Hidden Figures: The Value of Outcome Data Transparency

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Disclosures

• We have no relevant financial relationships with any of the products or services discussed today
• We do not intend to discuss unapproved or investigative use of commercial products
Data-driven decision making
Patient Engaged Care

Paternalistic  Patient-Centered  Patient Engaged
Patient Engaged Care

Providing the **opportunity** and **information** necessary to actively participate in the care of your child.
A Family’s Perspective

- Feelings
- Trust
- Family
- Travel
- Finances
- Data
Not just for those “in the know.”

All parents deserve information that is
• Accurate
• Accessible
• Relevant
• Effectively communicated
Why Transparency of Outcomes?

- Outcomes vary significantly between programs
- Not all hospitals report outcomes
- Not all outcome data is reported in the same manner
- Differences in quality and outcomes can mean:
  - A child’s life is lost unnecessarily
  - A child’s quality of life is impacted
  - The family’s life is forever changed
  - An increase in medical care needs
  - An increase in financial strain
Data as part of the conversation

- Removes emotional bias
- Helps build trust
- Helps improve outcomes
- Does not provide easy answers
CALL TO ACTION:
RECOMMENDATIONS FOR CHANGE

Achieving transparency at all levels in health care is a daunting task. It will require effort from all stakeholders: CEOs and leaders of health care organizations; doctors, nurses, and other clinicians; government agencies and regulators; private organizations; payers; and many more. We set out here the recommendations of the NPSF Lucian Leape Institute Roundtable on Transparency for action around common concerns and in each of the four domains discussed earlier.

Actions for All Stakeholders

1. Ensure disclosure of all financial and nonfinancial conflicts of interest.
2. Ensure patients have access to reliable, unbiased information presented in a form that is useful to them.
3. Consider carefully the perspective and needs of patients and families when displaying or presenting data.
4. Create and maintain organizational cultures that are supportive of transparency at all levels.
5. Share lessons learned and adopt best practices from peer organizations where feasible.
6. Expect all clinicians, organizational leaders, and board members to have core competencies regarding accurate and truthful communication with patients, families, other clinicians and organizations, and the public.
A Commitment to Transparency Between Clinicians and Patients

The commitment of CCH to transparency with patients was tested in 2001, when data from the Cystic Fibrosis Foundation showed that CCH—previously believed to be among the top in the country—actually ranked at the 20th percentile for cystic fibrosis (CF) care. According to Anderson, organizational leaders were anxious about revealing this information to the parents of patients with CF, but pressed forward because of their commitment to the organizational vision of being the leader in child health.

The hospital called a meeting of the parents, shared the data, and offered to assist them in finding care elsewhere, if they desired. Alternatively, if the parents elected to stay with CCH, they could help the organization improve. All of the families chose to stay at CCH.\textsuperscript{48} The organization applied best practices gleaned from top CF centers in the country and radically changed CF care. Today, the program consistently achieves key performance goals of cystic fibrosis care (e.g., relating to lung function and nutritional status) that are well above the national average and is ranked within the top five pediatric hospitals in the United States for pulmonary care.\textsuperscript{49–50}
Public Reporting

(Leonardi, McGory & Ko, 2007)
Public Reporting

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Website A</th>
<th>Website B</th>
<th>Website C</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Best</td>
<td>Average</td>
<td>Best</td>
</tr>
<tr>
<td>2</td>
<td>Worst</td>
<td>Best</td>
<td>Best</td>
</tr>
<tr>
<td>3</td>
<td>Not reported</td>
<td>Worst</td>
<td>Worst</td>
</tr>
<tr>
<td>4</td>
<td>Worst</td>
<td>Not reported</td>
<td>Best</td>
</tr>
</tbody>
</table>

(Leonardi, McGory & Ko, 2007)
Question 1. Improvements in quality of health care, including improvements in health care delivery structure or processes or patient outcomes.

