

PCORnet: An Overview of the National Healthcare Database

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TRANSLATIONAL SCIENCE

Today's Goals

1. The Network - **PCORnet**
2. “Data” and the Common Data Model
3. Request Process
4. Scope of use
5. COVID-19 & PCORnet



The Network

PCORI@osumc.edu



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Patient-Centered Outcomes Research Institute

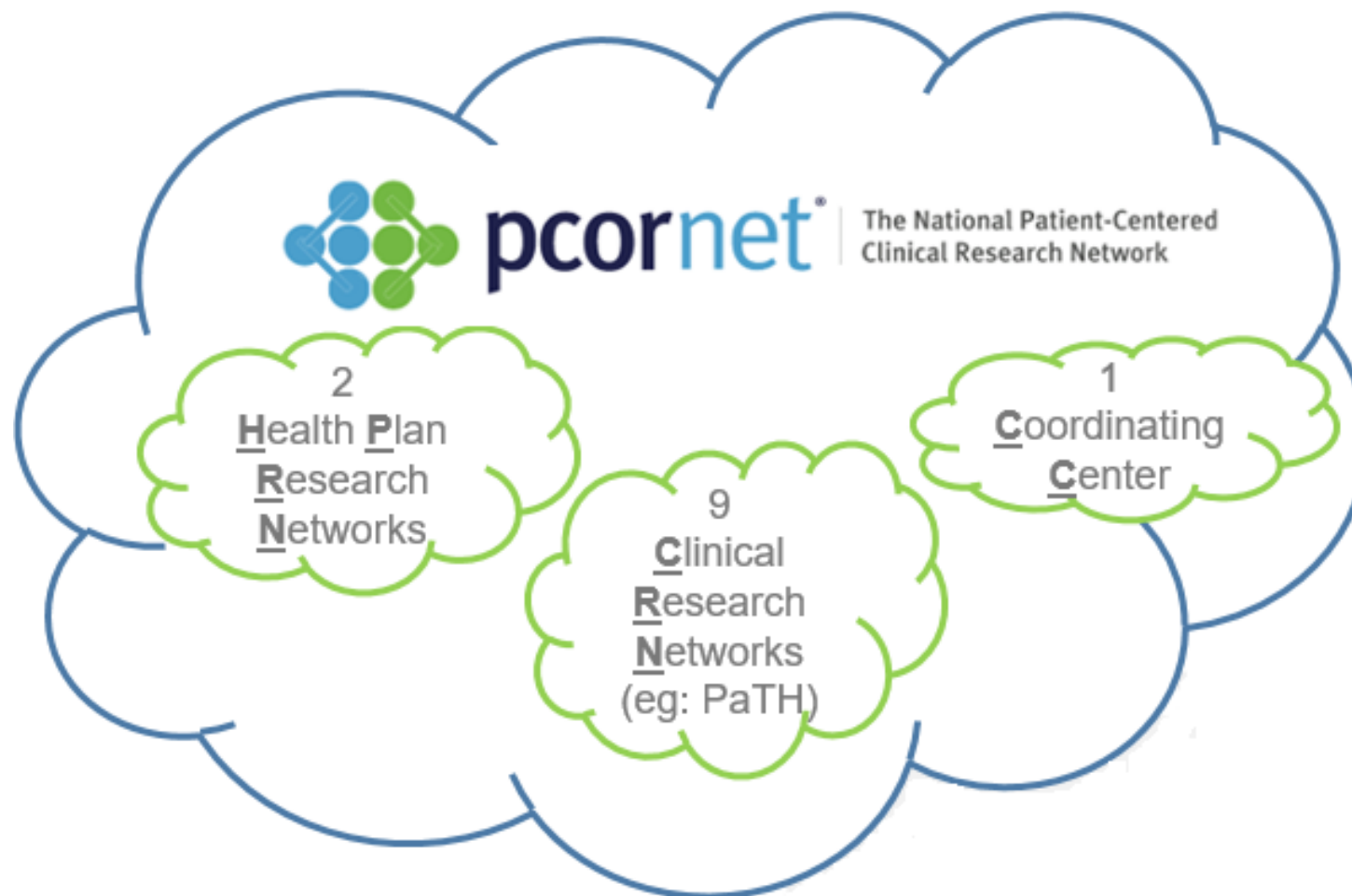
An independent, nonprofit, nongovernmental organization authorized by Congress in 2010 to fund studies that help patients and their caregivers make better-informed healthcare choices.

