



The Children’s National Hospital Outcomes Registry: a plea for a benchmarking tool that provides longitudinal outcomes for patients and families

Editorial

Cite this article: Venna A, Haverty M, Kreutzer J, Mehta R, Fetch A, Tongut A, Desai M, Yerebakan C, and d’Udekem Y (2024). The Children’s National Hospital Outcomes Registry: a plea for a benchmarking tool that provides longitudinal outcomes for patients and families. *Cardiology in the Young*, page 1 of 3. doi: [10.1017/S1047951124026325](https://doi.org/10.1017/S1047951124026325)

Received: 22 April 2024
Revised: 6 August 2024
Accepted: 17 August 2024

Keywords:
Benchmarking; long-term outcomes; registry

Corresponding author:
Yves d’Udekem;
Email: yves.dudekem@childrensnational.org

Alyssia Venna, Mitchell Haverty, Janet Kreutzer, Rittal Mehta, Alix Fetch, Aybala Tongut, Manan Desai, Can Yerebakan and Yves d’Udekem

Division of Cardiac Surgery, Children’s National Hospital, Washington, DC, USA

Abstract

Surgical advancements in paediatric cardiovascular surgery have led to improved survival rates for those patients with the most complex CHDs leading to greater numbers of patients who are living well into adulthood. Despite this new era of long-term survival, our current reporting systems continue to focus largely on using short-term postoperative outcomes as the criteria to both rate and rank hospitals. Using such limited criteria to rate and rank hospitals may mislead the intended audiences: patients and families. The goal of this article is to describe the creation of a local benchmarking report which aims to retrospectively review long-term outcomes from our single centre. This report is updated annually and published on our cardiac surgery webpage in an effort to be as transparent as possible for our patient and family communities.

The need for information

Patients with complex congenital heart anatomies and their families deserve access to fully transparent information regarding their condition and the potential impact that surgery will have on their life. In fact, parents of children with CHD report that they prefer to have more information than what is currently being offered to them.¹⁻³ Once parents and families receive information from their cardiac care team, many opt to seek additional information about their condition online through social media, various websites, and video platforms.⁴ On the other hand, a majority of expectant parents who are told their child will have a higher mortality risk tend to avoid online statistics and trust that their providers will share all necessary information with them.⁵ Overall, parents prefer more information regarding what to expect in the long term, obligating us to both provide as much as we can and to make data more accessible to our families in all formats.³ While current national databases such as the Society of Thoracic Surgeons Congenital Heart Surgery Database and Pediatric Cardiac Critical Care Consortium collect outcomes data for these patients, these reports are only based on short-term data, and the results are not readily accessible to our patient populations. Better systems are needed to improve communication of long-term outcomes and to optimise care.⁶

The bias of looking only at short-term outcomes

Limitations exist in the data that are readily available to our patient populations. Patients and families rely on the *U.S. News & World Report* to make choices about where they should go to receive what they interpret as the “best” care. The *U.S. News & World Report* provides the public with a score of each cardiac centre in terms of outcomes and experiences, numbers of patients and procedures, key programmes, services and staff, professional recognition, quality improvement efforts, and patient support.⁷ However, there are potential shortfalls of this report that should be made known to those who are primarily accessing it. Adjusted mortality rate from the Society of Thoracic Surgeons Congenital Heart Surgery Database is given the highest weight in the *U.S. News & World Report* ranking calculation even though the Society of Thoracic Surgeons believes that adjusted mortality rate metric is appropriate to use for rating hospitals but not ranking hospitals. The Society of Thoracic Surgeons uses adjusted mortality rate to rate hospitals by categorising their performance into the following three categories: “as expected,” better than expected,” or “worse than expected.” Further, there are other concerns about the weight that is given to other factors. For example, centres that have a heart transplantation programme are scored higher than those that don’t regardless of patient outcomes, which motivates centres in areas that are already oversaturated with transplant programmes to create one simply to increase their ranking. With its most recent release, the *U.S. News & World Report* has begun to incorporate health equity measures. Having measures

© The Author(s), 2024. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution and reproduction, provided the original article is properly cited.



related to the types of populations that we are serving is indeed a step in the right direction; however, these measures are not being factored into the ranking it provides.⁸ Further, the *U.S. News & World Report* does not capture long-term outcomes and does not consider how well patients are being followed years after their cardiac procedures, in all likelihood because of the fact that no multi-institutional database currently exists that captures these data! Such longitudinal outcomes would be a much better indication of the type of care that we as cardiac centres are providing to our patients and families.

