



Pediatric Congenital
Heart Association

Transparency

Amy Basken, MS

Bradley S. Marino, MD, MPP, MSCE

On behalf of:

PCHA Patients and Parents

PCHA Medical Advisory Board

Why Transparency?

- 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



Why Transparency?

- Patient-*engaged* care and informed decision making are achieved when patients and families are empowered with information and knowledge



Our Goal

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



Pediatric Congenital
Heart Association

Represent the Data

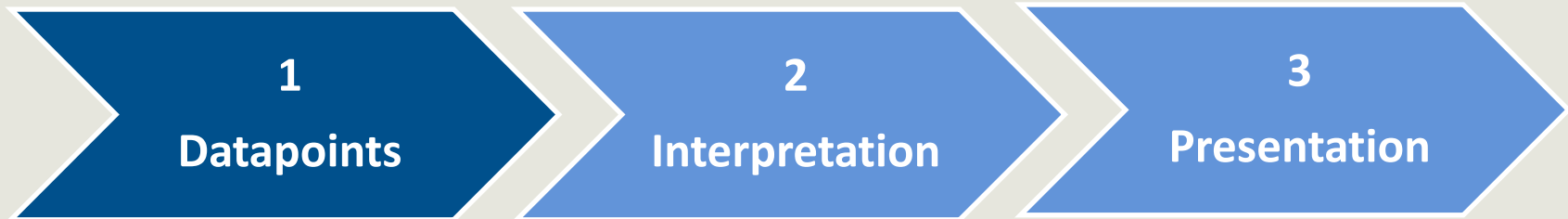
KAYAK[®]

of CHD
for patients and families



Pediatric Congenital
Heart Association

Achieving Our Goal: PCHA Transparency Tenets in Action



- Standardized key variables
- Validated
- Include Benchmark Lesions
- Short-Term Outcomes
- Long-Term Outcomes
- Patient and Family Experience
- Value

