Patient and staff perspectives on the concept of frailty and its role in assessment and decision making in treatment for older people with lung cancer

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Abstract

Purpose: Frailty influences outcomes in patients with cancer and should be considered when making decisions about treatment but concerns have been raised about possible negative consequences of doing this. Many patients with lung cancer have attributes of frailty and this study explores patient and staff perspectives on its role in decision making in older people with lung cancer.

Methods: The study adopted a two-phase qualitative approach using semi-structured telephone interviews and an in-person focus group. Data was analysed using framework techniques.

Results: Three key themes were identified: describing frailty, assessing frailty and perceptions of frailty. Each presented opportunities and challenges for using frailty in the context of treatment decision making. Frailty was described in relation to diverse attributes which made it difficult to define and assess. It was also associated with negative connotations, particularly by patients.

Conclusion: Frailty has the potential to inform decision making that balances the wish to provide optimum treatment against risks to patients who may not be able to tolerate it. The challenge for healthcare staff is to incorporate frailty assessment into clinical practice in a way that is acceptable to patients and avoids potential unintended harms.

Keywords

Frailty, older people, lung cancer, treatment decisions, patient perspective, staff perspective, qualitative

Introduction

Cancer is strongly associated with ageing; the incidence rises steeply from 55 to 59 years with half of all cancers in the UK occurring in people aged over 70 (CRUK 2023). While the relationship between frailty and aging is not causal, with many older people not being frail, the number of people who are deemed frail increases with age (Orum et al. 2018). Evidence suggests that frailty, rather than age alone, influences outcomes in patients with cancer including lower survival rates, higher risk of complications and side effects from cancer treatment and functional decline (Giri et al. 2022; Kirkhus et al. 2019). These factors have led to frailty being identified as an important consideration for the current and future delivery of services across the cancer pathway from diagnosis to treatment and end of life care (Royal College of Radiologists, 2023).

Definitions of frailty vary, but it is often conceptualised as vulnerability to stressors due to a reduced ability to cope placing the frail person at increased risk of adverse outcomes (Welford et al. 2022; Lawless et al. 2020). Negative consequences include reduced independence, falls, increased hospital admissions, reduced quality of life and mortality (Durepos et al. 2022; Junius-Walker et al. 2018). Cancer and cancer treatments can act as stressors and increase the risk of someone becoming frail, or worsen the situation of a person who is already frail (O'Hanlon et al. 2019). However, frailty can also be seen as a dynamic process that can be delayed or reversed with appropriate interventions, prevention and treatment (Orum et al. 2018; Travers et al.2019).

The potential impact of frailty on outcomes has led to recommendations that it should be considered when making decisions about appropriate diagnostic and treatment pathways in cancer (Royal College of Radiologists, 2023). Assessment tools have been developed to support this, such as the clinical frailty scale (CFS), the electronic frailty index, and the comprehensive geriatric assessment (NHS England, 2019). However, debates are ongoing regarding the most appropriate tool, with comprehensive assessments being seen as challenging to complete in time-pressured clinical settings while more focused tools are criticised as they omit items (O'Hanlon et al. 2019). In the UK frailty assessment tools are being used in some cancer services (Wham and Hallam, 2018) but their use is not mandated. Performance status (PS), a five-point scale, is used routinely to assess physical function and inform decisions about appropriate treatment but its narrow range of attributes have led some to question its ability to measure frailty (Simcock and Wright, 2020).

While the benefits of considering frailty in treatment planning and care have been advocated, possible adverse consequences have also been identified. Concerns have been raised about negative perceptions of frailty, how people feel about being defined as frail and unintended negative consequences of doing so (Lawless et al. 2020, Durepos et al. 2021). Gaps have also been highlighted in the evidence base for the use of frailty assessment tools in cancer practice, such as variability in the way frailty is defined, making it difficult to measure the impact of frailty on outcomes (Fletcher et al. 2023). These factors have led some to propose caution before their widespread implementation in practice (Mudge and Hubbard, 2018).

The use of frailty assessments to support treatment decision making, and optimise outcomes, has been recommended in lung cancer (Komichi et al. 2022). Lung cancer is predominantly a disease of older people; the median age of diagnosis with non-small cell lung cancer is 73 and small cell lung cancer 80 (Royal College of Physicians, 2022). In addition, features such as late-stage diagnosis, advanced symptoms on presentation and the presence of co-morbidities mean that people with lung cancer often have attributes of frailty on presentation or are at risk of developing them due to treatment (Komichi et al. 2022; Shulkes et al. 2017).

