



# Development of a patient engagement tool for people affected by lung cancer

## A case study



CANCER  
RESEARCH  
UK



United Lincolnshire  
Hospitals  
NHS Trust



Barts Health  
NHS Trust



UNIVERSITY OF  
LINCOLN



Queen Mary  
University of London

# Brief summary

Through in-depth interviews with patients diagnosed with lung cancer, their informal carers, and consultations with healthcare stakeholders, we identified challenges to patient engagement. Based on this evidence, we developed targeted recommendations, and a prototype engagement tool designed to inform and empower patients and their carers.

Our recommendations to improve patient engagement and experience are to:

- Ensure equitable access to timely, local and regional diagnostic and specialist treatment services, regardless of patient location or circumstances
- Empower patients and carers by providing clear, accessible and relevant information to support active participation in their care
- Address common barriers by signposting patients to local support services and charities that can offer practical and emotional assistance
- Strengthen communication between clinicians, patients and carers to support informed choice and decision making
- Recognise and support carers as integral to the care pathway and take steps to reduce caregiver burden
- Enhance the overall patient experience through holistic care and opportunities for peer support

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## Context

Lung cancer has the widest deprivation gap of all cancer types, with outcomes significantly worse for individuals in the most deprived communities. These disparities are further compounded by geographical barriers, which limit access to timely diagnosis and treatment. Without targeted action to improve equitable access to care, outcomes for these populations are likely to deteriorate further. As treatments become more effective but often more complex, this disparity is only likely to increase.

In 2023, Cancer Research UK funded a collaborative research project involving the University of Lincoln, Queen Mary University of London, United Lincolnshire Hospital Trust, and Barts NHS Trust. The project aimed to explore the factors influencing patient engagement with lung cancer services across areas with varying levels of deprivation and geographic accessibility, and to develop an intervention to address these challenges.

This case study outlines the key factors affecting patient engagement with the national optimum lung cancer pathway in Lincolnshire and North East London. It also introduces a prototype patient engagement tool designed to empower patients and carers, helping to reduce the impact of the barriers they face.

By sharing this case-study, we aim to:

1. Provide practical insights for health system leaders, service planners, and policymakers to reduce inequalities in lung cancer care and improve outcomes
2. Share learnings from the collaborative approach between academic institutions and NHS trusts in co-developing a patient-centered engagement tool.

3. Encourage healthcare professionals to consider ways in which they can improve the ways that patients and carers are supported in being able to access optimal individualised care.

## Methods

We directed three complimentary workstreams to understand the experiences of people with lung cancer, and to co-develop a supportive intervention. Our pragmatic approach integrated elements of theory and evidence-based design, partnership working, and 'target-population centred' methods. Intervention development was iterative and informed by emerging evidence.

The workstreams included:

- Semi-structured interviews with people diagnosed with lung cancer within the last 6-months (receiving surgical, radical radiotherapy, or advanced disease treatment) and their informal carers.
- Consultation workshops with cancer care professionals including clinicians, local authority / integrated care board staff, academics, and patient/public representatives
- A rapid literature review to synthesise evidence on the design and implementation of patient engagement interventions within lung cancer care.

A framework analysis of interview data explored factors influencing patient and carer capability, opportunity, and motivation to engage with the care pathway. The content and format of the intervention tool were refined through multiple feedback cycles from people with lived experience and care providers. This collaborative process ensured that the tool remained relevant, accessible, and aligned with the real-world needs and preferences of patients and carers.

## Key findings

### Knowledge and Understanding

People with lung cancer and their carers had varying levels of understanding about cancer and its treatment. Some participants found it difficult to fully comprehend the treatment options presented to them which could lead to confusion, increased anxiety, or delays in decision-making and treatment uptake. Misconceptions about the care pathway and pre-existing beliefs about cancer and its treatment also influenced how and when patients engaged with services. While many expressed a strong sense of urgency once investigations began, not all understood the importance of attending each step in the diagnostic and treatment process.

*"And that was the thing that freaked me out about the chemo, because I didn't know what to expect, so maybe they need to explain the chemo side of it a little bit more, that it's a drip, or it's an injection. You know? Because older people like me have got that vision in their head of metal tongs, and a radioactive test tube."*



## Location and System Factors

Accessing diagnostic and treatment services posed significant challenges for patients in both Lincolnshire and North East London, though the nature of these challenges varied by geography.

In Lincolnshire, a large rural and coastal county, patients had to travel long distances between hospitals for tests and treatment. Surgical procedures were typically performed out of county in Nottingham, requiring extensive travel. These journeys were often tiring, costly and logistically difficult. Due to limited public transport options, many patients relied heavily on family or friends for transportation.

