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Engaging high-risk groups in early lung cancer detection: a qualitative study of symptom presentation and intervention preferences amongst the UK's most deprived communities

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3	1	<u>Title page</u>
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6	3	Title: Engaging high-risk groups in early lung cancer detection: a qualitative study of symptom
/ 8	4	presentation and intervention preferences amongst the UK's most deprived communities
9	5	
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1 Abstract

Objectives

People at high-risk for lung cancer - current/former smokers, aged 40+ years, with serious lung
comorbidity (i.e. Chronic Obstructive Pulmonary Disease) and living in highly deprived areas - are
more likely to prolong symptom presentation, leading to advanced stage diagnosis. This qualitative
study aimed to understand the influences on early presentation with lung cancer symptoms in highrisk individuals and intervention preferences.

10 Methods

Semi-structured qualitative interviews with 37 high-risk individuals, identified through seven GP practices socioeconomically deprived areas of England, Scotland and Wales (most deprived 20%). A symptom attribution task was used to explore lung symptom perception and help seeking, underpinned by Leventhal's Common Sense model. Four focus groups with high-risk individuals and local stakeholders (healthcare professionals and community partners) to explore preferences for an intervention to promote early lung cancer symptom presentation. Data were synthesised using Framework analysis.

19 Results

Individual and area level indicators of deprivation confirm that our sample were highly deprived.
Fixation on managing 'treatable' short-term conditions (chest infections), led to denial and
avoidance of 'inevitable and incurable' longer-term conditions (lung cancer). Feeling judged and
unworthy of medical help because of their perceived social standing or lifestyle deterred medical
help seeking, particularly when difficult life circumstances and traumatic events lead to
current/former tobacco and alcohol addiction. Focus group participants suggested multi-faceted
interventions in community venues, with information about lung cancer symptoms and the benefits

27 of early diagnosis, led by a trained and non-judgemental facilitator.

29 Conclusions

30 This study was novel in engaging a high risk, highly deprived sample to provide in-depth

- 31 understanding of the broader contextual influences on self-management of lung cancer symptoms.
- 32 Perceived lack of health service entitlement and complex lives facilitated avoidance of recognising
- 33 and presenting with lung cancer symptoms. Community-based interventions are required to
- 34 empower this population to seek medical help.

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2 3	1	Key words: Lung cancer, deprived, qualitative, early diagnosis, medical help seeking, barriers.
4	2	
5 6	3	Strengths and limitations of the study
7	4	• This was the first study to use in-depth gualitative methods to explore how to engage
8 9	5	individuals who are highest risk for lung cancer in early lung cancer detection
10	6	A major strength of this study was the proactive and rigorous sampling procedures used to
12	0 7	ensure that all interview participants recruited were at highest risk for lung cancer
13 14	, 8	Accossment of individual and area lovel indicators of deprivation confirm that interview
15	0	Assessment of individual and area level indicators of deprivation community interview participants were bigbly deprived; all participants resided in the most deprived 20% areas of
16 17	9 10	three notices of the UK and most participants were weenendowed (seeking banefits and (or
18	10	three nations of the UK, and most participants were unemployed/seeking benefits, and/or
19 20	11	rented social nousing.
21	12	To overcome the methodological limitations associated with studying anticipated or
22 23	13	retrospectively recalled cancer symptom presentation, we recruited participants with no
24	14	previous diagnosis of lung cancer and did not mention lung cancer in the interview study
25 26	15	materials or during completion of the symptom attribution task.
27	16	Opportunistic recruitment of focus group participations was a potential limitation of the
28 29	17	study as participants may be more favourably disposed to an intervention.
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INTRODUCTION

2 Lung cancer is the leading cause of cancer mortality worldwide[1]. Outcomes are among the poorest 3 for all cancers, with only 10% of lung cancer patients surviving five or more years in the UK[2]. 4 Diagnosis of lung cancer at an early stage can enable curative surgical resection, meaning over 80% 5 of patients will survive one year or more when diagnosed at Stage I[3]. Delayed medical help seeking 6 for symptoms and the high proportion of lung cancer diagnoses through emergency departments 7 may partly explain why lung cancer is commonly diagnosed at an advanced, incurable stage[4]. Due 8 to low specificity of lung cancer symptoms and similarity to other acute and comorbid respiratory 9 conditions, patients face difficulty in knowing when to seek medical help[5,6].

10

1

11 Multiple symptoms and risk factors for lung cancer including older age, smoking, the presence of a 12 lung comorbidity and socioeconomic deprivation increase the likelihood that a symptomatic 13 individual has lung cancer [7-9]. Lung cancer is more common and mortality higher in areas of high 14 socioeconomic deprivation; it has been estimated that each year, socioeconomic inequalities 15 account for 11,700 excess cases of lung cancer and 9,900 potentially avoidable lung cancer deaths in 16 England[10]. High prevalence of smoking, lung comorbid conditions and industry-type work such as 17 mining, all of which are well documented risk factors for lung cancer, contribute to high lung cancer 18 incidence and mortality in deprived communities[11, 12].

19

20 The presence of lung comorbidity such as chronic obstructive pulmonary disease (COPD) and history 21 of smoking have been associated with a lower likelihood of presenting with lung cancer symptoms 22 early[13,14]. In the lead up to lung cancer diagnosis, vague symptoms may go unnoticed, or be 23 misattributed to smoking, aging or other comorbid conditions such as heart disease or emphysema, 24 thereby prolonging help seeking[5,13,15-26]. In addition, stigma attached to lung cancer[23,27-30] 25 and fear of lung cancer diagnosis can deter medical help seeking for symptoms, particularly among 26 smokers[23-25,29,31-33], leading to advanced stage disease at diagnosis[19]. To date, research has 27 mainly been conducted with lung cancer patients from a range of socioeconomic groups, 28

retrospectively exploring the barriers to symptom presentation.

29

30 The current study used a combination of interviews and focus groups to gain in-depth understanding 31 of the influences on lung cancer symptom presentation behaviour and intervention preferences in 32 high risk, highly deprived groups. We targeted socioeconomically deprived areas across three 33 nations of the UK to approach potential participants, and used rigorous sampling procedures to 34 ensure that our sample were at the highest risk for lung cancer. The focus groups, conducted in

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highly deprived areas, explored intervention preferences with stakeholders who live or work in
deprived communities. To our knowledge, this was the first study to explore the influences on early
lung cancer detection and intervention preferences in high risk groups living in the most deprived
quintiles in the UK.

METHODS

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The Consolidated Criteria for Reporting Qualitative Research (COREQ)[34] criteria were used to guide reporting (Supplementary File 1).

10 Participant recruitment and sampling

12 Interviews. Interview participants were recruited through seven general medical practices (GP) in 13 South Wales (Cwm Taf, n=3), England (Liverpool, n=1) and Scotland (Aberdeen, n=3). GP practices 14 with the highest proportion of their patients that reside in the lowest quintile of deprivation were 15 contacted. Practice managers were asked to screen GP practice databases purposively for eligible 16 study participants: men and women over the age of 40, who were current or former smokers, with a 17 lung condition (COPD including chronic bronchitis and emphysema, interstitial lung disease or 18 occupational lung disease). Participants were sampled purposively according to smoking status due 19 to an initially high response rate from former smokers. GP practices in Cwm Taf were asked to 20 recruit current and former smokers, with no parameter on number of years since quit attempt. One 21 GP practice in Aberdeen was asked to recruit current smokers and recent guitters (within ten years). 22 Two GP practices in Aberdeen and one GP practice in Liverpool recruited current smokers only. 23 24 To ensure that participants from highly deprived areas were invited to take part in the study, 25 individual postcodes were screened by the research team. Eligible patients from the initial database 26 screen were assigned a pseudo-anonymised participant identifier (PID). PID and postcode were 27 checked against Index of Multiple Deprivation score, and those that resided in the most deprived

28 quintile were eligible for the study. The final list of potentially eligible participants was checked by

- 29 the GP for ability to provide informed consent, uncontrolled drug or alcohol misuse or violence (i.e.
- 30 considered by the GP to be a risk to the interviewer or themselves) and general health status (i.e.
- 31 very seriously ill). Participants were excluded if they were diagnosed with lung cancer, were
- 32 terminally ill or did not have capacity to consent.

60

33

Focus groups. Participants for the focus groups with members of the public were recruited opportunistically through primary care or local community groups. Participant recruitment through primary care employed the same methods as those used to invite the interview participants. Pseudonymised participant identifiers were checked to ensure that those who took part in the focus groups had not already participated in the interviews. Additional participants were recruited opportunistically through local community respiratory support groups and non-health related groups in the local community centre. Local community group organisers in areas of high deprivation were contacted and asked for help to recruit members of the public in our target group. Local health service planning groups and health board staff facilitated recruitment for the healthcare professional and community partner (HPCP) focus groups. Study procedures Written consent and permission to audio-record were obtained prior to the interviews and focus groups. Interviews. Eligible participants were invited by letter with more detailed study information attached, with a reminder at two weeks to non-respondents. Those consenting were contacted by the interviewer (GM or JH) to arrange a suitable time and date for the interview, to outline the study and answer any questions. Interviews were conducted using a semi-structured topic guide based on the Common Sense Model to guide discussion around illness perceptions and coping strategies[35]. The interview aimed to explore experiences of their lung condition, symptom attribution, symptom experience and help seeking behaviour, the influence of smoking history on new or changing symptoms, and lung cancer awareness and beliefs. A symptom sorting task was used to provide participants with a concrete visual task to increase engagement with the interview in the context of potential low literacy. The task formed a basis for discussion about symptom attribution and experience, where participants were asked to order 11 symptoms from those they would go to the doctor with first, through to the last. The 11 symptoms were selected from the NICE guidance for referral of suspected lung cancer. The symptoms were re-worded to simplify the language in line with wording found on the NHS Choices website for lung cancer symptoms and any reference to time scale of symptoms was removed (Supplementary file 2).

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1	For example, a cough that lasts for 3 weeks or more was amended to 'persistent cough', and
2	haemoptysis was amended to 'coughing up blood'. The presentation order of the symptoms was
3	rotated between interviews.
4	
5	To explore potential lung cancer symptom attribution outside of a cancer context, there was no
6	mention of cancer in the study information packs or when participants completed the symptom
7	sorting task. If appropriate, participants were asked questions to explore lung cancer awareness and
8	beliefs at the end of the interview or when participants discussed lung cancer unprompted.
9	
10	Demographic data were collected using a short questionnaire, including three additional measures
11	of socioeconomic group: age, gender, smoking status (quantity and duration), home ownership,
12	occupation and educational attainment. Interviews were conducted until data saturation (no new
13	themes emerging[36]).
14	
15	Focus groups. Healthcare professionals (i.e. GP, nurse, community pharmacist) and community
16	partners (i.e. community worker) who work in areas of deprivation, and with people with smoking
17	history and/or lung conditions were sent information about the study and invited to take part in the
18	focus group. A mutually convenient time, date and location for the focus groups was agreed. The
19	focus groups were conducted using a semi-structured topic guide to explore preferences for an
20	intervention to promote earlier lung cancer diagnosis. Separate topic guides were used for the public
21	and professional groups. Topics for discussion were: preferred format of the intervention,
22	recommendations for intervention content, preferred location and facilitator for intervention
23	delivery, and recommendations for the inclusion of smoking cessation advice.
24	
25	Setting
26	Most interviews (n=34) took place face-to-face in participant's own homes, with three taking place in
27	a café, local community centre or over the telephone, and lasted between 46 and 146 minutes
28	(mean 83 minutes). Family members were present for three interviews but did not participate in the
29	study. Focus groups took place in primary care settings (n=2) or local community centres (n=2).
30	Members of the public who took part in the interviews or focus groups were given a ± 10 shopping
31	voucher to thank them for their time. Healthcare professionals and community partners were not
32	reimbursed for their time.
33	

Interviews and focus groups in England were conducted by JH (PhD), a trained and experienced female qualitative Research Fellow and Medical Sociologist. The Welsh and Scottish interviews and focus groups were conducted by GM (PhD), a female Health Psychologist and trained qualitative Research Associate. Data analysis Interviews and focus groups were audio-recorded and transcribed verbatim. Anonymised transcripts were analysed in detail using the Framework method[37]. The data were analysed in five stages: familiarisation, identification of a thematic framework, indexing, charting, and interpretation. A separate index was created on Microsoft Excel for the interview and focus group data; however, wherever possible, overlap was coded using the same indexing terms, for example 'barriers to symptom presentation' was commonly discussed in both the interview and focus groups. The index was developed by two researchers (GM and JH). Themes were generated independently and consolidated through discussion in nine interpretation workshops over a nine month period by GM and JH. The different perspectives of the researchers as noted above was a benefit during analysis and interpretation. Field notes were recorded for each interview and focus group, and incorporated into discussion during the analysis workshops. Interpretive themes were generated by JH and GM, and developed with all authors in monthly management meetings. Transcripts and study findings were not checked by participants; however, all participants were mailed a summary of the study findings. Ethical approval The study received ethical approval from Southampton Central- Hampshire A Research Ethics Committee (16/SC/0589). Patient and public involvement. Patient and public representatives (AMT and GN) were involved in the design of the study and interpretation of study findings in monthly management group meetings. All study materials and topic guides were developed with lay input (AMT and GN) and written to a reading age of 10 years due to potentially low literacy.

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1	RESULTS
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Interviews

Seventy-eight returned the study reply slip and declined to participate in the study; reasons for refusal unknown. The majority of our sample were female, current smokers, and with a mean age of 65 years (Table 1). Most had a diagnosis of COPD. All 37 participants resided in the lowest quintile of deprivation for their respective country, of whom 15 were in the most deprived decile. Most participants had left school before age 15 with no formal qualifications, lived in social housing, and claimed disability benefit or job seekers allowance.

12 Table 1. Qualitative interview sample characteristics

Sample characteristics	Total n=37
Gender	
Male	16
Female	21
Age, years	
Mean (range)	64.7 (48-84)
Smoking status	
Current smoker	18
Occasional smoker	3
Former smoker, recent quitter (within five years)	5
Former smoker (quit over five years ago)	11
Deprivation decile ⁺	
Welsh Index of Multiple Deprivation (WIMD)	4
Decile 1 (most deprived 10%)	5
Decile 2 (most deprived 10-20%)	10
Scottish Index of Multiple Deprivation (SIMD)	
Decile 1 (most deprived 10%)	4
Decile 2 (most deprived 10-20%)	12
English Index of Multiple Deprivation (IMD)	
Decile 1 (most deprived 10%)	6
Self-reported lung condition	
COPD	26
Chronic bronchitis	2
Chronic emphysema	2
Occupational lung disease	1
Unsure of diagnosis	4
Missing	2
Educational attainment	
Left school at/before age 15	29
Completed CSEs, O-Levels or equivalent	5
Completed A levels or equivalent	1
Completed further education but not degree	1
Missing	1

	Employment	
	Employed full-time	2
	Employed part-time	1
	lob seekers or disability benefit	17
	Retired	16
	Home/living arrangement	
	Own flat/house	14
	Rent from local authority/housing association	21
	Missing	1
1 2	⁺ Calculated using participant postcode and local a	uthority data
3		
4	Key themes were: strategies involved in symptom	detection and help seeking behaviour, fixation on
5	maintaining short term health, denial and avoidar	ice of longer term health, the desire to be a model
6	patient, and the importance of the relationship w	ith their healthcare professional. See Figure 1 for
7	illustrative quotes.	
8		
9	Symptom detection strategies and help seeking	
10		
11	Lung cancer symptoms were viewed as "part and	parcel" (male, 68, England, current smoker) of
12	their lung condition, other pre-existing comorbidi	ties or smoking habit, and were consequently
13	normalised and perceived not to require medical	help. Changes to vague or respiratory-type lung
14	cancer symptoms were only taken seriously when	remarked on by friends and family or when they
15	impacted on daily life.	
16		
17	Symptoms that could indicate a chest infection we	ere constantly monitored. Participants used
18	sophisticated strategies such as noticing changes	n the colour and consistency of their phlegm or
19	subtle audible changes in their cough to actively d	etect chest infections. Such strategies were used
20	to facilitate early detection and treatment for che	st infections through their primary care provider or
21	with rescue packs (emergency packs of steroids a	nd antibiotics that can be kept at home), due to
22	lung condition.	
23		
24	Constant monitoring of phlegm for control of lung	condition meant that participants could and
25	would notice haemoptysis, but few reported activ	ely looking for haemoptysis. Disparity between
26	actual and anticipated medical help seeking was f	ound for haemoptysis. Most participants had not
27	previously experienced haemoptysis, but would a	nticipate seeking medical help immediately due to

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1	the potentially serious nature of blood. However, some participants who had previously or were
2	currently experiencing haemoptysis reported normalisation, leading to delays in medical help
3	seeking or no help seeking.
4	
5	Focus on maintaining short term health
6	
7	When symptoms were easy to detect, they were attributed to what was perceived as a treatable
8	cause and represented an immediate health threat i.e. a chest infection due to lung condition,
9	participants sought medical help quickly. Participants could often request an appointment the same
10	day as permitted by their GP surgery policies. Prompt help seeking was due to fear of not being able
11	to breathe and the potentially life-threatening nature of chest infections, and is likely to reflect the
12	need to maintain good health in the short term.
13	
14	The focus on maintaining short term health may reflect low general expectations of health, where
15	some participants were surprised to live past 60 years of age. In addition, due to fear of potentially
16	hearing bad news, some participants expressed a preference to not ask questions during a
17	consultation or yearly review with the nurse. Furthermore, our highly deprived sample prioritised
18	day-by-day living over longer term planning, thereby focusing on health in the short term.
19	
20	Denial or avoidance of long term health outcomes
21	
22	Most participants were sceptical of the link between lung cancer and smoking. Conversely,
23	participants thought that lung cancer was inevitable due to their current or former lifestyle,
24	including smoking history, working conditions and the reported incidence of lung cancer in their
25	community. Beliefs about inevitability were often coupled with highly negative fearful and fatalistic
26	beliefs about lung cancer, with no cure and eventual death. Such claims were evidenced by a high
27	proportion of friends and family who were diagnosed with lung cancer and often died. A few
28	participants discussed that a cure for lung cancer involved luck or was 'some miracle' (male, 56,
29	Wales, occasional smoker), reflecting a perceived lack of control over early detection and treatment.
30	Consequently, actual or anticipated medical help seeking for lung cancer symptoms was motivated
31	by pain, or to seek a diagnosis and prognosis to notify family members. However, some participants
32	would anticipate refusal of treatment or even contemplate suicide.
33	

We found differences in how participants with and without dependent family responded to symptoms of lung cancer. Female participants with dependent children or grandchildren were all motivated to visit the doctor with symptoms suggestive of lung cancer, in order to receive a prognosis to enable childcare arrangements after death. Women with dependent children who held more positive beliefs about lung cancer treatment would seek help for treatment to 'stay healthy' and prolong life. Participants with no dependent family would be more likely to ignore lung cancer symptoms, or seek medical help if in pain but refuse treatment.

9 The model patient

Participants discussed a sense of lack of entitlement to health services due to smoking habit, where respiratory-type symptoms of lung cancer were perceived as self-inflicted. For some, this was reinforced by an actual or expected 'smoking lecture' each time they sought medical help; the lecture made participants feel ostracised, particularly when smoking was used as a coping mechanism and contributed to not feeling worthy of seeking medical help. Some participants perceived that they may be treated differently by health professionals because they live in an area of deprivation, and discussed a potential power imbalance during consultations. Conversely, participants were highly critical of people who were perceived to waste, exploit and overuse NHS resources. They cited drug addicts, illegitimate benefits claimers, older people wanting social interaction, and people with coughs and colds as over users of the health service. Such beliefs may reflect a downward comparison to other more stigmatised service users to legitimise their own help seeking. In order to be considered a model and non-problem patient, participants legitimise their own help seeking only when absolutely necessary - and often after trying their 'own cures' i.e. cough medicine from the pharmacist - to not burden the doctors. Infrequent attenders or 'good service users' felt a sense of superiority for being a model patient.

- 28 Relationship with the healthcare professional

Some participants disclosed traumatic events in their lives including physical and sexual abuse,
 leading to tobacco dependence and alcohol addiction. In addition, more than half of the sample

- 32 described symptoms of depression and anxiety. Therefore, the relationship with their healthcare
- 33 professional was important when considering whether to present with lung symptoms; to feel

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21understood by the healthcare professional, with their personal history taken into account in the42context of health behaviour such as smoking.6374Those who felt comfortable, safe and not judged by their chosen healthcare professional felt95encouraged to present with symptoms. Some participants were prepared to wait up to three of106for an appointment with their preferred healthcare professional to discuss worrisome and127potentially serious symptoms that could indicate lung cancer. Many participants reported pro148with maintaining continuity of care, highlighting problems with the stretched National Health159Service.	the weeks				
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18 19 11 [insert Figure 1 here, currently on an additional file]					
20 12					
21 22 13 Focus groups					
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25 15 Two public focus groups were conducted in Wales and England, respectively. Most participant	ts were				
16 female and former smokers, and all participants were diagnosed with a lung condition. Two					
28 17 professional focus groups were conducted in Wales. Most participants were female, and were	е				
30 18 medical professionals (Table 2).					
31 19					
32 33 20 Table 2. Focus group characteristics	Table 2. Focus group characteristics				
34 Members of the public N Healthcare professionals and N	Mombors of the public N Healthcare professionals and N				
participants community partners par	rticipants				
Group 1, England total n=7 Group 3, Wales total	al n=5				
Gender Gender					
30Female6Female2					
40 Male 1 Male 3					
41 Smoking status Occupation					
42 Current smoker 3 Community nurse 1					
43 Former smoker 3 Support group facilitator 1					
44 Never smoker 1 Community partner 1					
45 Self-reported lung condition Third sector representative 1					
46 COPD 7 Public health representative 1					
47					
48 Recruited through Primary Care Recruited through the Health Board					
49 and community groups					
E0	al n=7				
Group 2, Wales total n=9 Group 4, Wales tota					
S0Group 2, Walestotal n=9Group 4, Walestotal51GenderGenderGenderGenderGender					
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S0Group 2, Walestotal n=9Group 4, Walestotal51GenderGenderGender652Female5Female653Male4Male154Smoking status0ccupation155Current smoker3Practice manager1					

	Former smoker	4	Pharmacist	1
	Never smoker	2	GP	2
	Self-reported lung condition		Practice nurse	2
	COPD	9	Medical student	1
	Recruited through community		Recruited through the Health Board/	
	groups		Primary Care	
,				
	Key themes discussed were: barriers to early lung cancer detection, and preferences regarding the			
ŀ	format and content of an intervention for the early detection of lung cancer. See Figure 2 for			

5 illustrative quotes.

