

EXPRESS-DCE: Exploring the social and ethical implications of risk stratified screening for society

Survey outline

Part A. Introduction and consent

1. Introduction and instructions
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[Note that this content will be delivered online so the formatting will look slightly different to in this document. The participants will also not see the headings in shaded boxes or the references but these are included to illustrate where the questions have come from.]

Part A. Introduction and consent

1. Introduction and instructions
2. Participant information sheet
3. Consent
<i>Thank you very much for agreeing to complete this questionnaire.</i>
<i>Please answer every question. If you are uncertain about how to answer a question, then please select the closest option.</i>

Part B. Demographics and views towards cancer

4. Demographics		
Demographic information <i>In this first section we would like to ask you a few questions about yourself. These questions allow us to make sure we are including people from a range of different backgrounds and see if different groups of people have different views. We will not be able to identify you from your answers.</i>		
How old are you?	[free text] years	

What is your sex? (A question about gender identity follows)	• Female • Male	
Is the gender you identify with the same as your sex registered at birth?	• Yes • No (please enter your gender identity)	
What is your ethnic group? Choose one option that best describes your ethnic group or background.	• Asian/Asian British • Black/African/Caribbean/Black British • Mixed/Multiple ethnic group • White • Other (please describe)	
What is your highest education level?	• Finished school at or before the age of fifteen • Completed GCSEs, O-levels or equivalent • Completed A Levels or equivalent • Completed further education but not a degree • Completed a Bachelor's degree • Completed a Master's degree or PhD • Other (please describe)	
Which of the following best describes the <i>main income earner's</i> main/most recent job? This could be you: the main income earner is the person in your household with the largest income. If the main income earner is retired and has a pension, please answer for their most recent occupation. If the main income earner is not in paid employment but has been out of work for less than 6 months, please answer for their most recent occupation.	• Business owner – responsible for 1-4 employees • Business owner – responsible for 5-24 employees • Business owner – responsible for 25+ employees • Top/senior manager in large organisation; qualified senior professional <i>e.g. main board director, senior civil servant, headteacher, partner in professional practice, surgeon</i> • Middle manager or executive in large organisation; senior manager of small organisation; qualified professional (no senior management responsibility) <i>e.g. department manager, teacher, engineer, accountant, doctor, manager of small building firm</i> • Non-management office role; middle manager in small organisation; qualified nurse; performing artist <i>e.g. secretary, personal assistant,</i>	The ABC1–C2DE framework is a validated method of determining social grade (1). PAMCo uses an updated version of this question (2).

	<i>clerical worker, office worker, call centre agent, salesperson, nurse or nursery nurse, police constable/sergeant, actor, musician, sportsperson</i> • Manual worker - manager – responsible for 25+ employees • Manual worker - manager – responsible for 1-24 employees • Skilled manual worker (no responsibility for other employees) e.g. <i>HGV driver, train/bus/ambulance driver, chef, hairdresser, mechanic, plumber, bricklayer, carpenter, painter, electrician, caterer, specialised machinery operator, fire-fighter, pub/bar worker</i> • Unskilled or semi-skilled manual worker (no responsibility for other employees) e.g. <i>farm worker, cleaner, postal worker, van driver, care worker, waiter, taxi driver, shop assistant, apprentice/trainee in skilled trade</i> • Casual worker or no regular income • Full time student	
What is your tobacco smoking status?	• Never smoked cigarettes or cigars • Used to smoke cigarettes or cigars • Smoke up to 20 cigarettes or cigars per day • Smoke 20 or more cigarettes or cigars per day	
How would you describe your weight?	• Underweight • About the right weight • Slightly overweight • Very overweight	
Have you ever had cancer?	• Yes • No	
Have your parents or any brothers or sisters ever had cancer?	• Yes • No • Don't know	

