Attitudes to participation in a lung cancer screening trial: a qualitative study

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ABSTRACT

Background Earlier diagnosis of lung cancer is key to reducing mortality. New evidence suggests that smokers have negative attitudes to screening and participation in lung cancer screening trials is poor (<1 in 6 of those eligible). Understanding participation is important since uptake in screening trials is likely to predict uptake in screening programmes. A qualitative study of people accepting and declining participation in the Lung-SEARCH screening trial was conducted. Two questions were addressed: Are the screening methods offered acceptable to patients? Why do some people take part and others decline?

Methods The qualitative study used semi-structured interviews with 60 respondents from three groups: (a) trial participants providing an annual sputum sample; (b) trial participants with a sputum sample showing abnormal cytology and thus undergoing annual CT scanning and bronchoscopy; and (c) those declining trial participation.

Results Most respondents (48/60, 80%) viewed sputum provision, CT scanning and bronchoscopy as largely acceptable. Those declining trial participation described fear of bronchoscopy, inconvenience of travelling to hospitals for screening investigations and perceived themselves as having low susceptibility to lung cancer or being too old to benefit. Patients declining participation discounted their risk from smoking and considered negative family histories and good health to be protective. Four typological behaviours emerged within those declining: ‘too old to be bothered’, ‘worriers’, ‘fatalists’ and ‘avoiders’.

Conclusion Sputum provision, CT scanning and bronchoscopy are largely acceptable to those participating in a screening trial. However, the decision to participate or decline reflects a complex balance of factors including acceptability and convenience of screening methods, risk perception, altruism and self-interest. Improving practical and changing cognitive aspects of participation will be key to improving uptake of lung cancer screening.

INTRODUCTION

Lung cancer caused 22% of cancer deaths in the UK in 2007, more than double each of the next most common causes (colorectal 10% and breast 8%).1 Lung cancer has a poor prognosis largely because 75% of patients present at a late and incurable stage.2 There is intensive interest in the potential for population screening to improve detection and reduce mortality.3–6 The National Lung Screening Trial in the USA recently reported a 20% fall in lung cancer deaths in screened participants, and results of other large ongoing randomised trials are eagerly awaited.7 However, an important aspect of the cancer screening debate is uptake—that is, the percentage of subjects invited who actually have the screening test. Low uptake would render a national screening programme non-viable. A relatively high uptake is essential for the success of a national screening programme,9 but this has rarely been addressed in lung cancer screening trials. Of published trials, only one gave sufficient data to calculate a figure (16%),10 with 6% (1 in 17) joining the ongoing Lung-SEARCH screening trial (A Hackshaw, personal communication). Participation in trials of screening may predict uptake in an implemented programme. Uptake rates of 81%, 80% and 61% are recorded for current UK screening programmes for breast, cervical and colorectal cancer.9 However, lung cancer screening differs from these other cancers because it targets a higher risk subgroup of the population defined by lifestyle, usually smokers and ex-smokers. Emerging data suggest that smokers view screening nihilistically, perceiving early detection and intervention to be of limited use, and being less likely to consider screening than never-smokers.11 The literature on participation in lung cancer screening trials is sparse and limited to a single questionnaire study addressing the NELSON screening trial.12 In those who declined
screening, the main reasons were that: participation was too much effort, they lacked understanding of the purpose of the tests and lacked respiratory complaints.12

Lung-SEARCH is a multicentre randomised controlled trial to determine whether screening (annual sputum cytology/cytometry and, if positive, annual CT scanning and fluorescence bronchoscopy) of smokers and ex-smokers with mild or moderate chronic obstructive pulmonary disease (COPD) can identify patients who develop lung cancer at an earlier stage compared with the unscreened group.13 We sought to understand reasons for participation and non-participation to provide knowledge that can be used to improve participation in future trials and a national screening programme.

Questionnaire surveys provide some understanding of rationales for taking part or declining screening and the acceptability of the methods of screening. Semi-structured interviews potentially allow a deeper exploration of beliefs and attitudes. We therefore completed a qualitative interview study exploring acceptability of the methods of screening and reasons for participation and non-participation in the Lung-SEARCH trial. We wished to answer two questions: (1) Are the screening methods (annual sputum cytology, with the possibility of leading to annual CT and fluorescence bronchoscopy) in the Lung-SEARCH trial acceptable? (2) Why do some people decide to take part in the trial and others decline?