While the impact of frailty and frailty assessments on patient outcomes has been explored, the use of frailty assessments to support treatment decision making has received less attention. Our study aimed to explore this in the context of lung cancer from the perspectives of both patients and staff.

Aim

To provide insight into staff and patient perspectives of the concept of frailty and the implications of using frailty assessments in clinical practice and decision-making in lung cancer

Methods

The study adopted a two-phase qualitative approach using semi-structured telephone interviews with staff and patients and an in-person focus group with staff.

1.1 Participants and recruitment

Patients were invited to participate in interviews if they were aged over 70, diagnosed with lung cancer in the preceding 12 months and currently receiving treatment at a regional cancer centre. Patients who met the criteria were identified in the outpatient clinic by a member of the multi-professional team working in the lung cancer service and were provided with information about the study. If they expressed an interest in participating their details were given to a member of the research team to schedule a telephone interview. Staff and patient interviews were carried out by a member of the research team who had no role in the care of patients with lung cancer and no relationship with staff participants. Data was collected between October 2018 and May 2019.

Staff who were eligible to participate were currently involved in patient assessment and/or treatment decision making for patients with lung cancer. These included lung cancer clinical nurse specialists, respiratory physicians and clinical and medical oncologists. Staff were invited to participate by local emails (nurses and medical staff). In addition, nurses were invited via the website for Lung Cancer Nursing UK; a national professional forum for nurses working in lung cancer care.

Following initial analysis of the interview data a face-to-face focus group was held with staff from the regional cancer centre whose work involved caring for patients with lung cancer. Staff represented roles across the multi-professional team including physiotherapy, occupational therapy, inpatient, outpatient and chemotherapy nursing, therapeutic radiography and clinical nurse specialists. The focus group, facilitated by members of the research team, explored two specific themes identified in the interviews; definitions of frailty and the implications of using frailty assessment tools in clinical practice.

Interview schedules are detailed in figure one and focus group schedule in figure two.

2.2 Data analysis

Interviews were digitally recorded, transcribed and anonymised. Data was analysed using framework techniques (Ritchie et al. 2014). An initial thematic framework was developed by all members of the research team (CW, JU, JS, AT) who read the same selection of staff and patient interview transcripts independently and then met to agree the themes and framework. Appropriate data from each interview was then placed in each of the themes by JU. Descriptive accounts were developed for the themes which were reviewed, discussed and agreed by the research team.

National (IRAS: 231439) and local research ethics committee approvals were received for the study. Written and verbal informed consent was obtained from participants prior to the interviews and focus group.

2. Findings

Ten patients and eleven staff participated in the interviews. Details are in table one (patients) and table two (staff).

Three key themes were identified: describing frailty, assessing frailty and perceptions of frailty. Each presented opportunities and challenges for using frailty in the context of care and treatment decision making for older people with lung cancer.

3.1 Describing frailty.

This theme explores how staff and patients described frailty. While attributes associated with frailty were identified, participants also felt it was difficult to define accurately. Uncertainty was expressed about which characteristics were important, or needed to be present, for someone to be defined as frail.

Interview and focus group participants were asked to describe frailty. Diverse multi-dimensional characteristics were suggested including age, appearance, mobility, self-care, social networks, physical health, mental capacity, resilience and outlook on life. Deficits in each of these dimensions were described such as reliance on others, being vulnerable, struggling to self-care, less able to cope emotionally, not able to make decisions and "take things on board" (S5) and having multiple co-morbidities. While there were similarities between interview and focus group participants, those in the focus group included vulnerability, being at risk in general, and of falls in particular, in their descriptions more often.

Staff and patients felt that people who were frail would be more likely to struggle with cancer and its treatment, physically and psychologically, and find it more difficult to understand treatment options and make decisions. The multi-dimensional nature of participants descriptions is captured in the following examples.

