



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 about your experience of home test kits to collect blood samples 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 previously been offered and/or used a home test kit to collect blood for a test, using a finger prick lancet. This may have been a Covid antibody test, a sexual health test, preventative health check or another screening test. It does not matter what test you did, we are only interested in your experience of using the kit.

### **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 complete a short survey (3-5 minutes) about your past experience using a home test kit to collect a blood sample.

You will not be asked to take the blood test.

You can enter a prize draw to win 1 of 3 £20 Love2shop vouchers for taking part in the survey.

### **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, 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. The survey will include questions about your past experience using an at home kit to collect a blood sample from your finger, using a small lancet. For example "how confident you were doing this?" and "how difficult you found it?" If you want to be entered into the prize draw and/or are happy to be contacted

about the research in the future, you will be asked to leave your contact details. These will be kept separately from all other data to ensure your data remains anonymous.

### **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, 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.

### **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?**

All anonymised data will be destroyed after 5 years. Your contact details will be destroyed as soon as possible after completion of the study, within 6 months.

### **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](mailto: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, 30<sup>th</sup> 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  
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