

CVD-COVID-UK/COVID-IMPACT programme privacy statement

The British Heart Foundation (BHF) Data Science Centre, convened by Health Data Research UK (HDR UK), coordinates the CVD-COVID-UK/COVID-IMPACT programme, which provides access to data for research purposes via Trusted Research Environments (TREs). Please see the [website](#) for further details on how the programme is run. This privacy statement relates to the role of the BHF Data Science Centre in the process.

For further information on the processing of data within the TREs used in the CVD-COVID-UK/COVID-IMPACT programme, see:

- [NHS England's \(NHSE\) Secure Data Environment \(SDE\) service for England](#) (data for England);
- [SAIL Databank](#) (data for Wales); and
- [Public Health Scotland electronic Data Research and Innovation Service](#) (data for Scotland).

For details on how we manage your data when you sign up to newsletters, events, or via direct communication, please see HDR UK's privacy policy here: <https://www.hdruk.ac.uk/privacy-policy/>

Research project approval

The [CVD-COVID-UK/COVID-IMPACT](#) consortium is coordinated by the [BHF Data Science Centre](#) at 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.

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.

Consortium members may propose projects under the CVD-COVID-UK workstream, which aims to understand the relationship between COVID-19 and cardiovascular diseases, or the COVID-IMPACT workstream which is an expansion of this approach to the relationship of COVID-19 and other health conditions. All projects go through a rigorous approval process coordinated by the BHF Data Science Centre via the 'Approvals & Oversight Board'.

Collection, storage and sharing of data for this research

The BHF Data Science Centre coordinates the CVD-COVID-UK/COVID-IMPACT 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. See [here](#) for further detail on datasets.

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.

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

- NHS England via its SDE service (for health data for England);

- NHS Wales via its Secure Anonymised Information Linkage (SAIL) Databank (for health data for Wales); and
- Public Health Scotland via its Scottish National Safe Haven (for health data for Scotland).

Individual level patient data never leaves these TREs. Access to the data within these TREs 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/COVID-IMPACT programme, while protecting people's privacy and optimising the security of their data. COVID-IMPACT projects currently access data for England in NHS England's SDE only.

Researchers are unable to take individual level data out of the TREs. 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 TRE. All outputs of research analyses are checked in this way, and researchers are only able to take analysis results out of the environment once 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/COVID-IMPACT 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/COVID-IMPACT programme will not access data in the TRE beyond the period of relevant approvals.

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). Please see [here](#) for an up-to-date list of outputs from these research programmes.

Individual patients will not be identifiable from these results.

The BHF Data Science Centre has a team of health data scientists that have been granted approval to access data in the TREs under the same conditions as researchers in order to sort the data and prepare it for research ('data curation'). Within the SAIL Databank and the Scottish National Safe Haven, this work is undertaken under their employment contracts with HDR UK. Within the NHS England SDE, data curation is conducted under their honorary contracts with academic organisations (University of Cambridge, University College London, University of Liverpool). The nature of the processing is the same in all of the TREs. The difference in contracts used for access is dependent on the permissions of the individual TREs. This access is not used to conduct any research or to remove any data from the TREs.

Legal basis for using your information

The legal basis for using your information is:

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

Article (6)(1)(f): the processing is necessary for your legitimate interests or the legitimate interests of a third party, unless there is a good reason to protect the individual's personal data which overrides those legitimate interests.

Legal basis you for processing of special category data, under Article 9 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).

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/>

Your rights

The BHF Data Science Centre/HDR UK do not collect or hold any personal data for the CVD-COVID-UK/COVID-IMPACT programme. Data held within the TREs are de-identified but still considered personal data under data protection legislation. You have a number of rights relating to this 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/>

Please contact the TRE provider if you wish to exercise these rights.

For any queries relating to data protection please contact: DataProtection@hdruk.ac.uk

Data controller and contact details

With respect to accessing English data within the NHSE SDE, the partner organisations, i.e. those party to the related Data Sharing Agreement (currently Imperial College London, King's College London, London School of Hygiene & Tropical Medicine, Swansea University, University College London, University of Bristol, University of Cambridge, University of Dundee, University of Glasgow, University of Leicester, University of Liverpool, University of Manchester, University of Nottingham, University of Oxford, University of Sheffield, University of Southampton) and NHS England take on the formal role of being joint data controllers for the research programme.

Approved researchers accessing the data in the TREs in Scotland and Wales sign individual user agreements.

If you have any queries on the coordination of the programme, please contact: bhfdsc@hdruk.ac.uk

Complaints

If you are unhappy with the way in which your personal data has been processed, please contact:

DataProtection@hdruk.ac.uk

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

Relevant links and documents

[CVD-COVID-UK/COVID-IMPACT programme webpage](#), including links to the following:

- Protocol
- Dataset Provisioning Dashboard
- Dataset Summary Dashboard
- Consortium principles
- Project approval process and ways of working
- Research outputs

[HDR UK Privacy Policy](#)

[NHSE SDE website](#)

[SAIL Databank website](#)

[Public Health Scotland electronic Data Research and Innovation Service](#)