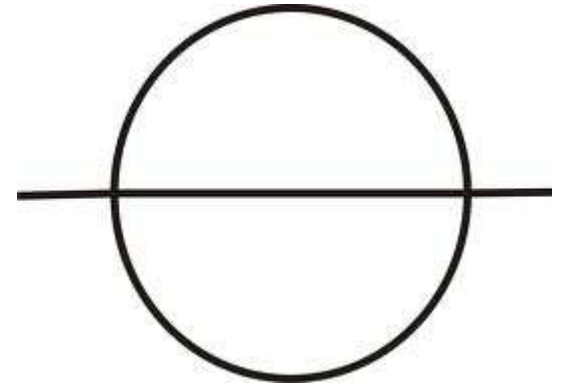# Agenda –Day 1

Start Time	Discussion
12:35 p.m.	Mary Tinetti, Ethan Basch, **Welcome**
12:40 p.m.	Lori Frank, Andrew Holtz, **Workshop Introduction**
12:45 p.m.	Hassan Murad, **Mayo Clinic**, Knowledge & Evaluation Resource Unit
1:05 p.m.	Q&A
1:20 p.m.	Pam Curtis, **Oregon Health & Sciences University**, Center for Evidence Based Policy
1:40 p.m.	Q&A
1:55 p.m.	Daniel Mullins, **University of Maryland**, Pharmaceutical Health Services Research Department
2:15 p.m.	Q&A
2:05 p.m.	Break
2:30 p.m.	**Group Discussion** —Research Teams, External Invitees, & Workgroup Members
4:45 p.m.	Summary & Adjourn
5:00 p.m. —7:00 p.m.	**Reception—** Remarks from Steven Lipstein, Vice Chair, PCORI Board of Governors

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A defining principle of PCOR is ensuring that the patient's voice and perspective drive every step of the research process, including **prioritizing** the **research questions**, **designing** and **conducting** the research, and **implementing** the results in practice.
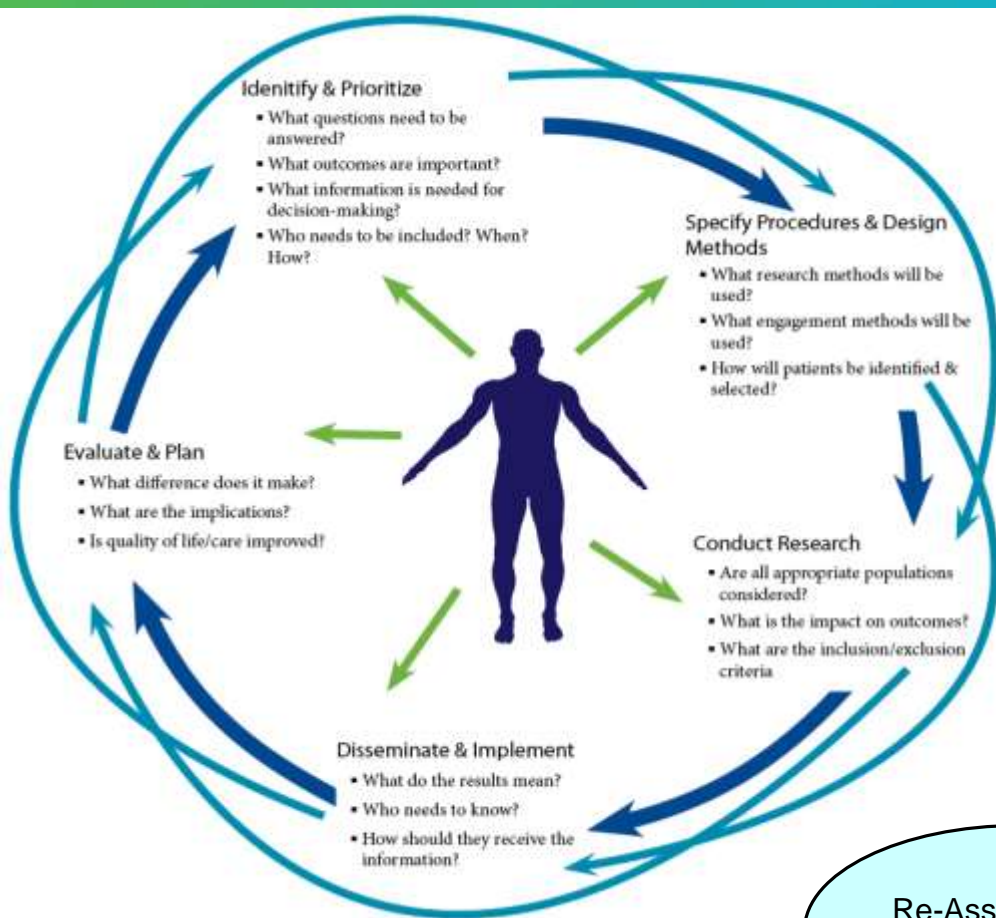
The PCOR process – linear or iterative?

