

NICOR - HES Data linkage for Heart Failure Population Analysis

Patient Notification

This patient notification document has been prepared to tell you how we are obtaining, linking and analysing NICOR patient data with Hospital Episode Statistics (from NHS Digital) in our Heart failure population study.

The Study

We are looking into the relationship between patient characteristics and patients being readmitted to hospital for heart failure. We will identify specific groups that are at an increased risk of re-hospitalisation. We are doing this because we believe a minority of patients may account for the majority of re-hospitalisations.

In order to do this, we will look at data from two large databases. One is run by NHS Digital and is called Hospital Episode Statistics (HES). This database stores data on all admissions, outpatient appointments and Accident & Emergency (A&E) attendances in England. It also includes data on diagnoses, patient information and medical procedures. HES does not include heart failure-specific information (such as the medication prescribed). Therefore, we need to combine the HES data with another source specific to patients with heart failure, which is the National Heart Failure Audit (NHFA). This is one of the specialist domains of the National Cardiac Audit Programme, managed by NICOR now hosted at NHS Arden and Greater East Midlands CSU, as part of NHS England.

By combining these two (NHFA and HES) datasets, we will be able to work out if certain population characteristics (such as having another illness or certain symptoms) increase the risk of being readmitted to hospital for heart failure.

What personal data will be collected and how will it be used

Data on patient readmissions, diagnoses and treatments will be provided by NHS Digital and combined with heart failure-specific data from the NHFA. NHS Digital will be responsible for combining the two datasets into one. They will use a patient identifier (NHS number) in order to link the databases together. This patient identifier will be removed by NHS Digital before the dataset is delivered to us. The data will be sent securely.

At KiTEC, data will be stored on encrypted, password-protected computers and will only be accessible to designated employees who are working on this project. When the results of the study are reported, individuals who have taken part will not be identified in any way.

All data processing will take place in line with the requirements of the data protection legislation.

Once the data analysis is complete, all patient data that has been provided to us will be permanently destroyed and no copies will be kept.

More information about HES can be found [here](#) and information on the NICOR National Heart Failure Audit can be found [here](#).

Reporting plans

The end of study will be marked by the production of a publication submitted to a peer-reviewed academic journal.

The data analysis will consist of statistical and health economic analyses.

Reported results will not contain any identifiable data.

Can I opt out?

The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning. Further information is available at the following link: <https://digital.nhs.uk/services/national-data-opt-out>

The Secretary of State for Health and Social Care has granted NICOR an exemption from the National Data Opt-Out Policy for audit and registry purposes. Patients in England may still opt out of the uses of their data for research purposes. In England the National Data Opt-out Policy will be implemented by NICOR when sharing any identifiable data. Whilst the National Data Opt-out Policy applies in England only, patients in other parts of the UK have the right to object to the use of their personal information, although you must give specific reasons for your objection based upon your concerns. This is not an absolute right and depending on the circumstances we may decide that there are compelling and legitimate grounds for us to continue to process your information. If we do decide to continue processing your information, we will let you know and explain the reasons for our decision to you. Any patient wishing to opt out of NICOR data sharing/linkage for research purposes can do so by writing to James Chal, NICOR Chief Operating Officer (j.chal@nhs.net).

Patients can view or change their national data opt-out choice at any time by using the online service at www.nhs.uk/your-nhs-data-matters or by clicking on "Your Health" in the NHS App, and selecting "Choose if data from your health records is shared for research and planning".

What if there is a problem?

If you have a concern about any aspect of this study, please contact the Principal Investigator, Anna Barnes by emailing anna.barnes@kcl.ac.uk.

If you remain unhappy and wish to complain formally, you can do this through the Guy's and St Thomas' Patients Advice and Liaison Service (PALS) on 0207 188 8801, pals@gstt.nhs.uk.