"...I just got fed up with going up and down to the hospital. It felt to me every five minutes I was going up there. Yes, and I wasn't getting very much information about it."

Accessing lung cancer care in rural, coastal, and urban settings

A multi-method exploration of the barriers and facilitators to patient engagement

February 2026

CANCER RESEARCH UK

Together we are beating cancer

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About Cancer Research UK

We're the world's leading cancer charity dedicated to saving and improving lives through research. We fund research into the prevention, detection and treatment of more than 200 types of cancer through the work of over 4,000 scientists, doctors and nurses. In the last 50 years, we've helped double cancer survival in the UK and our research has played a role in around half of the world's essential cancer drugs. Our vision is a world where everybody lives longer, better lives, free from the fear of

cancer.

Cancer Research UK is a registered charity England and Wales (1089464), Scotland (SC041666), the Isle of Man (1103) and Jersey (247).

List of acronyms

1. ACE - Accelerate Coordinate Evaluate
2. BPOS – British Psycho-Oncology Society
3. BTOG – British Thoracic Oncology Group
4. CASP - Critical Appraisal Skills Programme
5. CNS – Clinical Nurse Specialist
6. COM-B – Capability Opportunity Motivation – Behaviour
7. COREQ - Consolidated Criteria for Reporting Qualitative Research
8. ICBs - Integrated Care Boards
9. IMD - Index of Multiple Deprivation
10. IPOS – International Psycho-Oncology Society
11. MDT – Multi-Disciplinary Team
12. MMAT – Mixed Methods Appraisal Tool
13. NCEL – North Central East London
14. NHS – National Health Service
15. PC - Personal Computer
16. PDF – Portable Document Format
17. PPIE – Patient and Public Involvement and Engagement
18. PROSPERO - International Database of Prospectively Registered Systematic Reviews
19. QMUL – Queen Mary University of London
20. RAP - Rapid Assessment Procedure
21. ROB-2 – A revised Cochrane risk-of-bias tool for randomized trials
22. ROBINS-1 - Risk Of Bias In Non-Randomized Studies - of Interventions
23. SCAN - The South East Scotland Cancer Network
24. SDG - Sustainable Delivery Respiratory
25. SOP - Standard Operating Procedures
26. UoL – University of Lincoln
27. ULHT - United Lincolnshire Hospitals NHS Trust

Executive summary

Background

Lung cancer is the third most common cancer in the UK and the leading cause of cancer mortality globally. The deprivation gap in lung cancer care and outcomes is larger than any other cancer type. Outcomes are beginning to improve, in part because of increased accuracy of diagnosis and the introduction of novel treatments. However, these improvements come with greater complexity and specialisation of the diagnostic and treatment pathway. Patients also face multifaceted individual-level barriers (e.g. access to transport, effective infrastructure, restrictive employment or finances, English as a second language, education) which make effectively accessing and engaging with lung cancer care more challenging. These barriers need to be understood and targeted to address the deprivation gap. Tools are resources which aid users to complete a specific task. Digital tools are being used more frequently in healthcare to support delivery of high-quality care and to facilitate health monitoring and engagement by patients. Developing a tool to support patients on the lung cancer pathway may make navigating the complex lung cancer pathway more manageable and provide ways to overcome individual-level barriers.

We conducted a collaborative place-based research project across urban, rural, and coastal areas of England. The urban component took place in Northeast London, led by researchers from Queen Mary University of London (QMUL) and in collaboration with clinicians from Barts Health NHS Trust, which serves ~2.6 million people across five hospitals. The rural and coastal component was conducted in Lincolnshire, East Midlands and was led by researchers from the University of Lincoln (UoL), working with clinicians from United Lincolnshire Hospitals NHS Trust (ULHT) that serves ~770,000 people across a predominantly rural county with over 50 miles of coastline to the East.

Research approach

We conducted three interrelated workstreams to generate translatable evidence and inform the evidence-based design of a patient engagement intervention. The workstreams were as follows:

1. **A qualitative cross-sectional interview study** was conducted to explore factors influencing individuals' capability, opportunity, and motivation to engage with their lung cancer care pathway. Semi-structured Interviews were conducted with 55 patients (North East London n=30 / Lincolnshire n=25) and 31 carers (North East London n=13 / Lincolnshire n=18). Patients and carers were purposively recruited, and interviews were conducted in

person or by phone, either individually or as patient-carer dyads. Triangulation and analysis informed by a behavioural science framework (the COM-B model) identified modifiable intervention targets. These factors were then mapped against components of the Theoretical Domains Framework to assess implementation challenges and support intervention development.

2. **Mixed stakeholder workshops** were held at three timepoints (March, June, and December 2024) which aimed to explore the perspectives of administrative and clinical professionals from North East London and Lincolnshire regarding the barriers and facilitators to patient engagement, tool design, and implementation. Experienced researchers facilitated the series of workshops in person or via Microsoft Teams (1-hour). Individual consultations were also conducted where necessary to capture views from a range of stakeholders.

3. **A rapid evidence synthesis** was conducted to identify, collate, and synthesise academic evidence (published between 2014 and 2024) which describes patient engagement interventions that have been used to support people diagnosed with lung cancer. A narrative synthesis of extracted data was developed to report on intervention approaches to improving patient engagement and experience, intervention effectiveness, and implementation barriers/facilitators.

Key findings

Workstream 1: A qualitative cross-sectional interview study

- No matter where people live, people with lung cancer and their carers demonstrate a lack of accurate knowledge and understanding of lung cancer and their recommended care pathway.
- Patients were not always engaged in collaborative discussions with healthcare providers which could lead to uncertainty, anxiety and avoidance of treatment.
- Carers played an integral role in supporting patients with both the emotional and practical elements of care.
- Public transport and free travel ‘freedom passes’ were huge benefits for mobile individuals in London, whereas navigating multiple hospital sites combined with poor transport capabilities and support services were challenges for those in rural and coastal areas of Lincolnshire.

