

Participant Information **COBELT**

CO-DESIGN OF A BIORESOURCE AND EARLY-DETECTION LUNG CANCER TEST

What is the study about?

We invite you to take part in a research study. Lung cancer is the most common cause of cancer death in the UK. A new blood test can help detect it at an early stage and make it more treatable. We want to make sure the test reaches people who could benefit from it. COBELT co-design gives people a say in what the future of this test should look like. What barriers do you see for using the test? What should a lung health service look like? We also want to know how people would feel about blood from the test being used for further research.

Why have I been invited to take part?

You have been invited, because you are part of the group of people who might want to deliver the test in the future. We learn most from hearing diverse views, so it does not matter if you may or may not be interested in a test for lung cancer.

Do I have to take part?

This information has been written to help you decide if you would like to take part in the study. It is up to you alone whether you want to. You would be free to withdraw at any time without providing a reason.

What would I be required to do?

You will be asked to:

- take part in a collaborative discussion using Padlet or if you are uncomfortable using Padlet, take part in a brief online survey. Both are about ways to overcome the barriers raised in the previous interviews.

What are possible risks or disadvantages of taking part?

It is unlikely that there are any risks to taking part in this study. However, you might feel some discomfort or distress when talking about a lung cancer test. You can choose to not answer any questions you do not wish to.

Informed consent

It is important that you can give your informed consent before taking part in this study. You can ask any questions about the research before agreeing to take part.

Who is funding the research?

The project is funded by the Chief Scientist Office under the title: *Using co-design to mitigate the 'Inverse care law' in rolling out an early detection of lung cancer service.*

What information or recordings about me ('my data') will you be collecting?

All data you provide will be anonymous and we will not ask for any identifiable data. If you choose to use the Padlet we will ask that you sign up. This will mean we will be able to link your responses across the Padlet, using your username. You can use a pseudonymised name if you prefer. This will allow us to generalise responses across services without taking any personal data. Your data will still remain anonymous, as we will not have access to any personal details by doing this.

How will my data be securely stored, who will have access to it?

Your data will be stored in ANONYMISED form, as no identifiable data is being collected. Your

data will be stored in a secure folder on the University server, and only the named researchers will be able to access it.

How will my data be used, and in what form will it be shared further?

Your data will be analysed as part of the research study. Responses may be published in a report and/or academic journals. It may also be used for future scholarly research. The information will be shared (published and/or placed in a database accessible by others) in an **ANONYMISED** form. This means we will not refer to your name, nor be linked one-on-one to identifiable information. This means that no-one could use any reasonably available means to identify you from the data.

When will my data be destroyed?

Your data will be destroyed after five years.

Will my participation be confidential?

Yes, your participation will only be known to people immediately involved in the project.

Use of your personal data and data protection rights

The University of St Andrews (the 'Data Controller') is bound by the UK 2018 Data Protection Act and the General Data Protection Regulation (GDPR), which require a lawful basis for all processing of personal data (in this case

it is the 'performance of a task carried out in the public interest' – namely, for research purposes) and an additional lawful basis for processing personal data containing special characteristics (in this case it is 'public interest research'). You have a range of rights under data protection legislation. For more information on data protection legislation and your rights visit <https://www.st-andrews.ac.uk/terms/data-protection/rights/>. For any queries, email dataprot@st-andrews.ac.uk. You will be able to withdraw your data until it is anonymised. After it has been anonymised, we will not be able to withdraw it, because we will not know which data is yours.

Ethical approvals

This research proposal has been checked and given ethical approval by the University of St Andrews Teaching and Research Ethics Committee

Where can I file a complaint?

In the first instance, you are encouraged to raise your concerns with the researcher. However, if you do not feel comfortable doing so, then you should contact the School Ethics Contact (contact details below). A full outline of the procedures governed by the University Teaching and Research Ethics Committee is available at www.st-andrews.ac.uk/research/integrity-ethics/humans/ethical-guidance/complaints/.

Contact Information

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