7 Barriers to lung cancer symptom presentation

The focus groups confirmed our interview findings, where fear of wasting the doctor's time with trivial symptoms and fear of being judged or lectured about smoking deterred medical help seeking for lung cancer symptoms. In addition, the health professional group supported our findings that patients with lung conditions tend to fixate on chest infections. However, we found disparity between the patient-reported experience of the GP's approach to smoking and the healthcare professional reported approach to smoking cessation. Healthcare professionals in Wales discussed new guidance that discourages health professionals from 'lecturing' patients, suggesting the patient reported experience may be based on previous healthcare interactions, and they consequently anticipate a lecture.

 19 Potential format of an intervention to support earlier lung cancer detection

All groups discussed a preference for community based interventions, away from a traditional healthcare setting, for example a community event, talk in a community venue or health check bus, similar to breast screening mobile units. The anonymous and relaxed nature of such an intervention meant that intervention participants would feel they were not wasting GP time; rather it would act as a signal that their attendance at the event was desired. Participants compared this to a visit to the doctor, where they felt they were wasting the GP's time because they were not invited to attend. It was considered important that the intervention facilitator was knowledgeable or trained, non-judgemental, easy to talk to and approachable. Participants suggested a nurse, pharmacist, trained patient representative or community worker.

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2	1	Intervention content
3 4	1	Intervention content
5	2	
6 7	3	The public groups requested more information about the symptoms of lung cancer. However, the
8	4	healthcare professional groups felt that current lung cancer symptom information was too broad,
9 10	5	leading to dismissal and potentially denial of lung cancer information because people with smoking
11	6	history or comorbid lung conditions experience most of the symptoms daily. To overcome this
12 13	7	problem, the healthcare professionals groups discussed the need for more specific symptom
14	8	information, emphasising changes to normal symptoms and coupled with information about risk
15 16	9	factors for lung cancer.
17	10	
18 10	11	To modify negative beliefs about lung cancer, the health professionals groups suggested using
20	12	positive stories to communicate messages about the importance of lung cancer early diagnosis and
21	13	highlight the potential for survival outcomes with early stage detection
22	14	ingingin the potential for survival outcomes with early stage detection.
24	15	The inclusion of smoking cossistion information in a lung concer intervention was considered
25 26	15	The inclusion of smoking cessation information in a lung cancer intervention was considered
27	10	important by all groups. However, the manner in which smoking cessation could be approached was
28 29	1/	discussed as key to effective promotion of smoking cessation. Participants suggested highlighting the
30	18	benefits of stopping smoking in a gentle and relaxed manner to encourage choice to quit.
31 32	19	
33	20	[insert Figure 2 here, currently on an additional file]
34 35	21	
36	22	DISCUSSION
37 38	23	Our study was the first to explore the influences on lung cancer symptom presentation and
39	24	intervention preferences in high risk, highly deprived groups across three nations of the UK. We
40 41	25	found evidence from the interviews and focus groups that individuals who are high risk for lung
42	26	cancer fixate on maintaining health in the short term. Prioritising the daily management of their lung
43 44	27	condition led to avoidance of longer term health problems such as lung cancer, to gain a sense of
45	28	control over health in the context of difficult personal circumstances. Health beliefs were found to
46 47	20	undernin behaviour in relation to medical beln seeking, where percentions of 'inevitable but curable'
48	2)	chect infactions lad to immediate help seeking. However, 'inevitable but incurable' lung concer lad
49 50	21	the institute of the second state of the second
51	31	to inaction when faced with potentially serious symptoms and anticipated refusal of treatment.
52 53	32	Interview participants felt that the relationship with the healthcare professional was key when
54	33	considering medical help seeking. The importance of the interaction between provider and patient
55 56	34	was mirrored in the focus groups, where participants felt that a non-judgemental intervention
50 57		
58		15

facilitator was important. Multi-faceted community-based interventions, away from the traditional
 healthcare setting, were preferred by participants.

- A major strength of this study was the rigorous sampling procedures. We screened postcodes to ensure participants resided in the lowest quintile of deprivation, and measured multiple additional indicators of deprivation. Individual and area level indicators confirm that our sample was highly deprived, for instance most were unemployed and seeking benefits, and rented social housing. In addition, we recruited participants with no previous diagnosis of lung cancer, without mention of lung cancer until discussed by participants during the interview, or at the end of the interview. These recruitment and interview procedures meant we were able to explore actual and anticipated lung cancer symptom presentation in those who were symptomatic or asymptomatic. This strategy was employed to overcome the methodological limitations associated with studying either retrospective or anticipated symptom presentation in isolation [15]. Although we carefully sampled participants and collected additional demographic measures to validate our sampling frame, we were unable to conduct a focus group in Scotland due to low response, which is a potential limitation of the study. In addition, focus group participants were recruited opportunistically, with the potential that participants were more favourably disposed to an intervention.

Previous empirical studies report prolonged lung cancer symptom presentation due to misattribution[5,13,15-26,33,38,39] and in our study, we found evidence that participants normalised their lung cancer symptoms to smoking habit, and lung and other comorbid conditions. In contrast to previous studies that report haemoptysis as a facilitator to prompt medical help seeking[13,25,27,40-42], participants with experience of haemoptysis reported prolonged medical help seeking or described avoidant coping, and normalisation when blood was noticed. Denial and normalisation of haemoptysis may be specific to socioeconomically deprived groups. Our highly deprived sample reported daily struggles with complex physical and mental health needs, and with the challenges associated with living on no or limited income. Previous studies in socioeconomically deprived communities report that in the context of competing life demands, health was dealt with reactively and with low priority[43,44].

31 In addition, fear of being ineligible for treatment due to lifestyle, has the potential to deter medical 32 help seeking in deprived groups, conceptualised as Candidacy[44]. The underlying concept of health 33 service Candidacy[44] may explain why participants described feeling unworthy of seeking medical 34 help. In addition to challenging life circumstances, interview and focus group participants reported

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2 3	1	fear of being judged and ignored by health professionals due to their smoking habit or social
4 5	2	standing, contributing to perceptions of unworthiness. Furthermore, participants reported the
6	3	desire to be a model patient and to not waste valuable GP time, which influenced medical help
7 8	4	seeking. Although the desire to be a 'good citizen' has previously been reported[24,25], to our
9	5	knowledge, the current study was the first to explore perceptions of appropriate consultation
10 11	6	behaviour in a highly deprived sample. Our emerging findings related to Candidacy, combined with
12	7	the desire to exhibit 'good' consultation behaviour, may contribute to normalisation of symptoms
13 14	8	previously regarded as serious and therefore discourage help seeking. Consequently, high risk, highly
15 16	9	deprived participants are likely to focus on health in the short term, and ignore longer-term health
17	10	issues which may lead to advanced stage lung cancer diagnosis.
18 19	11	
20	12	We found that participants held seemingly contradictory views of their lung cancer susceptibility,
21 22	13	reporting scepticism about the causal role of smoking in lung cancer alongside perceived inevitability
23	14	of lung cancer. Beliefs about the link between smoking and lung cancer may reflect societal stigma
24 25	15	towards smoking, where participants downplay the negative effects of smoking, possibly to
26 27	16	legitimise medical help seeking for symptoms considered related to smoking. Perceived inevitability
27 28	17	of lung cancer is likely to reflect the high proportion of people that our sample of deprived
29 30	18	participants knew with lung cancer, as a consequence of high lung cancer incidence in areas of
31	19	deprivation. Perceived inevitability for lung cancer has previously been reported to minimise
32 33	20	normalisation of lung cancer symptoms and prompt help seeking[45]. However, we report
34	21	normalisation and ignoring of haemoptysis, possibly due to a combination of high fear and fatalism
35 36	22	of lung cancer, difficult life circumstances and low perceived health service Candidacy. Furthermore,
37	23	our findings raise questions of perceived social justice as influences on medical help seeking. High-
38 39	24	risk individuals who believe that they cannot legitimately seek medical help because of their former
40 41	25	or current lifestyle may therefore be resigned to the prospect of developing lung cancer.
41	26	
43 44	27	Practice and policy implications
45	28	
46 47	29	With a comorbid lung condition and smoking history, those who are high risk for lung cancer will, in
48	30	the main, be symptomatic. Therefore, as suggested by the focus groups, it is important to highlight
49 50	31	the significance of changing and multiple symptoms in an intervention, to avoid normalisation. High
51 52	32	risk individuals should be empowered to seek timely medical bein and made to feel welcome not
53	33	iudged or blamed for their current or former lifestyle. For instance, as suggested in the focus groups
54 55	34	interventions targeted at deprived groups could be conducted outside of a traditional healthcare
56	7	
57 58		
59		17

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setting and out to the community with non-judgemental facilitators. Our findings highlight the importance of an intervention where participants would be invited to attend, as opposed to the patient attending the GP surgery. An invitation may help to eliminate any potential perceptions of wasting GP time and make their attendance feel valued. Over half of the current sample described mental health problems and/or difficult current or former life circumstances. Intervention developers and HCPs in highly deprived communities should be aware of these wider social and contextual factors, and receive training to safeguard themselves. In addition, facilitators and HCPs should know how and where to appropriately signpost intervention participants who disclose difficult circumstances. Finally, the current UK health system potentially encourages patients with a lung condition to focus on short term management of their condition. GP prescribing of antibiotics and the use of rescue packs may inadvertently reinforce patients to detect and act on symptoms of a chest infection. There is potential that this current standard of care could

be adapted to educate and encourage patients with a lung condition to detect symptoms of lung cancer, thereby shifting the focus to longer term health. More research is required to understand how to motivate highly deprived groups to consider health in the long term, while recognising the wider social determinants of health[46].

19 Conclusion

The challenges of living in an area of deprivation with social exclusion issues, combined with fear of judgement by health professionals, contribute to denial and ignoring of lung cancer symptoms.
Multi-faceted community based interventions are required to highlight lung cancer symptoms, the

CZ:

23 Multi-faceted community based interventions are required to highlight lung cancer symptoms, the 24 importance of early diagnosis and empower people who are high risk for lung cancer to seek timely

25 medical help.

2	1	Additional information
4	2	
5 6	2	Ethics approval and consent to participate
7	5	The study received othical approval from Southampton Control, Hampshire A Possarch Ethics
8 9	4	Committee (16/56/0580). Written informed concent was obtained from all participants who took
10	5	committee (16/SC/0589). Written informed consent was obtained from all participants who took
11 12	0	part in the study.
13	/	
14 15	8	Consent for publication
16	9	Not applicable
17 18	10	
19	11	Data sharing
20 21	12	Qualitative data is not publicly available for this study to maintain participant confidentiality.
22	13	
23 24	14	Competing interests
25	15	The authors confirm that there are no conflicts of interest.
26 27	16	
28	17	Funding
29 30	18	This work was supported by Cancer Research UK (grant reference number: C16377/A22034).
31	19	
32 33	20	Author contributorship
34	21	All authors designed the study. GM and JH conducted, coded and analysed the interviews and focus
35 36	22	group data. All authors contributed to the interpretation of data. GM drafted the manuscript and all
37	23	authors contributed to the review and editing of the manuscript. All authors read and approved the
38 39	24	final manuscript.
40 41	25	
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49 50	21	for their encodes support and eduice throughout the study
51	22	for their ongoing support and advice throughout the study.
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37 38	23	Figure legends
39	24	Figure 1. Illustrative quotes (qualitative interviews)
40 41	25	Figure 2. Illustrative quotes (focus groups)
42	26	
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Figure 1. Illustrative quotes (qualitative interviews)

Theme	Quote
Symptom detection	
strategies and help seeking Friends and family notice symptoms Sophisticated symptom	"My daughter might [notice changes to symptoms] cos she mentions it now and thenshe'll give me a dig and she'll say 'your breathing's annoying me'. Cos it's heavy breathing so. Then again there's something wrong" (Male, 48, Scotland, former smoker) "If [phlegm is] white and bubbly it's not a chest infection. It's only when it goes green so you can tell yourself exactly how close you
detection strategies/ monitoring of chest infections	are to getting an infection There's just two different kinds of green spittle, if it's fluorescent green then you've got an infection, normal antibiotics won't work with me, if it's the lighter green I'm fine with that one it's handy to look out for, because you can get the right medication at the right timebecause if anything happens to me, there's no one for my kids." (Female, 48, Scotland, current smoker)
Normalisation of haemoptysis	"Coughing up blood, I do actually get some of that I don't know why, but it could be because of the ulcer thing and thatThere again then well I do get like nosebleeds, and then I'm thinking the blood maybe coming inside and coming down, you swallow it see. So then that will come back up won't it" (Male, 62, Wales, former smoker)
Focus on maintaining health in the short term	"I get worried about having chest infection, I get more worried about today or tomorrow rather than the future. The future that's going ahead for us anyway. Lung cancer's not an issue really" (male, 50, Scotland, former smoker)
Fear of bad news during a consultation	"I'm very poor in asking questions cos I don't want to know the results. Simple as thatno I don't ask when they say the oxygen [saturation] is alright I just think well it's alright and it's one thing less I haven't got to worry about" (Female, 69, Wales, former smoker)
Denial and avoidance of	
Scepticism about the link between smoking and lung cancer	"You hear occasions where people who don't smoke, who've never smoked. Well how do they get their lung cancer?I've got [lung cancer] in my head, I'm probably going to get it, if I haven't already got it because of the lifestyle I've had. Where I've worked and everything else, what I've worked with." (Male, 68, England, current smoker)
Perceived inevitability of lung cancer/ anticipate suicide	"[Lung cancer] is really, really on the forefront on the mindI just think 'oh god, please don't let me get cancer'I think if I was to get cancer, I've sometimes said to myself, I'd commit suicide. I would take a pill or something." (Female, 81, Scotland, current smoker)
	"[Lung cancer] worries me but I've got proper problems to worry

Avoidance of lung cancer due to social and contextual factors	about [carer for disabled son, problems with social services and benefits claims, insecurity of current council owned housing and problems with area of residence with 'junkies']. I won't worry about it until it's actually here. If I started worrying about eventualities I'd never get anywhere" (Female, 48, Scotland, current smoker)
Lung cancer fatalism/ anticipated refusal of treatment	"Until anything happened and I'm actually told that I've got [lung cancer], there's nothing I can do about it. I'm really a believer of what's in your cards is already written. So I don't look at anything like thatBut if they told me it was cancer, I would go ok then, but I wouldn't take any of the treatments if it's my time, it's my time. It just doesn't, I don't think I've got any more fight in me for all that. I think that would be the last straw for me. So I just live every day as it comes now, I don't really plan much. So I'm just living in the day, you know. Cos whatever happens, happens anyway." (Female, 49, Scotland, current smoker)
Response to lung cancer symptom/ female with dependent family	"I don't think they can treat [lung cancer]. You've just got to accept it haven't youI would go to the doctor [with a symptom], I think I would like to know how long I had. Not for me but for [my son] you know. For himIf it was just me I wouldn't want to know, but because I've got him, [I would] definitelyWhen I seen the blood I did think to myself, I flushed it away right awayI seen the blood and I thought no, and I thought I've got to, you know, because of [my son]. The only way I would want to know is because of him. If I was by myself I would just say, don't want to knowCan't just think about myself I've got to think about him as well." (Female, 68, Scotland, current smoker)
	4
The model patient Perception of healthcare professionals attitude to smokers	"You feel as though you're an alien because you smoke, you feel as so they just look at you and say 'urghh', you know" (Female, 52, Scotland, current smoker)
Critical of people who waste NHS resources	"I can guarantee if I went this Monday and go next Monday the same people are sitting there. I'm being honest, they're a drain on society on the NHS, but that's the way they livethese people that go there are not really ill, I think they're just seeking attention" (Male, 78, England, current smoker).
Relationship with	
healthcare professional Disclosure of highly sensitive personal problem	"Some people are friendly and not stony facedif [the HCP] can't even start a conversation with the simplest of ice breakers then how can people tell about pooping themselves when they're coughing up" (Female, 48, Scotland, current smoker)
	"I'm alright with [one GP], you could tell her anything, I've shocked
Good relationship with GP	<i>her sometimes</i> " (Female, 51, England, current smoker)

Figure 2. Illustrative quotes	(focus groups)
Theme	Quote
symptom presentation	
Fixation on chest infections	"People tend to be fixated on a [chest] infection and they want to next rescue pack ready cos almost as if it's inevitable; it's going happen in the next month or so." (Focus group 4)
Difference in perception around healthcare professional approach to patients' smoking	"I think there is a gulf between what people believe their GP w say to them if they do actually talk about [smoking] as oppose what that conversation actually is in realityBut certainly as f the formal training coming out of public health, if they are o that then there is, that's not a lectureBut that's what people for going to be what they're going to be told" (Focus group 3)
Potential format of an intervention to support earlier lung cancer detection	Participant 2: "So what I'm saying is, you know them mobile buses in the shopping area, where people go shops, or outside hospital So they set them up and people are walking past, and even though they can't be bothered to go to the doctors, and the look and they think I'll just pop in Participant 1: Cos you wouldn't hesitate you know, you'd just in. Participant 2: You're just a person, they don't know and they'n just seeing what's there, or what's there or what's the problem you. If there's no problem Participant 3: People think you don't want to think you're, fee if you're wasting the doctor's time" (Focus group 1)
Intervention content	N.
More specific symptom advice	Participant 1: "Yeah I think when you say 'cough' it's a bit brow and it's a bitYou know, you've had a cough for two weeks, off go. Participant 3: It'd be useful if it was a change in your regular cough" (Focus group 4)
Messages to combat negative beliefs	"Positive messages, particularly around lung cancer bec everybody, you know it's like a death knell isn't it? And actuall not, it doesn't have to be. You know you're talking here about diagnosis which is a big deal isn't it" (Focus group 3)
Smoking cessation	"You've got to include [smoking cessation information]I think is how you deliver the messagenot in such a way you feel asham for smoking. I've noticed [the nurse] has got a way of telling pat how to stop smoking, she does it in a, not in a 'well you should s smoking', that kind of way. She'll say 'have you ever thought ab giving it up. You know it would improve your chest a bit'. And I'v seen [the nurse do it] more in a non-lecturey basis, more of a, 'h you ever thought about it?' Relaxed, warmer manner. So I'm no lecturing you, it's your choice. You know it's bad for you." (Focus group 4)

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Supplementary File 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist with page numbers to indicate section of the article [34]

Ch	ecklist item	Questions to consider	Page number in article			
Do	Domain 1: Research team and reflexivity					
Pei	rsonal Characteristics					
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	8			
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	8			
3.	Occupation	What was their occupation at the time of the study?	8			
4.	Gender	Was the researcher male or female?	8			
5.	Experience and training	What experience or training did the researcher have?	8			
Re	lationship with participants	5				
6.	Relationship established	Was a relationship established prior to study commencement?	6			
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6			
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	8			
Do	main 2: study design	E.				
The	eoretical framework					
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory,</i> <i>discourse analysis, ethnography, phenomenology,</i> <i>content analysis</i>	8			
Pa	rticipant selection					
10.	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5-6			
11.	Method of approach	How were participants approached? e.g. face-to- face, telephone, mail, email	6-7			
12.	Sample size	How many participants were in the study?	9, 13			
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	9			
Set	Setting					
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	7			
15.	Presence of non- participants	Was anyone else present besides the participants and researchers?	7			
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	9-10, 13-14			
Data collection						
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6-7			

18. Repeat interviews	Were repeat interviews carried out? If yes, how	6
	many?	
19. Audio/visual recording	Did the research use audio or visual recording to	6, 8
	collect the data?	
20. Field notes	Were field notes made during and/or after the	8
	interview or focus group?	
21. Duration	What was the duration of the interviews or focus	7
	group?	
22. Data saturation	Was data saturation discussed?	7
23. Transcripts returned	Were transcripts returned to participants for	
	comment and/or correction?	
Domain 3: analysis and findings		·
Data analysis		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding	Did authors provide a description of the coding	8
tree	tree?	
26. Derivation of themes	Were themes identified in advance or derived from	8
	the data?	
27. Software	What software, if applicable, was used to manage	8
	the data?	
28. Participant checking	Did participants provide feedback on the findings?	8
Reporting		·
29. Quotations presented	Were participant quotations presented to illustrate	Figure 1,
	the themes / findings? Was each quotation	Figure 2
	identified 2 constituings: Was each quotation	-
	Identified? e.g. participant number	0.45
30. Data and findings	Was there consistency between the data	9-15
consistent	presented and the findings?	
31. Clarity of major themes	Were major themes clearly presented in the	10-15
	tindings?	
32. Clarity of minor themes	Is there a description of diverse cases or discussion	10-15
	of minor themes?	



Supplementary file 1. Symptom sorting task

Symptoms included in the symptom sorting task
Participants were asked 'We know that people decide go to the doctor at different times with symptoms. I'm going
to show you some pieces of card with symptoms on. I'd like you to rank them from the ones that you would go to
the doctor with first through to the last on this sheet of paper.'
Coughing up blood
Persistent chest infection
Chest or shoulder pain
Ache or pain when coughing or breathing
Persistent breathlessness
A cough that doesn't go away
A long standing cough that gets worse
Persistent tiredness or lack of energy
Loss of appetite or unexplained weight loss
Changes in the appearance of fingers such as the ends becoming curved or larger
Hoarse voice

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Engaging high-risk groups in early lung cancer detection: a qualitative study of symptom presentation and intervention preferences amongst the UK's most deprived communities

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7 8	1	presentation and intervention proferences amongst the UK's most deprived communities
9	4	presentation and intervention preferences amongst the OK's most deprived communities
10 11	3	
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Abstract **Objectives** People at high-risk for lung cancer - current/former smokers, aged 40+ years, with serious lung comorbidity (i.e. Chronic Obstructive Pulmonary Disease) and living in highly deprived areas - are more likely to delay symptom presentation. This qualitative study aimed to understand the influences on early presentation with lung cancer symptoms in high-risk individuals and intervention preferences. Methods Semi-structured qualitative interviews with 37 high-risk individuals (without a cancer diagnosis), identified through seven GP practices in socioeconomically deprived areas of England, Scotland and Wales (most deprived 20%). A symptom attribution task was used to explore lung symptom perception and help-seeking, developed using Leventhal's Common Sense Model. Four focus groups with 18 high-risk individuals and 16 local stakeholders (healthcare professionals and community partners) were conducted to explore preferences for an intervention to promote early lung cancer symptom presentation. Data were synthesised using Framework analysis. Results Individual and area level indicators of deprivation confirmed that interview participants were highly deprived. Preoccupation with managing 'treatable' short-term conditions (chest infections), led to denial and avoidance of 'inevitable and incurable' longer-term conditions (lung cancer). Feeling judged and unworthy of medical help because of their perceived social standing or lifestyle deterred medical help seeking, particularly when difficult life circumstances and traumatic events led to tobacco and alcohol addiction. Focus group participants recommended multi-faceted interventions in community venues, with information about lung cancer symptoms and the benefits of early diagnosis, led by a trained and non-judgemental facilitator. Conclusions This study was novel in engaging a high-risk population to gain an in-depth understanding of the broader contextual influences on self-management of lung cancer symptoms. Perceived lack of health service entitlement and complex lives facilitated avoidance of recognising and presenting with lung cancer symptoms. Community-based interventions have the potential to empower disadvantaged populations to seek medical help for lung symptoms.

