Establishing Infrastructure for Patient–Powered Research Networks: A Framework for Meaningful Patient Engagement

Patient-Centered Outcomes Research Institute (PCORI)
Community Engaged Network for All (CENA) Patient-Powered Research Network (PPRN)

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PCORnet: @PCORRnetwork

CENA project: @CENAproject
Creating a Framework for Meaningful Patient Engagement

- PCORI Methodology Standards
- Funding Criteria
- PCOR Engagement Principles
PCORnet’s Framework for Patient and Family Engagement

- Collection and Sharing of Data
- Network Recruitment and Retention
- Governance
- Network Collaboration
- PCOR Engagement Principles
CENA PPRN

1. Alström syndrome
2. Dyskeratosis congenita
3. Gaucher disease
4. Hepatitis
5. Inflammatory breast cancer
6. Joubert syndrome
7. Klinefelter syndrome and associated conditions
8. Metachromatic leukodystrophy
9. Pseudoxanthoma elasticum (PXE)

Also… UCSF and UCDavis; Genetic Alliance and Private Access
High level architecture of the PEER system powering CENA

The Platform for Engaging Everyone Responsibly

Core components of PEER

Custom Portals
- Customized expressly for each CENA group
- Delivered via a secure iFrame
- “Gamified” survey questions
- Privacy preferences
- Guides to assist
- Dynamic consent
- Audit trail
- Future (request EHR, labs and Rx data)

Data Entry Facility
Survey questionnaire, contact information, guide-based assistance, mobile interface, security and registration

PrivacyLayer®
To create and manage permissions for sharing patient data wherever that data resides and at any level of granularity

Data Query Facility
Search index, privacy-based ontology, simple and advanced search, alerts, access requests, security and registration

Health Data
De-identified data patient reported

Contact Info.
Personally identifying info

Privacy Directives
Set by patient, dynamic & easy

Permissible Information
From search and search alerts

Researcher Portals
- Using Private Access, each respects patients privacy wishes
- Custom search alerts
- Dynamic consent
- Currently returns data to each group’s REDCap account
- Mapped to query from PopMedNet for PCORnet inquiries
- Future plans for using i2b2 and TranSmart

#P4C2014
iFrame and PEER widget
(https://widget.peerplatform.org)

Video messages from trusted members of the affected community

Organization website
(https://jsrdf.org/JSLIFE)
Patient-centered research

- This is something really unique
- It puts the power with the patient
- This project gives patients the empowerment, the voice, and the opportunity to become more involved in research
- This is truly transformational
This builds **TRUST**

Nearly 90% of all respondents reported a high degree of trust in the system.

<table>
<thead>
<tr>
<th>Response</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete or general sense of trust</td>
<td>89.4%*</td>
</tr>
<tr>
<td>Only some trust</td>
<td>4.4%</td>
</tr>
<tr>
<td>Uncertain whether wishes will be followed</td>
<td>4.4%</td>
</tr>
<tr>
<td>Concerned wishes will not be followed</td>
<td>1.8%</td>
</tr>
</tbody>
</table>

* Average of 4 organizations. Joubert syndrome (JSRDF) was 100% (31.8% complete trust; and 68.2% general sense that wishes will be followed as directed).
Connect with PCORnet

• A laboratory of promising approaches for patient engagement
• Build on what’s working
• Stay tuned for more opportunities to participate in the first national patient-centered “network of networks”
• Stay connected: [WWW.PCORI.ORG](http://WWW.PCORI.ORG) [WWW.PCORNET.ORG](http://WWW.PCORNET.ORG)