Question 2. Harms, including any unintended negative consequence or adverse events for all populations.

Question 3. Changes in health care delivery structures and processes, including QI activities.

Question 4. Changes in the behavior of patients or their representatives, or purchasers of health care, particularly selection of an individual clinician or organization for health care.

Questions 5 and 6. Evidence that outcomes listed above are affected by characteristics of the reports and contextual factors.
Public Reporting (AHRQ 2012)

- PR is associated with improvement in health care performance measures.
- QI measures that are publicly reported improve over time.
- No evidence that PR affects the selection of health care providers by patients.
- Studies of health care providers’ response to PR suggest they engage in activities to improve quality when performance data are made public.
- Characteristics of the intervention and the context were rarely studied or even described.
- The amount of research on harms is limited and most studies do not confirm the potential harm.
Public Reporting (WHO 2014)

To increase use of publicly reported quality information for user choice, key considerations should include:

• Display relevant information
• Indicators to match the levels of users
• Improve presentation methods
• Educate patients and users about quality in health care & increase patient and user awareness of public reporting
• Enlist professionals in supporting public reporting systems; and designing decision aids and encouraging their use
• Examine financial/human resource needs
• Will reporting be mandatory or voluntary
• Will data might be generated as part of regulatory inspections or clinical audits
• Consider processes for addressing poor performance in data provision
Public Reporting (WHO 2014)

Conclusions

• Successful public reporting strategies to facilitate choice require the support of professionals, patients and users, who should collectively agree which indicators are to be measured and how success of the reports will be defined and measured.

• However, widespread use of quality information has been slow to materialize across health and long-term care, despite the extensive investment in reporting systems. There is some evidence that reporting encourages providers to address quality issues to improve their reputation in the sector.
Public Reporting (WHO 2014)

Norway
- [www.fritsykehusvalg.no](http://www.fritsykehusvalg.no) (helps public choose hospitals)

The Netherlands
- [www.kiesbeter.nl](http://www.kiesbeter.nl) (describes health and long-term care information and quality scores)
- Algemeen Dagblad and Elsevier (provide hospital rankings)

Sweden
- [www.socialstyrelsen.se/jamfor/aldreguiden/jamfor](http://www.socialstyrelsen.se/jamfor/aldreguiden/jamfor) (allows for nursing home and home care service comparison)
- [www.skl.se](http://www.skl.se) (öppna jämförelser) (allows for the comparison of a number of public services across regions)

Finland
- [www.palveluvaaka.fi](http://www.palveluvaaka.fi) (provides comparative information about health and long-term care providers)

Denmark
- [www.sundhed.dk](http://www.sundhed.dk) (a patient-facing web portal that hosts indicators from a national project)
- [www.sundhedskvalitet.dk](http://www.sundhedskvalitet.dk) (provides comparative information about health and long-term care providers)

Germany
- [www.weisse-liste.de](http://www.weisse-liste.de) (provides comparative information for health and long-term care);
- AOK-Gesundheitsnavigator (facilitates members by providing comments and ratings of providers, as well as searching for appropriate providers);
- [www.qualitätsskliniken.de](http://www.qualitätsskliniken.de) (a website that searches for and compares providers)

Austria
- [www.spitalskompass.at](http://www.spitalskompass.at) (describes hospital services)
- [www.gesundheit.gv.at](http://www.gesundheit.gv.at) (provides generic health information)
Denmark hosts a patient web portal with built-in quality information, Sundhed, which was developed by the Danish Regions in 2001 to provide a single point of access to health services and information. Patients can use the web portal to access quality of care data delivered by hospitals (for selected conditions) from a set of national indicators, as well as book appointments with their general practitioner, renew prescriptions and access their medication data (Carace et al., 2011).
Public Reporting in US

• The first high-profile public reporting initiatives in health were launched in the US, namely New York State and Pennsylvania’s Cardiac Reporting Systems in 1989 and 1992, respectively, and the publication of mortality rates by the Health Care Financing Administration in 1986 (now the Centers for Medicare & Medicaid Services).

