



Testing and Trust: Public perceptions, expectations and experiences of COVID-19 testing in Lothian, Scotland.

Information for University of Edinburgh student participants

We are inviting student volunteers to take part in a study investigating how experiences and expectations of COVID-19 coronavirus testing affect public trust in health services and government responses to the pandemic. This will involve a short survey to evaluate your experience of the asymptomatic testing programme for students, followed by an optional one-to-one interview over the telephone or internet call.

We hope the results of this research will help identify challenges to implementing and scaling up COVID-19 testing in Scottish Universities, and help improve the student experience of testing.

Please read the following information carefully before you decide whether or not to participate. There are five pages: you can move forwards or backwards by clicking on the 'next' and 'back' buttons at the bottom of each page. The information will tell you:

- Why the research is being done.
- What you will be asked to do.
- What we hope to learn.

If you do decide to take part, you will be asked to give your consent to volunteer using an online form. You will be free to withdraw from the study at any time, and without giving a reason.

ABOUT THE STUDY

We are conducting research on the asymptomatic Covid-19 testing programme for university students led by the University of Edinburgh. This research is being conducted by the School of Social and Political Sciences and the Usher Institute at the University of Edinburgh and is part of a broader project to understand public expectations, perceptions and experiences of COVID-19 testing in Lothian, Scotland. We have been approved to conduct this research by the SPS Research Ethics Committee (REC) and the study is sponsored by the University of Edinburgh (reference number: 269387).



The purpose of this research is to explore your experiences, concerns and expectations of COVID-19 testing. We are interested in your views about diagnostic testing for COVID-19, and your opinions about university, NHS, and government responses to the pandemic. This research will be fed back to decision makers in Scottish universities, the NHS and the Scottish Government to help inform testing and COVID-19 control strategies.

WHY HAVE I BEEN INVITED TO TAKE PART IN THE STUDY?

You are invited to participate in a short survey as a student who has undergone asymptomatic COVID-19 testing as part of the testing programme administered by the University of Edinburgh. We would like your valuable insights to learn more about student understandings of COVID-19 diagnosis and the social significance of testing, to help inform the development of COVID-19 testing strategies at Scottish Universities. There will also be the opportunity to take part in an optional in-depth interview

DO I HAVE TO TAKE PART?

No. After reading and talking about the information provided, you will be able to decide whether you want to take part in this study. If you decide to take part, you will be asked to select a box to provide your consent prior to filling out the anonymous survey form. At the end of the survey form you will be given the option of taking part in a follow-up interview. If you opt to take part in a follow-up interview then you will be asked to enter your name and contact details.

Please note that:

Your decision to take part is entirely voluntary. It is completely up to you to decide whether to take part in the survey and the interview.

You may take part in the survey without any obligation to take part in the interview.

Once a survey form is submitted it will not be possible to withdraw from this part of the study. This is because we will not store any identifiable information (name, contact details) with the survey data and it will not be possible to link individual responses to individuals.

If you choose to take part in the interview then you may withdraw from the interview stage of the study at any point. We will no longer use your interview data after the date of withdrawal and all interview data will be destroyed (interview transcript and audio recording). Please note that any data from your interview that we have published prior to the date that you withdraw from the study will remain in the public domain. You will still not be able to withdraw from the survey once the survey form is submitted.

Deciding not to take part or withdrawing from the study will not affect your healthcare or legal rights in any way.



WHAT WILL HAPPEN IF I TAKE PART?

After you have read through the information and once you feel that you understand what you will have to do, you will be asked to confirm that you give your consent to participate in the study. You will be asked to fill in a short survey about your experience of the asymptomatic Covid-19 testing programme administered by the University of Edinburgh. The survey will ask you to evaluate your overall satisfaction with the testing programme and how well informed and supported you felt throughout the testing process. The survey will take approximately 5-10 minutes.

