PCORnet Research Innovations: Engagement, Dissemination, and (Hopefully) Tech Transfer Pilots

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PCORnet is a "Network of Networks"

20 Patient-Powered Research Networks (PPRNs) + 13 Clinical Data Research Networks (CDRNs) + 1 Coordinating Center = A national infrastructure for people-centered clinical research
PCORnet Committee Structure

Engagement Committee
- Engagement approaches & best practices
- Stakeholder engagement evaluation metrics
- Engagement policy review and recommendation

Data Committee
- Common Data Model
- Data Quality
- Data Security and Privacy (Record Linkage)
- Social Determinants of Health
- Data Innovations

Research Committee
- PCORnet study designation
- Network collaborator requests
- Query prioritization
- Collaborative Research Groups (CRGs)
- Research innovations
Research Innovation Workgroup (RIWG)

Goal: To work in collaboration with the Coordinating Center and PCORnet networks to disseminate network-driven innovations that enhance the efficiency of pragmatic clinical trials.

Composition
- Research Committee (2)
- CDRNs (3) and PPRNs (2)
- Workgroup liaisons (5)
- Data Committee (2)
- PCORI and Coordinating Center

Expected outputs
- Engage networks to determine research innovation needs
- Disseminate innovative tools for cross-network learning and collaboration
- (Hopefully) facilitate cross-network pilot projects to test innovative tools across PCORnet
Collaboration with NCATS Recruitment Innovation Center

Early stages
- Informal conversations between Tom Carton (PCORnet) and Paul Harris (NCATS)
- Collaboration with PCORnet innovations needs survey to align with NCATS network engagement

Current stage
- Shared learning on network needs and dissemination approaches
- Discussing collaborative dissemination approaches to share across PCORnet and NCATS

Expanded/future stage
- Create cross-network WG with 3-4 members from PCORnet and NCATS
  - Document network engagement and lessons learned from PCORnet and NCATS sites
  - Given both network requests for information/tools, create unified PCORnet/NCATS list of desired tools
  - Cross-list NCTAS tools on the PCORnet Commons and PCORnet tools on any NCATS sourcing site (e.g. Research Match tools on Commons)
  - Promote joint dissemination through webinar series
RIWG Approach

Created PCORnet engagement survey to determine innovative tools with most interest across PCORnet (in conjunction with Data/Engagement Committees and NCATS RIC)

Domains
- Participant engagement/identification
- Participant contact/recruitment
- Trial management/retention
- Data capture
- Compensation
- Dissemination
- Clinician engagement

Distributed to network nodes

Received responses from most networks (CDRNs and PPRNs)
- 61 completed surveys from 18 PPRNs and 11 CDRNs
- Respondents were primarily from data and clinical teams

Scored tools on usefulness and willingness to share
- Total, by CDRN, by PPRN

Distributed survey results to WG

WG members voted for Top 5 tools to spotlight

<table>
<thead>
<tr>
<th>Usefulness score</th>
<th>Sharing score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all = -2</td>
<td>Have, willing to share = 1</td>
</tr>
<tr>
<td>Slightly = -1</td>
<td>Have, willing to pilot = 2</td>
</tr>
<tr>
<td>Moderately = 0</td>
<td>Need, want to learn more = 1</td>
</tr>
<tr>
<td>Very = 1</td>
<td>Need, willing to pilot = 2</td>
</tr>
<tr>
<td>Extremely = 2</td>
<td>Neither = 0</td>
</tr>
</tbody>
</table>
The Survey

1. How useful would you rate the following resources and tools – organized into seven broad categories?

<table>
<thead>
<tr>
<th>Resource</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Very</th>
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<tbody>
<tr>
<td>Patient engagement / Identification</td>
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<td>Tools/techniques to build trust between researchers and community groups</td>
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<td>A central point where potential participants can find information about clinical trials</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Assessment of feasibility based on inclusion/exclusion criteria</td>
<td></td>
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<tr>
<td>Tools to support the identification of potential study patients (including phenotyping)</td>
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<td></td>
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</tbody>
</table>

2. Does your network have resources to share? Is your network interested in receiving resource support?

<table>
<thead>
<tr>
<th>Resource</th>
<th>Have, willing to share</th>
<th>Have, willing to pilot with others</th>
<th>Need, want to learn more</th>
<th>Need, willing to pilot</th>
</tr>
</thead>
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<td>Patient engagement / Identification</td>
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</table>
## Network Responses

