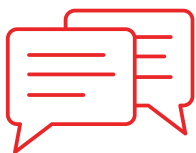# PC^4 Registry: Patient-Reported Outcomes Module

Engage patients beyond the hospital setting, and gain a complete view of longitudinal outcomes

Improvements in early survival following congenital heart surgery have made it increasingly important to understand longer-term patient outcomes. Physicians and care teams across the cardiac care continuum need to understand and optimize longitudinal outcomes such as survival, need for re-hospitalization or re-interventions, burden of disease and quality of life. Achieving this requires more than clinical data or other routine documentation captured in the hospital setting.
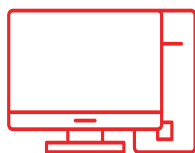

The Pediatric Cardiac Critical Care Consortium (PC^4) and Cardiac Networks United are now introducing a Patient-Reported Outcomes (PRO) Module to collect and analyze data directly from patients and their family members. PRO enables a longitudinal picture of health by engaging patients beyond the hospital setting and regardless of the location of clinical follow-up. Children's hospitals and centers participating in PC^4 can now begin collecting PROs to gain a more comprehensive view of the quality of care for patients with pediatric and congenital cardiovascular disease.

Goals of the Patient-Reported Outcomes Module

Engage patients and families

Track outcomes beyond the hospital

Gain insight into longitudinal trends

Reduce data collection burden

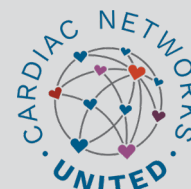**PCCCC PEDIATRIC CARDIAC CRITICAL CARE CONSORTIUM**

PC^4 Improving outcomes and quality through collaboration

Get Started with PROs in PC^4

The PRO Module is now available to all centers currently participating in PC^4. To get started using PROs, PC^4 participating centers can connect directly with the ArborMetrix team:

Email - CardiacNetworks@arbormetrix.com
Visit - PC4quality.org/patient-reported-outcomes
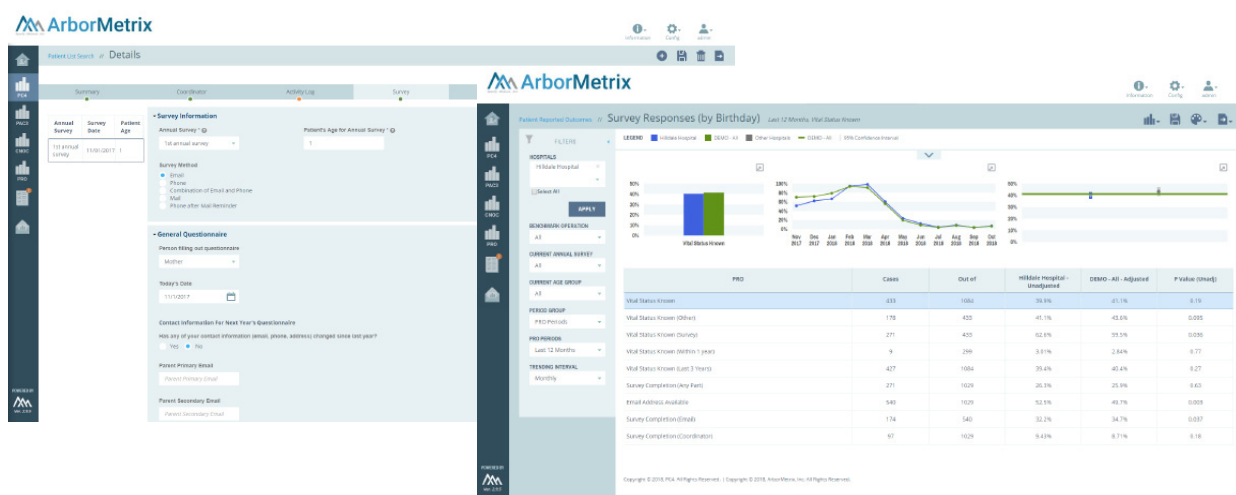
CARDIAC NETWORKS UNITED

Learn More about the PRO Module

Who can participate in PRO?
PRO is available to all centers participating in PC⁴.

What are the benefits of participating in PRO?
By participating in PRO, providers will drive deeper engagement with patients and their parents or primary caregivers to gain a longitudinal view into important outcomes such as survival, re-interventions/ hospitalizations, burden of disease, and quality of life. The PRO module is easy to use, and contains many automated features to aid in reducing data collection burden at participating hospitals. Standardized data collection across centers will allow for benchmarking and advancement of long-term outcomes. The data collected can also be used for reporting to third parties who request longitudinal outcomes information such as certain payers and organizations rating heart center performance.

How will PRO be implemented?
PRO data will be implemented into the current PC⁴ registry application on the ArborMetrix platform. The experience will be seamless for physicians, clinical champions, data abstractors, and other team members who use the registry.

How do patients provide data?
Patients and family members will respond to electronic surveys sent to them via email. This email will send them a pre-authenticated link to provide longitudinal information at regular intervals post-surgery. PC⁴ aims to have patients complete surveys annually on their birthdays. Phone and mail can be used as secondary methods of contact. The process of identifying eligible patients and collecting data is automated as much as possible to reduce data collection burden and personnel required.

How do I access my PRO data?
PRO data are displayed alongside PC⁴ data in real time as they are collected in the online ArborMetrix platform available 24/7. Filters, patient-level drill downs, trends over time, and benchmarking to other centers are all available.

Is the data my practice/patients provide secure?
Yes, the PC⁴ Registry and PRO Module are compliant with the Health Information Portability and Accountability Act of 1996 (HIPAA) and Health Information Technology for Economic and Clinical Health (HITECH) Act.

What is the cost to participate in PRO?
Hospitals and centers who participate in the registry pay an annual subscription fee. The PRO Module is licensed by each site as an additional annual subscription fee.