METHODS

Sampling

Purposive sampling14 was used to identify the three groups of respondents:

1. Trial participants giving an annual sputum sample.
2. Trial participants who had produced a sputum sample with cytology showing dysplastic cells and who then underwent annual annual bronchoscopy and CT scanning.
3. Those who declined taking part in the trial.

Recruitment

Patients are recruited into the Lung-SEARCH trial from both primary and secondary care using searches of GP records and outpatient appointment lists. To be eligible they must be current or ex-smokers with ≥20 pack years and/or ≥20 years of smoking (ex-smokers should have quit within 8 years), have mild to moderate COPD according to the GOLD criteria, a life expectancy ≥5 years and have no serious comorbid conditions.

The following three groups of patients were approached and invited to participate in the qualitative study by their Lung-SEARCH nurse:

Group a: those who had already agreed to participate and had given a sputum sample.

Group b: those who had had a sputum-positive result and so had undergone bronchoscopy and a CT scan.

Group c: those who declined their invitation to participate in the trial. They opted into the qualitative study of participation via a clause in the consent form which allowed us to approach them (if so indicated on the form).

Data collection

Interviews were conducted face-to-face in people’s homes where possible, otherwise by telephone. In-depth interviews were used to collect detailed personal information on people’s attitudes and beliefs.14 15 We continued recruiting until no new themes emerged from the interviews. Using pilot work and published literature, we developed a topic guide to steer interviews.

Box 1 Numbers and types of interviews

<table>
<thead>
<tr>
<th>Group</th>
<th>Interview Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>a</td>
<td>16 respondents in the LUNG-Search trial giving an annual sputum sample (9 face-to-face and 7 telephone interviews).</td>
</tr>
<tr>
<td>b</td>
<td>20 respondents in the trial receiving annual bronchoscopy and CT scanning (5 face-to-face and 15 telephone interviews).</td>
</tr>
<tr>
<td>c</td>
<td>24 respondents who declined to take part in the trial (10 face-to-face and 14 telephone interviews).</td>
</tr>
</tbody>
</table>

All interviews were digitally recorded and fully transcribed. Emerging themes influenced the topic guide for future interviews.16

The data were anonymised by removing all identifiable information and assigning an x-numeric code to transcripts.

Data handling and analysis

The framework approach was used to carry out a thematic analysis.17 This is widely used for applied or policy research. Although the process begins deductively with preset aims and objectives, there is an inductive ‘grounded’ reflection of the textual data. We used an iterative process where data analysis influenced further data collection, allowing emergent themes to be explored in future interviews. In addition we gave attention to negative cases contradicting the emerging findings.15–16 The steps of the framework approach are familiarisation, developing a thematic framework, indexing and charting, and interpretation.17 The software package MAX-QDA was used to aid data handling and Excel spreadsheets were used for charting.19

Transcripts were coded independently by two researchers (DP and AB). To test inter-rater reliability we calculated Mezzich’s K statistic, giving K=0.75 which indicates substantial agreement.20 To enhance validity we fed findings back to a group of respondents to determine if they agreed with conclusions.

RESULTS

Overview

A total of 60 interviews were conducted among the three groups. 22 face-to-face and 38 telephone interviews (box 1). Over 500 pages of transcripts were produced, subsequently generating nine categories with 48 sub-categories. These were refined to produce four main themes (box 2).

The demographics of the three groups of respondents in the study are given in table 1.

Acceptability of screening methods

Screening methods (sputum cytology, CT scanning and bronchoscopy) in the Lung-SEARCH trial were broadly acceptable to the majority of respondents (48/60; 80%). The exception was that bronchoscopy was perceived adversely by many (18/24: 75%) who declined participation in the trial.

Box 2 Main themes

- Acceptability of the screening methods
- Taking part
- Perceptions of risk
- Barriers to participation
Providing sputum samples
Most had no concerns about giving an annual sputum sample. Although two trial participants mentioned they were ‘not able to get phlegm’, it was a minor concern and did not discourage participation. One respondent who declined participation considered producing sputum disgusting and an important deterrent (box 3).

