The Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult Centered Care (CHI-RON study)

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Relevant financial relationship(s):

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PCORI SOE-2023C2-33450

Off Label Usage:

None

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Learning Objectives

- Review the current challenges in adult congenital heart disease (ACHD) clinical care
- Understand the gaps in longitudinal research in ACHD
- Learn how Real-World data can be used to develop research platforms in ACHD
- Discuss the importance of patient engagement in research

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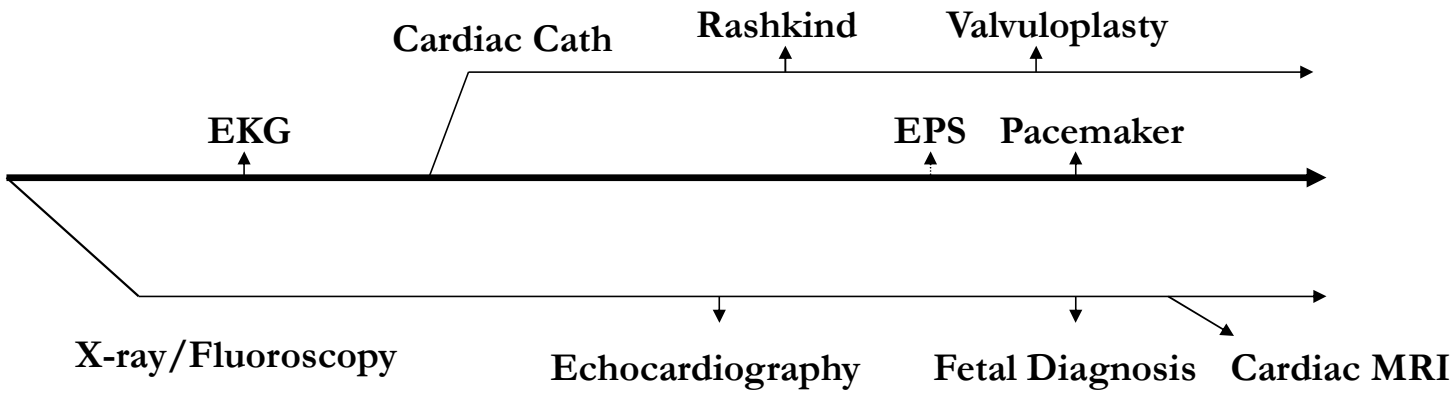
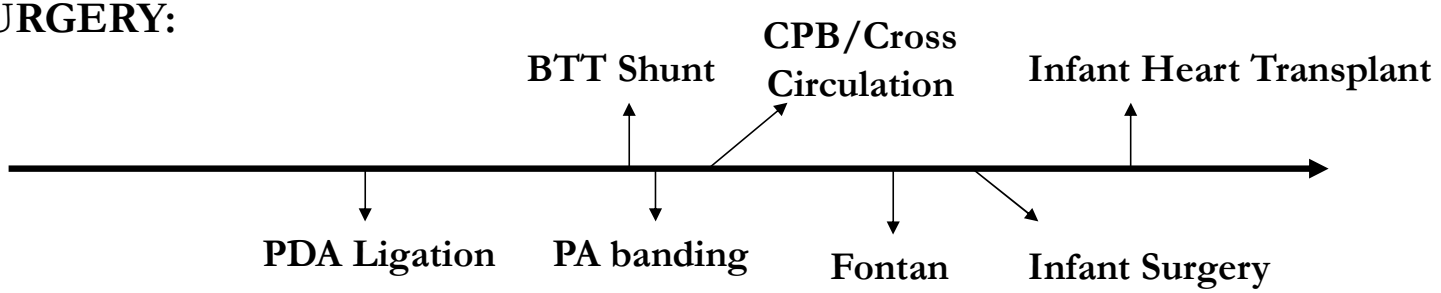
DIAGNOSTIC TOOLS:



SURGERY:



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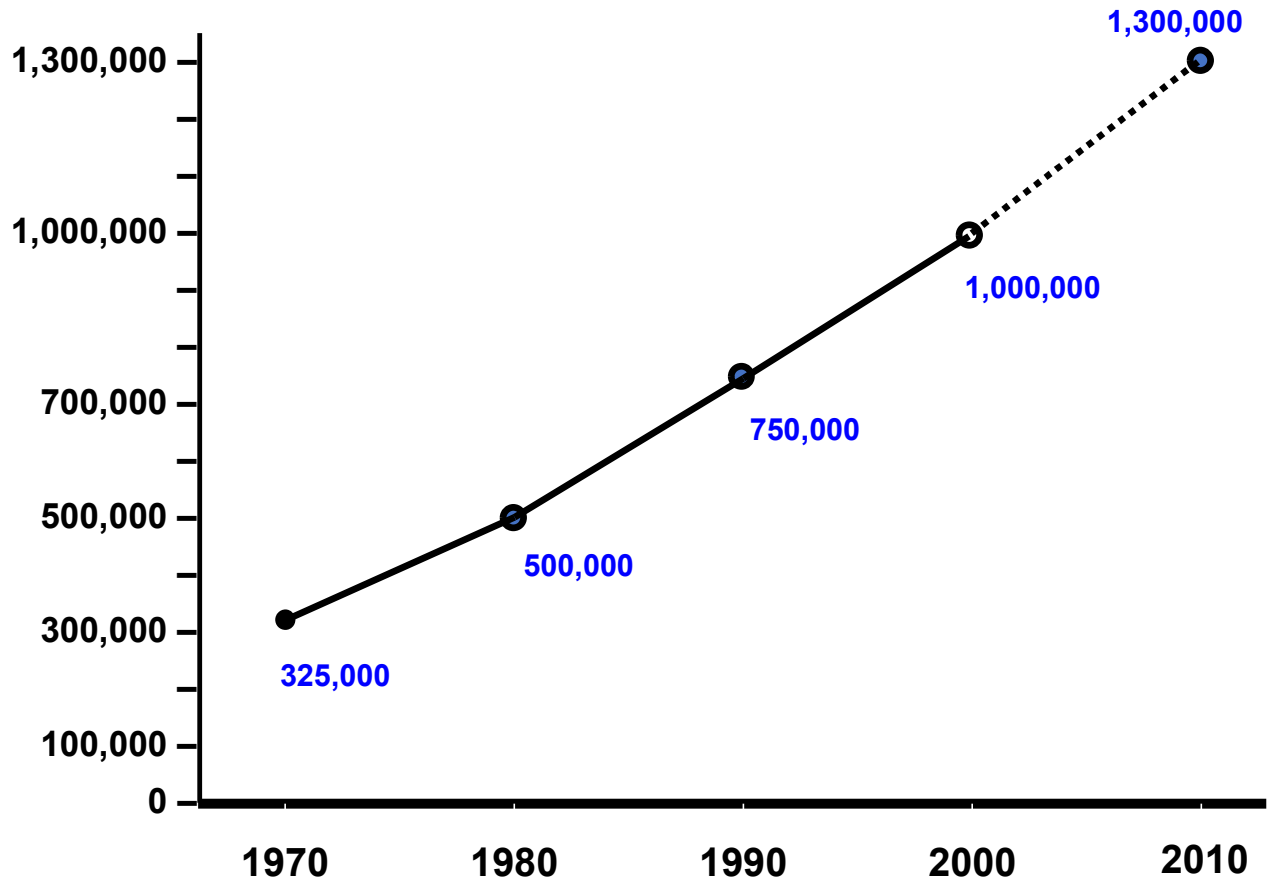
Number of Adults with CHD in the US



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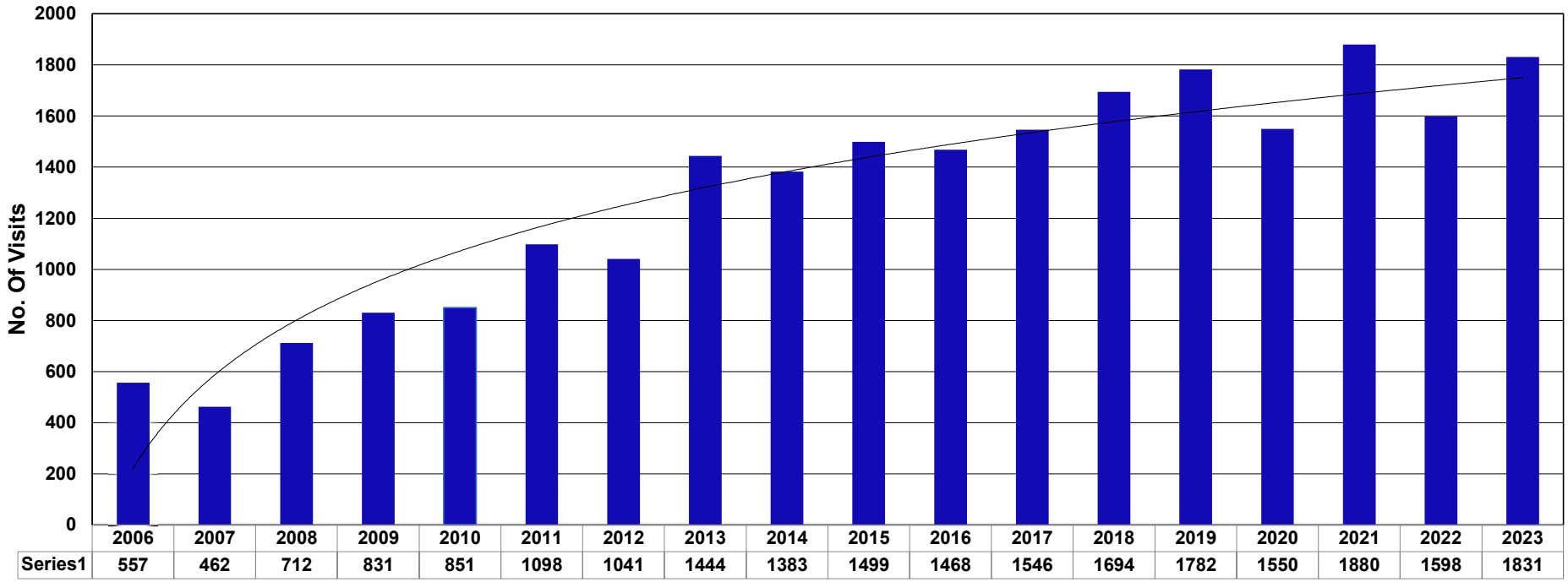
Washington Adult Congenital Heart



	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Series1	557	462	712	831	851	1098	1041	1444	1383	1499	1468	1546	1694	1782	1550	1880	1598	1831

