Patients' experiences of lung cancer

Insights from the United Kingdom

GLOBAL LUNG CANCER COALITION

Introduction

The Global Lung Cancer Coalition (GLCC), an alliance of 42 patient organisations from 30 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 February 2023, the GLCC commissioned Censuswide to conduct a survey of lung cancer patients.

The survey received **712 responses** from patients across **14 countries**. For more information about the global findings, please visit www.lungcancercoalition.org/surveys.

Key findings from the UK

Demographics

51

lung cancer patients responded

76% identified as male, **24%** identified as female

67% had non-small cell lung cancer

71%

were diagnosed in the last **five years**

Biomarker testing

- **75%** of respondents **had received** biomarker testing
- Almost **18%** were **unsure** if they had been tested

Of those who had been tested:

- **39% knew** what biomarker their cancer had
- **24% did not know**

These results suggest that while many patients have access to testing, there is **a substantial gap in communication between patients and treatment teams**

Screening

86%

of respondents were **aware** of a lung health check or screening programme in the UK

78%

of respondents attended a screening appointment and were **diagnosed with lung cancer as a result**

While the sample size of this survey was small and questions remain around participants' understanding of screening, these findings highlight **the value of screening programmes**

Patient involvement in decision making

Only 39% of respondents said they felt **fully involved in decisions** about their treatment and care. While patient preferences for involvement will differ, **treatment teams should ensure patients have the opportunity to be involved** in decision-making as much as they would like

Patient preferences about receiving information

The **majority** of respondents said they **prefer face-to-face appointments when finding out their diagnosis,** but preferences for video, telephone, or face-to-face conversations varied markedly depending on the situation, suggesting that **treatment teams should look to understand and accommodate individual patient preferences as much as possible**

Call to action

The GLCC is calling for the implementation in the UK 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's members in the UK are:

- **Asthma + Lung UK**: www.blf.org.uk
- **Lung Cancer Nursing UK**: www.lcnuk.org
- **Roy Castle Lung Cancer Foundation:** www.roycastle.org

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