Cardiac audit, data and registries: evolution of a national programme

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ABSTRACT
The UK is one of the few countries in the world with national registries that record key statistics across a broad range of cardiovascular disorders. The British Cardiovascular Society and its affiliated groups have played a central role in the development of these registries and continue to provide clinical oversight to the present day. Seven of the UK’s national registries are now integrated under the management of the National Institute for Cardiovascular Outcomes Research (NICOR) that currently holds records on nearly 6.5 million episodes of care since 1990. This represents a substantial data resource for national audit that has driven up standards of cardiovascular care in the UK with a palpable impact on patient outcomes. The registries have also spawned an impressive programme of research providing novel insights into the epidemiology of cardiovascular disease. Linkage with other datasets and international collaborations create the environment for new outputs, new opportunities for ‘big data’ research and new ways of performing clinical trials. As the centenary of the British Cardiac Society (now British Cardiovascular Society) approaches, its role in the development of the UK’s cardiovascular audits can be counted as one of its outstanding achievements.

INTRODUCTION
The UK national cardiovascular registries were created by clinicians driven by the need to describe contemporary clinical practice, demonstrate its safety and efficacy and provide transparent information on the expected outcomes (see graphical abstract). With very little support, they designed and implemented data collection systems and persuaded colleagues to participate.

In the run-up to the millennium, the revolution in information technology provided the impetus to move from collections of summary statistics to the development of a range of electronic patient-level disease registries that enhanced audit potential and paved the way for a new era of outcomes research. Always professionally led in concept and design, the initial small or hospital-based registries gained support from national societies and extended their reach across the UK. Initially, analyses were fed back to those hospitals that collected the data, but it became apparent that other National Health Service (NHS) agencies and researchers had a legitimate stake (figure 1).

In time, registry and national society leaders obtained governmental support for their programmes, largely due to recognition that the goals of the clinical community were aligned with key policy initiatives of the day. A particular impetus was the publication of the National Service Framework for Coronary Heart Disease in 2000, which emphasised the importance of equality of access to evidence-based treatments and a need for improvement in the provision of care. UK cardiovascular disease (CVD) registries have played a central role in delivering these aims and providing a platform for research and innovation. Clinical data collection is now firmly embedded in government reforms as exemplified by the technological transformation called for in NHS England’s Long Term Plan.

Work led by the National Clinical Director for Heart Disease, Sir Roger Boyle and his successor, Professor Huon Gray, paved the way for the national societies to unify a programme for the collection and analysis of national cardiovascular clinical data, using a single technology platform for data collection. The UK was a favourable environment for the development of national registries with its unified national health service in which every citizen is identified by a unique number allowing patients to be tracked across different healthcare providers and providing a basis for linkage across disease registries.

DEVELOPMENT OF CARDIOVASCULAR REGISTRIES BY THE PROFESSIONAL SOCIETIES
Cardiovascular disease registries were among the first to be established in the UK and were largely driven by the affiliated groups of the British Cardiac Society (now British Cardiovascular Society) and the Society for Cardiothoracic Surgery (SCTS), which retain clinical oversight to the present day.

Devices and electrophysiology
Dr Tony Rickards and Dr David Cunningham developed a pacing registry at the National Heart Hospital in 1974, and then established the National Pacing Database 4 years later, recording indications for pacemaker implantation, technical data and predefined outcomes. Data are now collected on all implanted devices and cardiac ablation procedures as part of the National Audit of Cardiac Rhythm Management Audit, with clinical oversight from the British Heart Rhythm Society.

Cardiac surgery
The SCTS in Great Britain and Ireland started to collect hospital-level data in 1977. The UK Heart Valve Registry developed in 1986 by Professor Kenneth Taylor was the first patient-level database and was subsequently transformed by Sir Bruce Keogh, Professor Ben Bridgewater and others into the current SCTS dataset that supports the National Adult Cardiac Surgery Audit. Development of risk-adjusted outcomes subsequently permitted...
meaningful comparisons of surgical mortality between centres across the country.