Has anyone close to you (e.g. a partner or close friend) ever had cancer?	• Yes • No • Don't know	
5. Numeracy		
Understanding of numbers <i>As the information we will be giving you about cancer screening includes numbers, we would like to know how you answer the following questions.</i>		
Imagine we flip a fair coin 1,000 times. • What is your best guess at how many times the coin would come up heads in 1,000 flips?	[free text] times out of 1,000	Schwartz scale(3)
In the UK National Lottery®, the chance of winning a £10 prize is 1%. • What is your best guess at how many people would win a £10 prize if 1,000 people each bought a single ticket to UK National Lottery®?	[free text] person(s) out of 1,000	
In the EuroMillions® Lottery, the chance of winning a car is 1 in 1,000. • What percent of the EuroMillions® tickets win a car?	[free text] %	
6. Thoughts and beliefs about cancer		
Thoughts and beliefs about cancer <i>The next section asks about your thoughts and beliefs about cancer. Please answer as honestly as you can as this will help us with our analysis. The questions are about YOUR opinion and so there is not a correct answer.</i>		
Below are some statements that are sometimes made about cancer. For each of these statements how much do you agree or disagree with them? • These days, many people with cancer can expect to continue with normal activities and responsibilities. • Most cancer treatment is worse than the cancer itself. • I would NOT want to know if I have cancer.	• Strongly agree • Agree • Neither disagree nor agree • Disagree • Strongly disagree	Kidney cancer beliefs, taken from Smits et al., 2018(1) (and made for cancer in general, rather than lung cancer), which were based on validated questions from the ABC measure(4).

• Cancer can often be cured. • Going to the doctor as quickly as possible after noticing a symptom of cancer could increase the chances of surviving. • Some people think a diagnosis of cancer is a death sentence.		
How likely do you think is it that you will get cancer at some point in the next 10 years?	• Extremely likely • Moderately likely • Slightly likely • Neither likely nor unlikely • Slightly unlikely • Moderately unlikely • Extremely unlikely	
For each of the following statements, select the option that best applies to you: • During the past month, how often have you thought about your own chances of getting cancer? • During the past month, how often have thoughts about your chances of getting cancer affected your mood? • During the past month, how often have thoughts about your chances of getting cancer affected your ability to perform your daily activities?	• Not at all • Rarely • Sometimes • Often • A lot	Lerman cancer worry scale(5)
Do you think that benefits of cancer screening outweigh the possible side effects, potential harms and inconvenience? <i>Select all that apply.</i>	• Yes, for everyone • No, for everyone • It depends on your age and sex • It depends on the type of cancer • It depends on how you feel about cancer • It depends on how you feel about screening tests	

Part C. Conjoint-analysis tasks

7. Explanation of each of the attributes and levels, and example

Instructions

We will now present you with a series of nine questions with two different strategies for cancer screening programmes in each question. For each question, you will be asked to select which programme you think is best. Again, the questions are about YOUR opinion and so there is not a correct answer. You might find some questions to be more straightforward than others. They will help us to understand which outcomes of the programme people think are most important.

We will provide the following information about each programme:

The population

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

The figure shows two possible cancer screening programmes and the outcomes for a population of 100,000 people aged 40 to 70 years.

For the purpose of this study, the number of people with cancer in the population of 100,000 people will be the same in each scenario (600 people with cancer).

Similarly, the same screening test will be used so the burden on each person tested, the cost per test and the accuracy of the test is the same. The impact of detecting the cancer through screening on survival will also be assumed to be constant.

Risk factors used to determine eligibility for screening

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

Only people with certain characteristics will be sent an invitation for screening. This is because not everyone has the same risk of developing cancer. The approaches for determining eligibility for screening using different risk factors include:

1. Age – Cancer is more common in older people, although being younger also does not mean someone is completely without risk of getting cancer. Everyone over a certain age could be invited for screening.

2. Age and sex – Some cancers are more common in males than females, or vice versa. All males over a certain age could be invited for screening, or males over a certain age and females over a different age.

3. Age, sex and other lifestyle risk factors such as weight, smoking and ethnicity – Just as cancer is more common in older people, other characteristics mean that some people are more likely to develop certain cancers than other people. For example, people who are overweight and those who smoke often have a higher risk. This does not mean that all people who are overweight or smoke develop cancer or that people who are not overweight and do not smoke do not develop cancer. It just means that on average people who are overweight or smoke are more likely to develop some types of cancer than people who are not overweight and do not smoke.

4. Age and genetic risk – Lastly, some people have certain genes that put them at higher risk of cancer, particularly as they get older.

Information about the risk factors would need to be collected for the risk assessment. This could be done through the GP records or questionnaires. A cheek swab or finger prick blood test could be used to assess genetics.

Experts have developed calculators to estimate how likely an individual is to develop certain cancers. The calculators are based on scientific research studies and use information about these risk factors to identify when someone should first have cancer screening. As with all of these approaches, they are not 100% reliable. Someone who is estimated to be at higher risk based on the calculator is not destined to get cancer. A low risk estimate also does not mean someone is completely without risk of getting cancer.

In the questions that follow, we won't explain exactly how the risk factors have been used to decide when to invite someone to screening. For example, using the risk factors 'age and sex' could mean screening:

- women over 50 years old and men over 60 years old, or
- women over 45 years old and men over 40 years old, or
- something else.

