

## Frequently Asked Questions

*For members of the public*

### **What will people joining the COVID-19 BioResource study be asked to do?**

When patients are admitted to participating hospitals with suspected coronavirus infection, they will be asked if they are willing to take part in this study. Those who consent will sign a consent form and specially trained research nurses will collect samples to use in the study. The samples collected will be nose and throat swabs (which are needed for diagnosis anyway) and a small sample of blood. They will also be asked some questions about their mental health and symptoms and to allow researchers access to their healthcare records. During their hospital stay, they may be asked for more blood samples when blood is being taken for normal clinical care. Once they have recovered, they may be asked if they would be willing to take part in further research to help researchers understand more about the causes of severe COVID-19. There is no obligation to take part in these further studies.

### **I've had symptoms of coronavirus (or had a positive test outside of a hospital setting) and would like to be able to participate. Can I join?**

At the moment we don't have safe ways of collecting samples from non-hospital settings or enough diagnostic tests to be able to confirm self-diagnosed cases. Once our testing capability is improved and travelling restrictions are relaxed, we hope to be able to invite participants to the COVID-19 BioResource who had mild symptoms and recovered at home. Until then, people who are interested in taking part in research are invited to join the [NIHR BioResource](#). You can also find other ways of getting involved in COVID-19 research on the NIHRs [BePartofResearch](#) page.

### **What is the NIHR BioResource and how do I join?**

The NIHR BioResource is made up from volunteers from around the country who are willing to be approached to participate in research studies and trials. Participants who have given their consent provide a biological sample (usually a small blood sample), answer a short questionnaire about their health and lifestyle and allow researchers to access their healthcare records.

The biological samples are analysed to provide genetic and other information, which is safely stored. Researchers who are carrying out research studies and trials that need participants with particular symptoms or genes can then invite matching BioResource participants to take part in their studies. BioResource participants are free to decide which (if any) studies they want to take part in.

There are 13 NIHR BioResource local centres throughout England, and they are located in Birmingham, Cambridge, Exeter, Leeds, Leicester, London – includes Barts, Guy's and St Thomas', Maudsley, Moorfields and UCLH; Manchester, Newcastle and Southampton. If you are interested in finding out more, please contact your [local centre](#).

It is currently possible to join the NIHR BioResource without providing a biological sample. If you are interested in joining, or have any questions, please email: [nbr@bioresource.nihr.ac.uk](mailto:nbr@bioresource.nihr.ac.uk)

## **What kind of studies are planned for the samples?**

There are already several studies planned for the samples. Initially, the swab samples will be used to test a new, faster way of diagnosing COVID-19 on the hospital ward and the blood samples will be used to test a way of finding out whether people have had the virus or not (these are called 'antibody tests'). Both of these studies will be crucial in helping the NHS through this pandemic, by helping to quickly separate infected and non-infected people in the emergency room, by helping to identify healthcare staff who have the virus but may be asymptomatic and by allowing staff who have had the virus and recovered back to work. These studies are led by Professor Ravindra Gupta, Professor of Clinical Microbiology at the University of Cambridge.

NIHR Cambridge BRC Theme Lead for Inflammation, Infection and Immunotherapeutics, Professor Ken Smith, and other researchers at the Cambridge Institute of Therapeutic Immunology and Infectious Disease (CITIID) will be studying how each participant's immune system has responded to the virus and whether particular types of immune 'response' are related to mild or severe symptoms. This information will help in the development of effective vaccines and may help doctors to identify people who are more at risk of severe symptoms before they are infected.

Our BRC Theme Lead for Mental Health, Professor Ed Bullmore, and his team will be studying the mental health of staff and patients with COVID-19. Some COVID-19 BioResource participants will complete a mental health questionnaire when they join the study, and this will help researchers to track what happens with participant's mental health as they recover and move forward.

The really exciting thing about the NIHR COVID-19 BioResource though, is that it enables research studies that haven't yet been thought of but need participants with COVID-19. If researchers identify an important link between infection and outcomes, they could apply to the BioResource to check for the link using the saved samples, data or by inviting the participants to participate in a new research study.

## **Who will have access to my personal information and genetic data?**

We use a process called 'pseudo-anonymisation' so that research staff who work with your samples cannot identify you. The database that holds the genetic and biological data is separate to the one that holds personal data. Access to both databases is restricted to trained staff at the NIHR BioResource. The database that holds all personally identifiable information such as names, addresses and the answers provided in your questionnaire can only be accessed by the recruitment team who may contact you in the future about your participation in research studies. The database that holds the genetic information is accessed by the research team and a limited number of the data services team only, who do not have access to the database that holds personal information. We do not share any of your personal data with other organisations.

## **What if I change my mind about taking part?**

Participants are free to withdraw from the NIHR BioResource at any time without giving a reason. You can choose to withdraw from your local NIHR BioResource and still be enrolled in the National NIHR BioResource (for example if you move houses and the local BioResource is not relevant to you anymore) or you can choose to withdraw from both the NIHR National BioResource and your local NIHR BioResource. Please contact us on 0800 090 22 33 or email with 'withdraw from NIHR BioResource' in the subject line, include your name, address and date of birth in the email, and we will initiate the withdrawal process.

## **Who do I contact if I have concerns?**

If you have any concerns or complaints about anything to do with the NIHR BioResource then you can call our Freephone number on: 0800 090 2233 Mon to Fri 9:00-17:00 or email us at [nbr@bioresource.nihr.ac.uk](mailto:nbr@bioresource.nihr.ac.uk)