Patients' experiences of lung cancer

Insights from Australia

GLOBAL LUNG CANCER COALITION

Introduction

The Global Lung Cancer Coalition (GLCC), an alliance of 41 patient organisations from 29 countries across the world, wanted to understand the challenges patients are currently facing to inform its patient advocacy work and the work of its member organisations.

In March 2024, the GLCC commissioned Censuswide to conduct a survey of lung cancer patients.

The survey received **905 responses** from patients across **18 countries**. For more information about the global findings, please visit www.lungcancercoalition.org/surveys.

Key findings from Australia

Demographics

50
lung cancer patients responded

92% identified as male;
6% as female;
2% as non-binary

30% had non-small cell lung cancer

94%
were diagnosed in the last **five years**

** Survey respondents were predominantly male, younger, and included a higher proportion of those with small cell lung cancer than the general lung cancer population.*

Experiences of biomarker testing

76% of eligible respondents **had been spoken to about** biomarker testing

54% did **not understand** what biomarker testing was when they were first spoken to about it

These results suggest a clear need for **improved communication around the topic of biomarker testing**.

Support preferences in coping with lung cancer

68% get **help** from **healthcare professionals**; **66%** from **family and friends**; **22%** from **online support groups**

More respondents **(72%)** would like to receive help through **healthcare professionals** than currently do

The respondents sought help from a variety of places. Their **preferences largely matched where they were already getting help**, except for a **greater desire for** support via **healthcare professionals**.

Involvement with treatment teams

96% of **respondents** said that they felt **involved** in decisions about their treatment and care

32% of respondents felt **fully involved**, but **54%** wanted to be **more involved**

While patient involvement was high, **treatment teams need to ensure** patients have the opportunity to be **involved in decision-making as much as they would like** to be.

Preferred methods of receiving information

Throughout the patient journey, **face-to-face interactions** were preferred, **except when respondents were worried** about a **change in their disease** or **finding out about the diagnosis**

Cancer support hotlines were the most popular format for receiving information (preferred by **60%**), followed by **print materials (10%)**

Whilst the results indicate a **preference for direct interaction** when receiving information, it remains crucial that treatment teams **understand and accommodate individual patient preferences**.

Call to action

While overall involvement in treatment decisions was still high in this year's Patient Experience Survey, **less respondents felt fully involved in their treatment and care decisions** when compared to last year's results. The results show that more needs to be done to ensure all patients feel as involved as they would like in decision-making, that treatment teams clearly communicate to patients on topics relevant to their condition, such as biomarker testing, and that patients can access the support options of their preference.

The GLCC is therefore calling for the **implementation of the rights set out in its Patient Charter**, to ensure that all lung cancer patients have access to quality healthcare; informed self-determination, which includes involvement in decision-making; and physical and mental integrity.

More information

The GLCC member in Australia is:

- **Lung Foundation Australia:** www.lungfoundation.com.au

For more information about this survey and the work of the GLCC, please visit our website: https://www.lungcancercoalition.org/ or email our secretariat at: glcc@roycastle.org