1 2		
2 3	1	Key words: Lung cancer, deprived, qualitative, early diagnosis, medical help seeking, barriers,
4 5	2	
6 7	3	Strengths and limitations of the study
8	4	• This was the first study to use in-depth qualitative methods to explore how to engage high
9 10	5	risk individuals from socioeconomically deprived areas in early lung cancer detection.
11 12	6	• A major strength of this study was the proactive and rigorous sampling procedures used to
13	7	ensure that our sample was at high risk for lung cancer.
14 15	8	Assessment of individual and area level indicators of deprivation confirmed that interview
16 17	9	participants were highly deprived; all participants resided in the 20% most deprived areas of
18	10	the three UK nations, and most participants were unemployed/seeking benefits and/or
19 20	11	rented social housing.
21 22	12	 To overcome the methodological limitations associated with studying anticipated or
23	13	retrospectively recalled cancer symptom presentation, we recruited participants with no
24 25	14	previous diagnosis of lung cancer and did not mention lung cancer in the interview study
26 27	15	materials or during completion of the symptom attribution task
28	16	Opportunistic recruitment of focus group participants who may have been more favourably
29 30	17	disposed to an intervention was a notential study limitation
31 32	17	disposed to an intervention was a potential study initiation.
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1 INTRODUCTION

Lung cancer is the leading cause of cancer mortality worldwide [1]. Outcomes are among the poorest for all cancers, with only 13% of lung cancer patients surviving five or more years in the UK [2]. Diagnosis of lung cancer at an early stage can enable curative surgical resection, meaning over 80% of patients will survive one year or more when diagnosed at Stage I[3]. Delayed medical help seeking for symptoms and the high proportion of lung cancer diagnoses through emergency departments may partly explain why lung cancer is commonly diagnosed at an advanced, incurable stage[4]. Due to low specificity of lung cancer symptoms and similarity to other acute and comorbid respiratory conditions, patients face difficulty in knowing when to seek medical help[5,6].

Multiple symptoms and risk factors for lung cancer including older age, smoking, the presence of a lung comorbidity and socioeconomic deprivation increase the likelihood that a patient presenting to their GP with symptoms indicative of lung cancer will receive a cancer diagnosis[7-9]. Lung cancer is more common and mortality higher in areas of high socioeconomic deprivation; it has been estimated that each year, socioeconomic inequalities account for 11,700 excess cases of lung cancer and 9,900 potentially avoidable lung cancer deaths in England[10]. High prevalence of smoking, lung comorbid conditions and asbestos exposure, all of which are well documented risk factors for lung cancer, contribute to high lung cancer incidence and mortality in deprived communities[11, 12].

The presence of lung comorbidity such as chronic obstructive pulmonary disease (COPD) and history of smoking have been associated with a lower likelihood of presenting with lung cancer symptoms early[13,14]. In the lead up to lung cancer diagnosis, vague symptoms may go unnoticed or not considered a legitimate symptom to seek medical attention for, or be misattributed to smoking, aging or other comorbid conditions such as heart disease or COPD, thereby prolonging help seeking[5,13,15-26]. In addition, stigma attached to lung cancer[23,27-30] and fear of lung cancer diagnosis can deter medical help seeking for symptoms, particularly among smokers[23-25,29,31-33], leading to advanced stage disease at diagnosis[19]. To date, research has mainly been conducted with lung cancer patients from a range of socioeconomic groups with varying levels of lung cancer risk, retrospectively exploring the barriers to symptom presentation. Evidence is lacking about how individuals who are at high risk, and without a diagnosis of lung cancer, attribute potential lung cancer symptoms and decide to seek medical help.

Strategies to prompt earlier help seeking for lung cancer symptoms are required. However, evidence
 is limited regarding optimal methods for promoting earlier detection through interventions targeted

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2		
3 4	1	at high risk, highly deprived groups. Mass media[34] and community based social marketing[35] lung
5	2	cancer campaigns report limited reach to the most deprived groups. A nurse-led primary care
7	3	intervention for older adults with a long smoking history or recent cessation reported increased and
8 9	4	sustained intentions to seek help with lung cancer symptoms[36]. However, the intervention was
10	5	not targeted at highly deprived groups. Novel methods to support the high risk groups to engage in
12	6	early lung cancer detection are required.
13 14	7	
15	8	The current study used a combination of interviews and focus groups to explore potential barriers to
16 17	9	early lung cancer detection and strategies to encourage early help seeking with individuals who are
18 19	10	the high risk for lung cancer. Qualitative interviews were used to gain an in-depth understanding of
20	11	the processes and motivations involved in symptom attribution and medical help seeking for
21 22	12	potential lung cancer symptoms in high risk, highly deprived individuals. We targeted
23 24	13	socioeconomically deprived areas across three nations of the UK to approach potential participants,
25	14	and used rigorous sampling procedures to ensure that our sample were at the high risk for lung
26 27	15	cancer. To overcome methodological limitations associated with retrospective recall, we recruited
28 29	16	participants with no previous diagnosis of lung cancer, and framed the interview around lung health,
30	17	rather than lung cancer. Findings from the interviews were presented to focus groups participants in
31 32	18	order to facilitate discussion about preferences and acceptability of interventions to engage high
33 34	19	risk, highly deprived groups in early lung cancer detection. The focus groups were conducted in
35	20	highly deprived areas with stakeholders who lived or worked in these communities. To our
36 37	21	knowledge, this was the first study to explore the influences on early lung cancer detection and
38 39	22	intervention preferences targeted at high risk groups living in the most deprived areas of the UK.
40	23	
41 42	24	METHODS
43 44	25	The Consolidated Criteria for Reporting Qualitative Research (COREQ)[37] criteria were used to
45	26	guide reporting (Supplementary File 1).
46 47 48 49 50 51 52 53 54 55	27	
	28	Participant recruitment and sampling
	29	Interviews. Thirty-seven interview participants were recruited through seven primary care general
	30	medical practices (GP) in South Wales (Cwm Taf: three practices), England (Liverpool: one practice)
	31	and Scotland (Aberdeen: three practices). Using routinely published index of multiple deprivation
	32	(IMD) data for England, Scotland and Wales, GP practices with the highest proportion of their
50 57	33	patients that reside in the most deprived quintile were contacted. Practice managers were asked to
58 59 60	34	screen GP practice databases purposively for eligible study participants: men and women over the

age of 40, who were current or former smokers, with a lung condition (COPD including chronic bronchitis and emphysema, interstitial lung disease or occupational lung disease). Participants were initially recruited from GP practices in Cwm Taf, where practice managers were asked to screen databases for current and former smokers, with no parameter set for number of years since quit attempt. Due to an initially high response rate from former smokers in Cwm Taf, subsequent participants in Aberdeen and Liverpool were sampled purposively according to smoking history. One GP practice in Aberdeen was asked to recruit current smokers and recent quitters (within ten years). Two GP practices in Aberdeen and one GP practice in Liverpool recruited current smokers only. To ensure that participants from highly deprived areas were invited to take part in the study, individual postcodes were screened by the research team. Eligible patients from the initial database screen were assigned a pseudo-anonymised participant identifier (PID). PID and postcode were checked against IMD score, and those that resided in the most deprived IMD quintile were eligible for the study. The final list of potentially eligible participants was checked by the GP for ability to provide informed consent, considered by the GP to be a risk to the interviewer or themselves and general health status (i.e. very seriously ill). Participants were excluded if they were diagnosed with lung cancer, were terminally ill or did not have capacity to consent. Focus groups. Eighteen participants for the focus groups with members of the public were recruited opportunistically through primary care or local community groups. Participant recruitment through primary care employed the same methods as those used to invite the interview participants. Pseudonymised participant identifiers were checked to ensure that those who took part in the focus groups had not already participated in the interviews. Additional participants were recruited opportunistically through local community respiratory support groups and non-health related groups in the local community centre. Local community group organisers in areas of high deprivation were contacted and asked for help to recruit members of the public in our target group. Local health service planning groups and health board staff facilitated recruitment of 12 participants for the healthcare professional and community partner (HPCP) focus groups. **Study procedures** Written consent and permission to audio-record were obtained on the day of the interviews and focus groups.

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3 ⊿	1	Interviews. Eligible participants were invited by letter with more detailed study information
5	2	attached, with a reminder at two weeks to non-respondents. Those who returned the study reply
6 7	3	slip via a FREEPOST envelope were contacted by the interviewer (GM or JH) to arrange a suitable
8 9	4	time and date for the interview, to outline the study and answer any questions.
10	5	
11 12	6	Interviews were conducted using a semi-structured topic guide to facilitate a discussion about illness
13 14	7	perceptions and coping strategies; development was guided by the Common Sense Model[38]
15	8	(Supplementary File 2). The interview aimed to explore experiences of their lung condition, symptom
16 17	9	attribution, symptom experience and help seeking behaviour, the influence of smoking history on
18 19	10	new or changing symptoms, and if appropriate, lung cancer awareness and beliefs.
20	11	
21 22	12	A symptom sorting task was used to provide participants with a concrete visual task to increase
23 24	13	engagement with the interview in the context of potential low literacy. The task formed a basis for
25	14	discussion about symptom attribution and experience, where participants were asked to order 11
26 27	15	symptoms from those they would go to the doctor with first, through to the last. The 11 symptoms
28 29	16	were selected from the NICE guidance for referral of suspected lung cancer
30 21	17	(https://www.nice.org.uk/guidance/cg121). The symptoms were re-worded to simplify the language
32	18	in line with wording found on the NHS Choices website for lung cancer symptoms and any reference
33 34	19	to time scale of symptoms was removed (Supplementary File 2, p.9). For example, a cough that lasts
35 36	20	for 3 weeks or more was amended to 'persistent cough', and haemoptysis was amended to
30 37	21	'coughing up blood'. The presentation order of the symptoms was rotated between interviews.
38 39	22	
40 41	23	To explore potential lung cancer symptom attribution outside of a cancer context, there was no
42	24	mention of cancer in the interview study information packs or when participants completed the
43 44	25	symptom sorting task. If appropriate, participants were asked questions to explore lung cancer
45 46	26	awareness and beliefs at the end of the interview or when participants discussed lung cancer
40 47 48 49 50 51	27	unprompted.
	28	
	29	Demographic data were collected using a short questionnaire, including three additional measures
52	30	of socioeconomic group: age, gender, smoking status (quantity and duration), home ownership,
53 54	31	occupation and educational attainment. Interviews were conducted until data saturation (no new
55 56	32	themes emerging[39]).
57	33	
58 59		
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Focus groups. High risk members of the public, and healthcare professionals (i.e. GP, nurse, community pharmacist/community partners working in areas of deprivation with people with smoking history and/or lung conditions were sent information about the study and invited to take part in the focus group. Focus group participants were explicitly informed that the study was about the development of an intervention about lung cancer. A mutually convenient time, date and location for the focus groups was agreed. The focus groups were conducted using a semi-structured topic guide to explore preferences for an intervention to promote earlier lung cancer diagnosis. Separate topic guides were used for the public and professional groups (Supplementary file 3 and 4). Participants were given a verbal summary of the key findings from the qualitative interviews, and asked to discuss preferences for a potential lung cancer intervention targeted at high risk, highly deprived individuals. Topics for discussion were: preferred format of an intervention, recommendations for intervention content, preferred location and facilitator for intervention delivery, and recommendations for the inclusion of smoking cessation advice. Setting Most interviews (n=34) took place face-to-face in participant's own homes, with three taking place in a café, local community centre or over the telephone, and lasted between 46 and 146 minutes (mean 83 minutes). Family members were present for three interviews but did not participate in the study. Focus groups took place in primary care settings (n=2) or local community centres (n=2). Members of the public who took part in the interviews or focus groups were given a £10 shopping. Healthcare professionals and community partners were not reimbursed for their time. Interviews and focus groups in England were conducted by JH (PhD), a trained and experienced female qualitative Research Fellow and Medical Sociologist. The Welsh and Scottish interviews and focus groups were conducted by GM (PhD), a female Health Psychologist and trained qualitative Research Associate. Data analysis Interviews and focus groups were audio-recorded and transcribed verbatim. Anonymised transcripts were analysed in detail using the Framework method[40]. Framework analysis is a well-respected and commonly used approach to qualitative data analysis. It was considered particularly suitable for this study due to its transparency and the team work involved[41]. Framework enabled the sharing of synthesised data charts among team members to facilitate participation in analysis and interpretation workshops.

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	57 58 59 60	33	deprivation for their respective country, of whom 15 were in the most deprived decile. Most

- 1 participants had left school before age 15 with no formal qualifications, lived in social housing, and
- 2 claimed disability benefit or job seekers allowance.

3 Table 1. Qualitative interview sample characteristics

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1 2		
3	1	Key themes were: strategies involved in symptom detection and help seeking behaviour, maintaining
4 5	2	short term health, denial and avoidance of longer term health, the desire to be a model patient, and
6 7	3	the importance of the relationship with their healthcare professional. See Table 2 for illustrative
8	4	quotes.
9 10	5	
11 12	6	Symptom detection strategies and help seeking
13	7	
14 15	8	Symptoms discussed during the task were viewed as "part and parcel" (male, 68, England, current
16 17	9	smoker) of their lung condition, other pre-existing comorbidities or smoking habit, and were
18	10	consequently normalised and perceived not to require medical help. Changes to vague or
20	11	respiratory-type lung cancer symptoms were only taken seriously when remarked on by friends and
21 22	12	family or when they impacted on daily life.
23	13	
24 25	14	Symptoms that could indicate a chest infection were reportedly constantly monitored. Participants
26 27	15	discussed using sophisticated strategies such as noticing changes in the colour and consistency of
28 20	16	their phlegm or subtle audible changes in their cough to actively detect chest infections. Such
30	17	strategies were considered important to facilitate early detection and treatment for chest infections
31 32	18	through their primary care provider or with rescue packs (emergency packs of steroids and
33 34	19	antibiotics that can be kept at home), due to lung condition.
35	20	
36 37	21	Constant monitoring of phlegm for control of lung condition meant that participants could and
38 39	22	would notice haemoptysis, but few reported actively looking for haemoptysis on a regular basis.
40	23	Disparity between actual and anticipated medical help seeking was reported for haemoptysis. Most
41 42	24	participants had not previously experienced haemoptysis, but would anticipate seeking medical help
43 44	25	immediately due to the potentially serious nature of blood. However, some participants who had
45	26	previously or were currently experiencing haemoptysis attributed the presence of blood to non-
46 47	27	cancer causes such as their stomach ulcer or a previous flu jab. One participant ascribed their cough
48 49	28	to lung cancer. Some of the participants with experience of haemoptysis did not seek medical help.
50	29	
51 52	30	Focus on maintaining short term health
53 54	31	
55	32	Participants reported seeking medical help quickly when symptoms were easy to detect, were
56 57	33	attributed to what was perceived as a treatable cause and represented an immediate health threat
58 59 60	34	i.e. a chest infection due to lung condition. Participants could often request an appointment the

same day as permitted by their GP surgery policies. Prompt help seeking was reportedly due to fear of not being able to breathe and the potentially life-threatening nature of chest infections, and is likely to reflect the need to maintain good health in the short term.

The focus on maintaining short term health may reflect low general expectations of health, where some participants disclosed surprise at living beyond 60 years of age. In addition, due to fear of potentially hearing bad news, some participants expressed a preference to not ask questions during a consultation or yearly review with the nurse. Participants discussed prioritising day-by-day living over longer term planning, thereby focusing on health in the short term.

Denial or avoidance of long term health outcomes

Most participants discussed scepticism about the link between lung cancer and smoking. Conversely, participants thought that lung cancer was inevitable due to their current or former lifestyle, including smoking history, working conditions, their lung condition and the reported incidence of lung cancer in their community. For many participants, the topic of lung cancer arose spontaneously. Lung cancer was discussed in the context of perceived inevitability when reflecting on their general lung health and during completion of the symptom task when recalling friends/family with lung cancer. Beliefs about inevitability were often coupled with highly negative fearful and fatalistic beliefs about lung cancer, with no cure and eventual death. Such claims were evidenced by knowing a high proportion of friends and family who were diagnosed with lung cancer and often died. A few participants discussed that a cure for lung cancer involved luck or was 'some miracle' (male, 56, Wales, occasional smoker), reflecting a perceived lack of control over early detection and treatment. Consequently, actual or anticipated medical help seeking for lung cancer symptoms was motivated by pain, or to seek a diagnosis and prognosis to notify family members. However, some participants anticipated refusal of treatment or would even contemplate suicide.

We found differences in how participants with and without dependent family reported responding to symptoms of lung cancer. Female participants with dependent children or grandchildren discussed a motivation to visit the doctor with symptoms suggestive of lung cancer, in order to receive a prognosis to enable childcare arrangements after death. Women with dependent children who held more positive beliefs about lung cancer treatment reported the need to seek help for treatment to 'stay healthy' and prolong life. Participants with no dependent family were more likely to ignore lung cancer symptoms, or anticipate seeking medical help if in pain but refuse treatment.

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1 The model patient

Participants discussed a sense of lack of entitlement to health services due to smoking habit, where respiratory-type symptoms of lung cancer were perceived as self-inflicted. For some, this was reinforced by an actual or expected 'smoking lecture' each time they sought help from healthcare professionals; the lecture made participants feel ostracised, particularly when smoking was used as a coping mechanism and contributed to not feeling worthy of seeking medical help. Some participants perceived that they may be treated differently by health professionals because they live in an area of deprivation, and discussed a potential power imbalance during consultations. Conversely, participants reported high criticism towards people who were perceived to waste, exploit and overuse NHS resources. They cited drug addicts, illegitimate benefits claimers, older people wanting social interaction, and people with coughs and colds as over users of the health

service. Such beliefs may reflect a downward comparison to other more stigmatised service users to legitimise their own help seeking. In order to be considered a model and non-problem patient, participants discussed legitimising their own help seeking by only consulting when absolutely necessary - and often after trying their 'own cures' i.e. cough medicine from the pharmacist - to not burden the doctors. Infrequent attenders or 'good service users' discussed feeling a sense of

19 superiority for being a model patient.

21 Relationship with the healthcare professional22

Some participants disclosed traumatic events in their lives including physical and sexual abuse, leading to tobacco dependence and alcohol addiction. In addition, more than half of the sample described symptoms of depression and anxiety. Therefore, the reported relationship with their healthcare professional was important when considering whether to present with lung symptoms. Participants discussed the need to feel understood and not judged by their healthcare professional, with their personal history taken into account in the context of health behaviour such as smoking.
Those who discussed feeling comfortable, safe and not judged by their chosen healthcare

31 professional felt encouraged to present with symptoms. Some participants reported that they were 32 prepared to wait up to three weeks for an appointment with their preferred healthcare professional 33 to discuss worrisome and potentially serious symptoms that could indicate lung cancer. Many

- 1 participants reported problems with maintaining continuity of care, highlighting problems with the
- 2 stretched National Health Service.