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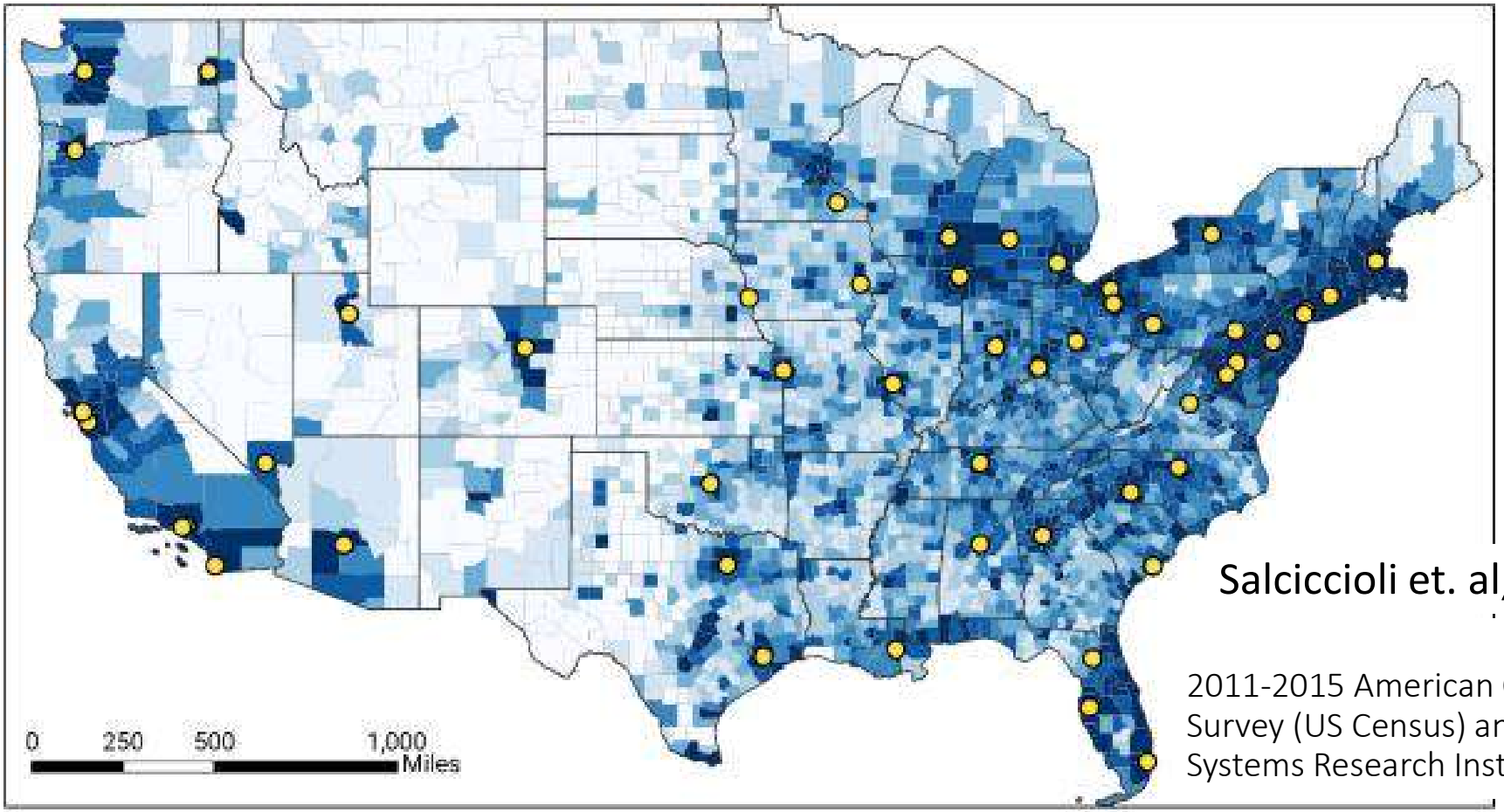


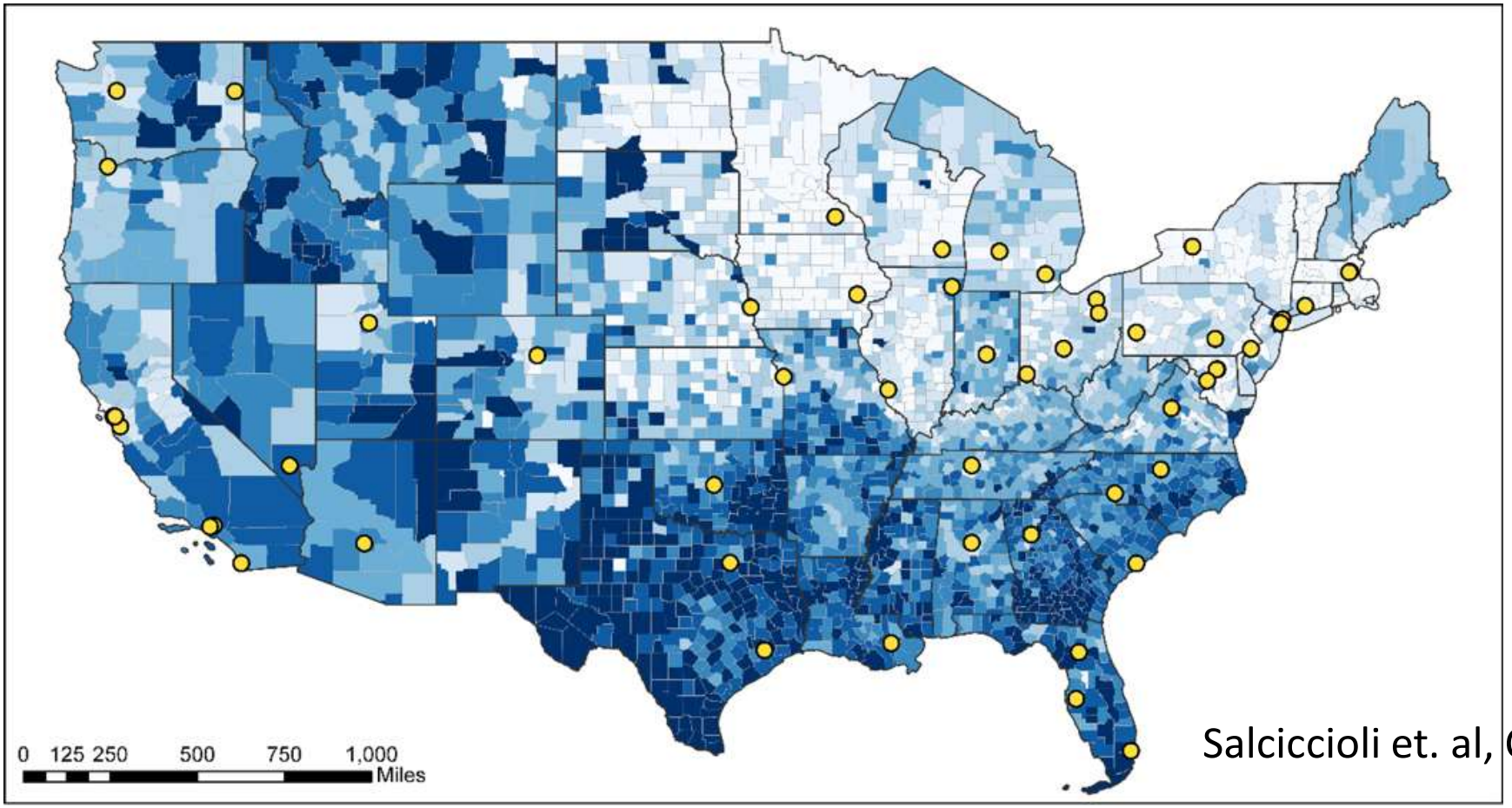
Salciccioli et. al, CHD, 2019

2011-2015 American Community Survey (US Census) and Environmental Systems Research Institute

Counties inside Continental US: Mid/high-volume ACHD centers and population density of adults (18+ years old). ACS 2012-16.

Population per square mile. Categories are seven-class quantiles (septiles)

- ≤5.6
- 5.61 ≤ 15.4
- 15.5 ≤ 26.6
- 26.7 ≤ 43.3
- 43.4 ≤ 74.3
- 74.4 ≤ 202.1
- 202.2 ≤ 61130
- ACHD Centers



Salciccioli et. al, CHD, 2019

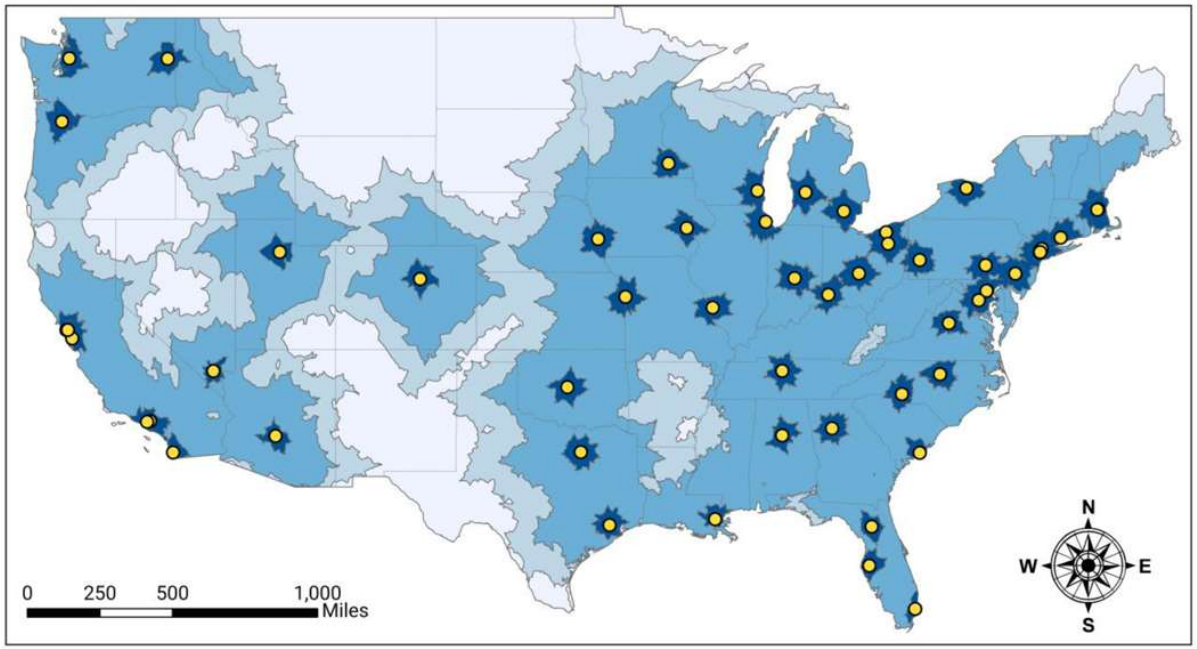
Counties inside Continental US: Health insurance among 18+ y.o. adults congenital heart disease (ACHD) patients. ACS 2012-16.

Percent uninsured. Categories are seven-class quantiles (septiles)

- ≤7.89
- 7.90 ≤ 9.95
- 9.96 ≤ 12.09
- 12.10 ≤ 14.18
- 14.19 ≤ 16.56
- 16.57 ≤ 19.79
- 19.80 ≤ 57.64
- ACHD Centers

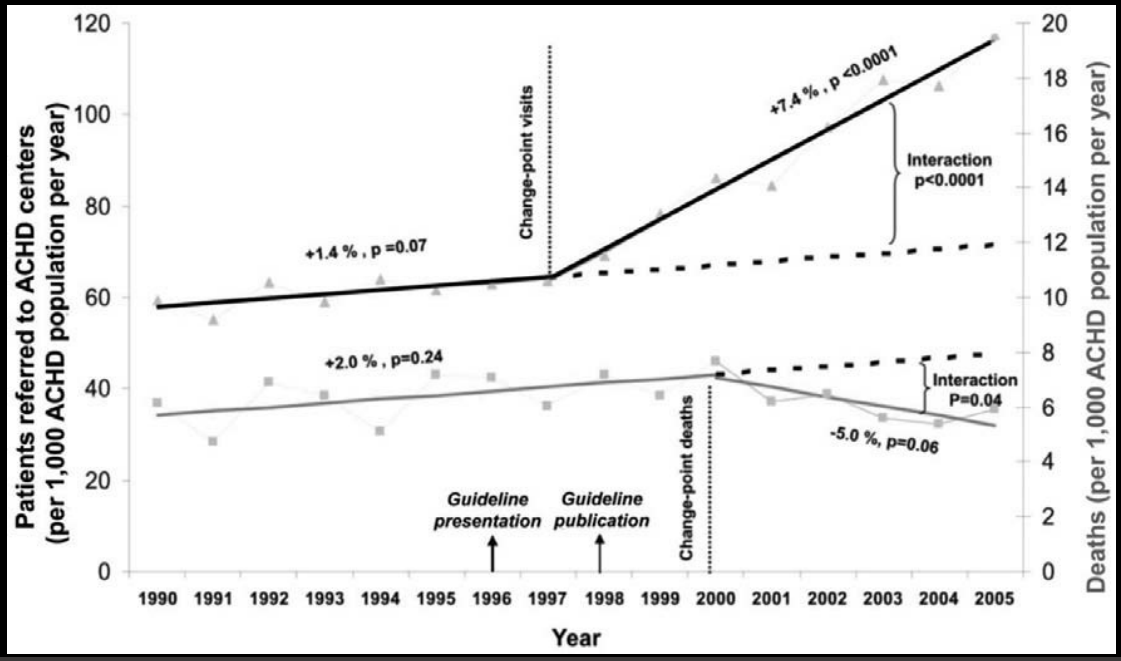
- 2011-2015 American Community Survey (US Census) and Environmental Systems Research Institute
- Mid-high volume ACHD centers (≥500 outpatient visits, ≥20 ACHD surgeries)

- 40% live 1-4 hours away
- > 6 hours vs < 1 hour: uninsured 29% vs 18%, below federal poverty level 19% vs 13%, no college 18% vs 12%)
- Hispanics more likely to live >6 hours (p< 0.001)



Salciccioli et. al, CHD, 2019

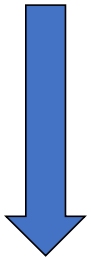
Specialized ACHD Care Reduces Mortality



Specialized ACHD referral centers were defined by: (1) the *expertise criterion*, at least 1 imaging or interventional cardiologist and at least 2 CHD surgeons with advanced training and experience with ACHD patients; (2) the *patient volume* criterion, requiring that =520 patients/ year

Mylotte D et al. Circulation. 2014 May 6;129(18):1804-12.

