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.
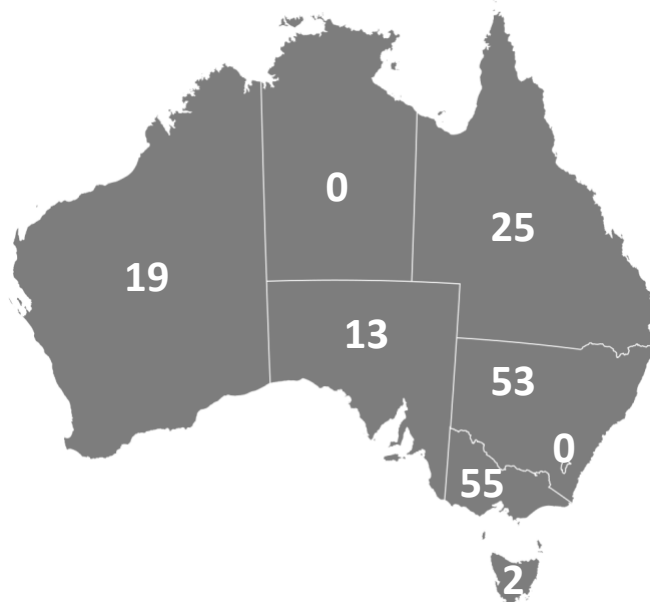

Figure 12.1: Distribution of clinical trials for lung cancer in Australia 2017-2022

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].

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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