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ARTICLE

Development and Implementation of a Patient Engagement Network for Advancing Research in Adult Congenital Heart Disease

Naomi Kalume[1,*], Shreya Papneja[1], Jamie L. Jackson[2], Richard Krasuski[3], Anushree Agarwal[4], Arwa Saidi[5], David Harrison[6,7], Matthew Lewis[8], Anita Mathews[1], Scott Leezer[9], Ken Woodhouse[10], Aliza Marlin[10], Danielle M. Hile[10], Ryan Joy O'Connor[11], Ruth Phillippi[1], Thomas Carton[12] and Anitha S. John[1]

[1]Division of Cardiology, Children's National Hospital, Washington, DC, USA
[2]Center for Behavioral Health, Abigail Wexner Research Institute at Nationwide Children's Hospital, Columbus, OH, USA
[3]Duke University Medical Center, Durham, NC, USA
[4]University of California San Fransico, San Fransico, CA, USA
[5]Congenital Heart Center, University of Florida, Gainesville, FL, USA
[6]Adult Congenital Heart Disease Program, Inova Medical Center, Fairfax, VA, USA
[7]University of Virginia School of Medicine, Charlottesville, VA, USA
[8]Columbia University Medical Center, New York, NY, USA
[9]CURA Strategies, Arlington, VA, USA
[10]Adult Congenital Heart Association, Philadelphia, PA, USA
[11]Harvard T.H. Chan School of Public Health, Boston, MA, USA
[12]Louisiana Public Health Institute, New Orleans, LA, USA
*Corresponding Author: Naomi Kalume. Email: nkalume@childrensnational.org

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ABSTRACT: Background: Adults with congenital heart disease (ACHD) experience lifelong medical and psychosocial challenges, yet research in this population is limited by incomplete longitudinal data and insufficient incorporation of patient perspectives. Although patient engagement is increasingly recognized as important, structured and sustainable engagement models in ACHD research remain limited. **Objectives:** The paper aims to describe the development and operational structure of the Congenital Heart Initiative (CHI) Engagement Network and to report outcomes from two annual patient-powered research meetings used to identify and refine ACHD research priorities. **Methods:** The CHI Engagement Network was established as a multi-stakeholder research infrastructure integrating patients, caregivers, clinicians, researchers, and advocacy organizations. Engagement activities included a Patient and Scientific Advisory Board, structured investigator intake and review processes, and annual patient-powered research meetings. Two network meetings were held in 2023 and 2024, each featuring mixed-stakeholder breakout groups focused on patient-prioritized domains. Qualitative data from the 2023 meeting were analyzed using reflexive thematic analysis. The 2024 meeting employed consensus-based co-design methods to generate actionable research concepts. **Results:** CHI Network activities contributed to the development of funded sub-projects, manuscripts, patient-facing dissemination products, and ongoing engagement initiatives. Across both network meetings, 105 participants representing patients with CHD, patient advocates, clinicians, researchers, and national stakeholders engaged in structured discussions. Consistent priority domains emerged, including mental health, access to specialized ACHD care, and precision medicine approaches. Patients emphasized personalization, clarity, and peer support; clinicians highlighted feasibility and workflow integration; and researchers prioritized data harmonization and scalability. Post-meeting surveys indicated high acceptability and perceived value. **Conclusions:** The CHI Engagement Network provides a feasible, replicable model for sustained patient engagement in ACHD research, linking governance, co-design, and priority setting to concrete study development and dissemination. This infrastructure advances patient-centered research and offers a roadmap for other rare disease communities.

KEYWORDS: Congenital heart disease (CHD); registries; quality improvement; research and advocacy; registry development and governance; data gaps and opportunities

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1 Introduction

Adults with congenital heart disease (CHD) face many challenges living with a chronic illness that can affect quality of life across their lifespan [1]. As more children with CHD are surviving into adulthood, there is a growing need to address their concerns and questions about comorbidities, complications, and long-term outcomes [2]. Researchers face many obstacles in improving 'evidence-based care' for patients in this rare disease population, due to a lack of longitudinal clinical and patient-reported outcomes data, as well as high rates of loss to medical follow-up [2]. Identifying the priorities of adults with congenital heart disease (ACHD) through qualitative research methods is important for understanding their lived experiences and perspectives [1]. Currently, there is no existing structure or framework to facilitate patient engagement and priority setting in CHD research.

Patient engagement in research is defined as the active, meaningful involvement of patients in the design, conduct, and dissemination of studies [3,4]. Patient engagement is increasingly recognized as essential to advancing patient-centered care [5]. When patients, clinicians, and researchers collaborate as equal partners, research questions are more aligned with real-world concerns, resulting in improved study relevance, greater implementation of findings, optimized recruitment, and enhanced care delivery [6,7]. Despite the benefits, evidence supporting best practices for patient engagement in ACHD research remains limited.

The Congenital Heart Initiative (CHI) was originally established as the first patient-powered registry for ACHD, collecting patient-reported outcomes selected by patients as being of high priority [8]. Built in close partnership with patients, the CHI, together with its first sub-study, the Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult Centered Care (CHI-RON), has developed into a robust research infrastructure. This includes an engagement network that relies on collaboration among patients, healthcare practitioners (HCPs), and advocacy organizations [9]. Beyond supporting researcher-initiated proposals, the CHI network hosts annual patient-powered research meetings to establish research priorities.