<table>
<thead>
<tr>
<th>Tool</th>
<th>Usefulness Score</th>
<th>Sharing Score</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tools to return study results to patients in a meaningful way</td>
<td>79</td>
<td>77</td>
<td>156</td>
</tr>
<tr>
<td>Tools to e-consent patients to registries and/or clinical trials</td>
<td>75</td>
<td>81</td>
<td>156</td>
</tr>
<tr>
<td>Tools to support the identification of potential study patients (including phenotyping)</td>
<td>66</td>
<td>75</td>
<td>141</td>
</tr>
<tr>
<td>Tools to support use of EHR for recruitment</td>
<td>66</td>
<td>74</td>
<td>140</td>
</tr>
<tr>
<td>Tools to consent patients to provide PROs and PGHD</td>
<td>66</td>
<td>72</td>
<td>138</td>
</tr>
<tr>
<td>Methods to disseminate study results to participating and non-participating clinicians</td>
<td>64</td>
<td>78</td>
<td>142</td>
</tr>
<tr>
<td>Outreach tools to broadly inform and engage clinicians in research</td>
<td>60</td>
<td>79</td>
<td>139</td>
</tr>
<tr>
<td>Obtaining socio demographics on participants in a scalable manner</td>
<td>56</td>
<td>78</td>
<td>134</td>
</tr>
<tr>
<td>Tools/techniques to build trust between researchers and community groups</td>
<td>56</td>
<td>76</td>
<td>132</td>
</tr>
</tbody>
</table>
WG Responses

Tools to return study results to patients in a meaningful...
Tools to e-consent patients to registries and/or clinical...
  Tools to support use of EHR for recruitment
  Tools to support the identification of potential study...
Outreach tools to broadly inform and engage clinicians...
  Tools to consent patients to provide PROs and PGHD
Methods to disseminate study results to participating...
  Tools to directly contact patients for research...
Tools/techniques to build trust between researchers...
  Methods to recruit and incentivize clinicians to...
  Tools to support the use of social media to target...
Materials/techniques to engage patients in mHealth
  Tools to evaluate recruitment
  Tools to survey patients remotely
Materials/techniques to establish partnerships with...
Results, WG Liaisons, and Dissemination Approach

Results - Five tool categories
- Tools to return study results to participants
- Tools to e-consent
- Tools to support ID of potential study participants
- Tools to support use of EHRs for recruitment
- Outreach tools to broadly engage clinicians

WG Liaisons
- Disseminate survey results and promote uploads through PCORnet weekly announcements
- Organize conference call with “sharing” network representatives to describe Commons use and facilitate uploads
- Connect directly with network representatives to offer Commons and upload support
- Start group discussion on Commons and encourage uploads of content

Dissemination Approach
- Organize a series of PCORnet Best Practices Webinars (coordinated with NCATS RIC) to highlight tool sets and promote tech transfer between networks
- Order determined by Commons group membership and actions to incentivize participation
PCORnet Commons

Tools to e-Consent
ACTIVE 41 MINUTES AGO | PRIVATE GROUP WITH 18 MEMBERS

This is a space for networks who reported they have or need, “Tools to e-Consent” and are willing to collaborate around these types of Tools. This is a Top 5 Tool identified through a survey done by the PCO [...] View Group

Outreach tools to broadly engage clinicians
ACTIVE 6 DAYS, 20 HOURS AGO | PRIVATE GROUP WITH 11 MEMBERS

This is a space for networks who reported they have or need, “Outreach tools to broadly engage clinicians” and are willing to collaborate around these types of Tools. This is a Top 5 Tool identified through a survey [...] View Group

Tools to support the use of EHRs for recruitment
ACTIVE 1 WEEK AGO | PRIVATE GROUP WITH 10 MEMBERS

This is a space for networks who reported they have or need, “Tools to support the use of EHRs for recruitment” and are willing to collaborate around these types of Tools. This is a Top 5 Tool identified through a survey done by the PCO [...] View Group
# Commons Group Members and Activity

<table>
<thead>
<tr>
<th>Tool</th>
<th>Members</th>
<th>Uploads</th>
<th>Discussions</th>
<th>Announcements</th>
</tr>
</thead>
<tbody>
<tr>
<td>Return study results to participants</td>
<td>11</td>
<td>0</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>eConsent</td>
<td>26</td>
<td>5</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Identification of potential study subjects</td>
<td>12</td>
<td>6</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Support use of EHRs for recruitment</td>
<td>15</td>
<td>3</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Engaging clinicians</td>
<td>14</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>
Challenges

Dual ask - use of Commons and submission of tools
- Technological adoption of the Commons will take time

Lack of engagement from the networks who indicated they have tools to share for various reasons
- ”Imperfect” tools
- Confusion over mechanism for sharing - white papers, screen shots, demo videos, etc.

Current communications may not be going to the appropriate people at each network to garner the most activity
- Iterative process of engagement to find the right network representative
Next Steps - Incentivize Tech Transfer

Proposal: To spur contributions/collaborations…

- Tech transfer mini-grants (5x $100k or 10x $50k)
- Promote extension of native innovations
- Money to cover implementation costs, not licenses
- Requirements:
  - Pilot implementation use cases (contributing network paired with extension network submit application)
  - Dissemination of results in standard format (to contribute to knowledge base)
- Contribute to global report on PCORnet innovations/tech transfer

Timeline/next steps

- Present to PCORI with Research Committee Chair
- Announcement in September/October to incentivize participation in webinar series (contributors and participants)
Questions/Discussion