Barriers to Surveillance and Long-Term Outcomes Research



Heterogeneity of CHD with Changing Treatment Strategies

No Longitudinal Registry in US

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Current Landscape in US…

Centers for Disease Control:
CHD Surveillance Studies

Pediatric Cardiac Critical Care Consortium
Pediatric Acute Care Cardiology Collaborative
Cardiac Neurodevelopmental Outcome Collaborative
Advanced Cardiac Therapies Improving Outcomes Network
National Pediatric Cardiac Quality Improvement Collaborative

Pediatric Cardiac Care Consortium

NYC CHS-COLOUR

Congenital Heart Surgeons' Society Data Center
Our Research Saves Lives

Hospital Based: Chest Pain-MI, Afib Ablation, Cath PCI, ICD, IMPACT, LAAO, PVI, STS/ACC TVT
Outpatient Based: Diabetes Collaborative and PINNACLE registry


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ABOUT THE REGISTRY

MISSION

Create a digital hub that collects health data from patients and providers in the ACHD community

VISION

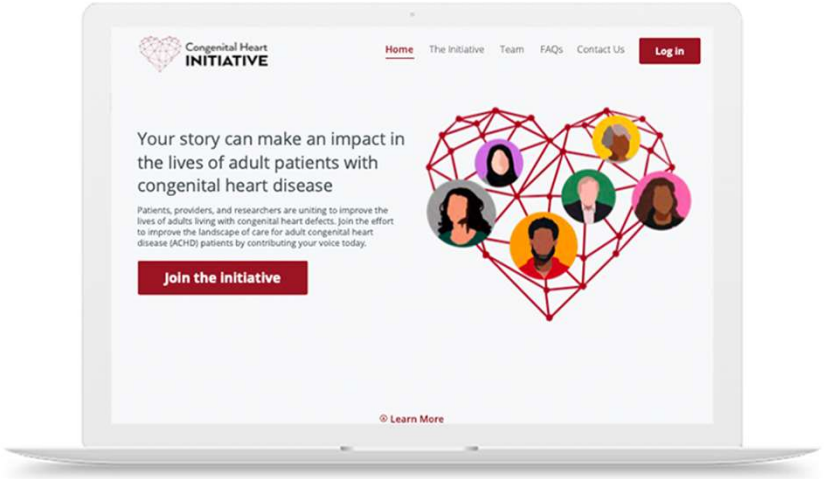
A community of ACHD patients and providers with a shared understanding of research needs and medical outcomes

PURPOSE

Improve quality of life for *all* ACHD patients

LAUNCHED December 2020

- **It takes less than 15 minutes to enroll and complete the first surveys**
- **Participants will be asked to provide demographics and health status**
- **Patient-Reported Outcomes: Participants will be asked questions related to their quality of life and physical and mental health**
- **The registry will ask participants to provide health status updates every four months**



@CongenitalHeartInitiative

@ACHD_CHI

- **Healthcare provider/EMR level data**

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Advances in Medicine from Children's National

Patient-centered study of adult congenital heart disease awarded $4.9 million

PCORI award to Louisiana Public Health Institute, Children's National Hospital supports outcomes research conducted via PCORnet®

April 26, 2021

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Patient-Reported Outcomes

66 Million Patient Records

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- Are ACHD patients who are receiving recommended care doing better than those who are not?
- What are the rates of complications or associated illnesses?
- How are patients using the healthcare system?
- What are the risk factors associated with having gaps in care?

Project Aims/Goals

Aim 1: Utilize PCORnet to establish an ACHD surveillance system that will gather real-world data on healthcare use and comorbidities of various CHD subtypes and will test the hypothesis that gaps in care are associated with inappropriate healthcare use and higher comorbidities and vary with complexity of CHD subtypes.

- *Research Question:* How does receiving current recommended care affect long-term outcomes and healthcare needs amongst the numerous rare disease subtypes of congenital heart defects?

Aim 2: Determine factors associated with gaps in recommended care.

We hypothesize that various patient-level factors (such as severity of illness, patient demographics, place of residence, insurance status) might influence patients' likelihood of receiving recommended care. This data will characterize the factors associated with gaps in care that include the vulnerable and disadvantaged segments of the U.S. population.

- *Research Question:* What factors are associated with gaps in recommended care?

Aim 3: Determine the impact of gaps in care on patient-reported outcomes (PROs).

By linking the CHI registry to PCORnet, the association of gaps in care and patient-prioritized outcomes can be assessed over time for various CHD subtypes. We hypothesize that gaps in care are associated with lower quality of life and other outcome measures across all CHD subtypes.

- *Research Questions:* Do patients report feeling better when they remain in specialty care?

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COLUMBIA
NewYork-Presbyterian
INSIGHT
Clinical Research Network
Mount Sinai Hospital
Ochsner
HealthCore
Weill Cornell Medicine
NYU Langone
MEDICAL CENTER
REACHnet
Research Action for Health Network
CVS Health
Congenital Heart
INITIATIVE
Adult
Congenital Heart
Association
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STRATEGIES
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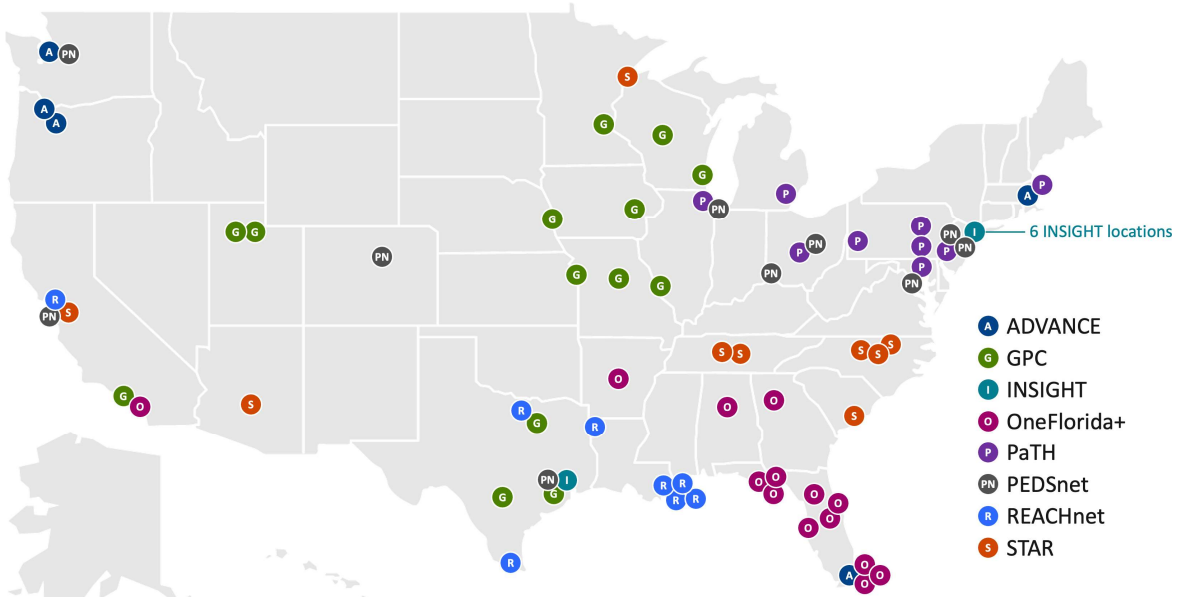
UCSF
University of California
San Francisco
NATIONWIDE CHILDREN'S
Children's Hospital
of Philadelphia
Nicklaus
Children's
Hospital
PEDSnet
A Pediatric Learning Health System
OneFlorida
Clinical Research Consortium
Cincinnati
Children's
Children's Hospital Colorado
UFHealth
UNIVERSITY OF FLORIDA HEALTH
UHealth
UNIVERSITY OF MIAMI HEALTH SYSTEM

Data Innovations via PCORnet®

PCORnet® Clinical Research Network Locations

PCORnet infrastructure offers access to real-world data through partnerships with Clinical Research Networks (CRNs)



What are Clinical Research Networks?

CRNs are groups of diverse healthcare institutions across the U.S., from large academic health centers to local community clinics, united by a commitment to speed patient-centered research via PCORnet.

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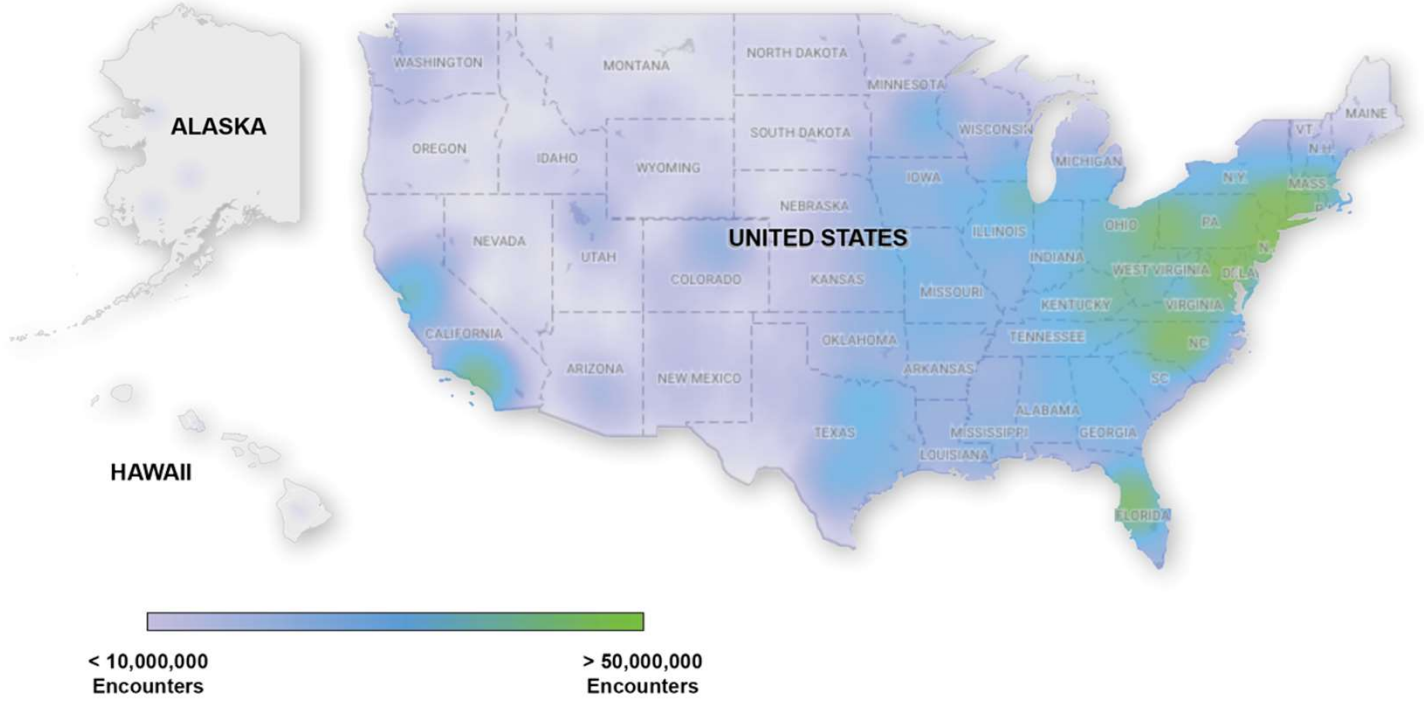
Scope of PCORnet-Accessible Data

PCORnet represents data from **everyday health care encounters with more than 47 million people** across the U.S. each year.



