

# REACT-CYP

REAL-TIME ASSESSMENT OF  
COMMUNITY TRANSMISSION - CHILDREN  
AND YOUNG PEOPLE

## JUMP TO SECTION



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# INFORMATION FOR PARTICIPANTS

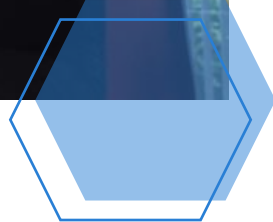
## TAKING PART IN THE CHILDREN AND YOUNG PEOPLE STUDY

You are being invited to take part in a research study. Whether you take part in the study is entirely up to you. Before you decide, it is important for you to understand why the research is being done and what you will need to do.

**Taking part is your decision but we would like you to read this leaflet with a parent or guardian so you can ask them any questions you want.**

\*If you are reading this information as a parent or guardian of a study participant, please note that **the study participants are children and young people aged 5 to 17 years**. Throughout this information sheet “you” refers to the participant which, if you are a parent or guardian, refers to your child.

\*For children aged 5-11 years and for those towards the lower end of the 12 to 17 age band we provide an accompanying simplified information sheet which a parent/guardian may wish to use to help explain the study to them.



# YOUR ROLE

## HOW DO I TAKE PART?

To take part in the study you need to follow the instructions in the study invite email or letter. You will be taken to an online survey that will take around 15 minutes to complete. You will be asked questions about your health, whether you have had COVID-19, any recent symptoms you have experienced and what impacts your health has had on your life since the start of the pandemic. After the survey you will also be asked if you would like to do an online test of your cognitive function, in simple terms a test of your thinking, memory, judgment, and your ability to problem solve and learn new things.

## WHY HAVE I BEEN INVITED TO TAKE PART?

You have been invited to take part in this study because you took part in the REACT-1 antigen (nose and throat swab) testing study and consented to be invited to take part in further research studies.

If you agree to take part in this REACT-Children and Young People (REACT-CYP) study then we will link data that we hold about you from the REACT study to this new study. This will include your NHS number and the information you answered in the questionnaire.

Participation from a range of children and young people who have had COVID-19 is extremely important for helping us understand the impact of the pandemic.

## HOW WILL THIS RESEARCH HELP OTHERS?

We want to understand the psychological and social impacts the pandemic has had on children and young people and how this differs between those who have had persistent symptoms due to COVID-19 and those that haven't. By helping us understand who is affected your participation will help us learn how to target possible interventions and treatments.

## WHAT DOES THE SURVEY INVOLVE?

The survey will contain a mix of multiple-choice and free text questions that will cover:

- About you (e.g. age, gender)
- Your current health status
- Any recent symptoms, illnesses or COVID-19 tests
- Impacts of your health and wellbeing on your day to day life (e.g. home, school or hobbies)
- Underlying health conditions
- Plus, further questions for people who have had COVID-19 and/or Long COVID exploring any symptoms related to COVID-19 and experiences of any care or support received.

At the end of the survey, you will be asked if you would also like to be considered for an online cognitive assessment to better understand how your cognitive function (the way your brain works, for example your memory or problem-solving ability) has been affected by the pandemic.

The assessment will take around 15 minutes to complete. This online 'test' will be made up of different games to test your brain. When you are finished you will be given your results to see how you did.

You may also be invited to complete a follow-up survey(s) from 6 to 24 months later.

# OUR ROLE

## WHO IS CARRYING OUT THIS RESEARCH?

This research is being run by doctors and researchers from Imperial College London. This research is funded by the National Institute for Health Research (NIHR) Biomedical Research Centre at Imperial College London.

## WHAT IS THE PURPOSE OF THE STUDY?

REACT-Children and Young People (REACT-CYP) is an extension study to the REal-time Assessment of Community Transmission (REACT) study which you took part in already.

The psychological and social impacts of ongoing symptoms following a Covid-19 infection, and the effects of the pandemic, could have a big impact on how children grow up, both physically and mentally. The main aim of this extension study is to explore the mental health and wellbeing journey alongside physical symptoms in children and young people who have had Covid-19. We are also interested in any changes in cognitive function (how your brain works) post-COVID-19 infection.

REACT-CYP will also explore the role that children and young people's health, social setting and demographics (things like sex and age) play in the development and duration of Long COVID. Such insight could improve patient care and support the development of better treatments.

## WHO HAS REVIEWED THE STUDY?

To protect your interests, all research at Imperial College London is reviewed by an independent group of people called a Research Ethics Committee. This study has been reviewed and granted approval by the South Central Berkshire B Research Ethics Committee.



**Imperial College  
London**

**NIHR | Imperial Biomedical  
Research Centre**

## WHAT WILL HAPPEN TO THE RESULTS OF THIS RESEARCH STUDY?

The results of this study will be shared in many different ways, such as being published in medical journals, presented at meetings of scientists and reported to both Imperial College London and the Health Research Authority who oversee and review how research takes place in England. No personally identifiable information about you (i.e your name, where you live or your date of birth) will be made available outside of the study team.

