

# Access to Care Framework for Congenital Heart Disease



**GOAL:** ALL infants, children, adolescents, and adults living with congenital heart disease (CHD) in the United States have access to comprehensive, high-quality, congenital cardiology care across their lifespan.

Amplification and Diversification of Workforce	Coverage & Reimbursement	Barriers to Access to Care Based on Social Determinants of Health (SDOH)	Patient & Family Engagement	Transition & Transfer
<b>PRIORITY OUTCOMES:</b> What changes in behavior, condition, or status are required?				
<p>A multi-disciplinary team of cardiologists, other physicians and advanced practice providers who are appropriately trained, representative of the communities they serve, experienced, and able to provide CHD care regardless of the patient's age, geographic location, socioeconomic status, ability to pay, or insurance coverage</p>	<p>People living with CHD have universal insurance coverage for their healthcare needs and all providers adhere to best practices and guidelines for CHD care, leading to improved health and enhanced health-related quality of life, regardless of patient geographic location or insurance coverage</p>	<p>Implement strategic interventions to reduce barriers to health care delivery to ensure equitable access to high-quality CHD care. This involves addressing structural and institutional racism, unequal SDOH, and various forms of interpersonal discrimination (e.g., implicit bias)</p>	<p>All patients and their families will receive patient-centered, safe, affordable, timely, and relevant care regardless of payer category or insurance status and be empowered by advocates and education that facilitates patient knowledge, skills and is based in cultural humility</p>	<p>All people living with CHD have access to a collaborative, structured, and seamless transition and transfer from pediatric to adult healthcare professionals who have expertise in CHD</p>
<b>CHALLENGES:</b> What are the public health challenges that create barriers to care?				
<b>SOLUTIONS:</b> What public and private sector initiatives will advance public health outcomes for congenital heart disease?				
<p><b>Challenge 1:</b> Lack of Adult Congenital Heart Disease (ACHD) physicians and non-physician clinicians to meet the physical and mental health needs of patients in most areas of the US</p> <p><b>Solution 1:</b> Expand the number and geographic reach of ACHD fellowship training programs; Shorten the length of ACHD fellowship training; Incentivize trainees to pursue ACHD through offering student loan forgiveness and improve ACHD provider reimbursements; Increase ACHD career awareness to diverse trainees and trainee communities</p>	<p><b>Challenge 1:</b> 1A. Lack of short – (acute care) and long-term data on the <u>efficacy</u> of experimental and investigational CHD care provided by select centers and individual clinicians under optimal conditions 1B. Lack of short — (acute care) and long-term data on the effectiveness of accepted CHD care provided by various centers and individual clinicians under “real world” conditions</p> <p><b>Solution 1:</b> Leverage existing data from multiple sources; Encourage payment for investigational treatments under specific circumstances; Invest in CHD outcomes research; Establish CHD centers for cardiovascular research and innovation; Encourage payment for high-quality outcomes and coordinated care; Incentivize appropriate referral to centers with high-quality outcomes; Apply relevant international data on successful interventions</p>	<p><b>Challenge 1:</b> Structural and cultural barriers to accessing high quality care for patients with CHD</p> <p><b>Solution 1:</b> Build systems of care and referral networks that address the intersection of patient complexity and SDOH to simplify and increase the adaptability of care processes for culturally diverse patients; Strengthen relationships between community organizations, their leaders and CHD programs</p>	<p><b>Challenge 1:</b> Patients &amp; families receive inconsistent communication and education regarding their CHD care</p> <p><b>Solution 1:</b> Utilize multidisciplinary care teams that include care navigators to support patients and families throughout their journey and provide care resources that are easy for the patient, family, and caregiver to access, at an appropriate level of understanding for the patient, and written/ shared in their spoken language</p>	<p><b>Challenge 1:</b> Lack of a structured healthcare transition process</p> <p><b>Solution 1:</b> Education and training on transition/transfer best practices, including the development of a framework of transition/transfer education and skills that maintains flexibility, and leverages technology and allied health professionals to expand patient access to ACHD centers</p>

