Introduction

The COVID-19 pandemic has had a profound impact on patients, including those living with lung cancer, and healthcare systems around the world.

The Global Lung Cancer Coalition (GLCC), an alliance of 42 patient organisations from 30 countries across the world, wanted to understand if COVID-19 is still impacting the care patients receive, and to compare the experiences of patients in different countries.

In December 2021, the GLCC shared a global online patient experience survey.

The survey ran for eight weeks and received 555 responses from patients across 21 countries.

Key findings from Ireland

Demographics

- 11 lung cancer patients or their carers responded
- 73% of respondents identified as female, 27% identified as male
- 91% were diagnosed in the last five years
- 100% have non-small cell lung cancer

55% of responding patients are currently having treatment and 45% had finished treatment.

Involvement in decisions

- 91% felt involved in decisions about their treatment and care.
- One patient said they were not involved but their caregiver was.

Accessing information

- 70% said they got the information they needed at the right time. But, some had to look for more information on their own.

Screening

- 91% of responding patients were unaware of a lung cancer screening programme in Ireland.

- One patient had a screening appointment but was diagnosed by another route.

- 100% said they would attend a screening appointment if they were invited.

Getting the lung cancer diagnosis had the biggest emotional impact for 60% of patients, followed by waiting to find out scan results (50%).

- 60% said they are fearful of relapse, while 40% are depressed about their health and future and 40% are worried about their family.

- Half (50%) of patients said that speaking to family and friends and to their treatment team were the most helpful in dealing with their emotions.

Treatment

- 100% of responding patients have been vaccinated against COVID-19.

- 70% of patients said they have carried on attending appointments during the pandemic. 40% said face-to-face appointments had been swapped to virtual (video or telephone). 50% of responding patients said they held back in contacting their treatment team because they are so busy.

The majority of patients prefer face-to-face appointments in most situations, particularly when finding out their diagnosis, for the first consultation. 40% would like to telephone if they are worried about something.

Emotional impact

Impact of COVID-19

- 45% of patients said they held back on making decisions against their own wishes because they are so busy.

- 50% of patients said they have carried on having treatment.

- 40% said face-to-face appointments had been swapped to virtual (video or telephone).

Call to action

The members of the GLCC are calling for the implementation of the rights outlined in its patient charter, namely ensuring 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 member in Ireland is the Irish Cancer Society: https://www.cancer.ie

For more information about this survey and the work of the GLCC, please visit our website: https://www.lungcancercoalition.org

You can email our secretariat at: glcc@roycastle.org