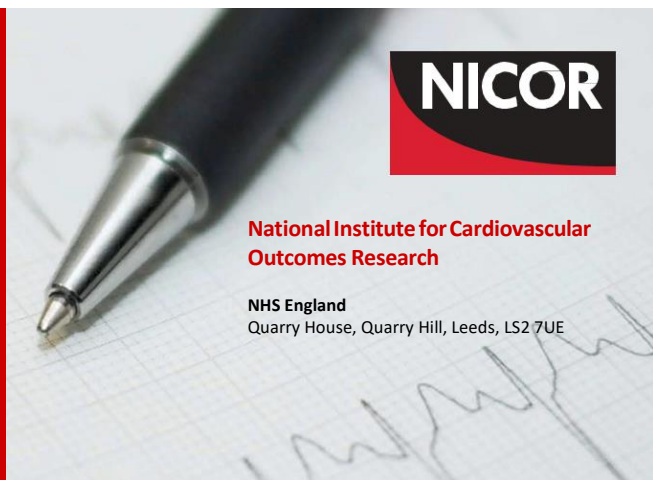


NICOR Patient and Public Information Leaflet

What are the national heart disease clinical audits?



1. ABOUT OUR PATIENTS

People with heart disease deserve to have the best possible care and a good quality of life after treatment. The National Institute for Cardiovascular Outcomes Research (NICOR) has an important role in working with UK hospitals (both NHS and private) and regulatory authorities to collect, assess and report information to assist improvements in the quality of care provided by hospitals to patients with heart disease.

This public and patient information leaflet tells you about how NICOR collects, stores, uses and reports patient information to influence quality improvement in patient care. It provides information about the National Cardiac Audit Programme (NCAP).

2. ABOUT US

NICOR is a national organisation with multiple stakeholders: it is a partnership between clinical and technical experts in many disciplines and patients to set up and manage national clinical audits and registries. Our team includes the following specialist expertise: technical computer system managers and software developers, information analysts (statisticians), academics, clinicians, patients and carers, project managers and administrators. We do not offer clinical advice, but you can use our reports to find out what care you should expect, as a patient with heart disease, and to see how your local hospital compares to other hospitals in England and Wales.

NICOR is led by the NICOR Director and managed by the NICOR Chief Operating Officer. The clinical leadership for each of the specialist domains of NCAP is provided by the relevant professional society for

each medical specialty. We also involve and engage with patients and members of the public via the NICOR Patient Representative Group.

3. ABOUT THE NATIONAL CARDIAC AUDIT PROGRAMME (NCAP)

NHS England and the NHS Wales (GIG Cymru) have commissioned NHS Arden and Greater East Midlands Commissioning Support Unit (Arden and GEM) to host NICOR to manage the National Cardiac Audit Programme (NCAP).

NICOR is responsible for managing the National Cardiac Audit Programme, which includes a number of national clinical audits and registries designed to improve the quality of care and outcomes of patients with heart disease. Clinical audit is a quality improvement process, in which NICOR collects and analyses data to provide health professionals with information to help them to review the quality and outcomes of patient care against national standards and guidance.

A patient registry is an organised system for collecting data about a population defined by a particular disease, condition, or treatment. Studies derived from patient registries provide a real-world view of clinical practice, patient outcomes, safety, and comparative effectiveness and cost-effectiveness.

NICOR collects patient data, produces analyses and reports, which enable hospitals and healthcare improvement bodies to monitor and improve the quality of care and outcomes of patients with cardiovascular disease. We aim to enhance the care of patients by systematically reviewing medical practice against explicit criteria, modifying it where necessary.

The NCAP comprises the following 11 audits/registries in specialist disease areas:

- Paediatric and adult congenital heart disease
- Heart attacks
- Angioplasty
- Adult cardiac surgery
- Heart failure
- Cardiac rhythm management (devices and ablation)
- Cardiac rehabilitation
- Percutaneous aortic valve implantation
- Percutaneous mitral valve and tricuspid repair procedures
- Percutaneous left atrial appendage occlusion (to prevent stroke)
- Percutaneous patent foramen ovale closure (to prevent recurrent stroke).

NHS England and NHS Wales (through Digital Health and Care Wales) are the Data Controllers for the data collected on patients in England and in Wales respectively. This means that they control the purpose and way in which NICOR may use the personal data collected for national clinical audits and registries.