Since the emergence of corrective congenital heart surgery in the early 1900s, we have made significant strides in improving mortality, though our rates of improving morbidities have plateaued and vary greatly across centres.^{9,10} Placing too much emphasis on attaining a lower short-term mortality might impede innovation and lead to potentially worse overall mortality by causing centres to perform less risky procedures and perhaps even turn away those seeking treatment for conditions that might have a lower chance of survival.^{11,12}

Accountability and its current shortfalls

In his memoir describing his 40 years as a paediatric cardiac surgeon, Marc de Leval refers to the number one quality that every centre of excellence should possess: accountability.¹³ To elaborate on this, he references the famed Florence Nightingale's pioneering work as a strong advocate of information-based medicine. She is identified as the first one to advocate for public reporting but already, in the 19th century, she recognised the limitation of focusing exclusively on short-term outcomes and identified the pitfalls of "risk-adjusted outcomes, data manipulation and inadequacy of using mortality as a single outcome measure."¹³ To be accountable, we must constantly assess the care that we provide and present areas to improve upon in a collaborated effort across centres.¹⁴ In our practice, we know that there is a wide variation in surgeon and centre techniques, especially for the most complex procedures.^{10,15} Because it is difficult to conduct risk-benefit analyses on such small numbers in single centres, we must work together to standardise efforts across institutions and over longer periods of time.¹⁵ As we make the case for more heart centres to provide more detailed, transparent information to the public, we can actively begin to assess our own failures and successes. The end goal of this is collaboration to make quality improvements within and among our heart centres.

Design of the Children's National Hospital Cardiac Surgery Outcomes Registry

The Children's National Hospital Cardiac Surgery Outcomes Registry is a longitudinal retrospective and prospective registry of all patients who have had cardiac surgery or an interventional catheterisation procedure in our Heart Center in Washington, DC. The registry has been granted a waiver of consent by the Institutional Review Board. To date, results from our five benchmark operations were initially reviewed and included aortic arch repair, arterial switch operation, atrioventricular septal defect repair, Fontan operation, and tetralogy of Fallot repair. These conditions have been the recent subject of 23 projects that are at various stages of publication.¹⁶ Follow-up includes data ranging from 1989 to present. Our intention is to prospectively update all follow-up data in the registry and analyse our outcomes on an annual basis. We hope to cover most of the lesions that are repaired

in our centre. Freedom from mortality and reintervention is now presented on our Cardiac Surgery Division website and will be updated annually. Having this information readily accessible to parents when they are seeking care helps prepare them for the lifetime commitment of raising a child with CHD and gives them an idea of what to expect from their specific heart centre across longer periods of time.

Additionally, as part of this registry, we have developed a protocol for assessing long-term outcomes of our lost-to-follow-up patients. Initially, we sought to contact the last known primary care or referring provider for those patients who have not been seen in 18 months. After only obtaining clinically relevant information back from 2% of providers, we created a justification to develop a call back programme to reach out directly to patients for clinical purposes. A clinical nurse has been tasked with calling each lost-to-follow-up patient to identify their clinical needs and to capture data for research purposes if they agreed. This process was able to capture more patients, with some who were not aware that they should have returned for follow-up each year. For those whom we have still not been able to get in contact with, we have also justified linking our data to the National Death Index, which is a centralised resource that was created by the Centers for Disease Control and Prevention and the National Center for Health Statistics to house all death information in the United States. As part of our call back programme and linkage to the National Death Index, we will continue to prospectively assess our long-term outcomes and proactively identify interventions to ensure follow-up with our patients.

Future perspectives

Reporting on long-term outcomes will allow us to better examine the quality of care we provide by allowing benchmarking of our work on a larger scale rather than only short-term outcomes related to hospital stay. Our local Children's National Hospital Cardiac Surgery Outcomes Registry will allow us to follow our progress and will provide much requested information for patients and families. Ultimately, we hope that it will facilitate the identification of gaps in care and discover pathways to overcome barriers to access care.

Competing interests. The authors declare none.