In North East London, patients were referred from local hospital to a central London site for treatment. While public transport was widely available and used by many, it was not suitable for those with mobility and health issues. As a result, patients and carers often depended on slow and expensive car or taxi journeys to attend frequent appointments. In both regions, hospital transport services were viewed as inadequate and unreliable.



*“We had to go to Grantham for one of the tests, and then we had to go to Hull for another one, because they cancelled the PET scan, they cancelled two... and they were going to give us one for another week later. And I said no, because obviously we were very stressed by this stage, not knowing what was going on. And we said no. We didn't want to wait anymore. Can we go somewhere else?”*

## Coping with and through Cancer

Patients and carers often described feeling overwhelmed and uncertain following a lung cancer diagnosis, making it difficult to absorb and understand information during this period. Many patients reported that maintaining a positive outlook and placing trust in their care team were key to coping and staying engaged with treatment.

Clinicians frequently observe that fear – particularly around treatments such as chemotherapy or surgery – can significantly hinder patient engagement with the lung cancer pathway, which This fear may lead some patients to delay or avoid appointments altogether.

Carers played a vital role in helping patients navigate their cancer diagnosis and care and provided both emotional and practical support.



*“It was all given quite quickly, and I'll tell you the truth, when I asked - Can you cure me? I don't remember anything from there. It was like curtains coming down, I didn't hear a thing. All I could think was I hope my wife is listening because I haven't got a clue what they're saying to me”*

## Collaboration and Communication

Healthcare professionals identified several communication barriers, such as language differences and the risk of misinterpretation during translation, difficulties reaching patients (e.g. unanswered phone calls or delays in post), and explaining complex medical information related to cancer diagnosis in plain language without causing undue fear. Patients did not

always have clear, open conversations with their healthcare team. This sometimes left them feeling unsure, worried, or wanting to avoid or delay treatment. Patients found it beneficial to have lay language explanations, the supporting evidence explained to them, to look at their scans, to be asked direct questions, and be shown compassion and patience.

### **Social Barriers and Physical Limitations**

Following a lung cancer diagnosis, many patients and carers experienced financial strain due to reduced income – often resulting from early retirement or an inability to work - and increased costs related to travel, healthy food, additional medication and equipment. These pressures were compounded by additional responsibilities, such as managing other health conditions or providing care for others, which placed further emotional strain and practical demands on both patients and carers. Healthcare professionals acknowledged that wider social factors – such as substance misuse, mental health challenges, smoking related stigma, insecure employment, and unstable housing - further hindered patient engagement with the lung pathway. Patients consistently valued the support and guidance provided by charities, and expressed a strong preference for automatic referrals to these services to help ease the burden and navigate their care more effectively.

## **The patient engagement tool**

As part of our initiative to improve patient engagement, we developed a prototype tool designed to support patients navigating the lung cancer pathway. This tool serves both as a practical intervention and a flexible plan that can be tailored to suit local contexts and be implemented across different locations.

The tool is an interactive document that provides a clear overview of the lung cancer pathway. It outlines key stages – including diagnostic tests, appointments, and decision points - explaining what each step involves, why it is necessary, and when it is likely to occur. By increasing transparency and understanding, the tool aims to help patients and carers feel more informed, prepared, and supported throughout their cancer journey.

In addition to pathway guidance the tool signposts users to trusted sources of information and local support services, helping to address common barriers they may experience such as emotional distress, logistical challenges and financial strain.

We propose that patients receive a tailored version of the tool at different stages of their journey:

- **Investigation Phase:** A version mapping the diagnostic process could be provided when patients are referred for tests by GPs, Targeted Lung Health Check teams, emergency departments, or secondary care teams.
- **Post-diagnosis Phase:** A more detailed version outlining treatment options could be introduced following a confirmed cancer diagnosis.

Clinical Nurse Specialists are well positioned to introduce and guide patients through the tool. To ensure accessibility, both paper and digital formats should be made available.

## **Practical recommendations**

Based on our findings, we propose the following recommendations to enhance patient engagement, improve access, and support both patients and carers throughout the lung cancer care pathway:

### **1. Empower patients and carers with clear and accessible information**

- Provide tailored, plain language information for each stage of the care pathway
- Use multiple formats – such as printed materials, video, mobile applications, digital infographics, translated resources - to meet diverse literacy and language needs.

### **2. Ensure timely access to diagnostics and treatment regardless of location**

- Partner with local transport providers to offer subsidised or on-demand transport for hospital appointments
- Signpost available travel services early in the pathway to support planning and access
- Include transport equity as a key consideration in service planning and commissioning

### **3. Strengthen clinician-patient communication to support informed choice**

- Integrate communication and shared decision-making training into clinicians ongoing professional development
- Promote the use of decision aids during consultations and use patient feedback to continually assess and improve communication practices

### **4. Support and involve carers to reduce caregiver burden**

- Include informal carers in discussions and consultations wherever possible.
- Provide carers with information, support, and training to help them effectively support patients.
- Offer training in both the practical and emotional elements of care to patients and carers alike.