A substantial excess of paediatric cardiac surgical deaths at Bristol Royal Infirmary during the period 1991–1995 led to a public inquiry chaired by Professor Sir Ian Kennedy. The Kennedy report in 2001 was revolutionary in its recommendations, calling for complete transparency in the reporting of cardiac surgical outcomes across the UK. The SCTS responded by publishing hospital mortality rates from its registry and then went a step further in 2004 by publishing the names of all consultant surgeons together with a statement as to whether they had achieved a defined mortality standard. These were put in the public domain in 2005 after a *Guardian* newspaper Freedom of Information request and have been made publicly available ever since. This SCTS programme led to the development of the specialty-wide Clinical Outcomes Publication, which is now managed by the Healthcare Quality Improvement Programme and incorporates 27 specialties.

Public and political attention after the Bristol inquiry added impetus to the creation of a UK database of cardiac surgical procedures for paediatric patients with congenital heart malformations that soon incorporated data on interventional, pacing and electrophysiology procedures. Under the auspices of the British Paediatric Cardiology Association, now the British Congenital Cardiac Association, and in collaboration with the SCTS, a central patient-level dataset with national coverage emerged in 2000, led initially by Dr John Gibbs. By 2007, specific risk models had been developed putting hospital-specific outcome data into the public domain.

**Acute coronary syndromes**

A six-hospital audit of thrombolysis for ST-elevation myocardial infarction (STEMI) was reported in 1992 by Dr John Birkhead. This saw the development of the Myocardial Infarction National Audit Project (MINAP), supported by the British Cardiac Society and the Royal College of Physicians of London. By 1997, data had been reported from 39 hospitals, and 3 years later, all hospitals in England and Wales were commissioned to collect patient-level data to audit their performance against standards defined in the National Service Framework (NSF).

MINAP’s influence was huge and provided a fine example of the power of national audit in driving up standards of care. Units across the country reported rapid reductions in door-to-needle times, and there was an increase in prescription of secondary prevention drugs towards target levels. MINAP is now known as the Myocardial Ischaemia National Audit Project and has become one of the world’s largest national registries of patients with acute coronary syndromes.

**Coronary intervention**

The British Coronary Angioplasty Group was formed in the early 1980s and became the British Cardiovascular Intervention Society (BCIS) in 1988. Hospital-level summary statistics were collected from the start, led by Dr Peter Hubner and subsequently Professor Huon Gray. In 2002, all UK hospitals were formally mandated to participate in the national programme and 3 years later the BCIS registry had achieved complete UK-wide coverage. The main purpose of the registry was to benchmark individual hospital practice in the UK against national standards.

It was inevitable that the transparency demanded of UK surgeons by the Kennedy report would become a requirement of the interventional cardiologists and by 2013 a risk model had been developed allowing risk-adjusted percutaneous coronary intervention (PCI) outcomes for individual operators to be published on the BCIS website and made available for public scrutiny.

**Heart failure**

The British Society for Heart Failure was formed in 1998 and recognised the need to evaluate and improve the quality of care for patients admitted with acute heart failure. Led by Professor Theresa McDonagh, its audit programme was launched in 2007, and it has grown to capture data on over 80% of heart failure patients in England and Wales. It has demonstrated that specialist...
care is associated with better adherence to evidence-based guidelines and better outcomes, and it has highlighted significant variation in hospital performance.27 28

