



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. Firstly, you will be invited to take part in a survey, this will ask for your views of past, similar videos, as well as needs and ideas for the video to be made. You will be asked to watch the videos and comment on them for example what you like and dislike about them. The videos are part of the survey, you will only need to click on them to play them. This will take around 15-20 minutes. You can enter a prize draw to win 1 of 3 £20 Love2shop vouchers for taking part in the survey.
2. You may then be invited to take part in a group discussion. This will focus on building the ideas from the survey and mapping these out. The video will then be made based on this information.
3. Afterwards you may be invited to provide feedback on the video.

All participation will be online or by telephone. You do not have to take part in all 3 stages, it is completely up to you if you take part or not.

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.

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 past videos and what you would like to see in a future video. If you want to be entered in to the prize draw or are happy to be contacted about the research in the future, we will ask you to provide your contact details. We will record the conversations of the group discussions in stages 2 and 3, if you consent to this.

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

If you do not provide contact details when completing the survey and if you only provide contact details to be entered into the prize draw, your data will be stored in **ANONYMISED form**.

If you leave your contact details at the end of the survey to be contacted about the research in the future and/or take part in the group discussions in stages 2 or 3 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.

Audio recordings taken of the group discussions in stages 2 and 3 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 and/or responses to the survey questions 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 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.

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, 30th June 2021. If your data is 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 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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