> Frail is someone who is weak and unable to do some of the simple tasks. They are mentally frail as well as physically, whose emotions could get the better of them, the sense of isolation could be more intense….they are unsteady, uncertain, they don't look confident (P2)
>
> Frailty is someone who's got very little energy, is quite slender, maybe has a poor appetite and has lost weight, is quite dependent, who is needing a lot of help with activities of daily living..often they have comorbidities..and may not be able to retain information….and are quite socially isolated (S11)

Social isolation featured in many staff and patient descriptions of frailty. This was characterised as living alone with limited social networks and family support, not being able to get out of the house or participate in social activities.

> If they live alone and haven't really got any friends and family to me that probably would make them more frail because having a network really does help with your quality of life (S4)

No participants felt there was a direct relationship between age and frailty. It was suggested the chance of someone being frail rose with increasing age, such as those in their late 80s or over 90, but many noted that people younger than 65 could be frail while those over 70 were often fit and well. A small number of patients wondered if their age had added to the difficulties they experienced with treatment.

> I'm talking about my age...if some person had had the same as me when he was 30 he would come out of it far stronger than what I have…I think a younger man would be better (P5)

Frailty was felt to be difficult to describe accurately due to it being comprised of many different elements. As one patient put it "you could write a thesis on this" (P2). There was also uncertainty over which characteristics were more or less important when defining frailty. Some noted that having one attribute of frailty did not necessarily mean someone was frail, particularly as this could be offset by other strengths. For example, if a person needed help with self-care but had strong social networks, they could be considered as less frail compared with someone who had little support. This was particularly evident in the patient interviews where frailty was often described as a balance of factors with deficits in one area, such as physical frailty, being overcome by other attributes, such as a positive attitude or social connectivity.

> Even though my wife's an invalid in a wheelchair she's still got all her faculties. We still get out and about and enjoy our family (P10)

3.2 Assessing frailty.

This theme describes participants perspectives on how frailty could, or should, be assessed. Staff participants had used informal and structured assessments in practice and discussed their advantages and limitations. Challenges for assessment included the diverse factors influencing frailty, the need to account for change, and applying assessments to decision-making, particularly when patients had borderline attributes of frailty.

The multi-dimensional nature of frailty created challenges for assessment which was described by staff as a layered process, with initial impressions needing to be followed by further exploration. Initial impressions, described by some as "the eyeball" or "the end of the bed test", were based on prior experience and included factors such as appearance, mobility and attending clinic unaccompanied.

> The walk past the end of the bed test and….you can tell by looking at somebody whether they're going to do well or not….whether we're aware of it or not, when they walk into the clinic, you're thinking, hmm, not sure, and so just using that experience. (S2)

It was also emphasised that first impressions were not to be relied on as someone might not appear frail but further discussion could reveal how dependent they were, while another person might appear frail but this may not be the case

> "It might well be that someone looks frail but when you dig a bit deeper it's just that they're a bit depressed, that they've had a frightening diagnosis or recently lost a partner" (S1)

Frailty was not seen as a static state and many highlighted that initial impressions had to be reviewed on an ongoing basis. For example, assessing someone while they were in hospital could give an inaccurate perspective, if they were newly diagnosed, recovering from an acute illness or invasive diagnostic tests. Conversely, the potential for rapid decline in lung cancer could cause someone to become frailer in a short space of time. The potential for change was also reflected in comments about the value of multi-disciplinary hospital and community interventions for people identified as frail, potentially improving their suitability for treatment or providing support when treatment was not appropriate.

Staff included a range of dimensions when assessing frailty. Physical factors were mentioned most often and included mobility, level of activity and self-care. Psychological factors included being able to understand information and make decisions, attitude (for example, fighting spirit versus adopting a sick role) and ability to cope.

> If someone doesn't seem to be able to retain the information, or isn't asking appropriate questions or just seems to be quite passive and accepting what I am saying…. then I suppose that might impact on me that they are a bit frail (S11)

Social context was assessed by three elements; who the patient lived with, availability of support from family and friends and participation in activities outside of the home. Physical, psychological and social factors were considered in combination by some when they discussed the impact of frailty on treatment options. For example, how frailty might impact on a person's ability to recognise side effects and take action, such as contacting the cancer centre, if they occurred.

Some staff described how the in-depth assessment of factors associated with frailty was often carried out by a clinical nurse specialist (CNS) before or after their consultation with the doctor. Many indicated that doctors did not always have the time for these discussions due to restricted appointment scheduling and noted that nurses had expertise in holistic assessments. The CNS role in organising interventions was also noted.