**The data density map illustrates single addresses that are associated with individual PCORnet® Network Partner encounters.*

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The PCORnet® Common Data Model

For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet® Common Data Model deliver fast insights.

Ready for Research			Available, But Still Evolving		
Demographics	Diagnoses	Procedures	Immunizations	Tumor Registry	Biosamples
Vital Signs	Labs	Clinical Observations	Social Determinants of Health	Patient-Generated Data	Genomic Results
Medication Orders & Administrations			Patient- Reported Outcomes	Natural Language Processing Derived Concepts	

Data available from Clinical Research Networks, in the PCORnet® Common Data Model and ready for use in research

Data available at some Clinical Research Networks, may or may not be in the PCORnet® Common Data Model and require additional work for use in research

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Unite Data and Communities for Faster, More Targeted Research

One PCORnet®, Many Possibilities

PCORnet is a national resource, funded by PCORI, where high quality health data, patient partnership, and research expertise deliver fast, trustworthy answers that advance health outcomes.

- **Real-world evidence studies**
- **Comparative effectiveness research**
- **Population health research**
- **Pragmatic research**
- **Health systems research**
- **And more**

More Than a Data Network

Access to patient partners and **thousands of clinicians** with expert knowledge of PCORnet-enabled data = meaningful research targets and faster answers.

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1. Process For Identifying CHD cohort

1. Literature review (practices for identifying adults with CHD using EHR data)
2. Conversations about data translation with clinical leads from Executive & Steering Committees
3. Agreed on CHD framework (Broberg et. al – hierarchy for assigning one primary diagnosis)
4. Code list development, review, and refinement (analysts, clinicians, researchers)
5. Integrate code list and logic into formal technical specifications document, continue to refine over time
6. Programming and user acceptance testing (Duke)
7. 3-month long beta testing process (2 partner sites, troubleshooting, results review among clinicians)
8. Query modifications to improve case detection, followed by “in house” beta testing at Duke
9. More formal validation across sites
10. Once finalized, formal query release

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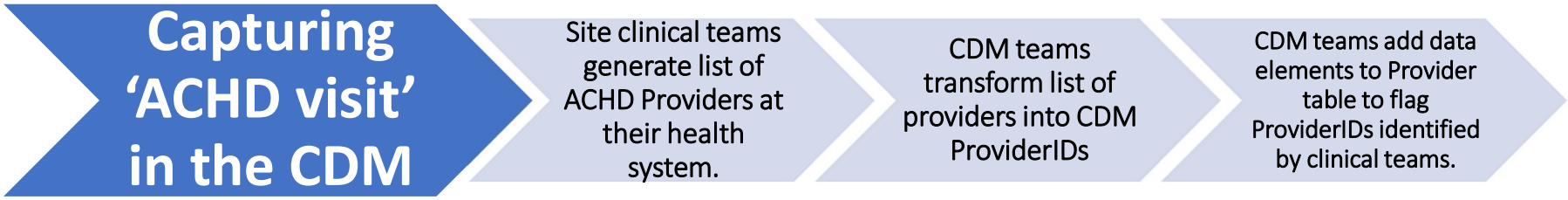
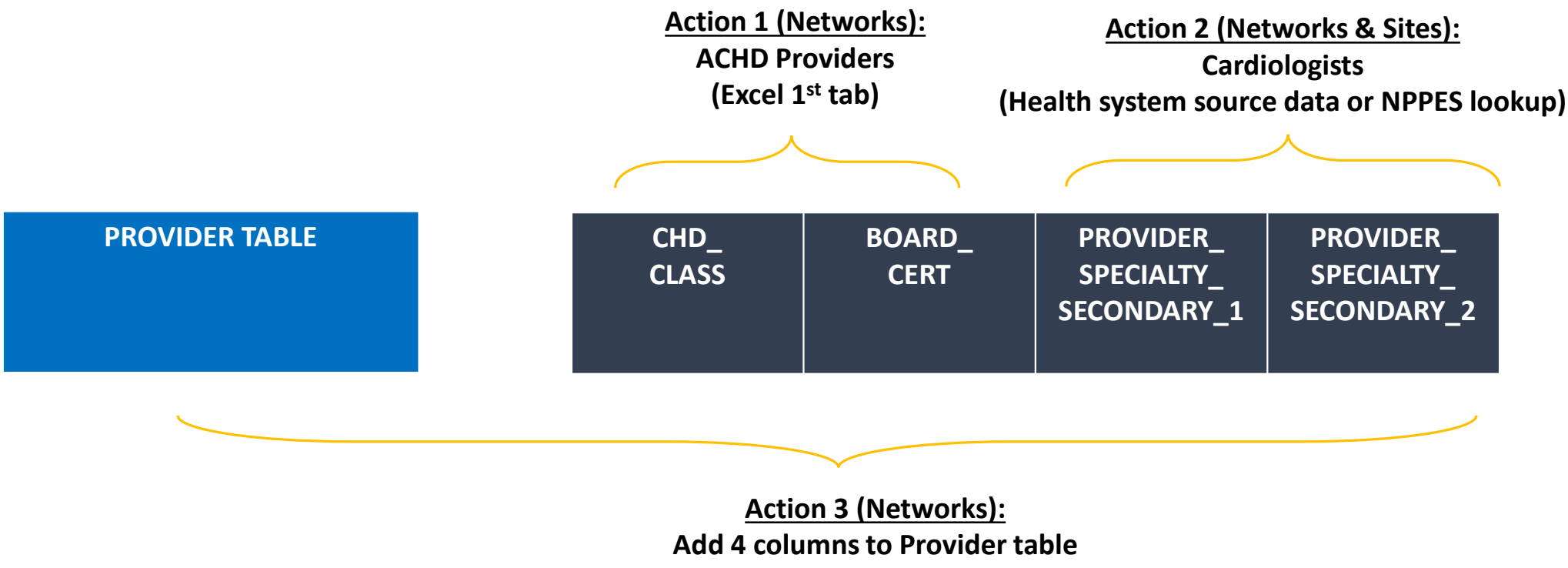
2. Identifying ACHD Providers: Approach



- Provider List solution meant that we did not have to rely exclusively on NPI or provider specialty (i.e., taxonomy codes) to define "in vs. out of care".
- Data Core prepared guidance for CDM teams to modify their Provider tables with additional data –
  - CHD_CLASS (flags providers on Provider List generated by Site PI)
  - Provider specialty secondary 1 & 2
- We encouraged Site CDM teams to populate primary and secondary specialty fields to their best ability to leave our options open for analysis.

Stepwise Process: ACHD providers



3. Using PCORnet to Improve Representation

- Developed a recruitment algorithm to prioritize recruitment of participants traditionally under-represented in research and previously under-represented in the CHI registry.
- This algorithm generated site-specific recruitment lists, specifically prioritizing patients who are
  - (1) Black/African American, Hispanic/LatinX, and other racial and ethnic minorities
  - (2) Males
  - (3) Patients identified as out of clinical care.

PatID	Order	Sex	Race	Severity	In/ Out	Facility ID	Date
X12	1	M	NW	1	Out	ABC	XX/YY/ZZ
Y34	2	M	NW	1	Out	DEF	XX/YY/ZZ
Z56	3	F	W	1	Out	GHI	XX/YY/ZZ
X12	4	M	NW	1	In	ABC	XX/YY/ZZ
Y34	5	M	NW	1	In	DEF	XX/YY/ZZ
Z56	6	F	W	1	Out	GHI	XX/YY/ZZ

4. Physiological Stage of CHD: Echo & Cardiac MRI data

- Problem
  - We can classify patients into CHD anatomical subtypes using diagnosis codes, but categorizing into physiological (i.e., “functional”) stage is more complex/requires more data elements
- Data Discovery Surveys (Collaboration with Steering Committee and Data Science Core)
  - Assessed the presence, availability, and format of 5-10 data concepts representing results obtained from 5 clinical tests (Echo, Cardiac MRI, Holter Monitor, Exercise Test, Electrocardiogram)
  - Reviewed availability and notes about extraction/transformation feasibility from all responding sites.
  - Selected 2 clinical tests (Echo and Cardiac MRI) and a subset of data concepts for each
  - Selected 3 pilot sites: Ochsner (REACHnet), Cornell (INSIGHT), CHOP (Pedsnet)
- Products
  - *Technical Specifications for Integrating Cardiac MRI & Echo Procedures Results into the CDM, v2* (contains implementation guidance, preferred LOINC codes, expected formats, mapping guidance)
  - Submitted formal request for 11 new LOINC codes to Regenstreif

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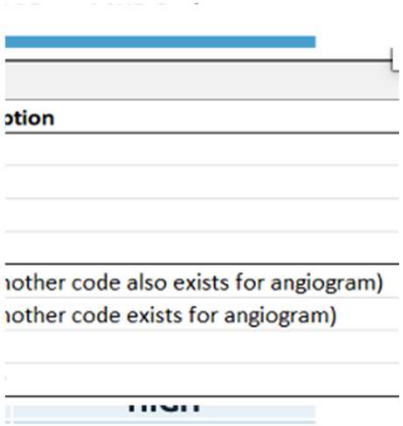
Echo & Cardiac MRI data

A	
Procedur	DATA
Echo	Degree of aortic valve
Echo	Degree of mitral valve
Echo	Degree of tricuspid valv
Echo	Degree of pulmonary v
Echo	Degree of aortic valve
Echo	Degree of mitral valve
Echo	Degree of tricuspid valv
Echo	Degree of pulmonary v

Reference #	1
Local observation code	
Local observation name	Tricuspid valve stenosis by US
Observation description	A LOINC code exists for Aortic valve Stenosis degree by US (77912-4), Mitral valve stenosis degree by US (77916-5), and Pulmonary valve stenosis degree by US (78183-1). We are proposing a similar code be created for the Tricuspid valve.



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OBSERVATIONAL COHORT

		Correct			Given CHD+	
Site #	CHD+	Primary Diagnosis	Complexity	CHD PPV	Probability Correct Diagnosis	Probability Correct Complexity
Site 1	36	33	33	91.25 (80.87, 97.79)	90.54 (79.40, 97.60)	90.54 (79.40, 97.60)
Site 2	34	32	32	82.14 (69.38, 92.02)	92.86 (82.44, 98.76)	92.86 (82.44, 98.76)
Site 3	34	28	28	84.15 (71.67, 93.49)	81.43 (67.19, 92.28)	81.43 (67.19, 92.28)
Site 4	37	34	32	91.46 (81.32, 97.84)	85.53 (72.89, 94.65)	85.53 (72.89, 94.65)
Site 5	39	35	38	96.34 (88.91, 99.73)	96.25 (88.64, 99.72)	96.25 (88.64, 99.72)
Site 6	38	35	35	93.90 (84.91, 98.95)	91.03 (80.41, 97.73)	91.03 (80.41, 97.73)
Site 7	36	32	33	91.25 (80.87, 97.79)	90.54 (79.40, 97.60)	90.54 (79.40, 97.60)
Site 8	36	32	31	89.02 (77.96, 96.53)	85.14 (72.20, 94.50)	85.14 (72.20, 94.50)
Site 9	32	29	27	79.27 (65.78, 90.06)	83.39 (77.05, 97.29)	83.33 (69.09, 93.78)
Site 10	35	30	30	86.59 (74.75, 95.07)	84.72 (71.48, 94.33)	84.72 (71.48, 94.33)
Site 11	34	27	30	84.15 (71.67, 93.49)	87.14 (74.41, 95.90)	87.14 (74.41, 95.90)
Site 12	36	31	31	89.02 (77.96, 96.53)	85.14 (72.20, 94.50)	85.14 (72.20, 94.50)

Table: Positive predictive value of CHD, CHD diagnosis, and CHD complexity

CARE STATUS FROM ALGORITHM

Limitations:
-Pediatric centers where ACHD program is based at the adult hospital
-Adult centers that are tertiary care referral sites
-Centers with satellite sites or affiliated clinics not part of EHR
-Patients receiving care elsewhere (ie, college)

SITE	CH						
1							
2	N	17	0	5	8	97.2 (86.5 - 100.0)	60.7 (35.0 - 83.5)
3*	N	16	3	1	15	82.5 (63.6 - 95.3)	91.2 (74.3 - 99.3)
5	N	22	0	8	4	97.8 (89.3 - 100.0)	34.6 (12.5 - 61.2)
6	N	30	3	2	4	89.7 (77.7 - 97.4)	64.3 (28.6 - 92.3)
7	Y	16	0	5	16	97.1 (85.7 - 100.0)	75.0 (55.4 - 90.3)
8*	N	12	2	0	20	83.3 (61.5 - 96.9)	97.6 (88.3 - 100.0)
10	Y	14	1	7	15	90.6 (72.8 - 99.3)	67.4 (47.4 - 84.5)
11	Y	14	0	6	12	96.7 (83.8 - 100.0)	65.8 (43.7 - 84.7)
13*	Y	15	0	0	23	96.9 (84.8 - 100.0)	97.9 (89.8 - 100.0)

CH: children's hospital (Yes/No); PPV: positive predictive value; NPV: negative predictive value. Asterisk indicates that site was included in select Aim 2 analyses.


