UK HFpEF Privacy Notice

1. Purpose for processing

Data collected about you as part of UK HFpEF will be stored in a Trusted Research Environment (TRE) for the purposes of linkage to health data and for research. The British Heart Foundation Data Science Centre (BHF DSC) UK Clinical Cohorts TRE ("UK CliC") is run by Health Data Research UK (HDR UK) in collaboration with SAIL (Secure Anonymised Information Linkage) Databank and UK SeRP (UK Secure eResearch Platform) both run by Swansea University. UK CliC supports the integration of disease-specific cohorts and registries with routinely collected health data in an accredited secure environment. UK-based bona fide researchers who are accredited by the Office for National Statistics or Medical Research Council can apply to access this data through a process managed by UK CliC. All Personal Data is processed in accordance with the requirements of the UK General Data Protection Regulation (UK GDPR) and the UK Data Protection Act 2018 (DPA18).

For more information on UK CliC, see here: https://bhfdatasciencecentre.org/areas/uk-clic-homepage/

2. Data processing activities

For UK HFpEF participants, Manchester University NHS Foundation Trust will send a file containing identifiable data, consisting of NHS number, forename, surname, address, postcode, date of birth, and/or gender, to Digital Health and Care Wales (DHCW) and NHS England (NHSE) for identification of the relevant health data records.

Once the records of UK HFpEF participants have been identified, all identifying data will be removed and a deidentified file containing the study ID and health data from routine NHS sources will be stored on a secure database at the SAIL databank in Swansea for access by approved researchers. DHCW will delete all identifiable data on UK HFpEF participants after each data linkage has occurred. If future linkages are required, the research team at Manchester University NHS Foundation Trust will re-send the necessary identifiable information to DHCW for that linkage.

Separately to this processing of routine NHS data, health data collected as part of UK HFpEF participation will be transferred in a de-identified format using the Study ID to SAIL. There it will be linked with the routine NHS data. Your data is stored on secure servers at Swansea University, a leader in providing this type of secure research server in the UK and internationally using their Secure eResearch Platform (SeRP). The servers are managed to information security best practice standards (including ISO 27001) and are regularly audited by external experts in information security.

UK HFpEF also has a separate area within SeRP for storage and processing of UK HFpEF data. This area is secure and can only be accessed by the UK HFpEF research team. Any identifiers stored here will be separated from the deidentified study data and can only be accessed by the research team data managers. No linkage or other health records will be held here.

3. The lawful basis for the processing

1) Performance of a task carried out in the public interest (Article 6(1)(e) in the UK GDPR); and

2) for the use of sensitive personal information, scientific or historical research purposes or statistical purposes (Article 9(2)(j) in accordance with Article 89(1)).

4. Legal basis for UK CliC to hold your data

HDR UK relies on legitimate interests under Article 6(1)(f) as its lawful basis for its processing of Personal Data in relation to the TRE. The legitimate interest being pursued is to facilitate health data research through the provision of the TRE, with the ultimate goal of the research to be a better understanding of medical conditions and potential treatment options.

As the TRE will involve processing Health Data, which is considered special category (sensitive) data under UK GDPR, one of the conditions in Article 9 UK GDPR must apply for the processing to be permitted. The most relevant condition is Article 9(2)(j) - Processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes.

5. The categories of personal data obtained

Personal data such as identifying data and information about your social and medical history will be collected from a number of sources, including:

a. Information collected by the UK HFpEF team including health and lifestyle questionnaires, assessment of your physical status, the results of analysis of blood samples, scans and other tests, and information from your local health records including GP and hospital records.

b. Clinical data that is routinely collected about the participant will be collected from other health and social care databases including: NHS England (such as Hospital Episode Statistics, Medicines Dispensed in Primary Care, cardiovascular disease, stroke, diabetes and other national audits, and Civil Registration of death and demographic data), Public Health Scotland, DHCW, the Department of Health Northern Ireland, and the Office for National Statistics.

6. The recipients or categories of recipients of the personal data

Only the research team at Manchester University NHS Foundation Trust and DHCW and NHS England will have access to participants' personal identifiable data and clinical data. Researchers at other organisations will only be able to apply for access to anonymised clinical data. The researchers and their research projects will go through a rigorous approval process and will not be able to access or take any identifiable or personal data out of UK CliC.

7. The right to withdraw consent

If you do not wish your data to be held in UK CliC, you should contact the research team at the hospital

where you enrolled, or the central study team on UK-HFpEF@mft.nhs.uk or Tel. 0161 291 4075. If you opt out, your data will not be used in future research investigations and new data from linkages will not be collected. Where your data is already being used in research projects we can't delete it, but UK CliC will make sure your data is not used in any new projects.

You can stop taking part in UK HFpEF at any time, without giving a reason. If you do, you will be asked to choose from a set of options that determine whether we continue to collect information about you and whether your remaining sample is destroyed. Information already collected about you will be kept. To withdraw, contact the research team at the hospital where you enrolled, or the central study team on UK-HFpEF@mft.nhs.uk or Tel. 0161 291 4075. Full details of the withdrawal options are set out in the UK HFpEF Participant Information Sheet, available on this website.

8. Data Subject rights

You have a number of rights relating to personal information before it is made anonymous. You can find out more about your personal data rights at the Information Commissioner's Office (ICO) website: https://ico.org.uk/for-the-public/

If you wish to exercise any of these rights, please contact the research team at the hospital where you enrolled, or the central study team on UK-HFpEF@mft.nhs.uk or Tel. 0161 291 4075.

9. National data opt out information

The National Data Opt Out (NDOO) allows patients to make a decision to stop their Confidential Patient Information (CPI) being used for research and planning purposes.

The NDOO will be applied to cohort studies prior to linkage and storage of data in UK CliC. The NDOO applies to patients in England and any Welsh residents who may hold health records in England. You can check and manage your choice via the NHS website.