EDITORIAL

Braz J Cardiovasc Surg 2026;41(5): e20260509
https://doi.org/10.21470/1678-9741-2026-0509
ISSN: 1678-9741

Learning From Every Child: Why Brazil Needs a National Database for Pediatric Cardiac Surgery

Leonardo Augusto Miana[1,2], MD, PhD; Juan Pedro Upegui Passos[3], MS; Valdester Cavalcante Pinto Júnior,[2,4,5], MD, PhD; Fábio Binhara Navarro[2,6,7], MD, PhD

[1]Instituto do Coração (InCor), Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo, São Paulo, São Paulo, Brazil.
[2]Department of Pediatric and Congenital Cardiovascular Surgery, Sociedade Brasileira de Cirurgia Cardiovascular, São Paulo, São Paulo, Brazil.
[3]Faculdade de Medicina, Universidade Federal de Juiz de Fora, Juiz de Fora, Minas Gerais, Brazil.
[4]Department of Pediatric Cardiovascular Surgery, Instituto do Coração de Fortaleza, Fortaleza, Ceará, Brazil.
[5]Department of Pediatric Cardiovascular Surgery, Hospital de Messejana, Fortaleza, Ceará, Brazil.
[6]Department of Pediatric Cardiovascular Surgery, Hospital Pequeno Príncipe, Curitiba, Paraná, Brazil.
[7]Department of Cardiovascular Surgery, Universidade Federal do Paraná, Hospital de Clínicas, Curitiba, Paraná, Brazil.

Pediatric cardiac surgery is one of the most complex areas of modern medicine. It brings together fragile patients, rare anatomical conditions, high-risk procedures, advanced technology, and coordinated decisions among surgeons, cardiologists, intensivists, anesthesiologists, perfusionists, and nurses[1]. In this field, outcomes are significantly influenced not only by surgical technique but also by institutional organization, specialized care, and the systematic use of data to mitigate variability and improve clinical standards[2,3]. Consequently, the development of robust national databases has become essential for benchmarking performance and optimizing care delivery in both high-resource and developing healthcare systems[3].

This complexity is not merely theoretical. Worldwide, outcomes after congenital heart surgery vary substantially across countries, regions, institutions, and even programs within the same health system. Brazil is no exception. As Miana et al.[4] recently showed, Brazilian pediatric cardiac surgery still faces wide regional and institutional variability, reflecting differences not only in surgical expertise but also in access, infrastructure, referral patterns, case complexity, and continuity of care

In such a scenario, the question is no longer whether data should be collected. The real question is "How long can we continue to make decisions without a structured, national, reliable, and clinically meaningful database?".

The culture of multi-institutional databases in cardiovascular surgery did not appear overnight. It was born from an uncomfortable idea that if we perform high-risk operations, we must be willing to measure our results[5].

One of the most important milestones came from New York, United States of America. In the late 1980s, the New York State Department of Health began systematically collecting and analyzing outcomes after coronary artery bypass grafting[6]. By 1990, it publicly released hospital-level, risk-adjusted mortality data for cardiac surgery, becoming one of the earliest and most influential examples of public reporting in surgery. Despite initial controversy and professional discomfort, this structured approach led to a 41% reduction in risk-adjusted mortality within the first four years[7]. Over the following decades, these registries demonstrated that consistent data collection and public reporting not only identified performance gaps but also drove institutional improvements and safer surgical practices[6,8].

Soon after, the Society of Thoracic Surgeons (STS) developed what would become one of the most successful clinical registries in the world. The STS Adult Cardiac Surgery Database was launched in 1989 and gradually evolved from a professional quality-improvement tool into a major national platform for benchmarking, research, risk adjustment, and public reporting[9]. Today, the STS National Database includes millions of procedures, and participation exceeds 90% of adult and pediatric cardiac surgery centers in the United States of America[2,9].

The STS Database was not born fully mature; it took time, trust, standardization, leadership, cultural change, and the recognition that measuring outcomes was not a threat to surgeons, but a pathway to professional credibility and better care.

