

Summit Series Background

August 2015: Ann and Robert H. Lurie Children's Hospital - Chicago, IL

The focus of the very first Summit was on selecting the Tenets of Transparency. Stakeholders present determined that transparency meant full disclosure; measurement equaled standardized variables, long-term outcomes, validated and risk-adjusted data; reporting should include benchmark lesions, supportive materials for patients and families, and be geographically presented. But how would this all be presented to patients and families in ways that were meaningful to them?

February 2016: Johns Hopkins All Children's Hospital - St. Petersburg, FL

After the framework was delivered, attendees at the 2nd Summit focused on identifying metrics to be reported for patients and families. They had to consider where the data would come from, and how it would be interpreted by the end user. These stakeholders identified more than 65 metrics!

January 2017: Children's Hospital Colorado - Aurora, CO

Considering available data sources, and forecasted data collection, stakeholders at our 3rd Summit had their work cut out for them. From 65 metrics, they narrowed the list to just 12, with 2-3 data points slated for future phases of reporting.

September 2017: C.S. Mott Children's Hospital/Michigan Congenital Heart Center - Ann Arbor, MI

By the 4th Summit, we were rocking and rolling! Patients and families were onboard and represented 50% of the meeting attendees. This meeting was marked by two days of focus groups who presented their ideas on design of a reporting portal, how to avoid opening Pandora's Box in terms of wanting all the data at once, solutions to collaborating with other societies, and suggestions in continuing to elevate the needs of the patient and family.

October 2018: Children's Wisconsin - Milwaukee, WI

Once the idea for a reporting portal was born, the 5th Summit focused heavily on collaboration and learning from others. Representatives from the UK spoke about their reporting mechanisms and transparency efforts in their population. Conquering CHD staff engaged patients and families in use of the Guided Questions Tool as a primer to a reporting portal. Having presentations from news media and surgical societies ensured we could reach beyond the "in crowd."



October 2019: Nationwide Children's Hospital - Columbus, OH

Between the 5th and 6th Summits, the reporting portal concept became Hospital Navigator. Conquering CHD convened many focus groups, including all stakeholders, to discuss design, presentation, implementation, education, and execution. Attendees at the 6th Summit received critical updates on current public reporting avenues from U.S. News and World Report, Society of Thoracic Surgeons, Congenital Heart Surgeons Society, and Cardiac Networks United. The year following the 6th Summit would be marked by testing of Hospital Navigator and a very successful public launch in August 2020!

September 2020: Virtual*

The 7th Summit saw a shift in the power of the patient and family voice. Representatives from U.S. News and World Report, Society of Thoracic Surgeons, and Congenital Heart Surgeons Society commented on how impactful our advocacy the previous six Summits had been. Our voices led to significant changes in their reporting and marketing methodology. Conquering CHD is also leading the way in the fight for equity in CHD care for *all* patients and families. The Health Disparities panel was poignant, emotional, and has led to a full meeting during our upcoming advocacy conference, February 28-March 1, 2021. Hospital Navigator is taking hold with 15 hospital participants and a full advocacy campaign launching in Fall 2020.

*Watch the Summit recording: <https://www.conqueringchd.org/involvement/transparency/>

