



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

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Introduction: The Global Lung Cancer Coalition (GLCC) is a partnership of 40 patient organisations from 29 nations. It is dedicated to improving disease outcomes for patients.

The GLCC wanted to understand the experiences of lung cancer patients in different countries, identifying common themes and differences. However, little comparative data on patient experience exists. The GLCC set out to run a global online survey of patients using its members' networks – the first time the GLCC had conducted a survey in this way.

Methodology: The survey was designed by a multi-national steering group, including patients, clinicians and advocates.



It was translated into seven European languages, checking terminology was applicable, and sent out by GLCC members via email, social media and newsletters in **nine European countries:**



Results: 63% of the patients who responded globally (574 out of the 907) were from Europe

Around **1 in 10** patients (11%) didn't know what type of lung cancer they had.

Around **1 in 5** patients (19%) were not involved in decision-making around their treatment and care, and not because they didn't want to be.

Around **1 in 10** (11%) patients felt they were only 'sometimes' or 'never' treated with dignity and respect by their medical team

The European findings were broadly similar to the global findings. Each member received a bespoke briefing for use in national campaigning. These are publicly available for anyone to download at: <http://www.lungcancercoalition.org/global-research/patient-experience-survey-report.html>

Conclusions: The numbers of responses indicates that patients are willing to contribute their time and insights to a global endeavour. The European findings suggest more could be done to improve patients' involvement in decisions around treatment and care and whether they feel treated with dignity and respect. The findings also merit further exploration at a national level, to test whether they are representative of the wider lung cancer patient population's experience.

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