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*Original Article*

# The development of a congenital heart programme quality dashboard to promote transparent reporting of outcomes

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**Abstract** In 2001, the Institute of Medicine identified healthcare transparency as a necessity for re-designing a quality healthcare system; however, despite widespread calls for publicly available transparent data, the goal remains elusive. The transparent reporting of outcome data and the results of congenital heart surgery is critical to inform patients and families who have both the wish and the ability to choose where care is provided. Indeed, in an era where data and means of communication of data have never been easier, the paucity of transparent data reporting is paradoxical. We describe the development of a quality dashboard used to inform staff, patients, and families about the outcomes of congenital heart surgery at the Stollery Children's Hospital.

Keywords: Public; transparency; quality; dashboard; paediatric; cardiac; critical care

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IN 2001, THE INSTITUTE OF MEDICINE OUTLINED healthcare transparency as one of ten principles necessary for the re-design of a healthcare system that emphasises quality.[1] The institute defined this as a system that should make available to patients and families information that enables them to make informed decisions when selecting a health plan, hospital, or clinical practice, or when choosing among alternative treatments. The Institute of Medicine advocated for inclusion of information describing the system's performance on safety, evidence-based practice, and patient satisfaction.

Nevertheless, whether motivated by fear, political, or financial factors, widespread adoption of transparent reporting has not been widely implemented.[2–5] The reluctance to make transparent outcome data available to patients and families is a paradox in an era when data are so readily acquired and communicated. Indeed, the opportunity to harness outcome data to improve healthcare quality by direct and unambiguous communication with patients has never been greater. The importance of transparent outcomes data collection and communication is especially relevant in the field of congenital heart surgery.

Despite advances in surgical techniques and medical management of children with congenital heart disease, the goal of zero mortality and morbidity remains elusive; however, transparent communication of outcomes and adverse events across centres would permit wide adoption of consistently successful approaches and the opportunity to focus on areas that require improvement across congenital cardiac programmes, as well as locally.

Databases from organisations such as the Society of Thoracic Surgeons, the Paediatric Cardiac Critical Care Consortium (PC4), and the Virtual PICU Systems (VPS) allow individual centres for congenital heart surgery to benchmark their own programmatic outcomes and to learn from centres that have better outcomes.[6] Although this collegial and transparent collaboration remains a relatively new approach to

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benchmarking and outcome improvement, the issue of public transparency remains contentious.

The transparent reporting of outcomes to the general public is not widespread and only a few programmes across North America make this information available to the general public.[7,8] Recently, reporters in the media have called for the universal adoption of public reporting to ensure that patients and families are well informed of the outcomes of high-risk congenital heart surgery. Therefore, we describe the development of a Pediatric Cardiac Intensive Care Unit Quality Dashboard with which we report our congenital heart programme's metrics of quality to the general public.

## Materials and methods

### *Defining the metrics*

Key stakeholders in the congenital heart programme were polled to identify metrics believed to be of importance to both caregivers and patients and families. We sought to identify standards that were nationally defined and accepted, allowing for equivalent benchmarking. Where database outcomes were utilised, we ensured compliance with the individual database reporting regulations. We considered metrics that were both already being collected and those that would require new collection methods.

### *Family-centred care council consultation*

Once the metrics had been identified, we collaborated with our institution's Family-Centred Care Council. The Family-Centred Care Council works on family-centred care priorities for our institution, including peer support, education and skill development for staff and physicians, decision making in care, and improving family experience and hospital services. We sought to determine the following:

- whether the format was easy to read and was understandable
- whether the information would be of value to the families

## Results

### *Defining the metrics*

From the information collected from stakeholders, it was clear that two groups of metrics emerged: those with nationally accepted definitions that could be benchmarked against and those with local importance (Table 1).

As indicated, there were metrics that were identified that were not being tracked in an accurate and consistent manner. For these outcomes, specific data collection tools were created (appendix 1) and subsequently were monitored for compliance. The data collected were verified by a secondary source at an arm's length to ensure agreement with established definitions.

