

VICORI

Information for Patients and the Public

This work uses data provided by patients and collected by the NHS as part of their care and support.

How we will use your personal health Information: The Fair Processing Statement

The Virtual Cardio-Oncology Research Institute (VICORI) team is responsible for reporting findings from this research programme. We intend to investigate the associations between cardiovascular disease and cancer. The results will inform clinicians' decisions when caring for patients with cardiovascular disease and cancer.

Responsibility for the study comes under the shared umbrella of:

- NHS England
- The University of Leicester

Improving health, care and services through research and planning

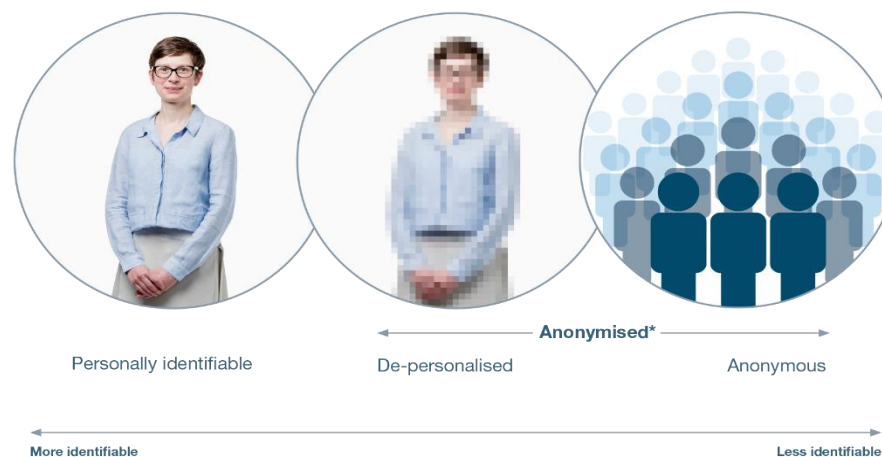
We will analyse the data held in two places within NHS England: the first place is with NICOR and the second is with NCRAS, which is the National Cancer Registration and Analysis Service. Our study will bring the two sets of data in these registries together so that we can better understand what happens in the care of persons with cancer who also have or are at risk of heart disease, or persons with heart disease who also have or are at risk of cancer.

NICOR and NCRAS hold detailed patient information about the majority of UK patients with cardiovascular disease or cancer.

Using anonymised data

We will only analyse data which is anonymous. This means that the NCRAS and the NICOR information we analyse comes from the anonymous end of a spectrum of identifiability. At one end of the spectrum, a person is fully identifiable. As you remove or encrypt information, you blur the image more and more, and it becomes more difficult to identify who that person is. At the other end of the spectrum, it is not possible to identify who someone is — they are effectively anonymous.

Spectrum of identifiability



*anonymised in accordance with the ICO code of anonymisation

The legal basis for looking at patient data

In order to link the two sets of health information we do need to connect the persons in the first place who have a common cancer and heart care need. The NCRAS and NICORI registries already record personal information, such as name, address, age, sex, date of birth and NHS number, which can be used to identify you. The government has given NCRAS and NICORI special permission to collect and store personal information without patient consent so it can be used for research. This is provided in section 251 of The NHS Act 2006.

All the data analysed by the VICORI team will be pseudo-anonymised. Therefore, the cardio-oncology study team do not need to ask individual patients for consent to analyse the NCRAS cancer data or the NICORI heart disease data.

The registries will provide VICORI with patients' information, including date of birth and NHS number. Only a few VICORI team members will have access to personal information when storing the data or linking the two registry datasets together. The rest of the group will only access and analyse pseudo-anonymised linked data.

Security of Personal Health Information

The VICORI group have the recognised training necessary to keep the pseudo-anonymised data safe and securely stored. As we will only analyse pseudo-anonymised data, there is no question of sharing personally identifiable data with anyone else or in publications.

Patient involvement in the study

We have developed our study concept and design in consultation with our patient and public involvement colleagues. Our patient representatives, as study collaborators, will ensure an appropriate patient-centred focus during project delivery and the dissemination of study findings. The patient representatives will attend the Programme Management Group meetings and support the drafting of 'Plain English' summaries of all study publications. These will appear as links on the websites of VICORI and the partner organisations to allow wider patient and public understanding of our findings and their implications.

We would like to thank The Wellcome Foundation for the information and guidance on their website:
<https://understandingpatientdata.org.uk/>