Workstream 2: Mixed stakeholder workshops

- The patient engagement tool was viewed as an important reference point for patients, especially during emotionally overwhelming periods and could empower patients to engage in their pathway and address barriers not discussed during appointments.
- Early 'buy-in' at each stage of the pathway improved patient engagement, as did facilitating carer support, and reducing travel by scheduling consecutive appointments at local hospitals.
- Linking with communities and signposting to local information and places was seen as key and could help overcome certain barriers (e.g. transport).
- It was agreed that a tool should be offered in both paper and digital formats.
- To encourage uptake by patients, a clear explanation of what the tool is, and its value is crucial.
- An education training session to maintain awareness of the tool, and endorsement by formal bodies such as the local Cancer Alliances, may aid clinical staff implementing the tool.
- Establishing the tool as a standard document for all 'urgent suspected cancer' referrals and including it in SOPs for admin staff would also facilitate implementation. Demonstrating tool impact across sites could drive wider Trust adoption.

Workstream 3: A rapid evidence synthesis

- A wide range of patient engagement interventions for lung cancer patients were identified. These were educational/Informational, navigational, decision support, system/pathway, psychosocial support, symptom assessment, care planning, and physical activity interventions.
- Barriers to intervention implementation included timing of intervention delivery, digital access and literacy issues, technical challenges, system and resource limitations.
- Enablers of intervention implementation included using co-production methods, providing training and support for implementers, caregiver involvement, and broad recruitment strategies.
- Interventions were shown to be effective in improving outcomes related to patient knowledge, patient activation, decision making, psychosocial well-being, whilst reducing healthcare use and symptom severity.
- Despite the effectiveness of interventions, the overall quality of intervention development or reporting was evaluated as poor. This reduces the potential applicability of the interventions into practice.

Overall findings and conclusion

The concept for a novel patient engagement tool has been developed that may enhance how lung cancer patients and carers engage with and experience their care. As the tool is in the early stages of development, further work is needed refine the tool and inform implementation. As the tool concept is for an adaptable 'blueprint', it has the potential to be implemented across diverse healthcare and geographic settings to inform patients and address common barriers.

Lay summary

Lung cancer is one of the most common cancers in the UK and causes more deaths than any other cancer. New tests and treatments mean that doctors can discover lung cancer earlier and people have a better chance of being cured of cancer or can live for longer with cancer. However, these new tests and treatments mean that healthcare has become more complicated to use.
On top of this, there are other things that may stop people receiving the care that they need. For example, where people live, or the skills, information, or resources that people have, may make it easier or harder for someone to receive help. This may cause potential problems that can leave people feeling confused and anxious about their lung cancer care and can sometimes make them avoid or delay treatment.

What did we do?
We ran a study to understand what makes it easier or harder for people with lung cancer to get the care they need and to help us design a simple tool to make people feel more involved and confident in following through with their cancer care.
The study was run in two places 1) North East London and 2) Lincolnshire. This meant we could look at what things were similar or different across cities, rural, and coastal areas to help us better support people affected by lung cancer in these different areas.

How did we do it?
We spoke with 55 people with lung cancer and 31 carers (close family and friends) across North East London and Lincolnshire, either face-to-face or by telephone or video call. These conversations helped us to understand what people with cancer and their carers go through, how they feel, what support they need, and what made their care easy or difficult.
We also had conversations with cancer professionals (e.g. people from the NHS, local government, and universities) to understand their views on how we could better support patients and how to design a tool to help people feel more involved in their lung cancer care.

What did we find? - Conversations with people with lung cancer and carers

- People with lung cancer, and their carers, often found it hard to fully understand the care and treatment being recommended to them. This was the case regardless of where people lived (i.e. urban, rural, or coastal areas).

- People with lung cancer and their carers did not always have clear, open, two-way conversations with their healthcare team. This sometimes left them feeling unsure, worried, or wanting to avoid or delay treatment.
- Carers were a big help to patients, helping them to understand their cancer and care and providing both emotional and practical support for them
- In Lincolnshire, patients often had to travel to different hospitals for tests and treatment, and surgery was always done outside of the county in Nottingham city hospital. In North East London, patients were referred to one central London hospital for treatment after their diagnosis.
- In rural and coastal Lincolnshire, unreliable public transport meant many patients had to rely on lifts from family or friends. In North East London, public transport made travel easier, but wasn't always suitable for older, disabled, or unwell patients to use. Hospital transport was viewed as poor and unfit for purpose across both areas.
- Patients and carers often felt overwhelmed by their diagnosis and found it hard to understand information during this time. Staying positive and trusting their care team helped them cope and stay on track with treatment.
- Patients and carers had mixed feelings about the healthcare system. Many said it was hard to get referred and diagnosed, but felt care usually got better once diagnosed and lung cancer care and treatment had started.

What did we find? - Conversations with cancer professionals

- The professionals told us that it was hard for patients to take part in their lung cancer care due to challenges with them understanding what was happening or what they were being told, and their emotions.
- When patients and carers did not fully understand what was happening or why it was important to attend appointments quicky it could lead to delays.
- There could be difficulties communicating with patients who did not speak English, contacting people by phone and post, and trying to explain information accurately but in plain English.
- When emotions were high and patients felt scared about tests or treatment they could be overwhelmed and struggle to make decisions. The professionals also identified wider issues for the patient that can have an effect on care, like job worries, feeling guilty about smoking, homelessness, using drugs, and mental health problems.

How did we use these findings?

We used what we learned from speaking with people living with lung cancer, their carers and cancer professionals to help design a tool that supports patients to be more involved in their care. We developed many versions of the tool, improving

each one by working closely with cancer professionals and people who have personal experiences of lung cancer. The tool has been designed to help patients and carers see what their lung cancer care journey will look like. It gives clear information on what tests and appointments to expect, why they are needed, and when they will likely happen, so that people feel more prepared and supported at every step.

Summary

Patients and carers in urban, rural and coastal areas face challenges when trying to access lung cancer care. More can be done to help patients feel informed and involved: such as provision of clear and easy-to-understand information at different stages of care and involving patients in decisions about their care. Developing a resource which can tell patients and carers about local and national support services may make it easier for them to manage challenges, take part in their care, and have a better experience.