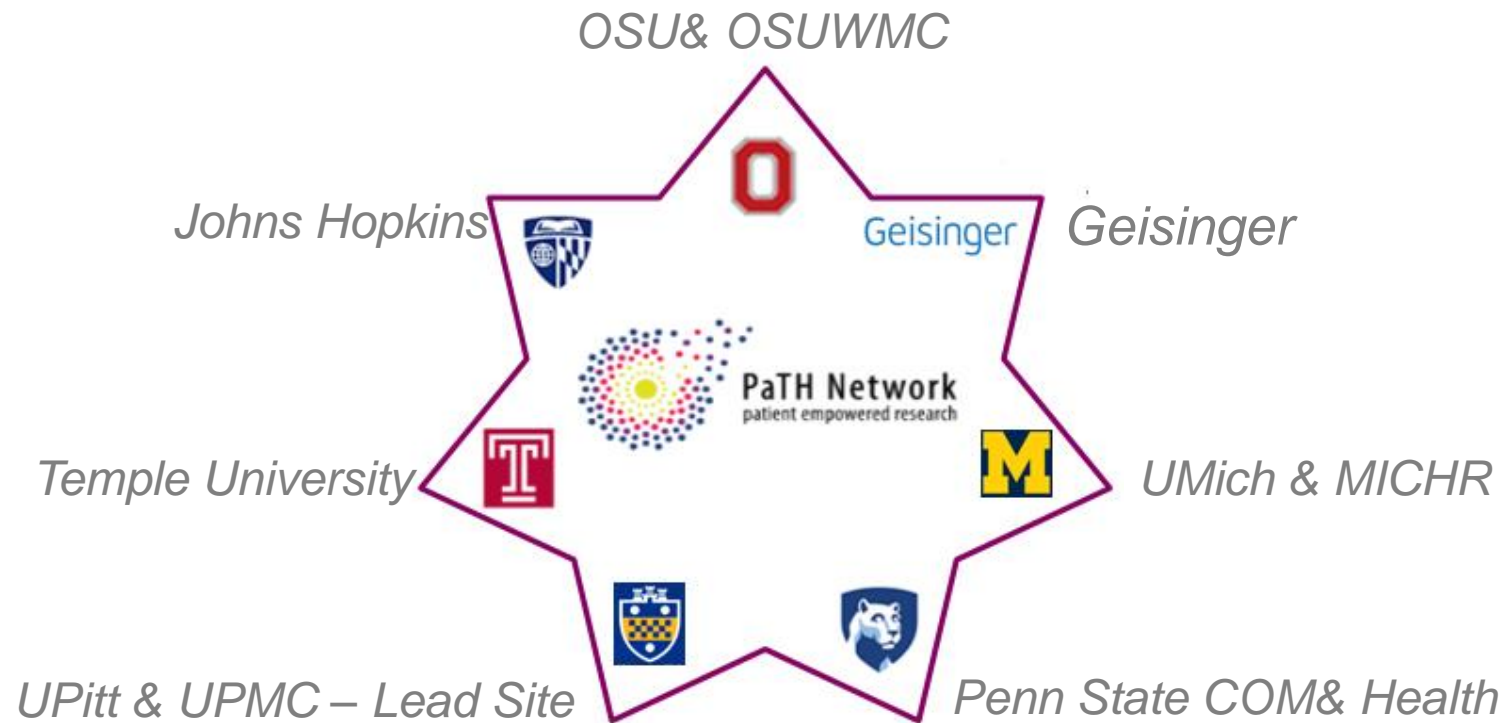




pcor^{net}

The National Patient-Centered
Clinical Research Network





The Data



PCORnet Common Data Model

- CDM standardizes data into a common organized structure
- Each network maps data to the same consistent format
- This platform enables rapid responses to research-related questions
- Data Quality ensured by CC through Data Curation

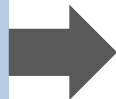
OSU PCORnet CDM is a Coded Limited Dataset



