The Lung Symptom Awareness and Health (LUSH) study

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Lung Cancer

- Lung cancer is the most common cancer worldwide\(^1\) and leading cause of cancer mortality in the UK and US\(^2,3\).

- Survival is poor - 5 year survival in the UK lower than 10%\(^4\).

- Socioeconomic inequalities in lung cancer incidence\(^5\) and outcomes\(^6\) exist.

- Advanced stage disease at diagnosis and prolonged symptom presentation.
The LUSH (Lung Symptom Awareness and Health) Study

Aim: To understand barriers to lung cancer symptom presentation in high risk groups. Develop an intervention to encourage timely medical help seeking behaviour.
The LUSH (Lung Symptom Awareness and Health) Study

1a: Interviews
Understand lung cancer symptom attribution and medical help seeking

1b: Focus groups
Explore intervention needs and preferences

1c: Intervention
Development
Phase 1a: Qualitative Interviews
(n=37)

Aberdeen (n=16)

South Wales (n=15)

Liverpool (n=6)
Interview Topic Guide

1. Experiences of lung condition
2. Symptom task
   a. Symptom experience
   b. Detecting change in symptoms
   c. Barriers to symptom presentation
   d. Influences of smoking
3. Lung cancer awareness and beliefs

Analysed using Framework

First to go to the doctor

Last to go to the doctor
Symptom Task

**First to go to the doctor**

1. Coughing up blood
2. Persistent chest infection
3. Chest or shoulder pain
4. Ache or pain when coughing or breathing
5. Persistent breathlessness
6. A cough that doesn’t go away
7. A long standing cough that gets worse
8. Persistent tiredness or lack of energy
9. Loss of appetite or unexplained weight loss
10. Changes in the appearance of fingers such as the ends becoming curved or larger
11. Hoarse voice

**Actively detect**
Monitor using sophisticated symptom assessments

**Passively detect**
Symptoms masked by lung condition or other co-morbidities.

**Last to go to the doctor**

Unnoticed normalise

Passively detect normalise
Focus on maintaining health in the short term

- Greater perceived control over short-term health (managing chest infections)
- Lower perceived control over longer term health (lung cancer)

“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, Scotland, former smoker)

“[lung cancer] worries me but I’ve got proper problems to worry about. I won’t worry about it until it’s actually here. If I started worrying about eventualities I’d never get anywhere” (Female, Scotland, current smoker)
Interview findings 2

Quest to be the model patient

• Do not feel worthy of seeking medical help
• Highly critical of people who waste NHS resources
• Only seek medical help when necessary

“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, Scotland, current smoker)

“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 live...these people that go there are not really ill, I think they’re just seeking attention” (Male, England, current smoker).
Interview findings 3
Preferred healthcare professional

• Relationship and individual personal style of HCP can encourage or discourage symptom presentation
• The need to feel safe and not judged

“Some **people are friendly** and not stony faced...if [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, Scotland, current smoker)

I’m alright with [one GP], **you could tell her anything**, I’ve shocked her sometimes (Female, England, current smoker)
Interview findings 4
Communication techniques

• Difficulty communicating symptom concerns/forget what to say during an appointment
• Prefer not to ask questions and hear bad news

“I’m very poor in asking questions cos I don’t want to know the results. Simple as that...no I don’t ask when they say the oxygen is alright I just think well it’s alright and it’s one thing less I haven’t got to worry about” (Female, Wales, former smoker)

“There’s locums that I’ve never seen before. You’ve got to explain everything and that was the hard part basically” (Male, Wales, former smoker)
Interview findings 5
Lung Cancer

- Perceived inevitability of lung cancer
- Deep seated fearful and fatalistic beliefs about lung cancer

“When I have a coughing fit and I get a pain in my chest, I say “oh god I hope I haven’t got cancer”. I say that daily. Cancer is really, really on the forefront on the mind...[I] say 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....I say my prayers every night you know, I’m not a very religious person...and say please don’t let me get cancer, because I’ve got a fear of cancer.” (Female, Scotland, current smoker)
The LUSH (Lung Symptom Awareness and Health) Study

To explore intervention preferences for an intervention to encourage timely medical help seeking behaviour for lung cancer symptoms in those who are high risk

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Phase 1b. Focus groups

Members of the public (n=2 groups) (current smokers, n=6; ex-smokers, n=7; never smokers, n=3)

HCPs and Community partners (n=3 groups) (community nurse, support group facilitator, community partner, charity representative, public health wales representative, practice manager, pharmacist, GP, practice nurse, medical student)
Preliminary findings: Suggestions for type and content of intervention

- Community based intervention
- Relationship with facilitator important
- Information about symptoms and challenge negative beliefs about lung cancer

“You need to show the success stories in treating lung cancer cos a lot of people think with lung cancer “that’s it, I’m going to be dead in a year”. It’s not always the case, so you’ve got to show the success rates” (HCP/CP Wales 1)

“Mobile health...in the shopping area, where people go shops, or outside the hospital... 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” (Public, England 1)

“Community workers like ourselves, our remit is to do healthy eating and cooking with families so it’s more of a relaxed environment where then we can add the extra message of you know, it’s less formal where they feel more receptive to it because you’ve got that relationship” (HCP/CP, Wales 1)
The LUSH (Lung Symptom Awareness and Health) Study: next steps

1a: Interviews
Understand lung cancer symptom attribution and medical help seeking

1b: Focus groups
Explore intervention needs and preferences

1c: Intervention
Theory based intervention development

The LUSH (Lung Symptom Awareness and Health) Study: next steps

School of Medicine
• **Focus on short term**, immediate and ‘treatable’ health concerns; **denial or ignoring of longer term**, ‘incurable’ health concerns

• Targeted **multifaceted interventions** could be used to counteract negative beliefs and highlight the importance of lung symptoms may promote early presentation.
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