In pediatric cardiac surgery, one of the most painful turning points was the Bristol Royal Infirmary scandal. Between 1984 and 1995,

Correspondence Address:
Leonardo Augusto Miana
E-mail: leonardomiana@gmail.com

Editor-in-chief: Henrique Murad
Associate Editor: Not Assigned

How to cite: Miana LA, Passos JPU, Pinto Júnior VC, Navarro FB. Learning From Every Child: Why Brazil Needs a National Database for Pediatric Cardiac Surgery. Braz J Cardiovasc Surg. 2026;41(5):e20260509. doi:10.21470/1678-9741-2026-0509.

Article received on March 10th, 2026.
Article accepted on May 22nd, 2026.
Fast Track.

serious concerns emerged about outcomes after pediatric cardiac surgery at Bristol, United Kingdom, particularly for complex neonatal and infant procedures, with mortality rates significantly higher than in other centers[10]. The public inquiry, published in 2001 as the Kennedy Report, described failures in leadership, accountability, teamwork, monitoring, and transparency[11]. The report became a landmark in patient safety and led to a fundamental reorganization of pediatric cardiac services[11].

Bristol taught the congenital heart community a difficult lesson: poor outcomes are not only technical events. They may also reflect organizational silence, weak governance, lack of external comparison, and absence of reliable data. The United Kingdom responded with one of the most scrutinized systems for monitoring congenital heart surgery, followed today with a level of transparency and public accountability that would have been difficult to imagine before Bristol.

The evolution of outcome measurement and quality improvement in cardiac surgery, from the New York State reporting system to the proposed Brazilian national database, is summarized in Figure 1.

The message for Brazil is not that data exists to punish programs or expose individuals. Quite the opposite: data exists to protect patients, support teams, identify risks early, and help institutions improve before problems become tragedies.

Brazil is not starting from zero. ASSIST, described by Carmona et al.[12] as the first Brazilian initiative to build a collaborative quality-improvement program in pediatric cardiology and congenital heart disease, showed that Brazilian teams were willing to work together and think collectively about quality improvement[12]. Recent analyses of national data continue to show that, while regional variations persist, the path toward excellence requires institutionalizing these efforts through a unified national database[4].

However, despite these efforts, Brazil still lacks a permanent, national, comprehensive, professionally governed database for pediatric cardiac surgery. The Department of Pediatric Cardiovascular Surgery, together with the Ministry of Health, has been working to make such a database a reality. This initiative represents more than a technical project; it is a strategic step toward the maturity of the specialty. Recent policy analyses documented this gap and proposed a framework for reorganizing congenital heart disease care within the Sistema Único de Saúde (or SUS, the Brazilian Unified Health System), including a robust, centralized clinical database independent of administrative billing data[13].

A national database would allow Brazil to understand its reality with far greater precision. How many children require surgery each year? Where are they being treated? What are the outcomes by age, diagnosis, complexity, urgency, region, and institutional profile? Where do delays occur? Which centers need support? Which practices yield better results? Which children are never reaching surgery?

Without answers, planning remains fragile. With them, public policy becomes stronger, training more targeted, and quality improvement less dependent on impressions and more grounded in evidence.

A national pediatric cardiac surgery database should be seen not as a bureaucratic repository of numbers, but as a living learning system. Each case represents a child, a family, a team, and a clinical journey. Collected responsibly, these data transform individual experiences into collective knowledge. They can reveal patterns that no single institution can see alone: where mortality is improving, where complications are concentrated, where access is delayed, and where resources are insufficient. This cycle, from standardized collection to risk adjustment, benchmarking, feedback, quality improvement, and public policy, is anchored by

