did not feel vulnerable	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes feeling vulnerable in general without giving a description	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	2	22.22	1	5.88

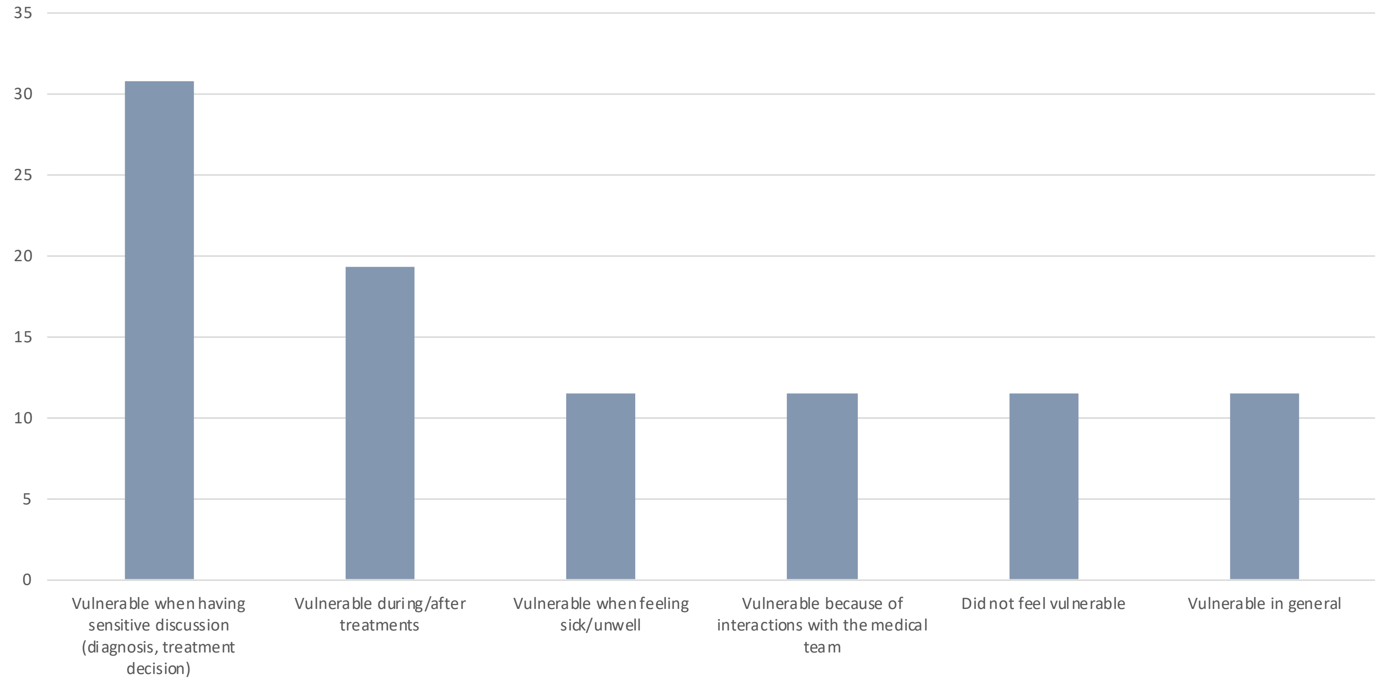


Figure 8.6: Experience of vulnerability

Table 8.12: Experience of vulnerability – subgroup variations

Theme	Less frequently	More frequently
Participant describes feeling vulnerable when having sensitive discussion, for example at diagnosis or when making treatment decisions	Male Aged 65 or older	Aged 35 to 64 Mid to low status
Participant describes feeling vulnerable while having treatments or the period following treatments	Mid to low status	Higher status
Participant describes feeling vulnerable when feeling sick or unwell	Metastatic Mid to low status	Non-metastatic
Participant describes feeling vulnerable because of interactions with the medical team	Male Aged 65 or older	
Participant describes that they did not feel vulnerable	Male	Aged 65 or older Mid to low status
Participant describes feeling vulnerable in general without giving a description		Mid to low status

Methods to manage vulnerability

In the structured interview, participants described ways that they managed feelings of vulnerability. The most common response was self-help (resilience, acceptance, staying positive) to manage the feeling of vulnerability (30.77%). This was followed by support from family and friends to manage the feeling of vulnerability (7.69 %), and being supported by nurse or treatment team (7.69%).

Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable

I've got to just try and think positive. I don't know what else I can do. I don't want to focus on this cancer all the time because that is such a downer.
Participant 001_2023AULUC

I just get through it. I get through it. I get out the other side. Luckily for me, I've had good scans every time and the doctors told me, "Yes, everything's fine," and I've relaxed again for a while but yes, there's nothing you can really do
Participant 002_2023AULUC

Really just a lot of stuff that I tend to do in any case, which is to do with my mindset and just focus on the positives and appreciating everything around you and appreciate the people where you live, natural beauty, all those sorts of things, to just put your mind in a better place where you start looking for the positives and not the negatives
Participant 021_2023AULUC

Participant describes that support from family and friends helped them manage feeling vulnerable

PARTICIPANT: When I was first diagnosed, I said to my husband, "I'm never going to see my son walk, crawl, or talk. I'm never going to see my daughter start her first day at school." I was grieving all the things that I never thought I would see. He told me I would. He reminded me of a time that he said was like climbing Mount Everest. He said, "You just have to remember when you look down from the top, it's easy to remember how you got there." He said, if I can do it, then I could do it again now. Then I worked with a neuro-linguistic programming guy. He helped to reset my values and my beliefs, he challenged my thoughts. We did a lot of visualization every week, twice a week. Just on empowering my mind to get stronger and to improve what I was going to dream of in the future. There's been another time when it spread to my brain. I thought, "Okay, this is it. Things are only going to get worse," so we went on our trip to Disney World. Just, I think, focusing on making as many memories as we can with each other. That's been the main focus. My husband had to refocus me and remind me that that's what our goal is, that's all we want to do. That has helped. Look, there's been lots of other times, but let's just stick to that.
Participant 015_2023AULUC

Honestly, I don't know. I think there is a point where you're in just shock. I think at that point, we probably need emotional support, and I've got that through home. Yes, there's probably a point where if someone doesn't have that they need to have someone they can talk to who isn't a specialist, but can just talk a little bit about the emotional side and a bit of reassurance that you'll get there, you'll get it under your belt. More of counseling sort of thing
Participant 020_2023AULUC

Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable

I go to my GP and I get him to reassure me, but that’s about the only way.
Participant 014_2023AULUC

This time I ended up in hospital. My biggest concern, these days they're trying to get you out of hospital as fast as possible, which some ways it's good. In my experience, I don't mind being in hospitals. I'm in no rush to go home. I live alone. My son lives virtually next door to me, so I'm alone but not alone. I've always asked to stay a bit longer. If I could, I've always tried to get an extra day or two in hospital. This time around because of the complications with my lung draining or whatever, not draining properly, they kept me there. Instead of five days I ended up being there for nine days. That was good.
Participant 028_2023AULUC

Table 8.13: Methods to manage vulnerability

Methods to manage vulnerability	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	8	30.77	8	32.00	0	0.00	3	30.00	5	31.25	6	37.50	2	20.00
Participant describes that they did not feel vulnerable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	3	18.75	0	0.00
Participant describes that support from family and friends helped them manage feeling vulnerable	2	7.69	2	8.00	0	0.00	0	0.00	2	12.50	2	12.50	0	0.00
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	2	7.69	2	8.00	0	0.00	2	20.00	0	0.00	1	6.25	1	10.00

Methods to manage vulnerability	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	8	30.77	7	41.18	1	11.11	2	15.38	6	46.15	0	0.00	8	33.33	2	22.22	6	35.29
Participant describes that they did not feel vulnerable	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	1	50.00	2	8.33	2	22.22	1	5.88
Participant describes that support from family and friends helped them manage feeling vulnerable	2	7.69	2	11.76	0	0.00	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	1	11.11	1	5.88

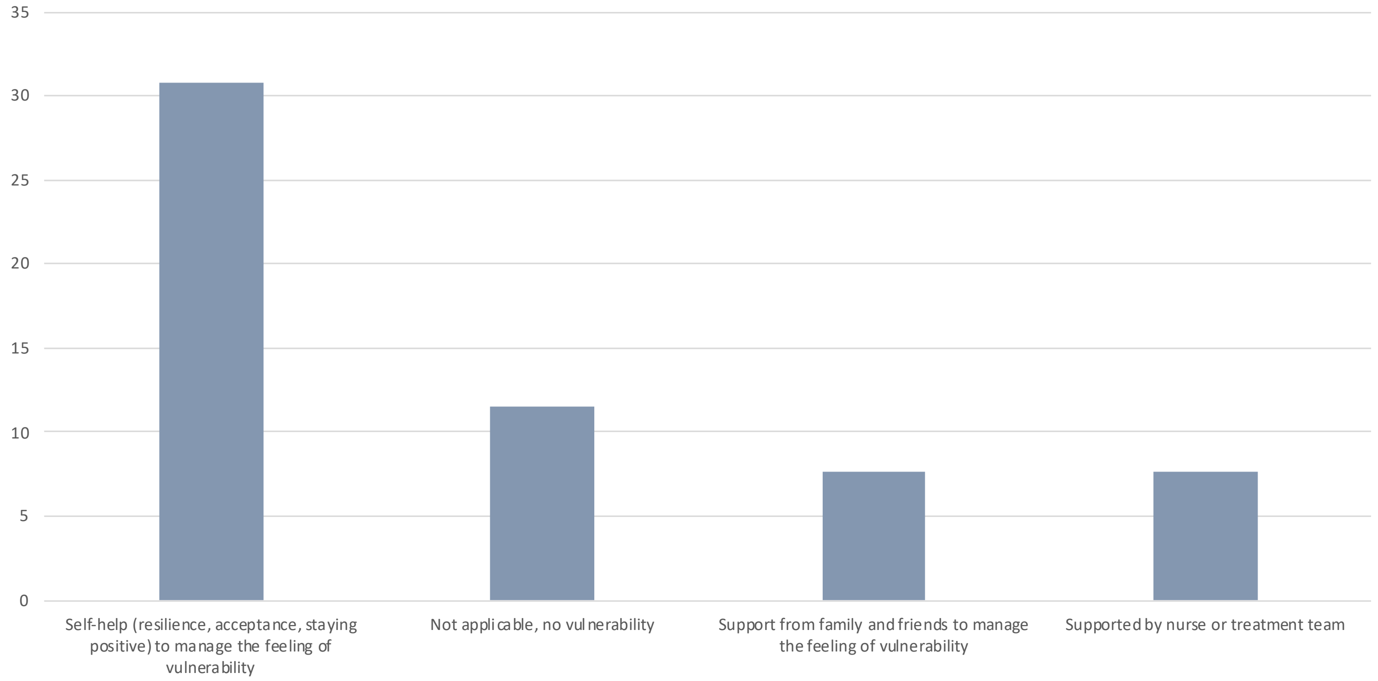


Figure 8.7: Methods to manage vulnerability

Table 8.14: Methods to manage vulnerability– subgroup variations

Theme	Less frequently	More frequently
Participant describes that self help, for example resilience, acceptance, and staying positive, helped them manage feeling vulnerable	Male Aged 65 or older Trade or high school	Aged 35 to 64 University
Participant describes that they did not feel vulnerable	Male	Aged 65 or older Mid to low status
Participant describes that support from nurses or their treatment team helped them manage feeling vulnerable	-	Non-metastatic

Impact on relationships

Most commonly, the descriptions suggested that overall, there was a negative impact on relationships (30.77%). Other participants descriptions suggested that overall, there was an impact on relationships that was both positive and negative (23.08%), there was a positive impact on relationships (19.23 %), there no impact on relationships (15.38%), and that, there was an impact on relationships that was neither positive nor negative (7.69%).

The most common themes in relation to having a negative impact on relationships from people not knowing what to say or do and withdrawing from relationships (34.62%), and that the dynamics of relationships changed due to anxiety, exacerbations and/or physical limitations of condition (23.08 %).

The most common themes in relation to having a positive impact on relationships from family relationships being strengthened(30.77%), and from people being well-meaning and supportive) (19.23%).

Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships

Well, I think my friends, I think they're all waiting for me to die. I think it's changed it that way and I don't want people feeling sorry for me. I just want to be the same person. You know what I mean?
INTERVIEWER: Yes.
PARTICIPANT: I think people look at you differently. You know what I mean?
Participant 001_2023AULUC

Yes definitely. Definitely. You realize who is actually supportive and who's gutless and runs away. You end up with a very small bubble around you of people that actually care about you, but after a year you realize that that's all you need. You don't need these other people that are cowards, that can't say the right thing. You learn that you just don't need them, and everything's better with just a small group of people that support you.
INTERVIEWER: That must have been a hard time though, going through that realization.
PARTICIPANT: Yes, it was a hard time for a year, but then where I am now, I think I'm a lot happier because I only have people that are just loving, kind, supportive. Anyone else who tries to tell me to eat more vegetables or crap like that, that, "You can heal, just eat more veggies," I don't speak to them anymore and I'm a lot happier, and it's good
Participant 004_2023AULUC

I think in some ways yes, mainly because I have a-- I think some people became strange or standoffish because I've got in some. Do you know what I mean? There's a whole range of other things associated with that.
Participant 026_2023AULUC

Participant describes relationships with family being strengthened

It's made them better. A lot more honest, because I've got limited time now. I tell people I love them a lot more. I hang out a lot more with them.
Participant 006_2023AULUC

I think it's probably made us a lot closer because I feel, perhaps, my life's been compromised, and I won't live for as long as I, perhaps, should. I'm not through my first five years, so, therefore, I don't know-- Only what, 18% make it through the first five years? I have every intention of doing that. I think I try to be as positive as I can with my personal relationships, and, yes, I think it has made a difference in that regard.
Participant 018_2023AULUC

It sorts out who's very close to you, who can handle it, and who you can talk frankly about what's coming up and how you feel. You really work at who's very close to you, and who's a step removed. It hasn't impacted negatively on any of those. I feel in a lot of ways it's made my husband and I who has a great relationship actually go, "Okay, we're in this together." It's brought us closer. I've got great relationship with my two kids. I've done my best not to let it be in forefront of their mind that I have this disease so all of that it's been about managing it positively. The more with it mentally, physically the people see me, the better they see me the less everyone else is worried, and unless I worry. I don't think it's had a huge impact. I think if anything, it's made some relationships closer.
Participant 020_2023AULUC

Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition

Yes, it has. It has because I'm limited to where I can go and what I can do on the time limit to be out of the house given that is a false risk.
Participant 030_2023AULUC

Yes, it has. Definitely. I'm no longer as sociable as I was before. I don't cope too well with large groups of people, so it had an impact on my social skills as well as my ability to want to do things. I hold back
Participant 007_2023AULUC

Well, I have a son and a daughter. They're just as stressed as what I am, as I've said about my son. It's caused him a great deal of anxiety, a great deal of stress. My daughter's in Brisbane, so we talk on the phone, and we text, but I haven't seen her for since September last year. They're just as worried as what I am and I try very hard not to complicate the matter and not to be down or let them know exactly how I'm feeling, so basically I'm lying to them. I have two friends that I can talk to and they're there for me if I need them. That's it.
Participant 003_2023AULUC

Participant describes a positive impact on relationships as people were well meaning and supportive

It has, but also in a positive way. When I first ended up in hospital with a seizure, it was just before COVID, so visiting was not an issue. I was in a hospital for 10 days, I had so many people come and see me and there were people that I hadn't seen for a long time that we just had lost connection with. Not a falling out, just a connection with and we rediscover those friendships and relationships. That was a real positive experience. Something really positive to come out of that negative situation and we have maintained those friendships. Yes, it does affect my relationship with my husband, especially at the moment because he's become the carer as well. Affects your relationships like that, but I can also see how I've experienced seeing other cancer patients a [unintelligible] actually. Someone, she passed away, but her marriage fell apart during her cancer treatment. The husband left her and I can understand that now why that would have happened because it can put a strain on your relationship. That's why I said to my husband from the start, he needs the counseling as well as me. He's been to one of the recent psychology sessions with me just to talk about things. Even I suppose with my kids, especially with this last diagnosis, I said to my son we have to embrace every moment we have together, we have to cherish every moment we have together. Keep creating memories because we just don't know.
Participant 005_2023AULUC

If anything, it slightly improved it. Particularly with friends, I send out a report after every scan that I have, I'm going to say, report-- It's a brief email just saying how things are going. My friends enjoy getting that information and I enjoy writing it. I'm not sure what more I can say on that.
Participant 022_2023AULUC

Table 8.15: Impact on relationships

Impact on relationships	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Overall, there was a negative impact on relationships	8	30.77	7	28.00	1	100.00	3	30.00	5	31.25	**7**	**43.75**	**1**	**10.00**
Overall, there was an impact on relationships that was both positive and negative	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	5	31.25	**1**	**10.00**
Overall, there was a positive impact on relationships	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	3	18.75	2	20.00
Overall, there no impact on relationships	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00
Overall, there was an impact on relationships that was neither positive nor negative	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	2	12.50	0	0.00
No particular comment	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Impact on relationships	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Overall, there was a negative impact on relationships	8	30.77	5	29.41	3	33.33	4	30.77	4	30.77	1	50.00	7	29.17	**4**	**44.44**	4	23.53
Overall, there was an impact on relationships that was both positive and negative	6	23.08	**6**	**35.29**	**0**	**0.00**	3	23.08	3	23.08	0	0.00	6	25.00	2	22.22	4	23.53
Overall, there was a positive impact on relationships	5	19.23	3	17.65	2	22.22	**1**	**7.69**	**4**	**30.77**	1	50.00	4	16.67	1	11.11	4	23.53
Overall, there no impact on relationships	4	15.38	1	5.88	**3**	**33.33**	3	23.08	1	7.69	0	0.00	4	16.67	**0**	**0.00**	4	23.53
Overall, there was an impact on relationships that was neither positive nor negative	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	**2**	**22.22**	0	0.00
No particular comment	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

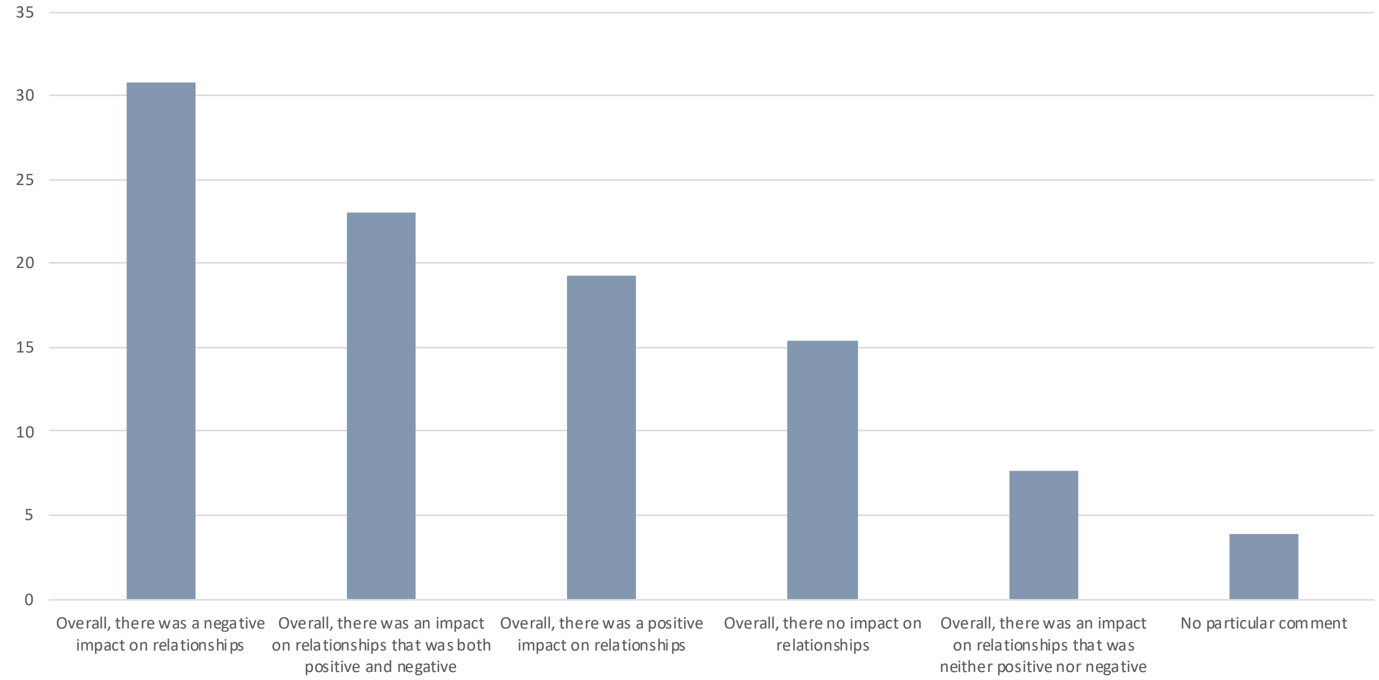


Figure 8.8: Impact on relationships

Table 8.16: Impact on relationships – subgroup variations

Theme	Less frequently	More frequently
Overall, there was a negative impact on relationships	Male	Female Mid to low status
Overall, there was an impact on relationships that was both positive and negative	Male Aged 65 or older	Aged 35 to 64
Overall, there was a positive impact on relationships	Trade or high school	University
Overall, there no impact on relationships	Mid to low status	Aged 65 or older
Overall, there was an impact on relationships that was neither positive nor negative	-	Mid to low status

Table 817: Impact on relationships (Reason for impact)

Impact on relationships (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	34.62	9	36.00	0	0.00	3	30.00	6	37.50	**8**	**50.00**	**1**	**10.00**
Participant describes relationships with family being strengthened	8	30.77	8	32.00	0	0.00	4	40.00	4	25.00	6	37.50	**2**	**20.00**
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	5	31.25	**1**	**10.00**
Participant describes a positive impact on relationships as people were well meaning and supportive	5	19.23	5	20.00	0	0.00	1	10.00	4	25.00	3	18.75	2	20.00
Participant describes no impact on relationships	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00

Impact on relationships (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	9	34.62	**8**	**47.06**	**1**	**11.11**	**3**	**23.08**	**6**	**46.15**	0	0.00	9	37.50	3	33.33	6	35.29
Participant describes relationships with family being strengthened	8	30.77	6	35.29	2	22.22	3	23.08	5	38.46	1	50.00	7	29.17	**1**	**11.11**	**7**	**41.18**
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	6	23.08	4	23.53	2	22.22	4	30.77	2	15.38	1	50.00	5	20.83	**3**	**33.33**	3	17.65
Participant describes a positive impact on relationships as people were well meaning and supportive	5	19.23	4	23.53	1	11.11	**1**	**7.69**	**4**	**30.77**	0	0.00	5	20.83	2	22.22	3	17.65
Participant describes no impact on relationships	4	15.38	1	5.88	**3**	**33.33**	3	23.08	1	7.69	0	0.00	4	16.67	**0**	**0.00**	4	23.53

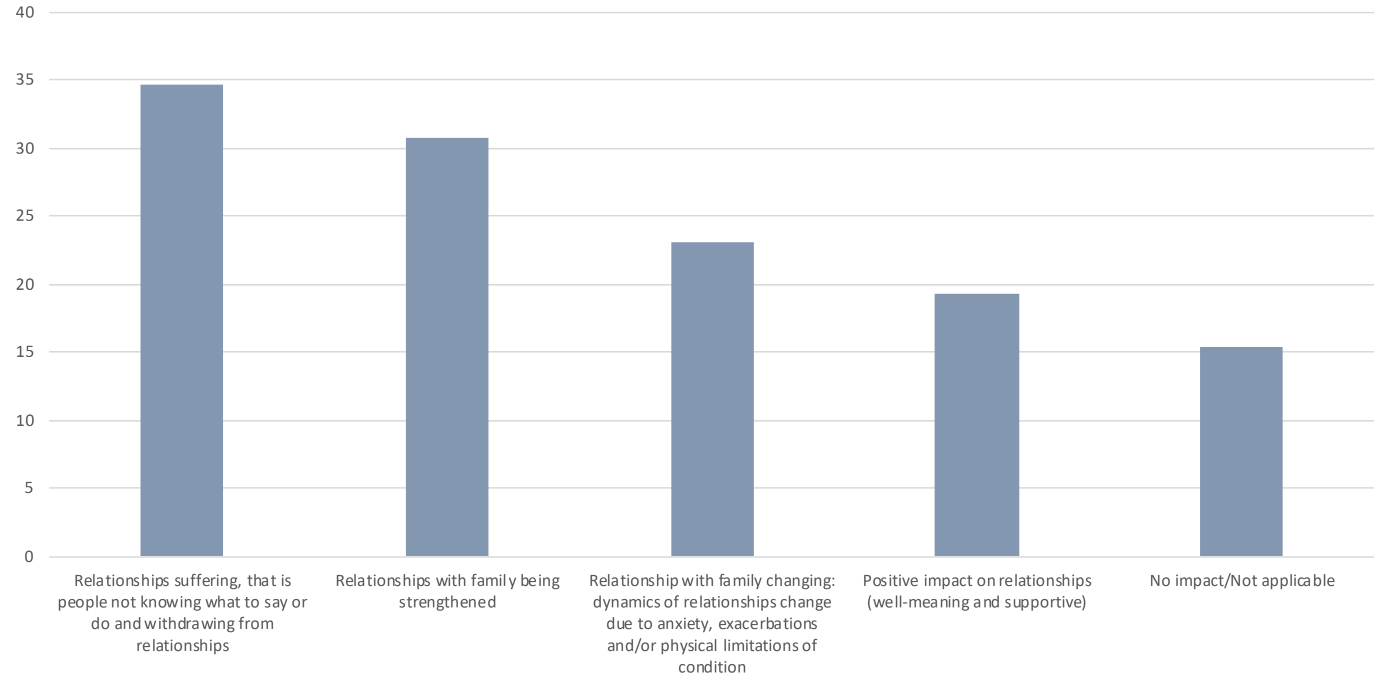


Figure 8.9: Impact on relationships

Table 8.18: Impact on relationships: Reason for impact – subgroup variations

Theme	Less frequently	More frequently
Participant describes relationships suffering, that is people not knowing what to say or do and withdrawing from relationships	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University
Participant describes relationships with family being strengthened	Male Mid to low status	Higher status
Participant describes relationship with family changing: dynamics of relationships change due to anxiety, exacerbations and/or physical limitations of condition	Male	Mid to low status
Participant describes a positive impact on relationships as people were well meaning and supportive	Trade or high school	University
Participant describes no impact on relationships	Mid to low status	Aged 65 or older

Burden on family

In the structured interview, participants were asked whether they felt that their condition placed additional burden on their family. Most commonly, the descriptions suggested that overall, there was a burden on their family (76.92%). Other participants descriptions suggested that overall, there was not a burden on their family (15.38%).

The main reason that participant described their condition being a burden was from the mental and emotional strain placed on their family (38.46%).

Overall, there was a burden on their family

Oh, absolutely. My mother would cry nearly every day when she found out. She's elderly, she's in her 90s, and she was in the late 80s when I was diagnosed, and that's a terrible thing for a mother to have to deal with, to know that her daughter is so sick, and for me to know that she was so upset was terrible. I felt awful. I felt guilty making her feel that way. It's been a burden to my husband, work-wise, and his emotion, not knowing when he was going to see me come out of surgery. There's lots of different impacts that happen that no one realizes.
Participant 018_2023AULUC

Oh, God, yes. Yes, definitely. Although I'm no physical burden to them it's an emotional one and it's that psychological thing that you try and protect the people you love from but I know it had an impact on them. I do feel I'm concerned about the future impact as the disease progresses and need becomes more physical issue. I think it has had an emotional burden on them, of course. At the moment, there's no physical burden because I totally [unintelligible] gosh I'm just like I was pre-diagnosis, I don't feel any different. I'm not doing anything particularly different.
Participant 020_2023AULUC

Well, yes, I do. I feel sorry because my daughter is living with us till she got a unit fixed up. I think she feels that she can't move out now because of me, but I want her to have a life. You know what I mean?