> To improve their general wellbeing, the clinical nurse specialist would take that on board and..be in contact with the patient at home, but also with the GP, and the district nurses….. to try to get the patient in the best possible condition before we would embark on something radical (S1).

Focus group staff used unstructured approaches to assessing frailty, but those who were interviewed used performance status (PS) assessments routinely in clinical practice to support treatment decisions. PS was seen to evaluate factors associated with frailty.

> We use performance status more of a marker of what we feel the patient can cope with rather than frailty. And I suppose in my mind frailty comes into performance status (S1)

Many noted that the ability of PS to measure performance, and by association frailty, could be compromised as the score could vary depending on the depth of the discussion and the questions that were asked. For example, asking a patient if they managed the stairs but not enquiring how frequently they had to stop to get to the top (S2) and identifying a patient as PS1 "because they look neatly dressed in clinic rather than ask them who got them dressed" (S7). Concerns were also raised about accounting for the impact of long-term and chronic conditions such as arthritis or chronic pain which could lead to a high assessment score but might be less meaningful when making decisions about cancer treatment.

A structured tool designed to assess frailty, the clinical frailty scale (CFS), was being used by a small number of staff participants who were involved in a national project exploring its use in cancer treatment. CFS was felt to provide a "greater degree of granularity" (S7) as it required the assessor to ask additional questions to "tease out more information" (S10). CFS was reviewed in the focus group where participants felt it was concise and easy to understand. However, they also identified the potential for subjective interpretation and noted omissions including cognition, psychological and emotional well-being and availability of social support.

An additional challenge for PS and CFS was assigning a score to a "borderline" patient. Patients who were fit and well, and those who had multiple significant characteristics of frailty, were seen as relatively easy to define as frail or not frail. Difficulties occurred with patients who fell between scores described as the grey area, or in relation to PS, the "good 2 versus the bad 2" (S7).

> It's very clear when patients are suitable, it's clear when they're definitely not, it's the in between that's a little bit harder sometimes to establish (S5)

Other factors could influence "borderline" scores, for example where a person had potentially curative cancer the scorer might err on the lower side. However, this was always discussed in the context of risks and benefits and the potential to do more harm than good if patients were given treatment they were not able to cope with.

> I don't want to deny them a potentially curable treatment option if I have one…. So, I may discount the three and say, let's give you the benefit of the doubt I'll say you're two….. you have to adapt the performance score based on the entire picture…. at the same time what you don't want to do is, if you over adjust the performance score then you are potentially going to put the patient at risk of harm (S6)

Age alone was not felt to influence frailty assessments, or the consideration of treatment options. Other factors were felt to be more significant.

> management (is) not just based on the fact that they are old or elderly. But, also on the stage of cancer found on radiology. Number two, the number of co-morbidities they have. Number three, there are ways of assessing their fitness. So, all those things come into play, so just their age never really is the single thing that would help me make a decision (S6)

3.3 Perceptions of frailty.

The theme perceptions of frailty describes how participants felt frailty was perceived in society and the possible implications of using it in practice. It also explores patients' thoughts on how they would feel about being described as frail.

Different perspectives were revealed among staff about the use of the word frail to describe a patient. Those who had been involved in the NHS initiative regarding frailty assessment seemed more comfortable with using the term and could identify benefits from it being used in clinical practice. However, all interview and focus group participants noted that the term could have negative consequences and raised concerns about patients feeling they were being labelled negatively. Some questioned whether this might influence how patients responded when assessed

> There may be some groups of older people who may be fearful that they'd be viewed as frail and might try and over-estimate their abilities during the assessment (S3)

All patient interviews contained implicit or explicit suggestions that frailty was a negative term. This was exemplified in their descriptions of frailty which focused on deficits and losses in a range of dimensions (see table three). It was also seen when they were asked what they thought about the term.

> "it's not a very nice word...it's a past term that perhaps we should be dropping nowadays" (P10).

> Interviewer: If someone was given the label frail, are there ways in which they would be?
> Patient: Annoyed (P8)

Negative connotations were also implied in patient responses to being asked if they would describe themselves as frail. Those who felt they were not frail expressed this emphatically and identified characteristics that demonstrated this.