Introduction

Lung cancer remains a major public health challenge in the UK [1]. It is the third most common cancer and the leading cause of cancer related mortality [1,2]. In England, Lung cancer has the largest deprivation gap compared to any other cancer type. Individuals living in the most deprived communities are more likely to be diagnosed at a later stage, experience emergency presentation, and have poorer survival outcomes compared to those living in less deprived areas [3-5].

Encouragingly, outcomes for lung cancer are beginning to improve [6]. Advances in the accuracy of diagnosis as well as the introduction of novel treatments are improving outcomes for many patients [6]. However, these developments have also increased the complexity and specialisation of the lung cancer pathway [6, 7]. Patients are now required to navigate more complicated diagnostic processes, multidisciplinary treatment planning, and are often required to visit multiple hospital sites [7]. As the pathway becomes more advanced, it may also become more challenging to navigate, particularly for individuals already facing structural or personal disadvantage [3,4,8].

Alongside structural inequalities, cancer patients may experience multifaceted individual-level barriers that can affect their ability to access and engage with care. These may include limited transport options [9], dispersed healthcare infrastructure [10], financial pressures [11], restrictive employment [12], low health literacy [13], English as a second language [14], and limited social support [15]. For patients living in rural and coastal areas, travel distances [16,17] and service distribution [18] may compound these challenges, while those in urban settings may face similar but also unique barriers such as housing instability, financial and employment hardship, substance misuse, unmet social support, complex transport systems [19,20]. Understanding how these structural and individual factors intersect is essential to addressing the persistent inequities in lung cancer outcomes across urban, rural, and coastal areas.

To explore these issues, we undertook a collaborative place-based research project across contrasting urban, rural, and coastal settings in England [21]. By examining lung cancer care in North East London and Lincolnshire (two regions with markedly different service structure, population demographics, and geographic challenges) we sought to understand how personal circumstances and location shapes patients' and carers' ability to access and engage with their care pathways. This comparative design allowed us to identify both shared and location-specific barriers to engagement, generating actionable insights to inform more equitable service delivery and targeted intervention development.

Digital tools are being used more frequently in healthcare to support delivery of high-quality care and to facilitate health monitoring and engagement by patients. Tools are resources which aid users to complete a specific task. Healthcare tools can include patient facing apps, symptom checkers, medical calculators, decision-support tools, wearable devices, and much more. Developing a tool to support patients on the lung cancer pathway may make navigating the complex lung cancer pathway more manageable and be one way to overcome the individual-level barriers that affect patients' ability to access and engage with care.

Research aims and objectives

This work initially formed part of a broader project run by Cancer Research UK's Accelerate Coordinate Evaluate (ACE) Programme. The project was focussed on achieving universal access to optimal specialist investigation and treatment for lung cancer patients. To capture experiences from patients and carers in different geographic setting, we focused on two distinct and contrasting regions (North East London and Lincolnshire).

The overarching aim of our research project was to:

1. Better understand the factors influencing patients' and carers' engagement in, and experience of, their recommended lung cancer care pathway, in urban, rural, and coastal settings.
2. Develop a patient engagement tool aimed at enhancing patient and carer participation in, and overall experience of, their recommended lung cancer care pathway.

We set out to understand the shared and context specific challenges faced by patients and carers, by conducting three interlinked work packages, with activities run at both locations.

The specific aims of the work packages were:

1. To explore and characterise how lung cancer patients' and carers' characteristics and their location in relation to specialist services intersect and impact on their capability, opportunity and motivation to engage optimally with (i.e., attend and participate in) their recommended lung cancer pathway, from diagnosis through treatment, in North East London.
2. To generate translatable evidence to inform the evidence-based design of a patient engagement intervention to improve lung cancer patients' and carers' participation and experience of the lung cancer care pathway.
3. To generate tool specific insights and broader recommendations for how an intervention to facilitate patient engagement with the lung cancer pathway may be best designed and implemented, to address inequalities in cancer care.
4. To identify, collate, and synthesise academic evidence describing patient engagement interventions that have been used to support people diagnosed with lung cancer.

Methods overview

This study comprised of three interrelated workstreams to generate translatable evidence and inform the evidence-based design of a patient engagement intervention. This included 1) A qualitative cross-sectional interview study, 2) Mixed stakeholders workshops, and 3) A rapid evidence synthesis. Ethical approval was granted by NHS Oxford B Research Ethics Committee and the NHS Health Research Authority (REC Ref: 23/SC/0255; IRAS ID: 328531; approved 04/08/23). The interview study protocol was pre-registered on the Open Science Framework [21]. The rapid evidence synthesis protocol was pre-registered on the International Database of Prospectively Registered Systematic Reviews (PROSPERO) (CRD42024521052) [22].