INTERVIEWER: Yes.
PARTICIPANT: I think it's affected her and I think she worries a lot. My youngest son, he was so devastated when he found out. I wouldn't like to tell him anything bad now, you know what I mean? Everything's good. I worry about my kids and I worry about my grandkids. Anyway.
INTERVIEWER: Sounds really difficult.
PARTICIPANT: Can be sometimes. Yes. I do worry about them. That's what upsets me more than anything but them
Participant 001_2023AULUC

Overall, there was not a burden on their family

No, not really. One thing I'm aware of as I hear patients talk about the stigma and shame of the diagnosis and I've not felt a shred of that. I know that if I had been a long-term smoker, I would feel it, but I don't feel that at all about my condition. It was just the short straw, in my view. It's been no problem at all.
Participant 022_2023AULUC

PARTICIPANT: Actually, I live next door to my son and I've got two granddaughters. Actually, I do more for them than they do for me. I do all my cleaning, I do my gardening, I do my washing. I do all my cooking. I bake. I baked nearly 800 different cakes. I don't get much sympathy from people because I look fairly…I also use a moisturizer. Actually, my granddaughter, a few years ago, she showed a photo of me with her and the person said, "You've got a very lovely grandfather. Looks he's really young," and my granddaughter says, "Yes, papa uses a moisturizer." Over the years, I'm slim fairly in good condition, so I have trouble getting sympathy from people because they look at me and say, "Oh, you must be okay. You are looking so good."
Participant 028_*2023AULUC*

Table 8.19: Burden on family

Burden on family	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Overall, there was a burden on their family	20	76.92	19	76.00	1	100.00	**6**	**60.00**	**14**	**87.50**	**17**	**106.25**	**3**	**30.00**
Overall, there was not a burden on their family	4	15.38	4	16.00	0	0.00	**3**	**30.00**	1	6.25	1	6.25	**3**	**30.00**
No particular comment	2	7.69	2	8.00	0	0.00	1	10.00	1	6.25	1	6.25	1	10.00

Burden on family	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Overall, there was a burden on their family	20	76.92	14	82.35	**6**	**66.67**	9	69.23	11	84.62	2	100.00	18	75.00	**8**	**88.89**	12	70.59
Overall, there was not a burden on their family	4	15.38	1	5.88	**3**	**33.33**	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
No particular comment	2	7.69	1	5.88	1	11.11	1	7.69	1	7.69	0	0.00	2	8.33	0	0.00	2	11.76

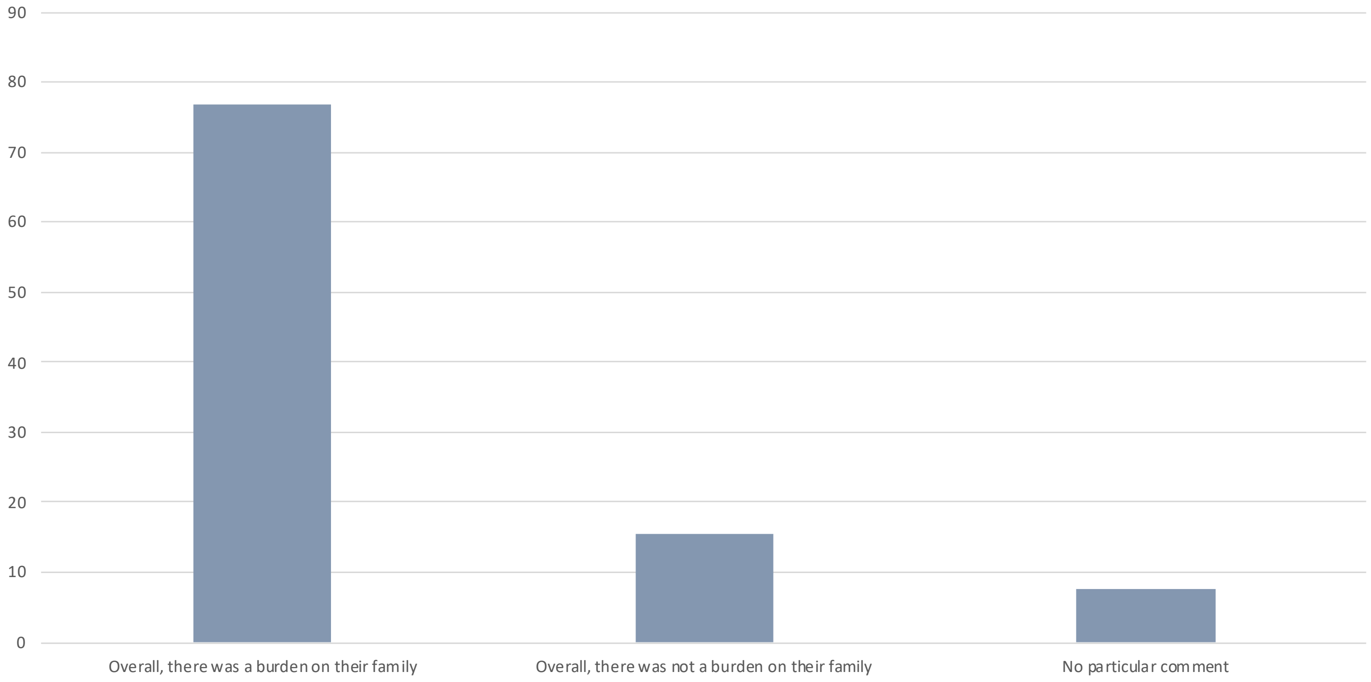


Figure 8.10: Burden on family

Table 8.20: Burden on family – subgroup variations

Theme	Less frequently	More frequently
Overall, there was a burden on their family	Non-metastatic Male Aged 65 or older	Metastatic Female Mid to low status
Overall, there was not a burden on their family	-	Non-metastatic Male Aged 65 or older

Table 8.21: Burden on family (description)

Burden on family (reasons)	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant describes the mental/emotional strain placed on their family	10	38.46	10	40.00	0	0.00	3	30.00	7	43.75	8	50.00	2	20.00
Participant describes their condition being a burden in general (No specific examples)	5	19.23	4	16.00	1	100.00	2	20.00	3	18.75	4	25.00	1	10.00
Participant described not being a burden without giving a description	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	2	12.50	2	20.00

Burden on family (reasons)	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant describes the mental/emotional strain placed on their family	10	38.46	8	47.06	2	22.22	3	23.08	7	53.85	1	50.00	9	37.50	2	22.22	8	47.06
Participant describes their condition being a burden in general (No specific examples)	5	19.23	4	23.53	1	11.11	2	15.38	3	23.08	1	50.00	4	16.67	4	44.44	1	5.88
Participant described not being a burden without giving a description	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65

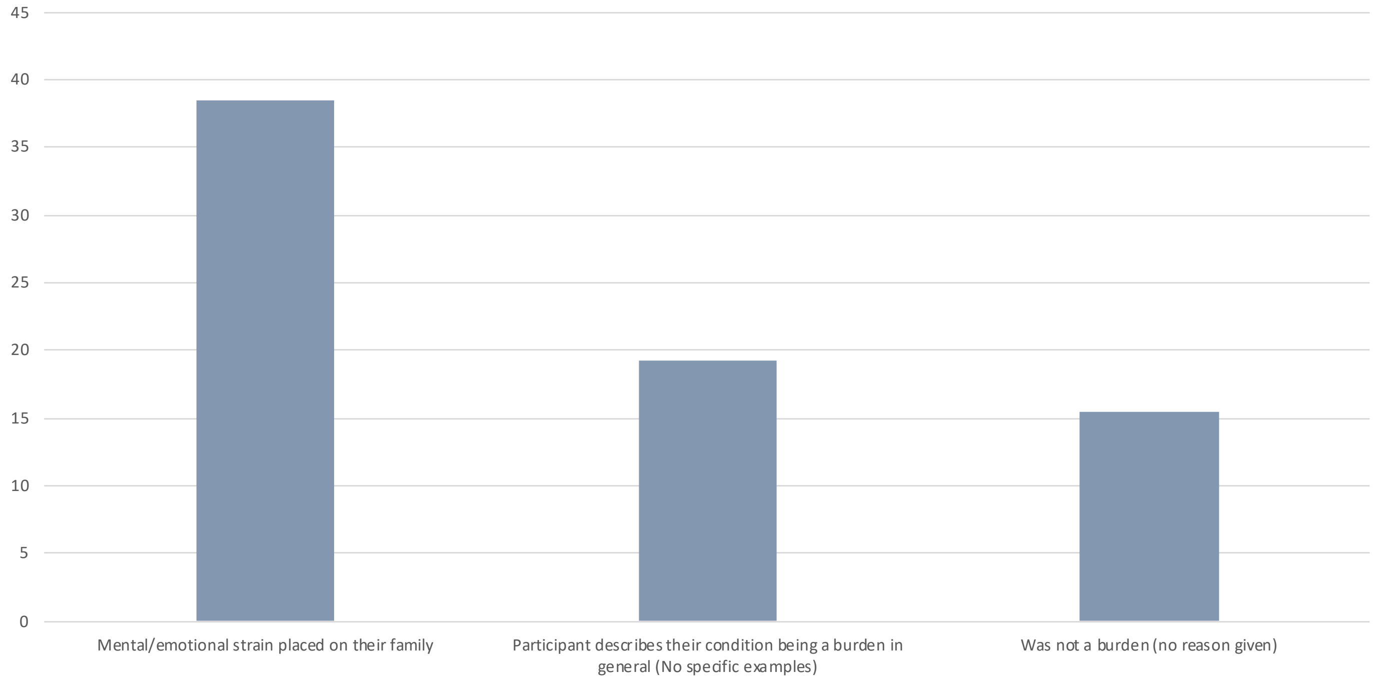


Figure 8.11: Burden on family (description)

Table 8.22: Burden on family (description)– subgroup variations

Theme	Less frequently	More frequently
Participant describes the mental/emotional strain placed on their family	Male Aged 65 or older Trade or high school Mid to low status	Female University
Participant describes their condition being a burden in general (No specific examples)	Higher status	Mid to low status

Cost considerations

In the structured interview, participants were asked about any significant costs associated with having their condition. The most common descriptions were that overall, there was at least some cost burden (61.54%), and that overall, there was no cost burden (34.62%).

Where participants described a cost burden associated with their condition, it was most commonly in relation to needing to take time off work (38.46%), and the cost of treatments (26.92%). Other costs included diagnostic tests and scans (15.38%), cost of parking and travel to attend appointments (including accommodation) (15.38%), the cost of specialist appointments (15.38%), and public or private gap payments (11.54%). Where participants described no cost burden associated with their condition, this was because nearly everything was paid for through the health system (26.92%)

Participant describes a cost burden in relation to needing to take time off work

The cost of financial loss? I haven't been able to work in the same capacity as I did before. I've not been able to work full-time. I had to stop my career and do a job that was less demanding and challenging. The impact of financial income has been massive. I have to pay a few $100, probably $1,500 a year on scans. Car parking alone, every time you to [unintelligible] get a car parking. The biggest impact is the job loss.
Participant 007_2023AULUC

Yes, I had to quit my job, obviously. It's cost us fortunes. We couldn't go into the public system because they were taking too long. We went into the private system. It's just constantly-- I went to the cardiologist a few weeks ago. It cost me $800.
Participant 002_2023AULUC

Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)

No, I wouldn't say compared to other people, we haven't been affected as heavily as what others have. Definitely, they're all little added costs. Every time you need an additional medication to support the side effects. Then with COVID having problems, the addition of-- The amount I've spent on masks and sanitizer. All additional things that you need as a result of your condition, but not necessarily specifically relating to the treatment itself, as in the side effects and the drug. Whether it's a cream for your face, or whether it's a tablet to reduce your cholesterol, or because of the side effects.
Participant 015_2023AULUC

The first op cost me. I mucked up my private insurance and I didn't have cardiac surgery, thoracic surgery. I can't believe it. I had to pay for that one.
Participant 024_2023AULUC

Participant describes a cost burden in relation to diagnostic tests and scans

I was very lucky because I was on the public trial, everything was free, but the $6,000 mutation test was not free, which is pretty disappointing. I had to have another one and I had to pay another $6,000, but that one they didn't get any information from. They repaid us, but it's $12,000 just to get access to a tablet. The thing is, they're doing tests in Australia, but they're not as good as that one. I've done collected surveys on that because they do some things in Australia, but they're obviously not as good. The waiting period can be eight weeks or three months. That is too long to wait when you've been diagnosed with cancer. You really just need everything done as quickly as possible.
Participant 019_2023AULUC

It's incredible, everything. Like I said, I'm in this private system, and everything, even my scans-- Luckily my blood tests don't cost me every month. I've got to have a CAT scan. At the moment I'm having-- Everything I have to pay for, call it CAT scan, the CT scan, the MRI, I have to pay for all of this.
Participant 027_2023AULUC

Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)

Treatment, minimal, because I was on a clinical trial, so there's the benefits there. Then just PBS-listed drugs since. I'm in a public system. Then car parking, that's a huge one.
Participant 015_2023AULUC

I probably would have been affected if I was still in the workforce. I'm having to work but not like I used to work. I wouldn't have been able to do that. I would have had to cut right back. Perhaps the income might have been affected. In my case, that wasn't the case because I'm only working voluntarily. Other than the driving in and out, which is about an hour in and then an hour back during busy times, and it always seems to be busy times when you go. With the fuel costs and the parking was probably the killer. The parking was costing up to $30 to $45 a day. That's ridiculous. You can get a discount on that, but you've got to actually go for two whole weeks, but you're still spending about $500 on parking before you start getting your discount. It does cut it down to probably about half of that.The Cancer Council, as I said, sent me a check for $200 for fuel, so that's helped that. Other than that, I did have to go out and buy a lot of creams and tablets and stuff like that, but I wouldn't say that was major.
Participant 017_2023AULUC

Extremely expensive for me. I was taken by accident by ambulance to a private emergency department of a private hospital and I needed to be put in ICU sooner.

It was $12,000 a night and I didn't know because I was unconscious. I think I spent two nights in ICU which was 24,000 just for two nights. That was a bit of a surprise. Then when I had chemotherapy and radiation, I'm between two hospitals, I did everything in taxi. I spent $6,000 in taxi to be driven there, and then be driven between hospitals. Then I had to pay $45 an hour for the children to be looked after at my place.
Participant 023_2023AULUC

Participant describes a cost burden in relation to the cost specialist appointments

Well, at the moment, I've got private insurance, and then I have to pay the first $500, which I got diagnosed, say 10th for December and then 1st of January, I have to pay another $500. It's a lot of costs involved, but I'm not paying at all for my actual treatment, which is great, but I'm spending a lot of money on seeing specialists and doctors and that cost me a lot because they might charge you $180 and you get about $40 back if you're lucky, for Medicare.
Participant 001_2023AULUC

Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, $90 whatever, $100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.
Participant 028_2023AULUC

Participant describes a cost burden in relation to public or private health gap payments

I went down the private path, so there was always an out-of-pocket somewhere in amongst the mix. Most of my bronchoscopies were covered. Thankfully, because I did change surgeons, my surgery was covered. I just had to pay my excess, but my radiation wasn't. I had to go on a payment plan, and, yes, you get something back from Medicare, but they have this convoluted bloody system that sounded dodgy that won't get out. Anyway, you're still out of pocket, $3,000 or $4,000. I'm a commission-only salesperson, so if I don't work, I don't have any money coming in. That makes things a bit tight. Then, of course, in the background, you are having people on hideous conversations with your insurance people, for your income protection, and what have you, to try and get that all sorted as well. [chuckles] It's been an interesting journey.
Participant 018_2023AULUC

I'm going to say just like with my breast cancer, it's damn expensive to be in the private system. Yes, you get that beautiful follow-up with the ones that are specialists, et cetera, but your surgery hospital that did all these costs involved. The diagnosis meant that I decided to early retirement, resigned from work, and I am blessed that I am financially able to because I just felt I did not have any longer the headspace for the sort of work I was doing. I don't think I've got the stamina to do the hours I used to do. It was the best thing. I took two months off, and I came to that conclusion that no, I wouldn't go back but it's incredibly costly. That means 100,000 plus a year income lost. It means I spent about 10,000 or so out of pocket with the surgery and everything and, of course, it's all ongoing with all the scans. I am so fortunate that I can afford it.
Participant 020_2023AULUC

Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, $90 whatever, $100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.
Participant 028_2023AULUC

Participant describes no cost burden and that nearly everything was paid for through the health system

I didn't keep a good track, but I did have to quit work. I went from working full-time to not working. I think it was for a year and a half, after that I didn't work. That was a fair drop. I had lots of sick pay and stuff like that which was good. The hospital I worked for was very good with monies and out-of-pocket tests, there's only been a couple. I can't really remember. I think originally to do the cytology, a $300 visit to a respiratory specialist, a couple of medical reports to get on the disability pension that I had to pay for out of pocket. Otherwise, most things have been covered by Medicare.
Participant 006_2023AULUC

The only costs were some of the medications that were prescribed for me. Some I got for nothing in the hospital and through the system. Some I had to purchase myself. In most cases it was small. It's small costs. I'm retired and my wife is retired so I was, what do you call it, on the public system, public health system. I had private, but then I have DVA as well, Gold cards. There was no cost to me as such except for a few ancillary bits and pieces of medications and stuff like that.
Participant 012_2023AULUC

All right, well, very favorable. The cost of my treatment electronic is $42 a month and if it were not for PBS, it would be $6,800 a month. That is why I say I could not afford to keep alive if it was going to drain my finances at that rate. A dilemma I currently don't face. The cost, look, it's been incredible. I had the surgery under Medicare from a top surgeon, just incredibly fortunate. No financial cost of any significance

Participant 022_2023AULUC

Table 8.23: Cost considerations

Cost considerations	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Experience described suggests that overall, there was at least some cost burden	16	61.54	16	64.00	0	0.00	5	50.00	11	68.75	15	93.75	1	10.00
Participant describes a cost burden in relation to needing to take time off work	10	38.46	10	40.00	0	0.00	3	30.00	7	43.75	9	56.25	1	10.00
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	6	37.50	1	10.00
Participant describes a cost burden in relation to diagnostic tests and scans	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	4	25.00	0	0.00
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	4	25.00	0	0.00
Participant describes a cost burden in relation to the cost specialist appointments	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Participant describes a cost burden in relation to public or private health gap payments	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Experience described suggests that overall, there was no cost burden	9	34.62	8	32.00	1	100.00	5	50.00	4	25.00	4	25.00	5	50.00
Participant describes no cost burden and that nearly everything was paid for through the health system	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	4	25.00	3	30.00
Other/No response	1	3.85	1	4.00	0	0.00	0	0.00	1	6.25	0	0.00	1	10.00

Cost considerations	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Experience described suggests that overall, there was at least some cost burden	16	61.54	12	70.59	4	44.44	6	46.15	10	76.92	2	100.00	14	58.33	6	66.67	10	58.82
Participant describes a cost burden in relation to needing to take time off work	10	38.46	9	52.94	1	11.11	3	23.08	7	53.85	2	100.00	8	33.33	4	44.44	6	35.29
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	2	22.22	5	29.41
Participant describes a cost burden in relation to diagnostic tests and scans	4	15.38	4	23.53	0	0.00	2	15.38	2	15.38	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	0	0.00	4	16.67	1	11.11	3	17.65
Participant describes a cost burden in relation to the cost specialist appointments	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	0	0.00	4	23.53
Participant describes a cost burden in relation to public or private health gap payments	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Experience described suggests that overall, there was no cost burden	9	34.62	4	23.53	5	55.56	6	46.15	3	23.08	0	0.00	9	37.50	3	33.33	6	35.29
Participant describes no cost burden and that nearly everything was paid for through the health system	7	26.92	5	29.41	2	22.22	1	7.69	6	46.15	1	50.00	6	25.00	2	22.22	5	29.41
Other/No response	1	3.85	0	0.00	1	11.11	1	7.69	0	0.00	0	0.00	1	4.17	0	0.00	1	5.88

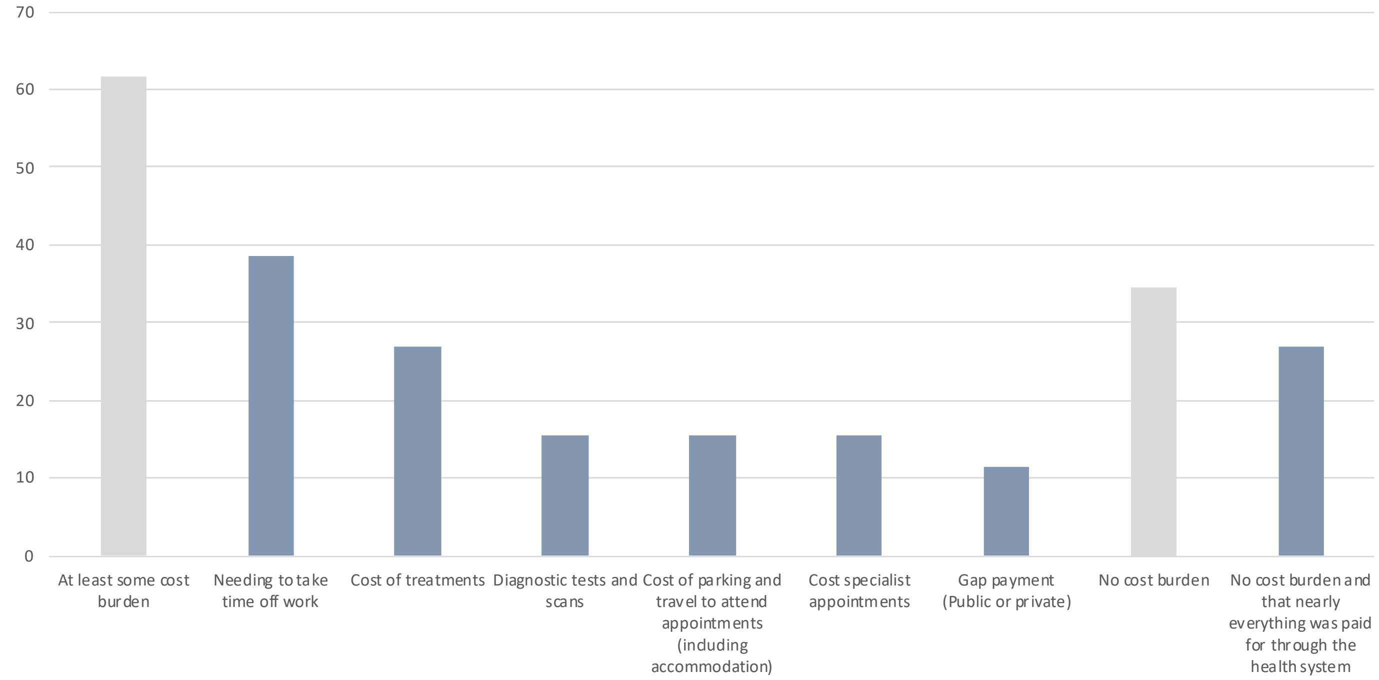


Figure 8.12: Cost considerations

Table 8.24: Cost considerations – subgroup variations

Theme	Less frequently	More frequently
Experience described suggests that overall, there was at least some cost burden	Non-metastatic Male Aged 65 or older Trade or high school	Female University
Participant describes a cost burden in relation to needing to take time off work	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University
Participant describes a cost burden in relation to the cost of treatments (including repeat scripts)	Male	Female
Participant describes a cost burden in relation to diagnostic tests and scans	Male Aged 65 or older	-
Participant describes a cost burden in relation to the cost of parking and travel to attend appointments (including accommodation)	Male	-
Participant describes a cost burden in relation to the cost specialist appointments	Mid to low status	-
Participant describes a cost burden in relation to public or private health gap payments	Mid to low status	-
Experience described suggests that overall, there was no cost burden	Aged 35 to 64 University	Non-metastatic Male Aged 65 or older Trade or high school
Participant describes no cost burden and that nearly everything was paid for through the health system	Trade or high school	University

Overall impact of condition on quality of life

In the online questionnaire, participants were asked to rate the overall impact their condition on quality of life. Quality of life was rated on a Likert scale from one to seven, where one is Life was very distressing and seven is life was great.

The average score was in the Life was a little distressing range (median=3.00, IQR=3.50) (Table 8.29, Figure 8.15).

Table 8.25: Overall impact of condition on quality of life

Impact of condition on quality of life	Number (n=27)	Percent
1 Life is/was very distressing	5	18.52
2 Life is/was distressing	8	29.63
3 Life is/was a little distressing	4	14.81
4 Life is/was average	3	11.11
5 Life is/was good	4	14.81
6 Life is/was very good	3	11.11
7 Life is/was great	0	0.00

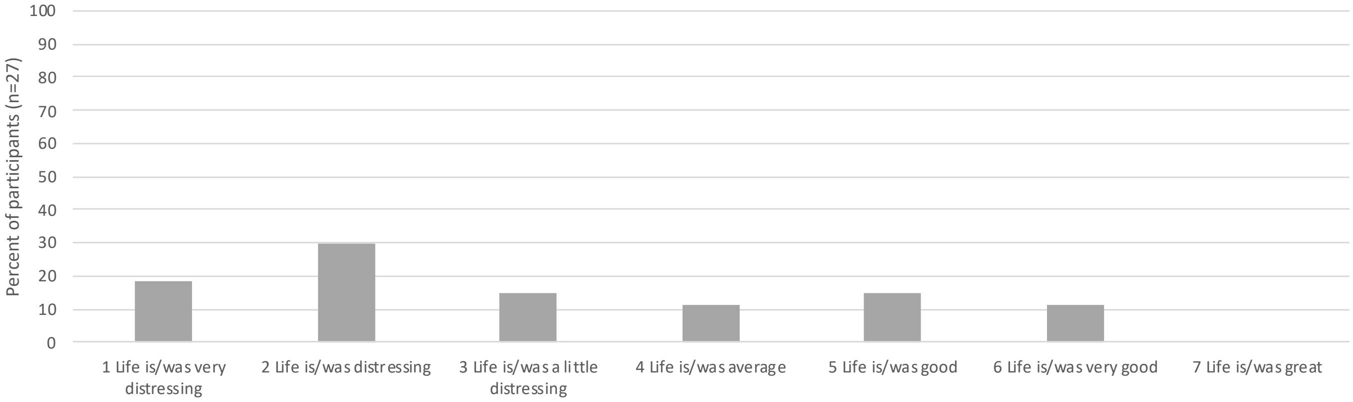


Figure 8.13: Overall impact of condition on quality of life

Experience of anxiety related to disease progression

Fear of progression

The Fear of Progression questionnaire measures the level of anxiety people experience in relation to their conditions. The Fear of Progression questionnaire comprises a total score, between 12 and 60, with a higher score denoting increased anxiety. Summary statistics for the entire cohort are displayed in Table 8.10.

The overall scores for the cohort were in the highest quintile for Fear of progression: Total score (mean=37.70, SD=11.27) indicating moderate levels of anxiety

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average fear of progression score for participants in this study indicated moderate levels of anxiety.

Table 8.26: Fear of progression summary statistics

Fear of progression (n=27)	Mean	SD	Median	IQR	Possible range	Quintile
Total score*	37.70	11.27	39.00	17.50	12 to 60	3

*Normal distribution use mean and SD as measure of central tendency

Fear of progression by participant type

There were 25 participants (92.59%) that had been diagnosed with lung cancer, and 2 participants (7.41%) that were family members or carers to people with lung cancer. Comparisons were not made because there were too few family members and carers. Summary statistics are displayed in Table 8.x

Table 8.27: Fear of progression total score by participant type summary statistics

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Total score	Person with lung cancer	25	92.59	36.76	11.07	38.00	17.00	3
	Family member or carer	2	7.41	49.50	7.78	49.50	5.50	-

Fear of progression by lung cancer stage

Comparisons were made by cancer stage, there were 11 participants (44.00%) with non-metastatic lung cancerand, 14 participants (56.00%) with metastatic lung cancer.

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.28).

A two sample t-test indicated that the mean score for the Fear of progression Total score scale [t(23) = -2.08, p = 0.0485] was significantly lower for participants in the **Non-metastatic** subgroup (Mean = 32.91, SD = 10.24) compared to participants in the **Metastatic** subgroup (Mean = 41.57, SD = 10.38.)

The **Fear of Progression** questionnaire measures the level of anxiety people experience in relation to their conditions. On average, participants in the **metastatic cancer** subgroup scored higher than participants in the **non-metastatic cancer** subgroup. This indicates that participants in the **metastatic cancer** subgroup had high levels of anxiety, and participants in the **non-metastatic cancer** subgroup had moderate levels of anxiety.

Table 8.28: Fear of progression total score by lung cancer stage summary statistics and T-test

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Non-metastatic	11	44.00	32.91	10.24	-2.08	23	0.0485*
	Metastatic	14	56.00	41.57	10.38			

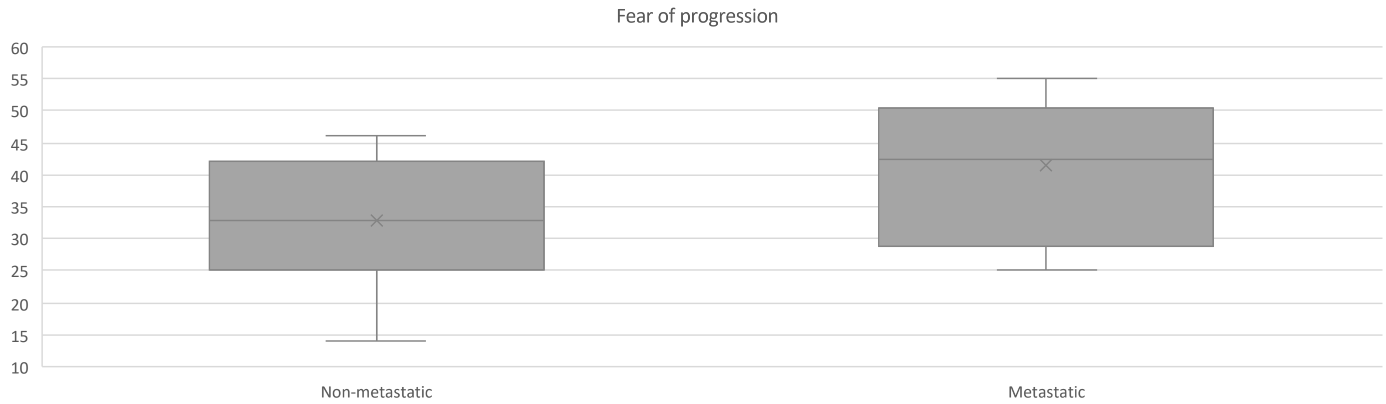


Figure 8.14: Boxplot of Fear of progression total score by lung cancer stage

Fear of progression by gender

Comparisons were made by gender, there were 20 female participants (74.07%), and 8 male participants (25.93%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.29).

No significant differences were observed between participants by **gender** for any of the Fear of progression scales.