> Getting back to the word frail, I have never felt frail, I have always felt in control of me (P2)
>
> I wouldn't describe myself as frail, no. Because I've always had an active life (P10)
>
> I wouldn't describe myself as frail by a long shot…. I mean I do a lot of fishing (P8)

Some patients felt they might have characteristics associated with frailty. For some this was a new experience, caused by the effects of their cancer treatment, while for others it was due to a long-term condition, such as arthritis. However, the way they talked about this suggested frailty was not a term they wanted to apply to themselves. For example, they might feel frail at times but they were not frail yet.

> I'm not as bad as that yet, but I wouldn't have described myself before this happened as being frail…. I do feel frail now at times (P7)

Discussion

The study provides new insights into staff and patient perspectives of frailty in the context of lung cancer. Frailty has been shown to lead to poorer outcomes in lung cancer (Komichi et al. 2022) and assessing for frailty has been identified as playing an important role in treatment decision making (O'Hanlon et al. 2019). Our findings highlight some of the challenges that may be faced when implementing this in practice.

Frailty was described by our participants in relation to diverse attributes which made it difficult to define and assess. This complexity is reflected in previous studies which identified frailty as a multi-dimensional concept in terms of how it is perceived by staff and patients (Junius-Walker et al. 2018; Durepos et al. 2021) and in relation to the range of factors that can influence whether someone is being, becoming or defined as frail (Mudge and Hubbard, 2018; Simcock and Wright, 2020). We also found that frailty was not viewed as a static state but as something that could change with people having the potential to move in and out of being frail, or along increasing and decreasing degrees of frailty. In addition, some described frailty as a balance, for example, where a person might have one or more attributes of frailty, these could be compensated for by strengths in another area.

Frailty is often defined as vulnerability to stressors due to a reduced ability to cope (Junius-Walker et al. 2018) and this perspective was evident in our participants accounts. However, our findings also suggest that there may be a nuanced relationship in the ways that individuals negotiate stressors and coping abilities. It suggests a patient-centred approach is needed to describe, or assess, frailty which takes account of this balance of factors at an individual level. One model which provides scope for this approach is the cumulative complexity model (Shippee et al. 2012). While the model was not developed specifically for frailty it provides insight that can be applied to the context of frailty, cancer and treatment-decisions.

The cumulative complexity model proposes that central to patient experience is the balance between the demands placed upon them (workload) and their capacity to meet these demands. Where workload exceeds capacity, this creates risks for patients, including disruptions in care, self-care and outcomes. If these persist, they can accumulate over time adding to demands and further depleting capacity. In a cancer context workload includes the complex everyday tasks and responsibilities patients face plus the additional demands of treatment, including appointments, taking medications, self-education and self-care. Capacity describes the physical, psychological and socio-economic resources and limitations that affect a person's ability to meet these demands. This includes the symptoms and side effects of cancer and its treatment.

Using this model, frailty can be conceptualised as an imbalance between workload and capacity. This approach provides space to consider the diverse range of complex physical, psychological and social factors associated with frailty and consideration of the ways in which these can increase workload or reduce capacity. It also recognises the potential to maintain, or regain, balance through interventions that mitigate against frailty or support people who are living with frailty. In the context of cancer and its treatment, the model allows this balance to be considered in light of the potential disruptive impact of illness and treatment alongside a patient's available resources (personal and external). Applying this approach to patient assessment reflects the diverse attributes and contributing factors to frailty and the multi-layered explorative approach staff took to assessment. However, to apply this approach to clinical practice also requires the use of frailty-specific assessment tools, to retain a focus on frailty and provide objective assessments in support of treatment decisions.

In our study performance status (PS) was used as a proxy for frailty, but participants felt the focus was too narrow. Concerns have been raised elsewhere that PS is unlikely to detect problems associated with frailty that could impact on patients' ability to cope with treatment and overlook interventions that might enable them to receive optimal treatment and/or improve their well-being (Simcock and Wright, 2020; Welford et al. 2022). Frailty-specific assessment tools have the potential to achieve these aims and their use in supporting treatment decisions in cancer care has been advocated (Orum et al. 2018; Kirkhus et al. 2019). More recently in the UK, national guidance has been developed recommending the use of frailty assessment tools across the cancer pathway, with an initial assessment, such as the clinical frailty scale, leading to more comprehensive, multi-domain assessments for patients identified as frail (Royal College of Radiologists 2023).