Views of bronchoscopy
Most, but not all, participants who had undergone bronchoscopy (Group b) considered it largely acceptable. Although some reported it ‘a little bit unpleasant’, this had not deterred them from having future bronchoscopies. One respondent, however, described a particularly distressing experience of bronchoscopy (box 4). Even those in the sputum only group who had not experienced bronchoscopy thought it worth the discomfort ‘if it was to be done on something suspicious’. Indeed, bronchoscopy was ‘having a good look inside me’ (box 4).

Respondents declining trial participation (Group c) perceived bronchoscopy adversely (box 5). Most had heard of or experienced negative aspects. For some the mere description of the test was ‘disgusting’.

Experiences and perceptions of CT scans
The majority of respondents (59/60; 98%) across the three groups gave positive views about CT scans; even those who declined participation had no concerns (box 6).

Motivations to take part
Key motivations for taking part included the possibility of early detection of lung cancer, the reassurance provided by negative test results, altruism, having known others with lung cancer and accurate risk perception (box 7).

Altruism
Most (4/7) of the older participants (age >70) offered altruistic reasons for agreeing to participate compared with younger participants. Altruism related to improving the research ‘for those doing the trial to learn’, for younger relatives, ‘I mean I’ve got grandchildren, so if something happens to them’, and ‘for people in general’. However, none agreed to participate purely for altruistic reasons; those who wished to act for the greater good also gave reasons representing self-interest (box 7).

Personal benefit
All participants who agreed to take part in the trial expressed views on the benefits of the trial for themselves, irrespective of age, gender or smoking status. By ‘having a good look inside me’, early detection of cancer was the main hoped-for personal benefit of participation in screening.

A few respondents who declined to take part in the trial also reported ‘early detection’ as a benefit of screening; however, their desire not to participate outweighed any perceived personal benefits of screening, perhaps because they considered themselves at low risk of cancer.

Reassurance
Participants also indicated that participation provided reassurance. This was expressed as a sense of security or relief, even ‘feeling wonderful’, particularly after a negative screening result. The idea that someone ‘was keeping an eye on them was a comfort that was appreciated. Acknowledging that spouses also worried about lung cancer encouraged some to participate.

Knowing other people with lung cancer
Having known friends or relatives with or dying of lung cancer led to a strong desire to prevent a similar fate for themselves. Perceived risk of lung cancer was highest in these participants.

Perception of risk of lung cancer
Perception of risk of lung cancer played a key role in the decision to take part or not. Over three-quarters of those taking part in the trial judged themselves to be at significant risk (28/36; 78%) which contributed to their decision. By contrast, those who declined appeared to underestimate or deny their risk. Reasons given by decliners included a lack of current or past lung complaints, adequate current care or a negative family history. Those who considered themselves at risk attributed this to many years of smoking and positive family histories of lung cancer.

Influence of family history on risk
Family history was raised as a key determinant of risk of lung cancer by those taking part and those declining participation. Some decliners perceived a negative family history as an

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**Table 1** Summary of the characteristics of the three interviewed samples

<table>
<thead>
<tr>
<th>Gender (M:F)</th>
<th>Age (years)</th>
<th>Pack years</th>
<th>Smoking status</th>
<th>Ex-smoker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group a:</td>
<td>Age (years)</td>
<td>Range</td>
<td>Average</td>
<td>Range</td>
</tr>
<tr>
<td>Group b:</td>
<td>10:6</td>
<td>70</td>
<td>52-81</td>
<td>54</td>
</tr>
<tr>
<td>Group c:</td>
<td>11:9</td>
<td>70</td>
<td>57-76</td>
<td>51</td>
</tr>
<tr>
<td>Group a:</td>
<td>8:16</td>
<td>71</td>
<td>57-79</td>
<td>53</td>
</tr>
</tbody>
</table>

Group a: participating in the randomised controlled trial, annual sputum testing (16 respondents).

Group b: participating in the randomised controlled trial, receiving annual CT scan and bronchoscopy (20 respondents).

Group c: those who declined to take part in the randomised controlled trial (24 respondents).