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<p><b>Challenge 2:</b> Care delivery systems are restrictive and lack integration</p> <p><b>Solution 2:</b> Fund hub-and-spoke models of care that extend ACHD care beyond “academic centers” that facilitate: 1) access to routine physical, neurodevelopmental and mental health, and reproductive care; 2) evaluation and stabilization for urgent and acute health needs at the community and/or local level; and 3) incentivize and remove insurance and geographic barriers to receive specialized care including across state lines</p>	<p><b>Challenge 2:</b> Lack of data transparency on outcomes and costs of services offered vs. covered; lack of informed shared decision-making</p> <p><b>Solution 2:</b> Establish data transparency on outcomes and costs (from the perspectives of various stakeholders--patients, providers, institutions, and payors): Expand shared decision-making and integrate emerging evidence into CHD guidelines</p>	<p><b>Challenge 2:</b> Systemic, structural, and institutional racism in the health care system</p> <p><b>Solution 2:</b> Training for health system leaders and clinicians to understand and address various forms of racism within their organization and advocate for policy solutions to address upstream health policies and SDOH that impact downstream CHD care</p>	<p><b>Challenge 2:</b> Lack of access to culturally competent care that is provided via a lens of cultural humility</p> <p><b>Solution 2:</b> Innovate clinician training to support the advancement of care with culturally humility and create a patient-centered onboarding process that considers personal factors essential to patient-centered care</p>	<p><b>Challenge 2:</b> Issues related to insurance coverage and reimbursement for CHD providers</p> <p><b>Solution 2:</b> Encourage value-based payment and joint reimbursement for in-person and telehealth visits between pediatric CHD and ACHD providers; Ensure providers are aware of best practices in CPT coding and the benefits of proper transition management</p>
<p><b>Challenge 3:</b> Inconsistency in providing comfort, confidence, and competence in addressing SDOH</p> <p><b>Solution 3:</b> Incentivize training and technical assistance to improve physician and non-physician clinician knowledge, confidence, and capacity to assess for SDOH and develop a care plan with the patient and family that address their unique needs</p>	<p><b>Challenge 3:</b> Need to improve insurance coverage to meet the care needs of patients with CHD more effectively</p> <p><b>Solution 3:</b> Fund projects that identify viable coverage/ reimbursement models that improve patient outcomes; Promote insurance coverage transparency; Incentivize insurers to cover appropriate care at out-of- network centers and to establish <i>a priori</i> criteria for covering needed testing/care</p>	<p><b>Challenge 3:</b> Lack of data integration and collaboration within the health care delivery system and between the health care system and the public health system</p> <p><b>Solution 3:</b> Integrate CHD data into public health systems; Modernize reporting laws to accurately capture sociodemographic data; Facilitate data collection through EHR systems and promote data transparency and advocacy for patients</p>	<p><b>Challenge 3:</b> Patients are lost to care and/ or have limited access to care (travel, access to care, parking, opportunity costs, logistical challenges)</p> <p><b>Solution 3:</b> Provide patients and families with early education on lifelong specialized care for CHD, ensure ongoing communication and care coordination, and offer networks (including peer support/modeling) for ongoing support and education</p>	<p><b>Challenge 3:</b> Lack of patient &amp; family engagement related to lifelong care, healthcare systems, and the impact of CHD on lifelong health</p> <p><b>Solution 3:</b> Engage patients and families early on the need for lifelong care and the differences between pediatric and adult healthcare systems and bring awareness of the impact of CHD on their overall, lifelong health</p>
<p><b>PERFORMANCE MEASURES:</b> How do we measure progress towards outcomes?</p>				
<p>% Increase in ACHD trainee graduates <i>(Bonus: record # ACHD graduates working at ACHD Certified centers &amp; # working in historically medically underserved communities.)</i></p>	<p>Increased capture of data on efficacy of experimental and investigational CHD care and of data on effectiveness of accepted CHD care</p> <p>Increased data on the association between types of coverage and reimbursement models and outcomes</p> <p>Increase the % patients with (network-based vs more flexible Insurance coverage plans)</p> <p>Decrease the % of types of care where clinically indicated CHD testing or care requires pre-authorization</p>	<p>% Increase of patients accessing patient-centered strategies</p>	<p>% of multidisciplinary care teams featuring patient navigators and clinicians who exhibit cultural humility in care delivery</p>	<p>% expanded access to ACHD centers and providers</p>

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<p>% increase CMS in payment models that incentivize integrated care for people with CHD</p> <p><i>(Bonus: payment models that address 1) care coordination for transition and transfer 2) geographic boundaries</i></p>	<p>Improved data transparency on outcomes and costs</p>	<p>% increase in physicians and non-physician clinicians trained on National Standards for Culturally and Linguistically Appropriate Services</p>	<p>Innovations in clinician training and educational programming to advance the provision of cultural humility in delivering competent care</p>	<p>% of physicians and non-physician clinicians trained on transition and transfer implementation</p> <p>% of programs delivering comprehensive transition and transfer implementation</p> <p>% of patients that have a formal transition and transfer process</p>
<p>% increase in regional access to specialized ACHD care; across state and insurance barriers</p>	<p>% increase in insurance coverage equitably provided and sufficient to meet the care needs of patients</p>	<p>% increase in trained health policy leaders that address SDOH through research and advocacy</p>	<p>% increase in team-based care</p>	<p>% of patients provided anticipatory guidance for ACHD care</p>
<p><b>KEY STRATEGIES:</b> Which programs will drive results?</p>				
<p>Work with ABIM/ABP/ACGME to increase applicant pool by reducing training length and maintaining quality. Federal agencies to provide loan repayment</p>	<p>Increasing transparency of linked outcomes data from multiple sources (electronic health records, clinical registries, administrative data)</p>	<p>Value-based care incentives to create linkages to community-based systems and supports</p>	<p>Model programs for communication with patients and families</p>	<p>Value based payment for transition collaboration between pediatric CHD provider and ACHD provider in tandem</p>
<p>CMS to incentivize care models for underserved and underrepresented patients with CHD</p>	<p>Expanded use of the “hub-and-spoke model” that coordinates care provided by local hospitals and designated referral centers</p>	<p>Care processes that address SDOH using personalized and cultural humility approaches</p>	<p>Technical assistance and templated materials that facilitate cultural and linguistic competencies to communicate and educate patients and families</p> <p>Community engagement programs to disseminate centralized credible materials to the target patients and caregiver groups regardless of health literacy level</p>	<p>Demonstration projects to improve patient retention and continuity of care throughout the lifespan and limit need for more expensive procedures resulting from gaps in care</p>
<p>State and federal legislatures to remove geographic and insurance barriers for integrated regional specialized CHD care</p> <p>Systematic evidence reviews regarding integrated care for people with CHD stratified by age, severity of CHD (mild, moderate, complex), and differences in SDOH</p> <p>Alternative models of integrated care- train an adult cardiologist/ medicine/ family med physician in care of ACHD patients - who participate in care meetings and care pathways with the ACHD parent team</p>	<p>Funding of research and innovation centers</p>		<p>Standardized training in unequal SDOH, cultural humility, and equity, diversity, and inclusion for physician and advanced practice providers</p>	