Number of people who will be offered screening

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

Depending on how these risk factors are used, different numbers of people will be invited to cancer screening. For example, more people will be offered screening if people over 50 years old are invited than if people over 60 years old are invited because there are more people alive over 50 than over 60.

Number of cancers detected by screening

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

People with a positive screening test will be offered further diagnostic tests for cancer such as a biopsy or scan. Cancer will be detected in some of these people. Many of those will then be offered treatment and their lives could be saved.

Number of people who will have unnecessary follow-up as a result of screening

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

No screening test is perfect, and some people who have a positive screening test don't actually have cancer. They too will be offered further diagnostic tests for cancer such as a biopsy or scan. This can cause anxiety and pain or discomfort.

Number of cancers missed as a result of not being invited to screening

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility 	Age and sex	Age and genetic risk score
Number of people who will be offered screening 	26,000	26,000
Number of cancers detected by screening 	175	50
Number of people who will have unnecessary follow-up as a result of screening 	250	515
Number of cancers missed as a result of not being invited to screening 	80	100

Just as most people with risk factors will not actually develop cancer, some people without risk factors will develop cancer. They won't have been offered screening because they weren't considered to be at high risk. They may not be diagnosed until they develop symptoms and treatment may be less successful if the cancer has been picked up later.

For the purpose of this study, the number of people with cancer in the population is the same in each scenario (600 people with cancer). Similarly, the same screening test is used so the burden on each person tested, the cost per test and the accuracy of the test is the same. The impact of detecting the cancer through screening on survival is also assumed to be constant.

On the next page, we will ask you three questions about this example so that we can check that we've explained these ideas clearly.

Once you click 'Next', you won't be able to come back to these instructions.

Example

Imagine that there were 100,000 people aged 40–70 years in a population. 600 people were expected to have a particular type of cancer.

The figure shows two possible screening programmes for this cancer and the outcomes for the population.

EXAMPLE	Programme A	Programme B
Number of people aged 40–70 years	100,000	100,000
Number of cancers expected	600	600
Risk factors used to determine eligibility	Age and sex	Age and genetic risk score
Number of people who will be offered screening	26,000	26,000
Number of cancers detected by screening	175	50
Number of people who will have unnecessary follow-up as a result of screening	250	515
Number of cancers missed as a result of not being invited to screening	80	100

Looking at the example, please respond true or false to the following statements:

- More people would be invited to screening in Programme A
- More people in Programme B would have unnecessary follow-up as a result of screening
- People would need to give a check swab or blood test in Programme B

- True
- False

8. Conjoint-analysis task/DCE

We will now present you with a series of nine questions with two different strategies for cancer screening programmes in each question. For each question, you will be asked to select which programme you think is best.

EXAMPLE		Programme A	Programme B
Number of people aged 40–70 years		100,000	100,000
Number of cancers expected		600	600
Risk factors used to determine eligibility		Age	Age and lifestyle risk score
Number of people who will be offered screening		45,800	26,000
Number of cancers detected by screening		175	52
Number of people who will have unnecessary follow-up as a result of screening		251	515
Number of cancers missed as a result of not being invited to screening		77	101
Which programme do you think is best?	• Programme A • Programme B		
<i>[This question will repeated nine times with different cancer screening programmes.]</i>			
9. Evaluation			
Please tell us how easy or difficult you found choosing between the different programmes.	• Very easy • Easy • Slightly easy • Slightly difficult • Difficult • Very difficult		
Please tell us a few words why you found choosing between the different programmes easy or difficult.	[Free text]		
Please rank the details about the programmes in order of their importance to you when choosing between the different programmes.	1 (most important) 5 (least important): • Risk factors used to determine eligibility • Number of people who will be offered screening • Number of cancers detected by screening • Number of people who will have unnecessary follow-up as a result of screening • Number of cancers missed as a result of not being invited to screening		

References

1. Smits SE, McCutchan GM, Hanson JA, Brain KE. Attitudes towards lung cancer screening in a population sample. *Heal Expect.* 2018;21(6):1150–8.
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questionnaire. Available from: <https://pamco.co.uk/how-it-all-works/interview-and-questionnaire>. Accessed 09 August 2021.

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5. Lerman C, Trock B, Rimer BK, Boyce A, Jepson C, Engstrom PF. Psychological and behavioral implications of abnormal mammograms. *Ann Intern Med*. 1991;114(8):657–61.