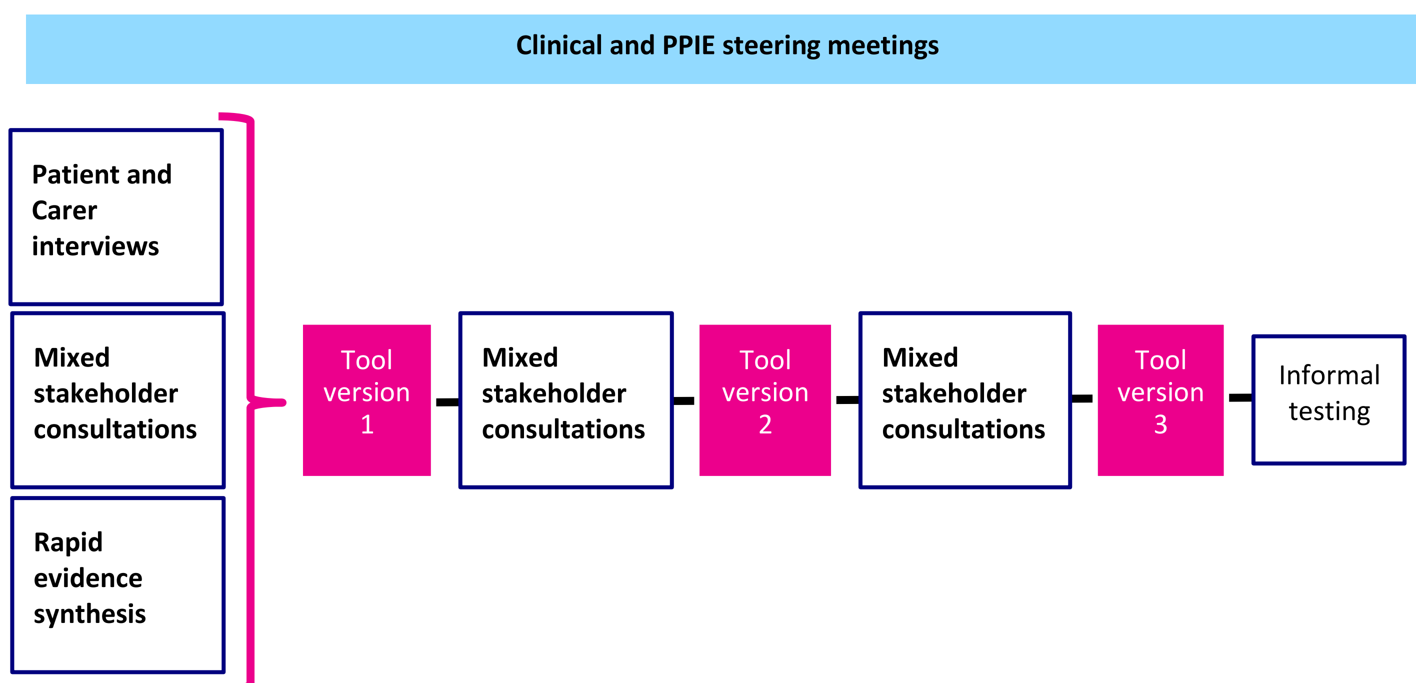


Figure 1. Overview of methods for generating evidence and developing an evidence-based patient engagement intervention

Interview

Study design

We used a cross-sectional qualitative interview study design, theoretically underpinned by the COM-B model of behaviour change (Capability, Opportunity, Motivation – Behaviour) [23]. The COM-B framework was used to guide both data collection and analysis, enabling systematic identification of behavioural and structural determinants influencing engagement with lung cancer care. COM-B was selected because it provides a structured yet flexible approach to understanding modifiable influences on health-related behaviour and offers a clear translational pathway into intervention development.

A person-centred pragmatic epistemological approach informed the study [24]. This approach recognises knowledge as grounded in lived experience and prioritises understanding real-world challenges, in order to generate actionable findings. The pragmatic orientation supported the integration of both inductive (data-driven) and deductive (theory-informed) analytic processes. Inductive analysis ensured that participants' unique experiences were captured without constraint, while deductive mapping onto COM-B domains enabled interpretation of findings in a way that supported intervention design and development. This study was reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ).

Participants and recruitment

Participants were identified and approached via clinical teams within Barts Health NHS Trust and United Lincolnshire Hospitals NHS Trust between November 2023 and October 2024. Clinical staff introduced the study to eligible individuals during routine appointments. Those who expressed interest were provided with study information and subsequently contacted by the research team to discuss participation. Written or verbal informed consent was obtained prior to interview.

Participants were adults diagnosed with lung cancer within six months of their initial diagnosis and receiving either surgery, radical radiotherapy, or treatment for advanced disease, including systemic anti-cancer therapy or specialist palliative/best supportive care where anti-cancer treatment had been offered. Informal carers of eligible patients were also invited to participate, provided the patient had been diagnosed within the same six-month timeframe. This timeframe was selected to capture experiences close to diagnosis and during active engagement with the care pathway, while minimising retrospective bias.

A purposive sampling strategy [25] was employed to ensure representation across

the two study regions (North East London and Lincolnshire) and across treatment pathways. Following initial recruitment, a maximum variation sampling approach was applied to enhance diversity in relation to gender, age, ethnicity, socioeconomic position, geography (urban, rural, coastal), and patient–carer relationship. This approach enabled exploration of both shared and context-specific experiences and ensured sufficient information power to support comparative analysis.

Data collection

Data were collected through semi-structured interviews conducted between November 2023 and October 2024. Participants were offered the option of taking part individually or, where appropriate, in a dyadic interview with their carer or the patient, enabling exploration of shared and relational experiences [26].

An interview topic guide was developed and informed by the COM-B model of behaviour change [23]. The guide explored experiences of investigation, diagnosis, treatment decision making, communication, travel, access to services, emotional responses, practical challenges, and sources of support. The semi-structured format allowed for consistent coverage of core domains while retaining flexibility to explore issues of particular relevance to each participant.

Demographic and clinical information, including age, gender, ethnicity, employment status, smoking history, performance status, and stage of disease, was collected during interviews or extracted from medical records with participant consent. Postcode data were used to derive Index of Multiple Deprivation (IMD) quintiles and classify participants according to the Office for National Statistics Rural–Urban Classification. Coastal status was defined as residence within 5 km of the coastline.

Throughout data collection, researchers completed Rapid Assessment Procedure (RAP) sheets to summarise key issues emerging from each interview. Regular cross-site meetings were held to discuss emerging insights, compare patterns across geographical contexts, and refine areas of enquiry. Reflexive practice was embedded throughout to ensure ongoing critical reflection on researcher positioning and interpretation.

Analysis

Interview data were analysed using Framework Analysis, following the five-stage approach outlined by Ritchie and Spencer (1994) [27]. This involved: 1) Familiarisation with the data, 2) development of a thematic framework; 3) systematic indexing of the data according to that framework; 4) charting data into structured matrices to enable comparison across cases; and finally, 5) mapping and interpretation to

identify patterns, relationships, and overarching themes. Rapid Assessment Procedure sheets and ongoing analytic meetings supported cross-site comparison and reflexive interpretation throughout the process.