References

1. Arya B, Glickstein JS, Levasseur SM, Williams IA. Parents of children with congenital heart disease prefer more information than cardiologists provide. *Congenit Heart Dis* 2013; 8: 78–85. DOI: [10.1111/j.1747-0803.2012.00706.x](https://doi.org/10.1111/j.1747-0803.2012.00706.x).
2. Lee BR, Koo HY. Needs for post-hospital education among parents of infants and toddlers with congenital heart disease. *Child Health Nurs Res* 2020; 26: 107–120. DOI: [10.4094/chnr.2020.26.1.107](https://doi.org/10.4094/chnr.2020.26.1.107).
3. Gramszlo C, Karpyn A, Christofferson J, et al. Meeting parents' needs for education and preparation following congenital heart disease diagnosis: recommendations from a crowdsourced study. *Am J Perinatol* 2022; 12: e446–e455. DOI: [10.1055/a-1906-8786](https://doi.org/10.1055/a-1906-8786).
4. Chou FL, Donovan DJ, Weller RJ, Fremed MA, Glickstein JS, Krishnan US. Disparities in resource utilisation by families of children with cardiac conditions. *Cardiol Young* 2024; 34: 325–333. DOI: [10.1017/S1047951123001634](https://doi.org/10.1017/S1047951123001634).
5. Harris KW, Hammack-Aviran CM, Brelsford KM, Kavanaugh-McHugh A, Clayton EW. Mapping parents' journey following prenatal diagnosis of CHD: a qualitative study. *Cardiol Young* 2023; 33: 1387–1395. DOI: [10.1017/S1047951122002505](https://doi.org/10.1017/S1047951122002505).

6. Spector LG, Menk JS, Knight JH et al. Trends in long-term mortality after congenital heart surgery. *J Am Coll Cardiol* 2018; 71: 2434–2446. DOI: [10.1016/j.jacc.2018.03.491](https://doi.org/10.1016/j.jacc.2018.03.491).
7. US News & World Report. FAQ: How and Why We Rank and Rate Hospitals. Available at: <https://health.usnews.com/health-care/best-hospitals/articles/faq-how-and-why-we-rank-and-rate-hospitals>
8. Lobo TN, Motairek I, Perzynski A, Al-Kindi S. Health equity metrics for the US news and world report honor roll hospitals. *J Gen Intern Med* 2023; 38: 2416–2418. DOI: [10.1007/s11606-023-08167-7](https://doi.org/10.1007/s11606-023-08167-7).
9. Gaies M, Pasquali SK, Banerjee M et al. Improvement in pediatric cardiac surgical outcomes through inter-hospital collaboration. *J Am Coll Cardiol* 2019; 74: 2786–2795. DOI: [10.1016/j.jacc.2019.09.046](https://doi.org/10.1016/j.jacc.2019.09.046).
10. Pasquali SK, Thibault D, O'Brien SM et al. National variation in congenital heart surgery outcomes. *Circulation* 2020; 142: 1351–1360. DOI: [10.1161/CIRCULATIONAHA.120.046962](https://doi.org/10.1161/CIRCULATIONAHA.120.046962).
11. Jonas RA. WJPCHS presidential address: threats to the continuing globalization of early primary repair. *World J Pediatr Congenit Heart Surg* 2019; 10: 58–65. DOI: [10.1177/2150135118815028](https://doi.org/10.1177/2150135118815028).
12. Collins RT, Shin AY, Hanley FL. Sacrificing the future for the sake of the present. *Ann Surg* 2020; 271: 225–226. DOI: [10.1097/SLA.00000000000003432](https://doi.org/10.1097/SLA.00000000000003432).
13. de Leval M. *Humanity and Humility: 40 Years in Children's Heart Surgery*, Amazon Digital Services LLC, KDP Print, US.2020.
14. Nightingale F. *Notes on Nursing: What It Is, and What It Is Not*. Cambridge Library Collection-History of Medicine., Cambridge University Press, 2010, 223–223. DOI: [10.1017/CBO9780511751349.018](https://doi.org/10.1017/CBO9780511751349.018).
15. Jacobs JP, O'Brien SM, Pasquali SK et al. Variation in outcomes for benchmark operations: an analysis of The Society of Thoracic Surgeons Congenital Heart Surgery Database. *Ann Thorac Surg* 2011; 92: 2184–2192. DOI: [10.1016/j.athoracsur.2011.06.008](https://doi.org/10.1016/j.athoracsur.2011.06.008).
16. Ozturk M, Tongut A, Sterzbecher V et al. Repair of the complete atrioventricular septal defect-impact of postoperative moderate or more regurgitation. *Interdiscip Cardiovasc Thorac Surg* 2024; 38: ivae053. DOI: [10.1093/icvts/ivae053](https://doi.org/10.1093/icvts/ivae053).