



The Virtual Cardio-Oncology Research Institute (VICORI)

What we do, your personal information, confidentiality and options.



Medical staff treating patients with cardiovascular disease or cancer pass on patient information to the cardiovascular disease registry or cancer registry. Cardiovascular and cancer registry data has been invaluable to help understand how to diagnose and treat these illnesses.

VICORI want to understand how diagnosis and treatment are different for patients with both cardiovascular disease and cancer. To achieve this, we will analyse combined cardiovascular registry and cancer registry data, which contains patient's personal information.

In this leaflet, we explain why we need to access personal information, how we will keep this information confidential, what we plan to do with the information and what to do if you wish to have your information removed from the study

Why do you need my personal information?

The cardiovascular and cancer registries collect details of UK patients' illnesses, including diagnosis and treatment. However, they also 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 registries special permission to collect personal information without patient consent so it can be used for research.

The cardiovascular disease registry and cancer registry will provide VICORI with patient's 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 anonymised linked data.

How will you keep my personal information confidential?

All data will be stored securely with only the necessary people having access to personal information.

VICORI will not share or publish personal information with anyone. We will only report summary findings from the linked data so individual patients cannot be identified.

What will you do with the information?

The aim of VICORI is to investigate the associations between cardiovascular disease and cancer. The linked data will allow us to investigate a wide range of research questions due to detailed information collected for each patient and the large numbers of patients in the registries. The results from the cardio-oncology research program will inform clinicians' decisions regarding managing and treating patients with cardiovascular disease and cancer.

What if I don't want my information included in the study?

You can ask us to remove your details from the linked data and be excluded from the cardio-oncology study. This decision will not affect your treatment or care.

If you would like to make a request, or contact us for any reason, our contact details are below:

Name:

Address:

Email:

Website: www.vicori.lcbru.le.ac.uk



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