This paper aims to describe the development and functioning of the CHI Engagement Network, highlighting its role in fostering collaboration among patients, healthcare providers, and researchers. We detail the multi-phase process used by the CHI to integrate patient perspectives into research. Additionally, we present the outputs of two of the CHI's annual patient-powered research meetings, which serve as a key mechanism for setting CHI research priorities that reflect the lived experiences and needs of ACHD. While the CHI Engagement Network builds upon an established foundation of patient partnerships, the principles and structures are also relevant for teams seeking to expand their capacity for patient partnerships. Adapting elements of the CHI approach can help scale current engagement approaches to a more advanced patient-centered-infrastructure.

2 Methods

2.1 Patient and Partner Engagement

In alignment with the Patient-Centered Outcomes Research Institute's (PCORI) Engagement Rubric, we employed a structured, iterative approach to engage patients and community partners as active members of the research team throughout the study [3,4]. Initial patient partners were identified through collaboration with the Adult Congenital Heart Association (ACHA), the Heart Research Alliance, and early volunteers from the development of the CHI [10–12]. Additional partners were recruited over time through CHI registry participation, referrals from existing partners, and investigator-initiated engagement for project-specific activities. Initial partners included individuals (>18 years) with lived experience of CHD, including patients, family members or caregivers who provide ongoing support to individuals with CHD, as well as clinical healthcare providers and researchers. Recruitment aimed to include variation across underlying cardiac diagnoses, surgical histories, functional status, and care trajectories. Initial interest surveys included age, gender identity, race and ethnicity, geographic location (urban and rural), and educational background to ensure broad representation. A patient and scientific advisory board (PSAB) was established to guide CHI registry development and proposal review.

To support meaningful participation, project-specific orientation and training sessions covered research ethics, study roles, and methods. Communication emphasized transparency and inclusivity through plain-language materials, virtual access, and flexible scheduling. Partner contributions were documented and used to refine engagement practices. All partners were offered compensation to recognize their expertise and time.

Ethical safeguards were integrated throughout all engagement activities to protect participant well-being and privacy. Support strategies for vulnerable populations included flexible participation options, clear role expectations, and referral to support resources if discussions elicited distress. Facilitators ensured psychological safety, particularly during discussions of sensitive topics such as medical trauma, mental health, and care access disparities, and paused or redirected conversations as needed.

2.2 Structure, Process, and Function

The CHI Engagement Network was developed to support patient-centered research in CHD by facilitating collaboration between researchers, patients, and other stakeholders. The process and structure were drawn from other models like the Community Engagement Studio and the Clinical and Translational Research Studio [13,14]. The CHI Engagement Network, however, was adapted specifically for CHD-related research development. The Network serves as a bridge, connecting investigators with patient partners to co-develop research projects using the CHI and/or CHI-RON data.

Operationally, the Network follows a structured process (Fig. 1). Researchers initiate collaboration requests, which are reviewed by the CHI Administrative Team to assess alignment and feasibility. Investigators then meet with staff and statisticians to clarify project needs, review available data, complete intake forms, prepare patient-facing materials, and present proposals to patient partners for feedback and refinement. Concurrently, patients and partners are offered opportunities to join advisory boards, participate in patient-powered meetings, or access educational resources on research engagement. Throughout, there is a strong emphasis on iterative, bidirectional communication. Patients provide feedback on study design, participate in research meetings, and may join study-specific working groups or cores. The network's central goals are to ensure research proposals are refined through patient input, align study priorities with lived experience, and establish a sustainable model for integrating patient voices throughout the CHD research process. The Network also organizes patient-powered research conferences to identify community-prioritized research topics and to build engagement capacity for future grants and studies.