Table 8.29: Fear of progression total score by gender summary statistics and T-test

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Female	20	74.07	39.10	10.20	1.09	25	0.2853
	Male	7	25.93	33.71	14.00			

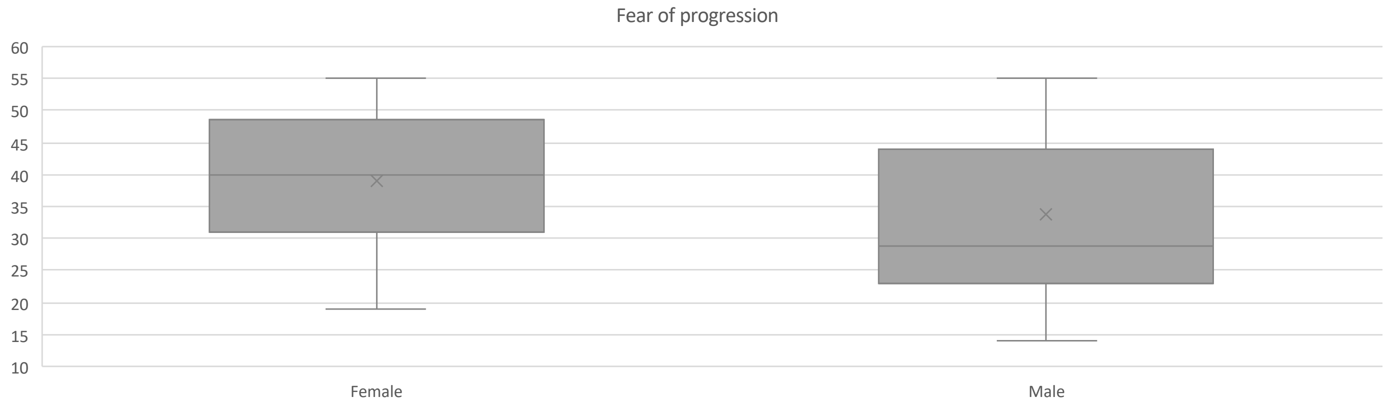


Figure 8.15: Boxplot of Fear of progression total score by gender

Fear of progression by age

Participants were grouped according to age, with comparisons made between participants aged 35 to 64 (n=15, 55.56%), and participants aged 65 or older (n=12, 44.44%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.30).

No significant differences were observed between participants by **age** for any of the Fear of progression scales.

Table 8.30: Fear of progression total score by age summary statistics and T-test

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Aged 35 to 64	15	55.56	40.67	9.95	1.57	25	0.1291
	Aged 65 or older	12	44.44	34.00	12.14			

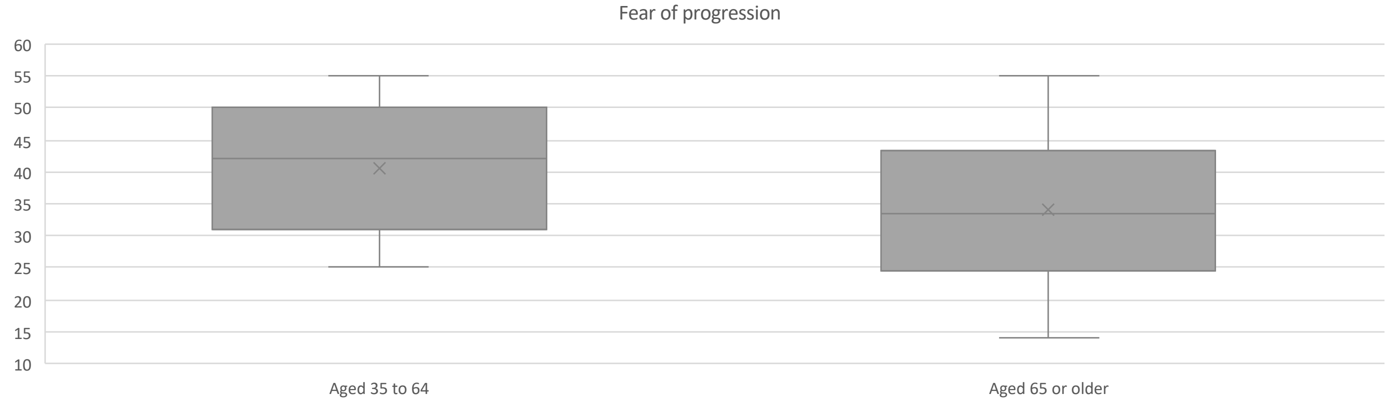


Figure 8.16: Boxplot of Fear of progression total score by age

Fear of progression by education

Comparisons were made by education status, between those with trade or high school qualifications (n=15, 55.56%), and those with a university qualification (n=12, 44.44%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.31).

No significant differences were observed between participants by **education** for any of the Fear of progression scales.

Table 8.31: Fear of progression total score by education summary statistics and T-test

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Trade or high school	15	55.56	36.53	11.38	-0.60	25	0.5568
	University	12	44.44	39.17	11.46			

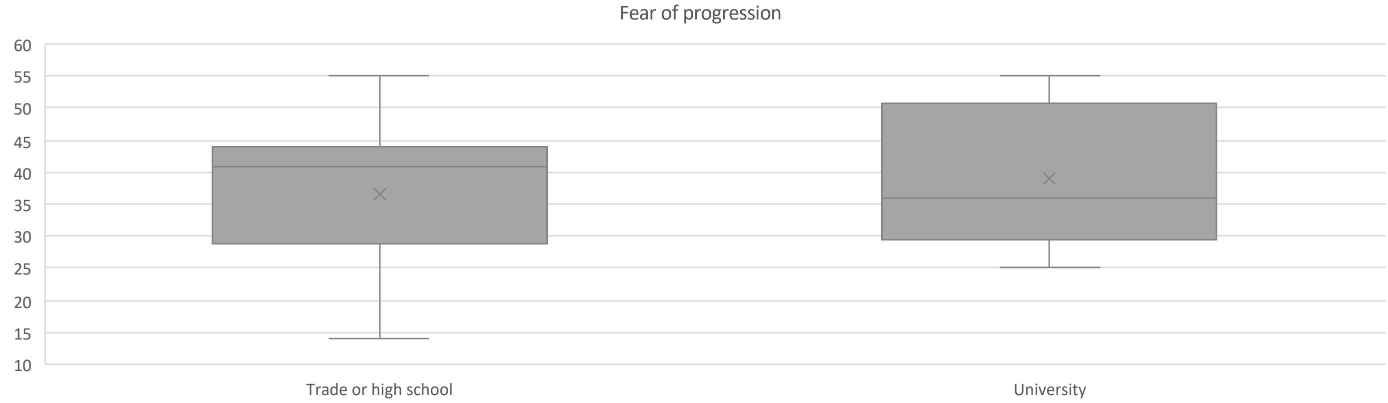


Figure 8.17: Boxplot of Fear of progression total score by education

Fear of progression by location

The location of participants was evaluated by postcode using the Australian Statistical Geography Maps (ASGS) Remoteness areas accessed from the Australian Bureau of Statistics. There were 2 participants (7.41%) living in regional or remote areas and 25 participants (92.59%) living in metropolitan areas. Comparisons were not made because there were too few participants lived in regional or remote areas. Summary statistics are displayed in Table 8.32

Table 8.32: Fear of progression total score by location summary statistics

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	Median	IQR	Quintile
Total score	Regional or remote	2	7.41	38.00	18.38	38.00	13.00	3
	Metropolitan	25	92.59	37.68	11.12	39.00	17.00	-

Fear of progression by socioeconomic status

Comparisons were made by socioeconomic status, using the Socio-economic Indexes for Areas (SEIFA) (www.abs.gov.au), SEIFA scores range from 1 to 10, a higher score denotes a higher level of advantage. Participants with a mid to low SEIFA score of 1-6, Mid to low status (n=10, 37.04%) compared to those with a higher SEIFA score of 7-10, Higher status (n=17, 62.96%).

Assumptions for normality and variance were met, a two-sample t-test was used (Table 8.33).

No significant differences were observed between participants by **socioeconomic status** for any of the Fear of progression scales.

Table 8.33: Fear of progression total score by socioeconomic status summary statistics and T-test

Fear of progression	Group	Number (n=27)	Percent	Mean	SD	T	dF	p-value
Total score	Mid to low status	10	37.04	39.50	12.13	0.63	25	0.5359
	Higher status	17	62.96	36.65	10.98			

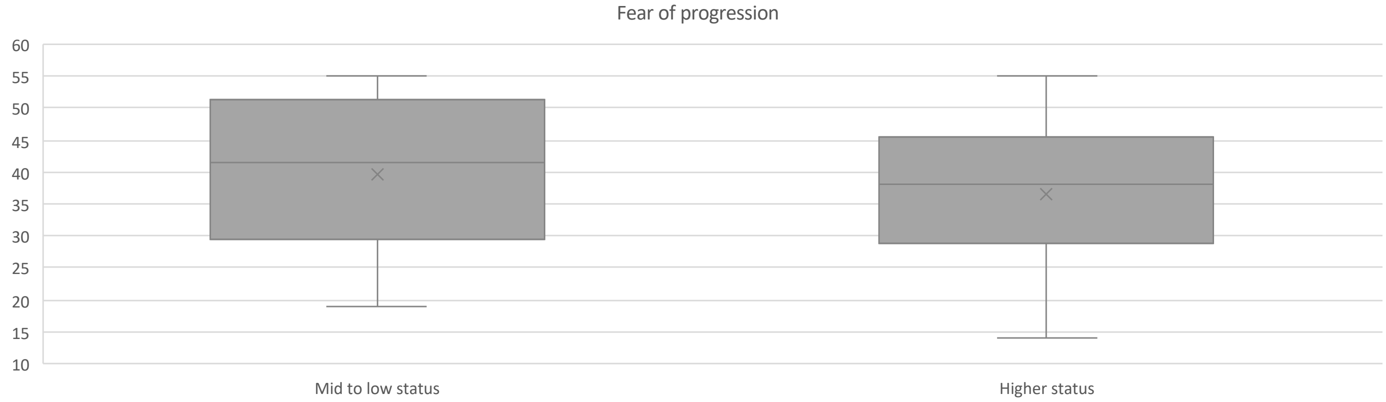


Figure 8.18: Boxplot of Fear of progression total score by socioeconomic status

Anxiety about treatment

An overview of responses to individual fear of progression questions is given in Table 8.34.

Fear of progression individual questions

On average, participants scored in the “Seldom” range for the following questions:, “Is disturbed that they may have to rely on strangers for activities of daily living” (mean=2.44, SD=1.34), “Anxious if not experiencing any side effects think it doesn’t work” (mean=1.96, SD=1.22).

On average, participants scored in the “Sometimes” range for the following questions: “Afraid of pain” (mean=3.19, SD=1.39), “Has concerns about reaching professional and/or personal goals because of illness:” (mean=2.70, SD=1.79), “When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation” (mean=3.22, SD=1.12), “The possibility of relatives being diagnosed with this disease disturbs participant” (mean=2.67, SD=1.59), “Worried that at some point in time will no longer be able to pursue hobbies because of illness” (mean=3.41, SD=1.47), “Afraid of severe medical treatments during the course of illness” (mean=3.26, SD=1.26), “Worried that treatment could damage their body” (mean=3.26, SD=1.02), “The thought that they might not be able to work due to illness disturbs participant” (mean=2.56, SD=1.60).

On average, participants scored in the “Often” range for the following questions:“Becomes anxious thinking that disease may progress” (mean=3.56, SD=1.22), “Is nervous prior to doctors appointments or periodic examinations” (mean=3.56, SD=1.31), “Worried about what will become of family if something should happen to participant” (mean=3.89, SD=1.22).

Table 8.34: Fear of progression individual questions

Fear of progression (n=27)	Mean	SD	Median	IQR	Average response
Becomes anxious thinking that disease may progress	3.56	1.22	3.00	2.00	Often
Is nervous prior to doctors appointments or periodic examinations	3.56	1.31	4.00	1.50	Often
Afraid of pain	3.19	1.39	3.00	2.50	Sometimes
Has concerns about reaching professional and/or personal goals because of illness:	2.70	1.79	2.00	4.00	Sometimes
When anxious, has physical symptoms such as a rapid heartbeat, stomach ache or agitation	3.22	1.12	3.00	1.00	Sometimes
The possibility of relatives being diagnosed with this disease disturbs participant	2.67	1.59	3.00	3.00	Sometimes
Is disturbed that they may have to rely on strangers for activities of daily living	2.44	1.34	3.00	2.00	Seldom
Worried that at some point in time will no longer be able to pursue hobbies because of illness	3.41	1.47	4.00	3.00	Sometimes
Afraid of severe medical treatments during the course of illness	3.26	1.26	3.00	1.00	Sometimes
Worried that treatment could damage their body	3.26	1.02	3.00	1.50	Sometimes
Worried about what will become of family if something should happen to participant	3.89	1.22	4.00	2.00	Often
The thought that they might not be able to work due to illness disturbs participant	2.56	1.60	2.00	3.00	Sometimes
Anxious if not experiencing any side effects think it doesn’t work	1.96	1.22	2.00	1.50	Seldom

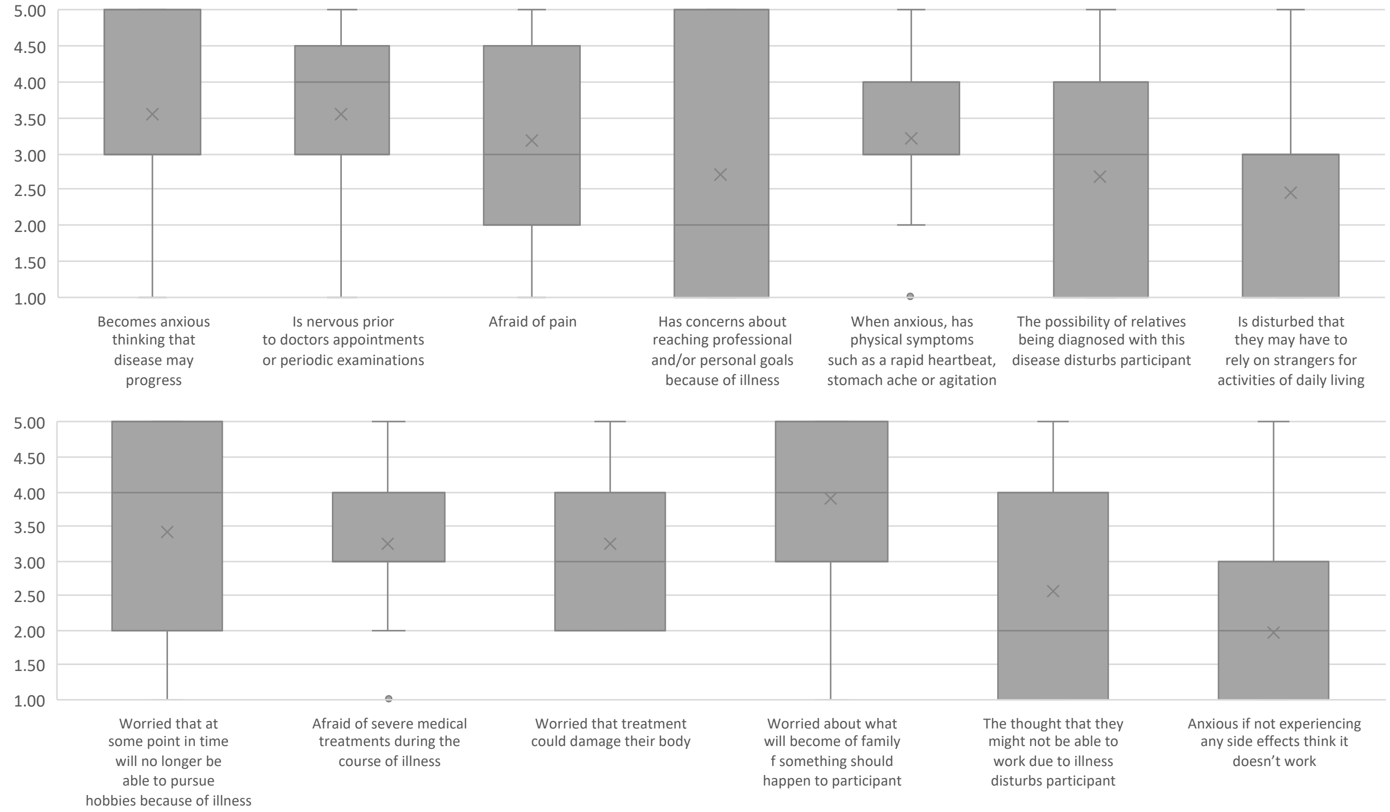


Figure 8.19: Fear of progression individual questions

Section 9

Expectations and messages to decision-makers

Section 9: Expectations of future treatment, care and support, information and communication

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (26.92%), and will involve more clinical trials (including to access new technologies and treatments and funding) (26.92%). Other expectations of future treatments included treatments with fewer or less intense side effects and more discussion about side effects (23.08%), will include having choice and transparency in relation to treatment options (23.08%), future treatment will be more effective and/or targeted (15.38%), easier to administer or able to administer at home (11.54%), and future treatments will allow for a normal life/quality of life (11.54%).

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible and easy to find (19.23%), include the ability to talk to or access to a health professional (19.23%). Other expectations of future information included more details about disease trajectory and what to expect (11.54%), and more details about symptom and side effect control (11.54%). There were 5 participants (19.23 %) that were satisfied with the information they had received and had no particular comment.

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (26.92%), and will include a multidisciplinary and coordinated approach (19.23%). Other expectations included that future communication will be more transparent and forthcoming (11.54%), and communication will include health professionals with a better knowledge of the condition (11.54%). There were 4 participants (15.38%) that were satisfied with the healthcare professional communication and had no particular comment.

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include specialist clinics or services where they can talk to professionals either in person, phone, or online (38.46%). Other expectations if future care and support included practical support for example home care, transport, or financials support (15.38%), a multidisciplinary and coordinated approach to care and support (15.38%), long-term condition management and care planning (15.38%), and it will be more holistic that includes emotional health (11.54%). There were 5 participants (19.23%).) that were satisfied with their care and support and had no particular comment.

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical treatments through the government (46.15%), healthcare staff, including access to specialists (42.31%), for the entire health system (34.62 %), and Timely access to treatment (15.38%). There were 4 participants that expressed the need for lower treatment costs and extend Medicare coverage (15.38%).

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it. The most important aspects reported were pain, nausea and vomiting and, tiredness and fatigue. The least important were mouth ulcers, loss of appetite and, hair loss.

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care. The most important aspects were “Ability to follow and stick to a treatment regime”, and “How personalised the treatment is for me”. The least important were “The severity of the side effects” and “Time impact of the treatment on my quality of life”.

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care. The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Value to access treatments that reduce symptoms and improve quality of life

Participants were asked in the online questionnaire, if there was any value to access treatments that reduce symptoms and improve quality of life, even if it did not offer a cure. The majority of participants (n = 18, 72.00%) responded that this was of very significant value.

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn’t offer a cure. The majority of participants (n = 14, 51.85%) would use a treatment for more than ten years for a good quality of life even if it didn’t offer a cure.

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were no participants (0.00%) that thought that medicine delivered by IV was most effective, 5 participants (18.52%) thought that pill form was most effective, and 11 participants (40.74%) that thought they were equally effective. There were 11 participants (40.74%) that were not sure.

Messages to decision-makers

Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?” The most common messages to the health minister were to help raise community awareness (23.08%), that more clinical trials or new treatments are needed (23.08%), and they want more timely and equitable access to support, care and treatment (23.08 %). Other messages included to invest in health professionals to service the patient population (19.23%), Increase investment in general (11.54%), Invest in research, including to find new treatments (11.54%), and that treatments need to be affordable (11.54%). There were 3 participants whose message was that they were grateful for the healthcare system and the treatment that they received (11.54%).

Expectations of future treatment

Participants were asked in the structured interview what their expectations of future treatments are. The most common responses were that future treatment will be more affordable (26.92%), and will involve more clinical trials (including to access new technologies and treatments and funding) (26.92%). Other expectations of future treatments included treatments with fewer or less intense side effects and more discussion about side effects (23.08%), will include having choice and transparency in relation to treatment options (23.08%), future treatment will be more effective and/or targeted (15.38%), easier to administer or able to administer at home (11.54%), and future treatments will allow for a normal life/quality of life (11.54%).

Future treatment will be more affordable

I think that radiation should be covered under private health. If you are a public patient, it gets covered, but if you are a private patient, you've got to pay for it. When you've sat in a waiting room where all these people, and some of them are a lot older than you, you know that they wouldn't have had super policies and things like that, which is a nightmare to get paid out on [unintelligible] They're spending their last cent to try and stay alive. This isn't necessarily lung cancer, this is just all radiation patients. That's ridiculous. Yet, it's considered outpatient, and yet, two stories above, I'm sitting in a chair, which is not a hospital, but that's for oncology and it's covered if you pay your excess, and yet radiation isn't. My treatment was $32,000. Now, I don't know too many people who's got a lazy $32,000 floating around to pay for. Of which, yes, you get some money back from Medicare, but somewhere in the mix, somebody's making-- To me, all this just reeks of a multimillion-dollar business, which is what cancer is, and it shouldn't be that way. That should be covered. My goal this year is to start writing letters to the health ministers and say, "Why? What the--" If they keep banging on about us having private health covers to take the pressure off the public system, of which is what I have done, and paid my whole way through my own life, and then I'm supposed to find a lazy $32,000 to pay for my treatment?
Participant 018_2023AULUC

PARTICIPANT: The PBS scheme is really important because a lot of the new treatments wouldn't be available, including one I'm on right now wouldn't be available to people.
INTERVIEWER: Because of cost, yes?
PARTICIPANT: Yes.

…I'd like to see some new treatments. I don't know how they found a cure for COVID and they can't find one for cancer for so long.
Participant 026_2023AULUC

Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)

I would love to see Australia dovetail onto-- like America is approving these lung cancer medications so quickly and they're-- what do they call them? The FDA, they're approved fast tracking all these tablets every year. There's six, seven, eight tablets, but in Australia, we're still waiting approval. I would love Australia to just be able to approve some of these ones. If America has approved it, they can just put it in place so people have more options.
Participant 004_2023AULUC

PARTICIPANT: I think in America they have a lot more drugs available which are not available on PBS in Australia. The only ones we've got are, I think it's about three, four but as you progress sometimes the tumor mutates and you get new mutations which are accessible to other targeted therapy drugs, and those other mutations they aren't generally available in Australia. That would be a vast improvement if we could. I realized they're very expensive you're not talking about cures still. In America, they go from one to the other, to the other, the other and they do mutation studies and then…I think that would be an area that we can improve on.
Participant 024_2023AULUC

I would like clinical trials to be conducted on older people because the majority of people with lung cancer are old. Yes, it's 70% are over the age of 60, and I think it's 60% over the age of 80. I would like at least to have that. To have some clinical trials conducted on older people so that we have more guidance on what is the right treatment.
Participant 023_2023AULUC

Future treatments will have fewer or less intense side effects/more discussion about side effects

The thing that I would like to see improved is the toxicity on the body. I hear that the toxic side effects might actually be doing-- Might shorten my lifespan as well. Mainly the toxicity on the body. Other than that, I'm doing okay. Participant 007_2023AULUC

I suspect what we'll see and what I hope that we see quickly is just improvement in the targeted therapy, type of therapy that has less side effects, much more specific, maybe doesn't build up resistance. A lot of research in that area. It's huge isn't it that whole area of research and what's coming out all over the place? Participant 025_2023AULUC

Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)

There's so many aspects to this. One you go, cost can be a huge thing because new treatments come out and they're not on PBS and that means access is only if you can get special consideration or you have lots of dollars. It's important that it's accessible not just to me but to anyone. I think cost is a huge thing for people. I'm thinking globally here, in big terms of accessibility as in rural remote. I just feel for the people who have to go and in the mouth to get seen and get treated and don't have the services that we do in a big city, I think they get impacted terribly. For me personally, I think, what I would value in treatment is that still allows, it's not impacting on my day-to-day, but I can fit it into my life, if that makes sense.
Participant 020_2023AULUC

There are side effects but I don't really care. As long as it's accessible for every-- Yes, it's the access and that there's education around it, I don't care, I just want there to be treatment. Do you know what? I don't even have any expectations on it, I just want treatment so I can spend more quality time with my family.
Participant 027_2023AULUC

Future treatment will be more effective and/or targeted (personalised)

I'd like the new treatment to be personalized to the tumor markers and makeup. Where they're able to access information about the tumor and then have a treatment that, say, they have a base treatment. Then based on your tumor makeup, they can add in a drop of this, a drop of that, a drop of something else, and then go into the-- Then that's what makes it up. I don't know, something a little bit more personalized. More personalized treatment, markers and makeup.
Participant 015_2023AULUC

If we were to look for the imagined treatment, it would be something that was significantly effective, and perhaps, in my view of a different type, that may not have the sort of limited lifespan that the current thing that our treatments have because of our body's capacity to work around that. My wish is for a treatment but it's so pervasively effective then. It can be expected to be a very long-term, if not lifelong, effective treatment. I think that's just wishful thinking on my part, but one of the effects of this has been to think about what I want to do with the rest of my life, given that I can't control what I know is going to happen. All I can say is that I want to spend time doing things that I think are worthwhile, remain connected to the community, and treat my life as if it's going to go on similarly to what if I wasn't sick, but I'm ready to pull the plug on work and do other things if my health was going to go through a decline, I'm prepared for that, perhaps underprepared but nevertheless prepared.
Participant 022_2023AULUC

Future treatment will be easier to administer and/or able to administer at home and/or less invasive

Like the infusion, because someone new having an immunotherapy now, I figured they could do that. They could have a district nurse really do it or have someone who's used to cytotoxic, whatever. I think you could have it at home just as easy, that'd be a lot nicer.
Participant 001_2023AULUC

Definitely more targeted therapy, a lot easier to manage. You can get on with your daily tasks because it's a matter of taking the medication in the morning. It doesn't involve having to organize trips to hospital or clinic, taking time out for treatment. I've encountered a lot of people who are going through treatment, and then they'll go to work because they're able to actually continue working normally. Targeted therapy definitely there don't seem to be as many side effects as, say, chemotherapy. Not as debilitating, let's say, as radiotherapy and chemotherapy, but having said that, I've had SABR treatment, which is a lot more targeted type of radiotherapy compared to

your conventional. I didn't experience any sort of burning. I know my mum did when she had hers. She had some burning on her chest. Yes, so definitely targeted.
Participant 005_2023AULUC

Future treatments will allow for a normal life/quality of life

There are side effects but I don't really care. As long as it's accessible for every-- Yes, it's the access and that there's education around it, I don't care, I just want there to be treatment. Do you know what? I don't even have any expectations on it, I just want treatment so I can spend more quality time with my family. Participant 027_2023AULUC

For dad, right now things are working, so why change the wheel when it's actually working? If it wasn't working, the side effects are a big thing. Seeing other people having treatments as well, they have lots of side effects. Maybe having less side effects for them and quality of life. That's about it really. Participant 030_1_2023AULUC

Table 9.1: Expectations of future treatment

Expectations of future treatments	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Future treatment will be more affordable	7	26.92	7	28.00	0	0.00	3	30.00	4	25.00	5	31.25	2	20.00
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	7	26.92	7	28.00	0	0.00	2	20.00	5	31.25	**6**	**37.50**	**1**	**10.00**
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	23.08	5	20.00	1	100.00	**1**	**10.00**	5	31.25	4	25.00	2	20.00
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	23.08	6	24.00	0	0.00	3	30.00	3	18.75	**6**	**37.50**	**0**	**0.00**
Future treatment will be more effective and/or targeted (personalised)	4	15.38	4	16.00	0	0.00	1	10.00	3	18.75	3	18.75	1	10.00
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	11.54	3	12.00	0	0.00	**0**	**0.00**	3	18.75	3	18.75	**0**	**0.00**
Future treatments will allow for a normal life/quality of life	3	11.54	2	8.00	1	100.00	**0**	**0.00**	3	18.75	1	6.25	2	20.00

Expectations of future treatments	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Future treatment will be more affordable	7	26.92	5	29.41	2	22.22	**2**	**15.38**	**5**	**38.46**	1	50.00	6	25.00	2	22.22	5	29.41
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	7	26.92	5	29.41	2	22.22	**1**	**7.69**	**6**	**46.15**	1	50.00	6	25.00	3	33.33	4	23.53
Future treatments will have fewer or less intense side effects/more discussion about side effects	6	23.08	5	29.41	**1**	**11.11**	4	30.77	2	15.38	0	0.00	6	25.00	2	22.22	4	23.53
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	6	23.08	5	29.41	**1**	**11.11**	3	23.08	3	23.08	1	50.00	5	20.83	2	22.22	4	23.53
Future treatment will be more effective and/or targeted (personalised)	4	15.38	4	23.53	**0**	**0.00**	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Future treatments will allow for a normal life/quality of life	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76

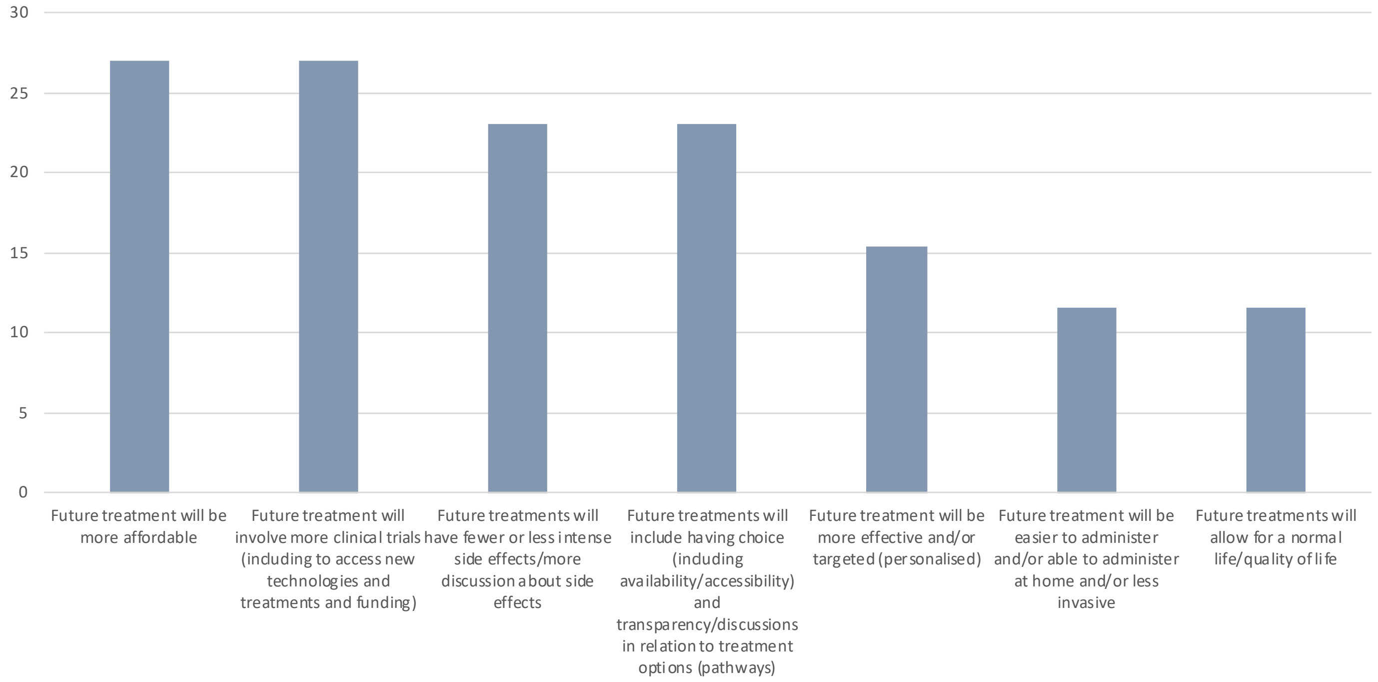


Figure 9.1: Expectations of future treatment

Table 9.2: Expectations of future treatment – subgroup variations

Theme	Less frequently	More frequently
Future treatment will be more affordable	Trade or high school	University
Future treatment will involve more clinical trials (including to access new technologies and treatments and funding)	Male Trade or high school	Female University
Future treatments will have fewer or less intense side effects/more discussion about side effects	Non-metastatic Aged 65 or older	
Future treatments will include having choice (including availability/accessibility) and transparency/discussions in relation to treatment options (pathways)	Male Aged 65 or older	Female
Future treatment will be more effective and/or targeted (personalised)	Aged 65 or older	
Future treatment will be easier to administer and/or able to administer at home and/or less invasive	Non-metastatic Male	
Future treatments will allow for a normal life/quality of life	Non-metastatic	

Expectations of future information

Participants were asked in the structured interview if there was anything that they would like to see changed in the way information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible and easy to find (19.23%), include the ability to talk to or access to a health professional (19.23%). Other expectations of future information included more details about disease trajectory and what to expect (11.54%), and more details about symptom and side effect control (11.54%). There were 5 participants (19.23 %) that were satisfied with the information they had received and had no particular comment.