Other national audits
The UK Transcatheter Aortic Valve Implantation (TAVI) Registry started data collection in 2007 and is overseen by the BCIS and the SCTS.29 Other national cardiovascular audits include the National Audit of Cardiac Rhythm Management (NACRM),1 1990 National Audit of Cardiac Rhythm Management British Heart Rhythm Society Dr Francis Murgatroyd 1 1476260
1998† National Adult Cardiac Surgery Audit Society for Cardiothoracic Surgery in Great Britain and Ireland Mr Andrew Goodwin 761168
2000 Myocardial Ischaemia National Audit Project‡ Royal College of Physicians and British Cardiac Society, then British Cardiovascular Society Dr Clive Weston 1810843
2000 National Congenital Heart Disease Audit British Congenital Cardiac Association and Society for Cardiothoracic Surgery in Great Britain and Ireland Dr Abbas Khushnood 218497
2000† National Audit of Percutaneous Coronary Intervention British Cardiovascular Intervention Society Professor Peter Ludman 1498175
2006 National Heart Failure Audit British Society for Heart Failure Professor Theresa McDonagh 671839
2007 Transcatheter Aortic Valve Implantation (TAVI Registry) British Cardiovascular Intervention Society and Society for Cardiothoracic Surgery in Great Britain and Ireland Professor Peter Ludman 31220

*Interrogated on 30 July 2021.
†The national patient-level audit programmes for adult cardiac surgery and percutaneous coronary intervention were launched after 2000, but retrospective data from the pilot phase were included in the database.
‡MINAP changed its name from the Myocardial Infarction National Audit Project to the Myocardial Ischaemia National Audit Project in 2008, to reflect the collection of data for and audit of patients with non-ST-elevation acute coronary syndromes.

NATIONAL INSTITUTE FOR CARDIOVASCULAR OUTCOMES RESEARCH
As the UK’s national cardiovascular registries became established, it became clear that a collaborative approach for data collection across the cardiovascular specialties was needed to enhance the potential for audit and research. Eventually, in 2006, the National Institute for Cardiovascular Outcomes Research (NICOR) was established under the leadership of Professor John Deanfield, and it aimed at taking the registries out of their silos with clinical oversight retained by the relevant Affiliated Groups of the BCS and the SCTS.13

NICOR is a partnership that is responsible for the six cardiovascular clinical audits that together form the National Cardiac Audit Programme (NCAP), in addition to a number of new health technology registries including the UK TAVI Registry (table 1). NICOR is the largest collection of national cardiovascular data in the world, currently holding records on nearly 6.5 million episodes of care since 1990 (figure 2). Commissioned by the Healthcare Quality Improvement Programme, and chaired by Professor Mark de Belder, it produces a range of outputs for its stakeholders, including a specific annual report for patients and the public.14

FROM AUDIT…
Although NICOR’s initial imperative was to provide assurance around survival after cardiac procedures, quality assurance at a local level requires the ability to evaluate performance against a range of clinical metrics. Each of the subspecialty programmes incorporate performance evaluations for important features of the clinical pathway.

Over the last 5 years, NICOR has improved the means of feeding information to hospitals incorporating a focus on quality improvement (QI) when a standard is not reached. New QI-focused data tools have been developed such that hospitals can monitor their performance in real time against the national average and leading hospitals.

The latest reports demonstrate significant improvements in many indices of clinical practice but have also highlighted areas of practice where the desired targets have not been met or, in some cases, have deteriorated.15 These include important measures such as a deteriorating call-to-door time for the management of
patients with STEMI, which impacts directly on survival. This may relate to current pressures on Ambulance Trusts. Another issue is the timeliness of angiography (when indicated) and PCI for patients presenting with non-ST-elevation myocardial infarction, with many bed days being consumed by patients awaiting these procedures. These data provide stimulus for a national strategy for change as well as demanding local action.