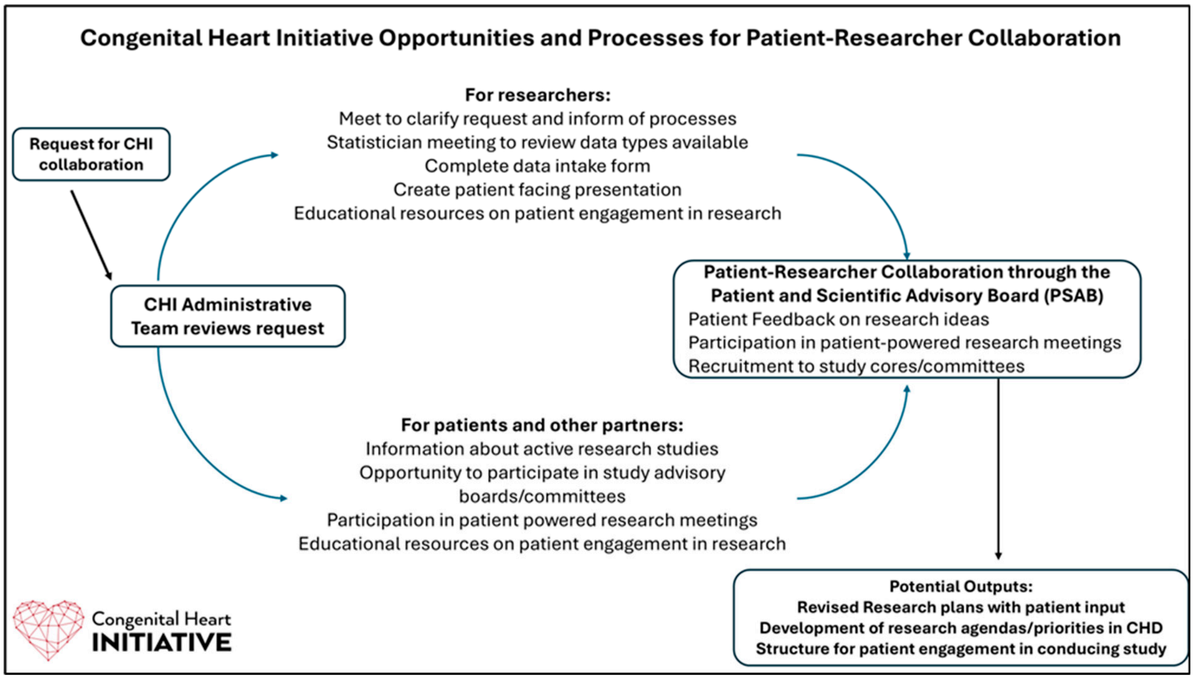


Figure 1: The Congenital Heart Initiative Network provides opportunities for patients with lived experience and other partners to work with and develop relationships with researchers to advance CHD related research that aligns with patient and community priorities.

2.3 Patient Powered Research Meeting Design

The research meetings were collaborative events designed to engage all partners in shaping the next phase of the CHI [15]. Attendees included ACHD patients, caregivers, pediatric and adult congenital cardiologists, advanced practice providers, clinical researchers, data scientists, and patient engagement specialists. Invitations were extended to both longstanding and new contributors to ensure diverse perspectives, with a deliberate balance of patient and professional voices. Two of the CHI-RON related meetings took place in person in Washington, D.C., on 8 May 2023, and 7 June 2024. Each was a full-day event featuring consistent formats of patient testimonials, plenary sessions, interactive breakout groups, and a final report-out.

Breakout groups, composed of mixed stakeholders, focused on predefined patient-prioritized topics to generate new research project ideas. Consistent with the Discover phase of human-centered design, the meetings created structured opportunities for participants to share experiences, surface needs, and collectively identify areas of inquiry most meaningful to the ACHD community [16,17]. Groups were co-led by a CHI study team member with subject-matter expertise (e.g., clinician or researcher) and a patient or scientific partner. Facilitators used structured guides to ensure balanced contributions, encouraging patients to share personal experiences while clinicians and researchers provided clarification on current clinical practice, feasibility, and research considerations. Facilitators promoted equitable participation, minimized medical jargon, and supported emotional safety.

In 2023, the in-person meeting focused on generating key themes and strategic directions for CHI investigators, while in 2024, the meeting focused on generating specific research questions and projects within similar domains. Topics for 2023 were pre-defined and approved by the PSAB. These included CHD Across the Lifespan; Mental Health for CHD Patients; and New Horizons in CHD Research and Care. Topics for 2024 were chosen based on the discussions from 2023 and included: Strategies to Improve Access to Specialized ACHD Care; Take Charge of Your Mental Health; and Personalized Medicine: Enhancing Care Models, Diagnostics, and Therapies.

2.4 Qualitative Analysis

Handwritten notes and a transcript of the voice recording were obtained from breakout sessions and analyzed by two members of the study team. *Recordings were made only if all participants of the breakout group consented.* The mental health breakout session was not recorded due to participant preference; instead, one group leader volunteered to take notes on the content covered. The recordings were then: (1) transcribed into textual data and (2) analyzed using reflexive thematic analysis. The recording was transcribed to a text file with "Otter.ai", followed by manual editing [18,19]. To ensure accuracy, the research staff reviewed the transcribed text and edited mistakes in the transcription.

For 2023, qualitative reflexive thematic analysis was conducted for the transcribed audio data for each breakout session and focus group as described by Braun and Clarke [18,19]. NVivo 14 (Lumivero Inc., Denver, CO, USA), a qualitative data analysis software, was used to assist with thematic analysis [20]. This was used in combination with manual coding by two researchers to ensure contextual accuracy and depth of interpretation. Initially, edited transcripts were uploaded into NVivo, and a list of common themes was generated for each breakout. The research team manually reviewed the transcripts to determine more complex themes discussed at the meeting. Two researchers analyzed the data separately, first going through each transcript and noting significant quotes, passages, and topics from each transcript. Based on this review, each researcher developed a set of themes and subthemes. The researchers then compared the two thematic analysis templates and, finding significant similarity between the derived themes, combined findings from individual analyses to yield a single set of themes for each breakout. For 2024, patient partners were asked to generate a pictorial description of their project idea. During the sessions, two research staff members actively coded discussions to generate a draft research idea and research questions, which were modified through group consensus as facilitated by the session moderator.

This study received ethical approval from the Children's National Medical Center Institutional Review Board (approval no. [FWA00004487]) on [1 October 2021]. This study has undergone annual continuing review and remains actively approved through September 2026.