Future information will be more accessible/easy to find

I think that it's the opposite. There's a lot of information out there and I think that's what threw me initially, that there was information overload for me just trying to deal with it all. There's plenty of information out there, it's whether you want to access it. I know there's people out there that don't access all the resources that we've actually got available here, such as exercise clinics. Even the Look Good Feel Good workshops. I feel like as cancer patients, we've got quite a bit of support out there, it's just finding it. I did get quite a bit of information while I was in the hospital the first time, and then I've accessed information at the excise clinic. They've got information there and there's even some at the treatment center I go to. Then I come across other groups via social media, like there's Cancer Australia, I think it's called. I came across that and I wasn't aware of that, but I have noticed that on a lot of these booklets, especially the ones that cancer puts out that quite often will put links to other resources.
Participant 005_2023AULUC

I wasn't given that much information. It's like you're given a diagnosis and the treatment option and then off you go. No. I could have gotten in contact with the Cancer Council and probably they could have given me information and things. Would it be nice if there was a little package to give out or something full of how to access…I thought Cancer Council was all that sunscreens, to tell you the truth. [chuckles] It never crossed my mind that they deal with cancer. Isn't that hilarious? [laughs] I don't know. A specific lung cancer information pack, wouldn't that be nice?
Participant 006_2023AULUC

Future information will include the ability to talk to/access to a health professional

I think the doctor should spend a bit more time with you in the beginning and give you the paperwork, but explain what you've got to go through and how it's going to work. It was just a muddle at the beginning. I didn't know what I was doing.
Participant 001_2023AULUC

Yes. I just wish that someone could spend time explaining it. I feel like I'm in a different position now because I've done my own research. There's really a lot of really difficult nights reading, researching, questioning, and I just wish…Now, I've just made three years, [inaudible]. I guess maybe-- I just wish there was more support.
Participant 027_2023AULUC

PARTICIPANT: I think it could be presented in the way of information for any type of cancer to have a pack ready for the family. We were given two sheets on it and that was about it and some lung, sorry, Cancer Council information about what they can offer but it'd be nice to have the charities like Lung Foundation have some information in there where you can go and have a look at their website, but also have some reading material for when the carers are ready to read

it because at that stage they're not ready, they're grieving for their loved one or if they're not terminal, they're trying to get them through the next couple of months while they have some intensive treatment…Yes, more information and a professional pack that you can refer back to later on when you're ready to read it. More support from the nurses. In the initial stages, we had a lung-- I know that this is a privilege because there's not a lot around, but a lung cancer nurse that supported us, but they attended one appointment, and then you can't get them on the phone because they're so bogged down with that many patients. That's never been a real service that we could utilize because there have been so many other people that they're supporting.
Participant 030_2023AULUC

Future information will provide more details about disease trajectory and what to expect

I don't know whether it's not available because people don't like to hear it. I would like to know what is going to happen. I know that's a hard question because things probably are different, but there's got to be an average of what happened, what can happen, or what happens next.
Participant 013_2023AULUC

They need a group. They need a support group. They need somewhere we can go to ask questions on a regular basis that we can discuss between patients what our own journeys have been like. I just think that that would be so beneficial, and to have a group where we can talk about end-of-life decisions and what we need to do to get ourselves in order for that. There's nothing out there, nothing
Participant 014_2023AULUC

Future information will provide more details about symptom and side effect control

I think I would've liked more information on the limitations post-surgery of what you should and shouldn't be doing at home, at work, et cetera, and what sort of timeframe you could be looking at to start recommencing activities. The hospital didn't supply anything, and the surgeon just said, don't lift anything over 5 kilos.
Participant 010_2023AULUC

I'd like to see a little bit more discussion on side effects for a start and not just routine generic stuff. For example, I will give you dexamethasone for your nausea. What if that doesn't work? What happens or time frames of how long it's going to work? Because of my PROFESSION background, more information on what it's doing, when [unintelligible] and all that business, when it peaks and when you have the trough with your white cell counts and all that information, I would have found interesting. I sourced it to a degree, [unintelligible] that information. I know I would have liked to go on to see the beginning a physio or exercise physiologist. I'm probably changing questions here. I would have loved to have had access maybe to a lung cancer nurse. Someone who knows. I have these big [unintelligible] coming in all the time saying things to me like, "[unintelligible] do we take your blood pressure on?" Each time I'd have to say, "I haven't got breast cancer. I've got lung cancer." Just read my notes for God's sake. Oh, just staff a little bit more and tune to what's going on, but I think a lung cancer nurse-- I'm in CITY. I think we've got one or two here and there in the public sector. Being a private patient, I don't have access to any of that. I'd love to see more access to that. They'd be a great point of communication. Participant 025_2023AULUC

Table 9.3: Expectations of future information

Expectations of future information	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Future information will be more accessible/easy to find	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	3	18.75	2	20.00
Future information will include the ability to talk to/access to a health professional	5	19.23	4	16.00	1	100.00	2	20.00	3	18.75	4	25.00	1	10.00
No particular comment - satisfied with experience	5	19.23	5	20.00	0	0.00	2	20.00	3	18.75	2	12.50	3	30.00
Future information will provide more details about disease trajectory and what to expect	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Future information will provide more details about symptom and side effect control	3	11.54	3	12.00	0	0.00	3	30.00	0	0.00	2	12.50	1	10.00

Expectations of future information	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Future information will be more accessible/easy to find	5	19.23	4	23.53	1	11.11	3	23.08	2	15.38	1	50.00	4	16.67	2	22.22	3	17.65
Future information will include the ability to talk to/access to a health professional	5	19.23	3	17.65	2	22.22	2	15.38	3	23.08	1	50.00	4	16.67	2	22.22	3	17.65
No particular comment - satisfied with experience	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	1	11.11	4	23.53
Future information will provide more details about disease trajectory and what to expect	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	2	22.22	1	5.88
Future information will provide more details about symptom and side effect control	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65

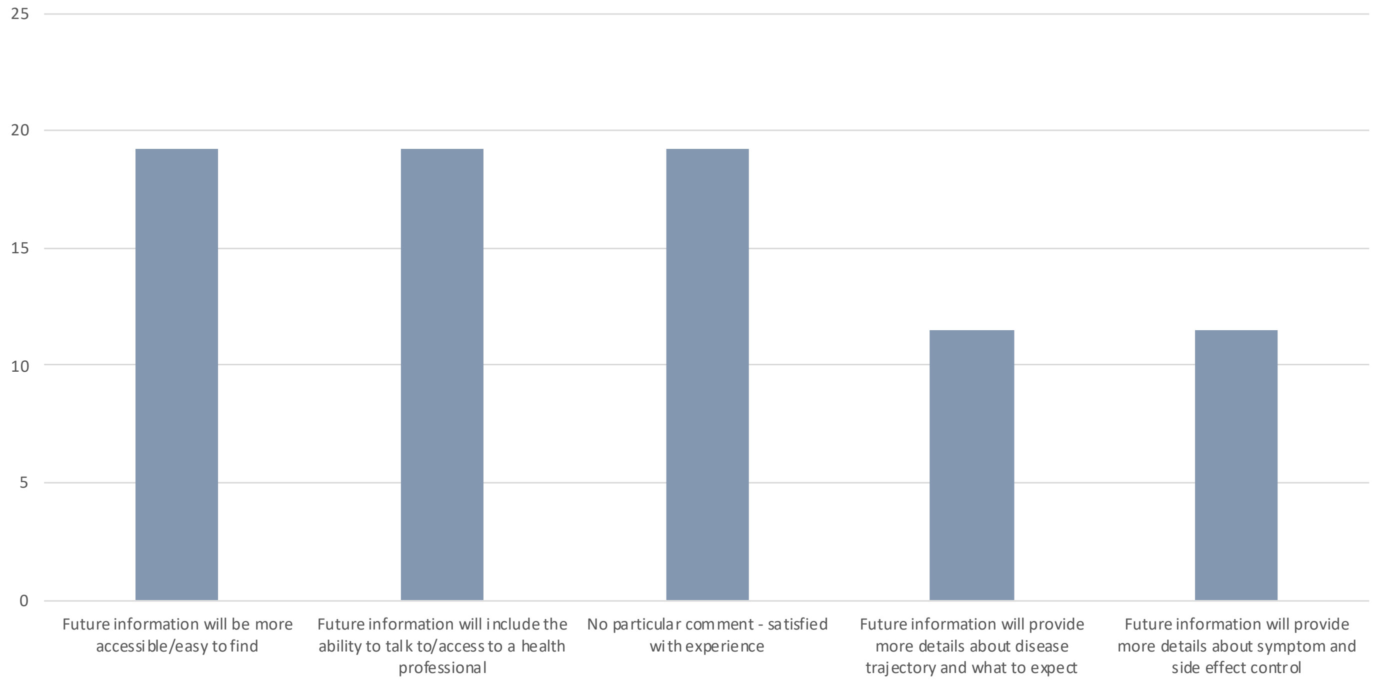


Figure 9.2: Expectations of future information

Table 9.4: Expectations of future information – subgroup variations

Theme	Less frequently	More frequently
No particular comment - satisfied with experience	-	Male Aged 65 or older
Future information will provide more details about disease trajectory and what to expect	Male	Mid to low status
Future information will provide more details about symptom and side effect control	Metastatic Mid to low status	Non-metastatic

Expectations of future healthcare professional communication

Participants were asked in the structured interview what they would like to see in relation to the way that healthcare professionals communicate with patients. The most common expectations for future healthcare professional communication were that communication will be more empathetic (26.92%), and will include a multidisciplinary and coordinated approach (19.23%). Other expectations included that future communication will be more transparent and forthcoming (11.54%), and communication will include health professionals with a better knowledge of the condition (11.54%). There were 4 participants (15.38%) that were satisfied with the healthcare professional communication and had no particular comment.

Future communication will be more empathetic

I think there's still a lot of change it needs to happen with health professionals and stigma. I think a lot of the health professionals carry the lung cancer stigma and it should start with them of removing the stigma. We shouldn't be treated any differently to a breast cancer patient because we've got lung cancer. Breast cancer patient get, "Oh, you've got breast cancer, you poor thing." Lung cancer, patient get, "Oh, well you must have smoked heavily before that." Health professionals I think need to be more compassionate for lung cancer patients, but also either be good to see more health professionals take up lung cancer as a professional. There's not very many lung cancer specialists, oncologists around, that would specialize in lung [unintelligible]. That would be really good if that would increase.
Participant 007_2023AULUC

Oh, my God. That just-- [laughs] I'd like to be treated with compassion and made to feel as if they, at least, care. The receptionist from the first surgeon, she was so rude to me, I actually said to her, "At no point have you made me feel of worth. At no point have you made me feel as if you care and that my life is worth anything." I had to pick myself up and move it to the other doctor. I said, "Because if you're that numb, you shouldn't be dealing with people in my condition." I would like to see that change. I understand they've got a job to do. I understand that they're protecting the doctor, I understand all of that. However, there are ways you can deliver news, and there are ways you can talk to people, and they need to learn that they-- Here's the thing, when you've got lung cancer, you're treated completely different to when if it's breast cancer. I know that because I've got friends who've had breast cancer, that "Oh, they were so lovely to me, and they're so supportive, and they're so this, and they're so that," and I'm going, "Really?' Man, I feel like I'm just beating my way through obstacle after obstacle, to be heard. I actually said to someone, I feel that I've become someone who I'm really not because I have to jump up and down and I have to be…and have a meltdown almost so [unintelligible] to be heard and to be taken serious or dealt with compassionately. That's the biggest thing that needs to change. That shouldn't happen. But I always feel like I have to be something, someone I'm not and someone I don't like, because it's the only way that I get listened to.
Participant 018_2023AULUC

Future communication will include a multidisciplinary and coordinated approach

Absolutely. Yes. For sure. I had a pulmonary function test and an echocardiogram of my heart back on the 4th of March, and I asked my GP today whether he had those results and he said no. So the hospital cannot even send those results to my GP, and he's requested them twice. Why? What's the break there? What's gone wrong?
Participant 003_2023AULUC

I think it's important that they communicate with each other so that there's one unified plan and that each professional understands what the other professional is doing so that it's a combined effort. I've got a friend, she doesn't have cancer, but eight years ago, she got diagnosed with preleukemia, so she had a bone marrow transplant and she's encountered some issues in the public system with communication between the different professionals. I experienced a bit of that when I was in hospital the first time because I got a bit frustrated towards the end because I was trying to get my results to the suit of appropriate department to then start working on my treatment plan. There seem to be a gap in the communication between the departments and everything seem to have to be faxed. I was lucky because my daughter was working there. She would physically take the paperwork from her area to the other area. I got very frustrated just before I left because I just found there was a bit of a gap in how the departments were communicating with each other. Having said that, with my latest diagnosis, my ophthalmologist actually referred me to the MRI, to have the MRI, so I had the MRI, and then I discovered this mess. My oncologist had the results. They diagnosed the brain tumor, and within a couple of days, my oncologist is ringing me, and then the neurosurgeon, and the ophthalmologist. I could see there was real communication between them and they'd already worked out a plan for surgery and treatment, et cetera. Now everyone knows that they made a difference because they were also in the private system. I don't know if there's a difference between doctors in the public system and doctors in the private system. I don't know if that really is a factor. I did feel like the doctors had already worked everything out before they even told me, which is encouraging. Participant 005_2023AULUC

I would like to see the health system change in that, there's one central point hospital of care for a person as opposed to going everywhere. My experience at the main hospital I am engaged with is really positive, *but it's not the same in others. I think if people are required to reschedule a surgery or anything else, they should be communicating with you verbally, not just sending a letter out to say that you are no longer getting seen. Participant 026_2023AULUC*

Future communication will be more transparent and forthcoming

In general, I'd say no, but in my experience in the hospital with the surgical team was that there was nowhere near enough communication. That was extremely stressful. Yes, that really didn't help. It was very stressful for me and very stressful for my wife. Participant 021_2023AULUC

Well, I think they've got to be totally honest and I think they should say to you, when they're booking you in for chemo that we'll give you something for the nausea we'll give you all the stuff for the side effects you might get and just explain to you why. When I got there, like the first time that they take [inaudible] what do I need that for? Even though I'm PROFESSION, I couldn't think why I needed it, what's that going to do. Supposedly that stops inflammation and help stop the nausea. They give you a [inaudible] you don't know what for.
Participant 001_2023AULUC

Future communication will include health professionals with a better knowledge of the condition

That's a good question. Look I don't care. You can't expect everything from an oncologist, everyone's different and it's just personality, different personalities, and everything. You just want them to know what they're doing. I don't care about the delivery. I always go to my oncologist, I always have someone with me and he just sits there and he just talks to me and that's how it should be. Every now and then my dad might ask something but it is between him and me and that's how it should be. He's the only one who knows anything about it, not all these people who have gone to Google stuff. What other things could have happened, they can do that but the oncologists I think, are busy. Well, most doctors are apart from a psychologist, but you book an hour. Who knows? I can deal with-- I just want a good doctor, I don't care about their delivery and whether it's got Asperger's or, he's got my interest with him. I even think to a point that he may have put me on the trial, just to access me to good treatment. Everyone talks about manners and politeness and everything. Yes, it's good but if it's not there, and the doctors looking after you and, helping you. I don't know, INTERVIEWER. The nurses it will be good to have more nurses but the doctor, it doesn't really worry me that I'm getting kind of good results. I don't have a problem with the way I've been dealt with with my oncologist. As I said, I had an amazing trial nurse. The nurse support has gone down now that I'm not on the trial because whenever I'm on trial, they've got all the blood tests and everything has to be documented but there definitely needs to be more lung care nurses.
Participant 019_2023AULUC

I don't have a huge expectation of the oncologist or the radiation specialists to support me emotionally because I think that's beyond their remit. What I do think they need to be able to do or no, not they, in particular, but what should be available, is there are breast care nurses when you have breast cancer, it's very easy to get in contact with that middle person who has medical knowledge, understands all the treatment pathways, can talk to you in general about things that you are concerned about, but which you don't want to go back to your oncologist and ask this. What might be a silly question? It's so hard to say, lung specialists. I think in the lung cancer space, we need lung cancer nurses. We need where there's very few of them and I think we need them more commonly available and we need them to know about them. Because I would've found that a fantastic resource in that person would've been in a way, a directory and said, "This is the pathway, this is the things you can access." You could ask the trivial question of where you are not going to make an appointment for an oncologist because it's not really that important, but you would like to get some help on something
Participant 020_2023AULUC

Table 9.5: Expectations of future healthcare professional communication

Expectations of future communication	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Future communication will be more empathetic	7	26.92	6	24.00	1	100.00	1	10.00	6	37.50	4	25.00	3	30.00
Future communication will include a multidisciplinary and coordinated approach	5	19.23	5	20.00	0	0.00	3	30.00	2	12.50	5	31.25	0	0.00
No particular comment - satisfied with experience	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Future communication will be more transparent and forthcoming	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Future communication will include health professionals with a better knowledge of the condition	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00

Expectations of future communication	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Future communication will be more empathetic	7	26.92	5	29.41	2	22.22	3	23.08	4	30.77	0	0.00	7	29.17	1	11.11	6	35.29
Future communication will include a multidisciplinary and coordinated approach	5	19.23	5	29.41	0	0.00	2	15.38	3	23.08	1	50.00	4	16.67	4	44.44	1	5.88
No particular comment - satisfied with experience	4	15.38	1	5.88	3	33.33	3	23.08	1	7.69	0	0.00	4	16.67	2	22.22	2	11.76
Future communication will be more transparent and forthcoming	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65
Future communication will include health professionals with a better knowledge of the condition	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	0	0.00	3	12.50	0	0.00	3	17.65

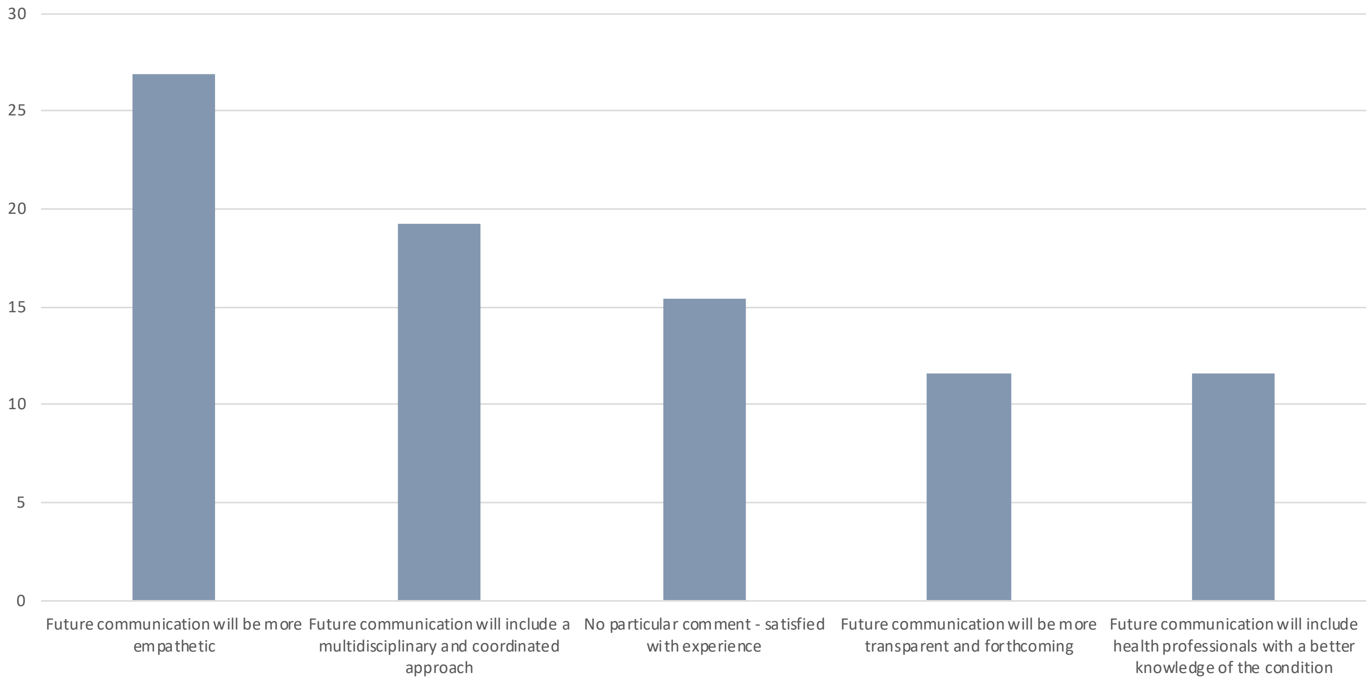


Figure 9.3: Expectations of future healthcare professional communication

Table 9.6: Expectations of future healthcare professional communication – subgroup variations

Theme	Less frequently	More frequently
Future communication will be more empathetic	Non-metastatic Mid to low status	Metastatic
Future communication will include a multidisciplinary and coordinated approach	Male Aged 65 or older Higher status	Non-metastatic Female Aged 35 to 64 Mid to low status
No particular comment - satisfied with experience	-	Aged 65 or older
Future communication will be more transparent and forthcoming	Mid to low status	Aged 65 or older
Future communication will include health professionals with a better knowledge of the condition	Male Aged 65 or older Mid to low status	-

Expectations of future care and support

Participants were asked in the structured interview whether there was any additional care and support that they thought would be useful in the future, including support from local charities. The most common expectation for future care and support was that it will include specialist clinics or services where they can talk to professionals either in person, phone, or online (38.46%). Other expectations if future care and support included practical support for example home care, transport, or financials support (15.38%), a multidisciplinary and coordinated approach to care and support (15.38%), long-term condition management and care planning (15.38%), and it will be more holistic that includes emotional health (11.54%). There were 5 participants (19.23%).) that were satisfied with their care and support and had no particular comment.

Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)

I reckon a dedicated hospital for cancer where you can go to ER with any cancer. Because I'm sure the ERs are all filled with people having some kind of fever or reaction. If one in two people are getting cancer, then I would love to see a hospital devoted to cancer where you can just go to the emergency and get seen to. They know all about targeted therapy and they can just help you out. Because a lot of the time, I've been to ER a few times and no one knows anything. You say, "Targeted therapy," they say, "Oh, immunotherapy," and you're like, "No, this is a completely different thing." I think there needs to be a gap filled there.
Participant 004_2023AULUC

I think a lung cancer nurse and somebody that you can talk to about the medication. Some [unintelligible] pharmacist or whatever that knows about the drug because I get it from somewhere and they don't know about the drug. Even the oncologist just chuck's you the generic piece of paper that lists all the side effects. When you look at that on its own, it's horrific. Why anyone would take [unintelligible] but you do [laughs].
Participant 025_2023AULUC

Future care and support to include practical support (home care, transport, financial)

Anything to make our life easier, even the Cancer Council. They give you $100 to have a cleaner, but only once which is fine. They were average, but some people they need that and why is it just one 100? It should be ongoing 100. I don't know maybe old people get more I think they might get more access to services. Yes, just help wherever we can get it. If someone has cancer, the other partner has to go to work and you need someone to get the kids off to school. I had friends coming in getting the kids off to school and yes, there are people who don't know people like that. Yes, there's a lot of room there where they can assist people. Really, anyone with lung cancer should be treated like an elderly person I think and they should access the same services. Participant 019_2023AULUC

Well. I think that perhaps even if they did a phone service to ring up and check on people, make sure they're right. I think down the track, I will need someone to help me at home because my husband's too old to do anything. I'm still doing all the shopping, cooking, everything, but anyway. [crosstalk]
Participant 001_2023AULUC

Future care and support will include a multidisciplinary and coordinated approach

No, I don't think so. I know I had a sister go in procedures [inaudible] and do you have follow-up phone calls with the hospital? It may be because of her particular operation that was warranted, but I didn't get any sort of follow-up, and I just don't know. Sometimes it would've been nice to say, "Oh, gee, I've still got this pain in my side, and is that normal?" There was no follow-up from the hospital.
Participant 010_2023AULUC

PARTICIPANT: It's definitely the idea of lung nurse someone, a nurse with that specialist knowledge who can be there. Yes. They become your point of contact. They can be that middle person between you and a specialist. They have a little bit more capacity because that's what they're there for, to steer you emotionally to where you might find resources, help, et cetera. I think that is solely lacking. The other thing I think is really lacking is public awareness. Again, having breast cancer, I saw what public awareness does. You can tell anyone, "Oh, I've got breast cancer," and they go, "Oh gosh, how are you going?" You tell them you've got lung cancer and they go, "Oh, how long did you smoke?" You go, "Oh, not a question to ask anyone." You do not bring about your own cancer deliberately. I think that's a public awareness thing. I don't know if that falls into arraignment, but that's what I think is poor in Australia. We don't understand it. Not a blame game. This can happen to anyone.
Participant 020_2023AULUC

Future care and support will include more long-term condition management (care planning)

The thing that we found is that when dad does decline and decline means that he would like to stay home. There is not enough support from My Aged Care to support him to stay dignified. His family is going to have to do it and that's something that he didn't want to do. There's not a lot of options for palliative care here in Queensland. Palliative care unit, it's like nearly an hour's drive or more in traffic. That's not something that he would like to utilize and then there's a

Hopewell House, but they've always got so many patients in there that you pretty much wouldn't get in there anyway. It's really not enough support when it comes to end-of-life I feel for patients.
Participant 030_2023AULUC

Yes, I think there needs to be survivorship care for people in the absence of a cure. Survivorship care in the absence of a cure for patients particularly with terminal lung cancer.
Participant 015_2023AULUC

Future care and support will be more holistic (including emotional health)

More mental health services. Access to mental health services. It's crucial.
Participant 007_2023AULUC

The only thing that I can think of really there is, everything was geared very much to my physical health, but not mental health. Like I said previously, I'm quite robust mentally. I think I was four weeks into my hospital stay before anybody asked me how I was. That was an orderly-- What do you call them? that person that does the cleaning and what have you. He asked me how I was when I collapsed in a heap, basically [laughs]. It was completely absent, the mental side of it. I thought that was a shame, really, because if somebody wasn't as robust as me, they would've probably collapsed in the heap a lot quicker than I did. It was a very, very challenging time.
Participant 021_2023AULUC

Table 9.7: Expectations of future care and support

Expectations of future care and support	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	38.46	10	40.00	0	0.00	**5**	**50.00**	5	31.25	**10**	**62.50**	**0**	**0.00**
No particular comment - satisfied with experience	5	19.23	5	20.00	0	0.00	**3**	**30.00**	2	12.50	2	12.50	**3**	**30.00**
Future care and support to include practical support (home care, transport, financial)	4	15.38	3	12.00	1	100.00	**0**	**0.00**	4	25.00	3	18.75	1	10.00
Future care and support will include a multidisciplinary and coordinated approach	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	4	25.00	**0**	**0.00**
Future care and support will include more long-term condition management (care planning)	4	15.38	3	12.00	1	100.00	**0**	**0.00**	4	25.00	3	18.75	1	10.00
Future care and support will be more holistic (including emotional health)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	2	12.50	1	10.00

