

Understanding patient experience: findings for Ireland and the UK and from the first Global Lung Cancer Coalition Patient Experience Survey

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 – the group had representatives from the UK and Ireland.

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 survey demonstrates the willingness of lung cancer patients in Ireland and the UK, as well as globally, to share their experiences. It also indicates that improvements could be made in lung cancer patients' involvement in decisions around treatment and care as well as ensuring they feel treated with dignity and respect. We are grateful to all patients who responded.

Results: Headline findings	Ireland	The UK	Global results
Total responses	42	158*	907
Felt they had 'never' or only 'sometimes' been treated with dignity and respect by their treatment team	13%	13%	9%
Were not involved in decision-making around their treatment and care, and not because they didn't want to be.	35%	15%	17%

*The UK recorded the greatest number of responses of any country taking part in the patient experience survey

NB: Not every patient answered every question

Acknowledgments: The Global Lung Cancer Coalition is grateful to all patients who responded to the survey, and those who submitted responses on their behalf. For more information please visit: www.lungcancercoalition.org or email the secretariat at: glcc@roycastle.org

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