Table 2. Illustrative quotes (qualitative interviews)

Theme	Quote		
Symptom detection			
strategies and help seeking Friends and family notice symptoms	"My daughter might [notice changes to symptoms] cos she mentions it now and thenshe'll give me a dig and she'll say 'your breathing's annoying me'. Cos it's heavy breathing so. Then again there's something wrong" (Male, 48, Scotland, former smoker)		
Sophisticated symptom detection strategies/ monitoring of chest infections	"If [phlegm is] white and bubbly it's not a chest infection. It's only when it goes green so you can tell yourself exactly how close you are to getting an infection There's just two different kinds of green spittle, if it's fluorescent green then you've got an infection, normal antibiotics won't work with me, if it's the lighter green I'm fine with that one it's handy to look out for, because you can get the right medication at the right timebecause if anything happens to me, there's no one for my kids." (Female, 48, Scotland, current smoker)		
Normalisation of haemoptysis	"Coughing up blood, I do actually get some of that I don't know why, but it could be because of the ulcer thing and that There again then well I do get like nosebleeds, and then I'm thinking the blood maybe coming inside and coming down, you swallow it see. So then that will come back up won't it" (Male, 62, Wales, former smoker)		
Focus on maintaining health in the short term	"I get worried about having chest infection, I get more worried about today or tomorrow rather than the future. The future that's going ahead for us anyway. Lung cancer's not an issue really" (male, 50, Scotland, former smoker)		
Fear of bad news during a consultation	"I'm very poor in asking questions cos I don't want to know the results. Simple as thatno I don't ask when they say the oxygen [saturation] is alright I just think well it's alright and it's one thing less I haven't got to worry about" (Female, 69, Wales, former smoker)		
Denial and avoidance of			
long term health outcomes Scepticism about the link between smoking and lung cancer	"You hear occasions where people who don't smoke, who've never smoked. Well how do they get their lung cancer?I've got [lung cancer] in my head, I'm probably going to get it, if I haven't already got it because of the lifestyle I've had. Where I've worked and everything else, what I've worked with." (Male, 68, England, current smoker)		
Perceived inevitability of lung cancer/ anticipate suicide	<i>"[Lung cancer] is really, really on the forefront on the mind…I just think 'oh god, please don't let me get cancer'…I think if I was to get cancer, I've sometimes said to myself, I'd commit suicide. I</i>		

	<i>would take a pill or something.</i> " (Female, 81, Scotland, current smoker)
Avoidance of lung cancer due to social and contextual factors	"[Lung cancer] worries me but I've got proper problems to worry about [carer for disabled son, problems with social services and benefits claims, insecurity of current council owned housing and problems with area of residence with 'junkies']. I won't worry about it until it's actually here. If I started worrying about eventualities I'd never get anywhere" (Female, 48, Scotland, current smoker)
Lung cancer fatalism/ anticipated refusal of treatment	"Until anything happened and I'm actually told that I've got [lun cancer], there's nothing I can do about it. I'm really a believer of what's in your cards is already written. So I don't look at anythin like thatBut if they told me it was cancer, I would go ok then, b I wouldn't take any of the treatments if it's my time, it's my tin It just doesn't, I don't think I've got any more fight in me for all that. I think that would be the last straw for me. So I just live eve day as it comes now, I don't really plan much. So I'm just living in the day, you know. Cos whatever happens, happens anyway." (Female, 49, Scotland, current smoker)
Response to lung cancer symptom/ female with dependent family	"I don't think they can treat [lung cancer]. You've just got to accept it haven't youI would go to the doctor [with a symptom think I would like to know how long I had. Not for me but for [my son] you know. For himIf it was just me I wouldn't want to kno but because I've got him, [I would] definitelyWhen I seen the blood I did think to myself, I flushed it away right awayI seen th blood and I thought no, and I thought I've got to, you know, because of [my son]. The only way I would want to know is because of him. If I was by myself I would just say, don't want to knowCan't just think about myself I've got to think about him o well." (Female, 68, Scotland, current smoker)
The model patient Perception of healthcare professionals attitude to smokers	"You feel as though you're an alien because you smoke, you feel so they just look at you and say 'urghh', you know" (Female, 52, Scotland, current smoker)
Critical of people who waste NHS resources	"I can guarantee if I went this Monday and go next Monday the same people are sitting there. I'm being honest, they're a drain of society on the NHS, but that's the way they livethese people the go there are not really ill, I think they're just seeking attention" (Male, 78, England, current smoker).
Relationship with healthcare professional Disclosure of highly sensitive personal problem	"Some people are friendly and not stony facedif [the HCP] can't even start a conversation with the simplest of ice breakers then how can people tell about pooping themselves when they're coughing up" (Female, 48, Scotland, current smoker)

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Good relationship with GP	"I'm alright with [one GP], you could tell her anything, I've shocked
	<i>her sometimes</i> " (Female, 51, England, current smoker)

Focus groups

Two public focus groups were conducted in Wales and England. Most participants were female and former smokers, and all participants were diagnosed with a lung condition. Two professional focus groups were conducted in Wales. Most participants were female, and were medical professionals (Table 3).

Table 3. Focus group characteristics

Members of the public	N	Healthcare professionals and	N
	participants	community partners	participants
Group 1, England	total n=7	Group 3, Wales	total n=5
Gender		Gender	
Female	6	Female	2
Male	1	Male	3
Smoking status		Occupation	
Current smoker	3	Community nurse	1
Former smoker	3	Support group facilitator	1
Never smoker	1	Community partner	1
Self-reported lung condition		Third sector representative	1
COPD	7	Public health representative	1
Recruited through Primary Care		Recruited through the Health Board	
and community groups		9	
Group 2, Wales	total n=9	Group 4, Wales	total n=7
Gender		Gender	
Female	5	Female	6
Male	4	Male	1
Smoking status		Occupation	
Current smoker	3	Practice manager	1
Former smoker	4	Pharmacist	1
Never smoker	2	GP	2
Self-reported lung condition		Practice nurse	2
COPD	9	Medical student	1
Recruited through community		Recruited through the Health Board/	
groups		Primary Care	
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Key themes discussed were: barriers to early lung cancer detection, and preferences regarding the

format and content of an intervention for the early detection of lung cancer. See Table 4 for

illustrative quotes.

1 2		
3 ⊿	1	Barriers to lung cancer symptom presentation
5	2	
6 7 8 9 10	3	The public and stakeholder focus groups confirmed our interview findings, where fear of wasting the
	4	doctor's time with trivial symptoms and fear of being judged or lectured about smoking was
	5	perceived to deter medical help seeking for potential lung cancer symptoms. In addition, the health
11 12	6	professional group supported our findings that patients with lung conditions tend to be preoccupied
13 14	7	by chest infections. However, we found potential disparity between the patient-reported experience
15	8	of the GP's approach to smoking and the healthcare professional reported approach to smoking
16 17	9	cessation. Healthcare professionals in Wales discussed new guidance that discourages health
18 19	10	professionals from 'lecturing' patients, suggesting the patient reported experience may be based on
20	11	previous healthcare interactions, and they consequently anticipate a lecture. Alternatively,
21	12	healthcare professionals may be unaware of new guidance, or not adhere to new guidance and
23 24	13	consequently continue to 'lecture' patients about smoking.
25 26	14	
20 27	15	Potential format of an intervention to support earlier lung cancer detection
28 29	16	
30 31	17	All groups discussed a preference for community based interventions, away from a traditional
31 32	18	healthcare setting, for example a community event, talk in a community venue or health check bus,
33 34	19	similar to breast screening mobile units. The anonymous and relaxed nature of such an intervention
35 36	20	meant that intervention participants would feel they were not wasting GP time; rather it would act
37	21	as a signal that their attendance at the event was desired. Participants compared this to a visit to the
38 39	22	doctor, where they discussed a feeling of wasting the GP's time because they were not invited to
40 41	23	attend. It was considered important that the intervention facilitator was knowledgeable or trained,
42	24	non-judgemental, easy to talk to and approachable, highlighting the importance of relational aspects
43 44	25	of a lung cancer intervention. Participants suggested a nurse, pharmacist, trained patient
45 46	26	representative or community worker.
47	27	
48 49 50 51	28	Intervention content
	29	
52	30	The public groups requested more information about the symptoms of lung cancer. However, the
53 54	31	healthcare professional groups felt that current lung cancer symptom information was too broad,
55 56	32	leading to dismissal and potential denial of lung cancer information because people with smoking
57 58	33	history or comorbid lung conditions experience most of the symptoms daily. To overcome this
58 59 60	34	problem, the healthcare professionals groups discussed the need for more specific symptom

information, emphasising changes to normal symptoms and coupled with information about risk
 factors for lung cancer.

4 To modify negative beliefs about lung cancer, the health professionals groups suggested using

- 5 positive stories to communicate messages about the importance of lung cancer early diagnosis and
- 6 highlight the potential for survival outcomes with early stage detection.
- 8 The inclusion of smoking cessation information in a lung cancer intervention was considered
- 9 important by all groups. However, the manner in which smoking cessation could be approached was
- 10 discussed as key to effective promotion of smoking cessation. Participants suggested highlighting the
- 11 benefits of stopping smoking in a gentle and relaxed manner to encourage choice to quit.

14 Table 4. Illustrative quotes (focus groups)

Table 4. Indstrative quotes (locus groups)			
Theme	Quote		
Barriers to lung cancer			
symptom presentation			
Fixation on chest infections	"People tend to be fixated on a [chest] infection and they want their next rescue pack ready cos almost as if it's inevitable; it's going to happen in the next month or so." (Focus group 4)		
Difference in perception around healthcare professional approach to patients' smoking	"I think there is a gulf between what people believe their GP would say to them if they do actually talk about [smoking] as opposed to what that conversation actually is in realityBut certainly as far as the formal training coming out of public health, if they are doing that then there is, that's not a lectureBut that's what people fear is going to be what they're going to be told" (Focus group 3)		
Potential format of an intervention to support earlier lung cancer detection	Participant 2: "So what I'm saying is, you know them mobile buses in the shopping area, where people go shops, or outside the hospital So they set them up and people are walking past, and even though they can't be bothered to go to the doctors, and they look and they think I'll just pop in Participant 1: Cos you wouldn't hesitate you know, you'd just go in. Participant 2: You're just a person, they don't know and they're just seeing what's there, or what's there or what's the problem with you. If there's no problem Participant 3: People think you don't want to think you're, feel as if you're wasting the doctor's time" (Focus group 1)		
Intervention content			
More specific symptom	Participant 1: "Yeah I think when you say 'cough' it's a bit broad		
advice	and it's a bitYou know, you've had a cough for two weeks, off you		
	go.		

Messages to combat

negative beliefs

Smoking cessation

cough" (Focus group 4)

group 4)

Participant 3: It'd be useful if it was a change in your regular

diagnosis which is a big deal isn't it" (Focus group 3)

"Positive messages, particularly around lung cancer because

everybody, you know it's like a death knell isn't it? And actually it's not, it doesn't have to be. You know you're talking here about early

"You've got to include [smoking cessation information]...I think it's how you deliver the message...not in such a way you feel ashamed for smoking. I've noticed [the nurse] has got a way of telling patients how to stop smoking, she does it in a, not in a 'well you should stop smoking', that kind of way. She'll say 'have you ever thought about giving it up. You know it would improve your chest a bit'. And I've seen [the nurse do it] more in a non-lecturey basis, more of a, 'have you ever thought about it?' Relaxed, warmer manner. So I'm not lecturing you, it's your choice. You know it's bad for you." (Focus

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DISCUSSION

Our study was the first to explore the influences on lung cancer symptom presentation in high risk, highly deprived groups across three nations of the UK. Preferences for an intervention targeted at high-risk groups were ascertained through focus groups. We found evidence from the interviews and focus groups that individuals who are at high risk for lung cancer tend to be preoccupied by maintaining health in the short term. Prioritising the daily management of their lung condition led to avoidance of longer term health problems such as lung cancer, to gain a sense of control over health in the context of difficult personal circumstances. Health beliefs were found to underpin behaviour in relation to medical help seeking, where perceptions of 'inevitable but curable' chest infections led to immediate help seeking. However, 'inevitable but incurable' lung cancer led to inaction when faced with potentially serious symptoms and anticipated refusal of treatment. Interview participants felt that the relationship with the healthcare professional was key when considering medical help seeking. The importance of the relational interaction between provider and patient was mirrored in the focus groups, where participants felt that a non-judgemental intervention facilitator was important. Multi-faceted community-based interventions, away from the traditional healthcare setting, were preferred by participants.

Previous empirical studies report prolonged lung cancer symptom presentation due to misattribution[5,13,15-26,33, 42] and in our study, we found evidence that participants normalised their symptoms indicative of lung cancer to smoking habit, and lung and other comorbid conditions. In contrast to previous studies that report haemoptysis as a facilitator to prompt medical help seeking[13,25,27,43-45], participants with experience of haemoptysis reported described avoidant coping, and normalisation when blood was noticed. Denial and normalisation of haemoptysis may be specific to socioeconomically deprived groups. Our highly deprived sample reported daily struggles with complex physical and mental health needs, and with the challenges associated with living on no or limited income. Previous studies in socioeconomically deprived communities report that in the context of competing life demands, health was dealt with reactively and with low priority [46,47].

Fear of being ineligible for treatment due to lifestyle has not been well described in studies with lung cancer patients or those at high risk[44,48]. In contrast, participants in the current study described feeling disentitled to medical services in the context of their lifestyle and circumstances. The underlying concept of health service Candidacy[47] may explain why participants felt unworthy of seeking medical help and is likely to be of particular importance in our highly deprived sample. In addition to challenging life circumstances, interview and focus group participants reported fear of

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being judged and ignored by health professionals due to their smoking habit or perceived social standing, contributing to feelings of unworthiness. Participants reported the desire to be a model patient and to not waste valuable GP time, which influenced medical help seeking. Although the desire to be a 'good citizen' has previously been reported [24,25], to our knowledge, the current study was the first to explore perceptions of appropriate consultation behaviour in a highly deprived sample. Our emerging findings related to Candidacy, combined with the desire to exhibit 'good' consultation behaviour, may contribute to normalisation of symptoms previously regarded as serious and therefore discourage help seeking. Consequently, disadvantaged populations are likely to focus on health in the short term, and ignore longer-term health issues which may lead to advanced stage lung cancer diagnosis.

We found that participants held seemingly contradictory views on their lung cancer susceptibility, reporting scepticism about the causal role of smoking in lung cancer alongside perceived inevitability of lung cancer. Beliefs about the link between smoking and lung cancer may reflect societal stigma towards smoking, where participants downplay the negative effects of smoking, possibly to legitimise medical help seeking for symptoms considered related to smoking. Perceived inevitability of lung cancer is likely to reflect high levels of exposure in social networks where there is high incidence and poor outcomes of lung cancer [10] and can to minimise normalisation of lung cancer symptoms and prompt help seeking[49]. However, contrary to previous studies, our sample reported feeling that lung cancer was inevitable, but normalised and ignored haemoptysis, possibly due to a combination of high fear and fatalism of lung cancer, difficult life circumstances and low perceived health service Candidacy. Furthermore, our findings raise questions of perceived social justice as influences on medical help seeking. High-risk individuals who believe that they cannot legitimately seek medical help because of their former or current lifestyle may therefore be resigned to the prospect of developing lung cancer.

A major strength of this study was the rigorous sampling procedure. We screened postcodes to ensure participants resided in the lowest quintile of deprivation, and measured multiple additional indicators of deprivation. Individual and area level indicators confirm that our sample was highly deprived, for instance most were unemployed and seeking benefits, and rented social housing. In addition, we recruited participants with no previous diagnosis of lung cancer, without mention of lung cancer until discussed by participants during the interview, or at the end of the interview. These recruitment and interview procedures meant we were able to explore previous and anticipated lung cancer symptom presentation in those who were symptomatic or asymptomatic. This strategy was

employed to overcome the methodological limitations associated with studying either retrospective

 or anticipated symptom presentation in isolation[15]. However, our qualitative study was unable to establish causal links between barriers and help seeking, nor can we generalise or compare the findings to high socioeconomic groups; instead, we conducted an in-depth study to explore how best to engage high risk, highly deprived individuals in early lung cancer detection. Although we carefully sampled participants and collected additional demographic measures to validate our sampling frame, some GP practices were asked to recruit by specific smoking status rather than the whole range of smoking status, potentially introducing bias to our sample. In addition, we were unable to conduct a focus group in Scotland due to low response, which is a potential limitation of the study. Finally, focus group participants were recruited opportunistically, with the potential that participants were more favourably disposed to an intervention. Practice and policy implications With a comorbid lung condition and smoking history, those who are high risk for lung cancer will, in the main, be symptomatic. To avoid normalisation, it is important to highlight the significance of changing and multiple symptoms. High risk individuals should be empowered to seek timely medical help and made to feel welcome, not judged or blamed for their current or former lifestyle. For instance, interventions targeted at disadvantaged populations could be conducted outside of the traditional healthcare setting. Our findings highlight the importance of an intervention where participants would be invited to attend, as opposed to presenting to the GP surgery, in order to eliminate concerns about wasting GP time and legitimise their attendance. Community based interventions have the potential to harness the relational aspects of help seeking, through interventions led by non-judgemental and welcoming facilitators. It is possible that previous mass media and social marketing lung cancer awareness interventions report low campaign reach to deprived groups [34,35] in part because they were not designed to motivate help seeking through intensive approaches to build trusting relationships and confidence. More research is required to understand how the relational aspects of help seeking could be operationalised in an intervention. Over half of the current sample described mental health problems and/or difficult current or former life circumstances. Intervention developers and healthcare professionals in highly deprived communities should be aware of these wider social and contextual factors; they should receive training to recognise such circumstances and know how to appropriately signpost. Finally, we suggest that the current UK health system may encourage patients with a lung condition to focus on

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3 ⊿	1	short term management of their condition. GP prescribing of antibiotics and the use of rescue packs
5	2	(prescribed antibiotics for storage at home in the event of an exacerbation) may inadvertently
6 7	3	reinforce patients to detect and act on symptoms of a chest infection[50]. There is potential that this
8 9	4	current standard of care could be adapted to educate and encourage patients with a lung condition
10	5	to detect symptoms of lung cancer, thereby shifting the focus to longer term health. More research
11	6	is required to understand how to motivate highly deprived groups to consider health in the long
13 14	7	term, while recognising the wider social determinants of health[51].
15	8	
16 17	9	Conclusion
18 19	10	
20	11	The challenges of living in an area of deprivation with social exclusion issues, combined with fear of
21	12	judgement by health professionals, contribute to denial and ignoring of lung cancer symptoms.
23 24	13	Multi-faceted community based interventions are required to, highlight lung cancer symptoms, the
25	14	importance of early diagnosis and empower people who are high risk for lung cancer to seek timely
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3 4	1	Additional information
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6 7	3	Ethics approval and consent to participate
8 9	4	The study received ethical approval from Southampton Central- Hampshire A Research Ethics
10	5	Committee (16/SC/0589). Written informed consent was obtained from all participants who took
11 12	6	part in the study.
13	7	
14 15	8	Consent for publication
16 17	9	Not applicable
18	10	
19 20	11	Data sharing
21 22	12	Qualitative data is not publicly available for this study to maintain participant confidentiality.
23 24	13	
25	14	Competing interests
26 27	15	The authors confirm that there are no conflicts of interest.
28 29	16	
30	17	Funding
32	18	This work was supported by Cancer Research UK (grant reference number: C16377/A22034).
33 34	19	
35	20	Author contributorship
30 37	21	All authors (GMM, JH, KH, PM, RDN, GN, ST, AMT, KB) designed the study. GMM and JH conducted,
38 39	22	coded and analysed the interviews and focus group data. All authors contributed to the
40 41	23	interpretation of data. GMM drafted the manuscript and all authors contributed to the review and
41	24	editing of the manuscript. All authors read and approved the final manuscript.
43 44	25	
45	26	Acknowledgements
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Supplementary File 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist with page numbers to indicate section of the article [34]

Ch	ecklist item	Questions to consider	Page number in article
Do	main 1: Research team and re	flexivity	
Per	rsonal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	8
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	8
3.	Occupation	What was their occupation at the time of the study?	8
4.	Gender	Was the researcher male or female?	8
5.	Experience and training	What experience or training did the researcher have?	8
Re	lationship with participants 🥒	5	
6.	Relationship established	Was a relationship established prior to study commencement?	7
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	8
Do	main 2: study design		
The	eoretical framework		-
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory,</i> <i>discourse analysis, ethnography, phenomenology,</i> <i>content analysis</i>	8-9
Pa	rticipant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	5-6
11.	Method of approach	How were participants approached? e.g. face-to- face, telephone, mail, email	6-7
12.	Sample size	How many participants were in the study?	5, 6, 10, 16
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	9
Set	ting		
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	8
15.	Presence of non- participants	Was anyone else present besides the participants and researchers?	8
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	9-10, 16
Da	ta collection		·
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix 2-4

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Supplementary File 2: Interview topic guide

Interview prologue

- Introduce the researcher, ensure the participant is comfortable.
- Explain purpose of the interview:
 - *"We are interested in lung health.*
 - We would like to know how people cope with lung symptoms and how they decide if they should go to the doctor or not.
 - Some of the questions I ask during the interview will be about smoking. I'm not here to tell you to stop smoking; I'm just interested if you have any experiences of smoking.
 - I'm not a clinician so I can't give you any advice on symptoms, but I can tell you where you can go to get help"
- Check understanding of interview purpose, role of researcher, and what will happen in the interview. Give opportunity for questions.
- Partners or family members will be welcome to join the interviews to explore relational influences on lung symptom awareness and help seeking, and the interview topic guide will be adapted accordingly.
- After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded. Obtain consent for the interview and for the recording. If not already done, set up and switch on the recording equipment while the participant signs the consent form.

Note to interviewer: the grey boxes signify the key topics to be explored during the interview. The questions listed below are examples of suggested prompts for each topic. You are not required to read these verbatim unless specified.

Overall aim of the qualitative interview:

-To explore how people with a history of smoking and respiratory conditions interpret and act on new or changing lung symptoms (how people cope with lung symptoms and how they decide to go to the doctor with symptoms) -To explore the influences of perceived risk, fear, shame, stigma, family and friends on lung symptom presentation

1. Experiences of lung condition

Establish what lung condition the participant has, how the lung condition affects them, the types of symptoms they experience and how they are usually managed. **Rationale**: introduce the participant to the format of a qualitative interview and make the participant feels comfortable. Establish details of their lung condition.

Potential prompts:

- Can you tell me about your lung condition?
- Tell me about your experiences with X lung condition.
 - How long have you had X condition?
 - What sort of symptoms do you experience?
 - How long do the symptoms usually last?
- What do you think causes these symptoms?
- How do you usually manage your symptoms?
- How are your symptoms usually managed/ treated by your healthcare professional?
 - How effective do you think this is?

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2. Symptom attribution task

Use as a tool for prompting an in-depth understanding of symptom attributions and confidence to interpret new or changing symptoms.

Include discussion around previous symptom experiences including: what action was taken, if and who they sought medical help from. Explore how their lung condition and smoking history might influence symptom attributions (i.e. do these mask symptoms?) and symptom presentation. **Rationale**: to explore lung symptom attribution; confidence in recognising and articulating symptoms; previous symptom experience; planning when/how to act on symptoms; influence of smoking history on perceptions of lung symptoms

Ask participant to order symptom cards from symptoms that they would seek medical help quickest for and those they would seek help slowest for (arrow and boxes below will be stretched to A4 size, see page 10). Ask participant to write numbers on the symptom cards. 1= first, 11=last. If they change the order of the symptom, ensure the previous number is crossed out and the new number written on card. Write PID on the back of each symptom card. Take photos of the task.

Say the following phrase verbatim: "We know that people decide go to the doctor at different times with symptoms. I'm going to show you some pieces of card with symptoms on. I'd like you to rank them from the ones that you would go to the doctor with first through to the last on this sheet of paper."

Cut individual symptom cards (see page 12) for the following symptoms. Please rotate the order:

- Coughing up blood
- A cough that doesn't go away
- A long standing cough that gets worse
- Pain in your chest or shoulder
- Persistent breathlessness
- Persistent chest infections
- Persistent tiredness or lack of energy
- Loss of appetite or unexplained weight loss
- Ache or pain when breathing or coughing
- A hoarse voice

See the **glossary of terms at the end of the topic guide** with standardised definitions and additional explanation of symptoms. If the participant does not understand what each symptom means, ask them what they think it means, then refer to the glossary of terms.

• Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger

First to go to the doctor

If the participant asks the interviewer what these symptoms are, first **ask the participant what they think they are**. If they ask again either suggest to move on and discuss what they could be after the interview (if appropriate) or say the symptoms have been taken from the NHS website for lung cancer. *Note to interviewer*: Aim to the complete the ordering of symptoms in the task first, and then ask questions in this section. However, if any of the following (2a, 2b, 2c, 2d) if bought up spontaneously by the participant whilst they are doing the card sorting exercise then explore these issues at that point. Then return to the card sorting exercise, followed by questions in the following section (2a, 2b, 2c, 2d).

Topics and prompts for symptom attribution task Once the symptoms have been ordered, ask:

Convertell requirements first?

- Can you tell me why you put x first?
- Can you tell me why you put x last?

2a. Symptom experience

To understand if the participant has experienced the symptom previously- what did they attribute the symptom to? What did they do? If they have not experienced the symptom before, what would they hypothetically do if they were to experience symptom in the future?

- Which of these symptoms have you had before?
 - What did you think the symptom(s) was/were?
 - Which symptom(s) did you go to the doctor with?
 - Why did you decide to go to the doctor with these symptoms?
 - What did the doctor say?
 - Which symptoms did you decide to not go to the doctor with?
 - Why did you decide not to go to the doctor with these symptoms?
- For the other symptoms we have not talked about, if you developed any of them what would you do?
 - How long do you think it would take you to go to the doctor with these symptoms?
 - Can you tell me why it would take you this amount of time to go to your doctor with this symptom?
 - What you think these symptoms could be?
- Are there any symptoms you wouldn't go to the doctor with?
 - Can you tell me why you wouldn't go to the doctor with these symptoms?

2b. Detecting change

Explore how the participant has/would notice new or changing symptoms and their confidence to detect new and changing symptoms. Ask this section generally, but if the participant is struggling then ask them about confidence to detect new and changing symptoms in the context of previous symptoms experiences. i.e. earlier you mentioned you felt breathless for a long time, how confident did you feel to know that this was a new or changing symptom?

- How would you normally tell if any lung symptoms have changed/ are new/ or unusual for you?
 - What would you do if you think you noticed a change in a symptom?
 - How confident would you feel in recognising a change in your usual symptom(s)?
 - How confident would you feel recognising new symptoms?
 - How would you notice a change in any of these symptoms?

2c. Barriers

Explore the influences of barriers and social influences on lung symptom presentation behavior

- Can you think of anything that would influence your decision to go to the doctor with any of these symptoms?
 - Probe barriers/enablers to going to the GP with a symptom:
 - Transport
 - Long wait times/ appointment policies
 - Worry about wasting the doctors time i.e. Some people have told us that they don't go to the doctor as they worry about wasting the doctors time. What do you think about this?
 - The influence of partner/ social influences (who suggested you go/ don't go to the doctor?)
 - How confident would you feel talking to the doctor about these symptoms?
 - How do you feel when you are talking to the doctor?

2d. Smoking

Explore the influence of smoking habit on the ability to notice new or changing symptoms. If/how smoking habit acts as a barrier to seeking medical help. If vaping comes up say something like- that is really interesting, do you mind if I ask you some questions later about vaping if we have time? If they vape then still explore the influence of past smoking on symptom perceptions.

- Would you expect to have any of the symptoms we have talked about because you smoke or used to smoke?
 - Thinking about smoking, how do you think your [past] smoking would affect how you notice if a symptom has changed or is new/ unusual for you?
 - Does your doctor ever discuss smoking with you?
 - How does this make you feel?

3. Lung cancer

If appropriate, explore lung cancer knowledge, beliefs about lung cancer and perceived risk here. If bought up spontaneously by the participant earlier in the interview, explore lung cancer then (if appropriate) Confidence to detect a lung cancer symptom. The influences of smoking and perceived risk, shame and associated with lung cancer.

Rationale: to explore lung cancer symptom awareness; to explore perceived risk of lung ca emotional consequences such as fear, fatalism blame; perceived causes and effectiveness of e detection and treatment; the influence of smol history on the formation of beliefs about lung of

If it is OK with you, I'm going to ask you some questions about lung cancer. If you feel uncomfortable with any of my questions, please let me know and we can move on.

Potential prompts:

- Earlier you mentioned some of the symptoms that could be lung cancer. Can you think of any other symptoms that you think might be lung cancer?
- What else do you know about lung cancer?
- Can you tell me a little more about what you think about lung cancer as a disease?
 - Where do you think that feeling comes from?
 - What do you think other people's views are on lung cancer?
- What do you think causes lung cancer? S
 - If yes and appropriate: How does that make you feel as a [past] smoker?
 - If appropriate: do you ever worry about lung cancer because you [used to] smoke?
 - How does that make you feel?
 - Is there anything in particular that makes you think your risk is high or low?
- How confident would you feel in recognising a symptom that could be lung cancer?
 - How does your [past] smoking affect your confidence in recognising a change in your body that could be lung cancer?
- What would you do if you had a symptom that you thought was lung cancer?

4. Social influences

Explore influences of social networks on help seeking behavior and basis of cancer beliefs.

Rationale: to explore social norms, influences and stigma around help seeking; people who they know who have had lung cancer and the effects on beliefs and perceptions; how social networks might influence help-seeking

- If you had a symptom you thought might be lung cancer, would you tell anyone about it?
 - Who would you tell?
 - Why would you tell that person?
 - What do you think they would say to you if you told them about a symptom?
 - Would they encourage/discourage you to visit your doctor?
- Has anyone ever noticed a symptom of yours and suggest that you go to the doctor?
 - Probe: who/ what happened.
- We know that lung cancer isn't as common as other types of cancer like breast cancer. Do you know anyone who has ever been diagnosed with lung cancer?
- Can you tell me about the effects that [person] having lung cancer has had on you?
 - How has this affected your views about lung cancer?

5. Closing questions

Final questions to end on a positive note

Rationale: to end the interview on a positive note

- If you were to offer anyone some advice on lung symptoms, what would it be?
- If the NHS were to make some changes to the services they offer to help people with lung symptoms get seen quicker, what would you suggest they change?
- Can you tell me about a positive experience of going to the doctor?

I know we've talked about a lot of things today, but would you like to tell me about anything else that we haven't talked about?

<u>Debrief</u>

- Summarise the interview and address any questions or concerns.
- Check whether it is ok to contact them if there is anything that needs to be clarified after listening back to the conversation.
- Ensure that they know how to contact us for further help/information/to add further information
- Thank them for their time and give them the gift voucher.
- If the participant discloses symptoms during the interview suggest they seek medical help from their GP. Offer lung cancer leaflet and site specific helpline numbers.
- Have stop smoking service details available if they request it
- Offer to provide a summary of study findings

Helpline numbers

Wales

• Tenovus Cancer Care support line on 0808 808 1010. The support line is open 8am-8pm, 7 days a week. Calls are free from a BT landline.

England and Scotland

- British Lung Foundation helpline on 03000 030555. This helpline is open 9am-5pm Monday to Friday. Calls cost the same as a local call.
- Roy Castle Lung Cancer Foundation helpline on 0333 323 7200. This helpline is open 9am-5pm Monday to Friday. Calls are free from a BT landline.

Symptoms in the symptom task:

Coughing up blood

A cough that doesn't go away

A long standing cough that gets worse

Pain in your chest or shoulder

Persistent breathlessness

Persistent chest infections

Persistent tiredness or lack of energy

Loss of appetite or unexplained weight loss

Ache or pain when breathing or coughing

A hoarse voice

Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger
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<u>Glossary of terms</u> Coughing up blood If you notice that there is some blood coming up when you cough

A cough that doesn't go away

If you have a nagging cough that just doesn't seem to go away

A long standing cough that gets worse

You have had a cough for a long time but you think that it might have got worse

Pain in your chest or shoulder

A sharp or achy pain in either your chest or shoulder, or both

Persistent breathlessness

You feel like you can't catch your breath or become out of breath when doing tasks you used to be fine with

Persistent chest infections

If you have had a few chest infections in a row and they don't seem to be getting better or keep coming back

Persistent tiredness or lack of energy

If you have been feeling tired for a while or just feel like you don't have any energy

Loss of appetite or unexplained weight loss

If you have been loosing weight without trying to and can't explain why or you just haven't been feeling up to eating the amount you normally would for a while

Ache or pain when breathing or coughing

If you have a sharp pain or achy feeling when you cough or breathe

A hoarse voice

A croaky or gravelly voice

Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger

If you notice that the ends of your fingers have changed shape

Persistent definition

Something that you notice you have had for a while and won't go away.

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58 59 60	For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Supplementary File 3: HPCP focus group topic guide

Focus group aim: To explore the needs and preferences from members of the public and local stakeholders (healthcare professionals/ community partners) for an intervention to support earlier lung cancer detection and diagnosis, targeted at high risk, harder to reach groups (over 40's, who are current/former smokers, living in areas of deprivation with serious lung comorbidity i.e. COPD).

Introduction

- Explain the aims of the focus group discussion. Emphasise that the focus group is not a test; we are interested in participants' preferences for an intervention for "lung health" to prompt earlier lung cancer symptom presentation, and how we could access people to take part in an intervention. All comments are welcomed: positive and negative.
 - 'We know that people who are high risk for lung cancer (people over the age of 40, living in deprived areas, who currently smoke or used to smoke and have a lung condition like COPD) are often diagnosed at a late stage, where treatment options are limited and a cure is less likely. This might be because they delay seeking medical advice with symptoms suggestive of lung cancer.

We are considering if we should develop something that will give people who are high risk for lung cancer information about symptoms and when/ where they should go and seek medical help from.

As healthcare professionals and people who work in deprived communities, we would like to know what you think about if we should do this. If you think this is a good idea, we would also like to know how best we can access this target group and invite them to take part in an intervention about lung health. Your ideas and suggestions are really valuable to us because of your wealth of experience, so all comments are welcomed (both positive and negative)'.

- Explain the <u>voluntary nature</u> of the study and that the focus group will be recorded with permission. If not already done, set up and <u>switch on the recording equipment</u> while participants sign the consent form.
- Before starting the focus group, remind participants <u>about confidentiality</u> and ask participants not to talk over each other. Go around the circle and ask participants to <u>introduce themselves</u> <u>for the transcription</u>.

Rationale: to explore whether the findings resonate with patients and members of the public in their local community

Part1. Phase 1 interview findings

Discussion of Phase 1 interview findings

Provide a short overview of key findings from Phase 1 interviews regarding barriers and enablers to lung cancer awareness and early symptom presentation in the target group. Ask the group to share their thoughts on the interview findings, and whether they resonate with them.

'We have been interviewing people across the UK who are high risk for lung cancer- people over the age of 40 who have a lung condition like COPD, who currently smoke or used to smoke and live in deprived areas. We wanted to understand how people think about symptoms of lung cancer, how and when people decide to go to the doctor with lung symptoms and the barriers to going to the doctor with these symptoms.

We found that people are completely fixated on detecting chest infections and look out for symptoms of a chest infection most days. They were really good at knowing when they had a chest infection and going to the doctor quickly to get antibiotics because they know it can be treated.

We also found that people tend to deny or ignore health problems that might affect them in the future, like lung cancer so may not go to the doctor with some serious symptoms. We think this is because they think that although lung cancer is inevitable, they also think that it cannot be cured so don't go and see the doctor

We want to develop something that can help people get these important symptoms of lung cancer seen to quicker by a medical professional, but we are not really sure how to do this. We would like to know what you think.'

- How can we do this?
- What do you think of these findings?
- To what extent do these findings resonate with you?

Rationale: to seek views on how to access the target group for an intervention and explore preferences for an intervention to support earlier presentation, including mode of delivery, target group, content and stop smoking information

Preferences on intervention content

- What sorts of things do you think people would like to know / what skills would they like to learn?
 - What do you think would be most useful to people?
 - What information would be the highest priority/most important for them?
 - Should we avoid any information?
 - Do you think it is best to focus on symptoms or health beliefs?

Preferences on intervention format

- How can we support people to seek medical help quickly with lung cancer symptoms? [what format]
 - Probe: a group one-off educational session to promote "lung health" in the local community; a leaflet/DVD; a lung health check; event in the community; posters in the local community
 - \circ $\,$ Do you think people want education or to learn 'skills for health'?
 - What sort of skills do you think people would like to know?
- Who do you think would be best to lead or facilitate an intervention about lung health/ encourage people to seek medical help quickly with lung cancer symptoms?
 - Probe: patient representative, lay advisor, community partner, healthcare professional (GP, practice nurse, smoking cessation counsellor, respiratory nurse specialist...?)
- When would be best to support people to manage their lung health?
 - What do you think about using the point at which they are diagnosed with a lung condition as a 'teachable moment' to do an intervention about lung cancer?
 - What about during a regular check-up appointment with the nurse i.e. six monthly COPD clinic reviews?
- What do you think about a brief intervention with health care professionals in addition to a public facing intervention?
 - What would be useful to you as healthcare professionals?
- The intention is that this intervention would be implemented across the UK. How do you think everything we have talked about today might need to differ based on where someone lives (i.e. different countries) or the person in the intervention?
 - How could we incorporate an intervention into the different models of care across regions/countries?
- How do you think this intervention could fit with other current or planned health promotion activities?

Accessing intervention participants

- Where could we approach our target group in an intervention about lung cancer/lung health?
- Probe: through community pharmacies, primary care, community nurses, existing groups for people with lung conditions?
 - Probe: on <u>utilising family / social networks</u> to encourage participation of MoP?
- \circ $\;$ Are you aware of any existing groups for people who fall into our target group?
 - What do you think about "piggybacking" onto these existing community groups or existing care plans with the nurse?
 - How do you think people would react to this?

Smoking cessation

- 'We know that people really don't like it when the doctor tells them to stop smoking and some people felt like they were treated differently by the doctors because they smoked. Sometimes this put people off going to the doctor with lung symptoms. On the other hand some people feel that it is only fair to be told to stop smoking. When we design something about lung cancer, we don't know if we should include something to help people to stop smoking or not.'
- What do you think about including stop smoking information in the intervention?
 - How do you think smokers might react to including stop-smoking information?
 - Can you think of ways we might be able to include stop-smoking information without putting smokers off?
 - What do you think about using signposting to stop smoking services instead of providing information about smoking cessation during the session?
- What do you think about using the intervention to cover things that are not related to lung health i.e. mental health or other factors that could be related to lung health?
 - How should we approach this?

<u>Debrief</u>

'Thank you for taking part in this study. We hope to use the findings from this focus group to develop an intervention based on the findings from the interviews and your recommendations to encourage earlier lung symptom presentation in those who are high risk for lung cancer. Anything you said will be treated as confidential. The voice-recoding will be stored securely. Any quotes used in published research will not have your name or anything that could identify you. Do you have any questions? [answer any questions] Here are my contact details if you have any further questions.'

Supplementary File 4: Members of the public focus group topic guide

Focus group aim: To explore the needs and preferences from members of the public and local stakeholders for an intervention to support earlier lung cancer detection and diagnosis. The intervention will be targeted at high risk, harder to reach groups (over 40's, who are current/former smokers, living in areas of deprivation with serious lung comorbidity i.e. COPD).

Introduction

- Explain the aims of the focus group. Emphasise that the focus group is not a test; we are interested in participants' preferences for an intervention for "lung health" to prompt earlier lung symptom presentation, and how we could access people to take part in an intervention. All comments are welcomed: positive and negative.
 - ^o 'We know that some people sometimes might take a bit longer to go to the doctor with important lung symptoms. I am thinking about developing something that will highlight important lung symptoms, and encourage people to go to speak to someone who is medically trained about their symptoms. I would like to know what you think about best ways to do this. I would also like to know how you think we can find people for this. Your ideas and suggestions are really valuable to us, so all comments are welcomed (both positive and negative)'.
- Explain the voluntary nature of the study and that the focus group will be recorded with permission. If not already done, set up and switch on the recording equipment while participants sign the consent form.
- Before starting the focus group, remind participants about confidentiality and ask participants not to talk over each other. Go around the circle and ask participants to introduce themselves for the transcription.

Discussion of Phase 1 interview findings

Rationale: to explore whether the findings resonate with patients and members of the public in their local community

Provide a short overview of key findings from Phase 1 interviews regarding barriers and enablers to lung cancer awareness and early symptom presentation in the target group. Ask the group to share their thoughts on the interview findings, and whether they resonate with them.

'We did some interviews across the UK with people who smoke or used to smoke and have a lung condition like COPD. We found that people look out for symptoms of a chest infection most days. They were really good at knowing when they had a chest infection and going to the doctor to get antibiotics. We also found that people try not to think about health problems that might affect them in the future, so may not go to the doctor with some symptoms that could be serious.

People really didn't like it when the doctor told them to stop smoking and some people felt like they were treated differently by the doctors because they smoked. Sometimes this put people off going to the doctor with lung symptoms.

We also found that people often had a favourite doctor at their GP practice and would wait up to three weeks for an appointment even if they thought a symptom was important. People don't like

going to doctors that they don't know because they felt that they did listen as much as their favourite doctor. But sometimes it was necessary to go to a doctor they don't know to get an appointment the same day.

We want to develop something that can help people get important lung symptoms seen to quicker by a medical professional, but we are not really sure how to do this or who should do this. We would like to know what you think.'

- What do you think of these findings?
- In what ways do you feel the same as what we found?
- In what ways do you feel different to what we found?

Rationale: to seek views on how to access the target group for an intervention and explore preferences for an intervention to support earlier presentation, including mode of delivery, target group, content and stop smoking information

Part 2. Needs and preferences for an intervention

Preferences on intervention format

- In what ways could we support people to manage their lung health?
 - Probe: a group one-off educational session to promote "lung health" in the local community; a leaflet/DVD; a lung health check; event in the community; posters in the local community
- Who do you think would be best to lead an intervention about lung health?
 - Probe: lung cancer survivor, lay advisor, community partner, healthcare professional
- If a health care professional was to lead the intervention, who would be best to lead a lung health intervention?
- Who is your favourite healthcare professional?
- When would be best to support people to manage their lung health?
 - What about when someone is diagnosed with a lung condition?
 - What about in one of your regular check-up appointments with the nurse i.e. sixmonthly COPD clinic review?

Preferences on intervention content

- What would you like to know? OR what skills would you like to learn?
 - \circ $\;$ What would be most useful or important for you?
 - \circ Can you think of anything that we should avoid or anything that is not as important?
- What do you think about including information to help people to stop smoking?
 - How would you react to stop-smoking information?
 - Can you think of ways we might be able to include stop-smoking information without putting smokers off?
 - What do you think about telling people where they can get help to stop smoking if they want to, instead of giving people information about stop smoking?

Accessing intervention participants

- Where could we approach people who smoke/used to smoke and have lung symptoms?
 - Probe: through community pharmacies, primary care, community nurses, existing groups for people with lung conditions/ utilising family and social networks / snowballing approaches?
- Are you aware of any community groups for these types of people?
 - How do you think people from these groups would react to being approached for a lung health intervention?

Debrief

'Thank you for taking part in this study. We hope to use the findings from this focus group to develop something to encourage people to go to the doctor with important lung symptoms. Anything you said will be treated as confidential. The voice-recoding will be stored securely. Any quotes used in published research will not have your name or anything that could identify you. Do you have any questions? [answer any questions] Here are my contact details if you have any further questions.'

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Engaging high-risk groups in early lung cancer diagnosis: a qualitative study of symptom presentation and intervention preferences amongst the UK's most deprived communities

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2 3	1	Title page
4 5	2	
6	3	Title: Engaging high-risk groups in early lung cancer diagnosis: a qualitative study of symptom
7 8	4	presentation and intervention preferences amongst the LIK's most deprived communities
9 10	5	
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37	22	
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2		
3 4	1	Abstract
5	2	
7	3	Objectives
8 9	4	People at high-risk for lung cancer - current/former smokers, aged 40+ years, with serious lung
10	5	comorbidity (i.e. Chronic Obstructive Pulmonary Disease) and living in highly deprived areas - are
11 12	6	more likely to delay symptom presentation. This qualitative study aimed to understand the
13 14	7	influences on early presentation with lung cancer symptoms in high-risk individuals and intervention
15	8	preferences.
16 17	9	
18 19	10	Methods
20	11	Semi-structured qualitative interviews with 37 high-risk individuals (without a cancer diagnosis),
21 22	12	identified through seven GP practices in socioeconomically deprived areas of England, Scotland and
23 24	13	Wales (most deprived 20%). A symptom attribution task was used to explore lung symptom
25	14	perception and help-seeking, developed using Leventhal's Common Sense Model. Four focus groups
26 27	15	with 18 high-risk individuals and 16 local stakeholders (healthcare professionals and community
28 29	16	partners) were conducted to explore preferences for an intervention to promote early lung cancer
30	17	symptom presentation. Data were synthesised using Framework analysis.
31 32	18	
33 34	19	Results
35	20	Individual and area level indicators of deprivation confirmed that interview participants were highly
36 37	21	deprived.
38 39	22	
40	23	Interviews. Preoccupation with managing 'treatable' short-term conditions (chest infections), led to
41 42	24	avoidance of acting on 'inevitable and incurable' longer-term conditions (lung cancer). Feeling
43 44	25	judged and unworthy of medical help because of their perceived social standing or lifestyle deterred
45	26	medical help seeking, particularly when difficult life circumstances and traumatic events led to
46 47	27	tobacco and alcohol addiction.
48 49	28	
50	29	Focus groups. Participants recommended multi-faceted interventions in community venues, with
51 52	30	information about lung cancer symptoms and the benefits of early diagnosis, led by a trained and
53 54	31	non-judgemental facilitator.
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56 57	33	
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1 2		
2 3	1	Conclusions
4 5	2	This study was novel in engaging a high-risk population to gain an in-depth understanding of the
6 7	3	broader contextual influences on lung cancer symptom presentation. Perceived lack of health
8	4	service entitlement and complex lives facilitated avoidance of recognising and presenting with lung
9 10	5	cancer symptoms. Community-based interventions have the potential to empower disadvantaged
11 12	6	populations to seek medical help for lung symptoms.
13	7	
14 15	8	Key words: Lung cancer, deprived, qualitative, early diagnosis, medical help seeking, barriers.
16 17	9	
18	10	Strengths and limitations of the study
19 20	11	• This was the first study to use in-depth qualitative methods to explore how to engage high
21 22	12	risk individuals from socioeconomically deprived areas in early lung cancer diagnosis.
23	13	• A major strength of this study was the proactive and rigorous sampling procedures used to
24 25	14	ensure that our sample was at high risk for lung cancer.
26 27	15	 Assessment of individual and area level indicators of deprivation confirmed that interview
28	16	participants were highly deprived; all participants resided in the 20% most deprived areas of
29 30	17	the three UK nations, and most participants were unemployed/seeking benefits and/or
31 32	18	rented social housing.
33 34	19	• To overcome the methodological limitations associated with studying anticipated or
35	20	retrospectively recalled cancer symptom presentation, we recruited participants with no
36 37	21	previous diagnosis of lung cancer and did not mention lung cancer in the interview study
38 39	22	materials or during completion of the symptom attribution task.
40	23	Opportunistic recruitment of focus group participants who may have been more favourably
41 42	24	disposed to an intervention was a potential study limitation.
43 44	25	
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INTRODUCTION

Lung cancer is the leading cause of cancer mortality worldwide [1]. Outcomes are among the poorest for all cancers, with only 13% of lung cancer patients surviving five or more years in the UK [2]. Diagnosis of lung cancer at an early stage can enable curative surgical resection, meaning over 80% of patients will survive one year or more when diagnosed at Stage I[3]. Delayed medical help seeking for symptoms and the high proportion of lung cancer diagnoses through emergency departments may partly explain why lung cancer is commonly diagnosed at an advanced, incurable stage[4]. Due to low specificity of lung cancer symptoms and similarity to other acute and comorbid respiratory conditions, patients face difficulty in knowing when to seek medical help[5,6].