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**Box 3 Providing sputum samples**

“I don’t think it takes nothing, you know. I mean just when you’ve got the phlegm, if I’m home I just put in the bottle, you know, nothing.”

AF68-47-9E English, 68, female, ex-smoker, group a – sputum

“I would find that difficult because I don’t, I’m virtually nearly sick when I see people doing it in the streets.”

CF67-23-265 English, 67, female, smoker, group c – decline
 indication that they were protected against the effects of their continued smoking.

**Influence of current health and medical care on risk**

Some respondents considered their risk of lung cancer in relation to their current health status, with absence of symptoms interpreted as indicating a low risk of cancer. Others felt that they were receiving adequate care for their COPD and were therefore not at risk.

**Barriers to participation**

**Travelling for screening tests**

The need to travel to study centres for CT scans and bronchoscopy in the event of positive sputum cytology was an important factor in the decision for those who declined participation. Half of the respondents said the possibility of travel was their most significant reason to decline. Several of the respondents said they would join the trial if any possible tests could be performed at their local hospital (box 8).

**Bad experiences of hospitals and doctors**

Inconvenience of cancelled appointments and 'very bad experiences' of hospitals and doctors led some to decide that involvement in the trial would have been an unnecessary burden.

**Perception of bronchoscopy**

As already discussed, negative perceptions of bronchoscopy were a powerful deterrent to participation.

**Reaching a decision about participation**

Reaching a decision about participation often involved weighing multiple factors for and against. Spouses sometimes contributed to the decision process (box 9).

### Box 4 Views of bronchoscopy (trial participants)

“I had such a bad time with that bronchoscopy that I didn’t want to ever do it again, I didn’t care if I died because I thought next time it would kill me anyway because I bled so much and I had so much pain and something was wrong. It’s too invasive…”

BM70-20-10E South African, male, 70, ex-smoker, group b-CT/bronch

“No problems, not if it’s going to help me... it wouldn’t bother me”

AM65-40-6E English, male, 65, ex-smoker, group a-sputum

### Box 5 Views of bronchoscopy (trial decliners)

“Yes, I’ve had that done... I had a very sore throat afterwards but as soon as I saw that in the paper, I thought, ‘No way, I’m not going to put myself through that’”.

CF73-37-24E English, female, 73, ex-smoker, group c-decline

“I would not have it done, I think it’s disgusting... I don’t like doing things like that having things going through my nose and stuff ever”

CF67-25-28E English, 67, female, ex-smoker, group c-decline

**Typologies of patients declining participation in screening**

Four attitudinal or behavioural typologies emerged from the analysis of those who declined the trial: (1) Many considered themselves ‘too old to be bothered’ or ‘too old to benefit’. (2) Worriers comprised female respondents who said participating in screening would only increase their anxieties. (3) Fatalists were all current smokers who believed in the inevitability or predetermination of events and reported that ‘if they were going to get it (lung cancer), then they would get it’ and taking part in screening was not going to change that. (4) Avoiders would rather not know if they had lung cancer (box 10). See online appendix for full list of respondents’ quotes.

**DISCUSSION**

**Summary of key findings**

Our study is the first using qualitative methods to examine attitudes to participation in a lung cancer screening trial, and only the second to address this topic. Our findings complement and extend those from previous quantitative work. Screening methods—sputum provision, CT scanning and bronchoscopy—were largely acceptable to participants in the Lung-SEARCH trial. For some who declined participation, fear of bronchoscopy was an important factor. Patients balanced a range of factors when reaching a decision about participation in the screening trial. These included their knowledge of screening tests, perceived risk of lung cancer, family history of cancer, senses of altruism and self-interest, potential to benefit in relation to their age, their current health, experiences of doctors and hospital care and convenience/practicalities of travelling for hospital tests. Those declining participation emphasised unacceptability and inconvenience of tests, underestimated their personal risk and, notably for older patients, felt that the benefit...
of early detection of cancer was negligible in the face of advanced years. Reluctance among elderly people to be screened is important since half of all lung cancers occur in patients aged >70 years.21 Self-interest was relevant to both those accepting and declining participation—for the former, the potential for early detection and the sense that they were being monitored for cancer were key, for the latter, self-interest reflected a desire to avoid unpleasant tests, inconvenience and discomfort, and raised anxiety. The potential to raise anxiety may be especially marked when screening for lung cancer, where patients are often acutely aware of their lifestyle risks. Breast and colon screening studies suggest that ‘cancer-related worry is often associated with perceived risk’.22 In the literature on cancer screening there is