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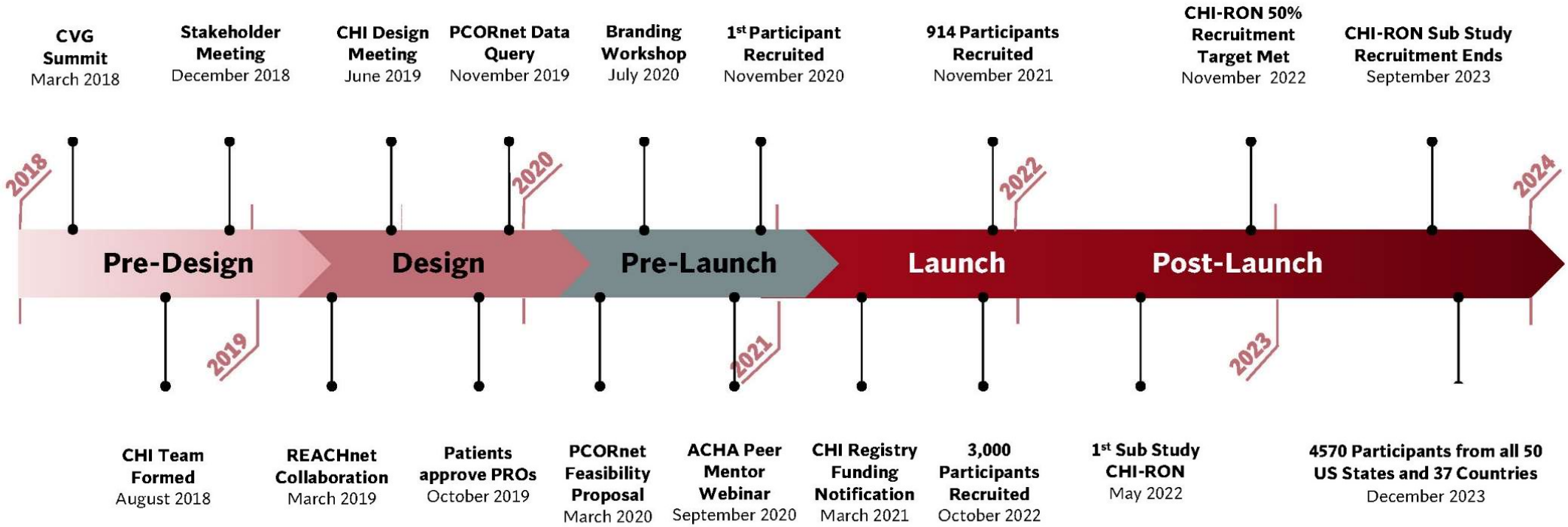
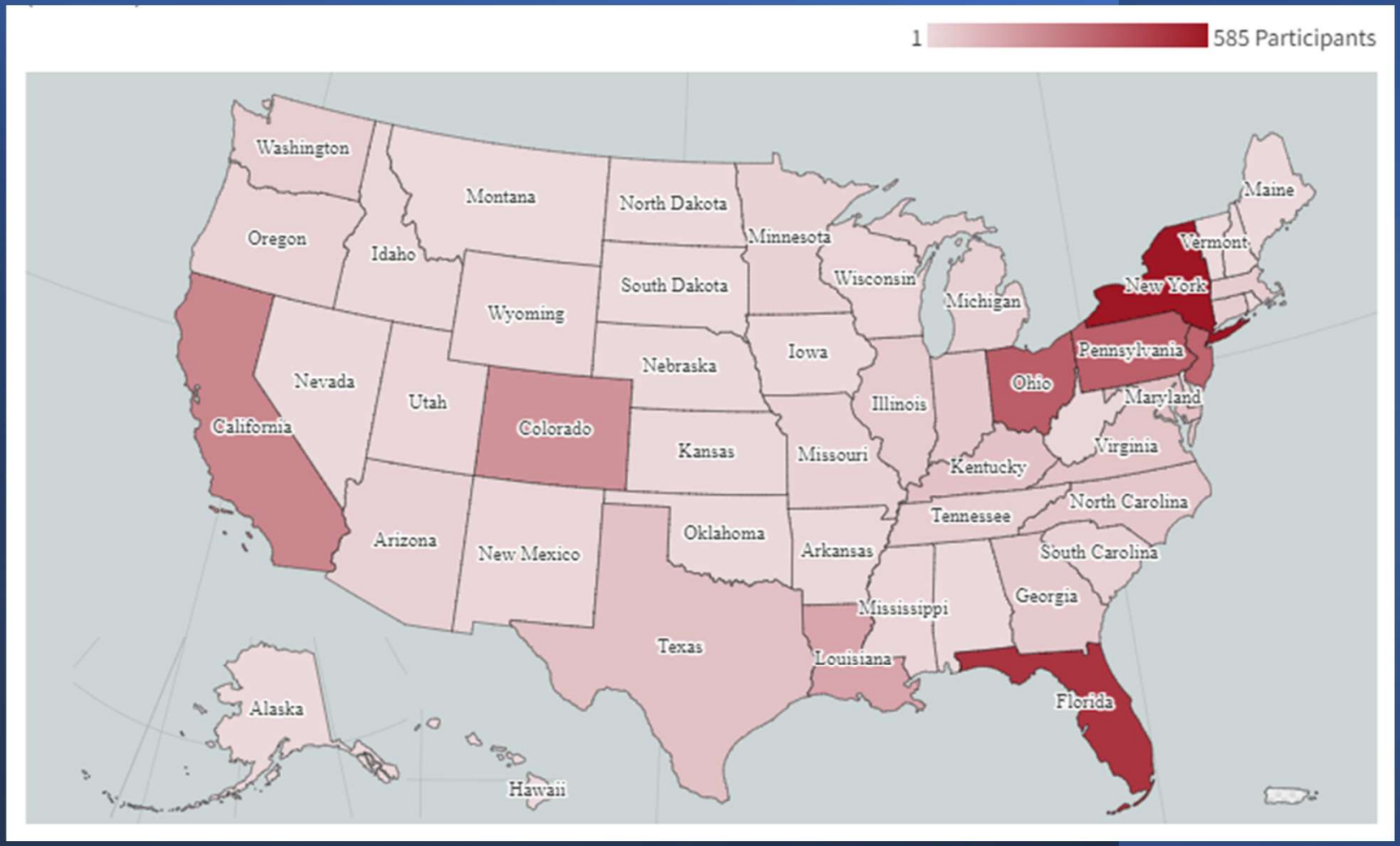
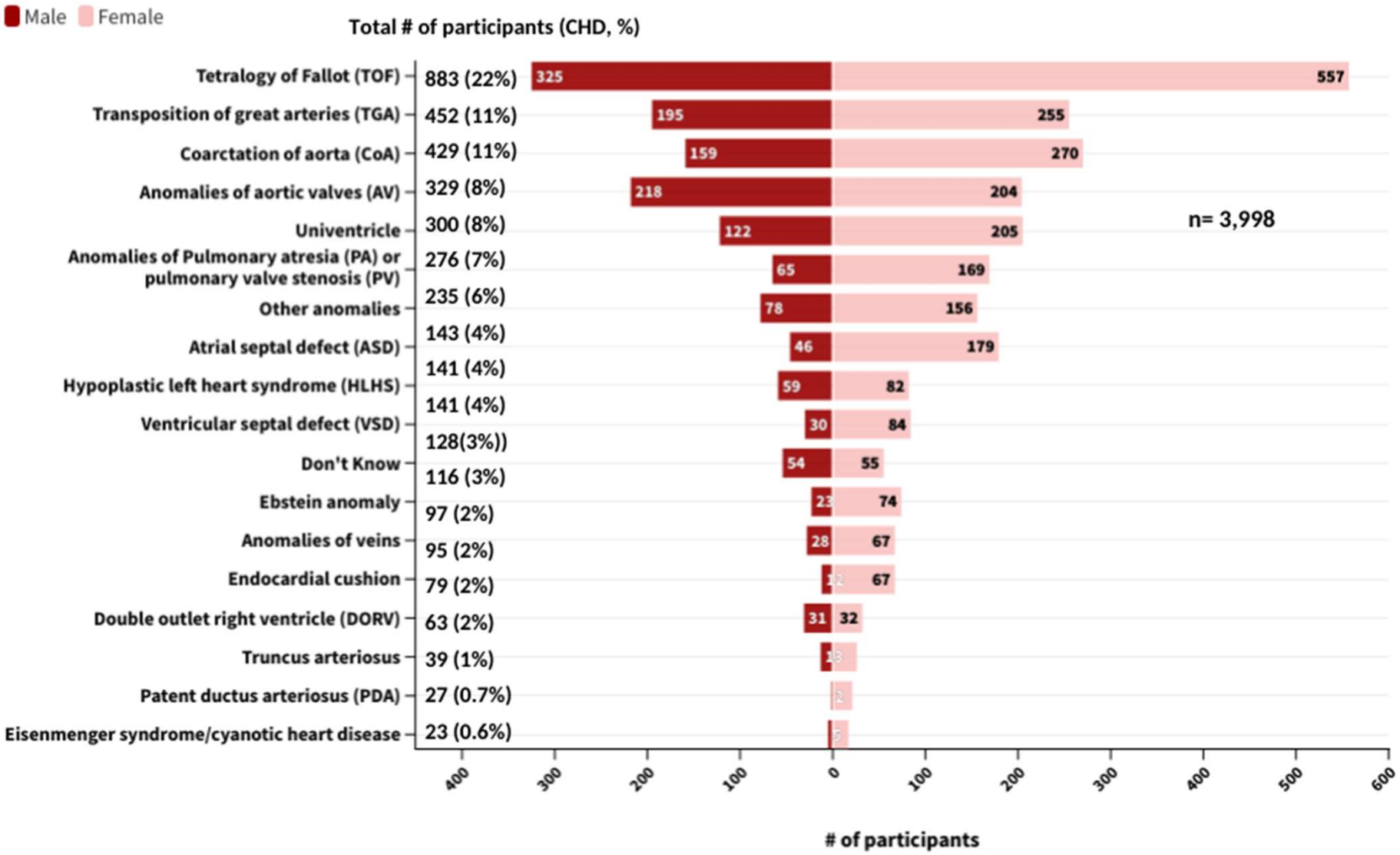
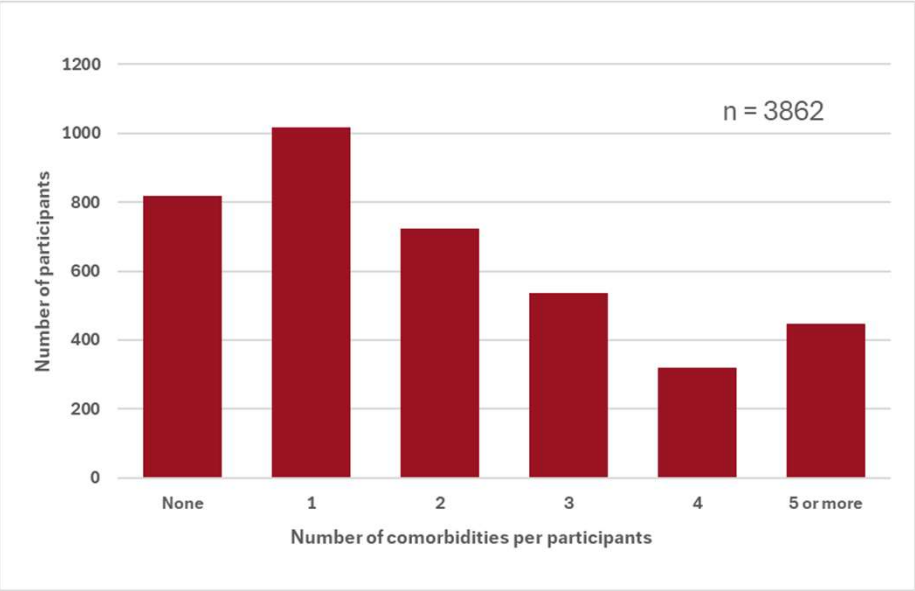