…TO RESEARCH
The MINAP academic group, led by Professor Adam Timmis, was the first such collaboration to be established in 2005 and oversaw a national programme of research involving centres across the country.36 Linkage of mortality data from the Office of National Statistics (ONS) had been an early win for MINAP, the largest of the national registries. This opened the door for outcome comparisons in major subgroups including women and ethnic minorities that delivered new, clinically relevant information about the epidemiology of myocardial infarction.37 38 Novel international comparisons followed, allowing UK performance to be benchmarked against other countries.39 40

The unique NHS number that identifies every UK patient made possible linkage of MINAP to the General Practice Research Database and other national CVD registries. This delivered ‘big data’ at scale allowing the Clinical Research using Linked Bespoke Studies and Electronic Health Records investigators, led by Professor Harry Hemingway, to develop a high-resolution picture of the patient journey spanning primary care, hospitals and ultimately death registries.41 42 For the first time, a cradle to grave epidemiology of CVD and its component phenotypes became available to further enhance the research potential of the national registries. A similar linkage exercise with the Public Health England National Cancer Registration and Analysis Service has produced the Virtual Cardio-Oncology Research Initiative, led by Professors David Adlam and Mick Peake42–44 and linkage with the National Chronic Kidney Disease Audit, is now under way in recognition of the influential role renal function has in determining CV outcomes.45

Risk modelling is an essential requirement in delivering comparative analyses of hospital performance. When off-the-shelf models are unavailable, the NICOR datasets have provided an invaluable resource for new model development such as the Partial Risk Adjustment in Surgery (PRAiS) and PRAiS2 models for use in paediatric congenital cardiac surgery as well as UK risk models derived from the NAPCI and TAVI datasets.12 13 25 46 Further work to develop new risk models is currently ongoing, and machine learning algorithms applied to the MINAP dataset have recently been used to externally validate a prediction model for 30-day mortality after STEMI.47

Observational quality of care and outcome analyses have been the main research outputs from the UK’s national registries often delivered by cross-institutional collaborations supported by the UK national cardiovascular societies. Recently, for example, NICOR collaborated with colleagues from the Universities of Oxford, Leeds and Keele to examine the impact of the COVID-19 pandemic on hospital admissions and therapeutic procedures.48–52 NICOR’s research ambitions, however, are now extending to randomised trials in collaboration with SWEDHEART investigators who have pioneered a new method using registry data to create the trial dataset and capture endpoints.13 34 The concept of the registry-based randomised clinical trial promises to enhance the speed of recruitment and simplify follow-up, and a number of groups in the UK are now exploring this design.

SUPPORTING NATIONAL INITIATIVES
NICOR data have played a vital role in support and development of national policy in key aspects of cardiovascular healthcare.

- MINAP data returns from coronary care units across the country underpinned the national audit of the NSF and the development of acute coronary syndrome guidelines by the National Institute for Health and Care Excellence (NICE).35 36 Only recently, MINAP and NAPCI data have been used to audit call-to-door times as required by the Healthcare Safety Investigation Branch.53

- NICOR data were drivers of the National Infarct Angioplasty Pilot Project (2004–2008), which influenced the government policy decision to recommend primary angioplasty as the default revascularisation treatment for patients with STEMI.58 NICOR data have also been important in deriving performance indicators to assist healthcare commissioners.

- NICOR hosted the ‘Commissioning through Evaluation’ datasets to help in the evaluation of service delivery for new technologies including percutaneous mitral valve repair, left atrial appendage occlusion and patent foramen ovale closure. Analysis by NICE assisted NHS England’s current commissioning policies for these innovations.39 60

- NICOR data also informed the development of NHS England’s Congenital Heart Disease Standards and Specifications as part of its Congenital Cardiac Services Review.61

- In the evaluation of hospital services, NICOR data have also been used by the Getting It Right First Time programme62 63 and the Care Quality Commission. The use of both administrative and clinical registry data enables a comprehensive dashboard of performance at both hospital and individual level. NICOR is currently working with the National Consultant Information Programme to broaden the range of audit outputs relating to individual and team performance.64

HANDLING THE DATA
The provision of information on hospital and individual performance raises important issues. There is a legitimate expectation for commissioners and patients to have access to outcome information, but all steps must be taken for the information to be correct and to accurately reflect performance, as misleading information can potentially jeopardise clinicians’ careers and be legally challenged. In the NCAP, a validation process, supported by the new data tools, allows centres to check their data quality. This is particularly important for case mix analysis and the data variables that feed the risk models.

