Progress and Related Projects

Lucila Ohno-Machado
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.
PCORnet embodies a “community of research” by uniting systems, patients & clinicians.

13 Clinical Data Research Networks (CDRNs) + 20 Patient-Powered Research Networks (PPRNs) = PCORnet: A national infrastructure for patient-centered clinical research.
Collaborations across the country

This map depicts the number of PCORI-funded Patient-Powered or Clinical Data Research Networks that have coverage in each state.

Numbers do not include the VA.
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
- AltaMed 607k
- TCC 240k
- QueensCare 19k
- SCANNE
Phase 2

30 Million people

14 health systems

UC ReX

UC Davis 2.3M

UCSF 3.2M

UCLA 4.3M

UC Irvine 300k

UCSD 2.3M

San Mateo Medical Center 77k

VA VINCI 11M

USC Keck 2M

LA Children’s 200k

LA DHS 600K

Altamed 200k

Children’s Clinic 24k

Queenscare 19k

University of Washington CTSA

Rutgers

Emory U

U Texas Houston
## Collaborating Patient-Powered Research Networks

<table>
<thead>
<tr>
<th>PPRN</th>
<th>Targeted Condition (IRB approved)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health eHeart</td>
<td>Heart Disease</td>
</tr>
<tr>
<td>AR-PoWER</td>
<td>Inflammatory Arthritis</td>
</tr>
<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>
</tr>
<tr>
<td>DuchenneConnect</td>
<td>Duchenne and Becker Muscular Dystrophy</td>
</tr>
<tr>
<td>iConquerMS</td>
<td>Multiple Sclerosis</td>
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### PPRN (in process)

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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>
</tr>
<tr>
<td>Crohn's &amp; Colitis Foundation of America (CCFA)</td>
<td>Crohn's Disease and Ulcerative Colitis</td>
</tr>
<tr>
<td>MoodNetwork</td>
<td>Mood Disorders</td>
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</table>
Studies are already underway, at the same time we are still running queries to assess data quality

• ADAPTABLE: clinical trial on aspiring dosage (UCLA)
• Bariatric surgery outcomes (UCI)
• Diabetes Risk, eCQM (USC)

• COPD medications
Immune-mediated diseases affect over 8 million patients. Rapidly changing treatment landscape, with effective, but expensive, immunosuppressive and immunomodulatory therapies, with concerning safety profile (cancer, serious infections, cardiovascular events).

**Aim #1:** To evaluate **comparative risks** for serious infections, cardiovascular risk, incident cancer, and mortality, with biologics and non-biologics for adult and pediatric immune-mediated diseases.

**Aim #2:** To evaluate the **comparative clinical effectiveness** of various medications using patient-generated data for a variety of disease-specific and generic patient reported outcome (PRO) domains.
A Network of Networks

pSCANNER will enable researchers to use data from distributed sites covering over 30 million patients in a privacy-preserving environment.
Preserving Privacy
Sharing Data, Tools, Systems

Data sharing ecosystem

1. **Data owner**
   - Data 1
   - Contributor DUA and QA

2. **Tool creator**
   - Tool 2
   - Contributor QA

3. **System creator**
   - VM 2
   - Contributor QA

4. **Tool creator**
   - Tool 1
   - Tool 2

5. **User DUA**
   - Data 2
   - Tool A

6. **Model 1. Traditional**
   - User downloads center data
   - Data 2
   - Tool A
   - User A

7. **Model 2. Remote desktop**
   - User computes with center-hosted data in center environment
   - User B

8. **Model 3. Virtualization and distributed computing**
   - User performs center computation in his or her own environment
   - Data C
   - VM 2
   - User C

**Keywords:**
- Differential privacy
- Homomorphic encryption
- Secure multiparty computation
- BioCADDIE indexing
- Data sharing ecosystem
Distributed architecture

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

User requests data for Quality Improvement or Research

Diverse Healthcare Entities in 3 different states (federal, state, private)

Trusted Broker(s)
- Identity & Trust Management
- Policy enforcement

Security Entity

## Horizontal and Vertical Partitions

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<tr>
<th>Patient</th>
<th>Age</th>
<th>Insurance</th>
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<tr>
<td>A1</td>
<td>45</td>
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Related Work in Patient-control of 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

User \( U \) requests Data \( D \) on individual \( I \)
Informed CONsent for Clinical data Use in Research
My Sharing Choices

<table>
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<tr>
<th>What clinical data am I sharing?</th>
<th>Who can access the clinical data I share?</th>
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<tr>
<td>Demographics</td>
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<tr>
<td>Age</td>
<td>[ ] UCSD and VA Hospital [ ] Non-profit Organizations [ ] For-profit Organizations</td>
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<td>Ethnicity</td>
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<td>Insurance Status</td>
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<td>Marital Status</td>
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<td>Income</td>
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*Courtesy of H Kim*
- Asked >1k patients
- 394 were interested in the study
- 124 went to web site to make selections
Stay tuned for today’s presentations
(and re-watch them online too at http://pscanner.ucsd.edu)