

## **Transparency Notice**

#### **SUMMARY INFORMATION SHEET**

In this research study we will use information from you/your child. We will only use information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study. Only the Principal Investigator will have access to this information. Imperial College researchers will not have access to your child's or your name or contact details, just a code number.

Everyone involved in this study will keep the data collated as part of this study, including your personal data, safe and secure. We will also follow all privacy laws and legislation that are relevant to the specifics of the study.

At the end of the study we will save some of the data in case we need to check it and/or for future research.

We will make sure no-one can work out who you are from the reports we write. The following information pack tells you more about this.

How will we use Information about you?

Research Study Title: Schools Transmission Study (Strep A/Scarlet Fever and COVID-19 arms)

**IRAS ID 225006** 

Imperial College London is the sponsor for this study and will act as the Joint Data Controller with the UK Health Security Agency (UKHSA). This means that we are responsible for looking after your information and using it appropriately. We will keep your personal data for:

- Ten years after the study has finished in relation to data subject consent forms.
- Ten years after the study has completed in relation to primary research data.

The study is expected to finish in 03/2029

For more information / confirmation regarding the end date please contact the study team, see 'WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED' for contact information.

We will need to use information (including personal data and data created as part of the study) from you/your child for this research project.

This information will include

- you/your child's name and age
- your contact details; phone or email and home address

People within the study team (see section 'Sharing your information with others') will use this information to do the research or to check your records (see information to be collected) to make sure that the research is being done properly and the information held (such as contact details) is accurate.

People who do not need to know who you are, will not be able to see your name or contact details. Your data will have a code number instead.

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We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

### **LEGAL BASIS**

This project will use personal data to conduct research to improve health, care and services. As a publicly-funded 2rganization, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. Our legal basis for using your information under the General Data Protection Regulation (GDPR) and the Data Protection Act 2018, is as follows:

• "performance of a task carried out in the public interest"; 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 <a href="UK Policy Framework for Health and Social Care Research">UK Policy Framework for Health and Social Care Research</a>

Where special category personal information is involved (most commonly health data, biometric data and genetic data, racial and ethnic data etc.), Imperial College and UKHSA rely on "scientific or historical research purposes or statistical purposes

Imperial College researchers will only have access to data that does <u>not</u> have your name or personal details.

## **INTERNATIONAL TRANSFERS**

There may be a requirement to transfer information to countries outside the United Kingdom (for example, to a research partner, either within the European Economic Area (EEA) or to other countries outside the EEA. Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a UK adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient research partner that incorporates UK approved standard contractual clauses or utilise another transfer mechanism that safeguards how your personal data is processed.

### **SHARING YOUR INFORMATION WITH OTHERS**

We will only share your encoded personal data with certain third parties for the purposes referred to in this participant information sheet and by relying on the legal basis for processing your data as set out above.

Other Imperial College London employees (including staff involved directly with the
research study or as part of certain secondary activities which may include support
functions, internal audits, ensuring accuracy of contact details etc.), Imperial College
London agents, contractors and service providers (for example, suppliers of printing
and mailing services, email communication services or web services, or suppliers who

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help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

• The Imperial College Healthcare Trust Molecular Diagnostics Unit (<u>coronavirus testing</u> only)

## POTENTIAL USE OF STUDY DATA FOR FUTURE RESEARCH

When you agree to take part in a research study, the information collected either as part of the study or in preparation for the study may, if you consent, be provided to researchers running other research studies at Imperial College London and in other organisations which may be universities or organisations involved in research in this country or abroad. Your information will only be used to conduct research in accordance with legislation including the GDPR and the UK Policy Framework for Health and Social Care Research.

This information will not identify you and will not be combined with other information in a way that could identify you, used against you or used to make decisions about you.

### WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have because some research using your data may have already taken place and this cannot be undone.

We need to manage your records in specific ways for the research to be reliable. This
means that we may not be able to let you see or change the data we hold about you if
this could affect the wider study or the accuracy of data collected.

### WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED

You can find out more about how we use your information:

- by asking one of the research team
- by sending an email to <a href="mailto:ispy.project.support@imperial.ac.uk">ispy.project.support@imperial.ac.uk</a>
- by ringing us on 07597 510347

### **COMPLAINT**

If you wish to raise a complaint about how we have handled your personal data, please contact the research team first by sending an email to <a href="mailto:ispy.project.support@imperial.ac.uk">ispy.project.support@imperial.ac.uk</a>, or by ringing us on 07597 510347.

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at <a href="mailto:dpo@imperial.ac.uk">dpo@imperial.ac.uk</a>, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.



If you remain unsatisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO)-via <a href="www.ico.org.uk">www.ico.org.uk</a>. Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.