### **5. Improve patient experience through holistic and peer support**

- Establish and promote peer support groups and emotional wellbeing services for patients and carers.
- Develop and share 'lived experience' resources to help patients prepare for their care pathway and find hope in others recovery stories.

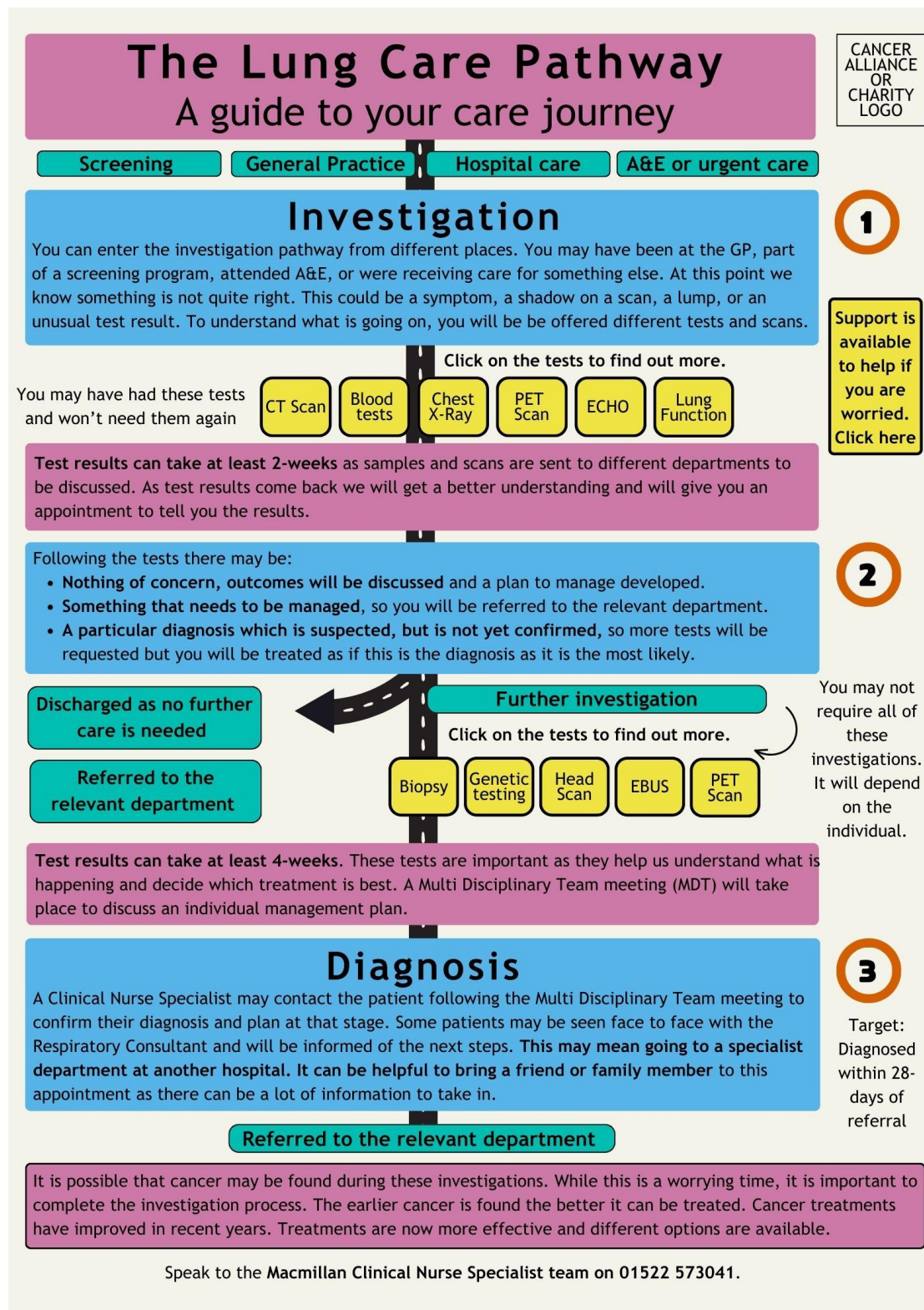
## Questions to consider?

Through this work, we have identified both common and context-specific challenges faced by patients with lung cancer. In response, we developed a prototype patient engagement tool designed to improve understanding, preparedness, and access to care. While this tool offers a promising approach, we recognise that some barriers – such as financial hardship, housing insecurity, and mental health challenges – require broader systematic solutions.