• Medicare.gov: Nursing Home Compare
  – Resident Assessment Instrument
  – Government health inspections
  – Level of staffing
  – Selected commentary on the characteristics of the facility

Schneider & Epstein, 1998; Shahian et al., 2011
Public Reporting in Pediatrics

• National Quality Forum (NQF)
  – Launched “Pediatric Measures” July 2015 to evaluate measures related to child health that can be used for accountability and public reporting for all pediatric populations & in all care settings
  – 15 Measures: Centers of Excellence in Pediatric Quality Measurement led to the development (Jun 2016)
    • Family Experiences with Coordination of Care
    • CT Radiation Dose
    • Adolescent Psychosis & Antipsychotics
    • Adult Transition
    • Sickle Cell
Public Reporting in CHD Care

• Public reporting mandated by select states
  – New York State Department of Health

• US News & World Report

• Society of Thoracic Surgeons
  – Public Reporting platform with 58% of member institutions
STS Congenital Heart Surgery Public Reporting

STS is pleased to release the star ratings for congenital heart surgery public reporting, which are based on the STS Congenital Heart Surgery Database (CHSD) mortality risk model. The STS CHSD public reporting initiative continues to grow, increasing from 23% of enrolled participants for the January 2015 data release to 33% in the current data release.

The Spring 2015 STS CHSD Feedback Report includes data from 116 participants in the STS CHSD, including 11 one star programs, 79 two star programs, and 6 three star programs. Twenty participants did not receive a star rating due to incomplete data.

<table>
<thead>
<tr>
<th>Hospital Name</th>
<th>Overall Star Rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advocate Children's Hospital</td>
<td></td>
</tr>
<tr>
<td>Oak Lawn, IL</td>
<td></td>
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<tr>
<td>Akron Children's Hospital</td>
<td></td>
</tr>
<tr>
<td>Akron, OH</td>
<td></td>
</tr>
<tr>
<td>Ann and Robert H. Lurie Children's Hospital of Chicago</td>
<td></td>
</tr>
<tr>
<td>Chicago, IL</td>
<td></td>
</tr>
<tr>
<td>Children's Hospital and Medical Center</td>
<td></td>
</tr>
<tr>
<td>Omaha, NE</td>
<td></td>
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<tr>
<td>Children's Hospital Colorado</td>
<td></td>
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<tr>
<td>Aurora, CO</td>
<td></td>
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<tr>
<td>Children's Hospital of Illinois</td>
<td></td>
</tr>
<tr>
<td>Peoria, IL</td>
<td></td>
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<tr>
<td>Children's Hospital of Michigan</td>
<td></td>
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<tr>
<td>Detroit, MI</td>
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<tr>
<td>Children's Hospital of Wisconsin</td>
<td></td>
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<tr>
<td>Milwaukee, WI</td>
<td></td>
</tr>
<tr>
<td>Children's Hospitals and Clinics of Minnesota</td>
<td></td>
</tr>
</tbody>
</table>

In this section

- About STS Public Reporting
- STS Public Reporting Data
- Adult Cardiac Surgery Database
- Public Reporting
- Congenital Heart Surgery Database Public Reporting
- Explanation of STS CHSD Mortality Risk Model and Star Ratings
- History of the STS National Database
- The STS National Database Today
- Rationale for Public Reporting
- Explanation of Adult Cardiac Composite Measures
- Potential Unintended Consequences of Public Reporting
- Publicly Reported Data Presentation
- Glossary
- STS Webinars

email. advocacy@conqueringchd.org • visit. www.conqueringchd.org
### Overall Star Rating