CVG Summit
March 2018
Stakeholder Meeting
December 2018
CHI Design Meeting
June 2019
PCORnet Data Query
November 2019
Branding Workshop
July 2020
1st Participant Recruited
November 2020
914 Participants Recruited
November 2021
CHI-RON 50% Recruitment Target Met
November 2022
CHI-RON Sub Study Recruitment Ends
September 2023
2018
2019
2020
2021
2022
2023
2024
Pre-Design
Design
Pre-Launch
Launch
Post-Launch
CHI Team Formed
August 2018
REACHnet Collaboration
March 2019
Patients approve PROs
October 2019
PCORnet Feasibility Proposal
March 2020
ACHA Peer Mentor Webinar
September 2020
CHI Registry Funding Notification
March 2021
3,000 Participants Recruited
October 2022
1st Sub Study CHI-RON
May 2022
4570 Participants from all 50 US States and 37 Countries
December 2023


1
585 Participants
Washington
Oregon
Idaho
Montana
North Dakota
Minnesota
Maine
Vermont
New York
Wisconsin
Michigan
South Dakota
Wyoming
Nebraska
Iowa
Pennsylvania
Ohio
Nevada
Utah
Colorado
Illinois
Maryland
California
Kansas
Missouri
Virginia
Kentucky
Tennessee
North Carolina
Arizona
New Mexico
Oklahoma
Arkansas
South Carolina
Georgia
Mississippi
Texas
Louisiana
Florida
Alaska
Hawaii

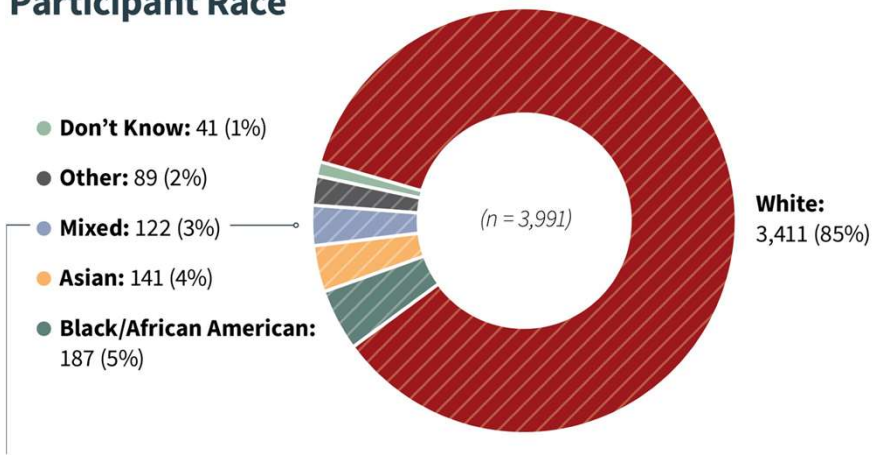

Male
Female
Total # of participants (CHD, %)
Tetralogy of Fallot (TOF)
883 (22%)
325
557
Transposition of great arteries (TGA)
452 (11%)
195
255
Coarctation of aorta (CoA)
429 (11%)
159
270
Anomalies of aortic valves (AV)
329 (8%)
218
204
Univentricle
300 (8%)
122
205
n= 3,998
Anomalies of Pulmonary atresia (PA) or pulmonary valve stenosis (PV)
276 (7%)
65
169
Other anomalies
235 (6%)
78
156
Atrial septal defect (ASD)
143 (4%)
46
179
Hypoplastic left heart syndrome (HLHS)
141 (4%)
59
82
Ventricular septal defect (VSD)
141 (4%)
30
84
Don't Know
128(3%))
54
55
Ebstein anomaly
116 (3%)
23
74
Anomalies of veins
97 (2%)
28
67
Endocardial cushion
95 (2%)
12
67
Double outlet right ventricle (DORV)
79 (2%)
31
32
Truncus arteriosus
63 (2%)
13
Patent ductus arteriosus (PDA)
39 (1%)
2
Eisenmenger syndrome/cyanotic heart disease
27 (0.7%)
5
23 (0.6%)
400
300
200
100
0
100
200
300
400
500
600
# of participants

Co-morbidity Burden



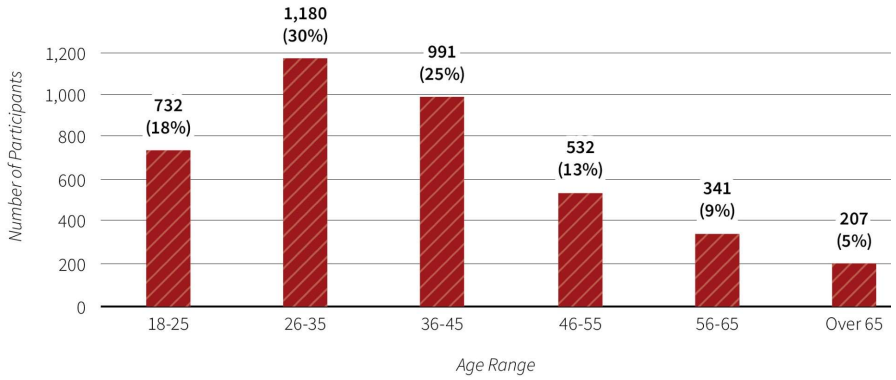
Non-Cardiac Morbidities	n (% of Participants)
Mood disorder	1326 (33%)
Asthma	575 (14%)
Anemia	464 (12%)
Obstructive sleep apnea	305 (8%)
Arthritis, gout, lupus	287 (7%)
Diabetes, pre-diabetes or sugar related problen	273 (7%)
Liver disease	266 (7%)
Cancer or malignancy of any kind	158 (4%)
An ulcer in stomach	122 (3%)
Lung disease	117 (3%)
Kidney failure	57 (1%)
Other chronic health problems	572 (14%)
Cardiac Morbidities	**n (% of Participants)**
Arrhythmias or heart rhythm problems	1300 (33%)
High blood pressure (hypertension)	757 (19%)
Congestive heart failure	585 (15%)
High cholesterol	418 (11%)
A stroke	245 (6%)
Clotting disoder	116 (3%)
Bleeding disorder	96 (2%)
Heart attack (coronary artery disease or myocardial infarction)	65 (2%)

Participant Race

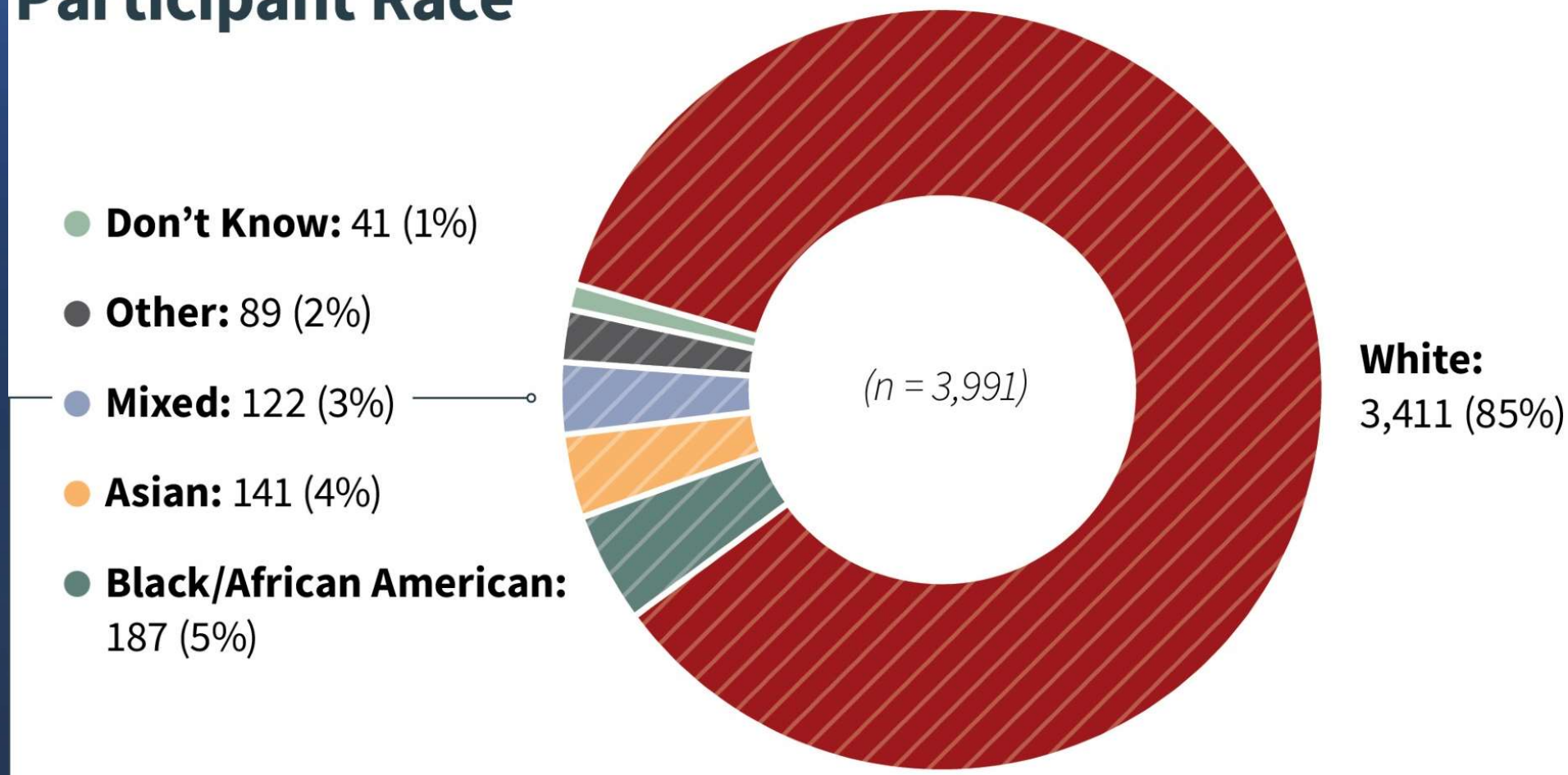


Participant Age Range

(n = 3,983)

