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Expect Better

The DECLINE Study

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UNITED KINGDOM
LUNG CANCER COALITION

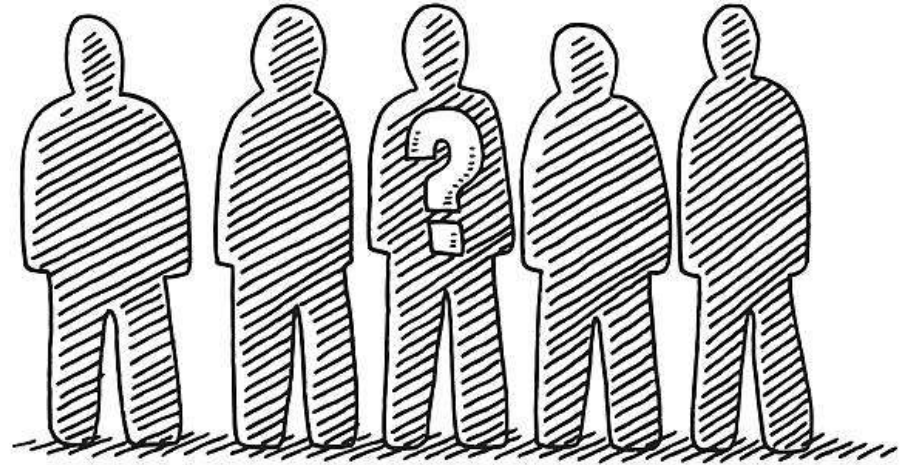
Disclosures

Nothing to disclose



Background

- 1 in 5 potentially eligible people don't receive treatment
- 1/3 of cases down to patient choice



1. National Lung Cancer Audit. State of the Nation 2025. London: National Cancer Audit Collaborating Centre, Royal College of Surgeons of England, 2025.
2. Navani N, Harden S, Khakwani A, *et al*, S115 Improving curative-intent treatment rates in early stage lung cancer – results from 775 patients in the NLCA spotlight audit, *Thorax* 2018;**73**:A72.



Study Design

- Mixed methods study
- Interviewed PS 0-2, stage I-II NSCLC
 - Health care practitioners (HCPs)
- 6 patients
 - Age 59-91
 - 3 with PS 0
 - 3 alternative treatment
- 6 declined to participate
 - 4 no research, 1 cognitive impairment, 1 bereaved
- 15 HCPs



<i>2016-2019, PS 0-2, Stage I-II</i>	No Active Treatment	
Total	140	100%
Patient choice	24	17%
Lung function	45	32%
Co-morbidities	51	36%
Unresectable	3	2%
Small cell	2	1%
Trial	0	0%
No reason recorded	15	11%



Themes

- Fear
- Practical barriers
- Health status
- Facilitators



Fear

'[Surgery or radiotherapy] could make me breathing worse' - 70F

'Dad's cancer... was playing on my mind' - 59M

'He's had lung cancer, he's had the surgery, and six months down the line he's still struggling.' - 70F



*‘something like a **house of horrors**’*

59M, stage II, chemorad



Practical Barriers

'one patient who refused an operation because it wasn't done closer to his home' - Thoracic surgeon 1

'it's the cost of parking that they mention' - Lung Cancer Nurse 5

'will you not have the surgery for those two or three days and then die earlier and therefore not be able to care for the family member' - Thoracic surgeon 2



Health Status

'Which is going to kill me? At the moment it's the emphysema' - 72M

'I'm 91... if I had been 71... I would have had it' - 91F

'if a particular treatment of their small localised lung cancer is the right thing to do or not' - Clinical Oncologist



Facilitators

'My sister comes with me. She can remember the big words' - 72M

'I go past Macmillan and I was thinking of going in there... All the money for all the taxis' - 63M

'[Lung cancer nurses] have been brilliant' - 59M



*'I think that **if I can draw** up really nicely and really well, the patients are more reassured that I have a **smooth artistic hand** and therefore **more confident** in my surgical techniques'*

Thoracic Surgeon 1



Key points

- Fewer people choosing not to have treatment than previously thought
- Emotional barriers are more impactful than practical barriers
- Family, charity, continuity – key facilitators



With thanks

Patient participants!

- Health care workers
- Roy Castle Lung Cancer Foundation
- Supervising team – Dr O'Dowd, Prof Baines, Prof Murray, Prof Baldwin, Prof Hubbard



