

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 meditation, 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, nausea 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.