3 Results

3.1 Demographics of Network Partners

A total of 38 patients and other partners were members of the CHI PSAB. Of the total membership, 27 were female (F) and 11 were male (M). Participants reflected a wide range of CHD diagnoses and included individuals at varying life stages and care engagement levels. The board reflects meaningful inclusion of multiple groups: 15 patients, 3 parents of patients, 17 scientists, and 16 physicians. In addition, the PSAB includes 4 members employed by advocacy organizations and 3 representatives from funding agencies.

3.2 Network Activities

The CHI engagement network facilitated the development of several funded sub-projects, grant submissions, and manuscripts (Table 1). Network contributions included review of patient-facing materials, protocol modification with incorporation of patient-prioritized outcomes, methodological input from researchers, and practical considerations for recruitment from clinical providers. Patients also critiqued the topic relevance of the proposed research, drawing on their lived experiences to highlight the significance of the proposed topics and outcomes. Collectively, these outputs reflect the role of the engagement network in translating patient-identified priorities into concrete research activities and products.

Table 1: CHI engagement network functions.

Research Topic	Investigator	Network Function	Network Recommendation	Outcomes
Co-Creation of the Congenital Heart Initiative Version 3.0	Professor of Pediatrics	Design of a more patient-centric registry	• Include data dashboards • Easy access to registry information • Recruitment material refinement • Social media content	• Registry re-launched with new features incorporated • New public website launched • Recruitment materials revised
Social Drivers of Health in ACHD Care	Associate Professor of Psychology	Share patient perspectives on factors critical to accessing care	• Refined analysis plans by clarifying the region of residence • Consider Medicaid expansion timeframes	• Revised analysis plan • Abstract presentation • Manuscript submission
Practice Patterns and Outcomes of Endocarditis in ACHD	Associate Professor of Cardiology	Review of proposal and presentation	• Examine the factors associated with • Future studies examining the role of antibiotic prophylaxis	• Revised analysis plans
Measures of Post-Traumatic Stress Disorder in ACHD Patients	Assistant Professor of Cardiology	Review of study protocol and presentationReview of recruitment strategies	• Input on questionnaire design • Input on recruitment strategies and areas of sensitivity for patients	• Grant funding obtained • Recruitment video created • Questionnaires modified
Priorities to Improve Reproductive Healthcare for CHD Patients	Professor of Pediatrics	Creation of a project-specific consortium with multiple partners through the identification of	• Develop priority areas needing further research • Participation in in-person meeting to define strategic roadmap projects • Co-creation of patient and health care provider questionnaires	• Strategic roadmap with action items • 4 published manuscripts
Incidence and Risk Factors of Stroke in ACHD	Assistant Professor of Neurology	Review of proposal and presentation	• Refinements of research questions and outcomes	• T32 project approval • NIH grant preparation
Examining the Relationship between Primary and Specialty Care Utilization in ACHD	2nd Year Medical Student	Review of proposal and presentation	• Provide patient input and refinement on research topic	• Moderated abstract presentation

Across proposals reviewed by the PSAB, patient input resulted in meaningful modifications, including refinement of primary outcomes, adjustment of eligibility criteria, and revision of patient-facing materials.

Investigators reported improved feasibility and recruitment strategy design following engagement, with several studies noting enhanced enrollment efficiency and early retention compared with prior investigator-led efforts. The assessment of engagement efficacy was formally assessed using the Patient Engagement in Research Scale (PEIRS-22) and published previously [21]. Most study team patient partners (86%) reported a very to extremely high degree of engagement (PEIRS-22 average score 101.6), especially in the subdomains of contributions, support, feeling valued, and benefits.

The CHI engagement network has also helped support funded studies utilizing the CHI infrastructure. For the CHI-RON study, participants reported wanting more connection with other patients. To help support this, a monthly virtual coffee hour (10/2022–9/2023) was hosted by a patient partner in conjunction with the ACHA for registrants of the CHI. Average attendance ranged from 8 to 19 registrants/event, with information shared about CHI activities.

Most participants said they would attend again (96%) and found the discussion useful (92%). Another key output from the network was the public-facing CHI website. Developed by patient partners with input from the engagement network, the site provides a centralized platform for sharing CHI research outputs, including annual reports and recent publications, using patient-facing, plain-language content [10]. In addition, the website facilitates registry enrollment, promotes participation in research activities, and enables researchers to submit data access and proposal requests, supporting bidirectional communication across the CHI network.

The network outputs also contribute to expanding the infrastructure through incorporating resources from additional studies, including a virtual educational curriculum focused on patient engagement in research [10] and the inclusion of patients with intellectual disabilities, in addition to CHD and their family members. These continual improvements have strengthened the network by adding resources that can be offered to other studies as well as enriching the network with more representative voices.

3.3 Meeting Attendance

The 2nd Annual CHI-RON Research Study Meeting included 50 total participants representing patients with CHD (n = 15, 30%), patient advocates (n = 15, 30%), clinicians (n = 14, 28%), researchers (n = 4, 8%), and national stakeholder organizations (n = 2, 4%). Participants were distributed across three breakout sessions: CHD Across the Lifespan (n = 13, 53% patients), New Horizons in CHD Care (n = 15, 27% patients), and a Mental Health breakout group (n = 15, 27% patients). The 3rd Annual CHI-RON Research Study Meeting included 55 participants, including individuals with CHD (n = 13, 24%), patient advocates (n = 7, 13%), clinicians (n = 21, 38%), researchers, site principal investigators, and research staff (n = 10, 18%), and national funding and policy representatives (n = 4, 7%). Participants were assigned to three themed breakout sessions: Strategies to Improve Access to Specialized ACHD Care (n = 16, 50% patients), Take Charge of Your Mental Health (n = 17, 47% patients), and A Personalized Medicine Approach (n = 17, 47% patients).

