

# LIMIT serology study

# Privacy notice

24 May 2023

#### **About UKHSA**

On 1 October 2021, the UK Health Security Agency (UKHSA) came into being. An executive agency of the Department of Health and Social Care (DHSC), UKHSA combines many of the health protection activities previously undertaken by Public Health England (PHE), together with all of the activities of the NHS Test and Trace Programme and the Joint Biosecurity Centre (JBC).

The processing activities previously undertaken by these organisations and their associated data processors have not changed with the establishment of UKHSA. Individual rights are not affected by this change.

We are responsible for planning, preventing and responding to external health threats, and providing intellectual, scientific and operational leadership at national and local level, as well as internationally. UKHSA will ensure the nation can respond quickly and at greater scale to deal with pandemics and future threats.

We collect and use personal information to fulfil our remit from the government.

Our main purposes for processing personal information are to:

- analyse use world-class science and data analytics to assess and continually monitor threats to health, identifying how best to control and mitigate the risks
- respond take rapid, collaborative and effective actions nationally and locally to mitigate threats to health when they materialise

The LIMIT Study is looking at antibody responses in people who have had mpox infection or vaccination. The study will compare the time of infection / vaccination with longitudinal antibody response to see if antibody levels wane over time, and to see what other factors (such as other health conditions) may influence antibody response.

DHSC is the data controller for the personal information which will be collected, stored and used for the study. The work will be done by staff at the UKHSA Rare and Imported Pathogens Laboratory and EPS Emerging Pathogens Serology Laboratory.

This privacy notice explains the personal information we collect, how we use it and who we may share it with for these purposes. It explains what your rights are if we hold your personal information and how you can find out more or raise a concern.

#### The information we collect

The types of personal information we will collect as part of the study include:

- demographic information, for example, your age bracket, gender and sex this will help us understand if age or sex can alter your antibody production
- your name or alias for consent
- your address and postcode so we can send you testing kits
- your email address so we can send you your questionnaire
- your telephone number so we can contact you with results
- health information for example, your physical health, as we want to know if this
  affects your antibody response, infection type and severity of symptoms
- treatment information for example, we will ask you about your laboratory test results, prescriptions and vaccination history

## How we collect your information

We collect all personal information directly from you.

#### Directly from you

We will ask you to complete a health questionnaire to collect your demographic information, and information about infectious disease symptoms.

The information will be pseudo-anonymised for storage and analysis, but we will need to collect and use identifiable data (your address, email address and phone number) in order to send you your consent form, the postal kits, and your results if you opt in to receive them.

## The purposes we use your information for

#### Analysing threats to public health

To identify trends and monitor the sources and epidemiology of mpox. For example, we link your laboratory test results to information from your survey to understand your antibody response, in order to help understand how best to prevent mpox infection in the future.

## How we protect your information

We have put in place a range of organisational processes and technical security measures to protect your personal information from loss, misuse and unauthorised access, disclosure, alteration and accidental destruction.

Your information is stored on computer systems that are kept up-to-date and regularly tested to make sure they are secure and protected from viruses and hacking. Our information technology systems use robust security protections.

Your personal information can only be seen by study staff who have been trained to protect your confidentiality and in understanding laws and regulations such as the Data Protection Act 2018 and the UK General Data Protection Regulation (GDPR).

Strict controls are in place to make sure they can only see your information if they need it for the study, and they are only provided with access to the minimum necessary information. We will not share your personal data with other organisations.

Whenever possible, we only use your information in a form that does not directly identify you. For example, we use pseudonyms (a non-identifying phrase or number that replaces your personal information) and substitute your date of birth with age in years to help protect your confidentiality. For this study, we will need to use identifiable data in order to send you your consent, sampling kits and results should you want them. For all other parts of the study, your data will be pseudo-anonymised.

No information that could identify you will ever be published by us.

## Where we store your information

We store your personal information in the UK.

### How long we keep your information

We will only keep your personal information for as long as we need it to protect public health or as otherwise required by law.

Most of the time, we will keep your information in accordance with the time periods specified in the <u>Records Management Code of Practice for Health and Social Care 2021</u>. For studies such as this, the standard retention period is 5 years.

As one of our purposes for collecting personal information is to recognise trends and monitor the impact of diseases and conditions that have a long natural history, we may need to keep your information for longer.

# Your rights over your information

Under data protection law, you have several rights over your personal information. You have the right to:

- ask for a copy of any information we hold about you
- ask for any information we hold about you to be changed if it is inaccurate
- ask us to consider restricting our use of your information, although this is not an absolute right and we may need to continue to use your information in the interests of public health – we will tell you why if this is the case
- object to us using any information we hold about you, although this is not an absolute right and we may need to continue to use your information – we will tell you why if this is the case
- delete any information we hold about you, although this is not an absolute right and we may need to continue to use your information – we will tell you why if this is the case
- ask us, in appropriate circumstances, to transfer your personal information to a recognised health authority in another country
- ask us, in appropriate circumstances, to transfer your personal information to a recognised health authority both in the UK and in other countries, but also to you or your private health provider in a machine-readable format

You can exercise any of your rights by contacting us at <a href="mailto:lnformationRights@UKHSA.gov.uk">lnformationRights@UKHSA.gov.uk</a> or by calling us on 020 7654 8000.

You will be asked to provide proof of your identity so that we can be sure we only provide you with your personal information.

You will not be asked to pay a charge for exercising your rights. If you make a request, we will respond to you within one month.

### Our legal basis to use your information

Our legal basis to collect, use and share your personal information may vary according to the purpose we use it for.

We process both personal information and special categories of personal information, including data about health. In most cases where we process your personal data to fulfil our remit, the sections of the UK GDPR and the Data Protection Act 2018 that apply will be:

- UK GDPR Article 6(1)(e) 'processing is necessary for the performance of a task carried out in the public interest'
- UK GDPR Article 9(2)(i) 'processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health'
- UK GDPR Article 9(2)(h) 'processing is necessary for the provision of health or social care or treatment or the management of health or social care systems and services'
- Data Protection Act Schedule 1 Part 1(3) 'public health'
- Data Protection Act Schedule 1 Part 1(2) 'health or social care purposes'

#### How to find out more or raise a concern

If you have any concerns about how we use and protect your personal information, you can contact the Department of Health and Social Care's Data Protection Officer at data protection@dhsc.gov.uk or by writing to:

Office of the Data Protection Officer
Department of Health and Social Care
1st Floor North
39 Victoria Street
London SW1H 0EU

You also have the right to contact the Information Commissioner's Office if you have any concerns about how we use and protect your personal information. You can do so by calling

the ICO's helpline on 0303 123 1113, visiting the ICO's website at <a href="www.ico.org.uk">www.ico.org.uk</a> or writing to the ICO at:

Customer Contact Information Commissioner's Office Wycliffe House Water Lane Wilmslow SK9 5AF

# **About this privacy information**

The personal information we collect and use may change so we may need to revise this notice. If we do, the publication date provided at this top of this notice will change.

For more information, please visit **UKHSA** privacy notice.