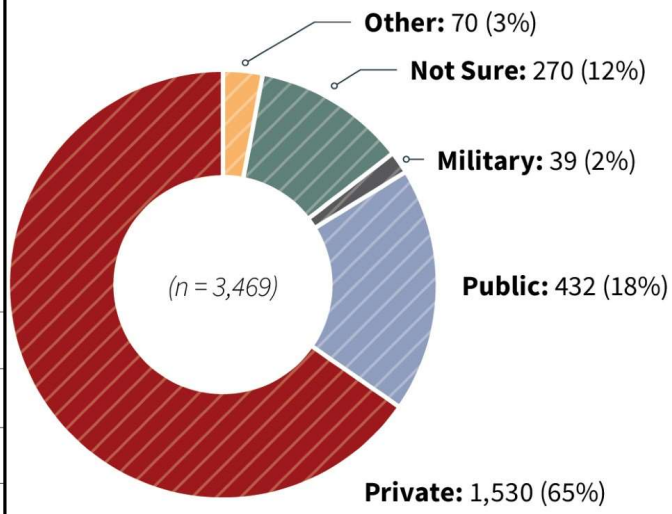


Participant Race



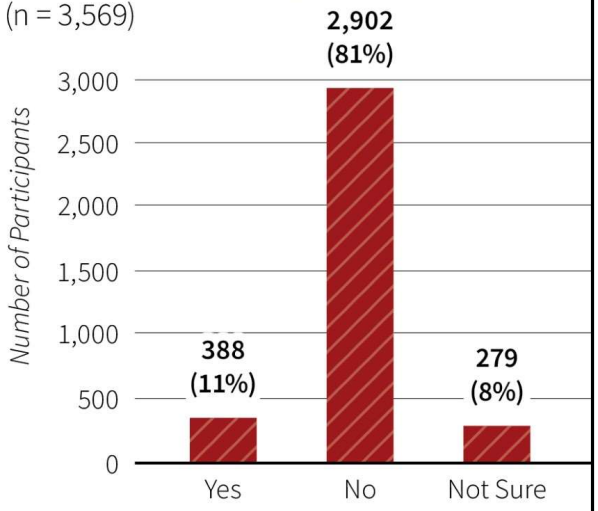
Participant Insurance Status

Insurance Coverage Type Amongst CHD Patients



Insurance Coverage Denied Amongst CHD Patients Throughout the Lifetime

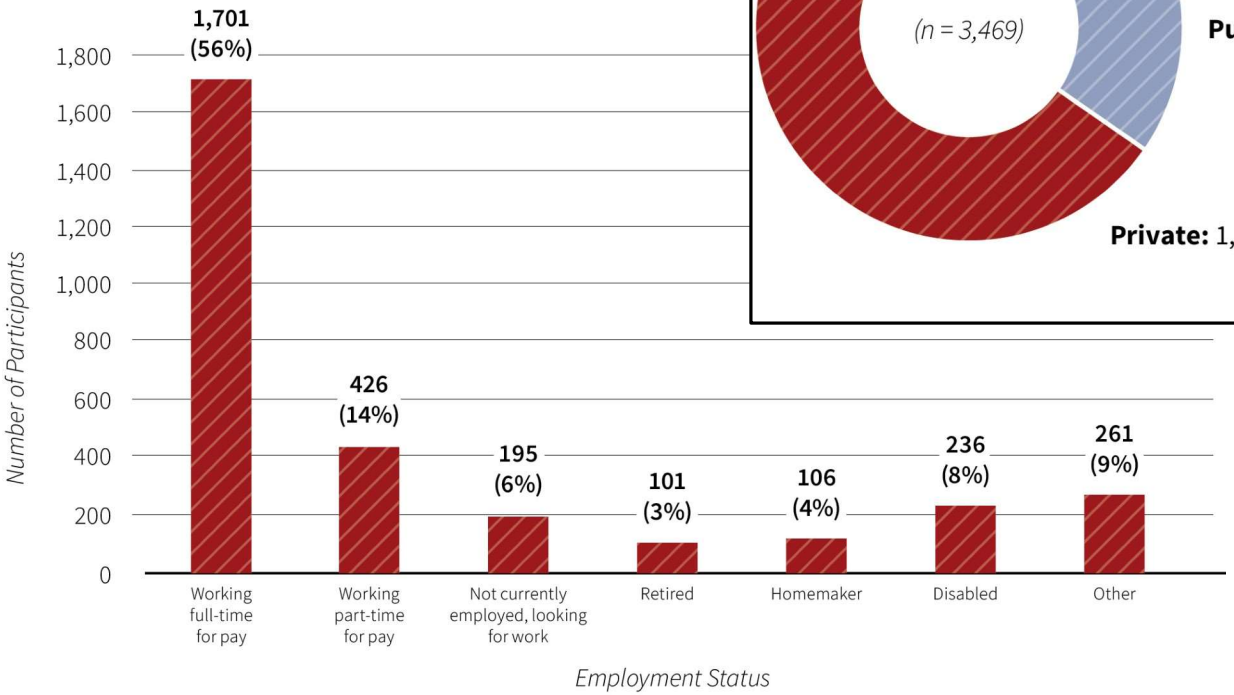
(n = 3,569)

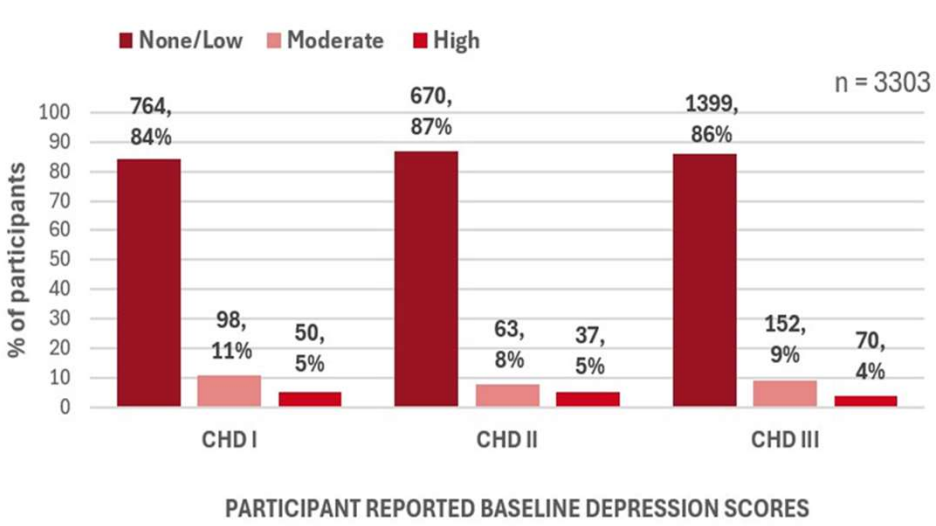


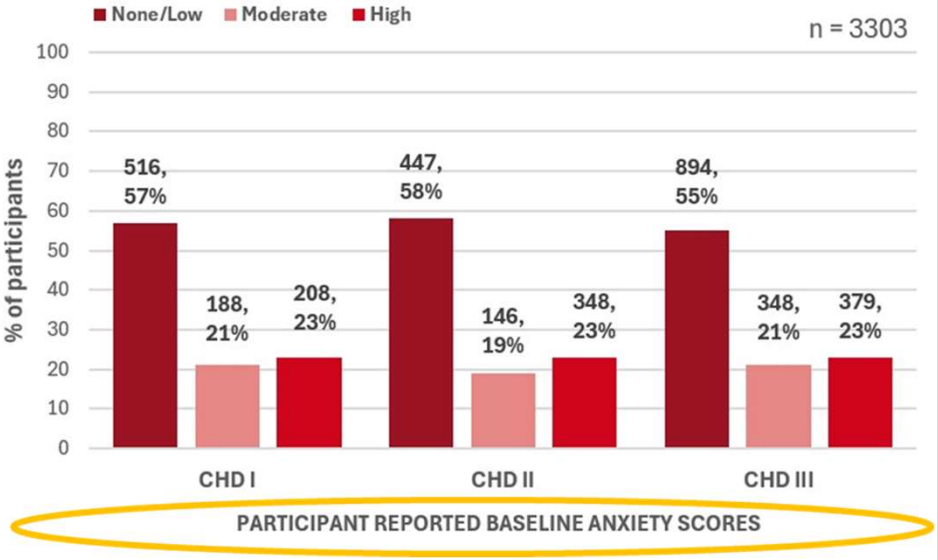
Throughout your lifetime, have you ever been denied health insurance?

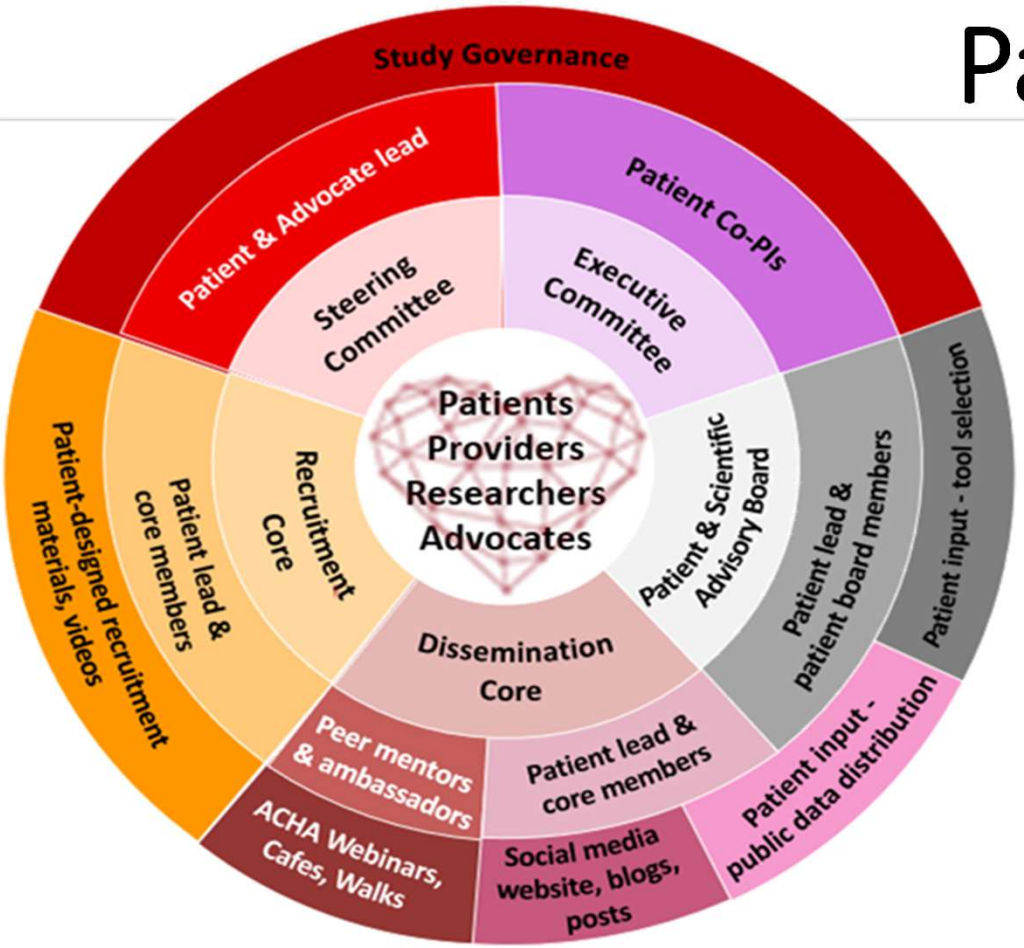
Participant Employment Status

(n = 3,026)




None/Low
Moderate
High
n = 3303
% of participants
100
90
80
70
60
50
40
30
20
10
0
764, 84%
98, 11%
50, 5%
670, 87%
63, 8%
37, 5%
1399, 86%
152, 9%
70, 4%
CHD I
CHD II
CHD III
PARTICIPANT REPORTED BASELINE DEPRESSION SCORES


None/Low
Moderate
High
n = 3303
% of participants
100
90
80
70
60
50
40
30
20
10
0
516, 57%
188, 21%
208, 23%
447, 58%
146, 19%
348, 23%
894, 55%
348, 21%
379, 23%
CHD I
CHD II
CHD III
PARTICIPANT REPORTED BASELINE ANXIETY SCORES



Partner Engagement

- ACHA Café: Virtual coffee hour with participants
- ACHA Peer Ambassador Training
- Dissemination of information to patients through social media
- Annual report with summary of data
- TikTok-style videos to present results (ACHA)
- Social media content: Twitter, Facebook, LinkedIn, Instagram
- 14 patients on leadership committees with two patient Co-PIs