- Risk-adjusted
- Relevant
- Supportive Materials
- Differentiation of Centers

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



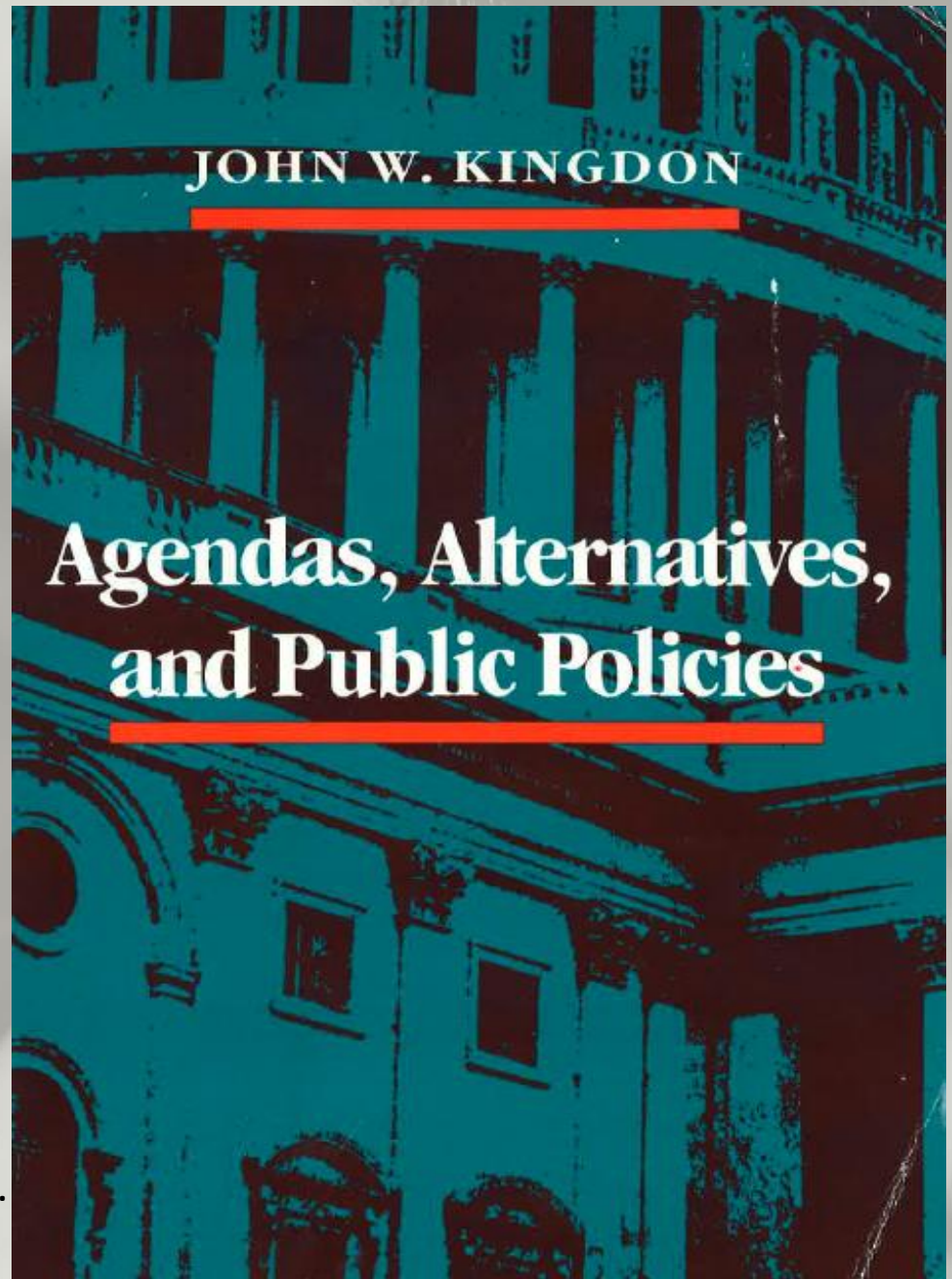


Pediatric Congenital
Heart Association

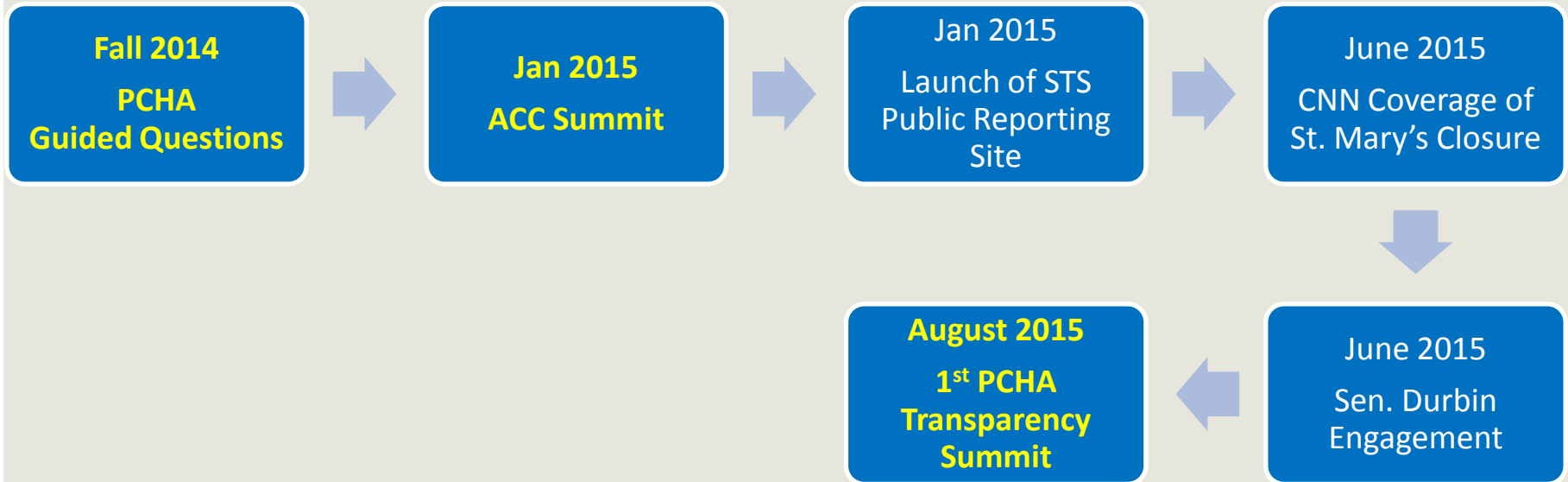
- **Transformative
Public Policy Shifts**

- Sentinel Events
- Champions
- Change Agents in
Government

Kingdon JW,
Agendas, Alternatives, and Public Policies.
Little Brown and Company, Boston, 1984.



