Recap of Day 1, Overview of Day 2

Sue Sheridan, MIM, MBA
Director of Patient Engagement

Charlotte W. Collins, JD
Co-Chair

Darius Tandon, PhD
Co-Chair

Patient-Centered Outcomes Research Institute
## Agenda for April 29

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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<tbody>
<tr>
<td>9:00 – 9:30 a.m.</td>
<td>Recap of Day 1, Overview of Day 2</td>
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<tr>
<td>9:30 – 10:30 a.m.</td>
<td>Evaluation Subcommittee Report</td>
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<tr>
<td>10:30 -10:45 a.m.</td>
<td>BREAK</td>
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<tr>
<td>10:45 – 11:15 a.m.</td>
<td>Update on Matchmaking and Partner Lists</td>
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<tr>
<td>11:15 a.m. – 12:00 p.m.</td>
<td>Compensation Subcommittee Report</td>
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<tr>
<td>12:00 – 12:15 p.m.</td>
<td>BOXED LUNCH</td>
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<tr>
<td>12:15 – 12:45 p.m.</td>
<td>Discussion on “Patient” Definition, Privacy Issues, and other Questions</td>
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<tr>
<td>12:45 – 1:30 p.m.</td>
<td>Update on PCORnet</td>
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<td>1:30 – 1:45 p.m.</td>
<td>Wrap-up and Conclusion</td>
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<tr>
<td>1:45 p.m.</td>
<td>Meeting Adjourned</td>
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PCORI Evaluation Framework: Comments from PEAP Evaluation Subcommittee

Evaluation Subcommittee
Mark Boutin, JD
Steven Blum, MBA
Sara van Geertruyden, JD
Darius Tandon, PhD
Process for Generating Recommendations

- Committee members reviewed draft PCORI evaluation framework (February 14th version)
- Conference call to generate initial impressions from subcommittee members
- In-person meeting to generate specific recommendations for PCORI to consider
Overarching Recommendations (a.k.a. our “Top 10 List”)

1. The evaluation plan should link to the PCORI brand of “research done differently.”
2. The evaluation plan should provide information that is useful for multiple key audiences, including those making decisions about PCORI reauthorization.
   - Need to have a 3-year framework in place
3. Metrics should be created that are relevant for a 3-year evaluation framework.
4. The evaluation plan must be communicated in user-friendly language to the array of key PCORI stakeholders.
5. Stakeholder valuation of PCORI needs to be incorporated into the evaluation plan.
Overarching Recommendations

6. More metrics need to be created to understand how stakeholder engagement resulted in greater stakeholder capacity to engage in research.

7. Additional qualitative measures examining the impact of PCORI’s emphasis on patient and stakeholder engagement should be developed.

8. Completion of surveys that measure attitudes toward engagement should be a contract requirement.

9. More attention should be given to how PCORI’s work influences others (e.g., funders).

10. More attention should be given to how PCORI findings and products are used.
15-Minute Break

Refreshments in the upper lobby foyer.
PCOR Partner List and PCORI’s Matchmaking App Challenge

Celeste A. Brown, MPH
Program Associate, Stakeholder Engagement
The PCOR Partner List
The PCOR Partner List

- A service on PCORI’s website, open to patients and stakeholders who want to partner on a PFA research team or on other PCORI initiatives
- PCORI’s initial approach to facilitate creation of partnerships, because engagement is something we demand from project teams
- Launch 1: March 4 – April 4
  - 112 responses
  - Sent names to researchers from pragmatic trials, obesity, and transitions in care - targeted PFAs
- Launch 2: April 23 – May 15
  - For the PCORI Matchmaking App Challenge

www.pcori.org/pcorpartnerlist
PCORI’s Matchmaking App Challenge
Motivation for the 2014 Matchmaking App Challenge

- Researchers often ask how to find patients interested in collaborating.

- Patients and stakeholders may have an idea but not the research experience to bring it to fruition.

- Matchmaking facilitates bi-directional initiation of research partnerships.
Goals of the 2014 PCORI Matchmaking App Challenge

- Increase the ability for all user types – patient, stakeholder, researcher – to initiate a PCOR relationship.

- Build a self-sustaining online community interested in patient-centered outcomes research.

