patient-centered
SCAlable
National
Network for
Effectiveness
Research

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(on behalf of the pSCANNER team, with most slides contributed by Drs. Katherine Kim and Jason Doctor)

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pSCANNER is a stakeholder-governed, distributed clinical data network that aims to make health data more accessible and usable for the generation of scientific evidence that patients, clinicians, and other stakeholders together use to make more informed health decisions.
Stakeholder-governed

Involve stakeholders—patients, patient advocates, clinicians, and researchers—as advisors in the pSCANNER work.
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Governance

Develop education and communication materials
Stakeholder-governed

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- Develop education and communication materials
- Set research priorities and design research
Stakeholder-governed

Involves stakeholders—patients, patient advocates, clinicians, and researchers—as advisors in the pSCANNER work.

Develop education and communication materials

Set research priorities and design research

- Weight management/obesity
- Congestive heart failure
- Kawasaki disease
Patient-Centered Outcomes Research (PCOR)

Focuses on patients’ needs and preferences and on outcomes most important to them.

*The word *options* implies the comparison of different types of treatments, medications, or healthcare practices.*
Patient-Centered Outcomes Research (PCOR)

Focuses on patients’ needs and preferences and on outcomes most important to them.

Helps patients and other healthcare stakeholders, such as caregivers, clinicians, insurers, policymakers and others, make better-informed decisions about health and healthcare options.*

*The word *options* implies the comparison of different types of treatments, medications, or healthcare practices.
Comparative Effectiveness Research (CER) is one type of Patient Centered Outcomes Research (PCOR).

Which of the two medications?
Comparative Effectiveness Research (CER) is one type of Patient Centered Outcomes Research (PCOR)

Which of the two medications?
Comparative Effectiveness Research (CER) is one type of Patient Centered Outcomes Research (PCOR)

Which of the two medications?
Three common types of PCOR and CER research design

Comparative Effectiveness Research (CER)
Three common types of PCOR and CER research design

Comparative Effectiveness Research (CER)

Randomized Control Trials
Three common types of PCOR and CER research design

Comparative Effectiveness Research (CER)

- Randomized Control Trials
- Pragmatic Trials
Three common types of PCOR and CER research design

- Randomized Control Trials
- Pragmatic Trials
- Observational Studies
PCORnet seeks to improve the nation’s capacity to conduct clinical research by creating a large, highly representative, national patient-centered network that supports more efficient clinical trials and observational studies.
PCORnet embodies a “community of research” by uniting systems, patients & clinicians

11 Clinical Data Research Networks (CDRNs)

+ 

18 Patient-Powered Research Networks (PPRNs)

= 

PCORnet: A national infrastructure for patient-centered clinical research
This map depicts the number of PCORI-funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.

13 CDRNs and 20 PPRNs Funded
Phase 1

24 Million Patients

9 health systems

UC ReX
UCD 2.3M
UCSF 3.2M
UCLA 4.3M
UCI 300k
UCSD 2.3M

VA VINCI 11M

USC LA

SCANNER

AltaMed 607k
TCC 240k
QueensCare 19k
Phase 2

30 Million people

14 health systems

UCSD 2.3M
UC Davis 2.3M
UCSF 3.2M
UCLA 4.3M
UC Irvine 300k
UCSD 2.3M
San Mateo Medical Center 77k
VA VINCI 11M
LA
USC Keck 2M
LA Children’s 200k
LA DHS 600K
Altamed 200k
Children’s Clinic 24k
Queenscare 19k

UC ReX

Rutgers
Emory U
U Texas Houston
Collaborating Patient-Powered Research Networks

<table>
<thead>
<tr>
<th>PPRN</th>
<th>Targeted Condition (IRB approved)</th>
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<tbody>
<tr>
<td>Health eHeart</td>
<td>Heart Disease</td>
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<tr>
<td>AR-PoWER</td>
<td>Inflammatory Arthritis</td>
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<tr>
<td>CENA</td>
<td>Alström Syndrome, Dyskeratosis Congenita, Gaucher Disease, Hepatitis, Inflammatory Breast Cancer, Joubert Syndrome, Klinefelter Syndrome and Associated Chromosomal Anomalies, Metachromatic Leukodystrophy, Pseudoxanthoma Elasticum</td>
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<tr>
<td>DuchenneConnect</td>
<td>Duchenne and Becker Muscular Dystrophy</td>
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<tr>
<td>iConquerMS</td>
<td>Multiple Sclerosis</td>
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<tr>
<td>PPRN (in process)</td>
<td>Targeted Condition</td>
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<tr>
<td>ImproveCareNow</td>
<td>Inflammatory Bowel Disease</td>
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<tr>
<td>PRIDEnet</td>
<td>Sexual and Gender Minorities</td>
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<tr>
<td>Crohn's &amp; Colitis Foundation of America (CCFA)</td>
<td>Crohn's Disease and Ulcerative Colitis</td>
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<tr>
<td>MoodNetwork</td>
<td>Mood Disorders</td>
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International collaborations are welcome and needed