Expectations of future care and support	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	10	38.46	8	47.06	**2**	**22.22**	4	30.77	6	46.15	1	50.00	9	37.50	**6**	**66.67**	**4**	**23.53**
No particular comment - satisfied with experience	5	19.23	**0**	**0.00**	**5**	**55.56**	**4**	**30.77**	**1**	**7.69**	0	0.00	5	20.83	2	22.22	3	17.65
Future care and support to include practical support (home care, transport, financial)	4	15.38	2	11.76	2	22.22	1	7.69	3	23.08	0	0.00	4	16.67	**0**	**0.00**	4	23.53
Future care and support will include a multidisciplinary and coordinated approach	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	0	0.00	4	16.67	**0**	**0.00**	4	23.53
Future care and support will include more long-term condition management (care planning)	4	15.38	2	11.76	2	22.22	2	15.38	2	15.38	1	50.00	3	12.50	1	11.11	3	17.65
Future care and support will be more holistic (including emotional health)	3	11.54	3	17.65	**0**	**0.00**	2	15.38	1	7.69	0	0.00	3	12.50	**0**	**0.00**	3	17.65

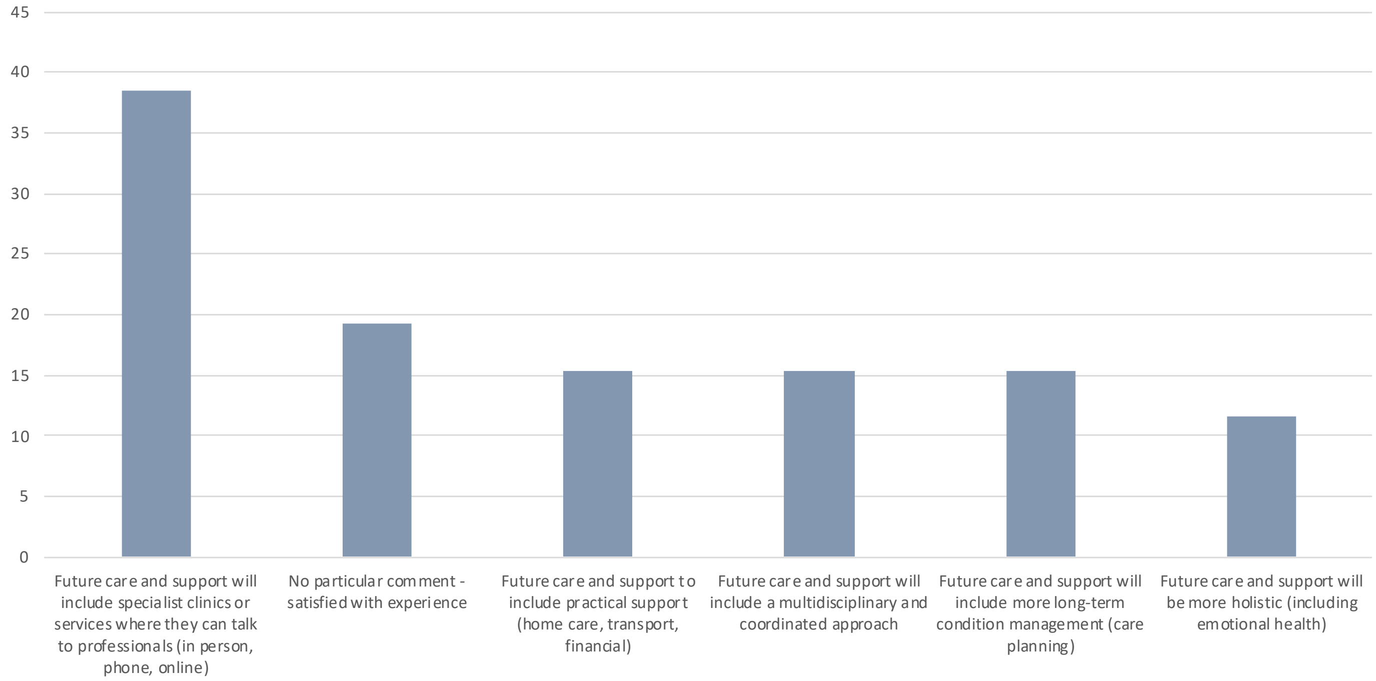


Figure 9.4: Expectations of future care and support

Table 9.8: Expectations of future care and support – subgroup variations

Theme	Less frequently	More frequently
Future care and support will include specialist clinics or services where they can talk to professionals (in person, phone, online)	Male Aged 65 or older Higher status	Non-metastatic Female Mid to low status
No particular comment - satisfied with experience	Aged 35 to 64 University	Non-metastatic Male Aged 65 or older Trade or high school
Future care and support to include practical support (home care, transport, financial)	Non-metastatic Mid to low status	-
Future care and support will include a multidisciplinary and coordinated approach	Male Mid to low status	-
Future care and support will include more long-term condition management (care planning)	Non-metastatic	-
Future care and support will be more holistic (including emotional health)	Aged 65 or older Mid to low status	-

What participants are grateful for in the health system

Participants were asked in the structured interview what aspects of the health system that participants are grateful for. The most common responses were that participants were grateful for low cost or free medical treatments through the government (46.15%), healthcare staff, including access to specialists (42.31%), for the entire health system (34.62 %), and Timely access to treatment (15.38%). There were 4 participants that expressed the need for lower treatment costs and extend Medicare coverage (15.38%).

Low cost/free medical treatments through the government

Oh look, the fact that these drugs are PBS is a life changer. I'm very grateful they are because 8,000 a month is not something you can stump up easily. If I had to pay for my own care, if I had to pay the whole lot of scans, et cetera, I would have to be keeping on working, and that would be physically and mentally really difficult to do, so I am really grateful medication too, the ongoing that is covered.
Participant 020_2023AULUC

I don't know whether it's totally worldwide, but we are very lucky in Australia. We're so far ahead of many countries including Britain I believe, and America, that we have such a system whereby your doctor can send a letter to a specialist, which he did. That started my journey for treatment and it cost me nothing. I end up with these magic people that are highly trained. You can tell that they'd love their job, the work they're doing, and the dedication that they put in so much is. The same with Silverchain. Unbelievable, these people. The nurses, the dedication that they have, the girls and boys that bringing your meals, I'm not saying all of them, but a lot of them are there to help
Participant 012_2023AULUC

My God, absolutely everything, and I mean everything. I have told so many people this, how lucky we are to live here because for what I've been given, would cost hundreds of thousands of dollars overseas and they wouldn't have been able to afford that, so, they probably died. Absolutely everything, very, very grateful.
Participant 017_2023AULUC

Healthcare staff (including access to specialists)

Oh, massively [chuckles]. Right away from when I first went into the hospital with those arm pains and the identification of it through having a chest X-ray then a CT scan and the diligence of the people that assessed those scans to actually see that there was this small nodule that I had in my lung. I'm extremely grateful for that, of course. Despite all of the problems that I had in the hospital, the complications and everything, the surgical team and the overall care and the outcome have been excellent. The access to CT scans and all that sort of thing, I'm very grateful for that, because, of course, that gives me a sense of confidence that it's all been dealt with. With a few exceptions, overall, the Australian Health System has been enormously beneficial, and I'm extremely grateful.
Participant 021_2023AULUC

Oh, everything. I don't quite know where to start with that one. Great GP. Great oncology team. Excellent thoracic surgeon. Even my pharmacist would say there are two patients that get my treatment from him, that he knows us both individually and I go there and he recognizes me and knows. He knows why I'm there and all of that contributes to superb experience if you can say that. To be sick is a bad thing, but to be sick and well cared for.
Participant 022_2023AULUC

I think we're really lucky. I know there's people that spend $10,000 a month for the medication that I'm on in other countries. I think PBS and even while I've said about the disjointedness of, I think the treat care teams are excellent, [unintelligible] and you've got options.
Participant 026_2023AULUC

Entire health system

I don't know whether it's totally worldwide, but we are very lucky in Australia. We're so far ahead of many countries including Britain I believe, and America, that we have such a system whereby your doctor can send a letter to a specialist, which he did. That started my journey for treatment and it cost me nothing. I end up with these magic people that are highly trained. You can tell that they'd love their job, the work they're doing, and the dedication that they put in so much is. The same with NAME. Unbelievable, these people. The nurses, the dedication that they have, the girls and boys that bringing your meals, I'm not saying all of them, but a lot of them are there to help
Participant 012_2023AULUC

My God, absolutely everything, and I mean everything. I have told so many people this, how lucky we are to live here because for what I've been given, would cost hundreds of thousands of dollars overseas and they wouldn't have been able to afford that, so, they probably died. Absolutely everything, very, very grateful.
Participant 017_2023AULUC

I think we are extremely lucky because I think our quality of care is quite good. Like I said, the quality of care, I thought, was quite good. I think our hospitals are quite good. I'm extremely lucky because I feel like I had options, in the sense that I went private, and I had a good array of doctors and what have you. No, I think we are lucky, but I just think that there's, from an administration point of view and from a care and compassion point of view, and to simplify the system, which is so complicated when it doesn't need to be, is what we need to work on.
Participant 018_2023AULUC

Need for lower treatment costs and extend Medicare coverage

Other than it's gotten very expensive. That's the only. Considering what's my insurance company paid and the government subsidizes, the huge amount of money that I still had out of pocket extra to paying the surgeon and things like this. Every time you go to a doctor, you out of pocket, $90 whatever, $100 whatever. I can afford it. It's not an issue but considering how much, years ago you were never out of pocket.
Participant 028_2023AULUC

Yes. I put it on the PBS, the drugs on the-- Oh at the moment-- Yes, the health system's great. It's just you've got to get the right doctors to get you in there. Well privately, as you know, every time I have a scan it costs me AUD200 out of my own pocket, and if I was public, I wouldn't be paying that. Every time I go and see the doctors, 200, I don't know. I lose track. Have a

lung function test that's AUD300, that all starts to add up. But yes, I could always go public and do that. I do think Medicare provides a lot. I just wish they put these drugs on the PBS.
Participant 025_2023AULUC

Timely access to treatment

We have got a good health system and I appreciate the timely manner that everything was done and that I didn't have to wait. Everything was done really efficiently. I don't know what it's like in other countries, but it makes such a difference for a patient. That was my experience.
Participant 010_2023AULUC

I think dad's just as blessed to be able to utilize immunotherapy. We know not so long ago it wasn't free. People had to pay a lot of money for each round of treatment, which is not cheap and we see that as a blessing and we don't take it for granted. In terms of that treatment, not a lot of people can access treatment like that in any other country for free.
Participant 030_2023AULUC

Table 9.9: What participants are grateful for in the health system

What participants are grateful for in the health system	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Low cost/free medical treatments through the government	12	46.15	11	44.00	1	100.00	4	40.00	8	50.00	10	62.50	2	20.00
Healthcare staff (including access to specialists)	11	42.31	11	44.00	0	0.00	6	60.00	5	31.25	7	43.75	4	40.00
Entire health system	9	34.62	9	36.00	0	0.00	6	60.00	3	18.75	6	37.50	3	30.00
Need for lower treatment costs and extend Medicare coverage	4	15.38	4	16.00	0	0.00	2	20.00	2	12.50	3	18.75	1	10.00
Timely access to treatment	4	15.38	3	12.00	1	100.00	1	10.00	3	18.75	3	18.75	1	10.00

What participants are grateful for in the health system	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Low cost/free medical treatments through the government	12	46.15	9	52.94	3	33.33	6	46.15	6	46.15	1	50.00	11	45.83	6	66.67	6	35.29
Healthcare staff (including access to specialists)	11	42.31	9	52.94	2	22.22	3	23.08	8	61.54	1	50.00	10	41.67	3	33.33	8	47.06
Entire health system	9	34.62	6	35.29	3	33.33	5	38.46	4	30.77	1	50.00	8	33.33	3	33.33	6	35.29
Need for lower treatment costs and extend Medicare coverage	4	15.38	3	17.65	1	11.11	1	7.69	3	23.08	0	0.00	4	16.67	1	11.11	3	17.65
Timely access to treatment	4	15.38	2	11.76	2	22.22	3	23.08	1	7.69	1	50.00	3	12.50	2	22.22	2	11.76

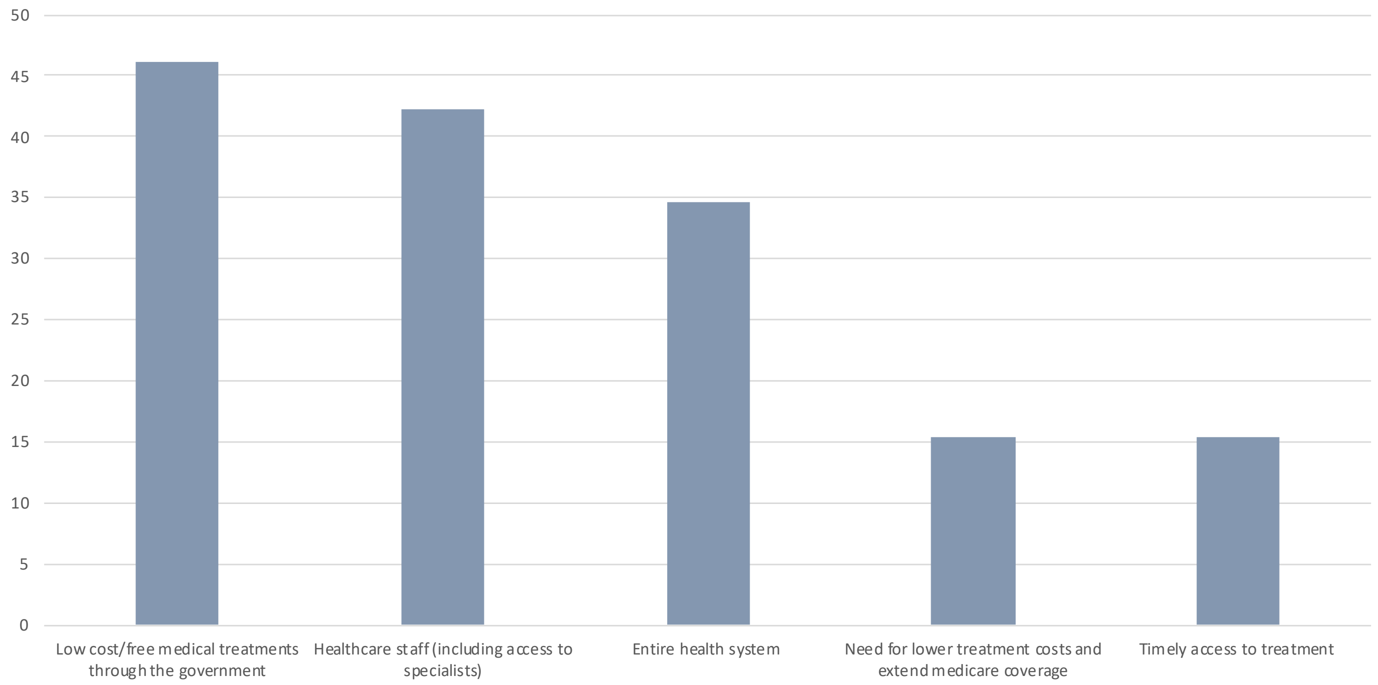


Figure 9.5: What participants are grateful for in the health system

Table 9.10: What participants are grateful for in the health system – subgroup variations

Theme	Less frequently	More frequently
Low cost/free medical treatments through the government	Male Aged 65 or older Higher status	Female Mid to low status
Healthcare staff (including access to specialists)	Metastatic Aged 65 or older Trade or high school	Non-metastatic Aged 35 to 64 University
Entire health system	Metastatic	Non-metastatic

Symptoms and aspects of quality of life

Participants were asked to rank which symptoms/aspects of quality of life would they want controlled in a treatment for them to consider taking it, where 1 is the most important and 8 is the least important. A weighted average is presented in Table 9.6, Figure 9.6. With a weighted ranking, the higher the score, the greater value it is to participants. The most important aspects reported were pain, nausea and vomiting and, tiredness and fatigue. The least important were mouth ulcers, loss of appetite and, hair loss.

Table 9.11: Symptoms and aspects of quality of life

Symptoms and aspects of quality of life	Weighted average (n=25)
Nausea and vomiting	6.2
Pain	6.72
Tiredness and Fatigue	5.52
Diarrhoea	4.32
Constipation	3.96
Mouth ulcers	3.52
Loss of appetite	3.32
Hair loss	2.44

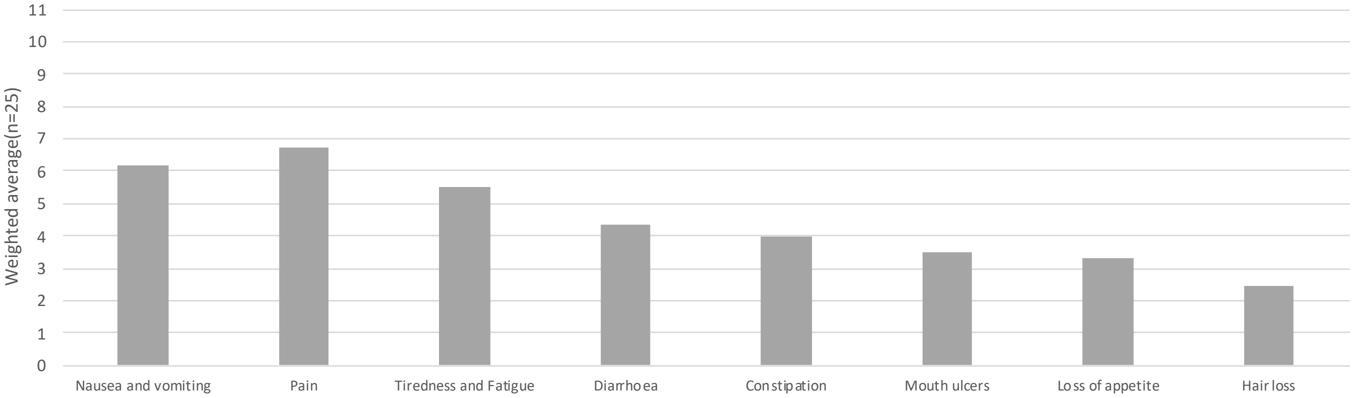


Figure 9.6: Symptoms and aspects of quality of life

Values in making decisions

Participants were asked to rank what is important for them overall when they make decisions about treatment and care, where 1 is the most important and 8 is the least important. A weighted average is presented in Figure 9.7. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important aspects were “Ability to follow and stick to a treatment regime”, and “How personalised the treatment is for me”. The least important were “The severity of the side effects” and “Time impact of the treatment on my quality of life”.

Table 9.12: Values in making decisions

Symptom	Weighted average (n=27)
How safe the medication is and weighing up the risks and benefits	6.33
The severity of the side effects	6.30
Time impact of the treatment on my quality of life	5.11
How the treatment is administered	3.85
How personalised the treatment is for me	4.26
The ability to include my family in making treatment decisions	2.63
Ability to follow and stick to a treatment regime	3.89
The financial costs to me and my family	3.63

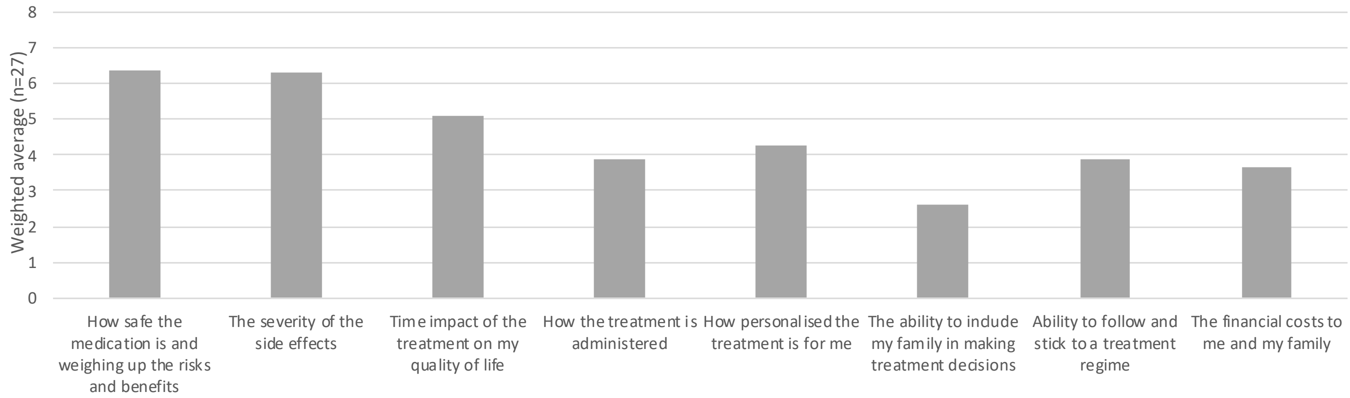


Figure 9.7: Values in making decisions

Values for decision makers

Participants were asked to rank what is important for decision-makers to consider when they make decisions that impact treatment and care, where 1 is the most important and 5 is the least important. A weighted average is presented in Figure 9.8. With a weighted ranking, the higher the score, the greater value it is to participants.

The most important values were “Quality of life for patients”, and “All patients being able to access all available treatments and services”. The least important was “Economic value to government and tax payers”.

Table 9.13: Values for decision makers

Values for decision makers	Weighted average (n=27)
Economic value to government and tax payers	1.52
Economic value to patients and their families	2.74
Quality of life for patients	4.19
Compassion	2.67
All patients being able to access all available treatments and services	3.89

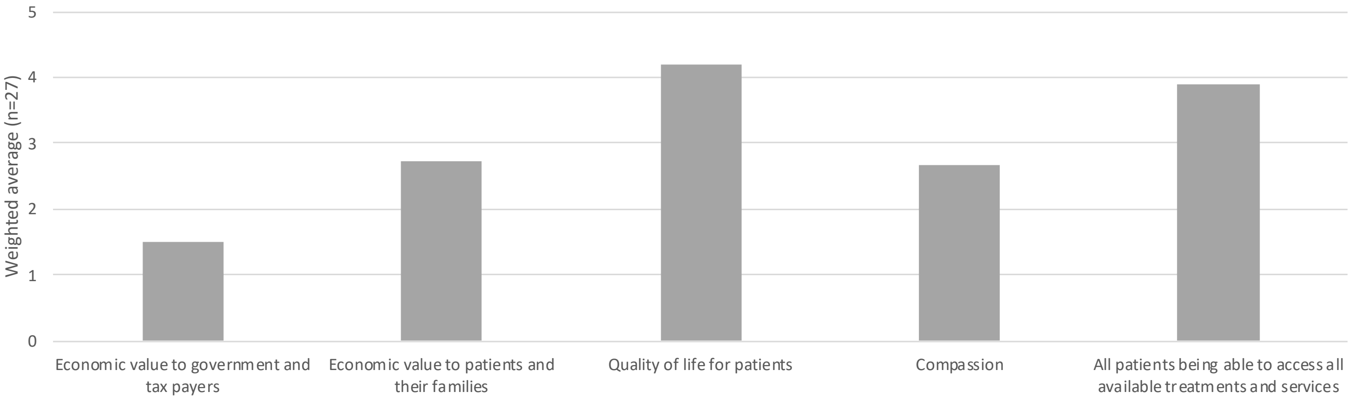


Figure 9.8: Values for decision makers

Value to access treatments that reduce symptoms and improve quality of life

Participants were asked in the online questionnaire, if there was any value to access treatments that reduce symptoms and improve quality of life, even if it did not offer a cure.

The majority of participants (n = 18, 72.00%) responded that this was of very significant value (Table 9.14, Figure 9.9).

Table 9.14: Value to access treatments that reduce symptoms and improve quality of life

Value to access treatments that reduce symptoms and improve quality of life, even if they don't offer a cure	Number (n=25)	Percent
Very significant value to me	18	72.00
Significant value to me	5	20.00
Moderate value to me	1	4.00
Some value to me	1	4.00

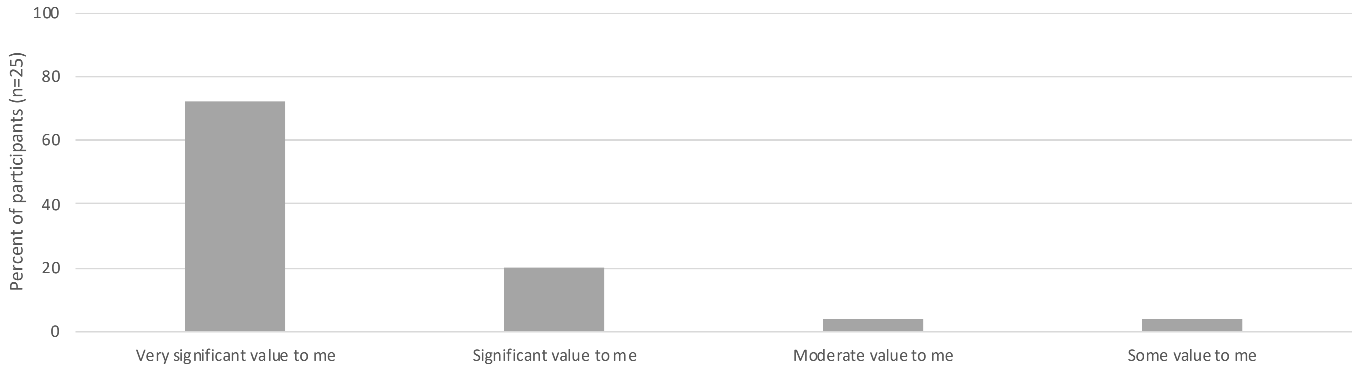


Figure 9.9: Value to access treatments that reduce symptoms and improve quality of life

Time taking medication to improve quality of life

Participants were asked in the online questionnaire, how many months or years would you consider taking a treatment, provided it gave you a good quality of life, even if it didn't offer a cure.

The majority of participants (n = 14, 51.85%) would use a treatment for more than ten years for a good quality of life even if it didn't offer a cure (Table 9.14, Figure 9.9).

Table 9.14: Time taking treatment to improve quality of life

Time taking medication to improve quality of life	Number (n=27)	Percent
Less than 1 year	3	11.11
1 to 5 years	14	51.85
5 to 10 years	4	14.81
More than 10 years	6	22.22

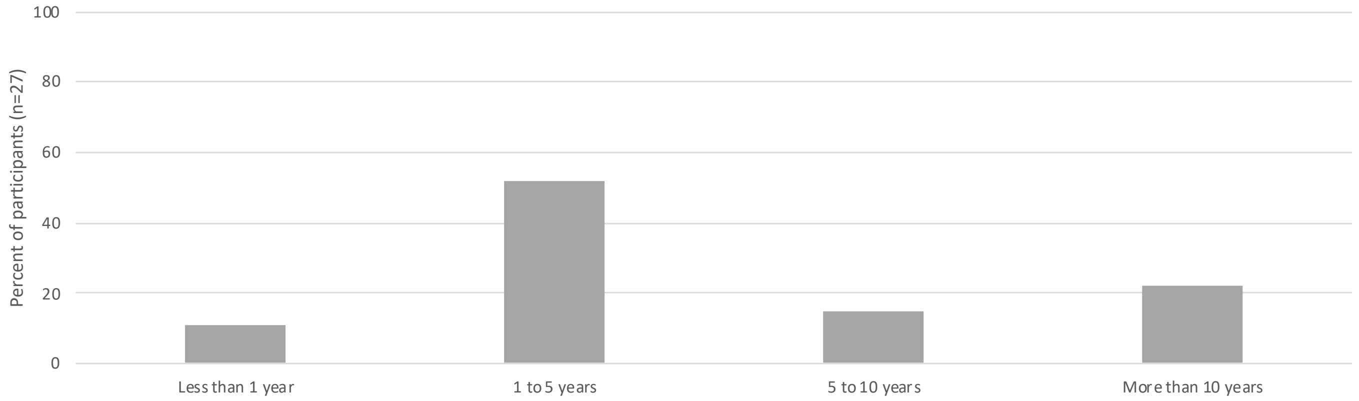


Figure 9.9: Time taking treatment to improve quality of life

Most effective form of medicine

Participants were asked in the online questionnaire, in what form did they think medicine was most effective in. There were no participants (0.00%) that thought that medicine delivered by IV was most effective, 5 participants (18.52%) thought that pill form was most effective, and 11 participants (40.74%) that thought they were equally effective. There were 11 participants (40.74%) that were not sure. (Table 9.15, Figure 9.10).

Table 9.15: Most effective form of medicine

Treatment most effective in what form	Number (n=27)	Percent
IV form (through a drip in hospital)	0	0.00
In a pill form that can be taken at home	5	18.52
Equally effective	11	40.74
Not sure	11	40.74

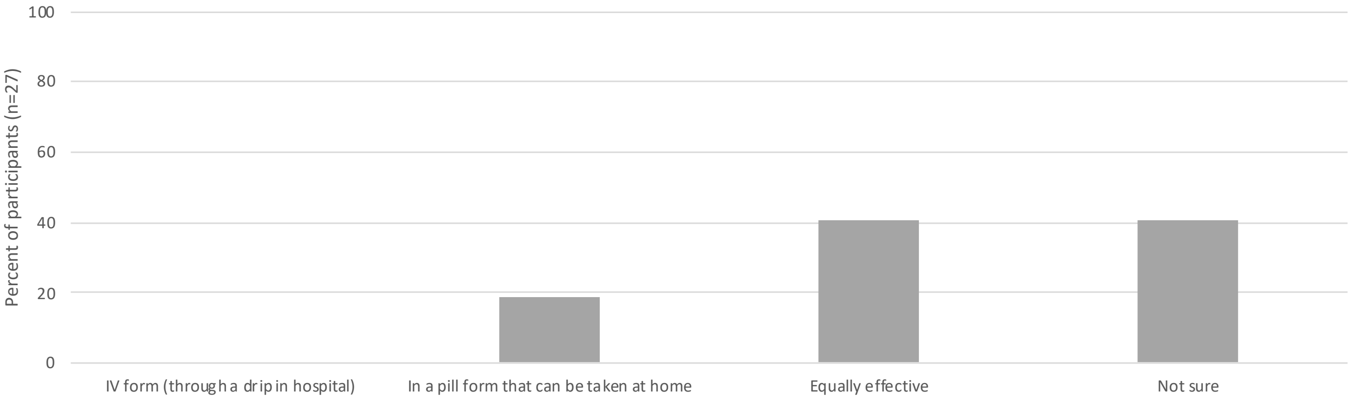


Figure 9.10: Most effective form of medicine

Messages to decision-makers

Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were to help raise community awareness (23.08%), that more clinical trials or new treatments are needed (23.08%), and they want more timely and equitable access to support, care and treatment (23.08 %). Other messages included to invest in health professionals to service the patient population (19.23%), Increase investment in general (11.54%), Invest in research, including to find new treatments (11.54%), and that treatments need to be affordable (11.54%). There were 3 participants whose message was that they were grateful for the healthcare system and the treatment that they received (11.54%).