A Little History...



1st Summit: Primary Goals

- 1. To inform, educate, and empower patients and families to actively participate in data-driven shared-decision making**
- 2. To improve pediatric and congenital cardiovascular outcomes, reduce variation, and increase value at *all* pediatric and congenital cardiovascular programs through data sharing and collaborative learning**
 - To identify programs that excel to learn from their systems and processes
 - To identify programs that have specific outcome improvement opportunities



1st Summit: Objectives

- **To achieve transparent public reporting of national and geographic performance from all pediatric cardiovascular programs for standardized validated data on:**
 - Surgical Outcomes
 - Other Cardiovascular Based Outcome Measures
 - Interventional Catheterization
 - Nursing
 - Perioperative Morbidity - ICU
 - Anesthesia
 - Patient and Family Experience
 - Long-term outcomes including QOL



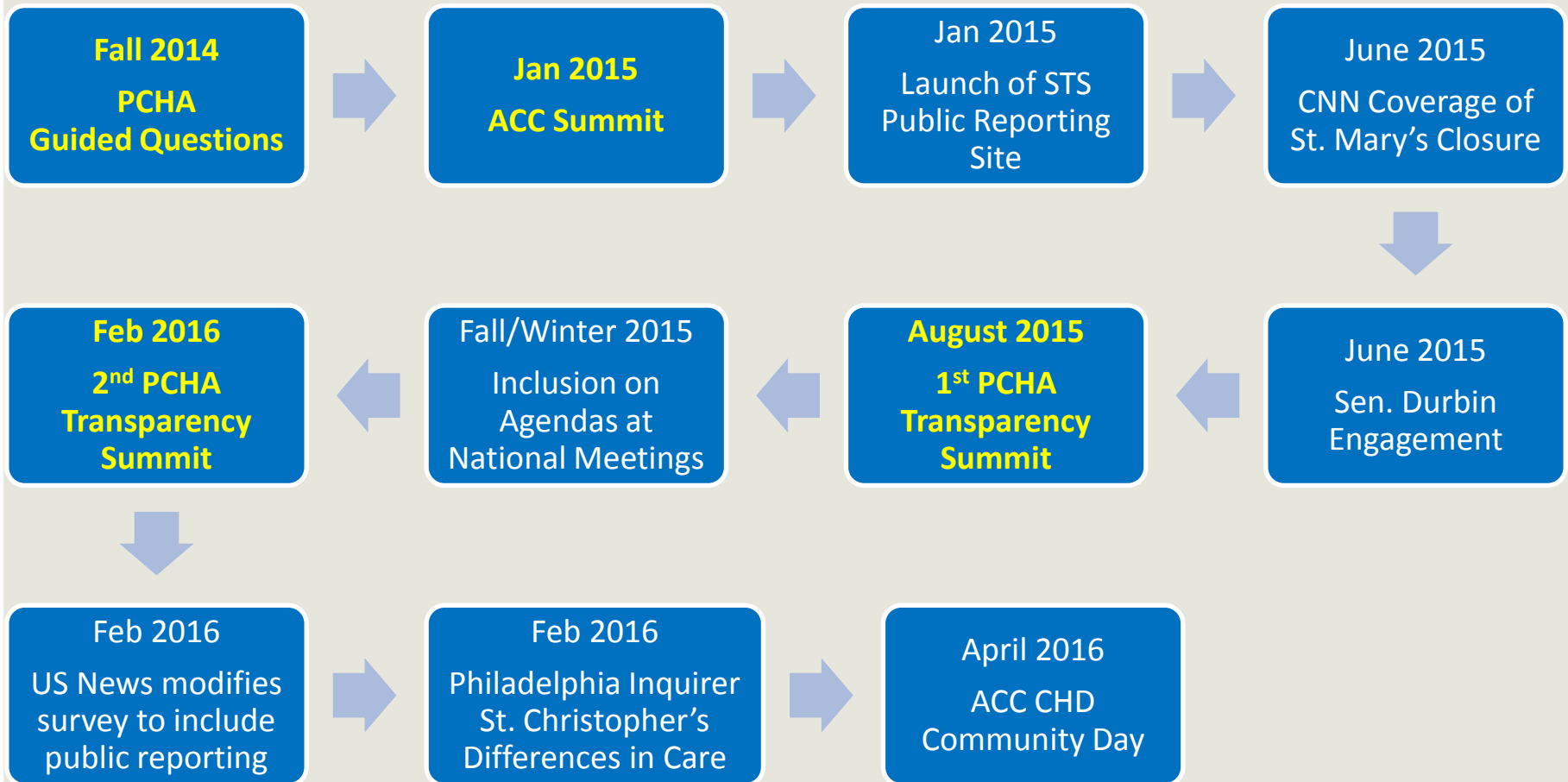
1st Summit Achievements:

