

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 secure environments called Trusted Research Environments (TREs) or Secure Data Environments (SDEs). 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/HDR UK in the process.

For further information on the processing of data within TREs/SDEs 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
- [National Safe Haven \(NSH\) - Electronic Data Research and Innovation Service \(eDRIS\) - Health intelligence and data management - Resources and tools - Public Health Scotland](#) (data for Scotland). [Accessed from February 2021 to September 2023].

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'. The BHF Data Science Centre/HDR UK do not have any voting rights on the Approvals and Oversight Board. The final approval decision for a project lies with the National Data Custodians: NHS England and SAIL Databank (and previously, Public Health Scotland).

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 anonymised. This means that any information like name and address is removed and identifiers like NHS number or system ID numbers are replaced so that individual patients cannot be identified. The

data are only made available to researchers within secure environments, TREs/SDEs. Data that could be used to identify patients cannot be added to these environments and there are also restrictions on taking data out of these environments. Currently, these are provided for this research programme by:

- NHS England via its SDE service (for health data for England); and
- NHS Wales via its Secure Anonymised Information Linkage (SAIL) Databank (for health data for Wales).

Access to the data within these TREs/SDEs 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.

Before researchers can share research results outside the environment, the results of analyses conducted within the TREs/SDEs 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/SDE. 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 carried 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/SDE beyond the period of relevant approvals.

The results of the 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/SDEs 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 on behalf of HDR UK. Within the NHS England SDE, data curation is conducted on behalf of academic organisations (University of Cambridge, University College London, University of Liverpool). The nature of the processing is the same in all of the TREs/SDEs. This access is not used to conduct any research or to remove any data from the TREs/SDEs.

Legal basis for using your information

The data in the TREs/SDEs is anonymous. However, as a matter of good practice, members of the consortium also have a legal basis for processing the data under UK GDPR.

The legal basis for BHF Data Science Centre/HDR UK processing patient data under Article 6 of GDPR: is **Article (6)(1)(f)**: the processing is necessary for our 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; and

The legal basis for processing of special category data, under Article 9 of GDPR:
is **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).

The legal basis for the consortium members (researchers) processing patient data under Article 6 of GDPR:

is **Article (6)(1)(e)**: 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; and

The legal basis for processing of special category data, under Article 9 of GDPR:

Is **Article 9(2)(j)** is that the 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/>

Data Protection Contact Details

The BHF Data Science Centre/HDR UK do not collect or hold any personal data for the CVD-COVID-UK/COVID-IMPACT programme. The consortium members can only carry out research on anonymous data. You have a number of rights relating to personal information before it is made anonymous by the TRE/SDE provider.

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

You can also contact our data protection officer. We have appointed Bird & Bird DPO Services SRL as our Data Protection Officer, and they may be reached:

- by using the following email: DPO.HDRUK@twobirds.com
- by mail at the following address: Bird & Bird DPO Services SRL, Avenue Louise 235 box 1, 1050 Brussels, Belgium

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 data has been processed, please contact HDR UK, or our Data Protection Officer, at the addresses above. 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](#)

[National Safe Haven \(NSH\) - Electronic Data Research and Innovation Service \(eDRIS\) - Health intelligence and data management - Resources and tools - Public Health Scotland](#)