<table>
<thead>
<tr>
<th>Box 6 Experiences and perceptions of CT scans</th>
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<tbody>
<tr>
<td>“CT scans....that’s nothing to be worried about at all”</td>
</tr>
<tr>
<td>BM64-50-15 Austrian, male, 64, smoker, group b - CT/Bronch</td>
</tr>
<tr>
<td>“That’s all right, no problems with that one”</td>
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<tr>
<td>CF73-30-22E English, female, 73, smoker, group c-decline</td>
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<tr>
<th>Box 7 Motivations to take part in a screening trial</th>
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<tr>
<td>Altruism mixed with potential for personal benefit</td>
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<tr>
<td>“Like I’ve said if I can be of any help in finding a cure or whatever they are looking for then you know I’ll go with that and I’m sure I could you know, if things turned out not too good then you know I’ll be taken care of also wouldn’t I?”</td>
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<tr>
<td>AF63-15-3E: Maltese, female, 63, ex-smoker, group a - sputum</td>
</tr>
<tr>
<td>Personal benefits of participation</td>
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<td>“for a start, they’re having a good look inside to see if there’s anything wrong, right, which is a plus, and if there is, they can get to it straightaway, and the sooner you get to it, the quicker, the better it is”</td>
</tr>
<tr>
<td>BF71-55-125 English, female, 71, smoker, group b – CT/bronch</td>
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<tr>
<td>Reassurance</td>
</tr>
<tr>
<td>“I know I’m all right, and that relieves the worry in my wife, because she thinks too much, so it’s a good thing”</td>
</tr>
<tr>
<td>AM77-15-45 English, male, 77, smoker, group a - sputum</td>
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<tr>
<td>Knowing others with lung cancer:</td>
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<tr>
<td>“I was all for it, having been through what I’ve just been through. My mum died of lung cancer in January this year...that was the kick start for me...”</td>
</tr>
<tr>
<td>AF52-39-17E English, female, 52, ex-smoker, group a - sputum</td>
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<tr>
<td>Perceptions (and denial) of risk</td>
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<tr>
<td>“Any cancer affects one in three people, so my chances are you know having smoked for so long what can I say – you know I’ll be a very lucky woman if I’m, if it had ermm no effect you know fingers crossed.”</td>
</tr>
<tr>
<td>AF63-8-2E: Maltese, female, 63, ex-smoker, group a - sputum</td>
</tr>
<tr>
<td>“No I don’t worry about that, people say that you should pack up but I’ve been smoking for 50 years, I can’t see that packing up is gonna make a difference”</td>
</tr>
<tr>
<td>CM67-56-29S English, male, 67, smoker, group c-decline</td>
</tr>
<tr>
<td>Family history and risk</td>
</tr>
<tr>
<td>“I know because nobody in my family ever had lung cancer and my sister is 10 years older than me, 77 and she still smokes.”</td>
</tr>
<tr>
<td>CM68-17-21E Italian, male, 68, ex-smoker, group c - decline</td>
</tr>
<tr>
<td>Current health and medical care, and risk perception</td>
</tr>
<tr>
<td>I’d almost be surprised if I did get it…. I don’t feel anything.</td>
</tr>
<tr>
<td>AM65-40-5E English, male, 65, ex smoker, group a - sputum</td>
</tr>
<tr>
<td>“No, because, as I said before, they’re looking after me at the hospital and I have my pumps and all the rest of it like. I can’t breathe properly, I know I can’t but they’re keeping it under control.”</td>
</tr>
<tr>
<td>CF73-17-23E, English, female, 73, ex-smoker, group c - decline</td>
</tr>
</tbody>
</table>
debate as to whether worry leads to or deters people from cancer screening.23 However, our findings suggest that anxiety deterred participation in screening.