<table>
<thead>
<tr>
<th>Population: Neonates, Infants, Children &amp; Adults</th>
<th># / Eligible</th>
<th>Observed</th>
<th>Expected</th>
<th>O/E (95% CI)</th>
<th>Adj. Rate (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>29 / 1134</td>
<td>2.6%</td>
<td>4.0%</td>
<td>0.6 (0.4, 0.9)</td>
<td>2.1 (1.4, 3.0)</td>
</tr>
<tr>
<td>STAT Mortality Category 1</td>
<td>1 / 278</td>
<td>0.4%</td>
<td>0.8%</td>
<td>0.5 (0.0, 2.6)</td>
<td>0.3 (0.0, 1.7)</td>
</tr>
<tr>
<td>STAT Mortality Category 2</td>
<td>3 / 396</td>
<td>0.8%</td>
<td>1.4%</td>
<td>0.5 (0.1, 1.6)</td>
<td>0.9 (0.2, 2.5)</td>
</tr>
<tr>
<td>STAT Mortality Category 3</td>
<td>0 / 131</td>
<td>0.0%</td>
<td>2.3%</td>
<td>0.0 (0.0, 1.2)</td>
<td>0.0 (0.0, 3.5)</td>
</tr>
<tr>
<td>STAT Mortality Category 4</td>
<td>11 / 254</td>
<td>4.3%</td>
<td>8.1%</td>
<td>0.5 (0.3, 0.9)</td>
<td>3.9 (1.9, 6.8)</td>
</tr>
<tr>
<td>STAT Mortality Category 5</td>
<td>14 / 75</td>
<td>18.7%</td>
<td>18.9%</td>
<td>1.0 (0.6, 1.6)</td>
<td>15.8 (9.0, 24.9)</td>
</tr>
</tbody>
</table>

### Operative and Adjusted Operative Mortality, Last 4 Years (January 2011-December 2014)

<table>
<thead>
<tr>
<th>Population: Neonates, Infants, Children &amp; Adults</th>
<th># / Eligible</th>
<th>Observed</th>
<th>Expected</th>
<th>O/E (95% CI)</th>
<th>Adj. Rate (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall</td>
<td>19 / 1133</td>
<td>1.7%</td>
<td>2.6%</td>
<td>0.6 (0.4, 1.0)</td>
<td>2.1 (1.3, 3.3)</td>
</tr>
<tr>
<td>STAT Mortality Category 1</td>
<td>2 / 483</td>
<td>0.4%</td>
<td>0.6%</td>
<td>0.7 (0.1, 2.7)</td>
<td>0.5 (0.1, 1.7)</td>
</tr>
<tr>
<td>STAT Mortality Category 2</td>
<td>2 / 317</td>
<td>0.6%</td>
<td>1.5%</td>
<td>0.4 (0.1, 1.5)</td>
<td>0.7 (0.1, 2.4)</td>
</tr>
<tr>
<td>STAT Mortality Category 3</td>
<td>1 / 99</td>
<td>1.0%</td>
<td>2.8%</td>
<td>0.4 (0.0, 1.9)</td>
<td>1.0 (0.0, 5.5)</td>
</tr>
<tr>
<td>STAT Mortality Category 4</td>
<td>13 / 213</td>
<td>6.1%</td>
<td>7.1%</td>
<td>0.9 (0.5, 1.4)</td>
<td>6.2 (3.3, 10.3)</td>
</tr>
<tr>
<td>STAT Mortality Category 5</td>
<td>1 / 21</td>
<td>4.8%</td>
<td>19.0%</td>
<td>0.3 (0.0, 1.3)</td>
<td>4.0 (0.1, 20.1)</td>
</tr>
</tbody>
</table>
TACKLING TRANSPARENCY IN PEDIATRIC CARDIOLOGY
Transparency

• With-in Centers
  – Internal Quality Improvement

• Between Centers
  – Collaborative quality improvement

• Between Providers and Patients
  – Open and honest conversations

• With the Public
  – Public Reporting
Began with a Culture Shift

• Built Consensus about the importance of public reporting and transparency
• Required reassurance about how data is presented
• Ultimately:
  Patients deserve this information
Evolution of a movement