Implementing frailty assessments also requires careful consideration of patient experience. Patients in our study felt that frailty was a negative term they would not like to be used to describe themselves. One explanation for this could be that all participants spoke of frailty in a context of deficits, decline and loss. A systematic review of studies exploring perceptions of frailty among older people found that the term frailty, and being diagnosed as frail, was seen as problematic unwanted negative labelling associated with age-related stereotypes (Durepos et al. 2022). The review also found evidence that classifying someone as frail can have detrimental consequences on their image of themselves, their self-esteem and behaviours and impact negatively on health outcomes and well-being (Durepos et al. 2022).

This poses a conundrum for using frailty assessment in discussions about treatment decisions; how to do this in a way which is acceptable to patients (Lawless et al. 2020) and prevents it from being a tool that disempowers those identified as frail (Mudge and Hubbard, 2018). Recommendations to support communication include avoiding labelling by using phrases such as a person living with frailty, rather than identifying someone as frail, and discussing individual and specific challenges rather than using frail as an overarching description of someone's health (Durepos et al. 2020). In addition, older frail people often define themselves by what they can achieve, rather than by what they are unable to do, highlighting the importance of capturing the positive and diverse ways they manage their lives, to provide care and support that meets their needs (Skilbeck et al. 2018).

Our study raises implications for clinical practice. The multi-faceted nature of frailty presents a challenge for healthcare staff as it makes it difficult to conceptualise all the elements that need to be considered. The model of cumulative complexity provides a way of approaching this, particularly when carrying out the multi-layered exploratory assessments that all staff, and nurses in particular, carry out with patients. Alongside this approach, frailty-specific assessment tools are needed to provide an objective structure for decision making that can be shared by the multi-disciplinary team. However, care should be taken when communicating with patients about frailty. This needs to be in a way which retains each patient’s sense of self-worth, such as acknowledging their abilities as well as any frailty concerns which may need to be considered in reaching a treatment decision.

Limitations

The sample size for staff and patients was intentionally small as this was an exploratory study which aimed to generate preliminary in-depth understanding. It was felt to be appropriate for this study where the intention is not to generate findings of statistical significance but to explore the perspectives of a group of older people and healthcare staff. While the number of staff participants was relatively small, they were from a range of professions, from different services across the country with a wealth of experience in providing care for patients with lung cancer.

A focus group was carried out with staff but not with patients. This could have added additional important insight into frailty and patient perspectives. Despite our intention to convene a patient focus group within the study we were unable to arrange this with an appropriate group or individuals in the time available.

Patients who participated in the study were receiving treatment at one regional cancer centre in the UK. Their experiences may be reflective of a local perspective, however, evidence from previous studies suggests they may be shared more widely.

Conclusion

Frailty was recognised by study participants as an influence on outcomes in patients with lung cancer. This extended beyond the ability to physically manage the impact of illness and treatment to multi-dimensional psychological and social factors. Balancing the wish to provide the optimum treatment available against potential risks if a patient was not able to tolerate it, was central to staff considerations of frailty. The cumulative complexity model (Shippee et al. 2012) provides an approach to identifying the complex demands patients face, their capacity to manage them and the potential for cancer and its treatment to disrupt and challenge this. Frailty-specific assessments play an important role in supporting this and have the potential to contribute positively to decision-making in lung cancer. However, care is needed to ensure they are implemented in a way that is acceptable to patients, and avoids unintentional harm.

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Figure one: Staff and patient interview schedules

Staff interview schedule

Describing and assessing frailty

- Frailty is a term that is becoming increasingly used: is it a term that you would use?
- How would you define frailty?
- Do you assess for frailty? If so, how?
- What factors do you consider relevant for assessing frailty?
- Do you use any measurement tools to assess frailty? If so, which ones?
- Do you think there are any challenges relating to using frailty assessment tools in your clinical practice?

Frailty and treatment decision-making:

- What factors do you consider when you are making a decision about treatment for frail older patients who have lung cancer?
- How useful are the frailty tool/s (or other assessment) you have mentioned in informing your decision-making about treatment options? (If they have not mentioned any, in what ways would they be useful?)
- If you anticipate that a patient could become frail (but they are not currently), how would this information impact upon your treatment decision-making?
- Is frailty re-assessed over the course of treatment for lung cancer?
- What additional support do you think might increase the ability of frail patients to receive cancer treatment? Do you provide this now?
- How effective and feasible would it be to undertake interventions to reduce frailty or improve a frail person's fitness for a more challenging cancer treatment?