Available DATA on SUBJECTS

SUBJECT Table

DEMOGRAPHIC
PATID
BIRTH_DATE
SEX
HISPANIC
RACE
SEXUAL ORIENTATION
SPOKEN LANGUAGE
GENDER IDENTITY



ENCOUNTER
ENCOUNTERID
ENC_TYPE
ADMIT DATE
DISCHARGE DATE
PROVIDERID
DISCHARGE DISPOSITION
DISCHARGE STATUS
PAYOR TYPE
FACILITY TYPE
ADMITTING SOURCE

PCORNET TRIAL
TRIAL ID
PARTICIPANT ID
WITHDRAW DATE
ENROLL DATE
END DATE

DEATH
DEATH DATE
DEATH SOURCE
DEATH CAUSE
CODE, TYPE

MEDICATION
PRESC, DISP, ADMIN
PROVIDERID
MEDICATION NAME
ORDER DATE & TIME
START & END DATE
RX QUANTITY
REFILLS
FREQUENCY
ROUTE
DOSE
UNIT
RXNORM Code
NDC Code

DIAGNOSIS & CONDITION
ICD Code
CODE Type
REPORT DATE
CONDITION STATUS

PROVIDER
GENDER
SPECIALTY

VITALS
MEASURE DATE
HT
WT
DBP
SBP
BMI
BP POSITION
SMOKING & TOBACCO

LAB RESULTS
LAB NAME
LOINC Code
PRIORITY
LAB ORDER DATE
SPECIMEN DATE & TIME
RESULT DATE & TIME
RESULT NUMBER
RESULT UNIT

PROCEDURE
PROCEDURE DATE
PROCEDURE TYPE
ICD or CPT Code

OSU PCORI Data

Sample Size on Apr 14th 2021

PCORI@osumc.edu

DATAMART_ALL_NOBS

Obs	Library Member Name	NOBS
1	DEMOGRAPHIC	1363189
2	ENROLLMENT	122362
3	ENCOUNTER	17755273
4	DIAGNOSIS	112256639
5	PROCEDURES	123585695
6	VITAL	56906909
7	LAB_RESULT_CM	446799389
8	PRESCRIBING	49502407
9	DISPENSING	4658868
10	DEATH	71250
11	HARVEST	1
12	CONDITION	11370132
13	PRO_CM	0
14	PCORNET_TRIAL	341
15	DEATH_CAUSE	149849
16	MED_ADMIN	103164541
17	OBS_CLIN	5880581
18	OBS_GEN	2020337
19	PROVIDER	59404
20	HASH_TOKEN	1363189
21	LDS_ADDRESS_HISTORY	1936249
22	IMMUNIZATION	106654
23	LAB_HISTORY	0

