The first successful congenital cardiac surgical operation in the world was ligation of a patent arterial duct in 1938 by Dr Robert Gross.[1] In the United Kingdom (UK), Dr. Alfred Blalock visited Lord Russell Brock in the late 1940s and performed the Blalock-Taussig shunt in 8 patients, at least one of whom is known to be alive today following a subsequently successful repair of tetralogy of Fallot.[1] Subsequently, repair of congenital heart defects was pioneered by Lord Brock and Dr. Donald Ross and the first successful repair of tetralogy of Fallot was performed in 1961 at Guy’s Hospital in London.[1]

In India, similar progress occurred in parallel with the rest of the world, although a few years behind. Dr. Betts performed the first palliation of tetralogy of Fallot with a Pott’s shunt in 1951 in Vellore. The first open heart operation to close an atrial septal defect using cardiopulmonary bypass was done in 1961 by Dr. Dastoor. In the same year a ventricular septal defect was closed by Dr. Gopinath using a pump oxygenator. Infant cardiac surgery progressed rapidly since early 1980s.

From the late 1960s, surgical repair of congenital cardiac defects has become common practice in a small number of specialist units in the UK. However, it is only in the last decade that outcome monitoring of surgical operations has become an important and integral component of everyday practice.[2]

In the last three decades, advances in various aspects, such as technology, procedural techniques and knowledge of heart defects, have allowed the treatment of more complex defects in younger and smaller patients. This progress has not been without complications or controversy in the UK and there has been recognition that there are areas within the speciality, which need monitoring and improvement.[3]

Although in the UK, data for surgical procedural outcomes have been available through Congenital Cardiac Audit Database (CCAD) since 1996 from a limited number of institutions, submission of these data became mandatory for all the congenital cardiac units from 2004. Monitoring has been based on standard 30-day outcomes, but there are no national data on the disease burden, based on the number of children diagnosed in utero or postnatally with a congenital cardiac defect. The issues of disease burden and healthcare provision for congenital heart disease in India are extremely difficult in the current healthcare systems. However, this should not deter the specialty from the acquisition of robust data relating to congenital heart disease.

In the UK, reporting in the public domain of antenatal detection rates in those babies who have undergone procedures for congenital heart disease in the first year of life, has resulted in changes of regional policy for provision of fetal cardiac screening.[4] There has been an increase in the rate of antenatal detection over the last seven years due to increased provision of funds and training of fetal sonographers [Figure 1].

It has to be recognized that the development of national databases to focus on the disease burden and procedural outcomes is complex and costly in the short-term and long-term.

![Figure 1: Improvement in antenatal detection](http://nicor5.nicor.org.uk/CHD/an_paeds.nsf/vwContent/Antenatal%20Diagnosis?Opendocument)
this is especially applicable in India. Data collection is an information gathering and supply exercise, which helps in establishing the correct policies to deliver the appropriate healthcare for the local population. These databases also may act as a stimulus for targeted research and innovation within India.

By 2030, India is predicted to have the largest population in the world.\(^5\) This population with its variable rural and urban mix is different from many highly developed countries. Therefore, it is a daunting task to set up a registry of children and adults with congenital heart disease.

In 2001, one of the key findings of the review of the Bristol Royal Infirmary results was that the risk data provided to parents reflected the national outcomes and not necessarily the outcomes for the individual surgeon or the unit specifically.\(^2\) Clinicians, parents and patients now have access to the UK institutional and the national data via the internet, owing largely to the work of the CCAD. Since 1st April 2011 CCAD has been incorporated into the National Institute of Cardiovascular Outcomes Research based at University College London, which has now become one of the largest validated databases for congenital heart disease treatment in the world. To develop an effective database, clear and fundamental agreements were required, which related to the dataset, data collection, reporting and analysis of the data. This was led by clinicians, national associations and mandated by the government. When the same principles are applied to India, these agreements and decisions need to be clinician-led, supported by national associations and mandated and funded by the government. Novel information technology (IT), of which there is no shortage in India, will form the backbone of the databases in order to capture data on all the patients. Not only is this vital for data quality, but also it will ensure a better understanding of the disease and procedural burden. To improve data quality, a process of validation must be built in and funded. Validated data of this volume that an Indian registry could provide, would easily become a global leader in congenital heart disease treatment monitoring, providing clinicians and researchers with the necessary tools to develop and deliver better healthcare. This will also provide the pioneering researchers with unique opportunities to develop better technology and techniques, which could be used globally. Important lessons can be learnt about the validation of acquired data. The Society of Thoracic Surgery (STS), European Association of Cardiothoracic surgery (EACTs) or more recently Congenital Cardiovascular Interventional Study Consortium (CCISC) have developed different types of data relating to surgery or catheter interventions. But all are based on a voluntary submission and validation is not carried out at every centre. As a result, institutional benchmarking is harder as there may be less confidence in the caseload ascertainment and data quality.

One disadvantage of the national database highlighted by the UK CCAD reporting is the lack of risk stratification other than by the procedure. Clinical condition and co-morbidities at the time of surgery do not play any part in the presentation of outcome data, but it is well recognised that these influence outcomes. In the UK, there is ongoing research work with CCAD in developing a variable life adjusted (VLAD) outcome tool, which would allow units to compare their outcomes with the national results. The use of VLAD tool has now also been mandated by each unit from 2014 onwards.\(^6\)

In the UK, since 2009, the congenital cardiac surgical services have been undergoing the single largest review of NHS specialist services to deliver improved outcomes and quality of care consistently across the whole country. The CCAD data has provided the backbone for the activity and outcome to inform this review. Unlike in the UK where the NHS delivers a free health service at the point of care, the current healthcare provision for patients with congenital heart disease is variable across India and is often dependent on the ability of the family to pay for the treatment, amongst other factors.\(^7\) Linking this to the burden of CHD patients on healthcare infrastructures, it is easy to understand why some clinicians and units may become reluctant to accept high risk complex cases. Access to healthcare and disease burden are never going to change unless accurate data are collected allowing units to truly compare themselves both nationally and internationally.

India has the opportunity to develop a world class registry, which combines diagnostic and procedural data. This would be the first such registry to look at congenital heart disease burden rather than focusing solely on procedural outcomes. With a population of 1.21 billion in 2011 census,\(^8\) any potential registry will shape not just local but global understanding of patients with congenital heart disease for generations to come. With availability of procedural data, the large volumes of cases would allow a more detailed and comprehensive review of outcome data in a much shorter time frame. Such a registry can deliver insights into congenital cardiac medicine and surgery that may potentially impact on the global provision of these services. This in turn can be an economic driver to grow the healthcare industry in India. Is Indian health care system, (clinicians, institutions, governments) ready for such a challenging commitment?

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