- Federated data for distributed analytics
- Common data model
- Minimal computational infrastructure
- Compatible institutional policies
- Agreement on rules of engagement
- Shared ethics principles
Research has focused on the priorities of scientists and clinicians, which may be different from those of patients, family members, and caregivers.
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Health research often requires large numbers of study participants but many individual healthcare organizations do not have enough patients with a given condition.
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Evidence from health research takes years to make it into practice because of the challenges in adapting and communicating research findings.
Data

1. Local data in EHRs, clinical, administrative systems
Data

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2. Standardized data from public health and other sources
Data

1. Local data in EHRs, clinical, administrative systems
2. Standardized data from public health and other sources
3. pSCANNER standardizes data into Common Data Model for PCORnet
Local Data are Cleaned and Harmonized for pSCANNER
pSCANNER supports big science

pSCANNER will enable researchers to obtain data from distributed sites covering over 32 million patients in a privacy-preserving environment.
Population & Outcomes Characterization

Can we use EHR data for research?
Population & Outcomes Characterization

Can we use EHR data for research?
Can we use EHR data for research?
Population & Outcomes Characterization

What are the environmental and genetic determinants of Kawasaki Disease?

Can we use EHR data for research?
What are the environmental and genetic determinants of Kawasaki Disease?

Do antibiotics contribute to childhood obesity?

Can we use EHR data for research?
Population & Outcomes Characterization

What are the environmental and genetic determinants of Kawasaki Disease?

Do antibiotics contribute to childhood obesity?

Which aspirin dose is better in coronary artery disease?

Can we use EHR data for research?
Preserving Privacy
Distributed architecture

- Predictive modeling and adjustment for cofounders require lots of data
- Some institutions (countries) cannot move data outside their firewalls

Horizontal and Vertical Partitions

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Future: Patient-controlled data

Healthcare Institutions

Trust broker
- Data use agreements
- Study registry

User U requests Data D on individual I
Future: Patient-controlled data

Healthcare Institutions

Trusted broker
- Data use agreements
- Study registry

User \( U \) requests Data \( D \) on individual \( I \)
Future: Patient-controlled data

Data use agreements

Study registry

Trusted broker

Healthcare Institutions

User U requests Data D on individual I
Future: Patient-controlled data

- Consent Management System
  - Do I wish to disclose data $D$ to $U$?

- Sharing Look-up
  - I can check that $U$ looked at my data $D$

- Trust broker
  - Data use agreements
  - Study registry

- Healthcare Institutions

- User $U$ requests
  - Data $D$ on individual $I$
Sharing Data, Tools, Systems

Data sharing ecosystem

Access controls
Policies
DUA management

Contributor DUA and QA

Data owner

Data 1

User DUA

Tool creator

Tool 2

Contributor QA

Model 1. Traditional:
User downloads center data

Data 2

Tool A

User A

Model 2. Remote desktop:
User computes with center-hosted data in center environment

User B

Model 3. Virtualization and distributed computing:
User performs center computation in his or her own environment

Data C

VM 1

Tool 3

VM 2

User C

VM 2

iDASH

pSCANNER

biocADDIE indexing

Sharing Data, Tools, Systems

Data sharing ecosystem

- Access controls
- Policies
- DUA management
- biocaddie
- indexing

User DUA

Data 1

Model 1. Traditional:
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- User B

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User performs center computation in his or her own environment

- Data C
- VM 1
- VM 2
- User C

- Tool 1
- Tool 2
- Tool 3

System creator

Tool creator

Data owner

- Data 1
- VM 1
- VM 2

pSCANER

Working to solve the challenges of large-scale, patient centered outcomes research.

Thank you