At the end of the survey, you will be asked whether you are willing to participate in an optional follow-up interview and asked to provide your name and contact address. You will be contacted by email to set up an interview date. We are planning to conduct interviews by telephone or online. This will involve detailed discussion with a member of our research team during a structured interview, where we will ask you about your experiences of the local, national, and international response to the COVID-19 pandemic. We would also like to hear your perspective on testing and testing strategies, including access to testing, your views on different types of diagnostic tests and their results, and what a test result would mean for you and your household. We are also interested to hear what the easing of lockdown restrictions means for you, and how these issues have affected your trust in local and national public health systems, the university and government.

At the beginning of the interview, we will run through the participant information again and ask you to confirm your consent to participate in the study. We will also ask for your permission to audio record the interview. This is for transcription purposes only. The interview will be structured but informal, and you will be encouraged to talk freely about anything you feel is relevant to the questions. There are no right or wrong answers and all your views will be respected. Anything you tell us in this interview will be confidential and not in any way identifiable to you.

The interview will take approximately 60 minutes, and will take place on a date and time of your choosing. If you need to leave and end the interview at any time, please feel free to notify the interviewer and we can arrange to continue with the interview at another time if you wish.

HOW CAN I BE INTERVIEWED UNDER THE CURRENT COVID-19 RESTRICTIONS?

Participating in this study will not require you to leave your home or meet anybody in person.

Owing to the ongoing COVID-19 pandemic and in accordance with the government's containment measures, we will be conducting recruitment and interviews for this study remotely. This can be done by telephone or using a secure online teleconferencing platform, such as Microsoft Teams, according to your preference. We will contact you by your preferred method to arrange a call at a time of your convenience, send confirmation of your appointment time and, if applicable, a secure link to an online teleconference call with our interviewer. At the date and time indicated in your appointment confirmation message, you will need to log into the call



by following the link, or, if you opt to be interviewed by telephone, you will receive a phone call by our interviewer. If you need to cancel or reschedule your interview for any reason, please let us know as soon as possible by replying to the email to arrange a new time.

Your physical and online safety as a study participant is paramount. We are aware of concerns about fraudulent schemes using the COVID-19 pandemic as an opportunity to target vulnerable people online or by telephone. We will never ask you to provide any sensitive information over the telephone or by email, and under absolutely no circumstances will ask you to divulge private or financial details.

WHAT ARE THE POTENTIAL DISADVANTAGES OR RISKS OF TAKING PART IN THIS RESEARCH?

We do not expect that you will experience any harm by taking part in this research. Taking part in the survey will take up to 5-10 minutes of your time but can be completed at a time that suits you. You can also choose to not answer any questions you do not feel comfortable with.

If you consent to take part in the interview, some of the questions asked in the follow-up interview may be sensitive and you may feel uncomfortable discussing them. You can pause or end the interview at any time if you feel uncomfortable. The interviewer will entirely respect your wishes and will not pressure you into continuing the interview or answering any questions you do not wish. The interview will also take around 60 of your time but it will be scheduled for a time that suits you.

WHAT ARE THE POTENTIAL BENEFITS OF PARTICIPATING?

There are no direct benefits but we hope that the information gained from the interviews will improve our understanding of how university testing for COVID-19 can be implemented, how the student experience of testing can be improved, and our understanding of how people in the community think about COVID-19 tests and diagnostics more generally. The findings will be published in working papers and academic publications, with a view to informing and improving policy decisions on COVID-19 testing strategies in Scotland and elsewhere.

WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

A survey form can be cancelled at any point up to its submission and no data will be saved or used. Once a survey form has been submitted it will not be possible to withdraw from this part of the study as your participation is anonymous.



If you agree to take part in the interview and provide your name and contact details then you may choose to withdraw from the interview stage of the study at any point.

