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

Appendix 1 – Full list of relevant quotes

Box numbers refer to boxes in manuscript
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

“when it comes up to the next specimen you know and I find it a bit difficult to errmm bring any phlegm up if there isn’t any there.”
AF63-8-2E Maltese, 63, 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.”
CF67-23-26S English, 67, female, smoker, group c- decline

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

“Going for a bronchoscopy, errm I don’t err, I’ve got no qualms about going through with that”
AF63-15-3E Maltese, female, 63, ex-smoker, group a-sputum

“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 6: Experiences and perceptions of CT scans

“CT scans....that’s nothing to be worried about at all”
BM64-50-1S Austrian, male, 64, smoker, group b- CT/Bronch

“That’s all right, no problems with that one”
CF73-30-22E English, female, 73, smoker, group c-decline

“Don’t bother me one little bit”.
CF57-40-23S English, female, 57, smoker, group c-decline
Box 7: Motivations to take part in a screening trial

Altruism mixed with potential for personal benefit
“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?”
AF63-15-3E: Maltese, female, 63, ex-smoker, group a - sputum

Personal benefits of participation
“If anything I’m happier with it that way because I know that they are analysing it and if there is anything wrong, it will be found now rather than, you know, later on”
AM61-30-2E Spanish, male, 61, ex-smoker, group a - sputum
“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”
BF71-55-125 English, female, 71, smoker, group b – CT/bronch

Reassurance
“Being part of this thing, it’s like they’re keeping an eye out for it, so it’s a comfort really”.
AF52-39-17E English, female, 52, ex-smoker, group a - sputum
“In fact when you get the result, when they’re good (laughs), it makes you feel wonderful!”
BF71-55-125 English, female, 71, smoker, group b- CT/bronch
“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”
AM77-15-4S English, male, 77, smoker, group a - sputum

Knowing others with lung cancer:
“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...”
AF52-39-17E English, female, 52, ex-smoker, group a- sputum

Perceptions (and denial) of risk
“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 errm no effect you know fingers crossed.”
AF63-8-2E Maltese, female, 63, ex-smoker, group a - sputum
“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”
CM67-56-29S English, male, 67, smoker, group c- decline

Family history and risk
“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.”
CM68-17-21E Italian, male, 68, ex-smoker, group c - decline
“I don’t think it will affect me at all if I go through my family history.”
AM61-68-1E Austrian, male, 61, ex-smoker group a- sputum

Current health and medical care, and risk perception
I’d almost be surprised if I did get it,... I don’t feel anything.
AM65-40-5E English, male, 65, ex smoker, group a- sputum
“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.”
CF73-17-23E, English, female,73, ex-smoker, group c - decline
Box 8: Barriers to participation

Travelling
“You’ve got to travel up to London and only this year I’ve stopped going to Bart’s, I only go up there once a year but I’ve stopped going up there because all the travelling on the trains and the underground, you know it was too much with the stairs.”
CF74-60-20E, English, female, 74, ex-smoker, group c – decline

“The travelling, that is my whole thing I cannot do and there’s no way can you drive up to these hospitals…. there’s no way can I get to Central London.”
CF64-20-28E, English, female, 64, ex-smoker, group c – decline

Researcher: “If these tests were at your local hospital, would that be OK with you?”
“Yes, yes, no I’ll go up Central Middlesex.”
CF64-20-28E, English, female, 64, ex-smoker, group c – decline

Researcher: “If you were able to go to your local hospital?”
“I could go to my local hospital, yes.”
CF67-56-30S, English, female, 67, smoker, group c – decline

Bad experiences of doctors and hospitals
“I’m not terribly fond of doctors; I’ve had very bad experiences with them… I don’t like anything that involves hospitals and doctors”
CF74-61-20S English, female, 74, smoker group c – decline

“My first appointment was cancelled twice before, I find it quite unnecessary. The less I, less I have to do with hospitals the better”
CF73-59-30E English, female, 73, ex-smoker, group c – decline

Negative perceptions of bronchoscopy
“I’ve heard of people that have had it done and, no, I’d pass, I’d have to pass
C67-56-30S English, female, 67, smoker, group c – decline

“I would not have it done, I think its disgusting and I don’t like doing things like that ever…..Well, I didn’t want tubes down my nose and things, I never like having any of that stuff done and I wouldn’t have it done… just wouldn’t, that’s just how I am and I wouldn’t allow that.”
CF67-25-28E, English, female, 67, ex-smoker, group c – decline

“Well I don’t really like having things going through my nose and stuff, I’ve never had them done before but if you have to have them done then you have to have them done. But personally, Id rather not unless I absolutely had to.”
CF65-25-32E, English female, 65, ex-smoker, group c – decline
Box 9: Deciding whether to take part

“I couldn’t see any cons other than going to the doctor’s surgery, which is not a big thing since it’s not very far away. And the pros far, far outweighed taking the time to go there and also the fact that if there was anything wrong, it would be found so it would be to my benefit.”

AM61-68-2E Spanish, male, 61, ex-smoker, group a- sputum

“Well the pros of it for me like I said, I suffer with emphysema and doing this trial, I think that it would be one way of picking up, you know should there be anything wrong....

AF63-8-2E Maltese, female, 63, ex-smoker, group a- sputum

“He’s had enough aches and pains and he’s also got Addison’s Disease and angina and he doesn’t want anybody pulling him around at all….it’s just that because of his illness, he can’t be bothered with anything like that.” Wife speaking,

CM71-171-25E, English, male, 71, ex-smoker, group c-decline

“If there was something, whether I’d want to know or whether I didn’t want to. Those are the pros and cons really, and is a fact I’ve got children, travelling and one thing and another, I won’t be able to do it if I had to travel.”

F57-50-23S English, female, 57, smoker, group c-decline

Box 10 Typologies of patients declining participation in screening

‘Too old to benefit’

“I’m too old to be bothered…all right?”

CM71-57-25E English, male, 71, ex-smoker, group c-decline

“It would be different if I was 50 or 40, I’d go through anything but I think at my age now, I can’t”. CF73-59-30E English, female, 73, ex-smoker, group c-decline

Worriers

“I’m a worrying sort, It would worry me, I’d be worried about the results all the time, I wouldn’t be able to go to sleep, no, dear, it would really worry me”.

CF73-30-22E English, female 73, ex-smoker, group c-decline

Fatalists

“I can’t see that this is gonna make a difference, if I’ve got it, I’ve got it, the damage has been done”

CM67-56-29S English, male, 67 smoker, group c-decline

“I think when your numbers up, your numbers up”

CF73-30-22E English, female 73, ex-smoker, group c-decline

Avoiders

“Fear. Some people like to know and some people don’t like to know. No, I don’t like to know”.

CF73-30-22 English, female 73, ex-smoker, group 3-decline