Results

A total of 86 participants were interviewed across Lincolnshire (total n=43; patients: n=25; carers: n=18) and North East London (total n=43; patients: n=30; carers: n=13). This comprised of 55 patients (surgical n=20, radical radiotherapy n=14, treatment for advanced disease n=21) and 31 carers (surgical n=11, radical radiotherapy n=9, treatment for advanced disease n=11). Among patients, 47.3% were female, while 63.6% of carers were female. The majority of participants identified as White British (patients: 74.5%; carers: 71%), with representation from Asian (patients: 10.9%; carers: 12.9%) and Black (patient: 7.3%; carers: 3.2%) ethnic groups. Over half of patients (approximately 55%) and over one-third of carers (35%) resided in areas of high socioeconomic deprivation (IMD quintiles 1–2).

Five overarching themes were identified, capturing the physical, social, and emotional factors influencing patient and carer engagement in the lung cancer care pathway across urban, rural, and coastal settings. These included 1) Location and system factors, 2) Knowledge and understanding of cancer and care, 3) Communication and collaboration across the pathway, 4) Emotions and coping through cancer, and 5) Support systems and social and physical constraints.

1. Location and System Factors

Geography significantly shaped access to care across urban, rural, and coastal areas. Patients in rural and coastal Lincolnshire faced dispersed services, long travel distances, limited public transport, and financial burden associated with travel, often requiring attendance at multiple hospital sites. In contrast, patients in North East London benefited from proximity to specialist centres and wider transport options, though challenges such as congestion, parking costs, and reliance on carers remained. Across both regions, hospital transport services were often viewed as inefficient and restrictive. Travel demands disrupted routine and for some patients and carers contributed to emotional, physical, and financial strain.

"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?" **Carer, Advanced, Urban Lincolnshire**

"Yes that was my choice. Mile End was my choice to do these exercises. I always, with my doctors I always used to go down for like blood tests or x-rays […] So it was always an easier option, no waiting, no queuing things like that. Mile End was always my choice of easy venues if you like."

Patient, Surgery, North East London

"I don't travel on public transport, I can't- Must be about 25 years since I've been on a bus or a train" **Patient, Radiotherapy, North East London**

2. Knowledge and Understanding of Cancer and Care

Knowledge and understanding of lung cancer and its treatments varied widely among patients and carers. Limited health literacy and exposure to outdated or fatalistic beliefs contributed to fear and hesitation in some patients, particularly surrounding engagement with chemotherapy and surgery. Online information was sometimes helpful but often triggered anxiety and confusion for patients and carers. Clear explanations, visual aids, and discussions with trusted clinicians or peers improved understanding and confidence. When patients had a wider understanding surrounding the rationale for recommended treatments, they were more willing to engage.

"And an aversion to being in hospital. Plus the fact that you don't know whether you are going to come round or not. This is going to sound very strange to you, I had, and I'm talking in the past tense, an aversion to going into hospital. You couldn't drag me there…." **Patient, Radiotherapy, Rural Lincolnshire**

"You think chemotherapy, it's going to come in a big syringe, and they're going to put it straight into your arm, and you're going to be glowing, […] and you're going to be sick every week, because that's all we used to hear about…" **Patient, Radiotherapy, North East London**

3. Communication and Collaboration Across the Pathway

The quality of communication and collaboration directly shaped patient and carer experience, with effective communication building trust and engagement, and poor communication leading to anxiety and uncertainty. Indirect language during diagnosis (e.g. healthcare professionals avoiding the use of the word "cancer"), inconsistent information, and technical terminology often caused confusion and distress among patients and carers. Several patients reported that they were initially told their cancer had not spread, only to later learn that it had, leading to confusion and distress about the seriousness of their diagnosis. Positive experiences were characterised by clear, compassionate communication, shared decision making, visual explanations, and allowing time to ask questions. Carers played a critical role in facilitating understanding and supporting decision making throughout the lung cancer pathway.

"You have a cancer in your lung, but the good news is that the cancer hasn't spread. I remember my son saying very quickly - That we would take any small wins. So she talked a lot about it, and then she said she would get the oncologist to come and have a word with me. So the oncologist came in, a very nice woman, I can't remember her name but I have it written down, and the Macmillan nurse was there as well, she said - What do you remember about what you have been told, because it's a lot to take in? I said obviously the good news is that it hasn't spread. And she said - I'm sorry to tell you but that's completely wrong, it has. It is in your bones and in your liver, the primary is in your lung" **Patient, Advanced, Rural Lincolnshire**

"It's too much, they hit you with medical jargon all the time, and I think if they just backed off from that and gave it to you in plain English, you would understand a lot more. " **Patient, Radiotherapy, Rural Lincolnshire**

4. Emotions and Coping Through Cancer

Diagnosis and treatment were emotionally overwhelming for many patients, often affecting their ability to process information and engage fully in discussions and appointments. Carers often assumed advocacy roles during this period and played an integral role in processing information, organising appointments, and providing emotional support. Emotional responses ranged from fear and distress to determination and proactive self-advocacy. For some, worry could motivate individuals to engage in their care but for others it acted as a barrier which often became overwhelming. Coping strategies included maintaining normality, adopting a positive outlook, setting goals, seeking peer support, and building trust with healthcare teams.

"Before the surgery, people were telling me about the same surgery that I was having and telling me the outcome. So, I thought if it's worked for them, then it could work for me" **Patient, Surgery, Rural Lincolnshire**

"I walked out the hospital a couple of times while I was waiting for it [surgery]. I just thought to myself, no I can't hack this." **Patient, Advanced, North East London**

5. Support Systems and Social and Physical Constraints

Financial strain was a prominent barrier for patients and carers, particularly related to travel costs and loss of employment. Managing comorbidities alongside lung cancer further complicated engagement in their care pathway. Carers provided essential practical, emotional, and administrative support, though their own health and financial circumstances sometimes limited capacity. Access to wider support services varied geographically, with inequities in translation services and community support. Where strong social networks and professional support were available, patients were better able to navigate and engage with care.

"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" **Patient, Advanced, Rural Lincolnshire**

"…He was like, "[Carer], I am feeling this", and I was like, "Actually, they did say that is one of the more extreme side effects, so that probably makes sense, but, yes, if it gets any worse, then just call 111, Dad. That is what they advised." **Carer, Advanced, North East London**

Stakeholder workshops

Study design

A series of mixed stakeholder workshops were conducted to explore the perspectives of administrative and clinical professionals from North East London and Lincolnshire. Each workshop had a specific focus and aims related to the development of a patient engagement tool for the lung cancer care pathway.

