

CVD-COVID-UK programme privacy statement

This Privacy Statement explains how the partners involved in the CVD-COVID-UK consortium collect, store, manage and protect your personal data. It outlines the types of data that are accessed and how we use them.

Who we are

The [CVD-COVID-UK](#) consortium is coordinated by the [British Heart Foundation \(BHF\) Data Science Centre](#) at [Health Data Research UK](#) (HDR UK) and includes a number of [partner academic and NHS organisations](#) in the UK. Members of this consortium consist of scientific researchers, clinicians and data analysts within these partner organisations.

CVD-COVID-UK consortium members are obliged to agree to the consortium [principles](#). These include working in a transparent and inclusive manner and following the framework that the consortium has put in place to ensure the appropriate, lawful and ethical use of data.

What information we use

We use information that is collected about NHS patients as part of their routine health care (e.g. by their GP when they have a GP appointment or by a doctor or nurse when they are admitted to hospital). This is called routinely collected health care data. We use this data to carry out health research on cardiovascular disease and COVID-19.

Before any researcher in the consortium can access the data to perform research analyses, it is first de-identified. This means that any information that could directly identify an individual (e.g. name, NHS number and address) is removed so that individual patients cannot be identified.

The information we use in this research is:

- *Hospital data*: health records summarising the diagnosis and healthcare of patients attending an NHS hospital. This includes information about inpatient care (including care in intensive or critical care units), outpatient care and care in the emergency department.
- *Primary care data*: health records from patients that are currently registered or have ever been registered with a general practitioner (GP) in the NHS.
- *COVID-19 laboratory testing data*: data on the results of test for the presence of the SARS-CoV-2 virus from NHS laboratories or from the large laboratories (Lighthouse laboratories) set up to provide COVID-19 testing services to the NHS.
- *COVID-19 vaccinations*: data on vaccinations performed and any recorded adverse reactions.
- *Medication data*: data on medication that has been prescribed and/or dispensed in hospitals and in the community.
- *Death data*: this contains records of all deaths registered in the UK.
- *Cardiovascular disease audit and registry data*: health data on specific cardiovascular diseases and their treatment.

To help the NHS respond to the coronavirus pandemic, your information may be used for some coronavirus research purposes even if you have chosen not to share it. Any information used will be shared appropriately and lawfully. If you want to find out more about this, please go to: <https://www.nhs.uk/your-nhs-data-matters/>

How we use your information

Members of the CVD-COVID-UK consortium are interested in finding out about how having COVID-19 might affect the risk of developing cardiovascular diseases (CVD), such as heart attacks, stroke and blood clots in the lung. They are also interested in whether patients with cardiovascular diseases may have an increased risk of getting COVID-19 and of developing severe consequences, including dying, as a result. The consortium want to look at ways of improving the treatment and care of patients who have cardiovascular diseases or may develop cardiovascular disease in the future.

The results of this research will be made publicly available in reports and publications to the scientific and clinical community, government and the public (for example, publications in scientific and medical journals, reports to government scientific advisors, and publicly accessible reports on websites). Results will help guide national decision-making to reduce the severity of COVID-19 outcomes in cardiovascular patients and inform the prevention and treatment of cardiovascular complications of COVID-19.

Individual patients will not be identifiable from these results.

Collection, storage and sharing of this information

The BHF Data Science Centre coordinates the CVD-COVID-UK consortium but does not itself collect or hold any routinely-collected NHS or other health data.

Data are provided for this research by national NHS organisations, which collect health data on behalf of the NHS from hospitals, primary care systems, specialist audit and registry systems and death registries.

De-identified patient data for this research is made available to researchers within secure environments, called trusted research environments. Currently, these are provided for this research programme by:

- NHS Digital via its Trusted Research Environment service (for English health data);
- NHS Wales via its Secure Anonymised Information Linkage (SAIL) Databank (for Welsh health data)
- Public Health Scotland via its Scottish National Data Safe Haven (for Scottish health data).

Individual level patient data never leaves these trusted research environments. Access to the data within these trusted research environments is restricted to approved, named researchers with certified training in the safe use of health-related data for research. These approved researchers access the data held in each environment remotely through a highly secure authentication system. This allows researchers to perform analyses for specified, approved projects that are part of the CVD-COVID-UK research programme, while protecting people's privacy and optimising the security of their data.

Researchers are unable to take individual level data out of the trusted research environments. Before researchers can share research results outside the environment, the results of analyses conducted within the environment are first checked to ensure that no individual level or potentially identifiable data are included. This checking is done by trained staff working for the organisation that provides the trusted research environment. All outputs of research analyses are checked in this way, and researchers are only able to take analysis results out of the environment one it is deemed safe for them to do so.

The research we carry out is done under the ethical approval for the CVD-COVID-UK programme (NHS Research Ethics Committee reference: 20/NE/0161) and is reviewed and approved by an independent panel within each devolved nation, who are responsible for assessing applications for access to routinely collected NHS data for research.

Researchers working on the CVD-COVID-UK programme will not access data in the trusted research environments beyond the period of relevant approvals (currently 1 June 2023).

Legal basis for using your information

Whenever we use personal data we must have a legal basis for doing so. The legal basis for using your information is:

Legal basis for processing personal data, under Article 6(1) of GDPR:

Article (6)(1)(e) of the GDPR: Public task - the processing is necessary to perform a task in the public interest or for official functions, and the task or function has a clear basis in law.

Legal basis you for processing of special category data, under Article 9(2) of GDPR:

Article 9(2)(j) processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1).

Your rights

You have a number of rights relating to your personal information.

You can find out more about your personal data rights at the Information Commissioner's Office (ICO) website: <https://ico.org.uk/your-data-matters/>

Data controller and contact details

With respect to accessing English data within the NHS Digital trusted research environment, the partner organisations, i.e. those party to the related Data Sharing Agreement (currently NICE, Swansea University, University College London, University of Bristol, University of Cambridge, University of Leicester, University of Liverpool, University of Oxford) and NHS Digital take on the formal role of being joint data controllers for the CVD-COVID-UK research programme.

The BHF Data Science Centre itself is not a data controller and does not access data in the trusted research environments. However, the BHF Data Science Centre does coordinate both the CVD-COVID-UK programme as well as the joint data controller organisations involved. Therefore, if you have a query about the CVD-COVID-UK programme, please contact the BHF Data Science Centre in the first instance, using the following email address:

bhfdsc@hdruk.ac.uk

Complaints

If you are unhappy with the way in which your personal data has been processed you may in the first instance contact the BHF Data Science Centre using the following email address:

bhfdsc@hdruk.ac.uk

CVD-COVID-UK
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If you remain dissatisfied, then you have the right to apply directly to the Information Commissioner at:

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

www.ico.org.uk