For risk-adjusted outcomes, analysis is performed using methodology developed by the Department of Statistical Science, University of London. This determines whether any hospital’s or individual’s performance lies outside an expected range. However, no risk-adjustment model is perfect, and there are always unmeasured confounders, and so the results of these analyses cannot be taken on their own to conclude that performance is unsatisfactory. However, they provide a flag to prompt further evaluation. Triangulation with other information collected at local level is recommended. The outlier process requires sensitive handling to ensure that the interpretation of analyses is appropriate and that responses are supportive and proportionate. The British Cardiovascular Society has created a multidisciplinary advisory document to assist hospitals and clinical directors with the issues that arise.45

All analyses and reports must comply with data governance legislation. NICOR is required to comply with the laws and regulations that apply to protecting the patient information that
it collects. These are the UK General Data Protection Regulation, the Data Protection Act 2018 and the common law duty of confidentiality. The collection of data without patient consent within the NHS 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. Some patients (currently 5.33% of those registered with a GP practice in England) do not wish their details to be used for audit or research and steps must be taken to ensure these are excluded from analyses.66 Outputs from the NCAP never reveal the identity of any particular patient. Reports are based on aggregate summaries of data. Interested parties requiring data outside of the purposes of the NCAP have to apply for a data sharing agreement with the relevant data controllers, understanding that different datasets have different data controllers. Clarification and simplification of the processes required would greatly assist the research community.

FROM ACORN TO OAKS: THE FUTURE OF UK CARDIOVASCULAR REGISTRY DATA
The UK national cardiovascular professional societies have championed the collection of clinical data that was started by a few pioneers and is now a national requirement. They have fostered a culture of participation in national audit and developed a system of quality assurance and QI.

Combining clinical registry data with administrative and other datasets provides a platform that is more powerful than the separate entities in supporting national audit, standard setting and government policy. There is new opportunity to broaden the range of metrics and provide additional outputs to assist individual clinicians and their multidisciplinary teams to improve services.

There is also opportunity to respond to emerging needs such as those raised in the Cumberlege report67 68 regarding patient safety and medical device regulation, for example with the development of a long-demand and comprehensive implantable device surveillance programme. A further focus is to develop new tools to inform patients and bring their voice to decisions about healthcare services. Further developments are in progress to increase the value of information provided to hospitals, ambulance trusts and commissioners as well as the patients who receive care.

Databases create a major platform for national and international research allowing comparisons of different populations and healthcare systems and mutual learning. The amassed data provide opportunities for novel research including the application of machine learning techniques. Collaborations with other countries, as has been demonstrated with NICOR’s partnership with the SWEdEHeart programme,69 will accelerate this. Mechanisms to assist the EuroHeart project, an international infrastructure initiative from the European Society of Cardiology,70 are being sought. International collaborations and novel methodologies will advance the pace and delivery of randomised trials that are essential for the evaluation of current treatments and future innovations. National registries have matured and probably surpassed their creators’ expectations; they continue to be an essential tool to monitor and drive quality of care, to assess and implement innovation and to improve outcomes for patients.

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Contributors All authors contributed to this manuscript.
Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study does not involve human participants.

Provenance and peer review Commissioned; externally peer reviewed.

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REFERENCES
5 Rickards A, Cunningham D. From quantity to quality: the central cardiac audit database project. Heart 1999;82 Suppl 2:18–22.
6 Sutton R. Early days of pacing in the UK – the British contribution to the field of pacing. Br J Cardiol 2018;25:57–10.


Ludman PF, UK TAVI Steering Group and the National Institute for Cardiovascular Outcomes Research. The UK Transcatheter Aortic Valve Implantation registry; one of the suite of registries hosted by the National Institute for Cardiovascular Outcomes Research (NICOR). Heart 2012;98:1787–9.


