



University of
St Andrews

Participant Information

Designing a video to help people take a future blood test, at home, to help detect lung cancer.

What is the study about?

In the future, people may be able to take a blood test to help find lung cancer at an early stage. This blood test can be taken at home. To help people do this, a step-by-step video will be provided with the future test. We invite you to take part in a research project that aims to design this video. We would like to ask you a few questions that will help us make a video that is suitable.

Why have I been invited to take part?

You have been invited to take part because you are part of the group of people who might want to use the video to help you take the test in the future, should it be approved.

Do I have to take part?

This information sheet has been written to help you decide if you would like to take part. It is up to you and you alone whether you wish to take part. If you do decide to take part you will be free to withdraw at any time without providing a reason, and with no negative consequences.

What would I be required to do?

You will be asked to help design a step-by-step video for the home test. This will mean the video will suit people who might use it. This will be done in 3 stages.

1. You are being invited to take part in a group discussion. This discussion will either take place face to face or online. We will discuss beforehand to agree which option will suit you best. The discussion will last 60-90 minutes and we will talk about your views on the content for the video. What you might like and dislike and what would work best for you. The video will then be made based on this information. You will receive a **£30** Love2Shop voucher for taking part.
2. Afterwards you may be invited to provide feedback on the video.

Taking part is completely voluntary.

You will not be asked to take the blood test.

Are there any risks to taking part?

We do not expect there are any risks in you taking part in this research. If you have any concerns or questions please contact the research team or ethics contact. Details can be found at the bottom of this sheet.

What precautions will you take to help protect me from the coronavirus?

In planning for this research, we have completed a University of St Andrews risk assessment. We will ensuring social distancing and face coverings are implemented in line with current recommendations. We will also collect your contact details to enable contact tracing, if necessary. You will not be expected to share equipment or put yourself in a situation of increased risk. The group discussions will take place in local community centres/churches and we will adhere to any further guidance implemented at these locations and/or within your group, if you are taking part as a member of a group that already meets.

Please let us know at any time if there is anything we could do to make you feel safer or if you ever want to reschedule or withdraw your participation.

Informed consent

It is important that you are able to give your informed consent before taking part in this study and you will have the opportunity to ask any questions in relation to the research before you provide your consent.

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

We will ask for your age, gender, postcode, smoking status and history of lung disease or illness. We will ask you questions around what you like and dislike about example videos and what you would like to see in a future video. You will have the opportunity to leave your contact details, if you are happy to be contacted about this research in the future. We will record the conversations of the group discussions, if you consent to this.

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

Your data will be stored in a **PSEUDONYMISED** form. This means that your data will be edited so that you are referred to by a unique reference such as a code number or different name, and the original data will remain accessible only to the research team. Your data will be stored on the lead researcher's University OneDrive, which is password protected, in line with University policy, and only members of the research team will be able to access it. There will be a 'key' document, which will link your unique reference to your real identity. The key will be kept in a separate secure file on the lead researcher's University OneDrive, protected by encryption, in line with university policy, it will not be stored alongside your data, and only the research team will have access to it and be able to reconnect your data to you at a later date. This will allow us to connect your data from both stages in the research to create a more complete picture. The key will be kept for a limited time to allow for this reconnection.

Audio recordings taken of the group discussions will be taken on an encrypted device and transcribed at the earliest opportunity before being destroyed. These will be stored on the lead researcher's University OneDrive, which is password protected, in line with University policy and only members of the research team will be able to access it.

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

Your research data will be analysed as part of the research study. Written down, anonymised parts of our conversations 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. Published data 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?

Any audio recordings will be transcribed at the earliest possible opportunity and originals destroyed. All identifiable data e.g. contact details and the “key” document will be destroyed within 6 months of completion of the study. All other data will be destroyed after 5 years.

Will my participation be confidential?

Yes, your participation will only be known to those on the research team.

Retention of contact information to facilitate NHS contact tracing

As well as your research data which we have described above, we will also collect your contact information. This is for the sole purpose of facilitating contact tracing by NHS Scotland, an important step in containing the spread of coronavirus.

Your contact information will not be accessed or shared with anyone other than the researcher, their supervisor (as a safeguard in the event of the researcher becoming unwell) and, only if requested, NHS Scotland for use in the track and trace scheme. This information will not be used for any other purpose and no other data collected as part of this research will be shared in this way. The lawful basis for collecting this data is legal obligation; the University has a common law duty of care to protect the welfare and wellbeing of individuals involved in research.

Your contact information, which is fully identifiable, will be stored separately, and with no obvious link, to the research data, in a secure encrypted and password protected file on University servers.

Your contact information will be retained only for the purposes stated above and destroyed 21 days after our last in-person face-to-face contact. Your contact information can only be withdrawn if we have not yet had in-person face-to-face contact.

Use of your personal data for research 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 before anonymisation is conducted at the end of the data collection period, within 3 months after completion of the study. If your data is anonymised, we will not be able to withdraw it, because we will not know which data is yours.

Contact information collected to facilitate contact tracing cannot be withdrawn but will be destroyed 21 days after our last in-person face-to-face contact.

Ethical Approvals

This research proposal has been scrutinised and subsequently granted ethical approval by the University of St Andrews Teaching and Research Ethics Committee.

What should I do if I have concerns about lung cancer?

If you have concerns about lung cancer please speak with your GP or contact the Macmillan support line on: 0808 808 00 00

What should I do if I have concerns about this study?

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 my Supervisor or School Ethics Contact (contact details below). A full outline of the procedures governed by the University Teaching and Research Ethics Committee is available at <https://www.st-andrews.ac.uk/research/integrity-ethics/humans/ethical-guidance/complaints/>.

Contact details

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**School
Ethics
contact**

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