Multiple symptoms and risk factors for lung cancer including older age, smoking, the presence of a lung comorbidity and socioeconomic deprivation increase the likelihood that a patient presenting to their GP with symptoms indicative of lung cancer will receive a cancer diagnosis[7-9]. Lung cancer is more common and mortality higher in areas of high socioeconomic deprivation; it has been estimated that each year, socioeconomic inequalities account for 11,700 excess cases of lung cancer and 9,900 potentially avoidable lung cancer deaths in England[10]. High prevalence of smoking, lung comorbid conditions and asbestos exposure, all of which are well documented risk factors for lung cancer, contribute to high lung cancer incidence and mortality in deprived communities[11, 12].

The presence of lung comorbidity such as chronic obstructive pulmonary disease (COPD) and history of smoking have been associated with a lower likelihood of presenting with lung cancer symptoms early[13,14]. In the lead up to lung cancer diagnosis, vague symptoms may go unnoticed or not considered a legitimate symptom to seek medical attention for, or be misattributed to smoking, aging or other comorbid conditions such as heart disease or COPD, thereby prolonging help seeking[5,13,15-26]. In addition, stigma attached to lung cancer[23,27-30] and fear of lung cancer diagnosis can deter medical help seeking for symptoms, particularly among smokers[23-25,29,31-33], leading to advanced stage disease at diagnosis[19]. To date, research has mainly been conducted with lung cancer patients from a range of socioeconomic groups with varying levels of lung cancer risk, retrospectively exploring the barriers to symptom presentation. Evidence is lacking about how individuals who are at high risk, and without a diagnosis of lung cancer, attribute potential lung cancer symptoms and decide to seek medical help.

Strategies to prompt earlier help seeking for lung cancer symptoms are required. However, evidence
 is limited regarding optimal methods for promoting earlier presentation through interventions

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3	1	targeted at high risk, highly deprived groups. Mass media[34] and community based social
5	2	marketing[35] lung cancer campaigns report limited reach to the most deprived groups. A nurse-led
6 7	3	primary care intervention for older adults with a long smoking history or recent cessation reported
8 9	4	increased and sustained intentions to seek help with lung cancer symptoms[36]. However, the
10	5	intervention was not targeted at highly deprived groups. Novel methods to support high risk groups
11	6	to engage in early lung cancer diagnosis are required.
13 14	7	
15	8	The current study used a combination of interviews and focus groups to explore potential barriers to
10	9	early lung cancer diagnosis and strategies to encourage early help seeking with individuals who are
18 19	10	the high risk for lung cancer. Qualitative interviews were used to gain an in-depth understanding of
20	11	the processes and motivations involved in symptom attribution and medical help seeking for
21	12	potential lung cancer symptoms in high risk, highly deprived individuals. We targeted
23 24	13	socioeconomically deprived areas across three nations of the UK to approach potential participants,
25 26	14	and used rigorous sampling procedures to ensure that our sample were high risk for lung cancer. The
20 27	15	focus groups were conducted in highly deprived areas with stakeholders who lived or worked in
28 29	16	these communities. To our knowledge, this was the first study to explore the influences on early lung
30 31	17	cancer diagnosis and intervention preferences targeted at high risk groups living in the most
32	18	deprived areas of the UK.
33 34	19	
35 36	20	METHODS
37	21	The Consolidated Criteria for Reporting Qualitative Research (COREQ)[37] criteria were used to
38 39	22	guide reporting (Supplementary File 1). We used a combination of interviews and focus groups
40 41	23	because the interviews were framed around lung health (not lung cancer), whereas the focus groups
42	24	were framed around preferences for a lung cancer intervention. In addition, key interview findings
43 44	25	were presented in the focus groups for consolidation and to facilitate discussion about intervention
45 46	26	preferences.
47	27	
48 49	28	Participant recruitment and sampling
50 51	29	Interviews. Thirty-seven interview participants were recruited through seven primary care general
52	30	medical practices (GP) in South Wales (Cwm Taf: three practices), England (Liverpool: one practice)
53 54	31	and Scotland (Aberdeen: three practices). Using routinely published index of multiple deprivation
55 56	32	(IMD) data for England, Scotland and Wales, GP practices with the highest proportion of their
57	33	patients that reside in the most deprived quintile were contacted. Practice managers were asked to
58 59 60	34	screen GP practice databases purposively for eligible study participants: men and women over the

 age of 40, who were current or former smokers, with a lung condition (COPD including chronic bronchitis and emphysema, interstitial lung disease or occupational lung disease). To overcome methodological limitations associated with retrospective recall, we recruited participants with no previous diagnosis of lung cancer. Participants were initially recruited from GP practices in Cwm Taf, where practice managers were asked to screen databases for current and former smokers, with no parameter set for number of years since quit attempt. Due to an initially high response rate from former smokers in Cwm Taf, subsequent participants in Aberdeen and Liverpool were sampled purposively according to smoking history. One GP practice in Aberdeen was asked to recruit current smokers and recent quitters (within ten years). Two GP practices in Aberdeen and one GP practice in Liverpool recruited current smokers only. To ensure that participants from highly deprived areas were invited to take part in the study, individual postcodes were screened by the research team. Eligible patients from the initial database screen were assigned a pseudo-anonymised participant identifier (PID). PID and postcode were checked against IMD score, and those that resided in the most deprived IMD quintile were eligible

16 for the study. The final list of potentially eligible participants was checked by the GP for ability to 17 provide informed consent, considered by the GP to be a risk to the interviewer or themselves and 18 general health status (i.e. very seriously ill). Participants were excluded if they were diagnosed with 19 lung cancer, were terminally ill or did not have capacity to consent.

Focus groups. Eighteen participants for the focus groups with members of the public were recruited opportunistically through primary care or local community groups. Participant recruitment through primary care employed the same methods as those used to invite the interview participants. Pseudonymised participant identifiers were checked to ensure that those who took part in the focus groups had not already participated in the interviews. Additional participants were recruited opportunistically through local community respiratory support groups and non-health related groups in the local community centre. Local community group organisers in areas of high deprivation were contacted and asked for help to recruit members of the public in our target group. Local health service planning groups and health board staff facilitated recruitment of 12 participants for the healthcare professional and community partner (HPCP) focus groups.

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1	Study	procedures
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Written consent and permission to audio-record were obtained on the day of the interviews and focus groups.

Interviews. Eligible participants were invited by letter with more detailed study information
attached, with a reminder at two weeks to non-respondents. Those who returned the study reply
slip via a FREEPOST envelope were contacted by the interviewer (GM or JH) to arrange a suitable
time and date for the interview, to outline the study and answer any questions.

Interviews were conducted using a semi-structured topic guide to facilitate a discussion about illness perceptions and coping strategies; development was guided by the Common Sense Model[38] (Supplementary File 2). The interview was framed the interview around lung health, rather than lung cancer. The interview aimed to explore experiences of their lung condition, symptom attribution, symptom experience and help seeking behaviour, the influence of smoking history on new or changing symptoms, and if appropriate, lung cancer awareness and beliefs.

A symptom sorting task was used to provide participants with a concrete visual task to increase engagement with the interview in the context of potential low literacy. The task formed a basis for discussion about symptom attribution and experience, where participants were asked to order 11 symptoms from those they would go to the doctor with first, through to the last. The 11 symptoms were selected from the NICE guidance for referral of suspected lung cancer (https://www.nice.org.uk/guidance/cg121). The symptoms were re-worded to simplify the language in line with wording found on the NHS Choices website for lung cancer symptoms and any reference to time scale of symptoms was removed (Supplementary File 2, p.9). For example, a cough that lasts

45 26 for 3 weeks or more was amended to 'persistent cough', and haemoptysis was amended to
46 47 27 'coughing up blood'. The presentation order of the symptoms was rotated between interviews.

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To explore potential lung cancer symptom attribution outside of a cancer context, there was no mention of cancer in the interview study information packs or when participants completed the symptom sorting task. If appropriate, participants were asked questions to explore lung cancer awareness and beliefs at the end of the interview or when participants discussed lung cancer unprompted.

Demographic data were collected using a short questionnaire, including three additional measures of socioeconomic group: age, gender, smoking status (quantity and duration), home ownership, occupation and educational attainment. Interviews were conducted until data saturation (no new themes emerging[39]). Focus groups. High risk members of the public, and healthcare professionals (i.e. GP, nurse, community pharmacist/community partners working in areas of deprivation with people with smoking history and/or lung conditions were sent information about the study and invited to take part in focus groups. Focus group participants were explicitly informed that the study was about the

10 development of an intervention about lung cancer. A mutually convenient time, date and location

11 for the focus groups was agreed. The focus groups were conducted using a semi-structured topic

guide to explore preferences for an intervention to promote earlier lung cancer diagnosis. Separate
 topic guides were used for the public and professional groups (Supplementary file 3 and 4).

14 Participants were given a verbal summary of the key findings from the qualitative interviews, and

15 asked to discuss preferences for a potential lung cancer intervention targeted at high risk, highly

16 deprived individuals. Topics for discussion were: preferred format of an intervention,

17 recommendations for intervention content, preferred location and facilitator for intervention

18 delivery, and recommendations for the inclusion of smoking cessation advice.

20 Setting

Most interviews (n=34) took place face-to-face in participant's own homes, with three taking place in a café, local community centre or over the telephone, and lasted between 46 and 146 minutes (mean 83 minutes). Family members were present for three interviews but did not participate in the study. Focus groups took place in primary care settings (n=2) or local community centres (n=2). Members of the public who took part in the interviews or focus groups were compensated with a £10 shopping. Healthcare professionals and community partners were not reimbursed for their time.

Interviews and focus groups in England were conducted by JH (PhD), a trained and experienced
 female qualitative Research Fellow and Medical Sociologist. The Welsh and Scottish interviews and
 focus groups were conducted by GM (PhD), a female Health Psychologist and trained qualitative
 Research Associate.

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2 3	1	Data analysis
4	2	Interviews and focus groups were audio recorded and transcribed verbatim. Aponymiced transcripts
6	2	were analysed in detail using the Framework method[10]. Framework analysis is a well-respected
7 8	у Д	and commonly used approach to qualitative data analysis. It was considered particularly suitable for
9 10	т 5	this study due to its transparency and the team work involved[41]. Framework enabled the sharing
11	5	of synthesised data sharts among team members to facilitate participation in analysis and
12 13	0	interpretation workshops
14 15	, 8	The data were analyzed in five stages: familiarization, identification of a thematic framework
16	0	indexing sharting and interpretation. A separate index was created on Microsoft Excel for the
17 18	9 10	interview and facus group data; however, wherever pessible, everlap was coded using the same
19 20	10	indevice terms for every la (berriers to every term presentation) was coded using the same
20	11	indexing terms, for example barriers to symptom presentation was commonly discussed in both the
22 23	12	interview and locus groups. The index was developed by two researchers (Givi and JH). Themes were
24 25	13	generated independently and consolidated through discussion in nine interpretation workshops over
25 26	14	a nine month period by GM and JH. The different perspectives of the researchers as noted above
27 28	15	was a benefit during analysis and interpretation. Field notes were recorded for each interview and
29	16	focus group, and incorporated into discussion during the analysis workshops. Although not formally
30 31	17	incorporated into the analysis plan, the positioning of each symptom in the attribution task was
32 33	18	considered during interpretive workshops. Interpretive themes were generated by JH and GM, and
34	19	developed with all authors in monthly management meetings. Transcripts and study findings were
35 36	20	not checked by participants; however, all participants were mailed a summary of the study findings.
37 38	21	
39	22	Ethical approval
40 41	23	The study received ethical approval from Southampton Central- Hampshire A Research Ethics
42 43	24	Committee (16/SC/0589).
44	25	
45 46	26	Patient and public involvement. Patient and public representatives (AMT and GN) were involved in
47 49	27	the design of the study and interpretation of study findings in monthly management group
48 49	28	meetings. All study materials and topic guides were developed with lay input (AMT and GN) and
50 51	29	written to a reading age of 10 years due to potentially low literacy. Reading age was calculated using
52	30	the Automated Readability Index (<u>www.readabilityformulas.com</u>).
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RESULTS

3 Interviews

5 Of the 397 invited to take part in the study, 78 people returned the study reply slip and declined to 6 participate in the study; reasons for refusal were unknown. Thirty-seven participants agreed to take 7 part in the study. The majority of the sample were female, current smokers, and with a mean age of 8 65 years (Table 1). Most had a diagnosis of COPD. All 37 participants resided in the lowest quintile of 9 deprivation for their respective country, of whom 15 were in the most deprived decile. Most 10 participants had left school before age 15 with no formal qualifications, lived in social housing, and 11 claimed disability benefit or job seekers allowance.

13 Table 1. Qualitative interview sample characteristics

Gender16Male16Female21Age, years64.7 (48-84)Mean (range)64.7 (48-84)Smoking status18Current smoker18Occasional smoker3Former smoker, recent quitter (within five years)5Former smoker (quit over five years ago)11Deprivation decileИстор (WIMD)Decile 1 (most deprived 10%)5Decile 2 (most deprived 11-20%)10	
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Scottish index of iviuitiple Deprivation (SliviD)	
Decile 1 (most deprived 10%) 4	
Decile 2 (most deprived 11-20%) 12	
English Index of Multiple Deprivation (IMD)	
Decile 1 (most deprived 10%) 6	
Self-reported lung condition	
COPD 26	
Chronic bronchitis 2	
Chronic emphysema 2	
Occupational lung disease 1	
Unsure of diagnosis 4	
Missing 2	
Educational attainment	
Left school at/before age 15 29	
Completed CSEs, O-Levels or equivalent 5	
Completed A levels or equivalent 1	
Completed further education but not degree 1	

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Missing	1
Employment	
Employed full-time	2
Employed part-time	1
Casual work	1
Job seekers or disability benefit	17
Retired	16
Home/living arrangement	
Own flat/house	14
Rent from local authority/housing association	21
Rent privately	1
Missing	1

2 Key themes were: strategies involved in symptom detection and help seeking behaviour, maintaining 3 short term health, avoidance of acting on longer term health, the desire to be a model patient, and 4 the importance of the relationship with their healthcare professional. See Table 2 for illustrative 5 quotes.

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7 Symptom detection strategies and help seeking

9 Symptoms discussed during the task were viewed as "part and parcel" (male, 68, England, current 10 smoker) of their lung condition, other pre-existing comorbidities or smoking habit, and were 11 consequently normalised and perceived not to require medical help. Changes to vague or 12 respiratory-type lung cancer symptoms were only taken seriously when remarked on by friends and 13 family or when they impacted on daily life.

15 Symptoms that could indicate a chest infection were reportedly constantly monitored. Participants 16 discussed using sophisticated strategies such as noticing changes in the colour and consistency of 17 their phlegm or subtle audible changes in their cough to actively detect chest infections. Such 18 strategies were considered important to facilitate early detection and treatment for chest infections 19 through their primary care provider or with rescue packs (emergency packs of steroids and 20 antibiotics that can be kept at home), due to lung condition. 21

22 Constant monitoring of phlegm for control of lung condition meant that participants could and 23 would notice haemoptysis, but few reported actively looking for haemoptysis on a regular basis. 54 55 24 Disparity between actual and anticipated medical help seeking was reported for haemoptysis. Most 56 57 25 participants had not previously experienced haemoptysis, but would anticipate seeking medical help 58 26 immediately due to the potentially serious nature of blood. However, some participants who had 59 60

previously or were currently experiencing haemoptysis attributed the presence of blood to noncancer causes such as their stomach ulcer or a previous flu jab. One participant ascribed the blood in their cough to lung cancer. Some of the participants with experience of haemoptysis did not seek medical help.

Focus on maintaining short term health

Participants reported seeking medical help quickly when symptoms were easy to detect, were attributed to what was perceived as a treatable cause and represented an immediate health threat i.e. a chest infection due to lung condition. Participants could often request an appointment the same day as permitted by their GP surgery policies. Prompt help seeking was reportedly due to fear of not being able to breathe and the potentially life-threatening nature of chest infections, and is likely to reflect the need to maintain good health in the short term.

The focus on maintaining short term health may reflect low general expectations of health, where some participants disclosed surprise at living beyond 60 years of age. In addition, due to fear of potentially hearing bad news, some participants expressed a preference to not ask questions during a consultation or yearly review with the nurse. Participants discussed prioritising day-by-day living over longer term planning, thereby focusing on health in the short term.

Most participants discussed scepticism about the link between lung cancer and smoking. Conversely, participants thought that lung cancer was inevitable due to their current or former lifestyle, including smoking history, working conditions, their lung condition and the reported incidence of lung cancer in their community. For many participants, the topic of lung cancer arose spontaneously. Lung cancer was discussed in the context of perceived inevitability when reflecting on their general lung health and during completion of the symptom task when recalling friends/family with lung cancer. Beliefs about inevitability were often coupled with highly negative fearful and fatalistic beliefs about lung cancer, with no cure and eventual death. Such claims were evidenced by knowing a high proportion of friends and family who were diagnosed with lung cancer and often died. A few participants discussed that a cure for lung cancer involved luck or was 'some miracle' (male, 56, Wales, occasional smoker), reflecting a perceived lack of control over early diagnosis and treatment. Consequently, actual or anticipated medical help seeking for lung cancer symptoms was motivated

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by pain, or to seek a diagnosis and prognosis to notify family members. However, some participants
 anticipated refusal of treatment or would even contemplate suicide.

We found differences in how participants with and without dependent family reported responding to symptoms of lung cancer. Female participants with dependent children or grandchildren discussed a motivation to visit the doctor with symptoms suggestive of lung cancer, in order to receive a prognosis to enable childcare arrangements after death. Women with dependent children who held more positive beliefs about lung cancer treatment reported the need to seek help for treatment to 'stay healthy' and prolong life. Participants with no dependent family were more likely to ignore lung cancer symptoms, or anticipate seeking medical help if in pain but refuse treatment.

12 The model patient

Participants discussed a sense of lack of entitlement to health services due to smoking habit, where respiratory-type symptoms of lung cancer were perceived as self-inflicted. For some, this was reinforced by an actual or expected 'smoking lecture' each time they sought help from healthcare professionals; the lecture made participants feel ostracised, particularly when smoking was used as a coping mechanism and contributed to not feeling worthy of seeking medical help. Some participants perceived that they may be treated differently by health professionals because they live in an area of deprivation, and discussed a potential power imbalance during consultations.

Conversely, participants reported high criticism towards people who were perceived to waste,
 exploit and overuse NHS resources. They cited drug addicts, illegitimate benefits claimers, older
 people wanting social interaction, and people with coughs and colds as over users of the health
 service. Such beliefs may reflect a downward comparison to other more stigmatised service users to
 legitimise their own help seeking. In order to be considered a model and non-problem patient,
 participants discussed legitimising their own help seeking by only consulting when absolutely
 necessary - and often after trying their 'own cures' i.e. cough medicine from the pharmacist - to not
 burden the doctors. Infrequent attenders or 'good service users' discussed feeling a sense of
 superiority for being a model patient.

