University of Hertfordshire – Privacy Notice Wrapped Project

This privacy notice explains how the University of Hertfordshire Higher Education Corporation (the **University**) processes your personal data in relation to its study entitled "Wrapped" (the **Wrapped Project**), which aims to increase condom use amongst young people aged 16-24 who are accessing STI self-sampling services online.

The University is the Data Controller in respect of your personal information collected and is subject to the Data Protection Act 2018 (the **DPA**) and the General Data Protection Regulation (the **GDPR**). The University is also a Joint Controller with Preventx Limited for the purposes of some of your personal information as set out below.

This privacy notice also outlines your rights in relation to the personal data we hold. Our full Data Protection and Privacy Policy is available at:

https://www.herts.ac.uk/ data/assets/pdf file/0017/233090/IM08-Data-Protection.pdf

Why are you collecting my personal data?

The Wrapped Project aims to increase condom use amongst young people (16-24 years) who are accessing STI self-sampling services online. Your data is being collected and used for the purpose of assessing whether and how it is possible to run a full trial of the Wrapped Project.

What personal data are you collecting?

In order to carry out the above project we need to collect some personal data from you, including sensitive personal information which is classed as special category data. Personal data is information which individually or in combination, allows a person to be identified. Special category data is information which may be considered sensitive, such as information relating to your health.

The personal/special category data being collected at each stage of this project is as follows:

Consent to involvement in study (data collected at the start of the study when you are agreeing to statements about what the study involves)

- Name,
- Participant unique study ID

Initial Survey Data

- Demographic data (sexual identity, postcode, gender, age, ethnicity)
- Contact information (email address, mobile phone number, postal address)
- Participant unique study ID
- Safeguarding concerns (where applicable)

Initial freetest.me test result

Self-reported chlamydia test result at baseline (0M), Participant unique study ID

Participant Website use data (Matomo)

• Internet Protocol (IP) address (restricted to 2 bytes e.g. 192.168.xxx.xxx),

Participant unique study ID

Chlamydia test results (3M and 12M)

- Name.
- Kit code,
- Test result (provided to the University by freetest.me operated by Preventx Limited)

Where will you collect my information from?

All of the personal data as set out in the section above, aside from your chlamydia test results at 3 months and 12 months will be information that you have provided directly to us,. In the case of the two sets of test results, we will be sent this information from Preventx Limited¹ who operate freetest.me and to whom you will return your completed tests.

We have a data sharing agreement in place with Preventx Limited to make sure that the test result information is shared in a safe and secure way. The University is a Joint Controller with Preventx Limited in relation to the two sets of test results. This Joint Controller relationship is solely for the purposes of passing to you the details of your chlamydia test results and passing those results to the relevant NHS Trust as set out below. For all other purposes in connection with the Wrapped Project, the University is the sole Data Controller of your personal information.

Preventx Limited are data controller for the data they collect and process through freetest.me as part of the testing process. Preventx Limited has a separate Privacy Notice which can be found here: privacy policy

What is the legal basis for processing my personal data?

Data protection legislation requires us to have a valid legal reason to process and use personal data about you. This is often called the 'legal basis' for processing.

In the context of research undertaken under the Wrapped Project, the legal basis for processing is as follows:

- a) processing your personal data is necessary for the performance of a task carried out in the public interest (Article 6(1)(e) of the GDPR); and
- b) processing special categories of your personal data (which is personal data about your health, ethnicity, sexual orientation, etc.) is necessary for scientific research purposes or statistical purposes (Article 9(2)(j) of the GDPR) and is carried out in accordance with the GDPR and DPA and is in the substantial public interest (Section 10 of the DPA and Schedule 1(1)(para 4)).

Details of participants who have received a positive chlamydia test result, and anyone under the age of 18 who has revealed information during the Wrapped Project which indicates that they may be at risk of significant harm will be shared with the relevant NHS Trust in line with existing sharing protocols that govern this data (see 'If you are sharing my data, who are you sharing it with' below).

