Congenital Heart Disease

Treatment approaches covered
Overall Health | Mental Health | Physical Health | Social Health

Health States: Minor, Moderate, Major or Complex and Critical Conditions
Stages: Pediatric | Adult

*AHA/ACC and Worldbank Severity Levels

Details
A Adult Outcome
P Pediatric Outcome

Patient Reported Outcome Measures (PROMs)
1 Measured by the Satisfaction with Life - Child
2 Measured by the Satisfaction with Life Scale
3 Measured by the Pediatric Cardiac Quality of Life Inventory (PCQLI)
4 Measured by the PROMIS scale v1.2 - Global Health
5 Measured by the Work Productivity and Activity Impairment Questionnaire-General Health v2.0
6 Measured by the Patient Health Questionnaire (PHQ-9)
7 Measured by the General Anxiety Disorder (GAD-7)

For a complete overview of this Set, including definitions for each measure, time points for collection, and associated risk factors, visit https://connect.ichom.org/patient-centered-outcome-measures/congenital-heart-disease/

© 2023 ICHOM. All rights reserved. When using this set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define more Patient-Centered Outcome Measures. Version 4.1.0 Revised: February 2023
Contributors

For more information about the process of developing a Set of Patient-Centered Outcome Measures, visit ichom.org/how-we-work/

The Sponsors

The Working Group

Project Team
Chair
Gerard Martin | Children’s National Hospital
Research Fellow
Kevan Hummel | University of Utah
Project Manager
Sarah Whittaker | ICHOM
Project Team Member
Lisa Hom | ICHOM
Research Associate
Shannon Quinn | ICHOM
Research Associate
Nick Sillett | ICHOM
Brazil
Ulisses Alexandre Croti | Hospital da Criança e Maternidade
Canada
Steven Schwartz | The Hospital for Sick Children
Colombia
Tomás Chalela | Fundación Cardioinfantil
India
Juile Chauhan | All India Institute of Medical Science, New Delhi
Mexico
Luis Antonio Garcia | Kardias A.C. Foundation
Almudena March | Kardias A.C. Foundation
Juan Samanego De La Parra*
Netherlands
Ingrid van Beynum | Erasmus University MC, Sophia Children’s Hospital, Rotterdam
Pakistan
Farhan Ahmad | Pakistan Children’s Heart Foundation*
Babar Hasan | The Aga Khan University
Laila Ladak | The Aga Khan University
Russia
Ekaterina Anikeeva | Research Institute for Complex Issues of Cardiovascular Diseases
South Africa
Monique Kemp | Global ARCH*
Spain
Joan Sanchez de Toledo | Hospital Sant Joan de Déu
Sweden
Malin Berghammer | University West, Queen Silvia Children’s Hospital*
Switzerland
Markus Schwerzmann | Center for Congenital Heart Disease, University Hospital Inselspital, University of Bern
Uganda
Michael Oketcho | Uganda Heart Institute
United States
Amy Basken | Conquering CHD*
Kathy Jenkins | Boston Children’s Hospital
Richard Jonas | World Society for Pediatric and Congenital Heart Surgery
Nicolas L. Madsen | Cincinnati Children’s Hospital
Disty Pearson | Boston Children’s Hospital*
James D. St Louis | Children’s Mercy Hospital, Kansas City
Amy Verstappen | Global ARCH*
Robert Williams | Children’s Hospital Los Angeles, University of Southern California
Bistra Zheleva | Children’s HeartLink
*Patient representative

*Patient representative

The Sponsors

The Working Group

Project Team
Chair
Gerard Martin | Children’s National Hospital
Research Fellow
Kevan Hummel | University of Utah
Project Manager
Sarah Whittaker | ICHOM
Project Team Member
Lisa Hom | ICHOM
Research Associate
Shannon Quinn | ICHOM
Research Associate
Nick Sillett | ICHOM
Brazil
Ulisses Alexandre Croti | Hospital da Criança e Maternidade
Canada
Steven Schwartz | The Hospital for Sick Children
Colombia
Tomás Chalela | Fundación Cardioinfantil
India
Juile Chauhan | All India Institute of Medical Science, New Delhi
Mexico
Luis Antonio Garcia | Kardias A.C. Foundation
Almudena March | Kardias A.C. Foundation
Juan Samanego De La Parra*
Netherlands
Ingrid van Beynum | Erasmus University MC, Sophia Children’s Hospital, Rotterdam
Pakistan
Farhan Ahmad | Pakistan Children’s Heart Foundation*
Babar Hasan | The Aga Khan University
Laila Ladak | The Aga Khan University
Russia
Ekaterina Anikeeva | Research Institute for Complex Issues of Cardiovascular Diseases
South Africa
Monique Kemp | Global ARCH*
Spain
Joan Sanchez de Toledo | Hospital Sant Joan de Déu
Sweden
Malin Berghammer | University West, Queen Silvia Children’s Hospital*
Switzerland
Markus Schwerzmann | Center for Congenital Heart Disease, University Hospital Inselspital, University of Bern
Uganda
Michael Oketcho | Uganda Heart Institute
United States
Amy Basken | Conquering CHD*
Kathy Jenkins | Boston Children’s Hospital
Richard Jonas | World Society for Pediatric and Congenital Heart Surgery
Nicolas L. Madsen | Cincinnati Children’s Hospital
Disty Pearson | Boston Children’s Hospital*
James D. St Louis | Children’s Mercy Hospital, Kansas City
Amy Verstappen | Global ARCH*
Robert Williams | Children’s Hospital Los Angeles, University of Southern California
Bistra Zheleva | Children’s HeartLink
*Patient representative

*Patient representative