Relationship with the healthcare professional

3	Some participants disclosed traumatic events in their lives including physical and sexual abuse,
4	leading to tobacco dependence and alcohol addiction. In addition, more than half of the sample
5	described symptoms of depression and anxiety. Therefore, the reported relationship with their
6	healthcare professional was important when considering whether to present with lung symptoms.
7	Participants discussed the need to feel understood and not judged by their healthcare professional,
8	with their personal history taken into account in the context of health behaviour such as smoking.
9	
10	Those who discussed feeling comfortable, safe and not judged by their chosen healthcare
11	professional felt encouraged to present with symptoms. Some participants reported that they were
12	prepared to wait up to three weeks for an appointment with their preferred healthcare professional
13	to discuss worrisome and potentially serious symptoms that could indicate lung cancer. Many
14	participants reported problems with maintaining continuity of care, highlighting problems with the
15	stretched National Health Service.
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17 Table 2. Illustrative quotes (qualitative interviews)

Theme	Quote
Symptom detection strategies and help seeking Friends and family notice symptoms	"My daughter might [notice changes to symptoms] cos she mentions it now and thenshe'll give me a dig and she'll say 'your breathing's annoying me'. Cos it's heavy breathing so. Then again there's something wrong" (Male, 48, Scotland, former smoker)
Sophisticated symptom detection strategies/ monitoring of chest infections	"If [phlegm is] white and bubbly it's not a chest infection. It's only when it goes green so you can tell yourself exactly how close you are to getting an infection There's just two different kinds of green spittle, if it's fluorescent green then you've got an infection, normal antibiotics won't work with me, if it's the lighter green I'm fine with that one it's handy to look out for, because you can get the right medication at the right timebecause if anything happens to me, there's no one for my kids." (Female, 48, Scotland, current smoker)
Normalisation of haemoptysis	"Coughing up blood, I do actually get some of that I don't know why, but it could be because of the ulcer thing and that There again then well I do get like nosebleeds, and then I'm thinking the blood maybe coming inside and coming down, you swallow it see. So then that will come back up won't it" (Male, 62, Wales, former smoker)

Focus on maintaining health in the short term	"I get worried about having chest infection, I get more worried about today or tomorrow rather than the future. The future that's going ahead for us anyway. Lung cancer's not an issue really" (male, 50, Scotland, former smoker)
Fear of bad news during a consultation	"I'm very poor in asking questions cos I don't want to know the results. Simple as thatno I don't ask when they say the oxygen [saturation] is alright I just think well it's alright and it's one thing less I haven't got to worry about" (Female, 69, Wales, former smoker)
Avoidance of long term	
health outcomes Scepticism about the link between smoking and lung cancer	"You hear occasions where people who don't smoke, who've never smoked. Well how do they get their lung cancer?I've got [lung cancer] in my head, I'm probably going to get it, if I haven't already got it because of the lifestyle I've had. Where I've worked and everything else, what I've worked with." (Male, 68, England, current smoker)
Perceived inevitability of lung cancer/ anticipate suicide	"[Lung cancer] is really, really on the forefront on the mindI just think 'oh god, please don't let me get cancer'I think if I was to get cancer, I've sometimes said to myself, I'd commit suicide. I would take a pill or something." (Female, 81, Scotland, current smoker)
Avoidance of lung cancer due to social and contextual factors	"[Lung cancer] worries me but I've got proper problems to worry about [carer for disabled son, problems with social services and benefits claims, insecurity of current council owned housing and problems with area of residence with 'junkies']. I won't worry about it until it's actually here. If I started worrying about eventualities I'd never get anywhere" (Female, 48, Scotland, current smoker)
Lung cancer fatalism/ anticipated refusal of treatment	"Until anything happened and I'm actually told that I've got [lung cancer], there's nothing I can do about it. I'm really a believer of what's in your cards is already written. So I don't look at anything like thatBut if they told me it was cancer, I would go ok then, but I wouldn't take any of the treatments if it's my time, it's my time. It just doesn't, I don't think I've got any more fight in me for all that. I think that would be the last straw for me. So I just live every day as it comes now, I don't really plan much. So I'm just living in the day, you know. Cos whatever happens, happens anyway." (Female, 49, Scotland, current smoker)
Response to lung cancer symptom/ female with dependent family	"I don't think they can treat [lung cancer]. You've just got to accept it haven't youI would go to the doctor [with a symptom], I think I would like to know how long I had. Not for me but for [my son] you know. For himIf it was just me I wouldn't want to know, but because I've got him, [I would] definitelyWhen I seen the blood I did think to myself, I flushed it away right awayI seen the blood and I thought no, and I thought I've got to, you know,

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	because of [my son]. The only way I would want to know is
	because of him. If I was by myself I would just say, don't want to
	knowCan't just think about myself I've got to think about him as
	well." (Female, 68, Scotland, current smoker)
The model patient	
Perception of healthcare	"You feel as though you're an alien because you smoke, you feel as
professionals attitude to	so they just look at you and say 'urghh', you know" (Female, 52,
smokers	Scotland, current smoker)
Critical of people who waste	"I can guarantee if I went this Monday and go next Monday the
NHS resources	same people are sitting there. I'm being honest, they're a drain on
	society on the NHS, but that's the way they livethese people that
	go there are not really ill, I think they're just seeking attention"
	(Male, 78, England, current smoker).
Relationship with	
healthcare professional	
Disclosure of highly sensitive	"Some people are friendly and not stony facedif [the HCP] can't
personal problem	even start a conversation with the simplest of ice breakers then
	how can people tell about pooping themselves when they're
	coughing up" (Female, 48, Scotland, current smoker)
Good relationship with GP	"I'm alright with [one GP], you could tell her anything, I've shocked
	her sometimes" (Female, 51, England, current smoker)
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Focus groups

Two public focus groups were conducted in Wales and England. Most participants were female and former smokers, and all participants were diagnosed with a lung condition. Two professional focus groups were conducted in Wales. Most participants were female, and were medical professionals (Table 3).

8 Table 3. Focus group characteristics

Members of the public	N	Healthcare professionals and	N	
	participants	community partners	participants	
Group 1, England	total n=7	Group 3, Wales	total n=5	
Gender		Gender		
Female	6	Female	2	
Male	1	Male	3	
Smoking status		Occupation		
Current smoker	3	Community nurse	1	
Former smoker	3	Support group facilitator	1	
Never smoker	1	Community partner	1	
Self-reported lung condition		Third sector representative	1	
COPD	7	Public health representative	1	
Recruited through Primary Care and community groups		Recruited through the Health Board		

total n=9	Group 4, Wales	total n=7
	Gender	
5	Female	6
4	Male	1
	Occupation	
3	Practice manager	1
4	Pharmacist	1
2	GP	2
	Practice nurse	2
9	Medical student	1
	Recruited through the Health Board/	
	Primary Care	
	total n=9 5 4 3 4 2 9	total n=9Group 4, Wales5Gender5Female4MaleOccupation3Practice manager4Pharmacist2GPPractice nurse9Medical studentRecruited through the Health Board/ Primary Care

Key themes discussed were: barriers to early lung cancer diagnosis, and preferences regarding the

format and content of an intervention for the early detection of lung cancer. See Table 4 for

illustrative quotes.

Barriers to lung cancer symptom presentation

The public and stakeholder focus groups confirmed our interview findings, where fear of wasting the doctor's time with trivial symptoms and fear of being judged or lectured about smoking was perceived to deter medical help seeking for potential lung cancer symptoms. In addition, the health professional group supported our findings that patients with lung conditions tend to be preoccupied by chest infections. However, we found potential disparity between the patient-reported experience of the GP's approach to smoking and the healthcare professional reported approach to smoking cessation. Healthcare professionals in Wales discussed new guidance that discourages health professionals from 'lecturing' patients, suggesting the patient reported experience may be based on previous healthcare interactions, and they consequently anticipate a lecture. Alternatively, healthcare professionals may be unaware of new guidance, or not adhere to new guidance and consequently continue to 'lecture' patients about smoking. Potential format of an intervention to support earlier lung cancer diagnosis All groups discussed a preference for community based interventions, away from a traditional healthcare setting, for example a community event, talk in a community venue or health check bus, similar to breast screening mobile units. The anonymous and relaxed nature of such an intervention meant that intervention participants would feel they were not wasting GP time; rather it would act as a signal that their attendance at the event was desired. Participants compared this to a visit to the

3	1	doctor, where they discussed	a feeling of wasting the GP's time because they were not invited to
4 5	2	attend. It was considered impo	ortant that the intervention facilitator was knowledgeable or trained,
6 7	3	non-judgemental, easy to talk	to and approachable, highlighting the importance of relational aspects
8	4	of a lung cancer intervention.	Participants suggested a nurse, pharmacist, trained patient
9 10	5	representative or community	worker.
11	6	. ,	
12 13	7	Intervention content	
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17 18	9	The public groups requested n	nore information about the symptoms of lung cancer. However, the
19	10	healthcare professional group	s felt that current lung cancer symptom information was too broad,
20 21	11	leading to dismissal and poten	itial avoidance of lung cancer information because people with
22	12	smoking history or comorbid I	ung conditions experience most of the symptoms daily. To overcome
23 24	13	this problem, the healthcare p	professionals groups discussed the need for more specific symptom
25	14	information, emphasising char	nges to normal symptoms and coupled with information about risk
26 27	15	factors for lung cancer.	
28	16		
29 30	17	To modify negative beliefs abo	out lung cancer, the health professionals groups suggested using
31 32	18	positive stories to communica	te messages about the importance of lung cancer early diagnosis and
33	19	highlight the notential for surv	vival outcomes with early stage detection
34 35	20		
36	20	The inclusion of smoking costs	tion information in a lung cancer intervention was considered
37 38	21	The inclusion of smoking cessa	ation mormation in a long cancer intervention was considered
39 40	22	important by all groups. Howe	ever, the manner in which smoking cessation could be approached was
40 41	23	discussed as key to effective p	romotion of smoking cessation. Participants suggested highlighting the
42	24	benefits of stopping smoking i	n a gentle and relaxed manner to encourage choice to quit.
43 44	25	Table 4. Illustrative quotes (fo	ocus groups)
45		Theme Berriere to lung concer	Quote
46 47		symptom presentation	
48		Fixation on chest infections	"People tend to be fixated on a [chest] infection and they want their
49		Thation on cliest infections	next rescue pack ready cos almost as if it's inevitable: it's aning to
50			happen in the next month or so." (Focus group 4)
51			
52		Difference in perception	"I think there is a gulf between what people believe their GP would
55 54		around healthcare	say to them if they do actually talk about [smoking] as opposed to
55		professional approach to	what that conversation actually is in realityBut certainly as far as
56		patients' smoking	the formal training coming out of public health, if they are doing that
57			then there is, that's not a lectureBut that's what people fear is going
58			to be what they're going to be told" (Focus group 3)
59			

	Potential format of an	Participant 2: "So what I'm saying is, you know them mobile
	intervention to support	buses in the shopping area, where people go shops, or outside the
	earlier lung cancer	hospital So they set them up and people are walking past, and
	diagnosis	even though they can't be bothered to go to the doctors, and they
		look and they think I'll just pop in
		Participant 1: Cos you wouldn't hesitate you know, you'd just go
		Participant 2: You're just a person, they don't know and they're
		just seeing what's there, or what's there or what's the problem with
		you. If there's no problem
		Participant 3: People think you don't want to think you're, feel as
		If you're wasting the doctor's time" (Focus group 1)
	Intervention content	
	More specific symptom	Participant 1: "Veab I think when you cay 'cough' it's a hit broad
	advice	and it's a bit. You know you've had a sough for two weeks off you
	advice	
		yu. Participant 2: It'd be useful if it was a change in your regular
		cough" (Focus group 4)
		cough (Focus group 4)
	Messages to combat	"Positive messages particularly around lung cancer because
	negative beliefs	everybody you know it's like a death knell isn't it? And actually it's
	hegative beliefs	not it doesn't have to be. You know you're talking here about early
		diagnosis which is a hig deal isn't it" (Focus group 3)
	Smoking cessation	"You've got to include [smoking cessation information]I think it's
		how you deliver the messagenot in such a way you feel ashamed
		for smoking. I've noticed [the nurse] has got a way of telling patients
		how to stop smoking, she does it in a, not in a 'well you should stop
		smoking', that kind of way. She'll say 'have you ever thought about
		giving it up. You know it would improve your chest a bit'. And I've
		seen [the nurse do it] more in a non-lecturey basis, more of a, 'have
		you ever thought about it?' Relaxed, warmer manner. So I'm not
		<i>lecturing you, it's your choice. You know it's bad for you."</i> (Focus
		group 4)
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1 DISCUSSION

Our study was the first to explore the influences on lung cancer symptom presentation in high risk, highly deprived groups across three nations of the UK. Preferences for an intervention targeted at high-risk groups were ascertained through focus groups. We found evidence from the interviews and focus groups that individuals who are at high risk for lung cancer tend to be preoccupied by maintaining health in the short term. Prioritising the daily management of their lung condition led to avoiding consideration of longer term health problems such as lung cancer, to gain a sense of control over health in the context of difficult personal circumstances. Health beliefs were found to underpin behaviour in relation to medical help seeking, where perceptions of 'inevitable but curable' chest infections led to immediate help seeking. However, 'inevitable but incurable' lung cancer led to inaction when faced with potentially serious symptoms and anticipated refusal of treatment. Interview participants felt that the relationship with the healthcare professional was key when considering medical help seeking. The importance of the relational interaction between provider and patient was mirrored in the focus groups, where participants felt that a non-judgemental intervention facilitator was important. Multi-faceted community-based interventions, away from the traditional healthcare setting, were preferred by participants. Previous empirical studies report prolonged lung cancer symptom presentation due to

misattribution[5,13,15-26,33, 42] and in our study, we found evidence that participants normalised their symptoms indicative of lung cancer to smoking habit, and lung and other comorbid conditions. In contrast to previous studies that report haemoptysis as a facilitator to prompt medical help seeking[13,25,27,43-45], current participants with experience of haemoptysis reported described avoidant coping, and normalisation when blood was noticed. Dismissal and normalisation of haemoptysis may be specific to socioeconomically deprived groups. Our highly deprived sample reported daily struggles with complex physical and mental health needs, and with the challenges associated with living on no or limited income. Previous studies in socioeconomically deprived communities report that in the context of competing life demands, health was dealt with reactively and with low priority[46,47].

Fear of being ineligible for treatment due to lifestyle has not been well described in studies with lung cancer patients or those at high risk[44,48]. In contrast, participants in the current study described feeling disentitled to medical services in the context of their lifestyle and circumstances. The underlying concept of health service candidacy (perceived eligibility for healthcare)[47] may explain why participants felt unworthy of seeking medical help and is likely to be of particular importance in

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our highly deprived sample. In addition to challenging life circumstances, interview and focus group participants reported fear of being judged and ignored by health professionals due to their smoking habit or perceived social standing, contributing to feelings of unworthiness. Participants reported the desire to be a model patient and to not waste valuable GP time, which influenced medical help seeking. Although the desire to be a 'good citizen' has previously been reported[24,25], to our knowledge, the current study was the first to explore perceptions of appropriate consultation behaviour in a highly deprived sample. Our emerging findings related to candidacy, combined with the desire to exhibit 'good' consultation behaviour, may contribute to normalisation of symptoms previously regarded as serious and therefore discourage help seeking. Consequently, disadvantaged populations are likely to focus on health in the short term, and ignore longer-term health issues which may lead to advanced stage lung cancer diagnosis.

We found that participants held seemingly contradictory views on their lung cancer susceptibility, reporting scepticism about the causal role of smoking in lung cancer alongside perceived inevitability of lung cancer. Beliefs about the link between smoking and lung cancer may reflect societal stigma towards smoking, where participants downplay the negative effects of smoking, possibly to legitimise medical help seeking for symptoms considered related to smoking. Perceived inevitability of lung cancer is likely to reflect high levels of exposure in social networks where there is high incidence and poor outcomes of lung cancer [10], which should minimise normalisation of lung cancer symptoms and prompt help seeking[49]. Contrary to previous studies, current participants reported feeling that lung cancer was inevitable while simultaneously normalising and ignoring haemoptysis, possibly due to a combination of high fear and fatalism about lung cancer, difficult life circumstances and low perceived health service candidacy. High-risk individuals who believe that they cannot legitimately seek medical help because of their former or current lifestyle may therefore be resigned to the prospect of developing lung cancer.

A major strength of this study was the rigorous sampling procedure. We screened postcodes to ensure participants resided in the lowest quintile of deprivation, and measured multiple additional indicators of deprivation. Individual and area level indicators confirm that our sample was highly deprived, for instance most were unemployed and seeking benefits, and rented social housing. In addition, we recruited participants with no previous diagnosis of lung cancer, without mention of lung cancer until discussed by participants during the interview, or at the end of the interview. These recruitment and interview procedures meant we were able to explore previous and anticipated lung cancer symptom presentation in those who were symptomatic or asymptomatic. This strategy was

employed to overcome the methodological limitations associated with studying either retrospective

 or anticipated symptom presentation in isolation[15]. However, our qualitative study was unable to establish causal links between barriers and help seeking, nor can we generalise or compare the findings to high socioeconomic groups; instead, we conducted an in-depth study to explore how best to engage high risk, highly deprived individuals in early lung cancer diagnosis. Although we carefully sampled participants and collected additional demographic measures to validate our sampling frame, some GP practices were asked to recruit by specific smoking status rather than the whole range of smoking status, potentially introducing bias to our sample. In addition, we were unable to conduct a focus group in Scotland due to low response, which is a potential limitation of the study. Finally, focus group participants were recruited opportunistically, with the potential that participants were more favourably disposed to an intervention. Practice and policy implications With a comorbid lung condition and smoking history, those who are high risk for lung cancer will, in the main, be symptomatic. To avoid normalisation of symptoms, it is important to highlight the significance of changing and multiple symptoms. High risk individuals should be empowered to seek timely medical help and made to feel welcome, not judged or blamed for their current or former lifestyle. For instance, interventions targeted at disadvantaged populations could be conducted outside of the traditional healthcare setting. Our findings highlight the importance of an intervention where participants would be invited to attend, as opposed to presenting to the GP surgery, in order to eliminate concerns about wasting GP time and legitimise their attendance. Community based interventions have the potential to harness the relational aspects of help seeking, through interventions led by non-judgemental and welcoming facilitators. It is possible that previous mass media and social marketing lung cancer awareness interventions report low campaign reach to deprived groups [34,35] in part because they were not designed to motivate help seeking through intensive approaches to build trusting relationships and confidence. More research is required to understand how the relational aspects of help seeking could be operationalised in an intervention. Over half of the current sample described mental health problems and/or difficult current or former life circumstances. Intervention developers and healthcare professionals in highly deprived communities should be aware of these wider social and contextual factors; they should receive training to recognise such circumstances and know how to appropriately signpost. Finally, we suggest that the current UK health system may encourage patients with a lung condition to focus on

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3 1	1	short term management of their condition. GP prescribing of antibiotics and the use of rescue packs
5	2	(prescribed antibiotics for storage at home in the event of an exacerbation) may inadvertently
6 7	3	reinforce patients to detect and act on symptoms of a chest infection[50]. There is potential that this
8 9	4	current standard of care could be adapted to educate and encourage patients with a lung condition
10	5	to detect symptoms of lung cancer, thereby shifting the focus to longer term health. More research
11	6	is required to understand how to motivate highly deprived groups to consider health in the long
13 14	7	term, while recognising the wider social determinants of health[51].
15 16	8	
17	9	Conclusion
18 19	10	
20 21	11	The challenges of living in an area of deprivation with social exclusion issues, combined with fear of
22	12	judgement by health professionals, contribute to avoidance and ignoring of lung cancer symptoms.
23 24	13	Multi-faceted community based interventions are required to highlight lung cancer symptoms, the
25 26	14	importance of early diagnosis and empower people who are high risk for lung cancer to seek timely
27	15	medical help.
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3	1	
4 5	2	Additional information
6 7	3	
8	4	Ethics approval and consent to participate
9 10	5	The study received ethical approval from Southampton Central- Hampshire A Research Ethics
11 12	6	Committee (16/SC/0589). Written informed consent was obtained from all participants who took
13	7	part in the study.
14 15	8	
16 17	9	Consent for publication
18	10	Not applicable
19 20	11	
21 22	12	Data sharing
23	13	Qualitative data is not publicly available for this study to maintain participant confidentiality.
24 25	14	
26 27 28 29 30 31 32 33 34	15	Competing interests
	16	The authors confirm that there are no conflicts of interest.
	17	
	18	Funding
	19	This work was supported by Cancer Research UK (grant reference number: C16377/A22034).
35	20	
36 37	21	Author contributorship
38 39	22	All authors (GMM, JH, KH, PM, RDN, GN, ST, AMT, KB) designed the study. GMM and JH conducted,
40	23	coded and analysed the interviews and focus group data. All authors contributed to the
41 42	24	interpretation of data. GMM drafted the manuscript and all authors contributed to the review and
43 44	25	editing of the manuscript. All authors read and approved the final manuscript.
45 46	26	
40 47	27	Acknowledgements
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50 51	29	who took part in the study; without these individuals this study would not have been possible. We
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53 54	31	Huws, David Lewis, Maura Matthews and Fiona Walter) and the study Administrator Lucy Watkins,
55 56	32	for their ongoing support and advice throughout the study.
57	33	
58 59 60	34	

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Supplementary File 1. Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist with page numbers to indicate section of the article [34]

Ch	ecklist item	Questions to consider	Page number in article
Do	main 1: Research team and re	flexivity	
Pe	rsonal Characteristics		1
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	8
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	8
3.	Occupation	What was their occupation at the time of the study?	8
4.	Gender	Was the researcher male or female?	8
5.	Experience and training	What experience or training did the researcher have?	8
Re	lationship with participants 🧪	5	
6.	Relationship established	Was a relationship established prior to study commencement?	7
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. <i>Bias, assumptions, reasons and interests in the research topic</i>	8
Do	main 2: study design		
The	eoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory,</i> <i>discourse analysis, ethnography, phenomenology,</i> <i>content analysis</i>	8-9
Ра	rticipant selection		
10.	. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	5-6
11.	Method of approach	How were participants approached? e.g. face-to- face, telephone, mail, email	6-7
12.	. Sample size	How many participants were in the study?	5, 6, 10, 16
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	9
Set	tting		
14.	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	8
15.	Presence of non- participants	Was anyone else present besides the participants and researchers?	8
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	9-10, 16
Da	ta collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix 2-4

18. Repeat interviews	Were repeat interviews carried out? If yes, how	6
	many?	
19. Audio/visual recording	Did the research use audio or visual recording to	6, 8
	collect the data?	
20. Field notes	Were field notes made during and/or after the	8
	interview or focus group?	
21. Duration	What was the duration of the interviews or focus	8
	group?	
22. Data saturation	Was data saturation discussed?	7
23. Transcripts returned	Were transcripts returned to participants for	
	comment and/or correction?	
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	8
25. Description of the coding	Did authors provide a description of the coding	8-9
tree	tree?	
26. Derivation of themes	Were themes identified in advance or derived from	8-9
	the data?	
27. Software	What software, if applicable, was used to manage	8-9
	the data?	
28. Participant checking	Did participants provide feedback on the findings?	8-9
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate	14-16, 18-19
	the themes / findings? Was each quotation	
	identified? e.g. participant number	
30. Data and findings	Was there consistency between the data	11-19
consistent	presented and the findings?	
31. Clarity of major themes	Were major themes clearly presented in the	11-19
	findings?	
32. Clarity of minor themes	Is there a description of diverse cases or discussion	11-19
	of minor themes?	



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Supplementary File 2: Interview topic guide

Interview prologue

- Introduce the researcher, ensure the participant is comfortable.
- Explain purpose of the interview:
 - *"We are interested in lung health.*
 - We would like to know how people cope with lung symptoms and how they decide if they should go to the doctor or not.
 - Some of the questions I ask during the interview will be about smoking. I'm not here to tell you to stop smoking; I'm just interested if you have any experiences of smoking.
 - I'm not a clinician so I can't give you any advice on symptoms, but I can tell you where you can go to get help"
- Check understanding of interview purpose, role of researcher, and what will happen in the interview. Give opportunity for questions.
- Partners or family members will be welcome to join the interviews to explore relational influences on lung symptom awareness and help seeking, and the interview topic guide will be adapted accordingly.
- After establishing what is understood about the study, and answering any questions, explain that the interview will be recorded. Obtain consent for the interview and for the recording. If not already done, set up and switch on the recording equipment while the participant signs the consent form.

