

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. 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 and other hospitals aim to provide the best patient care and NICOR plays an important part in this. This leaflet tells you about NICOR, the National Cardiac Audit Programme (NCAP) and how the information is used to help improve the quality of patients' care and inform patient choice.

THE NICOR CARDIAC AUDITS/REGISTRIES

Barts Health NHS Trust (Barts Health) hosts the **National Cardiac Audit Programme (NCAP)** which collects Relevant Personal Data (including personal health and demographic details) and reports on patient data from all NHS and private hospitals from throughout the UK and Ireland. NHS England and NHS Wales commission and fund Barts Health via the Health Quality Improvement Partnership (HQIP). NICOR is the delivery arm for the Barts Health's NCAP contract. HQIP and NHS England/Improvement are the joint Data Controllers for NCAP data collected under the HQIP contract. The Secretary of State for Health and Social Care has granted NICOR permission (i.e. exemption under Section 251 of the NHS Act 2006 through the Health Research Authority Confidentiality Advisory Group) to collect unconsented patients' data from NHS hospitals in England and Wales for national clinical audit and research purposes.

NICOR is funded by the Scottish Government (through Barts Health) to collect NCAP data from the Scottish NHS hospitals. Scottish patients' NCAP data is not consented and as it is not subject to Section 251 exemption the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland has granted NICOR permission to collect this data for national clinical audit purposes.

Hospitals from Northern Ireland, the UK independent healthcare sector and the Republic of Ireland (RoI) submit data for NCAP purposes. NICOR also manages other national clinical registries, which are endorsed by NHS England. The Data Controller for the NCAP data from Scotland, Northern Ireland, RoI and the independent healthcare sector as well as for the data from our national registries is Barts Health NHS Trust.

Clinical audit is a quality improvement process which aims to improve patient care and treatment outcomes. 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, ICT technical experts, information analysts (statisticians), academics, project management and administration staff.

The reports published by NICOR will never identify any patient.

NICOR collects and manages information using secure data collection systems, which are provided to NHS and independent hospitals (and the Ambulance Trusts for one of the domains) for submitting patient data for the following national clinical audits and registries:

1. The NCAP which comprises the following six specialist clinical domains:
 - a. Myocardial Ischaemia National Audit Project (MINAP) – heart attacks;
 - b. National Adult Cardiac Surgery Audit (NACSA) – cardiac surgery;
 - c. National Audit of Percutaneous Coronary Intervention (NAPCI) – angioplasty;
 - d. National Audit of Cardiac Rhythm Management (NACRM) – devices and cardiac ablation;
 - e. National Congenital Heart Disease Audit (NCHDA) - including surgery, interventions and prenatal diagnosis of congenital heart disease; and
 - f. National Heart Failure Audit (NHFA).
2. The UK Transcatheter Aortic Valve Implantation (TAVI) Registry [commissioned by NHSE].
3. The Commissioning through Evaluation Registries [which were 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:

- **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 hospitals providing care are following national guidance. NICOR produces annual reports which assess the care and treatment of all patients in the UK and Ireland. 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 hospitals, healthcare commissioners, clinicians, Care Quality Commission 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, and this facilitates performance comparisons at organisation 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. The audit data may be used for medical research and scientifically related studies, but we do not pass on personal details to researchers (unless appropriate approvals have been granted to the researchers by the Secretary of State for Health and Social Care, the Research Ethics Committee and the appropriate data controllers). The use of NCAP data for research within NICOR and by external researchers is covered in England and Wales by approval from the Secretary of State for Health and Social Care under Section 251 of the NHS Act 2006 (CAG approval). 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.
- NICOR also uses patient data for conducting research and to provide data, advice and information on public health issues and emergencies (such as the COVID-19 pandemic) to the UK Government, its agencies and other researchers. The legal basis for this data sharing is covered by the Direction from the Secretary of State under Section 254 of the NHS Act 2012 to establish and operate a system for the collection and analysis of the information specified for this service for COVID-19 purposes. This also includes an obligation on NHS Digital to onward share NICOR's English data with third parties conducting COVID-19 related research.
- Provide commissioners and policy makers with information to improve the delivery of cardiac services.
- Link NICOR data with information from other national 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 types 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 a 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 mortality and HES data. With NHS Digital's agreement, we share the anonymised ONS/HES linked patient data with our commissioners/funders 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 the National Cancer Research and Analysis Service (NCRAS) data 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 the common law duty of confidentiality, and approval from the Secretary of State for Health and Social Care, the NCAP is permitted to collect, use and store patient data from England, Wales and Scotland without informed consent. However, confidentiality for collecting and processing NCAP data from the private healthcare providers is met through obtaining informed