Help raise community awareness

PARTICIPANT: Lung cancer, there needs to be education that anybody-- you know, the normal stuff. Anybody with lungs can get lung cancer. They need to change the focus from it not just being a smoking disease because there's so much guilt, no one deserves to get cancer. It needs to be a focus and a shift to know that it's a deadly-- it's the leading cause of death. People put it down to smoking. Whenever anyone hears I've got lung cancer, they always...I say to them, "Have you got lungs? You might get lung cancer too." Participant 027_2023AULUC

PARTICIPANT: Also, why does lung cancer only attract, what is it 3% of the research dollar? Why is there not more research and also point out that it is not necessary just a smoker's illness, and a lot more younger people are getting afflicted by it now, aren't they?
Participant 025_2023AULUC

More clinical trials and/or new treatments

I think I would ask him to expedite the approval of lung cancer medicines and get that advertising campaign on lung cancer that can affect anyone, not just smokers ASAP. Participant 004_2023AULUC

I've actually sent the health minister my feedback on the poor care from when I had surgeries [unintelligible] I think really it's just about making sure that hospitals remember that they're talking to people not just a number and it's difficult for families. Well, it's difficult for people to manage. Personalized care is important. That's my main thing. PBS is important. New treatments are important and personalized care. Participant 026_2023AULUC

Timely and equitable access to support, care and treatment

Well, anybody that's got lung cancer should never have to wait after they're diagnosed for treatment. They've got to get on to that straight away. I was lucky, but some people aren't lucky.
Participant 013_2023AULUC

PARTICIPANT: I've already sat in front of the health minister. My message at that time was, you shouldn't have to be lucky or rich to have lung cancer.
Participant 015_2023AULUC

Invest in health professionals to service the patient population

More support in hospitals, more beds, more education programs around lung cancer and I would request that-- More support, more beds, more cancer nurses, there's a huge need for it, better support around mental health for people that are going through cancer. I find that's a big loop gets left behind. That's really all that I'd probably say to the health minister. [chuckles]
Participant 030_2023AULUC

Oh, no, no. Hang on. Lung cancer nurses I haven't even mentioned them. We desperately need funding for lung cancer nurses. That goes back to the mental health and I can't believe I'd left out lung cancer nurses through this whole thing. The amount of lung cancer nurses compared to percentage-wise of people with lung cancer compared to the other cancers is just ridiculous. We have the equivalent of 12 full-time lung cancer nurses around Australia. There's [unintelligible] lung cancer patients that get diagnosed every year, you just can't find a lung cancer nurse anywhere. I've never ever met a lung cancer nurse in clinical practice. I've met them through the foundation, but I've never met them actually in a clinic.
Participant 007_2023AULUC

Grateful for the healthcare system and the treatment that they received

Thank you. That would be my answer.
Participant 022_2023AULUC

Well, I suppose he's got to be a downer, so I'd have to give him a 9 out of 10, I've got to take one off for the ramping. [laughter]
Participant 017_2023AULUC

Increase investment (general)

More funding. More funding, please.
Participant 014_2023AULUC

I would say the public hospital that I went to was absolutely horrendous. The whole experience was hideous and that he needs to put his hand in his pocket and put a little more money into lung health nurses, specific nurses. Why not? Because anyone can get lung cancer and it's just the right thing to do.
Participant 019_2023AULUC

Invest in research (including to find new treatments)

My message would be to him that we need access to more funds for research because at the moment it's not fair how inequitable the funding is distributed across cancer topics so if I had him in front of me, I would ask for the money to be shared more equitably over the different treatments over the different types of cancer. Lung cancer needs more money to research.
Participant 007_2023AULUC

PARTICIPANT: Also, why does lung cancer only attract, what is it 3% of the research dollar? Why is there not more research and also point out that it is not necessary just a smoker's illness, and a lot more younger people are getting afflicted by it now, aren't they?
Participant 025_2023AULUC

Treatments need to be affordable

For starters, I would be begging him to allow those that are at high risk to enable them to have a CT scan on a yearly system because that would save 12,500 lives. The problem is lung cancer is never diagnosed until it's too late in lots of cases, which is why only 15% of people make it past five years. That would be my first thing. The second thing I'd be saying is "You need to put radiation care under private health so we can claim that as well."
Participant 018_2023AULUC

I feel at the moment I've got treatment and care I need. My thing would be to talk about the disparities no, hang on, it's not really disparity. I'm trying to say there's a public and a private system. The private system is fine. The public system's very good, but being privately insured and yet it's still cost few thousands upon thousands makes it really very difficult at times. Again, I say I'm lucky I can afford it, but there are plenty of privately insured people who are stuck in a cycle of scraping together the dollars for their care just because they're privately insured, and that to me is very wrong. To me, I'd say to a health minister, I think we shouldn't have a private public system. It should be public and well-funded.
Participant 020_2023AULUC

Table 9.16 Messages to decision-makers

Message to decision-makers	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Help raise community awareness	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	5	31.25	1	10.00
More clinical trials and/or new treatments	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	6	37.50	0	0.00
Timely and equitable access to support, care and treatment	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	6	37.50	0	0.00
Invest in health professionals to service the patient population	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	2	12.50	3	30.00
Grateful for the healthcare system and the treatment that they received	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00
Increase investment (general)	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Invest in research (including to find new treatments)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Treatments need to be affordable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Message to decision-makers	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Help raise community awareness	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	1	50.00	5	20.83	3	33.33	3	17.65
More clinical trials and/or new treatments	6	23.08	6	35.29	0	0.00	0	0.00	6	46.15	1	50.00	5	20.83	3	33.33	3	17.65
Timely and equitable access to support, care and treatment	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	2	100.00	4	16.67	3	33.33	3	17.65
Invest in health professionals to service the patient population	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Grateful for the healthcare system and the treatment that they received	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Increase investment (general)	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Invest in research (including to find new treatments)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Treatments need to be affordable	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65

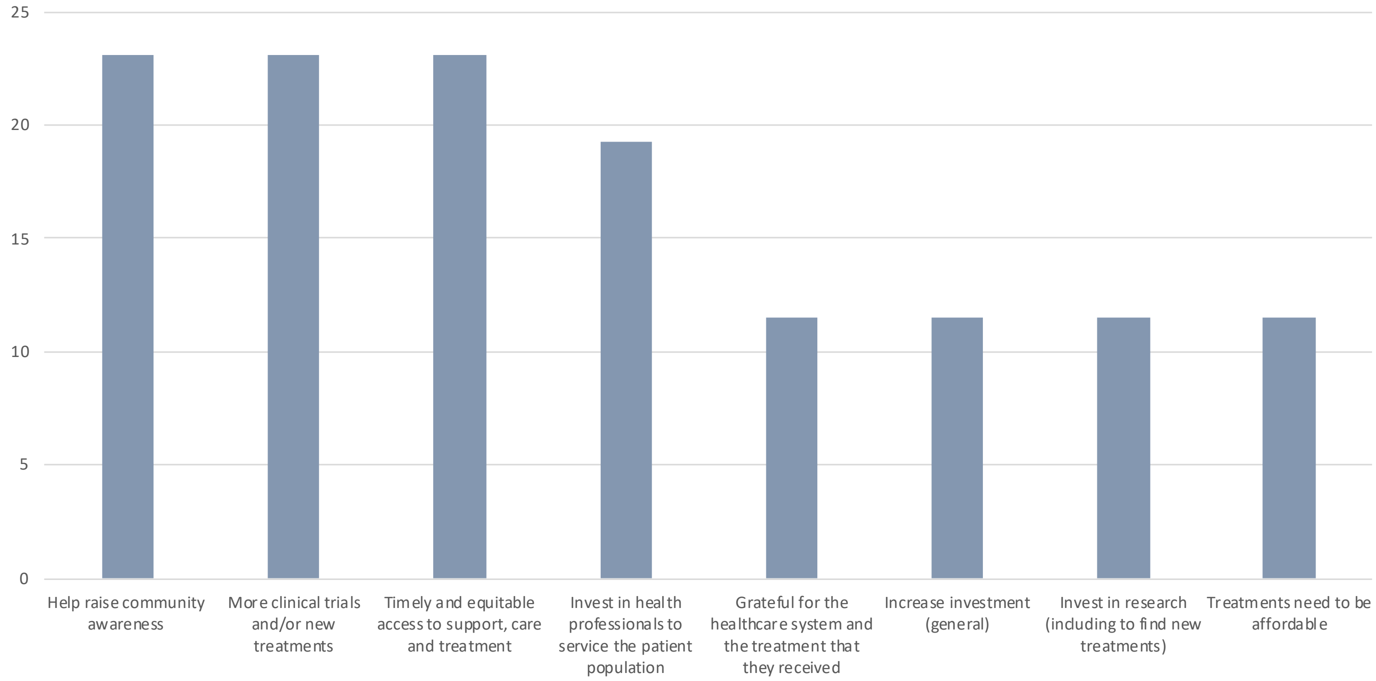


Figure 9.11: Messages to decision-makers

Table 9.17: Messages to decision-makers – subgroup variations

Theme	Less frequently	More frequently
Help raise community awareness	Male	Mid to low status
More clinical trials and/or new treatments	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University Mid to low status
Timely and equitable access to support, care and treatment	Non-metastatic Male	Female Mid to low status
Invest in health professionals to service the patient population	Mid to low status	Male Aged 65 or older Higher status
Grateful for the healthcare system and the treatment that they received	-	Aged 65 or older
Invest in research (including to find new treatments)	Male Aged 65 or older	-
Treatments need to be affordable	Mid to low status	-

Section 10

Advice to others in the future: The benefit of hindsight

Section 10: Advice to others in the future

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to communicate and increase understanding of lung cancer (23.08%), that they had known the early signs and symptoms (19.23 %), and to be assertive, an advocate, informed, and ask questions (15.38%).

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect and were satisfied with their care or treatment (38.46%). Others would accesses appropriate specialist or treatment sooner (11.54%), and some participants described a single negative experience that they would like to have changed (11.54 %).

Anything participants wish they had known earlier

In the structured interview, participants were asked if there was anything they wish they had known earlier. The most common things that participants had wished they'd known earlier were to communicate and increase understanding of lung cancer (23.08%), that they had known the early signs and symptoms (19.23 %), and to be assertive, an advocate, informed, and ask questions (15.38%).

Participant wishes they had known to communicate/increase understanding

Like I said, I'd like to have known, I suppose, just more information gently and comprehensively explained to me, as opposed to "Hey, go read this. The second chemo, I said, '"Oh, my gum is doing what have you," and this nurse said, "Aren't you doing--" or "Are you following your dental protocol?" What's dental protocol? It was in the notes, and she grabbed them off me, went to page seven, circled it with a red pen, with a big attitude and says, "It's right there." I went, "Yes, I'm sorry, I was probably a little bit preoccupied and hadn't got to reading that," so things like that need to change, things like that. I felt like I was suddenly 8 years old or 12 years old, and I just failed my maths exam. It was like, "What's that?" I'm the same age as woman, like, "Why am I getting treated like this? Things like that, I would like to have had explained to me. I'd like someone to have said to me-- It'd be nice to have a coordinator who said, "This is how your treatment plan, we feel, is best for you to go, and this is probably the best routine. this is how things will flow, to give me-- and you had some of that to some degree, but not enough for my liking.
Participant 018_2023AULUC

One of the questions I have is why I wasn't given some treatment to shrink the tumour first before I had the surgery, because I noticed they do that a lot in the UK and in America. Would that have allowed me to keep my lobe of my lung? I haven't dared ask the guys [unintelligible] they'll fob me off. That's not standard treatment. I've got questions like that. Then of course, like I said before, is the [unintelligible] going to save my life or is it actually going to give me something else, is it going to mess up some other organs in my body? It's all a bit hazy.
Participant 025_2023AULUC

Probably not from a lung cancer perspective because I have lung cancer primarily, I believe because of my genetic condition. I think in terms of that genetic condition, there's a lot of stuff that could have been [unintelligible] but scanning early which I think now they've got a screening process for adults, but they never historically did. I think that is part of the issue occurring.
Participant 026_2023AULUC

Participant described that they were satisfied with their experience and have no particular comment

Not that I can think of. No. Everyone's different, aren't they? It took time to process. I don't know. I thought I was going to die a lot quicker, and then I had a lot more time, which is nice because now I've had time to sort a lot more things out, whereas before, I was in a bit of a haze of medication and treatments and I was unwell for a good seven months, and then I felt better. Life changed.
Participant 006_2023AULUC

No, not really. It would've been lovely to pick this up before it was metastatic, but I understand even when I think, "Oh I had a funny little cough at times." There's no way you would've thought I was going to develop one cancer. I was not sitting there as a prime candidate. To be forewarned of what can happen, not until you're thrown in the big pool, do you need to know the ins and outs of everything because there's so much that can happen in your life. No, there's not really anything. I don't think I missed anything in my symptoms. I don't think anyone would've acted any earlier, and I don't think there's anything I needed to be forewarned because lung cancer is not one disease. It's a bazillion different little diseases and so you couldn't be forewarned about all the pathways, so not really.
Participant 020_2023AULUC

Participant wishes they had known the early signs and symptoms

I would like that commercial about lung cancer being a cancer that can happen to anyone, not just smokers, because you never think, "Oh, I'd better look out for these symptoms because it could be the lung cancer." Because you just think, "No, it won't happen to me."
Participant 004_2023AULUC

Yes, lung screening, definitely. Being more aware of what this issue was in my chest at the time and taking it further. I would occasionally get what seemed like bad indigestion six years ago. I would have felt the strong pains coming across my back. I saw my GP about it and it was treated as indigestion and she *gave me some medication, it seemed to go away, but there was never any discussion outside of that. One night, the pain got really strong and my husband decided to take me to a private hospital and focus was on my heart. I stayed overnight in ECG, kept me overnight for observation, my heart was fine.*

Participant 005_2023AULUC

Probably, it would've been nice if we could have diagnosed it earlier, because by the time, we've got it at stage 3, that's pretty devastating to get that even for me. I didn't let it affect me, but still, it did knock me a bit. Probably, an earlier diagnosis would've been better. I've been looking at that because I've already become aware of it at the signs and symptoms of lung cancer, a bit long before diagnosis, but they generally say that, by the time that you are diagnosed, you're at that stage because it's funny then that it becomes apparent that that's what the problem is.

Participant 017_2023AULUC

I wish I knew what to look for. I wish I knew dad could have-- In hindsight, dad has had the symptoms for at least six months and I wish there was more education to the general public about what lung cancer looks like because there's not enough [inaudible] We could have probably had six months off the tumor growing, whether that would've made any difference, I don't know, but something that you live with and you go, I could have but didn't.

Participant 030_2023AULUC

Participant wishes they had known to be assertive, an advocate, informed, & ask questions

Oh, so much. Firstly I wish I had known that a non-smoker could get lung cancer and I think more people should be told that. I wish I had known that I could stand up for myself and advocate for myself to my oncologist or any health professional rather than what they say is what needs to be done. Now I know that I can do my own research and I can say to him, what do you think of this and he's like, oh yes, I'll have a look at this. I think this, that, and the other and he's very open to it, whereas initially he's the professional and he knows what needs to be done. Right now I wish for everybody on diagnosis to know that they can have an impact on their treatment plans.

Participant 007_2023AULUC

Yes. Advocate more. Advocate and question more, ask for details. Don't feel like-- I just wish I was more knowledgeable about cancer. I just don't think as a society we talk about it openly enough. I don't know. The other thing is, can I just say, I don't even know what to do. I think I have to prepare a will and [crosstalk] I don't even know if it is that. No one had told me. I haven't thought, and probably I haven't gone looking for it, but [crosstalk] moment, the things that I should be doing because things could turn around really quickly.

Participant 027_2023AULUC

Table 10.1: Anything participants wish they had known earlier

Message to decision-makers	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Help raise community awareness	6	23.08	5	20.00	1	100.00	2	20.00	4	25.00	5	31.25	1	10.00
More clinical trials and/or new treatments	6	23.08	6	24.00	0	0.00	2	20.00	4	25.00	6	37.50	0	0.00
Timely and equitable access to support, care and treatment	6	23.08	6	24.00	0	0.00	1	10.00	5	31.25	6	37.50	0	0.00
Invest in health professionals to service the patient population	5	19.23	4	16.00	1	100.00	1	10.00	4	25.00	2	12.50	3	30.00
Grateful for the healthcare system and the treatment that they received	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	1	6.25	2	20.00
Increase investment (general)	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00
Invest in research (including to find new treatments)	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Treatments need to be affordable	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Message to decision-makers	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Help raise community awareness	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	1	50.00	5	20.83	3	33.33	3	17.65
More clinical trials and/or new treatments	6	23.08	6	35.29	0	0.00	0	0.00	6	46.15	1	50.00	5	20.83	3	33.33	3	17.65
Timely and equitable access to support, care and treatment	6	23.08	4	23.53	2	22.22	3	23.08	3	23.08	2	100.00	4	16.67	3	33.33	3	17.65
Invest in health professionals to service the patient population	5	19.23	2	11.76	3	33.33	3	23.08	2	15.38	0	0.00	5	20.83	0	0.00	5	29.41
Grateful for the healthcare system and the treatment that they received	3	11.54	1	5.88	2	22.22	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Increase investment (general)	3	11.54	2	11.76	1	11.11	1	7.69	2	15.38	0	0.00	3	12.50	1	11.11	2	11.76
Invest in research (including to find new treatments)	3	11.54	3	17.65	0	0.00	2	15.38	1	7.69	0	0.00	3	12.50	1	11.11	2	11.76
Treatments need to be affordable	3	11.54	2	11.76	1	11.11	2	15.38	1	7.69	0	0.00	3	12.50	0	0.00	3	17.65

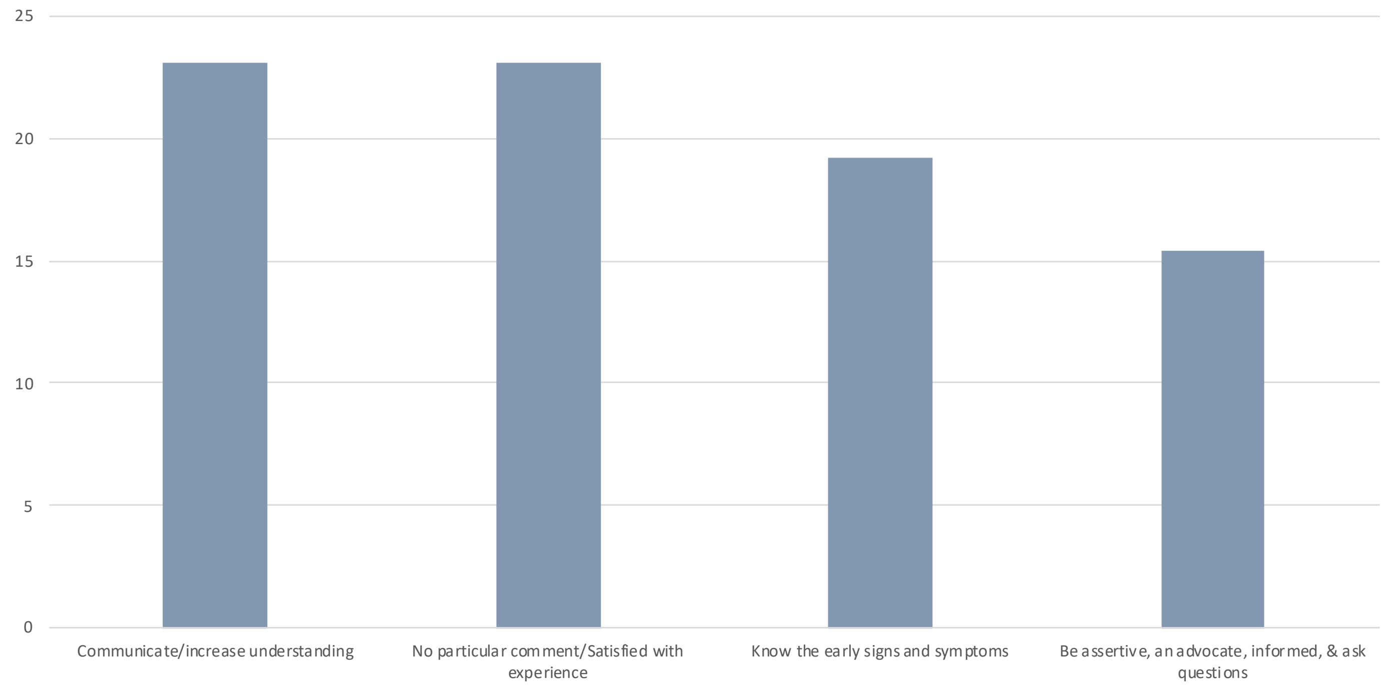


Figure 10.1: Anything participants wish they had known earlier

Table 10.2: Anything participants wish they had known earlier – subgroup variations

Theme	Less frequently	More frequently
Help raise community awareness	Male	Mid to low status
More clinical trials and/or new treatments	Male Aged 65 or older Trade or high school	Female Aged 35 to 64 University Mid to low status
Timely and equitable access to support, care and treatment	Non-metastatic Male	Female Mid to low status
Invest in health professionals to service the patient population	Mid to low status	Male Aged 65 or older Higher status
Grateful for the healthcare system and the treatment that they received	-	Aged 65 or older
Invest in research (including to find new treatments)	Male Aged 65 or older	-
Treatments need to be affordable	Mid to low status	-

Aspect of care or treatment they would change

In the structured interview, participants were asked if there was any aspect of their care or treatment they would change. The most common themes were that they would not change any aspect and were satisfied with their care or treatment (38.46%). Others would accesses appropriate specialist or treatment sooner (11.54%), and some participants described a single negative experience that they would like to have changed (11.54 %).

Participant would not change any aspect of their care or treatment/satisfied with care and treatment received

No, because I feel that this is the best treatment I could get. I can't knock any of it.
Participant 001_2023AULUC

No. Everything from my pharmacist to my nurse, that's very, very good.
Participant 022_2023AULUC

All the medical staff were excellent. The nurses were great. Excellent. That's what I found. Nurses are the backbone of the hospital.
Participant 024_2023AULUC

No. The care has been good from the nurses. Like I said, the oncologist not so much, but the nurses have been amazing. Each time he goes for treatment, they're very informative. They're comfortable, they're good in checking him with his mental health as well. They've just been supportive. Like I said, we've really had good experiences other than the lack of information from the oncologist.
Participant 030_2023AULUC

Participant would have liked to have access to a specialist in their condition, and treatment sooner

Yes [laughs]. I would never have gone for that respiratory physician if I'd known. Normal practice for that would have been to have the biopsy within a couple of weeks and I would have had surgery within four to five weeks. It would have been stage 1B or 1A-- No, it would have been 1B, it's bigger. It would have been 1B and I might have avoided some of this treatment. Definitely, it's out there. I was happy with the surgeon. I think I would get a second opinion of an oncologist now.
Participant 025_2023AULUC

Yes. I wouldn't have gone to that respiratory specialist. I want an oncologist. I should've questioned everything right from the start. They talk about that genomic testing, whatever, and the gene testing, someone should have sat and explained it to me. I'm just thankful that the thoracic surgeon center for testing, because, like he said, the respiratory specialist didn't even want to tell me I was out positive, [inaudible].
Participant 027_2023AULUC

Participant described a single negative experience that they would like to have changed

No, no, it was all good. Just the hospital stay was pretty diabolical. That was hideous.
Participant 019_2023AULUC

That's a hard one to answer. My hospital experience post when I had the complications, most of that was very traumatic and made worse by the way that I was treated. I've been through a lot of that. That really needed to change because it wasn't handled very well at all.
Participant 021_2023AULUC

Table 10.3: Aspect of care or treatment they would change

Anything they would change about treatment or care	All participants		Person with lung cancer		Family member or carer		Non-metastatic		Metastatic		Female		Male	
	n=26	%	n=25	%	n=1	%	n=10	%	n=16	%	n=16	%	n=10	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	38.46	9	36.00	1	100.00	2	20.00	8	50.00	6	37.50	4	40.00
Participant would have liked to have access to a specialist in their condition, and treatment sooner	3	11.54	3	12.00	0	0.00	1	10.00	2	12.50	3	18.75	0	0.00
Participant described a single negative experience that they would like to have changed	3	11.54	3	12.00	0	0.00	2	20.00	1	6.25	2	12.50	1	10.00

Anything they would change about treatment or care	All participants		Aged 35 to 64		Aged 65 or older		Trade or high school		University		Regional or remote		Metropolitan		Mid to low status		Higher status	
	n=26	%	n=17	%	n=9	%	n=13	%	n=13	%	n=2	%	n=24	%	n=9	%	n=17	%
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	10	38.46	5	29.41	5	55.56	5	38.46	5	38.46	0	0.00	10	41.67	4	44.44	6	35.29
Participant would have liked to have access to a specialist in their condition, and treatment sooner	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	2	22.22	1	5.88
Participant described a single negative experience that they would like to have changed	3	11.54	3	17.65	0	0.00	1	7.69	2	15.38	1	50.00	2	8.33	1	11.11	2	11.76

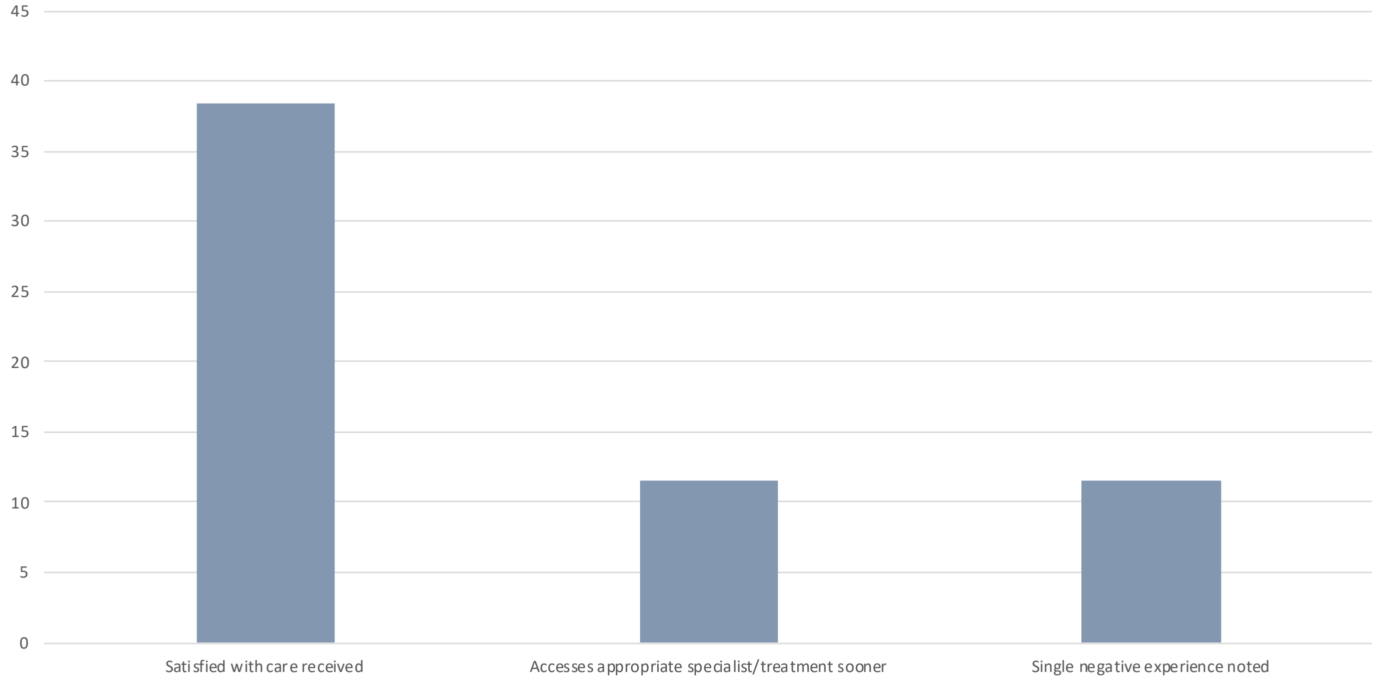


Figure 10.2: Aspect of care or treatment they would change

Table 10.4: Anything participants wish they had known earlier – subgroup variations

Theme	Less frequently	More frequently
Participant would not change any aspect of their care or treatment/satisfied with care and treatment received	Non-metastatic	Metastatic Aged 65 or older
Participant would have liked to have access to a specialist in their condition, and treatment sooner	Male Aged 65 or older	Mid to low status
Participant described a single negative experience that they would like to have changed	Aged 65 or older	-

Section 11

Discussion

Introduction

PARTICIPANT: Lung cancer, there needs to be education that anybody-- you know, the normal stuff. Anybody with lungs can get lung cancer. They need to change the focus from it not just being a smoking disease because there's so much guilt, no one deserves to get cancer. It needs to be a focus and a shift to know that it's a deadly…it's the leading cause of death. People put it down to smoking. Whenever anyone hears I've got lung cancer, they always…I say to them, "Have you got lungs? You might get lung cancer too."
Participant 027_2023AULUC

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.