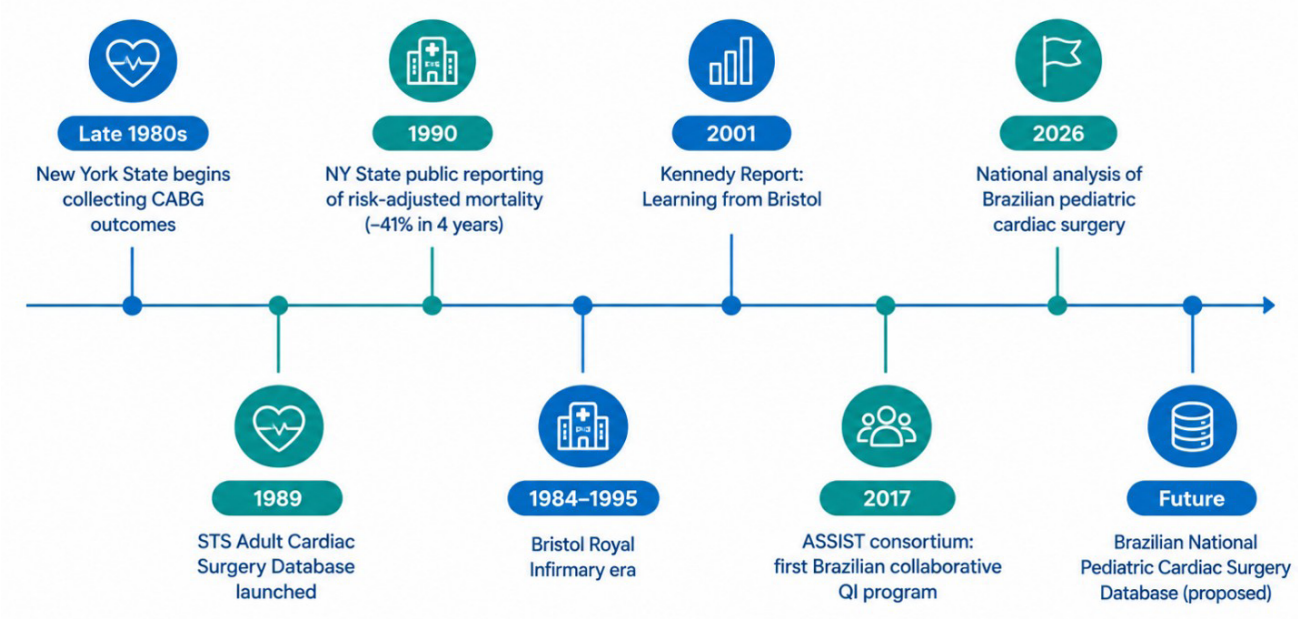

Figure 1 - *Timeline of key milestones in the development of outcome measurement and quality improvement in cardiac surgery, from the New York State cardiac surgery reporting system to the proposed Brazilian national database for pediatric cardiac surgery. CABG=coronary artery bypass grafting; NY=New York; QI=quality improvement; STS=Society of Thoracic Surgeons.*

professional governance, privacy, and ethics, as summarized in Figure 2.

This is particularly important in a country as large and unequal as Brazil. A national database can identify regional disparities and guide interventions to reduce them — supporting regionalization, referral pathways, centers of excellence, and smaller programs. It can also inform financing, workforce, telemedicine, and training decisions. A database is not only a scientific tool. It is also a tool for equity.

There is a common fear that databases reduce medicine to numbers. This fear is understandable, but it is incomplete. Poorly designed databases may indeed become simplistic. But well-designed clinical registries do the opposite: they help us understand complexity. In pediatric cardiac surgery, crude mortality alone is not enough. A serious database must include diagnosis, procedure, age, weight, prematurity, associated anomalies, surgical complexity, urgency, preoperative condition, postoperative complications, length of stay, reinterventions, and, whenever possible, follow-up. It must use standardized definitions and risk-adjustment methods. It must allow fair comparison, not superficial ranking. The purpose is not to create league tables. The purpose is to create learning.

A center with higher mortality may be treating sicker children, receiving late referrals, or working with insufficient intensive care unit resources. A center with excellent results may have practices that others can learn from. A national database allows these differences to be understood rather than guessed.