## CONTACT DETAILS

If you have any questions not covered here, you can contact a member of the imperial study team at: [react.lc.study@imperial.ac.uk](mailto:react.lc.study@imperial.ac.uk)



# YOUR DATA

## WHAT WILL YOU DO WITH MY DATA?

In this research study we will use information from you and your medical and educational records held by NHS Digital and UK Department for Education, respectively. 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. These will include Imperial research Team members and support staff.

Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

Your survey data will be held on secure servers at Ipsos and Imperial College London and given a unique study code so that your identity remains confidential.

Investigators will use your data to monitor the long term health and education status of participants from this study. Unless they really need to know who you are, they will not be able to see your name or contact details. Your data will have a code number instead. The number of people who access this information will be kept to a minimum.

We will keep all information about you safe and secure.

Imperial College and other research institutions both academic and commercial may continue to carry out research using the de-identified data collected during the study. The results of any research that is published, whether by Imperial College or anyone else, will never identify you. See 'Do you share my information with others' to learn more. From time to time we will inform you of other research studies that you might be interested in participating in. Even if you receive invites to future studies, there is no obligation to take part.

The information you share with us as part of this study will **only be used for the purpose of research or to contact you about future opportunities to participate in research**. It will not be used to make decisions about future services available to you, such as insurance.

## HOW WILL YOU PROTECT MY PRIVACY?

Your name, address, email will be kept separate from your study data and only linkable by your unique study code. This is in case the Imperial College study team need to contact you about research that your data has been used in. Your contact details will never be passed to another organisation without your permission and will not be visible to the investigators performing the analysis. The results of

any research that is published, whether by Imperial College or anyone else, will never identify you. See p6 'Do you share my information with others' to learn more.

From time to time we will inform you of other research studies that you might be interested in participating in. Even if you receive invites to future studies, there is no obligation to take part. And if you do agree to take part, you can drop out at any time.

### HOW WILL WE USE INFORMATION ABOUT YOU?

Research Study Title: REACT-Children and Young People (CYP) Study: Characterise and quantify the impact of SARS-CoV-2 infection on education and health outcomes, cognitive function and health-related quality of life in children and young people

IRAS ID: 314392

Imperial College London is the sponsor for this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it appropriately. Imperial College London will keep your personal data for:

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

The study is stated to finish in April 2025.

We will need to use information from you and from your medical and educational records held by NHS Digital and UK Department for Education respectively, for this research project. This information will include your:

- NHS number
- Name
- Contact details (email address, home address, phone number)

People within the College and study team (see section sharing your information with others) will use this information to do the research or to check your records to make sure that 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.

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.

As a university we use personally-identifiable information to conduct research to improve health, care and services. As a publicly-funded organisation, 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:

- Imperial College London - "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 UK Policy Framework for Health and Social Care Research.

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

### 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 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 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.

### 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 (such as contact details) 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.

### COMMERCIALISATION

Data from the study may also be provided to organisations not named in this participant information sheet, e.g. commercial organisations or non-commercial organisations for the purposes of undertaking the current study, future research studies or commercial purposes such as development by a company of a new test, product or treatment. We will ensure your name and any identifying details will NOT be given to these third parties, instead you will be identified by a unique study number with any data analysis having the potential to generate 'personal data'.

Aggregated (combined) or anonymised data sets (all identifying information is removed) may also be created using your data (in a way which does not identify you individually) and be used for such research or commercial purposes where the purposes align to relevant legislation (including the GDPR) and wider aims of the study. Your data will not be shared with a commercial organisation for marketing purposes.

### 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.

If you choose to stop taking part in the study, we would like to continue collecting information about your health and education from central NHS and Department for Education records. If you do not want this to happen, tell us and we will stop. This will not affect any healthcare or support you may be receiving separately.

We need to manage your records in specific ways for the research to be reliable. This means that we won't 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.

If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

### WHERE CAN I FIND OUT MORE ABOUT HOW MY INFORMATION IS USED?

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)

- by sending an email the research team: [react.lc.study@imperial.ac.uk](mailto:react.lc.study@imperial.ac.uk)

## COMPLAINT

If you wish to raise a complaint on how we have handled your personal data, please contact the research team first by sending an email:

- The REACT-CYP Study Team on [react.lc.study@imperial.ac.uk](mailto:react.lc.study@imperial.ac.uk)

Following our response, if you are not satisfied please contact Imperial College London's Data Protection Officer via email at [dpo@imperial.ac.uk](mailto:dpo@imperial.ac.uk), 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 [www.ico.org.uk](http://www.ico.org.uk). Please note the ICO does recommend that you seek to resolve matters with the data controller (us) first before involving them.

## CONTACT FOR FURTHER INFORMATION

If you wish to have further information on the study, please contact the research team by sending an email:

- The REACT-CYP Study Team on [react.lc.study@imperial.ac.uk](mailto:react.lc.study@imperial.ac.uk)