### *Family-Centred Care Council consultation*

Following the consultation with the Family-Centred Care Council, the dashboard was altered to make it easier to understand by the layperson. A legend was included that described the different metrics that contained medical jargon, as well as an explanation of the purpose of the dashboard was included.

Table 1. Metrics identified for the Pediatric Cardiac ICU Quality Dashboard.

| Metric | Collected at the outset of dashboard creation | Data collection source |
|---|---|---|
| National benchmarkable metrics | | |
| Overall cardiac survival | ✓ | STS Database |
| STAT Category 5 survival | ✓ | STS Database |
| Length of stay for each benchmark operation | ✓ | STS Database |
| Surgical volume | ✓ | STS Database |
| Catheter-acquired urinary tract infections | | *Physician Checklist |
| Central line-associated blood stream infections | ✓ | Infection Control |
| Unplanned extubations | | *Physician Checklist |
| Ventilator-acquired pneumonias | | *Physician Checklist |
| Pressure-related ulcers | | *Physician Checklist |
| Local metrics | | |
| Surgeries postponed due to PCICU | ✓ | |
| # of transferrable patients who do not receive beds | | *Charge Nurse Tracking |
| Re-admission within 48 hours of discharge | | *Physician Checklist |
| Hand hygiene | ✓ | |

STAT = STS-EACTS Mortality Category; # = number; STS = Society of Thoracic Surgeons
*Denotes a tool developed specifically as a result of dashboard creation

The dashboard was altered and re-examined by the council, until finally approved.

When asked whether the information provided in the dashboard would be of value, the consultation with the Family-Centred Care Council provided valuable insight. What follows are several excerpts from their comments:

Comment 1.

> "Yes, we do think that this info would be interesting for families. Families are given all sorts of probabilities as they go along through the process... it is nice to see the actual outcomes from the Stollery".

Comment 2.

> "… I think that staff often are reminded of the worst case scenarios that they encounter in practice as these situations have the tendency to stick in their memories... transparent statistics such as these are a great reinforcer for what "we" are doing well, and what "we" could do better.

Comment 3.

> "I love, love, love this idea and think it will of great interest to families!"

Comment 4.

> "Love love love the hand hygiene section!!"

Comment 5.

> "I'd love to see this in PICU and NICU as well!"

Not all comments were positive as one family member did comment that the information provided might be overwhelming but still should be displayed in some format.

### *The quality dashboard*

Once all the information had been collected from the Family-Centred Care Council Consultation, a visual representation of the dashboard was created (Fig 1a). In order to provide context, a description (Fig 1b) and associated definitions (Fig 1c) accompanied the dashboard.