3.4 Patient Powered Research Meetings

3.4.1 2023 Meeting Findings

The key findings and perspectives from the 2023 meeting are presented in Table 2. In the *Mental Health Concerns* group, the central theme focused on inadequate access to mental health services, with participants emphasizing the absence of resources and tools to close existing care gaps. Subthemes reflected a desire for new mental health care options, strengthened community support structures, and improved screening and access pathways. Patients consistently highlighted the importance of emotional well-being and opportunities for peer support, while providers underscored the need for mental health professionals familiar with CHD and practical tools for stress management and self-care. Researchers emphasized the importance of developing measures of medical trauma specific to CHD and identifying the optimal timing for interventions.

Table 2: 2023 in-person research priorities.

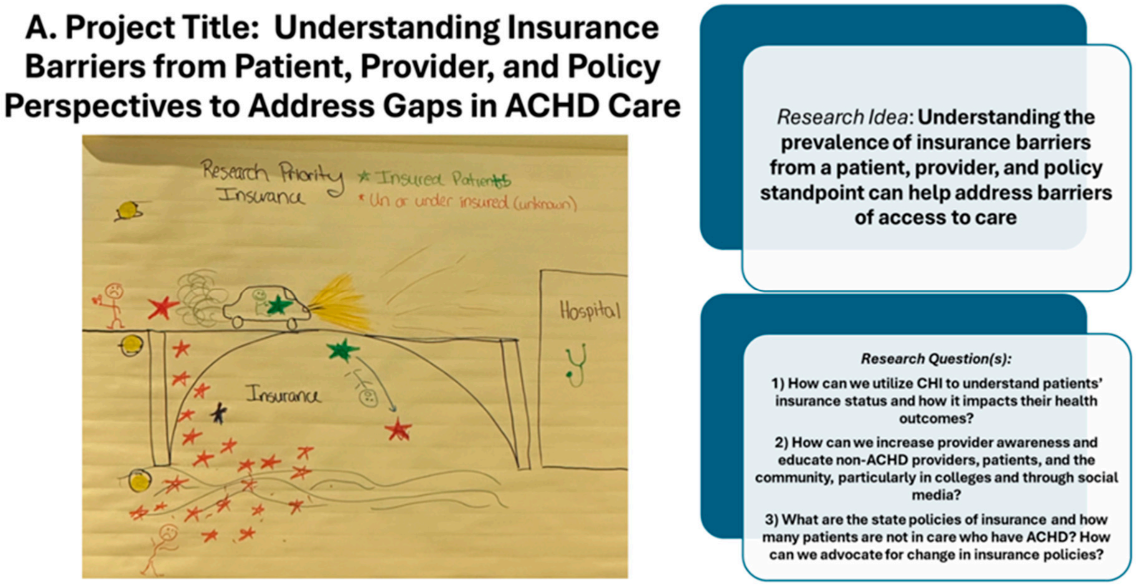
Breakout Topic	**Mental Health Concerns in CHD**	**CHD Care across the Lifespan**	**New Horizons in CHD Research and Clinical Care**
Central Theme of Discussion	Inadequate access to mental health care with no resources or tools to help close the access gap	Patient perspectives on CHD and CHD-related health needs change throughout their lives	Advancing care through an AI-enabled precision medicine ecosystem that delivers personalized guidance and predictive tools for people with CHD
Sub-Themes	(1) New mental health care resources and options (2) Improved mental health community support structures (3) Better access to mental health care, including screening tools	(1) Lifelong journey and shifting identity with ACHD (2) Navigating healthcare systems, especially during transitions of care (3) Increasing accessibility to all healthcare, addressing insurance and transportation barriers	(1) Need for personalized management plans for patients (2) Standardizing healthcare reporting with clinician-facing tools summarizing risk & functional status (3) Technology (wearables) for precise data collection
Topics	• Patients: Prioritized social and emotional wellbeing and peer support with other CHD patients • Providers: Increased need for mental health professionals who understand CHD and tools, including stress management, self-care activities, and mental health coaches • Researchers: Need for a measure of medical trauma in CHD and the correct timing of intervention	• Patients: Importance of connecting with other CHD patients • Providers: Standardization of practice and navigating healthcare systems • Researchers: Systematic integration of ACHD-related care into the healthcare system to improve outcomes • Increasing accessibility to all healthcare, addressing insurance and transportation	• Patients: Seeking highly tailored treatment plans, especially safe exercise guidance • Providers: Creating infrastructure that supports real-world clinical decisions, not just publications • Researchers: Develop pipelines for extracting data locally and across multiple centers • Collaboration with existing registries and research consortia are essential partners for creating a unified precision platform

The *CHD Care Across the Lifespan* group discussed how patients' health needs and identities shift over time, particularly during transitions of care. Subthemes centered on navigating complex healthcare systems and improving accessibility to care, including reducing insurance and transportation barriers. Patients stressed the value of connecting with other individuals with CHD, whereas providers highlighted the need for standardizing practice and supporting patients through transitions. Researchers pointed to the importance of systematically integrating ACHD care into broader healthcare structures to improve long-term outcomes.