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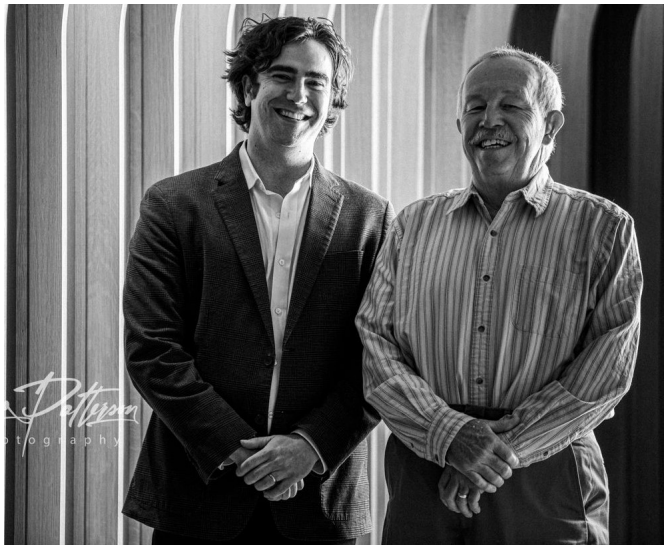
Congenital Heart INITIATIVE


CHI·RON
CHI·RON
Jessica Patterson
Photography


Patterson
Photography


Jessica Patterson
Photography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Jessica Patterson
Photography

Patient Partner Engagement Toolkit

Participant Recruitment and Retention

Informational & Educational Resources

-Fact sheets, brochures, presentations that inform about the project

-Webinars, videos, Podcasts that educate participants about research

Communication Tools

-Pre-written text for emails, phone calls, text messages, social media posts, press releases

-Guidelines for Communication with areas of potential concern, especially for vulnerable populations

Partner Engagement and Empowerment

Interactive Discussion Tools

-Surveys and electronic tools to gather feedback and priorities from partners

-Facilitation guides for patient powered research conferences

Engagement Strategies

-Outreach plans to engagement key partners

-Strategies to improve diversity and representation in research partners and recruitment sample

Patient Centered Measurement

Evaluation and Feedback Mechanisms

-Establishing feedback mechanisms using validated tools when possible

-Reporting feedback and proposed changes back to partners

Technology and Digital Platforms

-Websites, social media, virtual meetings to encourage engagement

-Digital tools to collect data, obtain consent, and improve recruitment

PCORnet Recruitment Algorithm + Engagement Strategy

	All Participants	CHI Participants[1]	CHI-RON Recruited[2]	p- Value	Test Type
Sex	**n (%)**	**n (%)**	**n (%)**		
Female	2512 (63.1%)	956 (72.1%)	1556 (58.7%)	**<0.001**	*
Male	1464 (36.8%)	370 (27.9%)	1094 (41.3%)		
Other	2 (0.1%)	0 (0%)	2 (0.1%)		
Total	**3978**	**1326**	**2652**		
Average age (years)					
All	38.2 +/-13.9%	43.5 +/-14.5%	35.5 +/-12.8%	**<0.001**	T
Race					
Black/African American	184 (4.6%)	42 (3.1%)	142 (5.4%)	**0.006**	*
Asian	139 (3.5%)	41 (3%)	98 (3.7%)		
Multiple	122 (3.1%)	46 (3.4%)	76 (2.9%)		
Native American	17 (0.4%)	7 (0.5%)	10 (0.4%)		
White	3396 (85.5%)	1179 (87.3%)	2217 (84.6%)		
Pacific Islander	2 (0.1%)	1 (0.1%)	1 (0%)		
Other	70 (1.8%)	27 (2%)	43 (1.6%)		
Don't Know	41 (1%)	8 (0.6%)	33 (1.3%)		
Total	**3971**	**1351**	**2620**		
Ethnicity					
Hispanic	384 (9.7%)	100 (7.4%)	284 (10.9%)	**<0.001**	*
Not Hispanic	3572 (90.3%)	1247 (92.6%)	2325 (89.1%)		
Total	**3956**	**1347**	**2609**		
Education					
No degree	1202 (30.2%)	325 (24%)	877 (33.4%)	**<0.001**	*
Associate degree	306 (7.7%)	100 (7.4%)	206 (7.8%)		
Bachelor degree	1254 (31.5%)	424 (31.4%)	830 (31.6%)		
Graduate or professional degree	1212 (30.5%)	501 (37.1%)	711 (27.1%)		
Don't know/not sure	4 (0.1%)	2 (0.1%)	2 (0.1%)		
Total	**3978**	**1352**	**2626**		

Congenital Heart Initiative 3rd Annual Report

https://www.achaheart.org/media/4396/chiannualreport2024.pdf

Active Research

JAMA Network Open

October 16, 2024

Original Investigation | Cardiology

Patient-Reported Outcomes Among Adults With Congenital Heart Disease in the Congenital Heart Initiative Registry

Scott Leezer, BS; Rittal Mehta, MS; Anushree Agarwal, MD; Sneha Saraf, MS; Mindi Messmer, MS; Ruth Phillippi, MS; Jamie L. Jackson, PhD; Mark Roeder, BA; Aliza Marlin, BFA; Noah D. Peyser, PhD; Mark J. Pletcher, MD, MPH; Richard Krasuski, MD; Matthew Lewis, MD; Leigh Reardon, MD; Arwa Saidi, MBBCh, MEd; Ronald Kanter, MD; Satinder Sandhu, MBBS; Thomas Young, MD; Roni Jacobsen, MD; Emily Ruckdeschel, MD; Adam Lubert, MD; Simran Singh, MD; Ali Zaidi, MD; Dan H. Halpern, MD; Anita Mathews, MS; Thomas Carton, PhD; Anitha S. John, MD, PhD

- For new project considerations: please contact achdresearch@childrensnational.org
- Our team will reach out to set up initial meeting and assign project priority on the docket and staff availability.

Social Determinants of Health on ACHD care

- **Used Social Vulnerability Index to Determine Factors Associated with 1. Mortality and 2. Access to Care**
- **Dr. Jamie Jackson (PI) and Rittal Mehta (stats lead)**
- **Project approved by SC 9/19/2023**
- **AHA abstract accepted for moderated poster presentation 11/2024**
- **Manuscript in progress**

Endocarditis in ACHD

- **Examining factors associated with endocarditis in ACHD**
- **Drs. Jasmine Grewal/Dan Halpern (PIs) and Eduardo Trujillo (stats lead)**
- **Project approved by SC 1/16/2024**
- **Analysis in progress**

CHI Patient Reported Outcomes Overview

- **Similar considerations to APPROACH-IS**
- **Dr. Matt Lewis (PI) and Sneha Saraf/Eduardo Trujillo (stats lead)**
- **Project proposal in development, presentation PSAB TBD (December 2024)**

CHI and Mental Health Overview

- **Examining factors associated with high anxiety/depression symptom burden in ACHD patients**
- **Drs. David Harrison and Jamie Jackson (PIs)**
- **Project proposal form completed, presentation to PSAB TBD (December 2024)**

New Projects

- **Using CHI/CHI-RON data base to review longevity of bio-prosthetic valves in early adult cohort** and explore factors contributing to early degeneration
  - Dr. Halpern Lead

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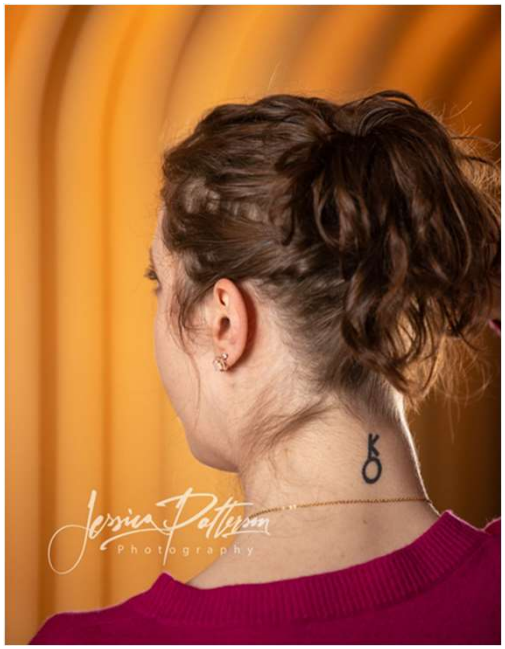

Wounded Healers

They are not born and they are not made...

They create themselves through conquering adversity, trial and error and extreme pain and suffering.

They conquer fear and find a way to speak their truth even when they are afraid.

In doing so they shine light for others who are lost and feeling alone, and in return their inner light ignites with renewed purpose.

A purpose greater than they ever could have imagined.

Data Scientists

Daniel Fort
Alex Loiacono
Charles Bailey
Mark Weiner
Sonya White
Levon Utidjian
William Hogan
Donald Weinbrenner
Brittany Roth Manning
Nelson Lee
Liz Crull
Arden Elmayan

Clinician Scientist Stakeholders

Brett Anderson
Tessa Crume
Rich Krasuski
Leigh Reardon
Abby Khan
Karen Uzark
Whitney Fairchild

Children's National & LPHI

Anitha John
Ruth Phillippi
Mindi Messmer
Anita Mathews
Sneha Saraf
Robert Podolsky
Tom Carton
Erica Johnson
Lindsey Rudov

Research Coordinators

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Annique Nyman
Victoria Grant
Alex Lee
Dorothy Mwachiro
Melissa Argenio
Stephanie Pena
Marta Russell
Maria Dornon
Olena Ashworth
Priscilla Haakenson
Wilson Jacobs
Fernando Park
Pilar Tlachi

PCORnet Coordinating Center

Keith Marsolo
Zachary Lampron
Kirubel Asfaw

CURA Strategies

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Diana Pressey
Savion Mercedes

UCSF/Eureka

Anu Agarwal
Noah Peyser
Carole McGuire
Madelaine Faulkner

Site PIs

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Ron Kanter
Satinder Sandhu
Matt Lewis
Dan Halpern
Ali Zaidi
Simran Singh
Emily Ruckdeschel
Roni Jacobsen
Adam Lubert
Craig Alexander
Jamie Jackson
Tom Young
Julie Miller

Patient Stakeholders

Aliza Marlin
Ry Rivard
John Latsha
Lena Morsch
Kelly DiMaggio
Susan Timmins
Marissa Mendoza
Alison Gill
Stephanie Alexander
Kristen Downing
Ryan O'Connor
Ken Woodhouse
Annie Ulchak
Michael Katchman
Jolie Palilo

ACHA

Mark Roeder
Danielle Hile
Terri Schaffer

Additional Advisory Organizations

CDC, NHLBI/NIH

REGISTRY FUTURE

Here's what we're working on:

- **CHI is moving! New platform and new website!**
- **Big data for heart failure therapeutics in ACHD – simulated clinical trials**
- **CER on care coordination models in pregnancy care**
- **Using the CHI to assess effectiveness of mental health interventions**
- **New Studies**
  - **Inclusion of individuals with neurocognitive deficits**

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Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care

Congenital Heart INITIATIVE

lphi

Children's National

Thank You!

- **anjohn@childrensnational.org**
- **ACHDresearch@childrensnational.org**
- **tcarton@lphi.org**

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Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care

ACHD Providers

- 2010 - 2022:
  - Total number of ACHD fellows: 93 (45%F; 55%M)
  - 2023 - 2024: 13-16/year
- Total number of board certified ACHD docs: 481
  - 2/3 likely practicing adult congenital cardiology
  - Most have other job components
  - Total # of pediatric cardiologists = 2521
- Current number of open positions in US > 30

Children's National

What research do you want the CHI to prioritize moving forward?

1. Evaluate long-term effects on outcomes of surgical interventions of patients considering quality of life and functional status.
2. Investigate neurocognitive and psychosocial impacts of ACHD: identify risk factors and develop intervention strategies to enhan mental health.
3. Use the registry data to study the efficacy of various treatments and interventions for CHD.
4. Study mental health issues that come along with being a CHD patient.
5. Partner with genetic research initiatives to explore the genetic components of CHD, which can lead to more personalized treatment approaches.

Total votes: 9403

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Congenital Heart Initiative: Redefining Outcomes and Navigation to Adult-Centered Care

Congenital Heart INITIATIVE