consent. NICOR is the legal data processor of the NCAP data for which HQIP is the data controller. The data protection legal basis for data collection and processing is given at the bottom of this document*. 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. Personal data for the national clinical audits and registries is retained indefinitely. The reason for this is that long-term longitudinal data (over many years) is required for trend analyses to demonstrate variations and changes in clinical practice and for improvements in quality of care. The minimum retention period for all NICOR audit records is 8 years; this is consistent with NHS Retention and Disposal Schedule guidelines. For reasons mentioned above there is no maximum retention period for national clinical audits. All records identified for retention for a period greater than 8 years are subject to review and justification, including specific outcomes and level of statistical merit derived from the individual audits by audit project groups. The disposal of any data will be clearly documented including date of disposal and the type of the data destroyed. Disposal methods include secure destruction of computer media in which the backups are held and the erasure of data from NICOR servers to the current NHS guidelines/standards.

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. When appropriate 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. Although we receive patient data from the United Kingdom and Ireland NICOR only process the data in England. If any data is required to be transferred outside of the UK for any purposes (audit or research) we will ensure that we have all appropriate permissions/approvals in place before the transfer can take place.

Analyses, reports and data derived from our audits and registries, which may be used for research purposes, are anonymised and do not contain any information that can be used to identify individual patients (unless appropriate approvals have been granted to the researchers by the Secretary of State for Health and Social Care, the Research Ethics Committee and the appropriate data controllers). In England the National Data Opt-out Policy will be implemented by individual hospitals submitting data and by NICOR when onward sharing any identifiable data. Whilst the National Data Opt-out Policy only applies in England, patients in other parts of the UK can still object to the use of their data for this audit through their doctor responsible for their care or to NICOR as detailed below.

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

You also have the right to access your data and request a copy of any information NICOR holds on you. You can do this by writing to your consultant at the hospital that provides your care or to James Chal at NICOR using the email address/postal address below. Your consultant or NICOR would be able to provide you with a copy of your information that is held at NICOR. It would be sent to you either as a paper record or as encrypted data on a CD/Pen drive, which would be sent to you by recorded delivery. Alternatively we can make your data available to you electronically via the NICOR's secure Dropbox. In order to access your data electronically we require your personal email address and a contact phone number. Once we have uploaded your data file we would need to contact you to give you the password to access your encrypted file.

You can also request rectification of any inaccuracies of your information. You can do this by writing to your consultant at the hospital that provides your care or by making a Subject Access Request to James Chal at the address below. Due to the nature of national clinical audit we need to include as many patients as possible, and we are not able to erase your data. However, you do have the option to opt-out, as described above. 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/>

There are two data controller for NICOR data: Barts Health and HQIP. Both data controllers have a Data Protection Officer (DPO) who makes sure we respect your rights and follow the law. If you have any concerns or questions about how we look after your personal information, please feel free to contact the data protection officer at:

1. **Barts Health NHS Trust** by email: dpo.bartshealth@nhs.net or by calling **07710064950**. Alternatively, you could write to: Data Protection Officer, Barts Health NHS Trust, Lower Ground Floor, 9 Prescott Street, Aldgate, London E1 8PR.
2. **Healthcare Quality Improvement Partnership** by email: data.protection@hqip.org.uk or by calling: **020 3857 5030**. Alternatively, you can write to: Data Protection Officer, Healthcare Quality Improvement Partnership, Dawson House, 5 Jewry Street, London, EC3N 2EX.

National Institute for Cardiovascular Outcomes Research

2nd Floor

1 St Martin's le Grand

London, EC1A 4NP

Tel: **0203 765 8542**

Email: bartshealth.nicor-generalenquiries@nhs.net

Website: <https://www.nicor.org.uk/>

* Legal Basis for processing data:

1. **GDPR:**
 - o **Article 6 (1) (e) processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.** This is justified through commissioning arrangements which link back to NHS England, Welsh Government and other national bodies with statutory responsibilities to improve quality of health care services.
 - o **Article 9 (2) (i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.** This is justified as all projects aim to drive improvements in the quality and safety of care and to improve outcomes for patients.
2. **Common Law Duty of Confidentiality.** This will be project specific, depending upon whether the project holds section 251 or uses consent ('reasonable expectations').