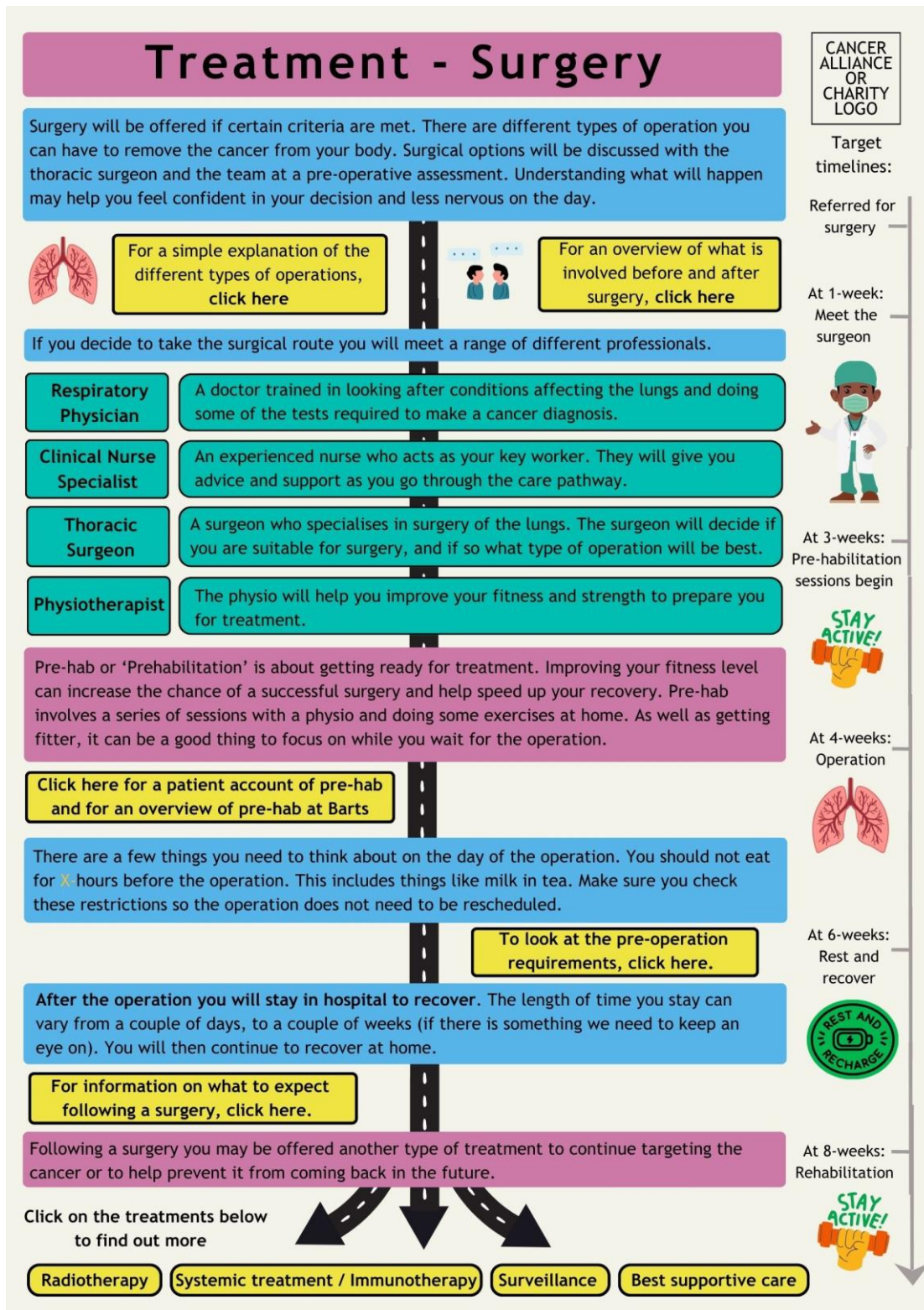
To ensure the success and sustainability of similar interventions, it is essential that they are tailored to local contexts and integrated into existing care pathways. As we look ahead, we invite health system leaders, service planners and local stakeholders to reflect on the following questions:

- Do you have access to up-to-date and comprehensive data on your local population and their engagement with your services?
- How can access to diagnostics and treatments be improved in your area particularly for underserved populations?
- What steps can be taken to better signpost and connect patients with local support services at the point of need?
- How can you better inform and prepare patients referred from primary care or via a Targeted Lung Health Check (TLHC) for their secondary care pathway?
- Are there clear opportunities emerging across the NHS to both deliver routine care in community settings and enhance appointment booking flexibility to improve accessibility and patient experience?

# Appendix A: Investigation pathway



# Appendix: Treatment pathway - Surgery



# Appendix: Treatment pathway – Radiotherapy