Fall 2014
PCHA Guided Questions

Jan 2015
Introducted at National Conference

Jan 2015
Launch of STS Public Reporting Site

June 2015
CNN Coverage of St. Mary’s Closure

Feb 2016
2nd PCHA Transparency Summit

Fall/Winter 2015
Inclusion on Agendas at National Meetings

August 2015
1st PCHA Transparency Summit

June 2015
Sen. Durbin Engagement

Feb 2016
US News modifies survey to include public reporting

2016
Additional Media and Conference Coverage of the issue

February 2017
3rd PCHA Transparency Summit

June 2017
US News reduces weight of Reputation score

Pediatric Congenital Heart Association
Current State of Public Reporting

- Hospital Websites
- U.S News and World Report Hospital Rankings
- Society of Thoracic Surgeons
- Consumer Reports
Getting the conversation started

- Empowers parents to ask questions about:
  - Quality
  - Patient Experience
  - Life Beyond Surgery
- Developed with patients and providers
- Pilot distribution Project
- Providers are ensuring they are equipped with the answers
- On our website: conqueringchd.org
Public Reporting

To create a centralized clearinghouse of publicly reported outcome measures that are **meaningful** and **relevant** to parents to facilitate shared-decision making and in turn improve quality and outcomes.
Represent the Data

KAYAK®

of CHD

for patients and families

Pediatric Congenital Heart Association
Reporting Mechanism

• Meaningful for consumers: Patients and Families

• Begin by using existing data sources
  – Society of Thoracic Surgeons
  – Hospital reported outcomes based on U.S. News Survey

• Build to include additional metrics as they become available

• Incorporate reliable interpretation and dissemination mechanisms
Achieving Our Goal: PCHA Transparency Tenets in Action

1. Metrics
   - Standardized key variables
   - Validated
   - Include Benchmark Lesions
   - Short-Term Outcomes
   - Long-Term Outcomes
   - Patient and Family Experience
   - Value
PCHA Transparency Tenets in Action

1. Metrics
   - Risk-adjusted
   - Relevant
   - Supportive Materials
   - Differentiation of Centers

2. Interpretation

3. Presentation
PCHA Transparency Tenets in Action

1. Metrics
   - Publicly Reported
   - Easily Accessible
   - Centralized
   - By Geography/Region
   - By Diagnosis/Surgery

2. Interpretation

3. Presentation
“All my decisions are well thought out.”
Moving the abstract into the clinical encounter

FROM PROSE TO PRACTICE
Has Public Reporting of Hospital Readmission Rates Affected Patient Outcomes?

Analysis of Medicare Claims Data

Adam D. DeVore, MD, Bradley G. Hammill, DrPH, N. Chantelle Hardy, MPH, Zubin J. Eapen, MD, MHS, Eric D. Peterson, MD, MPH, Adrian F. Hernandez, MD, MHS
Debating Next Steps

BACKGROUND  In 2009, the Centers for Medicare & Medicaid Services (CMS) began publicly reporting 30-day hospital readmission rates for patients discharged with acute myocardial infarction (MI), heart failure (HF), or pneumonia.

OBJECTIVES  This study assessed trends of 30-day readmission rates and post-discharge care since the implementation of CMS public reporting.

