# Patients' experiences of lung cancer

**Insights from Japan**

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 Japan

### Demographics

**50**
lung cancer patients responded

**88%** identified as male;
**10%** as female;
**2%** as non-binary

**84%** 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

**91%** of eligible respondents **had been spoken to about** biomarker testing

**36%** 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

**54%** get **help** from **healthcare professionals**; **44%** from **in-person support groups**;
**38%** from **online support groups**

**42%** would like to get help via **online support groups**, but only 38% get help that way;
**32%** via **social media communities**, but only **24% get help** that way

The respondents sought help from a variety of places. Their **preferences largely matched where they were already getting help**, except for a **greater need for online support groups** and **social media communities**.

### Involvement with treatment teams

**All respondents** said that they felt **involved** in decisions about their treatment and care

**36%** of respondents felt **fully involved**, but **32%** 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

Patient preferences varied across the patient journey, with **video calls** being preferred at the stage of **diagnosis (48%)** and for **regular check ups (44%)**; **telephone calls** during the **first consultation (54%)** and **face-to-face (40%)** when **there was a change in their disease**

**Cancer support hotlines** were the most popular format for receiving information (preferred by **36%**), followed by **apps (26%)**

Whilst the results indicate a slight **preference for telehealth** when receiving information, responses were varied, and it remains crucial that treatment teams **understand and accommodate individual patient preferences**.

## Call to action

This year's Patient Experience Survey highlighted **encouraging trends, including high levels of involvement in treatment and care decisions** by respondents. The results, however, also showed 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 Japan are:

- **West Japan Oncology Group:** www.wjog.jp
- **Cancer Net Japan:** www.cancernet.jp

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