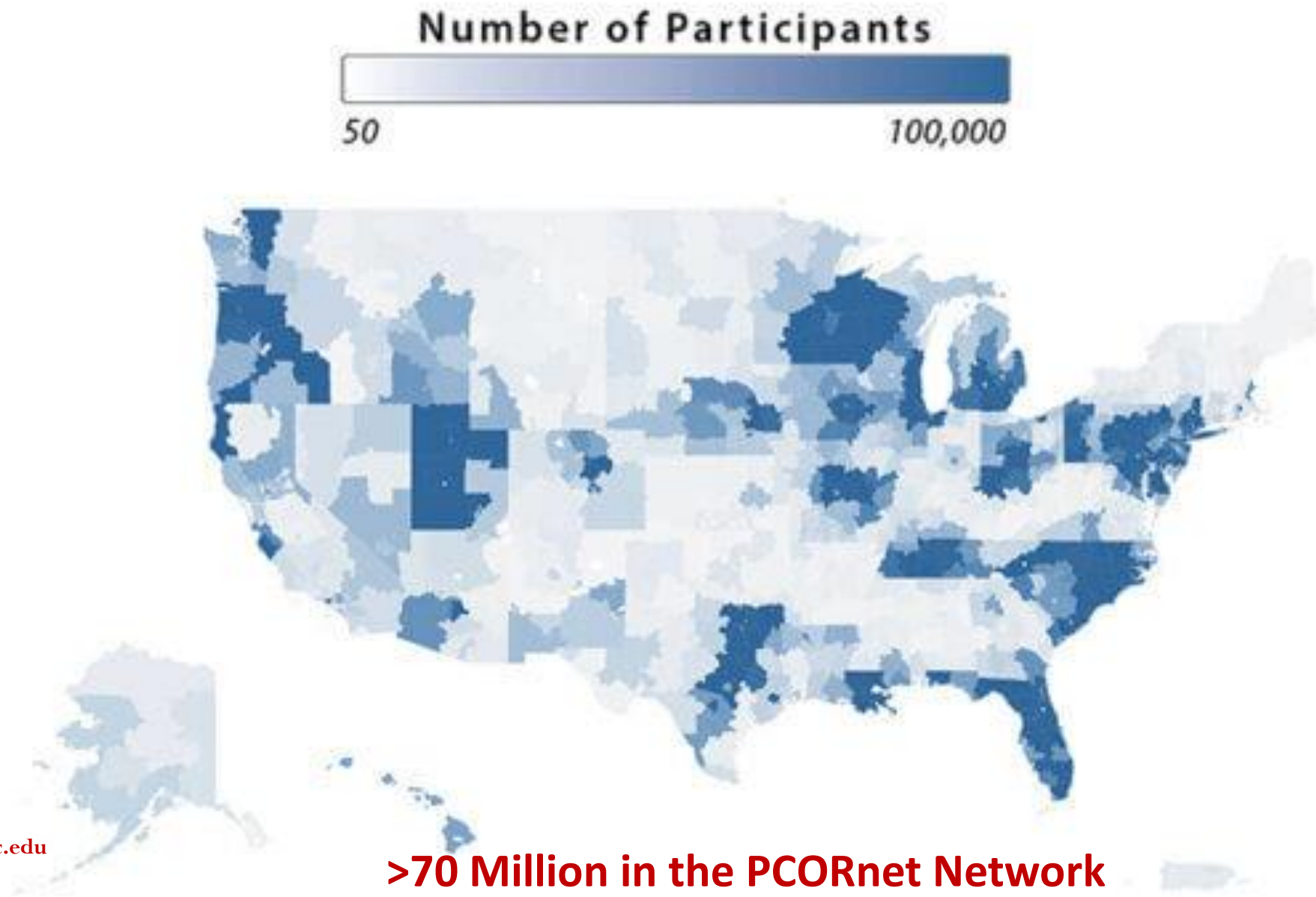


PaTH Network Level Data

Enrollment	Pitt/UPMC	PSCoM/HMC	TUHS	JHU	Geisinger	OSU	UofM	PaTH Total
total # of patients in CDM	3,769,209	1,193,654	1,199,151	2,480,478	2,082,953	1,326,701	1,958,971	14,011,117
Age								
0-19	20.30%	23.90%	11.60%	15.60%	17.50%	6.97%	11.60%	16.14%
20-44	30.40%	29.30%	33.60%	32%	32.30%	37.27%	18.00%	30.064%
45-64	23.80%	22.50%	26.80%	27%	23.80%	29.24%	33.40%	26.37%
65-74	12.30%	11.50%	13.40%	13.40%	11.20%	13.98%	24.20%	14.18%
75+	13.10%	12.80%	14.60%	12%	15.20%	12.53%	12.60%	13.20%
Sex								
Female	53.10%	53.30%	53.99%	55.40%	52.10%	55.28%	54.00%	53.78%
Male	46.90%	46.70%	46.00%	44.30%	47.90%	44.70%	45.70%	46.12%
Race/Ethnicity								
Black/African American	8.20%	5.46%	29.60%	22.80%	5.30%	13.99%	7.50%	12.40%
White	86.20%	68.70%	36.90%	54.60%	90.50%	71.37%	63.50%	70.96%
Other	12.80%	25.80%	33.50%	22.60%	4.20%	14.64%	29.00%	18.57%
Hispanic	1%	6.70%	13.30%	6.50%	5.20%	2.62%	2.70%	4.53%

Sample Size Fall 2020

PCORnet National Level Data



The Request Process



- Aggregate count data can be requested at the
 - National Level
 - Network Level - PaTH CRN data
 - Local Level - OSU dataset
- National & Network Level de-identified dataset available with a signed DUA.
- Local Coded limited data set available



