

What are the national heart disease clinical audits?



ABOUT OUR PATIENTS

Every patient with heart disease wishes to have the best possible care and continue with a good quality of life after treatment and this is usually what happens. People with heart disease are now living much longer, more fulfilling lives than would have been the case only a few years ago. This leaflet tells you how the National Institute for Cardiovascular Outcomes Research (NICOR) is working together with the NHS (and private hospitals) to make an important contribution to ensuring life will keep getting better for patients with heart disease in years to come.

ABOUT US

The NHS aims to provide patients with the best care possible and NICOR plays an important part in this. This leaflet tells you about NICOR, the national cardiac audit programme and how the information is used to help improve the quality of patients' care and inform patient choice.

THE NICOR CARDIAC AUDITS

The National Cardiac Audit Programme (NCAP) is hosted at Barts Health NHS Trust (Barts Health). NHS England and the Welsh and Scottish Governments have commissioned and funded Barts Health via the Health Quality Improvement Partnership (HQIP) to deliver the NCAP contract. The National Institute for Cardiovascular Outcomes Research (NICOR) is the delivery arm for Barts Health for the performance of the NCAP contract.

NICOR is responsible for delivery of NCAP (with its six clinical specialist domains) and other registries, all of which are designed to improve the quality of care and outcomes of cardiac patients. The national clinical registries are also endorsed/commissioned by NHS England (either directly or via another intermediary organisation).

Clinical audit is a quality improvement process which aims to improve patient care. NICOR provides information to patients, healthcare professionals, providers, regulators and commissioners to help them to review patient care against national standards and guidance, as well as review the outcome of the care. The NICOR team comprises the following specialist expertise: clinicians, IT technical experts, information analysts (statisticians), academics and project managers.

The reports published by NICOR will never identify any patient.

NICOR collects and manages information using secure data collection systems, which are provided to hospitals (and the Ambulance Trusts for some of the domains) to submit data for the following national audits and registries:

1. The NCAP which comprises the following six specialist clinical domains:
 - a. Myocardial Ischaemia National Audit Project (MINAP) – heart attacks;
 - b. Adult Cardiac Surgery;
 - c. Adult Coronary Intervention – angioplasty;
 - d. Cardiac Rhythm Management – Heart Pacemakers, Implantable Defibrillators and Cardiac Ablations;
 - e. Congenital Heart Disease (Surgery and Intervention) - including Prenatal diagnosis of Congenital Heart Disease; and
 - f. Heart Failure.
2. The UK Transcatheter Aortic Valve Implantation (TAVI) Registry [commissioned by NHSE]
3. The Commissioning through Evaluation Registries [commissioned by NHSE via the NICE External Assessment Centre hosted at The Newcastle upon Tyne Hospitals NHS Foundation Trust]:

- a. Percutaneous Mitral Valve Repair Registry;
- b. Left Atrial Appendage Occlusion Registry;
- c. Patent Foramen Ovale Closure Registry.

WHO DO WE WORK WITH?

Clinical leadership for each of the NICOR audit domains/ registries is provided by the relevant professional body including the:

- **British Cardiovascular Society**
- **Society for Cardiothoracic Surgery in Great Britain and Ireland**
- **British Congenital Cardiac Association**
- **British Heart Rhythm Society**
- **British Society for Heart Failure**
- **British Cardiovascular Intervention Society**

WHAT WE DO WITH THE INFORMATION

The information collected is used to:

- Check that NHS organisations providing care are following national guidance. NICOR produces annual reports which assess the care and treatment of patients in England and Wales. We produce reports every year to assess performance against national standards and review improvements that have been made. The reports are available to the Department of Health, the Welsh and Scottish Governments, patients and the public, participating organisations, clinicians, and hospital management. The reports are available on the NICOR web pages <https://www.nicor.org.uk/national-cardiac-audit-programme/>
- Enable both hospitals and ambulance trusts to evaluate their services and identify areas where delivery of care to patients can be improved. Hospitals collect ambulance data, combine it with treatment episode data and submit it to NICOR. Once in the NICOR database, these data can be viewed, by both services, in non-identifiable formats — this facilitates performance comparisons at Trust and national level.
- Identify when patients do not have access to the best cardiac care.
- Identify good practice and share it 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 rates of survival for patients who have had heart surgery, general information about different operations, the benefits of having heart surgery and details about what to expect after patients have had an operation. These are available at: www.scts.org/patients
- Inform on congenital heart disease centres, the number of procedures performed and survival rates, all available at: <http://tinyurl.com/b7xwk3a>
- Facilitate research to identify improved treatments and interventions. National cardiac audit data may be used for medical research and scientifically related studies but we do not pass on personal details to researchers. The audit data may be linked with other clinical data to give researchers a better understanding of care pathways and how disease and treatments are over time. The data has been used by several research groups to identify new and improved treatments for cardiac patients.
- Provide commissioners and policy makers with information to improve the delivery of cardiac services.
- Link NICOR data with information from other data sources for audit purposes. For example NHS Digital provides NICOR with Office for National Statistics (ONS) mortality tracking information, to enable NICOR to calculate how long patients live after different kinds of treatment. Hospital Episode Statistics (HES) data, also provided by NHS Digital, is valuable in determining case ascertainment within the audits, the burden of disease pre-and post-cardiac admission/intervention, and admission/readmission rate(s) following procedure. Patient identifiers, including patient's name, date of birth, NHS number and post code are sent to NHS Digital and used to assist linkage at NHS Digital for ONS mortality and HES data. NHS Digital only supplies NICOR with anonymised linked ONS and HES data. With NHS Digital's agreement, we share the anonymised ONS/HES linked patient data with our commissioners/funders [such as The Newcastle upon Tyne Hospitals NHS Foundation Trust, which hosts the NICE External Assessment Centre] so that timely independent reports of the assessment of the evidence for innovative medical devices and their cost effectiveness can be utilised by NHS England for policy development and decision-making purposes.
- Link NICOR data with data from the National Cancer Research and Analysis Service (NCRAS) for research purposes. Increasing numbers of people are living with both heart disease and cancer. In order to better understand how these diseases and their treatments interact we plan to link the NICOR registries (with linked HES and ONS data as above) to the NCRAS registries held at Public Health England. For more information

please click on this link: <https://www.nicor.org.uk/wp-content/uploads/2019/01/20180713VICORI-fair-processing19-07-2018.pdf>

HOW WE KEEP YOUR INFORMATION SAFE

Strict security measures are in place to safeguard information about you. We are very careful with the information hospitals provide about patients and their care and follow strict rules about how we keep it and who can use it.

The information is kept strictly confidential and stored and analysed in a very secure environment. It is only available to appropriate staff. We ensure the information collected conforms to the strict rules of confidentiality established by Acts of Parliament, including the Data Protection Act 2018, the General Data Protection Regulation (GDPR) (EU) 2016/679 and NHS Act 2006 and Health and Social Care Acts 2001/12.

In accordance with these regulations and approval from the Secretary of State for Health and Social Care, the national cardiac audit programme is permitted to use and store patient data without consent. An audit is most effective when it contains information from every patient. Patient details help teams to learn how best to treat heart disease, make sure they provide the best care and help find out the causes of heart disease. Data supplied, by NHS Digital and other national data providers, is stored on a secure system, password protected, file repository, accessible only by named individuals. The data is retained as long as approved by NHS Digital. The supplied data is securely destroyed using industry standard file shredding software and removed from any backup tapes. Data will not be stored on any physical media. Your data is not transferred outside of the UK.

Analyses, reports and data derived from this information, used for research purposes, are anonymised and do not contain any information that can be used to identify patients.

Any patient wishing to OPT OUT of data sharing/linkage can do so by writing to James Chal, NICOR Chief Operating Officer, at the address below or by leaving contact details on the telephone number or email below and this will not affect the quality of their healthcare.

You also have the right to request a copy of any information NICOR hold on you and to request rectification or erasure of this information. You can do this by making a Subject Access Request to James Chal at the below address. If you are not satisfied with NICOR's response you have the right to make a complaint to the Information Commissioner's Office (ICO) <https://ico.org.uk/>

The Privacy Notice for the NICOR website can be found at <https://www.nicor.org.uk/privacy-and-cookies/>

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