To do so, please inform the Principal Investigator, Dr Alice Street (alice.street@ed.ac.uk). You should note that your data may be used in published research outputs (e.g. journal articles, conference papers, theses and reports) prior to your withdrawal and these will remain in the public domain, so you are advised to contact the research team at the earliest opportunity should you wish to withdraw from the study. Once you have notified us that you wish to withdraw from the study we will no longer use your interview data and your interview transcript and audio recording will be destroyed. You will still not be able to withdraw from the survey once the survey form is submitted.

DATA PROTECTION AND CONFIDENTIALITY

Your data will be processed in accordance with Data Protection Law. All information collected about you will be kept strictly confidential. Your data will be referred to by a unique participant number rather than by name. Your data will only be viewed by the research team, but may be shared with research regulators on request for regulation purposes. This will not include any identifiable information about you.

All information collected in this study will be kept on a secure online server in accordance with the EU General Data Protection Regulation (GDPR), along with the UK Data Protection Act. All electronic data will be stored on a password-protected computer file. Your consent information will be kept separately from your survey responses in order to minimise risk.

Your anonymised data will be stored in a public repository. With your consent, this data will be available to other researchers to use in future ethically approved research. For further information about how your data will be stored, managed, used, and protected, please read the 'data protection information' sheet provided by the research team.

If you consent to take part in the follow up interview, the audio recording of your interview will be transcribed by Frances Armstrong of Armstrong Transcriptions, who has signed a privacy agreement with the study investigators. The audio recording from your interview may contain identifiable information, but the audio file name and transcription of the recording will not have your name attached to them. Your name and details will not be recorded in the notes written during the interview, in the transcription of the audio recording, or in reports from the study and your identity will remain private and confidential in all outputs. Reports about this study may quote some of the words you use in the interview, however you will not be identifiable from this information.

The University of Edinburgh is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and



will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The anonymised survey data, the anonymised transcript and the identifiable audio file will be retained on our secure server for a minimum of 5 years after the end of the study.

For general information about how we use your data go to:

<https://www.ed.ac.uk/records-management/privacy-notice-research>

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The results from this study will be published as a research brief in electronic and hardcopy. The research brief will be aimed at an audience of policy makers and public health experts and will feature key recommendations concerning the acceptability and social feasibility of different testing strategies in universities. These outputs will not identify your participation, personal information, or responses in any way.

A peer-reviewed paper will be published in an interdisciplinary academic journal and a series of comment pieces in mainstream and online media will also report and help disseminate the findings of the study and their implications for developing publicly acceptable pandemic response strategies. You will not be identifiable in these or any other output from this study.

HOW WILL I HEAR THE RESULTS OF THE STUDY?

Results and outputs from this study will be shared publicly on the study website <https://blogs.ed.ac.uk/testingtrust>. We expect to publish preliminary results from the survey in January 2020 and full results from the survey and interviews around June 2021.

WHAT IF I HAVE QUESTIONS OR NEED MORE INFORMATION?

Go to our website (<https://blogs.ed.ac.uk/testingtrust>) for further information about this study, funding, or the research team. If you cannot find the answers to your questions there, email our research team (testingtrust@ed.ac.uk) and they will be happy to answer your queries. You will also have the opportunity to ask one of our researchers any questions before your interview.

This study has been reviewed and approved by the University of Edinburgh's School of Social and Political Sciences Ethics Review Committee (REC), which ensures that people who take part in our research studies are protected from unnecessary harm. If you have any questions about your rights as a person taking part in a research study, please contact the Ethics Review Committee at: ethics.hiss@ed.ac.uk.



If you would like to discuss this study with someone independent of the study please contact the School of Social and Political Science Research Office at ssps.research@ed.ac.uk.

If you wish to make a complaint about the study, please contact:

The College of Arts, Humanities, and Social Sciences Research Governance Team (cahss.res.ethics@ed.ac.uk)

WHAT AM I REQUIRED TO DO?

If you would like to participate in this research, please fill out our survey and tick the consent boxes at the end of the form. If you indicate that you are happy to be contacted for a follow-up interview, we will contact you using the contact details you provide on the survey form.