PCORnet National Level

- Request form <http://pcornet.org/contact-us/>

PaTH Network Level

- Request form <https://www.pathnetwork.org/Researchers/index.html>

Local OSU Data

- Request form on the BMI website
<https://medicine.osu.edu/departments/biomedical-informatics/resources-and-services/pcori>

Scope



Feasibility Studies

Aim: Verify feasibility for conducting a research study, clinical trial or for site selection

Case Study: AKI Feasibility

Aggregate output of patients with AKI and comorbidities stratified by age, sex, race and ethnicity

Method: Study Design - Define Inclusion/Exclusion Criteria

- ICD codes- 584, N17
- Age at diagnosis – 20 to 50
- Diagnosis Date – 1/1/2015 - 12/31/2018

Patient Counts	AKI	AKI_Diab	AKI_HTN
Overall (N)	24,358	7,172	13,691
By Age Group ^a			
20-29	980	131	243
30-39	1,610	322	679
40-49	2,760	744	1,456
By Sex ^a			
Male	13,687	3,943	7,574
Female	10,671	3,229	6,117
Other/Missing	0	0	0
By Race ^a			
Asian	199	63	105
African American	5,787	2,152	3,898
White	17,574	4,749	9,337
Other/Missing	759	194	329
By Hispanic ^a			
Yes	240	82	130
No	23,863	7,076	13,535

Computable Phenotype (CP) Validation Studies

Aim: CP is a method for identifying patients with specific clinical characteristics (phenotype) using EHR data as input. Validate the CP algorithm before using it in decision making.

Case Study: Nephrotic Syndrome CP Validation
Identify patients based on the CP Algorithm based on diagnostic codes and Encounters

Method: CP algorithm executed against CDM to pull cohort and control group

Random selection of 50 cases and 50 non cases
Patient MRNs identified from EHR after IRB approval
Manual chart review done to evaluate accuracy of the algorithm

Cohort Studies with PRO/Survey Linkage

Aim: Identify a patient cohort, and collect PRO or additional data via surveys and link the de-identified data to the patients

Case Study: Heart Failure Cohort Study

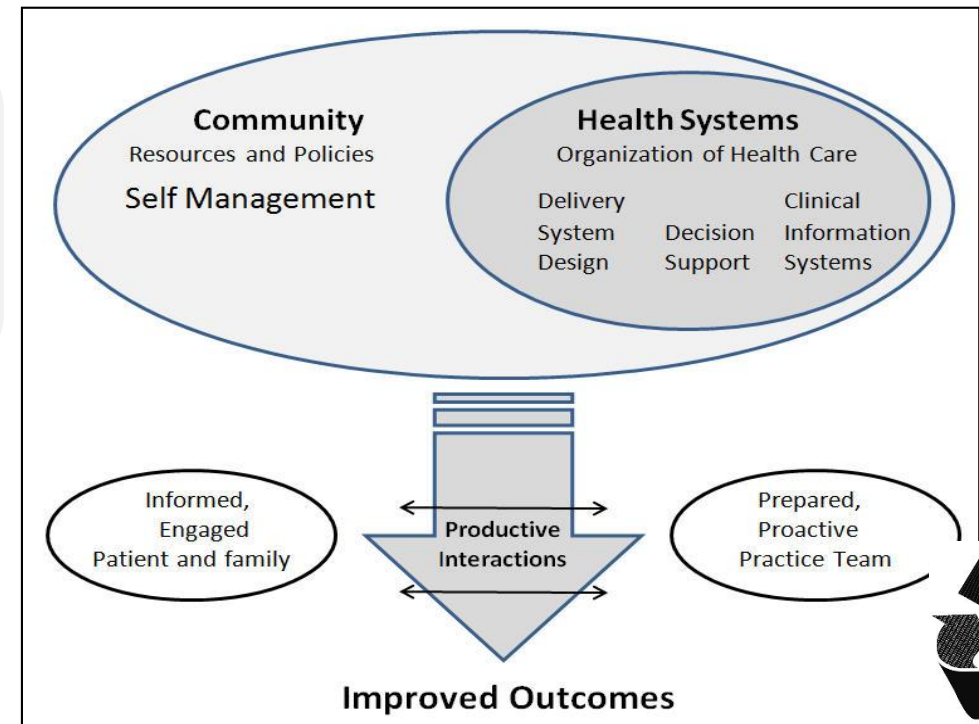
Identify patient centric factors important to HF patients and determine whether social support and self-management, lead to improved outcome based on Chronic Care Model