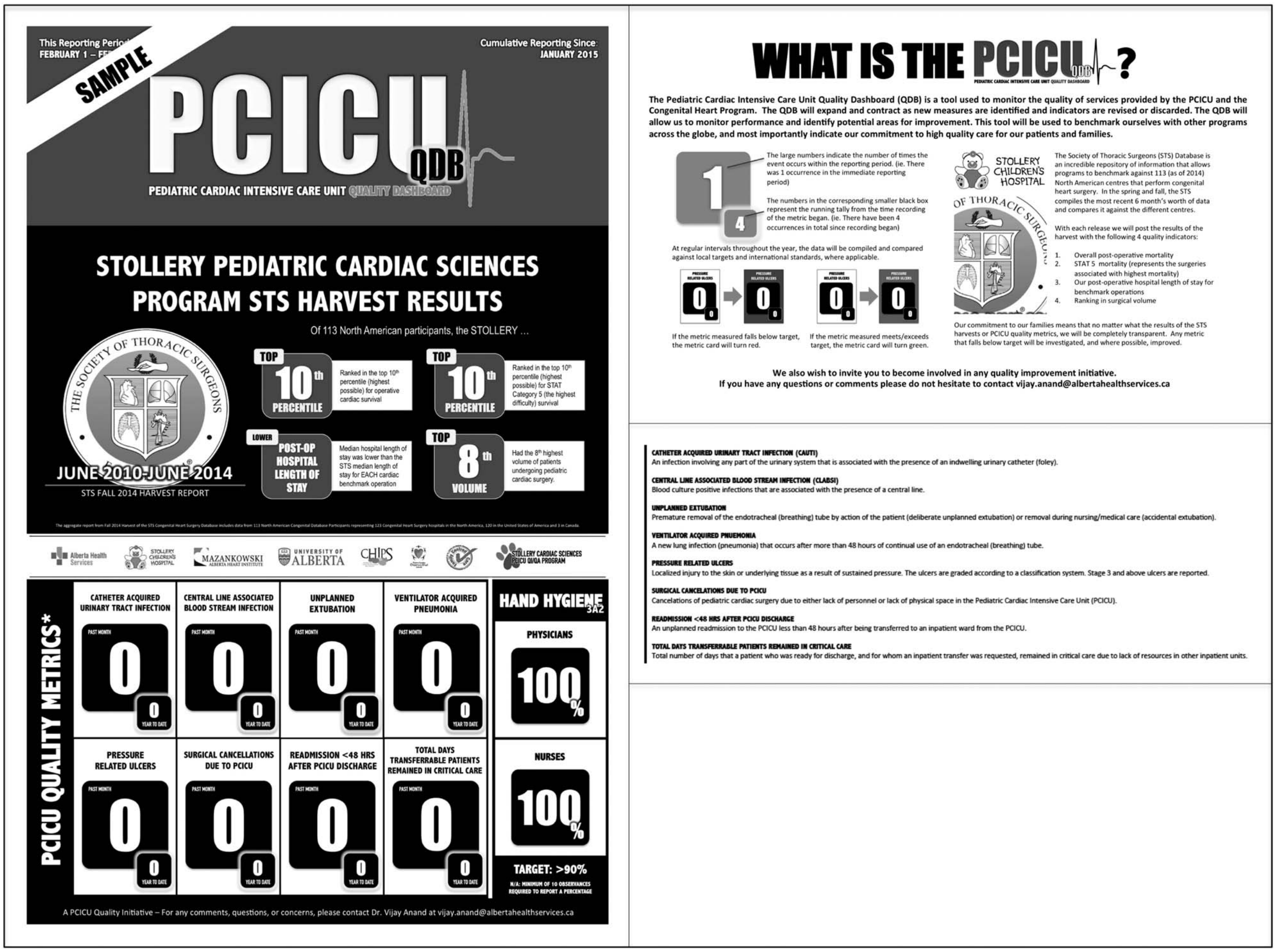
This dashboard is updated on a monthly basis and sent out to key stakeholders in the congenital heart programme, including the Family-Centred Care Council and each referral centre within the Western Canadian Children's Heart Network. The dashboard is accessible to the general public in various targeted areas within the hospital where it is visible to all staff, parents, and visitors. Upon completion of our website, the dashboard will also be made available on the world wide web. At regular intervals, the cumulative results are compared against national rates, and are also represented on the dashboard via a colour-coded system. When a quality metric is identified as concerning, we conduct a thorough investigation, and if indicated quality improvements projects are initiated.

## Discussion

The transparent reporting of both adverse and positive outcomes has been a topic of discussion within the medical community for a long time. There have been advocates for complete transparency in research[9,10] and informed consent[11,12] as well as the disclosure of medical error[13–15] within the medical community; however, patient advocacy groups have stimulated public interest and have fuelled the discussion and joined with those in the medical profession in favour of full disclosure. We suggest that complete transparent reporting of outcomes is critical for the development of quality-improvement programmes and describe our institution's development of a tool used for public transparency.

The Stollery Children's Hospital's Family-Centred Care Council was a willing partner in the development of the dashboard and indeed is instrumental in the acceptance and wider promotion of transparency in reporting outcomes. Families who look after sick children with complex illnesses become educated and knowledgeable about the outcomes of their children in a very short time. In addition, access to social media sites and parent-written blogs make it possible for the enquiring parent to discover relatively easily at least anecdotal outcomes both locally and in other centres. Thus, consolidating multiple metrics that referred to complications of treatment or adverse outcomes into one document rather than being overwhelming for families was, in contrast, well received and acknowledged as a positive effort on our part to improve quality of care in a population of children with complex illnesses and multiple co-morbidities. The transparent and full disclosure of our adverse events may reduce the spread of misinformation through anecdotal reporting via unmonitored information streams in the public domain.

