

Abstract for the European Virtual Lung Cancer Congress 2021

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Understanding patient experience in Europe: the first Global Lung Cancer Coalition Patient Experience Survey

Background

Little comparative European or global data exists on lung cancer patient experience. The Global Lung Cancer Coalition (GLCC), a partnership of 40 patient organisations across 29 nations, wanted to understand the experiences of lung cancer patients, identifying common themes and differences between countries. The GLCC therefore used its member networks to run a multi-national online survey of patients – the first time this had been attempted.

Methods

The GLCC convened a steering group with members from the UK, Ireland, and the Netherlands, including patients, clinicians and advocates. 10 questions were agreed and translated into multiple languages with appropriate terminology. As well as demographic questions, participants were asked what treatments they had received, whether they felt involved in decisions and were treated with dignity and respect, and how they describe themselves.

The survey was distributed by GLCC members via emails, newsletters and social media. The results were collated and analysed by the steering group.

The GLCC produced a global report with findings for all participating countries, as well as bespoke briefings comparing the perspectives of patients in each country to those of global respondents, for national campaigning.

Results

Nine of the 17 countries that took part are in Europe: Bulgaria, Czech Republic, Denmark, Ireland, Netherlands, Portugal, Spain, Sweden and the UK. 574 of 907 patients who responded were from Europe (63%).

Headline European findings include:

- 11% of respondents did not know what type of lung cancer they had (13% globally)
- 19% of respondents stated they did not feel involved in decisions about their treatment and care (18% globally)
- 11% felt they had 'never' or only 'sometimes' been treated with dignity and respect by their treatment team (9% globally)

Conclusion

The survey demonstrates that a pan-European patient experience survey can take place. It also suggests more could be done across nations to improve lung cancer patients' experience, particularly involvement in decisions around treatment and care. We are grateful to all the patients who responded and shared their experiences.