- Spread the method of patient engagement in research across the country.
PCORI Matchmaking App Challenge

- Polished, ready-to-publish apps

- Total Prizes: $150K
  - 1st Place: $100K (60/40 payment schedule)
  - 2nd Place: $35K
  - 3rd Place: $15K

- Must work with patients and/or stakeholders in product design
**Required Features**

- Facilitates creation of partnerships among **all user types**: researchers, stakeholder, patient
- Users must be able to **self-select the user type(s)** with which they primarily identify
- Internal (user-only) communication platform
- Ability to **translate** from English, or have a plan to translate the app into other languages
- Section 508 compliance
- Interoperability/ability to integrate with **preexisting research networks** (such as, clinicaltrials.gov, and the PCORnet CDRNs and PPRNs)
- A clear designation that **participation** in the application (web or mobile version) is **voluntary** and, therefore, disclosing personal medical information is the app user’s choice and responsibility
Suggested Features

- **Social media integration** for external networking
- Robust **user profiles**
- Advanced **search** options (e.g. geocoding)
- **Customizable displays**, which allows users to filter and display their network by category (disease condition, geography, individual. Consider the features LinkedIn uses to display existing relationships and suggested connections)
- An **admin dashboard**, which allows users to pull data about the reach and depth of their network
- An **analytics dashboard**, or feature, that other funders and research institutions could access to retrieve data and the existing network (displays such information as, where users access the network from, user concentration by geography, frequency of use, etc.)
Judging Criteria and Definitions

- **Creativity**: uniqueness and innovation in approach to fulfilling the mandatory requirements; the variety and value of additional features

- **User interface and user experience (UI/UX)**: overall look and feel of various displays and ease of use of all features

- **Evidence of co-design**: the inclusion of patients and stakeholders in the app design and development process

- **Sensitivity**: demonstrated cultural awareness; consideration of the variety of potential users (PCORI’s priority populations)

- **Incentive**: impetus users have to download the app and return to use it frequently

- **Past performance**: evidence of the volume and quality of the app developer’s previous experience (judged only from the “Past Performance” slide in the .PDF submission)
Timeline Overview

**Challenge Development Period**
- Challenge Launch Date: March 17, 2014
- PCORI Webinar for Promotion: March 20, 2014
- PCORI Webinar: April 30, 2014
- Application Submission Deadline: Aug. 15, 2014

**Judging Period**
- Virtual Judging Begins: Aug. 15, 2014
- Judging Completed: Aug. 31, 2014
- Winner Announced: Sept. 2014
Questions?

matchmaking@pcori.org

www.pcori.org/pcorpartnerlist

www.pcori.org/challenge
PCORI Principles of Compensation Parity

Compensation Parity Subcommittee
Charlotte Collins, JD
Sara van Geertruyden, JD
Regina Greer-Smith, MPH, FACHE
Lorraine Johnson, JD, MBA

Patient-Centered Outcomes Research Institute
Time and contributions of patient partners are valued and demonstrated in fair financial compensation as well as reasonable and thoughtful time commitment requests.
Issues That Matter

- Who is compensated?
- Who is providing the compensation?
- For what level of activities?
- How much?
- Mandated or suggested?
Who Is Compensated

- Patients
- Caregivers
- Patient Organizations

NOTE: Research subjects (study participants) are not included in this topic.
Cover Reasonable Expenses

- Travel
- Accommodation
- Meals
- Childcare
- Internet/telephone
- Conference fees
- Training participation
- Prompt, and even advance, reimbursement
Level of Activities

I. Simply informing
II. Consulting on decision
III. Deciding together
IV. Acting together
V. Encouraging independent initiatives

Research Subject

Fully Engaged Partner
Compensation Alignment with Activities

Parity reflects -

- commitment
- dedicated time
- skills
- expertise
  - level of patient engagement expertise
- commensurate with contributions by other collaborators
Other Considerations

- Align with level of activities
- Flexible – consider choice
- Non-cash incentives
- Opt-Out
- Consult with the patient/caregiver/organization
  - Public benefits eligibility risk
  - Organization’s internal policies
- Formal contract
- Mandatory vs. permissive
Boxed Lunch Break

*Boxed Lunch is served in the Upper lobby foyer.*
*We reconvene at 12:15 pm.*
Discussion on “Patient” Definition, Privacy Issues, and other Questions

Compensation Parity Subcommittee
Charlotte Collins, JD
Sara van Geertruyden, JD
Regina Greer-Smith, MPH, FACHE
Lorraine Johnson, JD, MBA
PCORnet Update
April 29, 2014

Jaye Bea Smalley
National Urban Fellow and Special Assistant to the Chief Engagement and Dissemination Officer

Sarah Daugherty, PhD, MPH
Senior Program Officer, CER Methods and Infrastructure
PCORnet Update

- Revised Infrastructure Rubric
- PCORI Patient Engagement Webinars
- Strategic Portfolio Management
- The ENACT Tool
- Common Data Model Version 1.0
- Update on Patient Engagement Activities
PCORI Network-Led Patient Engagement Webinars

