

## **REACT-GE Privacy Policy v1.1      IRAS Number 291775**

### **Imperial College London and Genomics England Study and your personal data: REal-time Assessment of Community Transmission (REACT) - Genomics England (GE) (REACT- GE): Multi-omics to identify biological pathways underlying severity of SARS-CoV-2 infection**

Imperial College London and Genomics England are collaborating to carry out this study.

Imperial College London and Genomics England are inviting you to take part in this research funded by UK Research and Innovation to help improve understanding of the biological pathways that underpin susceptibility to and severity from COVID-19 which may lead to new treatments and vaccines against COVID-19.

This Privacy Notice explains who we are, the personal data we collect, how we use them, who we share them with, and what your legal rights are.

- Imperial College London is a leading university closely involved in the COVID-19 response. You can find out more about Imperial College London at <https://www.imperial.ac.uk/medicine/research-and-impact/groups/react-study/>
- Genomics England sequences and analyses DNA for the NHS and is the guardian of the National Genomics Research Library. This contains the health data and genetic sequences of tens of thousands of NHS patients. They allow researchers to use their data to make discoveries and help develop new treatments. You can find out more about Genomics England at <https://www.genomicsengland.co.uk>

#### **How did you get my contact details?**

- Your details were provided to us by the Imperial College London REACT Programme as a participant in that study who has tested positive for COVID-19 and has given permission to be contacted in the future for further research
- Imperial College London and Genomics England will keep your data confidential and for this study will only use your contact details to send you this survey invitation and any reminders or results. If you agree to take part in the survey, we will then send you further information on how to take part in the study.
- If you take part in the study, your data will be shared with the research team at Imperial College London who will keep your data confidential and will be doing the analysis of the data with Genomics England.
- Once the study is finished Imperial College London will keep your data for up to 20 years.

#### **What is our legal basis for processing your personal data?**

- Imperial College London and Genomics England are the data controllers for the processing of personal data for this study. This means that they are responsible for ensuring that the processing complies with the General Data Protection Regulation (GDPR) and related legislation.
- The lawful basis for processing data in this research is Article 6(1) (e) - “processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller and Article 9(2) (j) ‘processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes’. This means that Imperial College London and Genomics England

can use the personal data they hold about you for research with appropriate safeguards in place. Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the UK Policy Framework for Health and Social Care Research.

- You can access Genomic England's Privacy Notice at: [covid.genomicc.org/privacy-policy](https://covid.genomicc.org/privacy-policy)

### **Do I have to take part?**

- Taking part is entirely voluntary. Registering to take part, attending the assessment centre to provide blood and urine samples and for measurements to be taken, and any answers you give to the online questionnaires, are given with your consent.
- The questionnaires will include questions about you, your lifestyle and your health.

### **Are national data opt-outs applied to this survey?**

- No. Imperial College London requests your consent to link the study data to other health information that the NHS holds about you. Since we would only do this with your consent the national data opt-out would not apply.

### **Have you got access to my health data?**

- Imperial College London has been given your name, address, email, phone number, date of birth, gender, and information which you provided to REACT in the survey.
- Your contact details are used to contact you regarding the study.
- Information about date of birth and gender will be used to make sure that the pseudonymised survey data matches the required study profile of the population as closely as possible.
- We will ask your consent for Imperial College London to link data held by NHS Digital and other NHS bodies to your survey data. You can withdraw this consent at any point.

### **What will I be asked to do?**

- We are initially asking you to register your interest in attending the assessment centre to provide blood and urine samples and for measurements to be taken, and to answer the online questionnaires.
- If you agree to take part, we will contact you by telephone or SMS to make an appointment for you to attend your most convenient centre.
- Prior to your appointment we would also like you to answer some questions online about you, your lifestyle and your health. After your appointment you may be asked to complete another questionnaire about your diet.

### **How will Imperial College London and Genomics England use any personal data including questionnaire responses you provide?**

- Imperial College London and Genomics England will keep your personal data and responses in strict confidence in accordance with this Privacy Policy.
- Your name and address and contact details will be kept separate from your data and answers and will only be shared with the research team at Imperial College London and Genomics England.
- If you consent, Imperial College London and Genomics England may use your personal data to contact you about participating in future research.
- Contact information may also be obtained through data linkage, but only if you consent to both data linkage and for Imperial College London or Genomics England to contact you about further research.