Finally, the *New Horizons in CHD Research and Clinical Care* group explored a vision for an AI-enabled precision medicine ecosystem capable of delivering personalized guidance and predictive tools. Subthemes reflected the need for individualized management plans, standardized reporting tools for clinicians, and the use of technologies such as wearables for precise, real-world data collection. Patients expressed interest in highly tailored treatment guidance. Providers emphasized building infrastructure that supports real-world clinical decision-making, and researchers discussed the importance of developing data pipelines within and across institutions, noting that collaboration with existing registries and consortia will be essential for creating a unified precision platform.

3.4.2 2024 Meeting Findings

In 2024, the focus shifted to practical, actionable strategies as shown in Figs. 2 and 3. The topics included: Strategies to Improve Access to Specialized ACHD Care; Take Charge of Your Mental Health; and Personalized Medicine: Enhancing Care Models, Diagnostics, and Therapies. The *Personalized Medicine* group identified several key components necessary for a precision medicine framework. Participants emphasized that feasibility depended on incorporating user-centered features, seamless workflows, and trusted partnerships, including integration with large health systems, academic institutions, and pediatric programs to support continuity during transitions of care. A patient-facing dashboard was viewed as a potential engagement and recruitment tool that could improve transparency, personalization, and perceived relevance of participation. The discussion focused not only on the key components but also on actionable implementation strategies necessary to optimize engagement, equity, and scalability of the framework.


A. Project Title: Understanding Insurance Barriers from Patient, Provider, and Policy Perspectives to Address Gaps in ACHD Care

Research Idea: **Understanding the prevalence of insurance barriers from a patient, provider, and policy standpoint can help address barriers of access to care**

Research Question(s):

1) How can we utilize CHI to understand patients' insurance status and how it impacts their health outcomes?

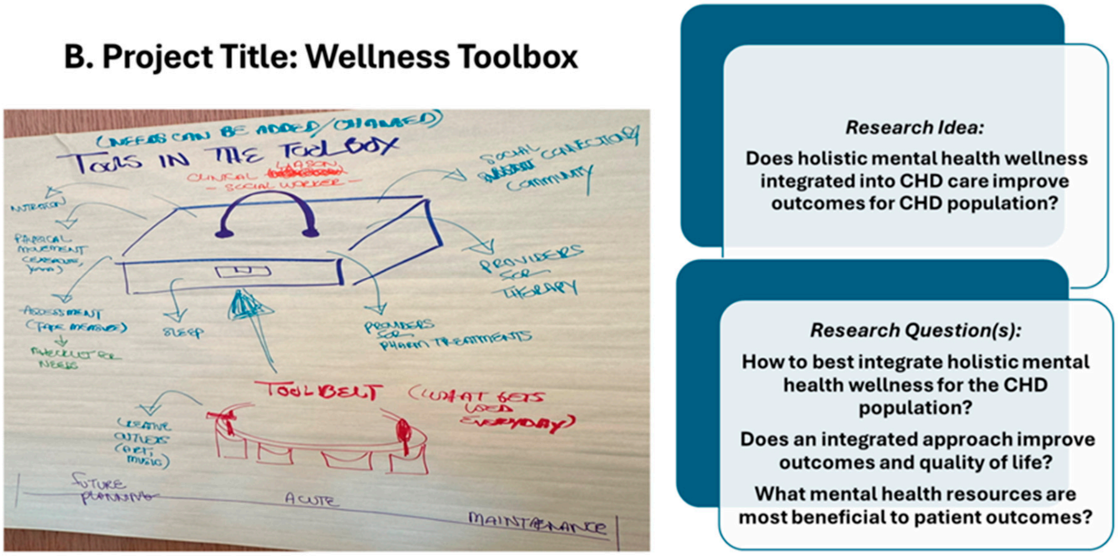
2) How can we increase provider awareness and educate non-ACHD providers, patients, and the community, particularly in colleges and through social media?

3) What are the state policies of insurance and how many patients are not in care who have ACHD? How can we advocate for change in insurance policies?

Figure 2: Pictorial conceptual illustration developed during the 2024 CHI patient-powered research meeting. The figure reflects research questions and ideas developed from themes initially identified in the 2023 meeting. A. Improving Access to Specialized ACHD Care.

The *Take Charge of Your Mental Health* group identified that mental health care needed to be flexible, adapting to the patient's needs with a variety of "tools" rather than a standalone service. Participants described a need for flexible, complementary resources, including mental health screening, peer and community support, provider-facilitated therapy, sleep and stress management, and future-oriented planning, that adapt across the lifespan. A key finding was the distinction between sustained "toolbox" resources supporting long-term mental health maintenance and a responsive "toolbelt" activated during periods of acute illness, psychosocial stress, or care transitions (Fig. 2). Together, these perspectives informed a unified Wellness Toolbox framework that organizes mental health resources across acute, transitional, and maintenance phases of CHD care.