This PEEK study in lung cancer includes 29 people diagnosed with lung cancer, 3 family members or carers to people with lung cancer throughout Australia.

Background

Lung cancer is the fourth most diagnosed cancer in Australia for both men and women[1], in 2015, it was the fourth most common cause of death and the most common cause of cancer deaths[2]. There were 13,078 new cases of lung cancer in 2018, with more men (7,168) than women (5,910) diagnosed[3]. In 2022, 8457 people in Australia died from lung cancer, 4,751 of these deaths were in men[4]. 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[4]. 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[5].

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[6].

There are two main types of lung cancer, small cell lung cancer (SCLC) and non-small cell lung cancer (NSCLC), the majority are NSCLC (85%)[7]. NSCLC can further be divided into adenocarcinoma, squamous-cell carcinoma, and large-cell carcinoma, the most common from is adenocarcinoma (about 40%)[8].

NSCLC can is divided into 6 stages based on size of tumour and where the cancer has spread to[9]:

- Occult (hidden) stage, cancer cells are detected in fluids but not in any other tests.
- Stage 0 tumours are non-invasive cancer that is confined to inner lining of lungs
- Stage I tumours are small and have not spread to lymph nodes or any other organs.
- Stage II tumours are may be large or have spread to lymph nodes
- Stage III tumours may be large, locally advanced, or have spread to lymph nodes but not too distant sites
- Stage IV tumours, the cancer has spread to either the other lung, the space around the lungs or heart, or distant sites.

Demographics

The demographic data we collect in the PEEK study helps us to understand how our PEEK participants compares to people in Australia, and with people that have lung cancer.

In this PEEK study, the proportions of participants that had non-school qualifications (certificate, diploma or degree), were all similar to that of the Australian population. There were fewer that were in paid employment, higher proportions that lived in areas with higher socioeconomic status, and higher proportions that live in metropolitan areas [10-12]. There were no participants from Tasmania, the Northern Territory, or Canberra, and there were a lower proportion of participants from NSW, while a greater proportion from Queensland and Western Australia compared to the proportion that live in each state[13].

Table 12.1: Demographics

Demographic	Australia %	Lupus PEEK %
Live in major cities	71	91
Non-school qualification	65	72
Higher socioeconomic status (7 to 10 deciles)	40	63
Employment (aged 15 to 64)	74	25
New South Wales	32	6
Victoria	26	31
Queensland	20	31
Western Australia	10	22
South Australia	7	9
Tasmania	2	0
Northern Territory	1	0
Australian Capital Territory	2	0

Health status

In PEEK studies we collect information about other health conditions that participants manage, as well as health-related quality of life (with the SF36 questionnaire). The purpose of this is to have an idea of the general health of the participants in the study. We can also compare this data with the Australian population, and with other studies with lung cancer participants.

Other health conditions

The National Health Survey was conducted in 2017 to 2018, it is an Australia wide survey conducted by the Australian Bureau of statistics. Almost half of the Australian population have one chronic condition[14]. Common chronic health conditions experienced in Australia in 2017-18 were: mental and behavioural conditions (20%), back problems (16%), arthritis (15%), asthma (11%), diabetes mellitus (5%), heart, stroke and vascular disease (5%), osteoporosis (4%), chronic obstructive pulmonary disease (COPD) (3%), cancer (2%), and kidney disease (1%)[14]. The Australian Bureau of statistics reports that 10% of Australians have depression or feelings of depression and 13.1% have an anxiety-related condition[14].

In this PEEK study, participants had an average of 2 other health conditions to manage, they had higher levels of anxiety (29% compared to 13%), depression (429% compared to 10%), and arthritis (29% compared to 15%) compared to the Australian population.

Similar to this PEEK study, other studies reported a high prevalence of anxiety and/or depression of between 30% and 53% of participants[15-18]. One study reported a significant association between depression and stigma[19], and numerous studies reported a negative association between anxiety and/or depression and health-related quality of life[18,20-22]. Another study noted that having co-morbidities increased use of healthcare services, impacted cancer treatment in some cases treatments not available due to poor health from co-morbidities, and that treatment for lung cancer exacerbated symptoms of comorbidities[23].

Baseline health

The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual[24]. The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function[24].

Population norms for the SF36 dimensions in Australia were assessed in the 1995 National health survey, while this was conducted 25 years ago, it can give an indication of how the lung cancer community in this PEEK study compares with the Australian population[25]. The 2023 lung cancer PEEK participants on average had considerably lower scores for all SF36 domains with the exception on emotional well-being. The lowest scores were recorded for Role functioning/physical and Role functioning/emotional, indicating that physical health and emotional problems interfered with work and other activities for participants in this study. One other study reported SF36 in an elderly Greek lung cancer population, the average subscales ranged between 42.7-62.61, and were highest for pain (75.0), and lowest for social function (42.8)[26].

PEEK Lung cancer SF36 summary of results

Good scores (second highest quintile) for:

- Physical functioning
- Emotional well-being
- Social functioning
- Pain

Moderate scores (middle quintile) for:

- Energy/Fatigue
- General health
- Health change

Poor scores (second lowest quintile) for:

- Role functioning/emotional

Very poor scores (lowest quintile) for:

- Role functioning/physical

A number of studies reported determinants associated with better or improved health-related quality of life. Studies reported that positive thinking, mindfulness, and physical activity were positively associated with health-related quality of life[27-32]. In terms of demographics, living with family, having a higher income, older age and higher education were associated with better health-related quality of life[26,33-

[35]. People who were more informed and better prepared had better quality of life, and quality of life improved after treatment[22,33,36].

Other studies of people with lung cancer described determinants associated with worse health-related quality of life. Poor sleep quality, sedentary behaviour, inability to perform work or daily activities and pursuing leisure-time activities, loneliness and smoking were all associated with poor health-related quality of life[30,33,35,37-41]. Certain demographic factors were associated with poor health-related quality of life, including older age, single, low income or financial toxicity, living on a disability pension [26,33,42]. It should be noted that old age was both associated positively and negatively with health-related quality of life. [26,34]. Health-related quality of life is worse during treatment and following disease progression[21,33,39,43-46], and symptoms and side effects including severe symptoms, anxiety and or depression, lung cancer stigma, fatigue, breathlessness, and pain[18-22,33,37,41,47-51]-fatigue[20,30,38,39,52].

In terms of subgroups, one study reported no differences in health-related quality of life between men and women[53], and no difference between those with and without COPD[54]. In this PEEK study, males had better scores for physical function and pain compared to females, and those with higher socioeconomic status had better scores for energy and fatigue compared to those with mid to low socioeconomic status.

Key points

- **Physical health and emotional problems interfered with work and other activities for participants in this study.**
- **High prevalence of anxiety, depression**

Risks and Symptoms

When I started the Osimertinib, it was a few weeks in and I actually did get relief from some symptoms that I hadn't realized were lung cancer, like a really minor cough that I hadn't even thought about until I got the diagnosis and went, "Oh, that does come." It totally went and I actually thought then it was working a few weeks in. Physical things, I think that was it. I didn't have many physical symptoms really, so I wasn't expecting to feel much, I was more expecting to see it on a scan.
Participant 020_2023AULUC

In the PEEK study, information about symptoms and quality of life from symptoms before diagnosis are collected in the online questionnaire, and in the interview, participants talk about the symptoms that actually lead them to get a diagnosis. Taken together, we can get an insight into the number and type of symptoms participants get, the symptoms that impact quality of life, and the symptoms that prompt medical attention.

The risk factors for lung cancer include smoking tobacco, alcohol consumption, workplace or occupational exposure, ionising radiation, air pollution, passive smoking, family history of lung cancer, lung disease and medical/pharmaceutical medicines [1,55]. Symptoms of lung cancer include persistent cough, coughing up blood (haemoptysis), chest pain, unexplained weight-loss, loss of appetite, shortness of breath, fatigue, ongoing chest infections, and some patients will present with symptoms from metastatic disease such as bone pain, jaundice or abdominal pain[56,57].

In other studies, symptoms at diagnosis were described including unspecific, flu-like symptoms, fatigue, disturbed sleep, distress, pain, shortness of breath, sadness, and drowsiness, and those with advanced disease had more severe symptoms[58,59]. PEEK participants had an average of three symptoms before diagnosis, most commonly fatigue, shortness of breath, coughing blood, shoulder or back pain, and a new persistent cough. Participants in this PEEK study also described having chest pain, recurring bronchitis or pneumonia, hoarseness, loss or appetite and unexplained weight loss.

Diagnostic pathway

One day I think I blew my nose and there may have been blood in it or something. I went back down to my GP for something completely-- I think it was the iron, and I said, "Oh, actually, also, I did cough up and there was a bit of blood, but I've got a cold, so I'm not worried about it." She said, "Oh, okay." She said, "Can you just go next door to the X-ray people, the radiologist, and just have a chest X-ray?"I went straight next door and got straight in, and the radiologist said to me, "Go straight back to your doctor."
Participant 019_2023AULUC

In other studies, the diagnostic pathway was delayed due to lung cancer not considered in those that are non-smokers and in otherwise good health[60], some were misdiagnosed because of non-specific flu-like symptoms[59]. From a patient perspective, diagnosis was delayed due to fear of what they may be diagnosed with, a lack of knowledge about screening, and having unspecific symptoms[59].

In this PEEK study, more than half the participants noticed symptoms and sought medical attention soon after. Delays in diagnosis were from having symptoms misattributed to aging or other less serious conditions, in addition, approximately a quarter had a complex diagnostic pathway where they saw multiple specialists before receiving a diagnosis.

Understanding and knowledge

Not a lot, to be honest. There is a public perception that is related to smoking and I've never been a smoker. I know non-smokers would get it too. I really didn't have much information about lung cancer and would've never considered that that was a possibility for me. I couldn't understand how it could be at my age with my level of fitness at the time. It wouldn't have been comprehensible to consider lung cancer as a diagnosis.
Participant 005_2023AULUC

Knowledge about chronic disease before diagnosis varies between individuals. Some will gain information from family and friends with the condition, though it can result in misconceptions and misunderstandings[61,62]. Some people will seek out information about a possible diagnosis, or explore the reasons for symptoms, before receiving a final diagnosis[63,64]others, especially those who have symptoms for long periods before diagnosis, will gain information in terms of how to live with or adapt to symptoms they experience[65]. For some people, the first time they have heard of their chronic condition is when they are diagnosed[64]. At the time of diagnosis, it may be useful for the healthcare professional to talk about how much a patient knows about a condition so that appropriate information can be given, and correct misconceptions[64]

In other studies, understanding of lung cancer at diagnosis was described in terms of risk factors, those that were non-smokers were unable to believe diagnosis, and others attributed their lung cancer to smoking, a history or cancer or a family history of cancer[59,66]. In this PEEK study, the majority of participants had little to no knowledge of lung cancer, for those that had knowledge did so because of a family history or having a professional background.

Biomarkers or genetic markers

It's a stage 4. They don't really give you a timeline. My oncologist said, "You can live the years and hopefully, there'll be new drugs coming out all the time." I think the prognosis there was a bit overhyped because I don't think there's that many clinical trials or good tablets for EGFR at the moment, but he didn't give me any timeframe. He just said, Years; I can keep you well for years."
Participant 004_2023AULUC

Biomarkers can be used for diagnosis, to monitor a condition, to predict response to therapy, or to predict disease course.

The use of biomarkers in the treatment planning of lung cancer has three main objectives, to differentiate between histological types, to determine therapeutic outcomes and to predict treatment outcomes [67-69]. However, pathologists are advised to use the minimal number of markers to preserve tissue for molecular testing and potentially avoid the need for repeat biopsies [69]. The Royal college of Pathologists Australasia report that TTF-1, Napsin A, CK5/6 and p63 are among the most reliable markers for distinguishing between squamous cell carcinoma and adenocarcinoma, which has treatment implications [69-71]. The profile of thyroid transcription factor-1 (TTF-1), cytokeratin 7 and 20 (CK7 and CK20) can distinguish between primary and metastatic lung[72].

The most common mutations of NSCLC that have therapeutic implications are the epidermal growth factor receptor (EGFR) mutation and ALK (anaplastic lymphoma kinase) translocation[73]. The EGFR mutation occurs in a small subset of patients, it is susceptible to EGFR tyrosine kinase inhibitors (EGFR-TKIs) such as erlotinib, gefitinib and afatininb[74,75]. The ALK translocation also occurs in a small subset of those diagnosed with adenocarcinoma, usually in those that had never smoked or were light smokers, in addition, it usually does not occur with the EGFR mutation[76,77]. The ALK translocation are susceptible to ALK-targeted therapies such as crizotinib, cerltinib and alectinib[69,78].

Mutations in KRAS (Kirsten rat sarcoma viral oncogene) are the most common mutations found, these are mostly in adenocarcinomas and in more smokers compared to those that have never smoked and does not occur with the EGFR mutation[79-82]. The KRAS mutation is associated with poor prognosis and predicts resistance to EGFR-inhibitors and chemotherapy[81-83]. High expression of ERCC1 protein (enzyme excision repair cross complementation group 1) is associated with poor prognosis and predicts resistance to platinum therapy[84,85], and low expression of RRM1 (ribonucleotide reductase catalytic subunit M1) is associated with good prognosis with gemcitabine/platinum therapy[84]. High expression of TS (thymidylate synthase) is associated with a poor response to chemotherapy drugs such as flurouracil[86].

In this PEEK study, just over half of the participants were able to report their status for at least one biomarker, this corresponds with the number of participants that reported having had biomarker testing. However, less than half of the participants recalled having discussed biomarkers in terms of their treatment plans.

Support at diagnosis

Other studies described that people with lung cancer described being disoriented and confused at diagnosis, and those that had a good understanding of their prognosis had poor emotional well-being demonstrating a need for support at diagnosis[18,87,88]. In this PEEK study, almost 70% the participants described having no support at diagnosis, with only 20% stating that they had adequate support.

Understanding of prognosis

The surgeon said that they got all the cancer-- I had a lobectomy in the right lung, and he said that they got all the cancer that was there. There is no chemotherapy or radiotherapy. At the moment, I think I'm diagnosed as NED, no evidence of disease. I have to have a CT scan every six months and see the surgeon for the next five years.
Participant 010_2023AULUC

In other studies, people with advanced cancer often thought the intention of treatment was to cure cancer or that their cancer was curable, and that oncological therapy prolongs life while palliative care does not[47,88,89]. Three studies described that those that had a better understanding of their prognosis had worse emotional well-being[18,88,90]. Likewise in this PEEK study, the there was some lack of clarity in prognosis. More than a third of participants were uncertain about their prognosis, and, despite over half of the participants having advanced lung cancer, only a quarter of participants described prognosis as poor or terminal. Prognosis was also described in terms of no evidence of disease or a specific timeframe.

Key points

- **Lack of support during diagnostic period**
- **Poor knowledge of condition at diagnosis**
- **Uncertainty around prognosis**

Decision making

The decision-making process in healthcare is an important component in care of chronic or serious illness[91]. Knowledge of prognosis, treatment options, symptom management, and how treatments are administered are important aspects of a person's ability to make decisions about their healthcare[92,93], highlighting the importance of healthcare professional communication. In addition, the role of family members in decision making is important, with many making decisions following consultation with family[94].

Goals of treatment and decision-making

Look, the respiratory specialist recommended that I have surgery because it was quite small the lesion but it was growing. He did say that obviously, I didn't have to have it done. If opted to, I could just have regular scans to monitor it for a while, but that wasn't his recommendation.
Participant 010_2023AULUC

Confidence to take part in decision-making is increased by knowledge, being prepared with relevant questions for their consultation, and summaries of previous consultations and results[95,96]. A number of studies described that people with lung cancer want to be involved in decision making[97-99]. Having sufficient information was described as an important factor to support decision making[97-99]. In this PEEK study, while multiple treatments were presented to more than 60% of participants, only about a third of participated in treatment decision making. In another study, people with lung cancer, about a third described that their surgeon recommended multiple types of treatment and that the surgeon described reasons for particular treatment preferences[22]. Almost a third got a second opinion about their treatment[22].

Changes in decision making

Basically, I was a bit in a state of panic where I didn't think very clearly. Plus, I have never dealt with health providers previously and I had this naive approach that they know best. I was not able to drive my care. I didn't have enough knowledge. Now I can.
Participant 023_2023AULUC

In this PEEK study, equal numbers changed decision making over time as those that didn't. Changes in decision making were due to becoming more informed and assertive. In contrast, another study, people with lung cancer most described that they had no change in treatment goals, for those that did change their goals, this was related to lowered expectations of treatment outcomes[100].

Treatment goals and considerations in decision making

Look, there's a few. Very much my relationship, the impact it's going to have on the adult, but my adult children and my partner. It's got to be manageable for them and not distressing for them what I do as well. Very much my cognitive functioning. That is one thing I'm very scared of losing, and quality of life. Quality of life is to me more important to be enjoying life and participating in a way that I want to, even if it's limited, but in a way that I find comfortable rather than just being alive for being alive sake.
Participant 020_2023AULUC

In other studies, people with lung cancer described considering side effects when making treatment decisions, in particular severity, type (pain, fatigue, shortness of breath), they described weighing up the risk of side effects with treatment benefit, and had expectations that immunotherapy would have fewer and less intense side effects[99,101-103]. Others considered their quality of life, maintaining physical function and independence, reaching an important personal goal, and being around for family[23,99-101,103-106]. Some described disease related goals such as survival, prevent recurrence, decrease tumour size, cure, or to be cancer free[23,99,102,104,105]. There were some that took the advice of their doctor, or felt that there were no choices available to them[23,103]. Others had preconceptions about poor success from cancer treatments after witnessing family or friends, others anticipated new therapies to become available and were wary of chemotherapy[23,66]. Finally, cultural beliefs, family needs, and availability of support networks were also reported as considerations when making treatment decisions[23,99,103]. These treatment goals were similar to those described by participants in this PEEK study, participants in this study also described considering cost and their own research.

Key points

- **Lack of participation in decision making**
- **Efficacy and side effects are an important treatment consideration and treatment goal**

Treatment and healthcare provision

In this PEEK study, to get an insight healthcare access, information about access to healthcare professionals, health insurance, health system, and financial consequences from having lung cancer are collected.

Access to health professionals

In terms of access to healthcare, one study described that people with lung cancer faced barriers to accessing psychosocial services[107]. Similarly in this PEEK study, only a third described using counselling or psychological support. Long term survivors described bureaucratic barriers to accessing services and entitlements because they were both terminal and continuing to live[87]. A study of advanced lung cancer described that less than a third had been seen by palliative care[108].

Affordability of healthcare

The cost of financial loss? I haven't been able to work in the same capacity as I did before. I've not been able to work full-time. I had to stop my career and do a job that was less demanding and challenging. The impact of financial income has been massive. I have to pay a few $100, probably $1,500 a year on scans. Car parking alone, every time you to [unintelligible] get a car parking. The biggest impact is the job loss.
Participant 007_2023AULUC

Almost half of the Australian population have private health insurance with hospital cover[109]. This can be used to partially or completely fund stays in public or private hospitals. Between 2006 and 2016, the proportion of private health care funded hospitalisations in public hospitals rose from about 8% to 14%[109]. In this PEEK study, a higher proportion had private health insurance compared to the Australian population.

In other studies, people with lung cancer described the cost of having lung cancer in terms of loss of income from either changing work conditions or early retirement[23,110,111]. A study conducted in Canada reported out of pocket costs of between $1000 to $5000 CAD[112], and other study in America described people with lung cancer struggling with decisions about work and finance while having an uncertain life expectancy[113]. In this PEEK study, participants did not struggle to pay for essential services or treatments and appointments. However, they did have out of pocket expenses, most commonly under $100 a month. Expenses were from treatment, scans and diagnostic tests, and costs of traveling to appointments. In addition, many had to make changes to their work status in particular reducing hours and quitting their job, the cost to those that had a reduced income due to lung cancer was in the thousands per month.

Key points

- **Healthcare was affordable but costs occurred from reduced income, treatment, scans and diagnostic tests, and costs of traveling to appointments**
- **Very few had counselling or psychological support despite high rates of anxiety and depression**

Treatment

The Australian Optimal Care Pathways, recommend that treatment planning be discussed by a MDT, and that clinical trials should be considered if available and appropriate [57]. The intent of treatment must be established, whether curative, to improve quality of life without expectation of cure, or symptom control [57]. Surgery is if offered for diagnostic purposes, for curative intent in early NSCLC and for later stages palliative symptom control [57]. Radiotherapy which may be in combination with systemic therapies may be offered for NSCLC that are not suitable for surgery, radiation may also be offered for palliative care. [57]

Treatment schedules for lung cancer are available on the NSW Government eviQ website (eviq.org.au), it lists combination therapies of chemotherapies, immunotherapies and targeted therapies, a summary of treatments is present in Table x. The treatments for NSCLC are generally for stage III and IV, The chemotherapy drugs include carboplatin, cisplatin, docetaxel, etoposide, gemcitabine, paclitaxel, pemetrexed, vinorelbine. The immunotherapy drugs include atezolizumab, bevacizumab, cemiplimab, durvalumab, ipilimumab, nivolumab, and pembrolizumab. The targeted therapies include afatinib, alectinib, brigatinib, entrectinib, lorlatinib, Osimertinib, sotorasib, and tepotinib.

In this Peek study, 41% had surgery, 44.44% had chemotherapy, 56% had immunotherapy, and 37% had radiotherapy. The most common immunotherapies used were Tagrisso and Alectinib, consistent with the advanced stages of the participants.

Non small cell lung cancer stage	Treatment
Stage I-III	Osimertinib
Stage II-III	Cisplatin and pemetrexed
Stage II-III	Cisplatin and vinorelbine
Stage III	Carboplatin and paclitaxel chemoradiation
Stage III	Cisplatin and etoposide chemoradiation
Stage III	Durvalumab
Stage III-IV	Atezolizumab
Stage III-IV	Brigatinib
Stage III-IV	Carboplatin and docetaxel
Stage III-IV	Carboplatin and gemcitabine
Stage III-IV	Carboplatin and paclitaxel
Stage III-IV	Carboplatin and pemetrexed
Stage III-IV	Carboplatin and vinorelbine
Stage III-IV	Cemiplimab
Stage III-IV	Cisplatin and gemcitabine
Stage III-IV	Entrectinib
Stage III-IV	Lorlatinib
Stage III-IV	Nivolumab
Stage III-IV	Tagrisso
Stage III-IV	Sotorasib
Stage III-IV	Tepotinib
Stage III-IV	Alectinib
Stage III-IV or recurrent	Pembrolizumab
Stage IV	Afatinib
Stage IV	Carboplatin paclitaxel ipilimumab and nivolumab
Stage IV	Carboplatin, paclitaxel and pembrolizumab
Stage IV	Carboplatin, pemetrexed and pembrolizumab
Stage IV	Cisplatin, pemetrexed and pembrolizumab
Stage IV	Docetaxel
Stage IV	Gemcitabine
Stage IV	Vinorelbine
Stage IV	Carboplatin paclitaxel atezolizumab and bevacizumab
Stage IV	Pemetrexed

Clinical Trials

Clinical trials are essential for development of new treatments. The benefits to participants include access to new treatments, an active role in healthcare, and closer monitoring of health condition. The risks to participants include new treatment may not be as effective, and side effects. In one study, people with lung cancer described reasons for participating in a clinical trial. They described hoping to maintain or regain quality of life, hope for the tumour shrinking or stop growing, hope for a longer life, and hope for a cure[103].

A search of the Australian New Zealand Clinical Trials Registry was conducted on February 6 2023 The search included any study that included participants with lung cancer, was conducted in Australia, and was open to recruitment in the last five years. A total of 74 studies were identified that had a target recruitment of between 8 and 1383 participants (median=230), there were 68 studies that were international, and 6 studies that were conducted exclusively with in Australia. There were 48 studies that included exclusively lung cancer participants, and 26 that included lung cancer participants and participants with other conditions. The most common types of studies were treatment studies (n=70), two studies were observational, and two diagnostic or prognostic studies.

There were 55 studies conducted in Victoria, 53 studies in New South Wales, 25 in Queensland, 19 in Western Australia, 13 in South Australia, and 2 in Tasmania. There were no studies conducted in the Australian Capital Territory, or the Northern Territory.

In this PEEK study, less than 40% had discussions about clinical trials with their treatment team, and two participants had taken part in a clinical trial.

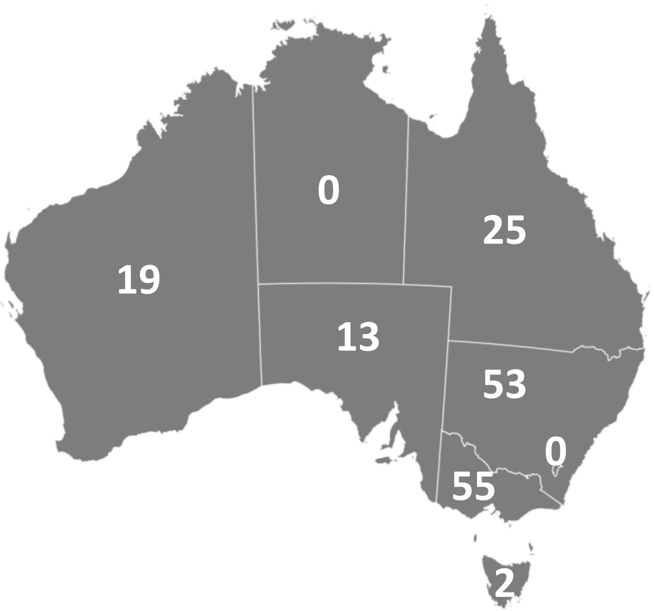


Figure 12.1: Distribution of clinical trials for lung cancer in Australia 2017-2022

Patient treatment preferences

> *Mild to me is really what I've got where I get a little bit of discomfort. Yes, it might at times impact a little on what I do because of pain or just feeling that I don't want to go out socially, but not often. It would be severe to me if it meant that I couldn't function in my day-to-day life, do what I normally do.*
> *Participant 020_2023AULUC*

Clinical guidelines that are aligned to patient preferences are more likely to be used and lead to higher rates of patient compliance[114-116]. Patient preferences and priorities vary across different health issues, preferences are associated with health care service satisfaction, they refer to the perspectives, values or priorities related to health and health care, including opinions on risks and benefits, the impact on their health and lifestyle[114,117].

To help inform patient preferences in the lung cancer community, participants in this PEEK study discussed side effects, treatment administration, adherence to treatment. In this PEEK study, participants described the most important side effects that they wanted to manage were pain, nausea and vomiting and, tiredness and fatigue. Mild side effects were described by providing examples, or as side effects that are self-managed or do not interfere with life. Examples of specific mild side effects included pain, rash, gastrointestinal distress, fatigue and being short of breath. In a similar way, participants describe severe side effects, broadly as those that impact everyday life, or using the examples of shortness of breath, pain, and the emotional or mental impact of the condition. It is interesting to note that participants described, shortness of breath and pain as both mild and severe side effects. Discussing both a list of side effects and the potential impact on daily life may be important for treatment decision making.

In other studies, people with lung cancer described side effects using examples such as fatigue, sleep disruption, pain, depression, changes in appetite[23,107,118]. They also described them in terms on impact on daily activities, physical function or quality of life[107,118,119]. Some described the timing of side effects, that they were worst at diagnosis due to stress and during treatment, and that some side effects remained well past the completion of treatment[23,118,119]. Some described the differences of side effects between treatments, with immunotherapy having fewer and less intense side effects compared to chemotherapy and radiotherapy[23,108,120]. People with lung cancer found it difficult to distinguish between side effects of treatment and symptoms of lung cancer, they also found it difficult to know when to seek help or disclose side effects to their doctor[120,121].

Adherence to treatment

It's a bit of a hypothetical, but my approach would be to discuss that very point with my treatment team and say, "How often are you expecting to see me and what should I do if I have some concerns between those sessions?" That's the discussion I had with my first treatment. I'll start this, what should I expect and what do I do if something unexpected happens? That's part of why I like the team.
Participant 022_2023AULUC

In this PEEK study, participants had very good adherence to treatment according to the scores from the Partners in Health Adherence to Treatment scale. They described that they most commonly described not giving up on any treatment. Others in this PEEK study described adhering to treatment while side effects were tolerable, and according to the advice of their clinician. In other studies, people with lung cancer described that they had good adherence to treatment, however, doctors described that fewer patients had good adherence[23,122]. Some barriers to adherence include poor access to medication, lower education levels, nicotine dependence, poor physical function, poor emotional function, poor social function, and financial difficulties[122,123]. In addition side effects were a barrier to adherence to treatment, in particular fatigue, pain, appetite loss[123].

In this PEEK study, participants described needing to have evidence of stable disease or no progression, or reduction in physical signs, symptoms, and side effects to know that treatment had worked. In one study, people with lung cancer described their definition of a treatment that had worked, this included having an improved quality of life, a treatment that shrinks tumour or stops it growing, and treatments that cure cancer[103].

Self-management

Self-management of chronic disease encompasses the tasks that an individual must do to live with their condition. Self-management is supported by education, support, and healthcare interventions. It includes regular review of problems and progress, setting goals, and providing support for problem solving[124]. Components of self-management include information, activation and collaboration[124].