Some may argue that transparency is infinitely more palatable when outcomes are good; however, it is important to note that our dashboard reported results that were both favourable and adverse – for example, 6 months into our dashboard's existence, our benchmarking revealed a higher-than-desired rate of central line-associated blood stream infections. This red flag was not hidden from public view, but instead was highlighted as a concern. A quality improvement project was initiated that was communicated publicly.



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FEBRUARY 1 – FE

SAMPLE

Cumulative Reporting Since:
JANUARY 2015

PCICU QDB
PEDIATRIC CARDIAC INTENSIVE CARE UNIT QUALITY DASHBOARD

STOLLERY PEDIATRIC CARDIAC SCIENCES
PROGRAM STS HARVEST RESULTS

Of 113 North American participants, the STOLLERY …

JUNE 2010-JUNE 2014
STS FALL 2014 HARVEST REPORT

TOP 10th PERCENTILE — Ranked in the top 10th percentile (highest possible) for operative cardiac survival

TOP 10th PERCENTILE — Ranked in the top 10th percentile (highest possible) for STAT Category 5 (the highest difficulty) survival

LOWER POST-OP HOSPITAL LENGTH OF STAY — Median hospital length of stay was lower than the STS median length of stay for EACH cardiac benchmark operation

TOP 8th VOLUME — Had the 8th highest volume of patients undergoing pediatric cardiac surgery.

The aggregate report from Fall 2014 Harvest of the STS Congenital Heart Surgery Database includes data from 113 North American Congenital Database Participants representing 123 Congenital Heart Surgery hospitals in the North America, 120 in the United States of America and 3 in Canada.

PCICU QUALITY METRICS*

| CATHETER ACQUIRED URINARY TRACT INFECTION | CENTRAL LINE ASSOCIATED BLOOD STREAM INFECTION | UNPLANNED EXTUBATION | VENTILATOR ACQUIRED PNEUMONIA |
|---|---|---|---|
| PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 |
| **PRESSURE RELATED ULCERS** | **SURGICAL CANCELLATIONS DUE TO PCICU** | **READMISSION <48 HRS AFTER PCICU DISCHARGE** | **TOTAL DAYS TRANSFERRABLE PATIENTS REMAINED IN CRITICAL CARE** |
| PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 | PAST MONTH 0<br>YEAR TO DATE 0 |

HAND HYGIENE 3A2
PHYSICIANS 100%
NURSES 100%
TARGET: >90%
N/A: MINIMUM OF 10 OBSERVANCES REQUIRED TO REPORT A PERCENTAGE

A PCICU Quality Initiative – For any comments, questions, or concerns, please contact Dr. Vijay Anand at vijay.anand@albertahealthservices.ca

WHAT IS THE PCICU QDB?
PEDIATRIC CARDIAC INTENSIVE CARE UNIT QUALITY DASHBOARD

The Pediatric Cardiac Intensive Care Unit Quality Dashboard (QDB) is a tool used to monitor the quality of services provided by the PCICU and the Congenital Heart Program. The QDB will expand and contract as new measures are identified and indicators are revised or discarded. The QDB will allow us to monitor performance and identify potential areas for improvement. This tool will be used to benchmark ourselves with other programs across the globe, and most importantly indicate our commitment to high quality care for our patients and families.

The large numbers indicate the number of times the event occurs within the reporting period. (ie. There was 1 occurrence in the immediate reporting period)

The numbers in the corresponding smaller black box represent the running tally from the time recording of the metric began. (ie. There have been 4 occurrences in total since recording began)

At regular intervals throughout the year, the data will be compiled and compared against local targets and international standards, where applicable.