The aims were as follows:

Workshop 1:

1. Explore administrative and healthcare professional perspectives of what the barriers and facilitators are for patient engagement in their recommended lung cancer pathway.
2. To generate ideas to inform the development of a patient engagement tool to support patient engagement and experience.

Workshop 2:

1. To present our prototype tool and provide an overview of the envisioned direction.
2. To gather attendees' reflections, insights and suggestions to inform the design, content and format of the patient engagement tool.
3. To learn from experience in other cancer areas and specialities to inform the future implementation of the patient engagement tool.

Workshop 3:

1. Identify facilitators and barriers to implementing a patient engagement tool in the lung cancer care pathway of Barts Health/United Lincolnshire NHS Trust.
2. Discuss strategies and approaches which may make the implementation and delivery of the patient engagement tool more effective in clinical practice.

Participants and recruitment

Clinical and administrative stakeholders were identified at both sites by clinical members of the steering committee and were invited to participate by email. Workshop 2 was held in-person at the Lincolnshire Cancer Summit, and conference attendees could sign up to attend the workshop. The conference was a local cancer congress which drew in clinical, academic, policy, and organisational

professionals. Participating stakeholders included healthcare professionals (oncologists, respiratory physicians and consultants, lung cancer nurse specialists, thoracic nurse specialists, surgeons, physiotherapists), care coordinators, and pathway or programme managers, and those involved in integrated care boards (ICBs), cancer alliances, primary care practices, hospitals, universities, and private corporations.

Data collection

Mixed stakeholder workshops were held at three timepoints (March, June, and December 2024). Experienced researchers facilitated the series of workshops in person or via Microsoft Teams (1-hour). Individual consultations were conducted where necessary to capture views from a range of stakeholders. Each workshop began with the facilitators welcoming the stakeholders, providing brief project background, an overview of the work conducted, key definitions, and setting out the aims of the workshop. The group discussed the topics as a whole and notes were taken by members of the research team. To ensure all stakeholders had the opportunity to share their perspective, any additional comments could be provided on paper handouts or by email.

Analysis

After each workshop, the notes were reviewed by the research team and synthesised to produce a report of key findings. Findings from workshop one helped us to better understand the factors influencing patients' and carers' engagement in, and experience of, their recommended lung cancer care pathway, from a clinical stakeholder perspective. Findings from workshops 1-3 informed the development of the patient engagement tool and the plan for implementation.

Results

Perspectives on tool features and characteristics
Stakeholders felt a patient engagement tool needed to adapt to patient needs as they progressed through the pathway and direct them to relevant local information. Including information on the local cancer pathway, such as expected timelines, instructions on what to bring to appointments, and local contact numbers for support were thought to be beneficial. The tool content would need to be adapted to local contexts, as processes, timelines, and services varied between region and hospital. Signposting local support services was suggested to help patients overcome barriers to access. For instance, charities, volunteer groups, support groups, and council services, to help with transport, interpretation or translation, legal and financial advice. Additionally, stories of people who have

undergone similar cancer experiences and 'Frequently Asked Questions' were seen as useful.

Stakeholders felt the tone and content of the tool needed to be suitable for all levels of health literacy. The presentation, format, and language also need to be suitable for those who are colourblind, have a low reading age, or are non-English speaking. High quality translation of the tool into multiple languages was strongly recommended. There was wide agreement that the tool should be available in both paper and digital formats. Digital materials were seen as a useful way of delivering large amounts of information in an accessible form. However, concerns about digital access and digital literacy were repeatedly raised. Stakeholders flagged that patients in rural and deprived communities may have unstable internet connections, older populations may be less technology literate, and deprived populations may not have reliable access to smartphones and computers. Paper documents were therefore felt to be appropriate and essential for the lung cancer population. Additionally, signposting to services and resources is more challenging on paper compared to the use of digital hyperlinks. Lastly, stakeholders recommended having the tool available in multiple formats (e.g. mobile, PC, PDF, website, printouts) as delivery could then be adapted to patient preferences.

Perspectives on implementation

Stakeholders reiterated the need to introduce a tool early in the pathway to encourage early engagement and minimise misinformation. The first clinical appointment with the respiratory team may be the right time to discuss patient engagement in-depth, as CNSs are often present, bad news has been delivered, and this appointment can be useful for identifying specific barriers. It was also felt that offering a tool at one timepoint was too restrictive as patients enter the lung cancer pathway in different ways and undergo different diagnostic tests. Reintroducing the tool throughout the pathway was thought to offer more opportunities to engage. It was suggested that the benefit of the tool needed to be communicated clearly during the initial introduction, and that to maximise the benefit, patients need to keep going back to the tool. Initial awareness could be raised by advertising through patient advocacy groups, nursing forums, charities, and professional societies.

Directing patients to digital resources was seen as challenging within the NHS. It was not easy to share information with patients via email, and not all departments had text-messaging services enabled due to cost. Stakeholders felt that paper documents would be easier to distribute to patients within the NHS as paper copies of the tool could be incorporated into existing systems, such as sending with appointment letters or handed to patients in-person. Stakeholders noted that

challenges to implementation would arise at each location due to differences in department processes and systems. While staff could be encouraged to deliver the tool by linking it with Standard Operating Procedures (SOPs) or recommended guidelines, stakeholders noted that introducing additional steps for manual processes could be burdensome. Stakeholders identified training and support, and buy-in from senior staff and management, as essential for effective implementation.

Rapid Review

To further inform the design of the patient engagement intervention, we conducted a rapid systematic review [22]. We wanted to learn from interventions used previously with lung cancer populations to facilitate patient experience and patient engagement. We chose to apply rapid review methodology so the evidence could be generated in a timely manner and therefore support the pragmatic development of our patient engagement intervention.

The objectives of the review were:

1) Describe the nature of interventions, including their components, theoretical underpinnings, delivery method, dose and intensity, and where they were implemented.
2) Descriptively summarise the effectiveness of these interventions.
3) Identify the barriers and facilitators associated with the implementation of these interventions.