Method: Cohort identified from CDM based on HF CP and survey outcomes linked back to CDM

- IRB approval obtained to contact the cohort
- Survey with pertinent questions were created
- Consented patients were mailed the survey
- De-identified results collected and analyzed
- Results to be linked to the CDM

~2400 patients contacted

~425 survey results collected



Registry Data Linkage Studies

Aim: Improve data completeness and expand available data in patient registries

Case Study: Transcatheter Valve Therapy Registry (TVTR) Study
Multisite study to demonstrate feasibility and utility of Registry linkage and expansion

Method: Identify TVTR patients in the CDM based on CPT code and link them to TVTR to create crosswalk

All patients in the US who get heart valve replacement surgery are part of TVTR
Patient identified from CDM were successfully linked to TVTR
To expand registry data further Echocardiogram result which is not part of the CDM was added by creating a supplemental table

Clinical Trials

Aim: Facilitate widespread identification and recruitment of large numbers of potential patients in clinical trials

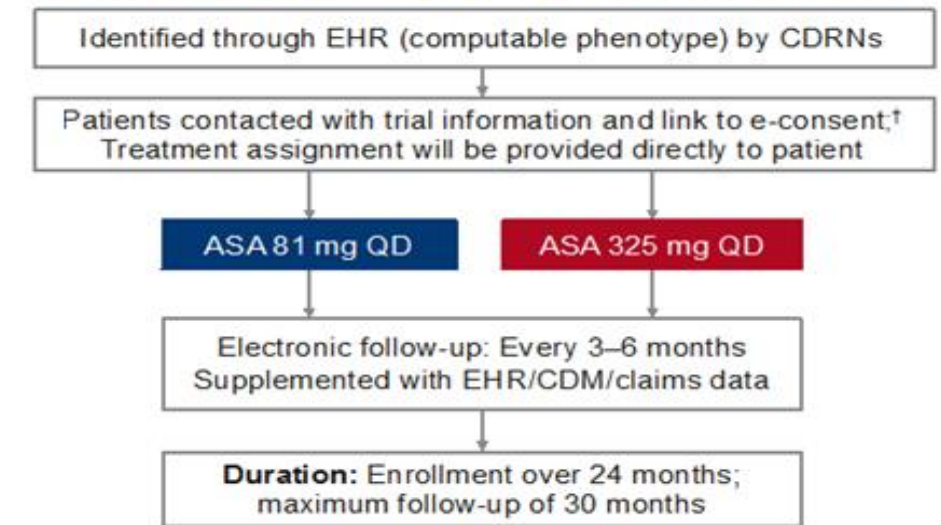
Case Study: ADAPTABLE

Large national pragmatic multi site study to determine whether 81 mg or 325 mg Aspirin is more effective for patients with heart disease

Method: Cohort identified from CDM based on ADAPTABLE CP and then recruitment followed all protocols and regulations within the site with PCORnet guidance

- IRB approval obtained to contact the cohort
- Consented patients were enrolled into the trial
- Enrolled patients are given a Trial ID in the CDM
- CDM is queried periodically to longitudinally follow the patients for analysis

Patients with known ASCVD + ≥ 1 "enrichment factor"*



~90 patients enrolled at OSU



COVID-19 and PCORnet



PCORnet COVID-19 Data Model

- Responding to current crisis by creating a COVID-19-specific CDM
- Immediate goal was to quickly initiate a basic snapshot of infected patients
- Allow researchers to use information gathered from patients across PCORnet's vast network to better define and understand who is getting infected with SARS-CoV-2 and how the virus affects them.





Healthcare Worker Exposure
Response & Outcomes

- To unite healthcare workers across America to study and address the problems our healthcare heroes face in real time—and over time.
- Participants will receive surveys and could be selected to participate in clinical trials.
- The registry will follow a protocol developed by the DCRI and data guidelines to keep healthcare worker information secure.
- Study design – Clinical trial and registry with 2 parts
 - HERO Registry
 - Trial
- In the future, the HERO Registry will help speed additional clinical studies that address unmet needs for healthcare workers.

<https://heroesresearch.org>



u.osu.edu/pcori



Thank you!