

The Norwich Testing Initiative Privacy Notice

Ethics reference 2019/20-140

This privacy notice applies to all participants who enroll and take part in in the first stage of the Norwich Testing Initiative (referred to here as ‘the study’). It explains how the University of East Anglia (UEA) will process participant personal data during this study. Further information can also be found in the study’s Frequently Asked Questions.

The study will require UEA to collect and use some of your personal data. We (UEA) will process information about you when you register your interest, when you complete the online registration process that will enable you to participate, and when you submit test swabs. This will include sensitive data about you.

UEA is a registered data controller and will collect and process information in accordance with UK data protection legislation.

1. Study Aims

The aim of the study is to test whether a C-19 screening process can be run successfully from the Norwich Research Park, with the long-term objective of being able to provide a large-scale screening facility for the City of Norwich. The study will determine how to optimise the roll-out of testing, based on participant experience and feedback, as well as turnaround times and performance of sampling methods.

2. The information we use, and our reasons for using it

Data	Purpose
Contact details: your full name, email and phone number.	<ul style="list-style-type: none"> • To enable you to register your interest in participating in the project • To enable us to create a secure, unique record for you, linked to a participant ID and barcode in your test kit • To allow you to book testing slots, receive testing instructions and facilitate email reminders • To enable us to link your record to your test results (using the participant ID/barcode only) • To enable you to review your test results • To contact you with results • To contact you for anonymous feedback • Where relevant, to allow us to share positive test results with Public Health England, in line with the statutory duty to report notifiable diseases
Age band, gender, and ethnicity type	<ul style="list-style-type: none"> • To help us understand different groups’ interaction with the screening process
Your genetic data from the swabs and results of the C-19 tests	<ul style="list-style-type: none"> • To test if you have C-19 or not • To allow us to measure the success of the testing process, quality and accuracy of the swab method • Where relevant, to allow us to share positive test results with Public Health England, in line with the statutory duty to report notifiable diseases

3. How we collect and use participant information

Individuals will register on an online portal, providing the personal information described in section 2 to create a record and enable the study to take place. Once registered, participants will collect four barcoded swab testing packs from the locations across the Norwich Research Park and register their assigned set of barcodes against their online record.

Participants will be asked to test themselves twice a week for two weeks by conducting nasal and throat self-swabbing. Samples will be dropped off at the same location on the park by the participant. Samples will be securely delivered to the Earlham Institute (EI) for processing in a secure testing facility.

These samples, and the genetic data they contain, can only be linked to participants through the participant ID/barcode. Because that link only exists in the participant's online record, only UEA will have the ability to identify a participant by their sample.

Test results will be securely transferred from EI to UEA. Using a pseudonymised swab barcode, we will link the result to the participant. We will then provide the participant with their test results.

If a test result is positive, we have a statutory duty to report this to the NHS Track and Trace programme. This is because C-19 is classed as a notifiable disease. This referral will happen after the participant has been informed by UEA of the positive test and fully briefed on what action to take next.

4. Our legal basis for using participant information

Our legal basis for processing participant data is listed in Article 6(1)(e) of the General Data Protection Regulation, as this allows us to process personal data when it is necessary to perform our public tasks as a University.

Where we are obliged to share positive test results with Public Health England, our legal basis will be Article 6(1)(c), as we have a legal obligation to share this information.

All processing of ethnicity, health, and genetic data will be based on the conditions listed in Article 9(2)(i), which relates to public health, and Article 9(2)(j), which relates to archiving, research and statistics purposes. These conditions are linked to Schedule 1(1), paragraphs 3 and 4 of the Data Protection Act 2018, which concern public health and research.

5. Where will the data be stored?

Personal data will only be stored in UEA IT systems, in a secure database. As described in section 3, a pseudonymised swab barcode and genetic sample data will be processed by the Earlham Institute.

6. Who has access to participant information?

Access to the database and participant data (as described in section 2) will be limited to a small number of UEA staff who have developed and will manage the database during the study, and a small administration team will be able to access participants' records. Nobody outside UEA will be able to access the database.

Information from the database will not be shared with any other organisation other than to report C-19 infection to Public Health England in line with statutory responsibilities described in section 3.

Earlham Institute will act as a data processor on behalf of UEA. They will process only pseudonymised participant data as described in section 3. They will not be able to link those data to any individual, nor access UEA's database. Earlham Institute's privacy statement can be found [here](#).

7. How long we retain participant information

Personal data will be retained for two weeks following the end of the swab testing period. We will then securely destroy any personal identifiers (that is, the contact details listed in section 2) from the database, to ensure any records are fully anonymised.

The resulting fully anonymised dataset will be retained for five years following the end of the project. Any data processed by Earlham Institute will also be retained for five years.

8. Your rights and further information

If you have any questions about the study, contact Mark Hitchcock at ueahscp@uea.ac.uk.

General information on your rights, and who to contact if you have any concerns about the handling of your personal data can be accessed [here](#).

9. Changes to this privacy notice

This privacy notice was produced in July 2020 to cover the C-19 testing study. It is not expected that it will need revision as all data will be deleted shortly after the study completes. However, if any changes are required, we will update all participants registered for the study via email.