Building on recent feedback to create a continued dialogue and a sharing of promising practices, the goals for the engagement webinar series are to:

- Promote PCOR readiness
- Encourage the development and sharing of promising practices among PCORnet
- Foster collaboration among networks
- Identify existing resources
- Identify issues and challenges in patient-engaged network development
PCORnet STEERING COMMITTEE

Members represent:
- Each Clinical Data Research Network
- Each Patient-Powered Research Network
- Patients
- HHS agencies:
  - NIH
  - FDA
  - AHRQ
  - CDC
  - CMS
  - ONC
  - ASPE
- Medical product and device manufacturers
- PCORI and Coordinating Center

11 CLINICAL DATA RESEARCH NETWORKS

18 PATIENT-POWERED RESEARCH NETWORKS

PROJECT MANAGEMENT OFFICE

TASK FORCES
- GOVERNANCE
- DATA PRIVACY
- ETHICS & REGULATORY
- DATA STANDARDS & SECURITY
- HEALTH SYSTEMS INTERACTIONS
- PATIENT & CONSUMER ENGAGEMENT
- PATIENT GENERATED OUTCOMES
- CLINICAL TRIALS
- RARE DISEASES
- BIOREPOSITORIES
- OBESITY
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<tr>
<th>Milestone</th>
<th>Description</th>
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<tr>
<td>3.1</td>
<td>Description of patient roles and responsibilities in governance is developed and submitted to PCORI</td>
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<tr>
<td>3.2</td>
<td>Approaches for enhancing patient involvement in governance are developed and submitted to PCORI</td>
</tr>
<tr>
<td>3.3</td>
<td>Approved approaches for enhancing patient involvement in governance implemented</td>
</tr>
<tr>
<td>3.4</td>
<td>Report summarizing patient engagement activities is submitted to PCORI</td>
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<tr>
<td>3.5</td>
<td>Report summarizing patient engagement activities is submitted to PCORI</td>
</tr>
<tr>
<td>3.6</td>
<td>Report summarizing patient engagement activities is submitted to PCORI</td>
</tr>
<tr>
<td>3.7</td>
<td>Approaches for patients to ask and prioritize research questions are developed and submitted to PCORI</td>
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<tr>
<td>3.8</td>
<td>Approved approach for patients to ask and prioritize research questions is implemented</td>
</tr>
<tr>
<td>3.9</td>
<td>Approaches for enabling patients to communicate with each other are developed and submitted to PCORI</td>
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<tr>
<td>3.10</td>
<td>Approved approaches for enabling patients to communicate with each other are implemented</td>
</tr>
<tr>
<td>3.11</td>
<td>Approaches for enabling patients to receive research finding results are developed and submitted to PCORI</td>
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<tr>
<td>3.12</td>
<td>Approved approaches for enabling patients to receive research finding results are implemented</td>
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## PCORnet Patient Engagement Milestones

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<tr>
<th>Milestone Description</th>
<th>Status</th>
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<tr>
<td>Approaches to enable patients to identify PROs for inclusion into database are developed and submitted to PCORI</td>
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</tr>
<tr>
<td>Approved approaches to enable patients to identify PROs for inclusion into database are implemented</td>
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</tr>
<tr>
<td>Approaches for patients to securely extract their own data through EHRs and/or health claims data are developed and submitted to PCORI</td>
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<tr>
<td>Approved approaches for patients to securely extract their own data through EHRs and/or health claims data are implemented</td>
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Strategic Portfolio Management

- Monthly calls with awardee teams
- Quarterly progress reports
- Completion of ENACT tool is required as part of progress report
- Summative analysis at 6, 12, 18 months
- Site visits
- Monthly assessment of technical assistance provided
Engaging Patients in Infrastructure

Engage

Enhance

Evaluate
PCORnet ENACT Tool Protocol

Integrate end-users into developing assessment tool, interpreting findings, and disseminating results
- Patient and Consumer Engagement Task Force
- Evaluation working group established

Timing: Baseline and 6-month assessments

Respondents: PI, lead patient representative, clinical partners

Dissemination: aggregate results to network partners
PCORnet Common Data Model Version 1.0

- Demographics
  - Date of birth
  - Sex
  - Race
  - Hispanic
- Enrollment data, including dates
- Encounter data, including inpatient and outpatient; visit type, provider type
- Vital signs
  - Weight
  - Length (0 to 2-3 y)
  - Height (2-3 + y)
  - Blood pressure, position taken
- Codes for diagnoses, procedures
Thank you!

Safe travels home!