While altruism was largely expressed by participants as the desire to help other people by taking part in research, it was also seen as helping relatives by reassuring them that the participant did not have lung cancer. Those declining participation did not discuss altruism, perhaps because it would reflect them in a bad light. Although previous work has highlighted the importance of altruism in decisions concerning trial participation,26 our study shows that altruism was often accompanied by self-interested motives. Altruism is perhaps the only factor we explored that did not relate to participation in a future screening programme.

Figure 1 illustrates these factors and the ways in which they overlap in patients’ deliberations and decisions.
Strengths and weaknesses of the study
Qualitative methods are well suited to exploring attitudes and beliefs. A constant comparison approach allowed us to explore emerging themes such as age and perceived benefit of screening. We achieved data saturation and interviewed a large number of people who declined participation in the trial, who are often hard to reach. We enhanced the validity of our findings through respondent validation—feeding findings back to a group of respondents to determine if they agreed with the conclusions. Our findings triangulated well with those of the questionnaire study of participation in the NELSON trial.²² Reliability was ensured in several ways. The interviews were digitally recorded and professionally transcribed, thus eliminating potential bias through note-taking and researcher transcription. The framework of codes was developed by group discussion and inter-rater reliability was achieved through comparison of individually coded transcripts. MAX-QDA software was used to allow systematic searches through the data to retrieve relevant sections.

Weaknesses of the study include a limited number of respondents in work (most were retired) and limited numbers of ethnic minority patients. Although our figures are representative of the trial population, this may limit generalisability of our findings.

Comparison with other data
Our findings echo and extend those of Bergh et al who used a questionnaire survey to examine participation in the NELSON screening trial.¹² The most common reason for participation in the NELSON trial was the possibility of early detection of lung cancer, followed by heavy smoking, desire for reassurance and altruism. For those who declined participation, the most common reasons were ‘too much effort’, followed by lack of understanding of the purpose of the tests, lack of lung complaints and anxiety about lung cancer.¹²

Patients who undergo bronchoscopy as an investigation (rather than a screening tool) report moderate to high satisfaction, with 71% and 98% of patients saying they would definitely return for a bronchoscopy.²⁷ ²⁸ This is consistent with our findings.

While spiral CT scanning may prove to be the optimal primary screening test rather than sputum cytology,¹¹ both tests were largely acceptable to our respondents. CT scanning requires
travel to a central facility which might affect uptake slightly in a screening programme.

Questionnaire studies have found that smokers and ex-smokers underestimate their risk of lung cancer,\textsuperscript{11} \textsuperscript{12} and our findings reiterate this. Bergh \textit{et al}\textsuperscript{12} also reported that those declining screening underestimated the risk of cancer compared with those accepting screening.

Echoing the findings of Silvestri \textit{et al},\textsuperscript{11} we found that ex-smokers predominated over smokers in the groups we interviewed who accepting screening and vice versa for those declining (table 1), suggesting a negative attitude among smokers towards screening.

**Implications of our findings**

Our findings have implications for the conduct of screening programmes and trials. For research, further work could explore how people perceive risk and how this is related to ageing, and the role of fatalism in the health behaviour of smokers. For screening programmes and trials, if bronchoscopy is found to be useful as part of a screening programme, more work needs to be done to present it as an acceptable screening tool. In addition, attempts to maximise participation in lung cancer screening programmes should recognise that decisions to take part involve complex judgements by patients. These judgements reflect practical issues (such as getting to hospital, acceptability of bronchoscopy) and cognitive (risk/benefit) judgements, the latter often affected by personal traits and experience. Tools to make explicit to patients their risk of cancer may be only partially effective without parallel interventions to address these other factors.

**Acknowledgements**

We thank all participants, members of the Lung-SEARCH teams who helped identify patients for participation and Cancer Research UK for funding the Lung-SEARCH screening trial.

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**Competing interests**

None.

**Patient consent**

Obtained.

**Ethics approval**

Ethics approval was provided by South West London Multi Research Ethics Committee.

**Contributors**

CG and SS had the original idea for the study. The design was elaborated by all the authors. DP, AA and CG carried out interviews and analyses. All the LUNGSEARCH recruitment teams supported recruitment to the study. All authors commented critically on the analysis and the drafts of the paper.

**Provenance and peer review**

Not commissioned; externally peer reviewed.

**Data sharing statement**

Our primary data is available for examination on request.

**REFERENCES**


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