There is also a deep ethical reason for building a national database. Clinical data are not abstract. Each data point represents a child who underwent surgery, a family who trusted the system, and a team that made decisions under pressure. For this reason, data governance must be rigorous. Confidentiality, privacy, data protection, and responsible use of information are essential. The database must comply with ethical and legal standards, including Brazilian data protection principles. It must be professionally led, scientifically sound, and protected from political or commercial misuse.

At the same time, collecting data creates responsibility. If we identify a pattern of preventable risk and fail to act, the problem is no longer a lack of information. It becomes an omission. A national database must therefore be linked to action, feedback to centers, quality-improvement initiatives, training, technical support, and public policies that can reduce avoidable deaths.

The implementation of a Brazilian national pediatric cardiac surgery database will require surgeons and hospitals to trust that the project's purpose is improvement, not punishment. The success of STS and other mature registries depended not only on software, but on professional leadership. Surgeons must see themselves not as passive providers of information, but as owners of the quality-improvement process. The database must belong to the specialty, serve patients, and support the health system.

For the Sociedade Brasileira de Cirurgia Cardiovascular and its Department of Pediatric Cardiovascular Surgery, this is an opportunity to lead a transformative national movement. For the Ministry of Health, it is an opportunity to plan care based on real-world evidence. For hospitals, it is an opportunity to benchmark and improve. For families, it is a promise that the system is willing to look at itself honestly.

Artificial Intelligence Usage

The authors declare use of ChatGPT for English language review and illustration creation. The content produced by the artificial intelligence tool was revised and edited by the authors as necessary, and they take full responsibility for the content to be published.

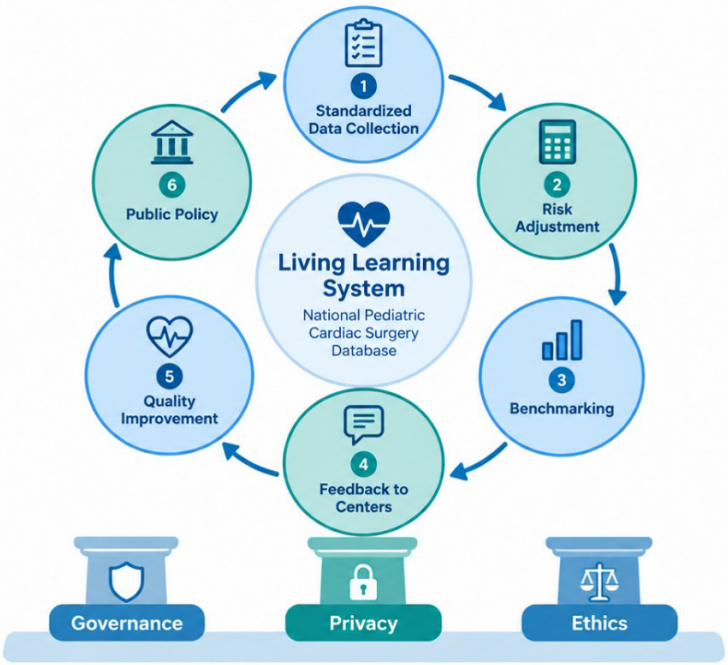

Figure 2 - *Conceptual framework of the proposed Brazilian national database for pediatric cardiac surgery as a living learning system. Standardized data collection, risk adjustment, benchmarking, feedback to centers, quality improvement, and public policy form a continuous cycle anchored by professional governance, data privacy, and ethics.*

