

Privacy Statement

This is a statement from the Optimise HFpEF investigators:

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Further information about Optimise HFpEF investigators:

<https://www.optimisehfpef.phpc.cam.ac.uk/investigators/>

Optimise HFpEF is a multi-site study with the aim to develop a programme of optimised management by improving our understanding of needs and experiences of patients with HFpEF, clinical decision-making and management in primary care, and integrating research findings with patient and clinical expertise. We collect data from patients with HFpEF so that we can understand the problems and challenges that patients live with, what helps them and events like hospitalisation.

Please see the scientific summary here:

<https://www.optimisehfpef.phpc.cam.ac.uk/scientific-summary/>

Further detail can be found in the protocol here:

<https://www.optimisehfpef.phpc.cam.ac.uk/study-documents/>

Details are also published here:

<https://bjgpopen.org/content/3/4/bjgpopen19X101675.long>

About your Privacy

The investigators of the Optimise HFpEF study take your privacy very seriously and all information that is collected is strictly confidential. We will hold your contact information separately from any data collected and securely in a password protected file. Any information that is stored for the project will have your name and address removed so that you cannot be identified and data will be identified by a study identification (ID) number only.

Only members of the research team will have access to the information. Data will be held in secure storage and destroyed after ten years. Any information that you give will be used for research purposes only.

Optimise HFpEF follows the regulations set out by the General Data Protection Regulation (GDPR), which governs how we can access data.

The University of Cambridge is the data controller for this study and details are available on their role and responsibility here: <https://www.cam.ac.uk/about-this-site/privacy-policy> and here: <https://www.information-compliance.admin.cam.ac.uk/data-protection/general-data>

We also comply with guidance set out by Cambridge University Hospitals NHS Foundation Trust, details of which can be found here: <https://www.cuh.nhs.uk/about-us/our-responsibilities/looking-after-your-information/what-happens-information-held-about-you>

In this study we the research team will process the information you provide in line with the privacy policy set out by University of Cambridge. Processing of data is performed with your consent and is designed to understand more about HFpEF in order to improve care. You also agreed that we could share some of your data (date of birth and NHS Number) in order to understand episodes of hospitalisation. This data will only be shared with NHS Digital who will process it under GDPR articles:

6,1 (e)	“processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.”
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) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.”

More Information on Data linkage

Patients who consented to be part of the longitudinal cohort study consented that their personal information could be used to link with specific information held by NHS Digital. These data are civil registration and hospital episode statistics (information on hospital stays and emergency department attendances). We send personal identifying data (study ID, NHS number) in a protected file to NHS Digital. They return to us a file with study ID and civil registration and hospital episode statistics, but not the personal identifying data. In this way your personal identifying information always stays separate from any other data that we have collected about you. In other words, our analysis is always by study ID, and never by information that would identify you.

The anonymised data are reviewed by the study investigators, and there is no automated decision making.

Your Rights

This does not affect your rights in anyway, your rights in relation to GDPR can be found here:

<https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/>

You have the right to withdraw from the study at any time without giving a reason. This will not affect your treatment or care. If you withdraw we will only retain and use any personal information you have provided up to that point if you give us permission to do so. If you become unwell during the study to the extent that you are no longer able to provide consent, we will withdraw you from the study and retain and use the information you have provided up to that point.

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions.

If you wish to speak to somebody who is independent you can contact Cambridge University Hospital's Patient Advice and Liaison Service (PALS):

Address: Box 53, Cambridge University Hospitals, Cambridge Biomedical Campus, Hills Road, Cambridge, CB2 0QQ

Phone: 01223 216756 (Monday to Friday: 9am to 4pm)

Email: pals@addenbrookes.nhs.uk

Expressing Concerns or Making a Complaint

If you have concerns about our use of your personal data, please contact us first.

However, you also have a right to lodge a complaint with the Information Commissioner's Office:

The Information Commissioner's Office

Wycliffe House

Water Lane

Wilmslow

Cheshire, SK9 5AF

Telephone: 0303 123 1113

Web: <https://ico.org.uk/>

Details on submitting a complaint can be found here: <https://ico.org.uk/make-a-complaint/>