¹ Preventx Limited is a company incorporated and registered in England and Wales with company number 6603066 whose registered office is at MBP 5 Meadowhall Business Park, Carbrook Hall Road, Sheffield South Yorkshire, England, S9 2EQ.

The legal basis for processing special category personal data on positive chlamydia test results and passing it to the relevant NHS Trust is that:

- a) it is necessary for the purposes of providing health treatment (Article 9(2)(h) of the GDPR); and
- b) it is necessary for health or social care purposes, in this case treatment (Section 10 of the DPA and Schedule 1(1)(para 2)).

The legal basis for processing special category personal data which indicates that a person aged under 18 may be at risk of significant harm, and passing that to the relevant NHS Trust is that:

- a) it is necessary for reasons of substantial public interest to safeguard the fundamental rights of the data subject (Article 9(2)(i) of the GDPR); and
- b) the processing is necessary for reasons of substantial public interest and it is necessary for the purpose of protecting an individual who is under the age of 18 from physical, mental or emotional harm and protecting their wellbeing and we cannot reasonably be expected to obtain the individual's consent (Section 10 of the DPA and Schedule 1(2)(para 18)).

If you are sharing my data with others, who are you sharing it with?

Your personal data will only be accessed by the University's Wrapped Project research team and by nominated non-University individuals who are specifically working on the Wrapped Project who will be given access to the information in University systems as appropriate.

We will share positive chlamydia test results data with the relevant NHS Trust in line with the existing processes and sharing protocols that govern this data.

We will also share with the relevant NHS Trust your details if you are under the age of 18 and have revealed information during the Wrapped Project which indicates that you may be at risk of significant harm. Data sharing agreements between us (the University) and each NHS trust are in place to ensure that your data is treated with the utmost care and security.

In order to operate the Wrapped Project and provide products and services in connection with it, we use Twilio (an American cloud communications platform), RedCap (a secure web application for building and managing online surveys and databases) and Matomo (analytics software) to carry out tasks on our behalf. These third parties are known as data processors and when we use them we have contractual terms, policies and procedures to ensure confidentiality is respected. The University remains responsible for your personal information as the Data Controller.

In using Twilio we will be processing data within the USA. We have put measures in place to minimise the amount and sensitivity of the data transferred. The data will be held on Twilio's system for only a short period of time.

How long will you retain my personal data?

Personal data collected as part of this project will only be held by the University for as long as is necessary to allow for collection and analysis of the data to take place. Data will be deleted, or anonymised at the earliest opportunity so it is no longer attributed to you.

Data collected by Preventx Limited through freetest.me as part of the testing process will be held for different timescales. Further information can be found in the freetest.me <u>privacy</u> policy.

Data collected by NHS will also be subject to separate retention times. More information on how the NHS process your data can be found here - https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information

What are my rights and how can I enforce them?

You have certain rights under data protection laws which allow you to say how you wish you data to be processed. There are exemptions from some of these rights where personal data is used for the purposes of research. Further detail on your rights can be found here: https://www.herts.ac.uk/ data/assets/pdf_file/0016/233620/IM08-apxII-Data-Subjects-Rights.pdf

In the first instance, please contact the University's Data Protection Officer: dataprotection@herts.ac.uk if you would like to discuss any aspect of your rights in relation to your personal data, including your rights in relation to the jointly controlled data with Preventx as described in the section 'Where will you collect my data from'

How can I raise concerns about the processing of my personal data?

If you have any feedback or concerns in relation to the processing of your personal data by the University please contact the University's Data Protection Officer: dataprotection@herts.ac.uk.

If you have any feedback or concerns in relation to the processing of your personal data by Preventx Limited, please contact dpo@preventx.com

External advice is available from the Information Commissioner who can be contacted via: Post: Information Commissioners Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK95AF. Tel: 0303 123 1113. Website: http://www.ico.org.uk

You also have the right to raise a complaint with the Information Commissioner who can be contacted using the details above.