Patient interview schedule

Understandings of 'frailty':

- What do you understand by the term 'frail'?
- If you had to describe an older person as frail what would that description include?
- In your opinion what has influenced your description of frailty?
- Is frail a term you would ever use to describe yourself?
- If someone were to be frail, do you think this might influence their treatment for lung cancer?

Treatment decision making:

Thinking about when treatment for your lung cancer was first discussed with you:

- Did you want to be involved in the decisions about your treatment? (Did you have any preferences or opinions?) Have they changed over time?
- What support were you given to help you make your decision? Did anyone else help you make your decision (e.g. family, nurse, GP)
- What were your concerns about cancer treatment
- What did you want to get from your treatment?
- Do you think your age had any influence on the treatment decisions that were made?

Figure two: Staff focus group schedule

Staff focus group schedule

Section A – personal experience and practice

- Describe what you think frailty means to you – using post its write down any words/terms/ concepts individually – then share with the group
- Do you have any experiences to share about how patients feel about the term frailty

Section B – current service

- Is frailty currently assessed as part of your service?
- Is this formally using an objective measure or more of an informal subjective approach

Section C – frailty assessment tools

- Performance status is used nationally for treatment decision making. What are your thoughts on this. Our participants thought there were some grey areas – what might these be from your perspective
- Group exercise: review two assessment tools (Edmonton frailty scale and clinical frailty scale) from the perspective of their use in supporting decision making in people with cancer.
- Some of our participants felt that PF and CFS don’t cover all that is needed and trigger questions might be useful. What might these be? What would your priorities be for topic areas?

- How do you feel about “frailty” being part of an assessment to determine treatment decisions in patients with lung cancer. What added value might this bring to the assessment and patient care? Are there any unintended consequences that you can think of?

Table one: Patient participant characteristics

Number	Age	Gender	Treatment(s)
1	73	M	Radiotherapy, chemotherapy
2	70	M	Surgery, chemotherapy
3	71	F	Chemotherapy
4	86	M	Chemotherapy
5	70	M	Surgery, Chemotherapy
6	72	F	Chemotherapy
7	81	M	Chemotherapy
8	73	M	Chemotherapy
9	75	F	Immunotherapy
10	74	M	Chemotherapy

Table two: Staff participants role and years of experience in oncology

Number	Years in oncology	Professional role
1	23	Therapy Radiographer
2	24	Lung Cancer CNS
3	18	Lung Cancer CNS
4	4	Lung Cancer CNS
5	15	Lung Cancer CNS
6	10	Consultant Respiratory Physician
7	27	Consultant Clinical Oncologist
8	22	Consultant Medical Oncologist
9	19	Consultant Respiratory Physician
10	19	Consultant Medical Oncologist
11	17	Consultant Clinical Oncologist

Table three: Examples of patient's descriptions of frailty

Theme	**Illustrative extracts from patient's descriptions of frailty**
Appearance	*Like a matchstick (P1)* *Weak (P2)* *Unsteady, uncertain, doesn't look confident (P2)* *Looks old (P3)* *Doddery, shaking hands (P9)*
Mobility	*Uses a waking aid (P1)* *Difficult to get about (P1)* *Not able to walk or go upstairs (P9)*
Dependence	*Needs help from others (P1)* *Unable to do simple tasks (P2)* *Can't do a lot (P3)* *Having quite a number of problems with day-to-day living (P4)* *Someone who can't do things (P5)* *Difficulty doing typical everyday things (P6)* *Unable to cover your own needs (P6)* *You need help all the time (P7)* *Not able to do a great deal for themselves (P9)*
Social isolation	*Doesn't go out (P1)* *Isolated, sense of isolation intense (P2)* *Not getting out (P8)* *Can't get out, isolated (P10)*
Psychological	*Mentally frail, emotions can get the better of them (P2)* *Feel old (P3)* *Can't always fight things the same (P3)* *How you feel mentally (P7)* *Feeling older than you are (P8)* *Not making an effort (P8)*
Global	*Basic human traits that make you who you are get a lot weaker (P2)*