Note to interviewer: the grey boxes signify the key topics to be explored during the interview. The questions listed below are examples of suggested prompts for each topic. You are not required to read these verbatim unless specified.

Overall aim of the qualitative interview:

-To explore how people with a history of smoking and respiratory conditions interpret and act on new or changing lung symptoms (how people cope with lung symptoms and how they decide to go to the doctor with symptoms) -To explore the influences of perceived risk, fear, shame, stigma, family and friends on lung symptom presentation

1. Experiences of lung condition

Establish what lung condition the participant has, how the lung condition affects them, the types of symptoms they experience and how they are usually managed. **Rationale**: introduce the participant to the format of a qualitative interview and make the participant feels comfortable. Establish details of their lung condition.

Potential prompts:

- Can you tell me about your lung condition?
- Tell me about your experiences with X lung condition.
 - How long have you had X condition?
 - What sort of symptoms do you experience?
 - How long do the symptoms usually last?
- What do you think causes these symptoms?
- How do you usually manage your symptoms?
- How are your symptoms usually managed/ treated by your healthcare professional?
 - How effective do you think this is?

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2. Symptom attribution task

Use as a tool for prompting an in-depth understanding of symptom attributions and confidence to interpret new or changing symptoms.

Include discussion around previous symptom experiences including: what action was taken, if and who they sought medical help from. Explore how their lung condition and smoking history might influence symptom attributions (i.e. do these mask symptoms?) and symptom presentation. **Rationale**: to explore lung symptom attribution; confidence in recognising and articulating symptoms; previous symptom experience; planning when/how to act on symptoms; influence of smoking history on perceptions of lung symptoms

Ask participant to order symptom cards from symptoms that they would seek medical help quickest for and those they would seek help slowest for (arrow and boxes below will be stretched to A4 size, see page 10). Ask participant to write numbers on the symptom cards. 1= first, 11=last. If they change the order of the symptom, ensure the previous number is crossed out and the new number written on card. Write PID on the back of each symptom card. Take photos of the task.

Say the following phrase verbatim: "We know that people decide go to the doctor at different times with symptoms. I'm going to show you some pieces of card with symptoms on. I'd like you to rank them from the ones that you would go to the doctor with first through to the last on this sheet of paper."

Cut individual symptom cards (see page 12) for the following symptoms. Please rotate the order:

- Coughing up blood
- A cough that doesn't go away
- A long standing cough that gets worse
- Pain in your chest or shoulder
- Persistent breathlessness
- Persistent chest infections
- Persistent tiredness or lack of energy
- Loss of appetite or unexplained weight loss
- Ache or pain when breathing or coughing
- A hoarse voice

See the **glossary of terms at the end of the topic guide** with standardised definitions and additional explanation of symptoms. If the participant does not understand what each symptom means, ask them what they think it means, then refer to the glossary of terms.

• Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger

First to go to the doctor

If the participant asks the interviewer what these symptoms are, first **ask the participant what they think they are**. If they ask again either suggest to move on and discuss what they could be after the interview (if appropriate) or say the symptoms have been taken from the NHS website for lung cancer. *Note to interviewer*: Aim to the complete the ordering of symptoms in the task first, and then ask questions in this section. However, if any of the following (2a, 2b, 2c, 2d) if bought up spontaneously by the participant whilst they are doing the card sorting exercise then explore these issues at that point. Then return to the card sorting exercise, followed by questions in the following section (2a, 2b, 2c, 2d).

Topics and prompts for symptom attribution task Once the symptoms have been ordered, ask:

Convertell requirements first?

- Can you tell me why you put x first?
- Can you tell me why you put x last?

2a. Symptom experience

To understand if the participant has experienced the symptom previously- what did they attribute the symptom to? What did they do? If they have not experienced the symptom before, what would they hypothetically do if they were to experience symptom in the future?

- Which of these symptoms have you had before?
 - What did you think the symptom(s) was/were?
 - Which symptom(s) did you go to the doctor with?
 - Why did you decide to go to the doctor with these symptoms?
 - What did the doctor say?
 - Which symptoms did you decide to not go to the doctor with?
 - Why did you decide not to go to the doctor with these symptoms?
- For the other symptoms we have not talked about, if you developed any of them what would you do?
 - How long do you think it would take you to go to the doctor with these symptoms?
 - Can you tell me why it would take you this amount of time to go to your doctor with this symptom?
 - What you think these symptoms could be?
- Are there any symptoms you wouldn't go to the doctor with?
 - Can you tell me why you wouldn't go to the doctor with these symptoms?

2b. Detecting change

Explore how the participant has/would notice new or changing symptoms and their confidence to detect new and changing symptoms. Ask this section generally, but if the participant is struggling then ask them about confidence to detect new and changing symptoms in the context of previous symptoms experiences. i.e. earlier you mentioned you felt breathless for a long time, how confident did you feel to know that this was a new or changing symptom?

- How would you normally tell if any lung symptoms have changed/ are new/ or unusual for you?
 - What would you do if you think you noticed a change in a symptom?
 - How confident would you feel in recognising a change in your usual symptom(s)?
 - How confident would you feel recognising new symptoms?
 - How would you notice a change in any of these symptoms?

2c. Barriers

Explore the influences of barriers and social influences on lung symptom presentation behavior

- Can you think of anything that would influence your decision to go to the doctor with any of these symptoms?
 - Probe barriers/enablers to going to the GP with a symptom:
 - Transport
 - Long wait times/ appointment policies
 - Worry about wasting the doctors time i.e. Some people have told us that they don't go to the doctor as they worry about wasting the doctors time. What do you think about this?
 - The influence of partner/ social influences (who suggested you go/ don't go to the doctor?)
 - How confident would you feel talking to the doctor about these symptoms?
 - How do you feel when you are talking to the doctor?

2d. Smoking

Explore the influence of smoking habit on the ability to notice new or changing symptoms. If/how smoking habit acts as a barrier to seeking medical help. If vaping comes up say something like- that is really interesting, do you mind if I ask you some questions later about vaping if we have time? If they vape then still explore the influence of past smoking on symptom perceptions.

- Would you expect to have any of the symptoms we have talked about because you smoke or used to smoke?
 - Thinking about smoking, how do you think your [past] smoking would affect how you notice if a symptom has changed or is new/ unusual for you?
 - Does your doctor ever discuss smoking with you?
 - How does this make you feel?

3. Lung cancer

If appropriate, explore lung cancer knowledge, beliefs about lung cancer and perceived risk here. If bought up spontaneously by the participant earlier in the interview, explore lung cancer then (if appropriate) Confidence to detect a lung cancer symptom. The influences of smoking and perceived risk, shame and associated with lung cancer.

Rationale: to explore lung cancer symptom awareness; to explore perceived risk of lung ca emotional consequences such as fear, fatalism blame; perceived causes and effectiveness of e detection and treatment; the influence of smol history on the formation of beliefs about lung of

If it is OK with you, I'm going to ask you some questions about lung cancer. If you feel uncomfortable with any of my questions, please let me know and we can move on.

Potential prompts:

- Earlier you mentioned some of the symptoms that could be lung cancer. Can you think of any other symptoms that you think might be lung cancer?
- What else do you know about lung cancer?
- Can you tell me a little more about what you think about lung cancer as a disease?
 - Where do you think that feeling comes from?
 - What do you think other people's views are on lung cancer?
- What do you think causes lung cancer? S
 - If yes and appropriate: How does that make you feel as a [past] smoker?
 - If appropriate: do you ever worry about lung cancer because you [used to] smoke?
 - How does that make you feel?
 - Is there anything in particular that makes you think your risk is high or low?
- How confident would you feel in recognising a symptom that could be lung cancer?
 - How does your [past] smoking affect your confidence in recognising a change in your body that could be lung cancer?
- What would you do if you had a symptom that you thought was lung cancer?

4. Social influences

Explore influences of social networks on help seeking behavior and basis of cancer beliefs.

Rationale: to explore social norms, influences and stigma around help seeking; people who they know who have had lung cancer and the effects on beliefs and perceptions; how social networks might influence help-seeking

- If you had a symptom you thought might be lung cancer, would you tell anyone about it?
 - Who would you tell?
 - Why would you tell that person?
 - What do you think they would say to you if you told them about a symptom?
 - Would they encourage/discourage you to visit your doctor?
- Has anyone ever noticed a symptom of yours and suggest that you go to the doctor?
 - Probe: who/ what happened.
- We know that lung cancer isn't as common as other types of cancer like breast cancer. Do you know anyone who has ever been diagnosed with lung cancer?
- Can you tell me about the effects that [person] having lung cancer has had on you?
 - How has this affected your views about lung cancer?

5. Closing questions

Final questions to end on a positive note

Rationale: to end the interview on a positive note

- If you were to offer anyone some advice on lung symptoms, what would it be?
- If the NHS were to make some changes to the services they offer to help people with lung symptoms get seen quicker, what would you suggest they change?
- Can you tell me about a positive experience of going to the doctor?

I know we've talked about a lot of things today, but would you like to tell me about anything else that we haven't talked about?

<u>Debrief</u>

- Summarise the interview and address any questions or concerns.
- Check whether it is ok to contact them if there is anything that needs to be clarified after listening back to the conversation.
- Ensure that they know how to contact us for further help/information/to add further information
- Thank them for their time and give them the gift voucher.
- If the participant discloses symptoms during the interview suggest they seek medical help from their GP. Offer lung cancer leaflet and site specific helpline numbers.
- Have stop smoking service details available if they request it
- Offer to provide a summary of study findings

Helpline numbers

Wales

• Tenovus Cancer Care support line on 0808 808 1010. The support line is open 8am-8pm, 7 days a week. Calls are free from a BT landline.

England and Scotland

- British Lung Foundation helpline on 03000 030555. This helpline is open 9am-5pm Monday to Friday. Calls cost the same as a local call.
- Roy Castle Lung Cancer Foundation helpline on 0333 323 7200. This helpline is open 9am-5pm Monday to Friday. Calls are free from a BT landline.

Symptoms in the symptom task:

Coughing up blood

A cough that doesn't go away

A long standing cough that gets worse

Pain in your chest or shoulder

Persistent breathlessness

Persistent chest infections

Persistent tiredness or lack of energy

Loss of appetite or unexplained weight loss

Ache or pain when breathing or coughing

A hoarse voice

Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger

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<u>Glossary of terms</u> Coughing up blood If you notice that there is some blood coming up when you cough

A cough that doesn't go away

If you have a nagging cough that just doesn't seem to go away

A long standing cough that gets worse

You have had a cough for a long time but you think that it might have got worse

Pain in your chest or shoulder

A sharp or achy pain in either your chest or shoulder, or both

Persistent breathlessness

You feel like you can't catch your breath or become out of breath when doing tasks you used to be fine with

Persistent chest infections

If you have had a few chest infections in a row and they don't seem to be getting better or keep coming back

Persistent tiredness or lack of energy

If you have been feeling tired for a while or just feel like you don't have any energy

Loss of appetite or unexplained weight loss

If you have been loosing weight without trying to and can't explain why or you just haven't been feeling up to eating the amount you normally would for a while

Ache or pain when breathing or coughing

If you have a sharp pain or achy feeling when you cough or breathe

A hoarse voice

A croaky or gravelly voice

Changes in the appearance of your fingers, such as becoming more curved or their ends becoming larger

If you notice that the ends of your fingers have changed shape

Persistent definition

Something that you notice you have had for a while and won't go away.

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60	For peer review only - http://bmjopen.bmj.com/site/about/guidelines.xhtml

Supplementary File 3: HPCP focus group topic guide

Focus group aim: To explore the needs and preferences from members of the public and local stakeholders (healthcare professionals/ community partners) for an intervention to support earlier lung cancer detection and diagnosis, targeted at high risk, harder to reach groups (over 40's, who are current/former smokers, living in areas of deprivation with serious lung comorbidity i.e. COPD).

Introduction

- Explain the aims of the focus group discussion. Emphasise that the focus group is not a test; we are interested in participants' preferences for an intervention for "lung health" to prompt earlier lung cancer symptom presentation, and how we could access people to take part in an intervention. All comments are welcomed: positive and negative.
 - 'We know that people who are high risk for lung cancer (people over the age of 40, living in deprived areas, who currently smoke or used to smoke and have a lung condition like COPD) are often diagnosed at a late stage, where treatment options are limited and a cure is less likely. This might be because they delay seeking medical advice with symptoms suggestive of lung cancer.

We are considering if we should develop something that will give people who are high risk for lung cancer information about symptoms and when/ where they should go and seek medical help from.

As healthcare professionals and people who work in deprived communities, we would like to know what you think about if we should do this. If you think this is a good idea, we would also like to know how best we can access this target group and invite them to take part in an intervention about lung health. Your ideas and suggestions are really valuable to us because of your wealth of experience, so all comments are welcomed (both positive and negative)'.

- Explain the <u>voluntary nature</u> of the study and that the focus group will be recorded with permission. If not already done, set up and <u>switch on the recording equipment</u> while participants sign the consent form.
- Before starting the focus group, remind participants <u>about confidentiality</u> and ask participants not to talk over each other. Go around the circle and ask participants to <u>introduce themselves</u> <u>for the transcription</u>.

Rationale: to explore whether the findings resonate with patients and members of the public in their local community

Part1. Phase 1 interview findings

Discussion of Phase 1 interview findings

Provide a short overview of key findings from Phase 1 interviews regarding barriers and enablers to lung cancer awareness and early symptom presentation in the target group. Ask the group to share their thoughts on the interview findings, and whether they resonate with them.

'We have been interviewing people across the UK who are high risk for lung cancer- people over the age of 40 who have a lung condition like COPD, who currently smoke or used to smoke and live in deprived areas. We wanted to understand how people think about symptoms of lung cancer, how and when people decide to go to the doctor with lung symptoms and the barriers to going to the doctor with these symptoms.

We found that people are completely fixated on detecting chest infections and look out for symptoms of a chest infection most days. They were really good at knowing when they had a chest infection and going to the doctor quickly to get antibiotics because they know it can be treated.

We also found that people tend to deny or ignore health problems that might affect them in the future, like lung cancer so may not go to the doctor with some serious symptoms. We think this is because they think that although lung cancer is inevitable, they also think that it cannot be cured so don't go and see the doctor

We want to develop something that can help people get these important symptoms of lung cancer seen to quicker by a medical professional, but we are not really sure how to do this. We would like to know what you think.'

- How can we do this?
- What do you think of these findings?
- To what extent do these findings resonate with you?

Rationale: to seek views on how to access the target group for an intervention and explore preferences for an intervention to support earlier presentation, including mode of delivery, target group, content and stop smoking information

Preferences on intervention content

- What sorts of things do you think people would like to know / what skills would they like to learn?
 - What do you think would be most useful to people?
 - What information would be the highest priority/most important for them?
 - Should we avoid any information?
 - Do you think it is best to focus on symptoms or health beliefs?

Preferences on intervention format

- How can we support people to seek medical help quickly with lung cancer symptoms? [what format]
 - Probe: a group one-off educational session to promote "lung health" in the local community; a leaflet/DVD; a lung health check; event in the community; posters in the local community
 - \circ $\,$ Do you think people want education or to learn 'skills for health'?
 - What sort of skills do you think people would like to know?
- Who do you think would be best to lead or facilitate an intervention about lung health/ encourage people to seek medical help quickly with lung cancer symptoms?
 - Probe: patient representative, lay advisor, community partner, healthcare professional (GP, practice nurse, smoking cessation counsellor, respiratory nurse specialist...?)
- When would be best to support people to manage their lung health?
 - What do you think about using the point at which they are diagnosed with a lung condition as a 'teachable moment' to do an intervention about lung cancer?
 - What about during a regular check-up appointment with the nurse i.e. six monthly COPD clinic reviews?
- What do you think about a brief intervention with health care professionals in addition to a public facing intervention?
 - What would be useful to you as healthcare professionals?
- The intention is that this intervention would be implemented across the UK. How do you think everything we have talked about today might need to differ based on where someone lives (i.e. different countries) or the person in the intervention?
 - How could we incorporate an intervention into the different models of care across regions/countries?
- How do you think this intervention could fit with other current or planned health promotion activities?

Accessing intervention participants

- Where could we approach our target group in an intervention about lung cancer/lung health?
- Probe: through community pharmacies, primary care, community nurses, existing groups for people with lung conditions?
 - Probe: on <u>utilising family / social networks</u> to encourage participation of MoP?
- \circ $\;$ Are you aware of any existing groups for people who fall into our target group?
 - What do you think about "piggybacking" onto these existing community groups or existing care plans with the nurse?
 - How do you think people would react to this?

Smoking cessation

- 'We know that people really don't like it when the doctor tells them to stop smoking and some people felt like they were treated differently by the doctors because they smoked. Sometimes this put people off going to the doctor with lung symptoms. On the other hand some people feel that it is only fair to be told to stop smoking. When we design something about lung cancer, we don't know if we should include something to help people to stop smoking or not.'
- What do you think about including stop smoking information in the intervention?
 - How do you think smokers might react to including stop-smoking information?
 - Can you think of ways we might be able to include stop-smoking information without putting smokers off?
 - What do you think about using signposting to stop smoking services instead of providing information about smoking cessation during the session?
- What do you think about using the intervention to cover things that are not related to lung health i.e. mental health or other factors that could be related to lung health?
 - How should we approach this?

<u>Debrief</u>

'Thank you for taking part in this study. We hope to use the findings from this focus group to develop an intervention based on the findings from the interviews and your recommendations to encourage earlier lung symptom presentation in those who are high risk for lung cancer. Anything you said will be treated as confidential. The voice-recoding will be stored securely. Any quotes used in published research will not have your name or anything that could identify you. Do you have any questions? [answer any questions] Here are my contact details if you have any further questions.'

Supplementary File 4: Members of the public focus group topic guide

Focus group aim: To explore the needs and preferences from members of the public and local stakeholders for an intervention to support earlier lung cancer detection and diagnosis. The intervention will be targeted at high risk, harder to reach groups (over 40's, who are current/former smokers, living in areas of deprivation with serious lung comorbidity i.e. COPD).

Introduction

- Explain the aims of the focus group. Emphasise that the focus group is not a test; we are interested in participants' preferences for an intervention for "lung health" to prompt earlier lung symptom presentation, and how we could access people to take part in an intervention. All comments are welcomed: positive and negative.
 - ⁶ 'We know that some people sometimes might take a bit longer to go to the doctor with important lung symptoms. I am thinking about developing something that will highlight important lung symptoms, and encourage people to go to speak to someone who is medically trained about their symptoms. I would like to know what you think about best ways to do this. I would also like to know how you think we can find people for this. Your ideas and suggestions are really valuable to us, so all comments are welcomed (both positive and negative)'.
- Explain the voluntary nature of the study and that the focus group will be recorded with permission. If not already done, set up and switch on the recording equipment while participants sign the consent form.
- Before starting the focus group, remind participants about confidentiality and ask participants not to talk over each other. Go around the circle and ask participants to introduce themselves for the transcription.

Discussion of Phase 1 interview findings

Rationale: to explore whether the findings resonate with patients and members of the public in their local community

Provide a short overview of key findings from Phase 1 interviews regarding barriers and enablers to lung cancer awareness and early symptom presentation in the target group. Ask the group to share their thoughts on the interview findings, and whether they resonate with them.

'We did some interviews across the UK with people who smoke or used to smoke and have a lung condition like COPD. We found that people look out for symptoms of a chest infection most days. They were really good at knowing when they had a chest infection and going to the doctor to get antibiotics. We also found that people try not to think about health problems that might affect them in the future, so may not go to the doctor with some symptoms that could be serious.

People really didn't like it when the doctor told them to stop smoking and some people felt like they were treated differently by the doctors because they smoked. Sometimes this put people off going to the doctor with lung symptoms.

We also found that people often had a favourite doctor at their GP practice and would wait up to three weeks for an appointment even if they thought a symptom was important. People don't like

going to doctors that they don't know because they felt that they did listen as much as their favourite doctor. But sometimes it was necessary to go to a doctor they don't know to get an appointment the same day.

We want to develop something that can help people get important lung symptoms seen to quicker by a medical professional, but we are not really sure how to do this or who should do this. We would like to know what you think.'

- What do you think of these findings?
- In what ways do you feel the same as what we found?
- In what ways do you feel different to what we found?

Rationale: to seek views on how to access the target group for an intervention and explore preferences for an intervention to support earlier presentation, including mode of delivery, target group, content and stop smoking information

Part 2. Needs and preferences for an intervention

Preferences on intervention format

- In what ways could we support people to manage their lung health?
 - Probe: a group one-off educational session to promote "lung health" in the local community; a leaflet/DVD; a lung health check; event in the community; posters in the local community
- Who do you think would be best to lead an intervention about lung health?
 - Probe: lung cancer survivor, lay advisor, community partner, healthcare professional
- If a health care professional was to lead the intervention, who would be best to lead a lung health intervention?
- Who is your favourite healthcare professional?
- When would be best to support people to manage their lung health?
 - What about when someone is diagnosed with a lung condition?
 - What about in one of your regular check-up appointments with the nurse i.e. sixmonthly COPD clinic review?

Preferences on intervention content

- What would you like to know? OR what skills would you like to learn?
 - \circ $\;$ What would be most useful or important for you?
 - \circ Can you think of anything that we should avoid or anything that is not as important?
- What do you think about including information to help people to stop smoking?
 - How would you react to stop-smoking information?
 - Can you think of ways we might be able to include stop-smoking information without putting smokers off?
 - What do you think about telling people where they can get help to stop smoking if they want to, instead of giving people information about stop smoking?

Accessing intervention participants

- Where could we approach people who smoke/used to smoke and have lung symptoms?
 - Probe: through community pharmacies, primary care, community nurses, existing groups for people with lung conditions/ utilising family and social networks / snowballing approaches?
- Are you aware of any community groups for these types of people?
 - How do you think people from these groups would react to being approached for a lung health intervention?

Debrief

'Thank you for taking part in this study. We hope to use the findings from this focus group to develop something to encourage people to go to the doctor with important lung symptoms. Anything you said will be treated as confidential. The voice-recoding will be stored securely. Any quotes used in published research will not have your name or anything that could identify you. Do you have any questions? [answer any questions] Here are my contact details if you have any further questions.'