The *Access to Specialized Care* group identified insurance as a central barrier to accessing specialized ACHD care. Participants described how insurance instability and coverage limitations, in addition to limited ACHD providers, can lead to disrupted care and delayed referrals, particularly during life transitions such as aging out of parental coverage or entering college or the workforce. Patients emphasized challenges navigating complex insurance requirements, while clinicians highlighted administrative burdens, including prior authorizations and coverage denials, that constrained timely care delivery. Across perspectives, participants identified patient and provider education, improved transition support, and policy advocacy as key opportunities to improve access to specialized ACHD services (Fig. 3).



B. Project Title: Wellness Toolbox

Research Idea:

Does holistic mental health wellness integrated into CHD care improve outcomes for CHD population?

Research Question(s):

How to best integrate holistic mental health wellness for the CHD population?

Does an integrated approach improve outcomes and quality of life?

What mental health resources are most beneficial to patient outcomes?

Figure 3: Pictorial conceptual illustration developed during the 2024 CHI patient-powered research meeting. The figure reflects research questions and ideas developed from themes initially identified in the 2023 meeting. B. Take Charge of your Mental Health Wellness Toolbox.

Across both meetings, an important observation was the similarity and differences of priorities between patients, clinicians, and researchers (Table 3). Patients emphasized clarity, personalization, and practical guidance, particularly in areas such as mental health, physical activity, and navigating complex care systems. Clinicians focused on feasibility, workflow integration, and interpretability of data within real-world clinical settings. Researchers prioritized data harmonization, methodological rigor, and scalability.

3.5 Satisfaction Survey

Post-meeting satisfaction surveys were completed by participants at both annual in-person research meetings. In total, 27 participants (30% patients) from the 2nd Annual Research Meeting and 24 participants (35% patients) from the 3rd Annual Meeting completed surveys. Across both years, participants overwhelmingly agreed that the meetings supported the project mission (100% in both years) and felt comfortable interacting with one another (100% in both years). All participants in Year 2 and 94% in Year 3 felt that patient perspectives were well incorporated. Participants also endorsed the meetings as contributing to study goals (100% in Year 2; 94% in Year 3), with breakout groups in Year 3 rated as highly valuable (100%). Qualitative feedback emphasized the impact of mixed-stakeholder breakout groups and patient storytelling, while suggesting improvements such as smaller group sizes, more discussion time, clearer communication of next steps, and expanded patient co-leadership in breakout facilitation.

Table 3: Differences in perspectives and insights from key partners gained from the patient powered research summits.

	Patients	**Healthcare Providers**	**Researchers**
Viewpoint	• Grounded in lived experience and day-to-day survival. • Emphasize information access, validation, and being heard.	• Grounded in clinical expertise and scope of practice. • Balancing being a “medical home” vs. staying in specialty boundaries.	• Grounded in categorizing themes, generalizing patterns, and designing interventions. • Incorporate patient/provider experiences into research ideas and test solutions.
Priorities	• Transparency and accessibility of research and testing results. • Improve accessibility to ACHD providers, mental health, and other subspecialists • Holistic guidance beyond the heart (i.e., reproductive health). • Trust in HCPs and community	• Safe clinical management of ACHD-specific complications (arrhythmia, liver disease, Fontan failure). • Improving access the HCPs (PCPs, mental health providers, subspecialists). • Increasing ACHD specialists and clinical support for ACHD programs.	• Understanding comorbidities and lifespan outcomes. • Examining how patient–provider communication shapes care quality. • Measuring quality of life, transitions, and systemic barriers. • Identifying financial and policy implications.
Concerns	• Dismissal of feelings and symptoms. • Invisibility (adults not acknowledged in CHD campaigns). • System frustrations (insurance, ACHD clinic distance, PCP turnover).	• Limited visit time (15–20 min). • Lack of PCPs willing/able to take complex patients. • Institutional gaps in transition models. • Lack of clinical support in ACHD programs	• Complexity of ACHD with evolving treatments can make studies difficult to design. • Difficulty operationalizing multi-center studies in research frameworks.
Strategies	• Self-advocacy, peer-to-peer support • Improved healthcare transition from pediatric to adult care • Increase accessibility to ACHD and other HCPs	• Advocating for telemedicine, multidisciplinary networks, and institutional investment. • Regional strategies to partner with tertiary care centers to provide clinical care	• Achieving data harmonization among diverse sources. • Designing patient-centered frameworks that bridge medical, psychosocial, and systemic levels. • Advocating for larger systems-level studies, registries, and collaboration.

4 Discussion

This study describes the development, structure, and outcomes of the CHI engagement network and demonstrates how patient-powered research meetings can be used to meaningfully integrate patient perspectives into research priority setting in ACHD. This infrastructure not only allows investigators to leverage existing CHI-collected data and propose new studies but also ensures ongoing opportunities for direct patient feedback throughout the research process. The CHI patient-powered research meetings functioned as a structured mechanism for identifying and refining research priorities while also highlighting the different perspectives of attendees. These perspectives underscore the necessity of co-design in ACHD research.