The data controllership details are provided in the NICOR Privacy Notification on our website:

<https://www.nicor.org.uk/for-patients-carers-charities-and-the-public/>

4. WHAT WE DO WITH THE INFORMATION

The information provided to NICOR by hospitals is used to:

- Produce annual reports about patient care provided against national standards and guidance, as well as the outcomes of care provided. The reports produced by NICOR never identify any

patient. The reports are used by patients, healthcare professionals, hospital management, regulators and commissioners of healthcare services. The reports are published on the NICOR website: <https://www.nicor.org.uk/national-cardiac-audit-programme/>

- Enable both hospitals and ambulance trusts to evaluate their services and identify areas where the quality of care delivered to patients can be improved. The hospitals and ambulance trusts collect and submit their patient data into NICOR's secure database where these data can be viewed, by both services, for quality improvement purposes by facilitating performance comparisons at organisation and national level.
- Identify when patients do not have access to the best cardiac care and to identify good practice which is shared with other healthcare organisations.
- Inform patients of the risks and benefits of different cardiac operations and procedures to help them make informed choices. This includes the survival rates for patients who have had heart surgery, as well as rates of the main complications. Additional information about different operations, the benefits of having heart surgery and details about what to expect after the operation is available at: <https://scts.org/patients>
- Inform the number of procedures performed at hospitals that treat patients with congenital heart disease and their survival rates; additional information is available at: <https://tinyurl.com/b7xwk3a>
- Provide commissioners of NHS services and policy makers with information for commissioning purposes and to improve the delivery of cardiac services.
- Enable UK regulators such as the Care Quality Commission (CQC) and the Medicines and Healthcare products Regulatory Agency (MHRA) to use the information for quality assurance purposes. The information is also useful for service improvement and research.
- Facilitate research to identify improved treatments and interventions.
- Conduct research to provide data, advice and information on public health issues and emergencies (such as the COVID-19 pandemic).
- Link NICOR data with data from other national databases for research purposes e.g., the National Renal Registry and the National Cancer Research and Analysis Service (NCRAS) data. Further information is available on: <https://vicori.le.ac.uk/patients-and-public/>

5. HOW WE KEEP YOUR INFORMATION SAFE

Strict security measures are in place to safeguard your information. We meet NHS standards of keeping patient data safe, called the Data Security and Protection Toolkit. We are very careful with the information that we receive from hospitals, NHS England or other national data providers and follow strict information governance and data security rules about how we store and use it. The information is kept strictly confidential. It is stored on a secure system with password protection in a file repository and analysed in a secure environment, accessible only to appropriately approved staff who have been trained in confidentiality.

An audit is most effective when it contains information from every patient. This information is useful for discovering the causes of heart disease, assessing how best to treat heart disease and ensuring that hospitals provide the best care and help. Personal data for the national clinical audits and registries are retained indefinitely. The reason for this is that long-term longitudinal data (over many years) are required for trend analyses to demonstrate variations and changes in clinical practice and for improvements in quality of care.

NICOR processes patient data for audit purposes in England. However, we are also involved in an international clinical trial (run in the UK and Sweden) for which appropriate approvals (including

informed patient consent) have been obtained for NHS England to transfer data, for patients in the heart attack domain of NCAP, to Sweden for processing.

Analyses, reports and data derived from NCAP are anonymised and do not contain any information that can be used to identify individual patients. We sometimes grant researchers access to data that identifies patients, if it is necessary for their study, and they have the relevant ethics and confidentiality approvals to use it with the right security controls in place.

The Secretary of State for Health and Social Care has granted NICOR exemption for the National Data Opt-Out Policy, for national clinical audit (and registry) purposes, so that hospitals in England will continue to collect and submit information on all patients required for NCAP. Patients in England may, however, contact us directly to object to the use of their data by NICOR.

You also have the right to access your data or request a copy of the information we hold on you or request rectification of any inaccuracies of your information held by us. However, due to the nature of national clinical audit, where we need to include as many patients as possible, we would consider any request for erasure of data on a case-by-case basis.

You can exercise the rights described above by contacting NHS England's Data Protection Officer (DPO). Please see contact details below. This will not affect the quality of your healthcare.

Further details about our privacy and fair processing of information are available in the NICOR Privacy Notice on the NICOR website: <https://www.nicor.org.uk/for-patients-carers-charities-and-the-public/> and in the NHS England Privacy Notice on the NHS England website: <https://www.england.nhs.uk/wp-content/uploads/2018/05/NHS-England-Privacy-Notice-version-1.51.pdf>

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