If the metric measured falls below target, the metric card will turn red.

If the metric measured meets/exceeds target, the metric card will turn green.

The Society of Thoracic Surgeons (STS) Database is an incredible repository of information that allows programs to benchmark against 113 (as of 2014) North American centres that perform congenital heart surgery. In the spring and fall, the STS compiles the most recent 6 month's worth of data and compares it against the different centres.

With each release we will post the results of the harvest with the following 4 quality indicators:

1. Overall post-operative mortality
2. STAT 5 mortality (represents the surgeries associated with highest mortality)
3. Our post-operative hospital length of stay for benchmark operations
4. Ranking in surgical volume

Our commitment to our families means that no matter what the results of the STS harvests or PCICU quality metrics, we will be completely transparent. Any metric that falls below target will be investigated, and where possible, improved.

We also wish to invite you to become involved in any quality improvement initiative.
If you have any questions or comments please do not hesitate to contact vijay.anand@albertahealthservices.ca

**CATHETER ACQUIRED URINARY TRACT INFECTION (CAUTI)**
An infection involving any part of the urinary system that is associated with the presence of an indwelling urinary catheter (foley).

**CENTRAL LINE ASSOCIATED BLOOD STREAM INFECTION (CLABSI)**
Blood culture positive infections that are associated with the presence of a central line.

**UNPLANNED EXTUBATION**
Premature removal of the endotracheal (breathing) tube by action of the patient (deliberate unplanned extubation) or removal during nursing/medical care (accidental extubation).

**VENTILATOR ACQUIRED PNUEMONIA**
A new lung infection (pneumonia) that occurs after more than 48 hours of continual use of an endotracheal (breathing) tube.

**PRESSURE RELATED ULCERS**
Localized injury to the skin or underlying tissue as a result of sustained pressure. The ulcers are graded according to a classification system. Stage 3 and above ulcers are reported.

**SURGICAL CANCELATIONS DUE TO PCICU**
Cancelations of pediatric cardiac surgery due to either lack of personnel or lack of physical space in the Pediatric Cardiac Intensive Care Unit (PCICU).

**READMISSION <48 HRS AFTER PCICU DISCHARGE**
An unplanned readmission to the PCICU less than 48 hours after being transferred to an inpatient ward from the PCICU.

**TOTAL DAYS TRANSFERRABLE PATIENTS REMAINED IN CRITICAL CARE**
Total number of days that a patient who was ready for discharge, and for whom an inpatient transfer was requested, remained in critical care due to lack of resources in other inpatient units.

Figure 1.
*(**a**) The Pediatric Cardiac Intensive Care Unit Quality Dashboard. (**b**) A description of the background and rationale for the Dashboard. (**c**) Definition of quality outcomes.*

We would suggest that public display of the dashboard has had the unexpected and unintended outcome of improving bedside interest in quality improvement. Since the inception of the reporting, there has been a steady increase in both interest in the information provided and the bedside tracking of outcomes. This in turn has led to a better investigation of adverse outcomes and the introduction of new metrics to better track the outcomes of our patients. We believe that the inclusion of locally specific metrics played a large part in this.

A limitation of our dashboard is that, although it focusses heavily on surgical and ICU outcomes, there is a paucity of quality indicators in other key areas within our programme – namely, ambulatory paediatric cardiology and the inpatient ward are currently under-represented. Although these metrics were certainly discussed, we were not able to achieve consistent reporting, and thus they have not been included at present. In the near future, we hope to address the deficiencies outlined.

We fully support recent calls for public transparency in the reporting of outcomes and describe the process through which we have contributed a method of publicly displaying the outcomes at our centre. Empowering patients and families who entrust their loved ones into our care is a humbling but ultimately rewarding endeavour that builds rather than diminishes trust. Declaring both our successes and failures may expose our vulnerability; however, without that transparent exposition, the ability to improve the care we deliver becomes infinitely harder. We firmly believe that families who give their child to our care deserve the right to be informed of all potential outcomes, and more specifically the local outcomes achieved.

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## Conflicts of Interest

None.

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