A central feature of the PSAB is its shared leadership model, with patients, providers and physician scientists serving as co-leaders to ensure that lived experience and scientific expertise guide decision-making equally. CHI governance necessitates approval from the PSAB prior to utilizing data for future research. The board is intentionally multidisciplinary, broadening the scope of expertise and perspectives. This structure promotes collaborative dialogue and ensures that research priorities and recommendations are informed by both scientific rigor and the lived realities of patients and families. Building on prior successful ACHD and CHD studies that have incorporated patient perspectives, patient engagement in this field has rarely been supported by systematic, longitudinal research infrastructure [22–24].

The reproducibility and scalability of the CHI Engagement Network are important considerations for research teams seeking to adopt similar strategies. While not all communities will begin with the same level of infrastructure or patient partnership, several aspects of the model are adaptable for groups at earlier stages. Key replicable components include: (1) establishing a patient advisory group that serves as a consistent partner in shaping study priorities; (2) creating structured opportunities for co-developing research questions (i.e., research meetings); (3) integrating patient-reported outcomes early in project design to ensure relevance and sustainability; and (4) creating feedback loops so patient partners can observe how their input influences study design and outputs. By focusing on these core processes, research teams can adapt and scale efforts based on their level of existing funding and partnerships.

Core standardized operating protocols guide the CHI Engagement Network to ensure consistency, transparency, and scalability. The PSAB operates under written governance guidelines outlining membership terms, requirements, and decision authority for data access and proposal approval (Supplementary Material). Patient partners are offered training curricula covering research ethics, study design, patient reported outcomes, and effective advisory participation as has been previously described [25]. Proposal review follows a standardized workflow including investigator submission of proposal summary, PSAB presentation and feedback, and documentation of revisions. Proposal intake forms and publication policies are available to the public on the CHI website, researchers tab [26].

Findings from the CHI engagement network underscore the critical role of policy and funding agencies in supporting patient-driven research infrastructures that enable equitable participation and real-world impact. The translation of patient-identified priorities into funded projects demonstrates how engagement-informed research can address systemic exclusions embedded in traditional study designs. For policymakers, the prioritization of insurance-related barriers and transition challenges highlights the need for research that informs coverage continuity, network adequacy, and access to specialty care for rare disease populations [27,28]. Funding agencies can further advance patient-centered outcomes research by supporting longitudinal engagement models, cross-sector partnerships, and infrastructure grants that allow priorities identified through patient-powered processes to be iteratively refined and evaluated.

Notable limitations include self-selection bias and limitations in generalizability. Participants were invited from those already engaged in CHI-related activities, which may limit generalizability to less-connected ACHD populations. Consistent with trends observed in other ACHD initiatives, women, individuals with higher educational attainment, and those already connected to advocacy networks were overrepresented. To mitigate self-selection bias, the CHI Engagement Network has implemented targeted strategies including direct outreach through community-based organizations, travel and virtual access support, and intentional oversampling of underrepresented groups during meeting invitations. Further work is needed to improve representation. Additionally, qualitative findings reflect group discussions rather than individual interviews and may underrepresent dissenting views. These efforts were also dependent on stable funding sources to support staff and resources. Despite these limitations, the consistency of themes across meetings and stakeholder groups supports the credibility of the findings.

Research priorities identified during the 2023 patient-powered meeting have progressed into funded and active studies, including grants focused on mental health and ACHD care [29]. Several concepts generated during the 2024 meeting informed subsequent grant submissions and manuscript development using CHI infrastructure. A closed-loop feedback mechanism was established where patient partners receive updates via PSAB meetings, quarterly newsletters, and annual convenings detailing the status of proposals, funding decisions, and study milestones. This approach ensures transparency and reinforces the visibility of patient contributions across the research lifecycle.

5 Conclusion

The CHI engagement network demonstrates how structured, patient-powered collaboration can inform meaningful research priority settings in ACHD and may serve as a model for other rare disease communities. By centering lived experience, fostering equitable partnerships, and integrating patient engagement into governance and infrastructure, the CHI provides a model for advancing patient-centered research in rare disease populations. Future work will focus on evaluating the downstream impact of this engagement on research quality, funding success, and ultimately, access to and outcomes of specialized ACHD care.

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Availability of Data and Materials: Aggregate data supporting the findings of this study are available from the corresponding author upon reasonable request and subject to applicable data use agreements. Qualitative datasets generated during patient engagement meetings are not publicly available due to confidentiality considerations and the sensitive nature of participant discussions.

Ethics Approval: The engagement activities described in this manuscript were conducted as part of research infrastructure development and priority setting efforts. All participants provided consent for participation in engagement meetings and for the use of de-identified notes and recordings for research and dissemination purposes. Ethical oversight was provided in accordance with institutional policies governing patient engagement and human-subjects related activities. This study received ethical approval from the Children's National Medical Center Institutional Review Board (approval no. [FWA00004487]) on [1 October 2021]. This study has undergone annual continuing review and remains actively approved through September 2026.

Conflicts of Interest: The authors declare no conflicts of interest. All members of the CHI Engagement Network disclose potential conflicts, and identified conflicts are managed in accordance with CHI governance policies.

Supplementary Materials: The PSAB Scientific and Patient Subcommittee Charter is provided as supplementary material in the attached documents. The supplementary material is available online at https://www.techscience.com/doi/10.32604/schd.2026.081700/s1.

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