Methods

A search was conducted on MEDLINE which included variations on the terms 'lung cancer', 'intervention', and 'patient engagement'.

We searched for peer-reviewed publications which reported qualitative, quantitative or mixed-method research on interventions designed to improve patients experience and/or engagement with their recommended lung cancer care. Eligible study populations were adults, who had received a lung cancer diagnosis. Studies needed to be written in English and conducted in a high-income country (as defined by the Organisation for Economic Co-operation and Development).

Exclusion criteria were; non-empirical studies, non-peer reviewed studies, interventions not aimed at facilitating engagement with the diagnosis or treatment pathway, studies of lung cancer survivors, and papers where lung cancer populations could not be separated from other cancer types of health conditions.

All the records were title and abstract screened, and those which met the criteria were full text screened to confirm eligibility.

Analysis

Data extraction was conducted using an extraction form. The form included the components of the TiDieR checklist for intervention description [28]: Intervention name, rationale, materials, procedures, provider, mode of delivery, location, dose and intensity, intervention tailoring, modifications, and intervention fidelity. We also

extracted author, study aim, year of publication, study setting, study design and methods, population characteristics, outcomes, and a summary of study findings. Studies which evaluate intervention effectiveness was evaluated for quality using the suitable tool (ROB-2, ROBINS-1, CASP, or MMAT) [29-32]. A narrative synthesis [33] was then conducted to descriptively summarise the effectiveness of the interventions, and the barriers and facilitators to implementation

Results

Intervention type and components
The review identified a diverse body of research evaluating interventions to enhance engagement in lung cancer care. Most studies focused on patient-level interventions, although some targeted clinician practice or system-level processes. Eight broad intervention types were identified: informational and educational (n=9), navigational (n=8), decisional (n=6), pathway-level (n=4), symptom assessment (n=2), psychosocial (n=2), advanced care planning (n=1), and physical activity (n=1). Outcomes commonly assessed included patient knowledge, patient activation, decision-making, symptom burden, psychosocial wellbeing, healthcare utilisation, and quality of care indicators.

Interventions were delivered across clinical settings, home settings, embedded within routine care with some delivered remotely. Delivery was led predominately by healthcare professionals, trained navigators, or lay staff, using face-to-face, telephone, digital, or printed formats depending on intervention type. Timing varied across the care pathway, from pre-treatment to extended follow-up, and intensity ranged from single-session interventions to structured programmes delivered over several months, with some lasting up to one year.

Intervention effectiveness
interventions showed positive but variable effects across engagement related outcomes. Educational approaches generally improved patient and caregiver knowledge, while decisional interventions reduced decisional conflict and strengthened shared decision-making. Improvements in patient activation were observed across some symptom assessment interventions, though findings were not consistent. Several interventions were associated with improved healthcare use and access, including reductions in unplanned admissions and improved timeliness of treatment. Symptom-focused interventions reduced symptom severity and improved management. Psychosocial interventions demonstrated benefits in reducing distress, anxiety, stress, and caregiver burden, and in improving confidence and self-efficacy. Patient satisfaction findings were mixed: navigation and pharmacy integrated models improved satisfaction, and clinician communication training enhanced perceived communication quality, but

pathway-level and distress screening interventions did not consistently improve satisfaction.

Barries and facilitators to intervention implementation
Common barriers to participation included patients feeling too emotionally overwhelmed or too unwell, limited time, lack of perceived benefit, and poor timing of intervention delivery (e.g. too close to diagnosis). Digital interventions were challenged by low digital literacy, limited internet access, and the technical elements of interventions, particularly among older patients. Practical constraints such as transport difficulties, form completion, and limited home support also affected engagement. From a provider perspective, time pressures, workflow constraints, extensive training materials, and organisational changes within healthcare systems created additional implementation challenges. Patients with poor performance status were often underrepresented due to illness severity and attrition.

Key facilitating factors included the use of co-production and participatory approaches involving patients, carers, and healthcare professionals in intervention design, which enhanced relevance and acceptability. Providing structured training and ongoing support to those delivering interventions was also critical to successful implementation. Flexible recruitment strategies, inclusion of carers, adaptable delivery formats, and practical supports (e.g., travel reimbursement) were identified as important strategies to improve uptake and engagement.

Discussion

Development of a prototype patient engagement tool

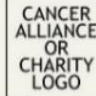
Based on interviews with patients and carers, and consultations with stakeholders, we explored the barriers to patient engagement experienced by people on the lung cancer pathway in rural, coastal, and urban areas. We combined these insights with the learnings from the literature review, to develop a concept for a patient engagement tool. The tool content and appearance were adapted in an iterative process of feedback and refinement.

The concept for the tool is a document which provides information on the lung cancer pathway to help patients understand the purpose of appointments, set expectations, and direct them to local guidance and support. Signposting services can help to addressing barriers to patient engagement (such as travel, finances, and mental health) and improve the patient experience.

Ideally the tool would be divided into two parts: 1) Investigation and 2) Diagnosis and treatment. Part 1 could be delivered at entry into the lung cancer pathway by GPs, Targeted Lung Health Check teams, Emergency room staff, or secondary care staff following referral. Part 2 could be delivered in the respiratory clinic by a CNS after the patient has received their diagnosis. This division would ensure that patients are informed but not overwhelmed with information which is not yet relevant to them. A digital and paper version of the tool should be available to meet the needs of the diverse patient population and the capacity of local context.

The Lung Care Pathway

A guide to your care journey



Screening | General Practice | Hospital care | A&E or urgent care

Investigation

1

You can enter the investigation pathway from different places. You may have been at the GP, part of a screening program, attended A&E, or were receiving care for something else. At this point we know something is not quite right. This could be a symptom, a shadow on a scan, a lump, or an unusual test result. To understand what is going on, you will be be offered different tests and scans.

Support is available to help if you are worried. Click here

Click on the tests to find out more.

You may have had these tests and won't need them again

CT Scan | Blood tests | Chest X-Ray | PET Scan | ECHO | Lung Function

Test results can take at least 2-weeks as samples and scans are sent to different departments to be discussed. As test results come back we will get a better understanding and will give you an appointment to tell you the results.

