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

Introduction

Little comparative 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 globally, identifying common themes and differences. 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 of patients, clinicians and advocates, including members from Ireland and the UK, who agreed 10 survey questions.

The survey asked how involved patients felt in decisions about their care and whether they felt treated with dignity and respect. Demographic questions were also included. It was distributed by GLCC members via emails, newsletters and social media with results analysed by the steering group.

The GLCC produced a global report and bespoke briefings for each participating country.

Results

42 patients from Ireland and 158 patients from the UK responded, accounting for 22% of the 907 global respondents. Not every patient answered every question. Headline findings include:

- 35% of Irish respondents (13/37) and 15% of respondents from the UK (23/155) did not feel involved in decisions about their treatment and care, (17% of patients globally)
- 13% of Irish respondents and 13% of respondents from the UK said they felt they had 'never' or only 'sometimes' been treated with dignity and respect by their treatment team, (9% of patients globally)

Conclusion

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.

References



N/A