Considerations for Reporting

- Recommend mandatory *participation* in clinical data registry
- Recommend mandatory *public* reporting via clinical data registry
- Data reported should include:
 - Surgical outcomes
 - Interventional cardiology outcomes
 - Peri-operative morbidity and medical care utilization data
 - Patient and family experience
 - Long-term outcomes including quality of life
- Streamline data acquisition to increase the efficiency of data collection



A Little History (con't)...



Achieving Our Goal: PCHA Transparency Tenets in Action

1

Datapoints

- Standardized key variables
- Validated
- Include Benchmark Lesions
- Short-Term Outcomes
- Long-Term Outcomes
- Patient and Family Experience
- Value

2

Interpretation

- Risk-adjusted
- Relevant
- Supportive Materials
- Differentiation of Centers

3

Presentation

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



Pediatric Congenital
Heart Association

“We don’t know what we don’t know!”

What parents care most about:

- Will my baby live?
- What will their life be like/will they grow up?

But what about quality?

What questions **SHOULD** we be asking?

- Pump Cases?
- Survival Rate, 30 days and beyond?
- Complication rate?
- ICU care?
- Patient Satisfaction?

THE LOOK I GIVE



**WHEN I'M COMPLETELY
OVERWHELMED**

Short - Term Outcomes

- Volume
 - Total Volume
 - Volume by Benchmark Procedure
 - Total Catheterizations
 - Interventional Cath Procedure
- Survival
 - Operative Mortality
- Complications
 - Surgical Complications
 - Hospital Acquired Conditions
 - Readmission Rates
- Training
 - Total Number of Surgeons
 - Total Number of Cardiologists
 - Number who are certified
- Hospital Experience
 - Length of Stay
 - Dedicated CICU
 - Interstage Program (y/n)