Information is a key component of health self-management[125,126]. The types of information that help with self-management includes information about the condition, prognosis, what to expect, information about how to conduct activities of daily living with the condition, and information about lifestyle factors that can help with disease management[125,126].

Access to information

I actually like to talk to the oncologist to get a general overview and then I love being referred to something online because it's always there. I don't want to find that bit of paper that they handed me with it on and I can always refer back to it because you don't take everything in at a consultation. It's great to have a reliable source that they will say, go and get this information here that I can refer back to. Online for me is really handy.
Participant 020_2023AULUC

One other study described that information about physical well-being and functioning was most frequently discussed with healthcare professionals and end of life care was discussed least often[111]. In this PEEK study, the most commonly given information from healthcare professionals were about treatment options, disease cause, and physical activity.

People with lung cancer described getting preferring information from their doctor, having telephone support, the internet and from family and friends[22,59,118]. Reasons for verbal information preference was that they had too much written information, reasons for written was that they wanted information to revisit if they forgot verbal information [118]. Others described that they were unable to use computers and smart phones, and that a variety of resources are need to make sure everyone has access to information[118].

In contrast, participants in this PEEK study, participants described getting information from the internet, health charities, social media, medical journals, newsletters and pamphlets, and conferences and webinars. They most commonly had a preference for talking to someone plus online information. The preference for talking to someone was because they were able to ask questions, and the online information was described as accessible, and being able to digest information at their own pace.

In other studies, people with lung cancer described wanting information right from the beginning, however, at this time the consultations are rapid, they are in shock and have no knowledge about their condition, others describe information before treatment as useful, and that they need more detailed information the longer they have been diagnosed[120,127]. Similarly, in this PEEK study, participants had preferences for information at different times, most often right from the beginning at diagnosis and when they have been given results from treatments or follow up scans. Some participants in this PEEK study felt they were more able digest information after treatment or after the shock of diagnosis, while others wanted information to be given continuously.

I think probably post-treatment once because in terms of emergency, your brain is not, actually it's a flight or fight. It's this survival thing where you have this tunnel vision and the tunnel vision is, okay, you are the specialist. I've got that. What do I need? If you frame it into the perspective that I was trusting the medical system and the health system, which I've lost total trust in now, so at the time the last thing I wanted, it was just throw me a hand, save me from that, and do whatever you think. Once you do the first treatment, you finish the first treatment. After I think you've done something, at least it's action. Then in the time where you finished the treatment that you've been given, then the emergency has passed because you've done whatever you had to do at the time. That's when you start accumulating information and integrating information. I certainly don't need it at the beginning.
Participant 024_2023AULUC

Helpfulness of information

People with lung cancer have described that general information about lung cancer is helpful, as is what to expect in terms of side effects and prognosis, information specific to their type of lung cancer, treatment, and healthcare navigation[22,23,66,127]. Information that helped people with lung cancer self-manage was helpful, in particular information about how to self-manage side effects and symptoms, in information about support groups[22,23]. In addition, people with lung cancer wanted information in plain language, they reported that nurses were helpful as they made information understandable, and they appreciated follow up calls where healthcare professionals made sure that they understood information[98,113].

In this PEEK study, participants described that other people's experiences were most helpful. Others found talking to their doctor, hearing about what to expect, scientific information and information from health charities as being helpful. Information sources that were not credible or lacked evidence were not helpful, they also described worse case scenarios as not helpful, and at times information from healthcare professionals was not helpful. Some described that no information was not helpful, or that they were confident in deciding whether information was helpful or not. In other studies, people with lung cancer described contradictory information, unanswered questions, an incomplete information about what to expect as not being helpful[22,119,120].

Activation (skills and knowledge)

Patient activation is the skills, knowledge, and confidence that a person has to manage their health and care; and is a key component to health self-management. Components of patient activation are support for treatment adherence and attendance at medical appointments, action plans to respond to signs and symptoms, monitoring and recording physiological measures to share with healthcare professionals, and psychological strategies such as problem solving and goal setting.

Patient activation is measured in the PEEK study using the Partners in Health questionnaire[128]. In this PEEK study, participants had very good knowledge about their condition and treatments, they were good at coping with their condition, were very good at recognising and managing symptoms, and were very good adhering to treatment. There were no significant differences between subgroups.

Communication and collaboration

Collaboration is an important part of health self-management, the components of collaboration include healthcare communication, details for available information, psychosocial and financial support [125,126] Communication between healthcare professionals and patients can impact the treatment adherence, self-management, health outcomes, and patient satisfaction[129-132].

An expert panel identified the fundamental elements of healthcare communication that encourages a caring, trusting relationship for patient and healthcare professional that enables communication, information sharing, and decision-making[133].

Building a relationship with patient, families and support networks is fundamental to establishing good communication[133]. Healthcare professionals should encourage discussion with patients to understand their concerns, actively listen to patients to gather information using questions then summarising to ensure understanding[133]. It is important for healthcare professionals to understand the patient's perspective and to be sympathetic to their race, culture, beliefs, and concerns. It is important to share information using language that the patient can understand, encourage questions and make sure that the patient understands[133]. The healthcare professional should encourage patient participation in decision-making, agree on problems, check for willingness to comply with treatment and inform patient about any available support and resources[133]. Finally, the healthcare professional should provide closure, this is to summarise and confirm agreement with treatment plan and discuss follow up.

Communication and collaboration with healthcare professionals was measured in this PEEK study by the Care Coordination questionnaire[134]. The participants in this study experienced good quality of care, and moderate coordination of care. They had a moderate ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals. No differences by subgroups were observed.

In other studies, people with lung cancer described that care coordination was good when different departments worked together to coordination care[135]. However, when coordination between departments failed, people with lung cancer experienced treatment gaps, and felt that they had to take on coordination themselves[135]. Others described poor coordination due to long waiting times to get appointments, long waiting times at the appointment, and delays in getting results[120]. One study of advanced lung cancer described a lack of referral to palliative care and unmet needs for pain and symptom control, support systems, goals of care discussions, support for anxiety and depression[136]

Communication with healthcare professionals

I think the initial beautiful diagram I got from the first oncologist, it was fantastic. I remember going to her initially and then she did tests, and then she couldn't see me. I think it was 10 days later, and I just rang her up on day seven, and I said, "I'm really sorry." I said, "I cannot wait another day." She said, "Come in and see me tomorrow." She saw me and wrote down the results, and then she said, "Look, I haven't got all the tests back, however, this is where we're going." Participant 019_2023AULUC

In this PEEK study, participants described that overall communication with healthcare professionals was good, some with the exception of one or two occasions. Good communication was described as holistic, with two-way, comprehensive, and supportive conversations. In other studies, people with lung cancer described good communication as sensitive, and patient centred, transparent[59,89]. They described the importance of having enough time in appointments, building trust, and the healthcare professional having regard for the patient's decision making abilities[59,89,120].

Approximately a third of participants in this PEEK study described poor communication with healthcare professionals. This was mostly due to conversations that were one-way and dismissive. Poor communication was described in other studies by people with lung cancer. Poor communication from healthcare professionals was described as judgmental or aggressive, having rushed appointments, and incomplete or delayed communication[59,120]:[137]. In addition, they described a lack of holistic care and poor communication between healthcare professionals[59,120,137]. Some noted that their inexperience with medical appointments made it difficult to know what questions they should ask their healthcare professionals[119]. Poor communication had an impact on overall wellbeing, satisfaction, trust, and feeling secure[59,120]

Care and support

Yes. Definitely I feel supported by the people in the groups, the online, the Facebook one, and the HOSPITAL group. People will reach out if they think you're not doing well. Yes, definitely supported there. The Peer Connect program through Lung Foundation Australia. I am a primary peer there, so I will contact people, but it works both ways, even though I do the primary calling and it works both ways. That back and forth with someone who's got the same lived experience is supportive.
Participant 020_2023AULUC

In this PEEK study participants were asked what care and support they had received since diagnosis. Nearly a third reported that they did not receive any formal support, while almost 20% described that they did not seek or need any support. For those that did receive support, it was primarily from charities or from peer support. However, when asked about maintaining health, a quarter of participants described that family and friends were important to maintain mental health, and approximately 15% said family and friends were important in maintaining health in general.

In other studies, people with lung cancer described getting support from family and friends, support groups, religious communities, health charities, healthcare professionals, and health services[23,26,98,118,138]. The types of support described were help with domestic tasks, help with showering and dressing, and emotional support[23]. One study described that people with lung cancer that live with their own family are better supported than single people, also those with a higher income had better social support[26]. Another study described that some people with lung cancer decline psychological support as they either do not feel it is needed or do not want additional healthcare appointments[47]. People with advanced lung cancer described not having enough support and attributed this to doing well medically[113]

Key points

- **Information from other people with lung cancer, and information about what to expect was helpful**
- **People with lung cancer need information at different times; after the shock or diagnosis and initial treatments, and after results of check up scans and tests**

Anxiety associated with condition

The rates of depression and anxiety are higher in people with chronic conditions compared to the general population. In a meta-analysis of 20 qualitative studies, it was reported that people with chronic conditions experienced anxiety or depression as either as independent of their chronic condition or as a result of, or inter-related with the chronic disease, usually however, anxiety and depression develops as a consequence of being diagnosed with a chronic disease[139].

In this PEEK study, anxiety associated with lung cancer was measured by the fear of progression questionnaire[140]. The participants in this PEEK study had moderate levels of anxiety in relation to their condition, those with metastatic disease had more anxiety compared to those with non-metastatic disease. Participants were most anxious before medical appointments and examinations, they were worried about not being able to do hobbies in the future due to their condition getting worse, and they worried about what will happen to their families if any thing happens to them.

In other studies, people with lung cancer described fear and anxiety related to their condition. They had anxiety while waiting for results, were worried about being treatable, were distressed before treatment and surgery, and worried about the effectiveness and side effects of treatments[23,108,110,141]. Some described distress from symptoms, in particular pain, fatigue, cough and sleep problems[108,141,142]. Others described worry about the future, worry about prognosis, and having a fear of recurrence[88,107,110,138]. One study reported that 90% of participants with lung cancer had elevated distress levels[47]

Quality of life

Yes, definitely. We were staring potential death in the face. It was pretty confronting. I'd like to think that there have been positives that have come out of that in terms of appreciating each other and probably stronger relationships as a result of it, which is obviously a great outcome. It's certainly been a tough time for everyone in the family. More extended family as well, like my mother and sister back in COUNTRY. It's been tough for everyone, particularly because it was COVID as well.
Participant 021_2023AULUC

Most participants this PEEK study described that lung cancer had a negative impact on their quality of life. This was primarily due to the emotional strain on themselves and on their family, but also from reduced capacity of physical activity, financial strain and reduced interaction. Some described a positive impact, mostly from their condition bringing people together and experiencing supportive relationships.

In other studies, people with lung cancer described their quality of life was affected by symptoms and side effects, in particular shortness of breath, pain and fatigue[58,119]. In addition, physical limitations and changes in physical appearances had a negative impact on quality of life[23,138]. Others described the negative impact on quality of life of their insecurities about the future, having mental health issues, their awareness of own mortality, and feeling powerless [89,110,113,138]. Some described that lung cancer takes over their life, the changes that they had to make to work and general activities, having a reduced desire to socialise and the life style changes they needed to make[23,58,89]. Finally, the fear of recurrence or progression, having a recurrence or progression or having to change treatment due to progression also had a negative impact on quality of life[87]. However, quality of life improvements occurred when treatment was finished, when feeling physically better and regaining aspects of pre-cancer life[87].

Activities for mental health

PARTICIPANT: Yes, I do. I go for that walk every day and have a moment to try going to the carers group. I've got someone that comes to the house to look after the girls. My girls are still very young, they're 11 and 12, [crosstalk] 13 now. Then I started trying to-- you just caught me, I'll go to hydro. I use the girls' NDIS so I can leave the house. Now my husband works from home on Friday, so I can go off and do shopping. I can grab a coffee or something on a Friday
Participant 027_2023AULUC

In this PEEK study, most participants experienced a negative impact on their mental health. To manage their mental health, participants commonly described the importance of family and friends, the importance of physical activity, mindfulness, and remaining social and pursuing hobbies. In other studies, people with lung cancer described maintaining their mental health in similar ways to PEEK participants. Some described using positive thinking and mindfulness, not letting cancer dictate their entire life, acceptance of their condition, and the importance of celebrating small achievements. [32,87,89,118]. Others described that undergoing treatment gives them hope and helps with their mental health, also being physically active and exercising, taking holidays, enjoying hobbies, and generally keeping busy [23,89,98,118]. In addition, people with lung cancer have described the importance of family and friends, and of socialising in managing their mental health[89,98].

Activities for general health

I need to keep fit, and I do yoga each week to keep my body moving and [unintelligible] twice a week. I get, like I said before, weekly massages and acupuncture. All of those things keep my body functioning and my lungs clear so that I don't get chest infections again.
Participant 007_2023AULUC

In this PEEK study, participants described activities for general health which included physical exercise or being physically active, and understanding their limitations. Other activities included complying with treatment or management , maintaining a healthy diet, maintaining a normal routine, self care including more rest, accepting help, pacing, socialising with friends and family, being organised and planning ahead, and mindfulness or meditation.

People with lung cancer have described ways that they maintain health. Some describe maintaining routines, taking initiative for their health, actively seeking information and staying informed, and being physically active [28,89,118]. Others described the importance of acknowledging their own limitations and adapting their daily activities, accepting help from others, and eating more take-ways or prepared foods [23,89,118].

Impact on relationships

Yes definitely. Definitely. You realize who is actually supportive and who's gutless and runs away. You end up with a very small bubble around you of people that actually care about you, but after a year you realize that that's all you need. You don't need these other people that are cowards, that can't say the right thing. You learn that you just don't need them, and everything's better with just a small group of people that support you.
Participant 004_2023AULUC

Participants in this PEEK study described a mixture of both positive and negative impacts of lung cancer on their relationships. Positive impacts were that relationships were strengthened, and that people were well-meaning and supportive. Negative impacts were from people not knowing what to say or do and withdrawing from relationships, and that the dynamics of relationships changed due to anxiety, exacerbations and/or physical limitations of condition.

In other studies, people with lung cancer described impact to relationships due to their diagnosis in similar ways to this PEEK population. The impact to their family was described, such as a change in their role within the family, Sadness of leaving behind partner and children, and the emotional stress on their family[89,119,138]. Some described that their relationships with family became closer, others that they were stressed by the unwanted advice from families or that they withheld their diagnosis from family and friends [23,118]. People with lung cancer described re-evaluating friendships, keeping only positive and important friends and family, and rejecting people who were negative about their situation, others described that people were often well-meaning with advice however the advice was not wanted[87,89,119]. The changes in ability to socialise and to take part in physical activities had an effect on relationships, leaving some feeling socially isolated[118,119].

Burden on family

Oh, God, yes. Yes, definitely. Although I'm no physical burden to them it's an emotional one and it's that psychological thing that you try and protect the people you love from but I know it had an impact on them. I do feel I'm concerned about the future impact as the disease progresses and need becomes more physical issue. I think it has had an emotional burden on them, of course. At the moment, there's no physical burden because I totally [unintelligible] gosh I'm just like I was pre-diagnosis, I don't feel any different. I'm not doing anything particularly different.
Participant 020_2023AULUC

Almost all participants described that they were at some time a burden on their family, and this was primarily due to the mental and emotional strain placed on their family. In other studies, people with lung cancer also descried the emotional burden on families, in addition they described the burden of the demands on their time, additional tasks and duties they take on, financial burden and having to make changes to work status[23,119,143,144].

Key points

- **Lung cancer had a negative effect on quality of life and mental health**
- **Emotional strain had a negative impact on quality of life, relationships, and was the most common cause of burden to family**

Future expectations

Future treatment

I suspect what we'll see and what I hope that we see quickly is just improvement in the targeted therapy, type of therapy that has less side effects, much more specific, maybe doesn't build up resistance. A lot of research in that area. It's huge isn't it that whole area of research and what's coming out all over the place?
Participant 025_2023AULUC

Participants in this PEEK study described their expectations of future treatments are. The most common responses were that future treatment will be more affordable, and will involve more clinical trials and new treatments. Other expectations of future treatments included treatments with fewer or less intense side effects and more discussion about side effects, having choice and transparency in relation to treatment options, more effective targeted treatments, treatments that are easier to administer or can be given home, and treatments that offer improvements in quality of life. In contrast, other studies, people with lung cancer described what expectations they had for future treatment to be more holistic, that appointments were easier to schedule or reschedule, and that healthcare professionals took into account having to travel long distances when scheduling and organizing appointments[23,59,113,119,120].

Future information

I don't know whether it's not available because people don't like to hear it. I would like to know what is going to happen. I know that's a hard question because things probably are different, but there's got to be an average of what happened, what can happen, or what happens next.
Participant 013_2023AULUC

Participants in this PEEK study described their expectations for future information is presented or topics that they felt needed more information. The most common responses were that future information will be more accessible and easy to find, and that they will be able talk to or access to a health professional.

Other expectations of future information included more details about disease trajectory and what to expect, and more details about symptom and side effect control.

In other studies, people with lung cancer described expectations for future information. In terms of presentation of data, they wanted information in clear, easy to understand language with pictures to help with their understanding[98,119]. In addition, they wanted information in small digestible amounts, and like the PEEK participants, they want time with their doctor to confirm understanding of information, and the ability to contact healthcare professionals between appointments or treatment cycles[98,120]. In relation to information topics, people with lung cancer wanted practical information, information about access to support and services, and information about mental and emotional support[23,98,119]. They wanted information about making lifestyle changes, maintaining a social life, how to manage symptoms, and self-management following treatment or discharge form hospital[23,98,119,127]. Similar to PEEK participants, people with lung cancer wanted information about what to expect, risk of recurrence or progression, information about treatment including the advantages and disadvantage, side effects, and efficacy, information about the mental and emotional impact of lung cancer, how to interpret test results, and end of life planning [59,97,98,119,120].

Future care and support

PARTICIPANT: It's definitely the idea of lung nurse someone, a nurse with that specialist knowledge who can be there…They become your point of contact. They can be that middle person between you and a specialist. They have a little bit more capacity because that's what they're there for, to steer you emotionally to where you might find resources, help, et cetera. I think that is solely lacking. The other thing I think is really lacking is public awareness. Again, having breast cancer, I saw what public awareness does. You can tell anyone, "Oh, I've got breast cancer," and they go, "Oh gosh, how are you going?" You tell them you've got lung cancer and they go, "Oh, how long did you smoke?" You go, "Oh, not a question to ask anyone." You do not bring about your own cancer deliberately. I think that's a public awareness thing. I don't know if that falls into arraignment, but that's what I think is poor in Australia. We don't understand it. Not a blame game. This can happen to anyone.
Participant 020_2023AULUC

Participants in this PEEK study described their expectations of future care and support. The most common expectation for future care and support was that it will include specialist clinics or services where they can talk to professionals either in person, phone, or online. Other expectations if future care and support included practical support, for example home care, transport, or financials support. They would like a multidisciplinary and coordinated approach to care and support, long-term condition management and care planning, and holistic care that addresses emotional health.

In other studies, people with lung cancer described what expectations they had for future care and support. Like PEEK participants, they described needing to address emotional health, in particular needing additional support to cope with stigma, access to counselling, more social support and support to help them make lifestyle changes[113,119,138]. They also described needing help navigating the healthcare system and making necessary appointments, the needed more support from healthcare professionals after the treatment phase of their journey, help getting to and from medical appointments and treatments, and the ability to buy better hospital food[23,119,120].

Future communication with healthcare professionals

I think in the lung cancer space, we need lung cancer nurses. We need where there's very few of them and I think we need them more commonly available and we need them to know about them. Because I would've found that a fantastic resource in that person would've been in a way, a directory and said, "This is the pathway, this is the things you can access." You could ask the trivial question of where you are not going to make an appointment for an oncologist because it's not really that important, but you would like to get some help on something
Participant 020_2023AULUC

Participants in this PEEK study described their expectations of future healthcare professionals communication. The most common expectations for future healthcare professional communication were that communication will be more empathetic, and will include a multidisciplinary and coordinated approach. Other expectations included that future communication will be more transparent and forthcoming, and communication will include health professionals with a better knowledge of the condition. Similar to the PEEK study, another study described that people with lung cancer would like future communication to be more compassionate, more understanding, have more empathy. In addition they described communication needs of family, the need for more information to help care for person with lung cancer[119].

Key points

- **In future, participants would like to be able to talk to a specialist healthcare professional for information and care and support**
- **In future, participants when having treatment, participants would like more conversations about side effects, and discussions about all treatments available to them**

What people with lung cancer were grateful for in Australia

Participants in this PEEK study described what they were grateful for in their experience with lung cancer. They were most commonly grateful for low cost or free medical treatments through the government. In addition, they were grateful for healthcare staff and access to specialists, and timely access to treatment. However, some expressed the need for lower treatment costs and extend to Medicare coverage. In another Australian study, people with lung cancer also described being grateful for free or low cost treatments available from the Australian government, they were grateful for nursing and healthcare staff who helped relieve treatment burden, in addition, those that quit smoking were grateful for having extra money otherwise spent on cigarettes[23].

Message to decision makers

PARTICIPANT: Also, why does lung cancer only attract, what is it 3% of the research dollar?...Why is there not more research and also point out that it is not necessary just a smoker's illness, and a lot more younger people are getting afflicted by it now, aren't they?
Participant 025_2023AULUC

PEEK Participants were asked, “If you were standing in front of the health minister, what would your message be in relation to your condition?”. They wanted the health minister to raise community awareness about lung cancer, in particular that it wasn’t just caused by smoking. They wanted more clinical trials or access to new treatments, and they want more timely and equitable access to support, care and treatment. Other messages included to invest in health professionals to service the patient population, in particular specialist lung cancer nurses, to increase investment in research, and that treatments need to be affordable .

Likewise, in a Canadian study, people with lung cancer’s messages included wanting quicker access to new treatments, in addition they need better information to make decisions, and more treatment options[99].

I would like that commercial about lung cancer being a cancer that can happen to anyone, not just smokers, because you never think, "Oh, I'd better look out for these symptoms because it could be the lung cancer." Because you just think, "No, it won't happen to me."
Participant 004_2023AULUC

Characterisation

There were 29 people diagnosed with lung cancer, 3 family members or carers to people with lung cancer throughout Australia. The majority of participants lived in major cities, they lived in all levels of economic advantage. Most of the of participants identified as Caucasian/white, aged mostly between 55 and 74. About half of the participants had completed some university, and most were not in paid employment. The majority of the participants were not carers to family members or spouses.

Physical health and emotional problems interfered with work and other activities for participants in this study.

On average they had 3 symptoms before diagnosis, usually fatigue, shortness of breath, and coughing up blood which all contributed to poor quality of life.

This is a group that had health conditions other than lung cancer to deal with, most often sleep problems, anxiety, depression, and anxiety.

This is a patient population that experienced shortness of breath or a persistent cough that led to diagnosis which they recalled clearly. Most participants sought medical attention after noticing symptoms and were diagnosed after their general practitioner referred them to a specialist.

This is a cohort that on average, three diagnostic tests for lung cancer, they were diagnosed by a respiratory specialist in a hospital. The cost of diagnosis was not a burden to them and their families. They were mostly diagnosed with non-small cell lung cancer and had stage 4 disease. This is a group that did not have enough emotional support at the time of diagnosis. This is a cohort that did not have conversations about biomarker/genomic/gene testing, and had knowledge of their biomarker status.

This is a study cohort that had limited knowledge of lung cancer before they were diagnosed. This patient population were uncertain about their diagnosis or described that they had a terminal condition.

This is a patient population that had discussions about multiple treatment options, and about a third participated in the decision-making process.

This is a study cohort that took into account efficacy, and the advice of their clinician as part of many considerations when making decisions about treatment.

Within this patient population, similar numbers of participants had changed decision making over time and hadn't changed over time, for those that changed, this was linked to being more informed and assertive.

When asked about their personal goals of treatment or care participants most commonly described wanting to be cancer free, avoid recurrence and live longer.

This is a group who felt they were mostly treated with respect throughout their experience. They were cared for by a medical oncologist, but also had access to radiation oncologists and general practitioners to manage their lung cancer.

Almost 60% of this cohort had private health insurance and were most often treated as public patients. This is a group that did not have trouble paying for healthcare appointments, prescriptions, and paying for basic essentials. They did however have monthly expenses.

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family did not have to change employment status. The loss of family income was often in the 1000s per month.

More than half of the participants had immunotherapy, surgery, chemotherapy and radiotherapy was also common.

About a third had conversations about clinical trials, and the majority would take part in a clinical trial if there was a suitable one for them.

This is a patient population that described mild side effects using specific examples such as aches and pain, or as those which can be self-managed and do not interfere with daily life.

This is a study cohort that described severe side effects as symptoms such as being short of breath, they also described severe side effects as those that impact everyday life and the ability to conduct activities of daily living.

This is a patient population which described adherence to treatments in terms of not giving up on any treatment. This is a study cohort that needed to see evidence of stable disease or no disease progression to know that treatment was working.

In this PEEK study, participants had very good knowledge about their condition and treatments, they were good at coping with their condition, were very good at recognising and managing symptoms, and were very good adhering to treatment.

Participants were given information about treatment options, disease cause, and physical activity from health care professionals, and searched for disease management, disease causes, and treatment options most often. This is a group who accessed information from non-profit, charity or patient organisations most often.

This is a patient population that access information primarily through the internet, their health charities or social media.

This is a study cohort that found information about other people's experience as being helpful.

Participants commonly found information from sources that were not credible, and worst-case scenarios as not helpful.

This is a group that preferred to get their information by talking to someone plus online information. This is a study cohort that generally felt most receptive to information from the beginning, at diagnosis, or after they have results from their treatment or follow up scans.

Most participants described receiving an overall positive experience with health professional communication (some with a few exceptions) which was holistic, two way and comprehensive. For those that had a negative experience it was mostly communication was dismissive with one-way conversations.

The participants in this study experienced good quality of care, and moderate coordination of care. They had a moderate ability to navigate the healthcare system, and experienced moderate communication from healthcare professionals.

This is a patient population that did not receive any formal support. When participants felt supported, most found support through charities, or peer support or other patients.

This is a patient population that experienced a negative impact on quality of life largely due to emotional strain on family, and changes to relationships.

This is a study cohort that experienced at least some impact on their mental health and to maintain their mental health they used coping strategies such as physical exercise, and mindfulness and mediation, and noted the importance of family and friends in maintaining their mental health.

Within this patient population, participants described being physically active, and the understanding their limitations in order to maintain their general health.

Participants in this study had felt vulnerable especially when having sensitive discussions about their condition, and during or after treatments. To manage vulnerability, they relied on self-help, such as resilience, acceptance and staying positive.

This cohort most commonly felt there was an overall negative impact on their relationships, with the dynamics of relationships changing due to anxiety of difficult decisions.

Participants felt they were a burden on their family, due to the emotional strain.

Most participants felt there was some cost burden which was from needing to take time off work, and the costs of treatments.

Life was a little distressing for this group, due to having lung cancer.

The participants in this PEEK study had moderate levels of anxiety in relation to their condition.

Participants would like future treatments to be more affordable, and for there to be more access to clinical trials and new treatments.

This is a study cohort that would like information to be easier to find, and will include to talk to a healthcare professional.

Participants in this study would like future communication to be more empathetic, and that will include a coordinated multidisciplinary approach.

Participants would like future care and support to include specialist clinics or services where they can talk to professionals.

This patient population was grateful for low cost or free treatments available through the government, and healthcare staff including specialists.

It was important for this cohort to control pain, nauseas and vomiting, and fatigue to improve quality of life. Participants in this study would consider taking a treatment for more than 1 to 5 years if quality of life is improved with no cure.

Participants’ message to decision-makers was to help raise community awareness, provide new treatments or clinical trials for lung cancer, and to provide timely and equitable access to support, care and treatment.

This is a patient population that wished they had communicated and increased their understanding of their condition.

Many participants would not change any aspect of their treatment or care, though some would have accessed treatment or their specialist sooner.

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Section 12

Next steps

Next steps

At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

Information: People with lung cancer need more information about what to expect in general about their condition, what treatments and support are available to them, and more detailed information about side effects and management of side effects. To help with earlier detection and reduced stigma, community awareness is needed about the symptoms of lung cancer and dispelling myths that only smokers get lung cancer.

Care coordination: There is a need for better access and coordination of healthcare services, better access to specialist nurses, and allied health. (This group has poor quality of life: symptoms and side effects, anxiety and depression. Only about 30% had counselling or psychological support, and 30% a lung cancer nurse)

Costs: The biggest cost for people in this study was having to make changes to their employment status. Initiatives that support people with lung cancer who want to continue working to do so and support for those who are unable to work and may have reduced income causing hardship or become isolated.

2023 PEEK study in lung cancer

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2023 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Lung cancer 2023 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	70.00	70.00
	Role functioning/physical	0.00	0.00
	Role functioning/emotional	33.33	33.33
	Energy/Fatigue*	40.00	40.00
	Emotional well-being*	68.00	68.00
	Social functioning	62.50	62.50
	Pain*	57.50	57.50
	General health*	40.00	40.00
	Health change	50.00	50.00
Knowledge of condition and treatments (Partners in Health)	Knowledge	25.15	28.00
	Coping*	15.89	16.00
	Recognition and management of symptoms*	19.89	20.00
	Adherence to treatment	13.41	15.00
	Total score	74.33	78.00
Care coordination scale	Communication*	34.30	32.00
	Navigation*	23.37	25.00
	Total score*	57.67	56.00
	Care coordination global measure	5.96	6.00
	Quality of care global measure	6.81	8.00
Fear of progression	Total score*	37.70	39.00
		Percent	
Accessed My Health Record	-	35.48	-
Participants that had discussions about biomarkers/genetic tests	-	44.83	-