- No identifiable data will be shared outside the two research teams (unless you agree to data linkage in order that we can make that linkage), and it will not be possible to identify you in any published results.

#### **Who is your personal data is shared with?**

- Imperial College London and Genomics England are working with a number of supplier organisations to assist us in running this COVID-19 research. We only permit third parties to process your personal data for specified purposes and in accordance with our policies. They are required to delete all participant information after use for the approved purpose.

#### **How will Imperial College London and Genomics England ensure my personal information is secure?**

- Imperial College London and Genomics England take their information security responsibilities seriously and apply various precautions to ensure your information is protected from loss, theft or misuse. Security precautions include appropriate physical security of offices and controlled and limited access to computer systems.
- Imperial College London has regular internal and external audits of their information security controls and working practices and is accredited to the International Standard for Information Security, ISO 27001.

#### **Does this survey use Cookies or similar code?**

- Some online surveys collect information through the use of 'cookies'. These are small files stored on your computer. These files are used as sparingly as possible and only for quality control, validation and, more importantly, to prevent us sending you reminders for an online survey you have already completed. It is possible for you to delete 'cookies' or to prevent their use by adjusting the browser settings on your computer.
- We also automatically capture information about your operating system, display settings and browser type in order to ensure that the survey questionnaire is delivered in a form suited to the software your computer is using. We do not capture any other information from your computer.

#### **How long will Supplier Organisations retain my personal data and identifiable responses?**

- Supplier organisations will only retain your data in a way that can identify you for as long as is necessary to carry out their role in the research project and findings. In practice, this means that once we have satisfactorily obtained the research data, they will securely remove your personal, identifying data from their systems.

#### **How long will Imperial College London and Genomics England retain my personal data and identifiable responses?**

- Imperial College London and Genomics England will only retain your data in a way that can identify you for as long as is necessary to support the research project and findings.
- If you consent to Imperial College London and Genomics England contacting you about future research, your data may be held for up to 20 years.
- If you consent to data linkage, Imperial College London may link the results to other health information that the NHS holds about you. This linkage would be done by the NHS. If you consent to data linkage retention may be up to 20 years.
- Researchers (under the supervision of Imperial College London and Genomics England) who wish to access the data from this study and/or to contact participants about future research will have to apply to a data access committee composed of at least 3 of the study investigators and at least one public representative.

### **Has the survey received ethical approval?**

- This study has received formal ethical approval from South Central - Berkshire B Research Ethics Committee.

### **Your rights and the General Data Protection Regulation (GDPR)**

- Once you have submitted your response to the study your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
- You have the right to request access to your personal data within the period Imperial College London and Genomics England holds it.
- If you want to exercise your rights, please contact us as below for Imperial College London or Genomics England.
- We must generally respond to requests in relation to your rights within one month, although there are some exceptions to this.
- You have the right to lodge a complaint with the Information Commissioner's Office (ICO) or another data protection regulator, if you have concerns on how we have processed your personal data. You can find details about how to contact the Information Commissioner's Office at <https://ico.org.uk/global/contact-us/> or by sending an email to: [casework@ico.org.uk](mailto:casework@ico.org.uk).
- The ICO does recommend that you seek to resolve matters with the data controller first before involving the regulator. Please see their contact details below.

### **Where will my personal data be held and processed?**

- All of your personal data used and collected for this survey will be stored at Imperial College London and Genomics England in data centres and servers within the United Kingdom and EEA.

### **How can I contact Imperial College London and Genomics England about this survey and/or my personal data?**

- If you have any questions about the research, please contact our service desk on 0808 2819 535 or email us at [ge-servicedesk@genomicsengland.co.uk](mailto:ge-servicedesk@genomicsengland.co.uk)

If you wish to raise a complaint on how we have handled your personal data, please contact:

#### **Genomics England: 0808 2819 535**

**Email:** [dataprotection@genomicsengland.co.uk](mailto:dataprotection@genomicsengland.co.uk)

**Post:** REACT-GE

Data Protection Officer,  
Genomics England  
Dawson Hall  
Charterhouse Square  
London  
EC1M 6BQ

#### **Imperial College London:**

**Email:** Data Protection Officer at: [dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk)

**Post:** REACT-GE

Data Protection Officer  
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Exhibition Road  
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London SW7 2BU