REFERENCES

1. Backer CL, Overman DM, Dearani JA, Romano JC, Tweddell JS, Kumar SR, Marino BS, Bacha EA, Jaquiss RDB, Zaidi AN, Gurvitz M, Costello JM, Pierick TA, Ravekes WJ, Reagor JA, St Louis JD, Spaeth J, Mahle WT, Shin AY, Lopez KN, Karamlou T, Welke KF, Bryant R, Husain SA, Chen JM, Kaza A, Wells WJ, Glatz AC, Cohen MI, McElhinney DB, Parra DA, Pasquali SK. Recommendations for centers performing pediatric heart surgery in the United States. J Thorac Cardiovasc Surg. 2023;166(6):1782-1820. doi: 10.1016/j.jtcvs.2023.09.001.
2. Kumar SR, Goldstone AB, Heuerman H, Jacobs JP, O'Brien JE Jr, Pizarro C, Subačius H, Eghtesady P. The Society of Thoracic Surgeons Congenital Heart Surgery Database: 2024 Update on Outcomes and Research. Ann Thorac Surg. 2026;121(4):790-802. doi: 10.1016/j.athoracsur.2025.12.002.
3. Das D, Das S, Zheleva B, Sivalingam S, Croti UA, Cury B, Iyer KS. Quality Improvement in Congenital Heart Surgery Requires Data: Is This Asking too Much in Low- and Middle-Income Countries? World J Pediatr Congenit Heart Surg. 2026;17(6):834-842. doi: 10.1177/21501351261444019.
4. Miana LA, Jacobs JP, Passos JPU, Jatene MB. Regional Variation in Congenital Heart Surgery in Brazil: A National Database Analysis. World J Pediatr Congenit Heart Surg. 2026 Sep;17(5):592-602. doi: 10.1177/21501351261418275.
5. Makary M. Unaccountable: what hospitals won't tell you and how transparency can revolutionize health care. New York: Bloomsbury Press; 2012. 243 p.
6. Hannan EL, Kilburn H Jr, Racz M, Shields E, Chassin MR. Improving the outcomes of coronary artery bypass surgery in New York State. JAMA. 1994 Mar 9;271(10):761-6. PMID: 8114213.
7. Hannan EL, Kumar D, Racz M, Siu AL, Chassin MR. New York State's Cardiac Surgery Reporting System: four years later. Ann Thorac Surg. 1994;58(6):1852-7. doi: 10.1016/0003-4975(94)91726-4.
8. Hannan EL, Cozzens K, King SB 3rd, Walford G, Shah NR. The New York State cardiac registries: history, contributions, limitations, and lessons for future efforts to assess and publicly report healthcare outcomes. J Am Coll Cardiol. 2012;59(25):2309-16. doi: 10.1016/j.jacc.2011.12.051.
9. Iribarne A, Zwischenberger B, Hunter Mehaffey J, Kaneko T, Wyler von Ballmoos MC, Jacobs JP, Krohn C, Habib RH, Parsons N, Badhwar V, Bowdish ME. The Society of Thoracic Surgeons Adult Cardiac Surgery Database: 2024 Update on National Trends and Outcomes. Ann Thorac Surg. 2025;119(6):1139-1150. doi: 10.1016/j.athoracsur.2025.03.011.
10. Mayor S. Mortality for paediatric cardiac surgery at Bristol was twice that at other centres. BMJ. 2001;323(7305):125. PMID: 11463668; PMCID: PMC1120772.
11. Teasdale GM; Council of the Society of British Neurological Surgeons. Learning from Bristol: report of the public inquiry into children's heart surgery at Bristol Royal Infirmary 1984-1995. Br J Neurosurg. 2002;16(3):211-6. doi: 10.1080/02688690220148815.
12. Carmona F, Manso PH, Ferreira MN, Ikari NM, Jatene MB, Amato L, Turquetto AL, Caneo LF. Collaborative Quality Improvement in the Congenital Heart Defects: Development of the ASSIST Consortium and a Preliminary Surgical Outcomes Report. Braz J Cardiovasc Surg. 2017;32(4):260-269. doi: 10.21470/1678-9741-2016-0074.
13. Miana L, Zheleva B, Passos JPU, Mattos R, Damiano AP, Afiune JY, Horowitz ESK, Jatene MB. National Policy on Congenital Heart Disease: Reflections and Proposals for Strengthening Care in Brazil. Arq Bras Cardiol. 2026;123(8):e20260225. Portuguese, English. doi: 10.36660/abc.20260225.

This is an open-access article distributed under the terms of the Creative Commons Attribution License.