CONCLUSIONS  The release of the CMS public reporting of hospital readmission rates was not associated with any measurable change in 30-day readmission trends for MI, HF, or pneumonia, but it was associated with less hospital-based acute care for HF.  (J Am Coll Cardiol 2016;67:963–72) © 2016 by the American College of Cardiology Foundation.
Debating Next Steps

Are there negative consequences of public reporting? The hype and the reality

James S. Tweddell, MD, Jeffrey P. Jacobs, MD, and Erle H. Austin III, MD

In summary, public reporting of healthcare performance is new and potentially disruptive. Appropriate risk adjustment is critical to achieve effective and fair transparency, but there are little objective data of harm associated with public reporting. We must understand that the data are not ours to share but rather, these data belong to our patients and their families. Although we must continue to look at the cost effectiveness and meaningfulness of the metrics we report and how the public uses the data to make informed decisions, these efforts are likely to result in minor course changes and the effort to inform and educate our patients and their families must continue.
Debating Next Steps

Potential benefits and consequences of public reporting of pediatric cardiac surgery outcomes

J. William Gaynor, MD, a Sara K. Pasquali, MD, MHS, b Richard G. Ohye, MD, b and Thomas L. Spray, MD a

There is a paucity of data concerning the best designs of PR programs to promote improvements in care and outcomes and avoid unintended consequences, including inadvertently steering patients toward a less-than-ideal hospital for their care, risk aversion among practitioners, and diversion of limited hospital resources from other, potentially more effective quality improvement efforts. DeVore is an example of the type of critical assessments that are needed to optimize our methods of PR. Further study is needed to ensure that the substantial resources needed to support these programs are well spent, that the public is provided with the most accurate and reliable data possible, and that public reporting initiatives have the greatest potential to improve outcomes while avoiding unintended consequences.
Debating Next Steps

Content AND Delivery Matter
Transparent & Public is not Enough

- Presentation of information is (nearly) as important as the information itself
- Data presented without “interpretation aids” is of measurably reduced value

Shared Decision Making: clinician explaining medical evidence for different options & family members discussing options in the context of their values.
Shared Decision Making

• Appropriate for preference-sensitive decisions
  – >1 medically reasonable option
    • Time, Location, Management
      – “Best Choice” depends on: Patient/family values and trade-offs between options

• Decisional Aids require two experts
  – Health care provider/team – the data
  – Patient/Parent – the value of what is at stake

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Shared Decision Making

- Informative
- Paternalistic

Doctor

Patient

Passive

Active

"Patient's Choice"

"Doctor's Orders"

Shared Decision Making
Shared Decision Making

- Dynamic Partnership
- Mutually Accountable
- Trust and Respect
- Transparent Information
- Health Literacy Interpretation
- Effective Communication
- Acknowledge Individual Variation

Decision Support and Tools

Communication

Shared Decision
DAs Change the Outcome

- Increase Knowledge & Realistic Expectations
- Increase Active Involvement
- Increase Value Congruence with Chosen Option
- Symptom Relief Balanced with Avoiding Harm
- Decrease rate of elective surgery by 24%

Cochrane Systematic Review
86 Randomized Controlled Trials

Stacey et. al, 2011

email. advocacy@conqueringchd.org • visit. www.conqueringchd.org
Challenges for Parents

• Intimidating
• Poor Understanding of Expectations
• Lack of Background Knowledge
• Health Literacy
• Parenting a chronically ill child
  – Time
  – Consistency
  – Fatigue
Start the Conversation

• There is agreement around the desire for transparency and public reporting, but how should we then proceed?

• Need to start with the basics: What matters to “you”?
  – Ask what matters.
  – Listen to what matters.
  – Do what matters.
Start the Conversation

- Patients/parents need to identify themselves (values) in order to properly match themselves with the data otherwise we simply provide data repository
  - If there is a public scaling process (STS stars), then be sure to understand upon who’s scale are those stars based?
Transparency & Public Reporting

While we appreciate that the equation for ideal transparency & public reporting has not been solved, we argue that the absence of effort is no longer an acceptable course of action. And while it is also true that full attention to avoiding harm is critical, immediate next steps are possible and can begin when we take the time to understand the “values” of the patients/parents/provider equation.
“Be the change you want to see in the world” - Ghandi

Thank You!

Amy Basken
abasken@conqueringchd.org

email. advocacy@conqueringchd.org • visit. www.conqueringchd.org