

Patient-Centered Outcomes Research Institute

Charting the Course – Exploring Top Proposals from Poster Sessions

July 3, 2012



Opportunity Identification and Prioritization

Breakout Groups

- All participants were assigned to seven breakout groups focused on:
 1. Governance
 2. Data Standards & Interoperability
 3. Architecture & Data Exchange
 4. Privacy & Ethical Issues
 5. Methods
 6. Unconventional Approaches
 7. Incorporating Patient Reported Outcomes into Electronic Data

Recommendation Development

- Each group was tasked with generating 3-4 actionable recommendations that support PCORI's mission. Recommendations included the following dimensions:
 1. Time Horizon
 2. Cost
 3. Feasibility
 4. Criticality of PCORI's Role
 5. Efficiency of Resource Usage

Voting Process

- Each group generated a “poster” showcasing its recommendations. The posters were displayed and all participants, using a controlled number of positive and negative votes, supported or opposed recommendations

Ranking Process

- This morning, we will discuss the top recommendations along with any recommendations which appeared to be polarizing

Top 10 Recommendations

Rank	Recommendation Name	Green Votes	Red Votes
10	Define mechanism to authorize use of data for PCOR purposes: a) Policies to vet and approve use of network resources and b) define expectations of data holder and networks	23	4
9	Sponsor and advocate for refinement and curation of clinical information models and associated value sets, common data elements that merge clinical and research requirements	25	2
8	Sponsor and advocate for development of data standards about the care environment in order to facilitate the analysis of care options	27	1
7	Identify and address barriers and incentives for developing and using PROs in healthcare systems and PHRs	28	4
6	Develop methods to develop an “n=1” research environment to investigate impact on patient experiences using diverse eData	29	0

Top 10 Recommendations (cont'd)

Rank	Recommendation Name	Green Votes	Red Votes
5	Ask patients what they think are the most important research questions and create a transparent, dynamic list of PCORI research priorities , with explanations that incorporate patient and expert input	34	4
4	Architecture and Exchange: Develop 360° Patient-centered longitudinal view, Identity Mgt, Data Curation	36	0
3	Improve outcomes and advance knowledge for patients, clinicians and researchers with Rapid Learning Networks	44	3
2	Be the national leader to ensure meaningful and representative patient engagement in research networks' governance (ex. ID people, train people, advise, etc.)	44	0
1	Establish PCORI criteria for governance for focus on: a) meaningful and representative patient engagement , b) data stewardship , c) dissemination of information, and d) sustainability	46	0

Lowest Ranking Recommendations

Rank	Recommendation Name	Green Votes	Red Votes
1	Seek to broadly understand patient benefit	1	0
2	Understand which groups engage and why to ensure inclusiveness	3	0
3	Conduct survey of initiatives for implementation of PROs in healthcare systems & PHRs	4	1
4	Explore IRB models that facilitate patient engagement	5	0
5	Support methods to develop a portfolio of studies to balance the eData trade-off and developing methods to assess level of control of confounding in the data	7	0
5	Develop a manual for EHR based research reporting standards	7	7

Governance

Establish PCORI criteria for governance

- a) meaningful/representative pt engagement
- b) data stewardship
- c) dissemination of information
- d) sustainability

Governance

Be national leader to ensure meaningful and representative patient engagement in research networks' governance

(e.g., ID people, train people, advise, etc.)

Unconventional Approaches

1. The National Patient Network
2. Rapid Learning Networks to Improve Outcomes and Advance Knowledge

Data Standards & Interoperability and Architecture and Exchange

Patient-Centered Longitudinal View

Sponsor Development of Data
Standards About the Care Environment
to Facilitate Analysis of Care Options

Data Standards & Interoperability and Architecture and Exchange

Sponsor and Advocate For:

- Development of Data Standards About the Care Environment In Order to Facilitate the Analysis of Care Options

Data Standards & Interoperability and Architecture and Exchange

1. Sponsor and Advocate For:

- Sponsor and advocate for refinement and curation of clinical information models and associated value sets, common data elements that merge clinical and research requirements

Data Standards & Interoperability and Architecture and Exchange

Architecture and Exchange

- Patient-Centered Longitudinal View
- Identity Management
- Data Curation

Incorporating Patient Reported Outcomes into Electronic Data

Identify and address barriers and incentives for developing and using PROs in healthcare systems and PHRs

Methods

Methods to develop an n=1 research environment to investigate impact on patient experiences using diverse eData.

Thank you for your participation!