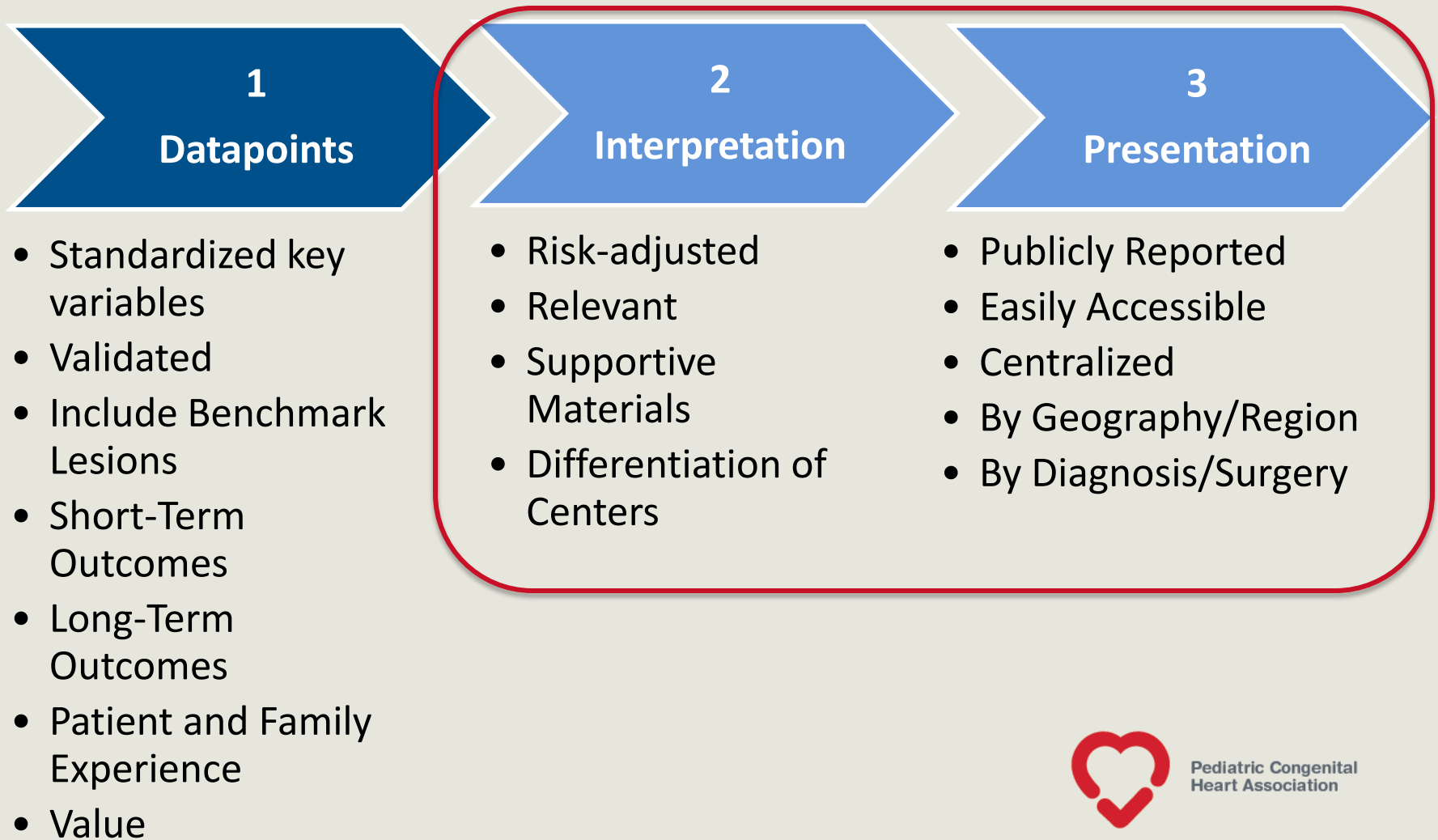
Long - Term Outcomes

- 5-year survival
- Total Life Expectancy
- Morbidities
- Neurodevelopmental
- Single Ventricle Follow-up program

Data Points

**Presently Available vs
Need to be Developed**

Achieving Our Goal: PCHA Transparency Tenets in Action



Interpretation and Presentation: Perspectives of Present/Future Sources

- US News and World Report – General Public
- Society for Thoracic Surgery – Providers/Surgery
- ACC Scorecard – Providers/Cardiology
- **PCHA Interface – Patient and Parent**
- Individual Centers – Individual Cardiovascular Program



Considerations when developing mechanisms

The Interpretation and Presentation should be:

- Thoroughly vetted by target audience
- Accessible
 - Public
 - Centralized
 - Neutral
- Relevant
 - Geographically/Regionally Displayed
 - By Diagnosis not procedure alone
- Easily understood
 - Health Literacy
 - Accommodate Individual Preferences
- Differentiate Between Centers
 - Risk-adjusted



The Movement Continues – Future Transparency Summits

- Summer 2016 – Atlanta
- Winter 2017 – Denver
- Summer 2017 – Milwaukee



Pediatric Congenital
Heart Association

“Unity is strength...
when there is teamwork
and collaboration,
wonderful things can be
achieved.”

- Mattie J.T. Stepanek



Pediatric Congenital
Heart Association