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.

More information

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.

Key findings from The Netherlands

- **44** lung cancer patients or their carers responded
- **73%** of respondents identified as female
- **82%** were diagnosed in the last five years
- **86%** have non-small cell lung cancer

Demographics

- Nearly half (48%) of responding patients are currently having treatment. 45% had finished treatment
- 98% of responding patients felt involved to some extent in decisions about their treatment and care. One patient said they were not involved but would like to have been
- 82% said they got the information they needed at the right time. Two patients had to look for more information on their own, and one patient said that what they received wasn’t helpful or was given too late

Accessing information

- **80%** of responding patients said they would attend a lung cancer screening appointment if they were invited
- Five patients said they would not attend and four patients said they were not sure whether they would attend

Screening

- 53% of patients said that getting the lung cancer diagnosis had the biggest emotional impact on them, followed by waiting for scan results (42%) and telling family and friends (39%)
- 81% said that speaking to their family and friends was the most helpful information they needed at the right time
- Two patients had non-small cell lung cancer, and one patient said they needed help from a therapist or counsellor

Emotional impact

- 94% of responding patients have been vaccinated against COVID-19. Only one respondent chose not to get the vaccine but might consider it in the future
- Half (50%) of patients said there was no difference in how easy it has been to contact their treatment team during COVID-19. 38% said treatment has continued as normal.
- The majority of patients prefer face-to-face appointments in most situations, particularly when finding out their diagnosis and for the first consultation. 25% of patients would like to telephone if they are worried about something

Impact of COVID-19

- 72% said they are fearful of relapse. 42% said they are worried about the impact on their family and 39% are worried about their health and future
- 29% of patients said that dealing with their emotions was too late

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 The Netherlands is Longkanker Nederland: https://www.longkanker nederland.nl/

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

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