2

Following the tests there may be:

- **Nothing of concern, outcomes will be discussed** and a plan to manage developed.
- **Something that needs to be managed,** so you will be referred to the relevant department.
- **A particular diagnosis which is suspected, but is not yet confirmed,** so more tests will be requested but you will be treated as if this is the diagnosis as it is the most likely.

Discharged as no further care is needed

Referred to the relevant department

Further investigation

Click on the tests to find out more.

Biopsy | Genetic testing | Head Scan | EBUS | PET Scan

You may not require all of these investigations. It will depend on the individual.

Test results can take at least 4-weeks. These tests are important as they help us understand what is happening and decide which treatment is best. A Multi Disciplinary Team meeting (MDT) will take place to discuss an individual management plan.

Diagnosis

3

A Clinical Nurse Specialist may contact the patient following the Multi Disciplinary Team meeting to confirm their diagnosis and plan at that stage. Some patients may be seen face to face with the Respiratory Consultant and will be informed of the next steps. **This may mean going to a specialist department at another hospital. It can be helpful to bring a friend or family member** to this appointment as there can be a lot of information to take in.

Target: Diagnosed within 28-days of referral

Referred to the relevant department

It is possible that cancer may be found during these investigations. While this is a worrying time, it is important to complete the investigation process. The earlier cancer is found the better it can be treated. Cancer treatments have improved in recent years. Treatments are now more effective and different options are available.

Speak to the **Macmillan Clinical Nurse Specialist team on 01522 573041**.

Strengths and limitations

This project was novel in its exploration of urban, rural and coastal inequalities in access to lung cancer care. The large qualitative interview sample facilitated an in-depth exploration of the patient experience across the two distinct areas. This allowed us to explore the shared and separate challenges faced by people with lung cancer and begin to explore ways in which these could be addressed. The application of behaviour changes theories (such as the COM-B model and Theoretical Domains Framework) ensured our analysis was theory driven and contributed to the evidence-based design of the intervention. As well as gaining new insights into patient experience and patient engagement, the project resulted in the early-stage development of a tool to target local barriers and facilitate patient engagement. This work should be continued and the tool built-upon in future research. Lastly, through this work we established strong academic links between QMUL and UoL, and the collaborations with clinical teams at Barts Trust and ULHT were crucial for study success.

Our work also had some limitations. It is worth noting that while attempts were made to include participants with a range of characteristics, the majority of the sample were of White British ethnicity. This reflects the demographic makeup of Lincolnshire County. Within the London sample, participants of varying ethnicities were recruited, however the sample was also skewed towards White British participants. Additionally, all the study participants had received a diagnosis of lung cancer prior to participating in the study. We were therefore unable to gather experiences from people who struggled to engage with care so early in the pathway they did not reach diagnosis. It will be important to include participants who struggle to engage with the early stages of the pathway in future work, as they face the greatest risk of late-stage diagnosis or emergency presentation.

Lastly the patient engagement tool offers an example of what an intervention to facilitate patient engagement within lung cancer care may look like. The tool is in the early stages of development and is therefore not ready to be implemented into clinical practice. The findings of the review and workshops can be used to further tailor the prototype tool in future work to ensure it is feasible to implement.

Dissemination

The study has generated multiple significant outputs. To maximise the impact of the existing findings and to ensure that findings reach key stakeholders in a range of formats, a set of workshops and webinars were conducted.

A workshop designed for a clinical audience and a workshop designed for a PPIE audience were conducted to share the final results and hear the reflections and perspectives of the public and professionals. Additionally, a series of webinars for

health systems leaders across England, Scotland, and Wales, were conducted to disseminate the findings to specific audiences. We shared our work with the Scotland Regional Health Board SCAN (32 Attendees), Scotland Regional Health Board North (26 Attendees), the Cancer Alliance Health Inequalities Network (24 Attendees), and the Centre for Sustainable Delivery Respiratory (SDG) Meeting (34 Attendees). We also produced a written case study for health systems leaders, and an accessible summary (reviewed by PPIE members).

Additional dissemination tasks included:

- Two peer-reviewed publications (with two further papers in progress)
- Ten published abstracts (International Journal of Psycho-oncology, Lung Cancer)
- Five oral conference presentations (IPOS 2023, CRUK Early Diagnosis Conference 2024, the London Cancer Week 2024 Conference, UK Society for Behavioural Medicine Conference 2025, and the UK Lung Cancer Coalition annual conference 2025)
- Six international conference poster presentations (IPOS 2023, IPOS 2024, World Conference on Lung Cancer 2025)
- Seven national conference poster presentations (BPOS 2023, BTOG 2024, BTOG 2025, British Thoracic Oncology Group Conference 2025, the Lung Cancer Nurse UK Conference 2025).
- A workshop at the Lincolnshire Cancer Summit 2024.
- Invited presentations (NHS England Lung Clinical Expert Group, NCEL Lung Cancer MDT Research and Education Away Day, Lung Cancer Nurse Research Special Interest Group 2025, North East London Respiratory Research Collaborative meeting Autumn 2024, University of Aberdeen, Summer 2024, and Oxford Brookes University, Spring 2024)
- A written summary included in the Lung Cancer Nurse UK newsletter

The development of a prototype patient engagement tool informed by our findings will also form the basis of further academic and clinical partnership, patient and public evaluation, or a small pilot.

Conclusion

Patients and carers in urban, rural and coastal areas face challenges when trying to access lung cancer care. More can be done to help patients feel informed and involved: such as provision of clear and easy-to-understand information at different stages of care and involving patients in decisions about their care. Developing a resource which can tell patients and carers about local and national support services may make it easier for them to manage challenges, take part in their care, and have a better experience. A concept for a patient engagement tool has been developed that may enhance how lung cancer patients and carers

engage with and experience their care. As the tool is in the early stages of development, further work is needed refine the tool and inform implementation. As the tool concept is for an adaptable 'blueprint', it has the potential to be implemented across diverse healthcare and geographic settings to inform patients and address common barriers.

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