1. selecting research questions
2. identifying comparators
3. selecting outcomes
4. designing the study
5. recruiting participants
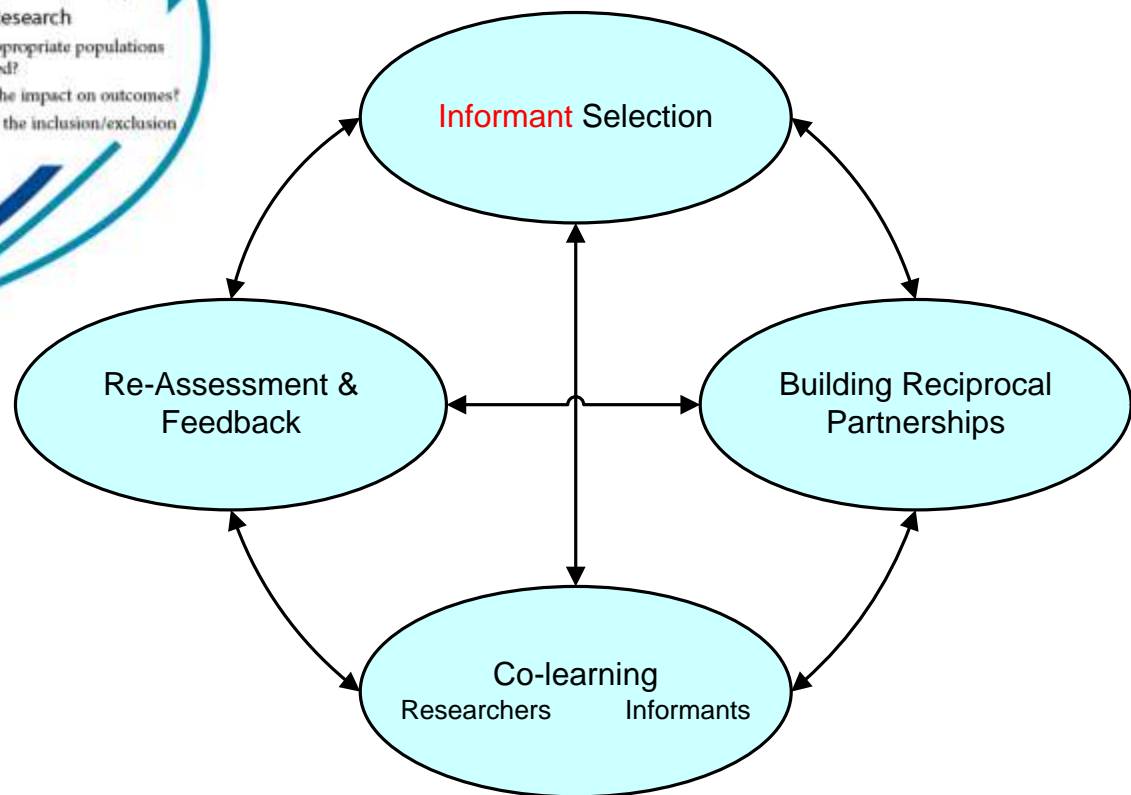6. disseminating results
7. implementing findings

Where in the process do the standards apply?

Representations of the Research Process

Identify & Prioritize
- What questions need to be answered?
- What outcomes are important?
- What information is needed for decision-making?
- Who needs to be included? When? How?

Specify Procedures & Design Methods
- What research methods will be used?
- What engagement methods will be used?
- How will patients be identified & selected?

Evaluate & Plan
- What difference does it make?
- What are the implications?
- Is quality of life/care improved?

Conduct Research
- Are all appropriate populations considered?
- What is the impact on outcomes?
- What are the inclusion/exclusion criteria

Disseminate & Implement
- What do the results mean?
- Who needs to know?
- How should they receive the information?

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Juan Pablo Domecq Garces, M.D.
Nathan Shippee, Ph.D.
M. Hassan Murad, M.D., MPH

Pam Curtis, MS
Valerie King, MD, MPH
Cathy Gordon, MPH

Informant Selection

Building Reciprocal Partnerships

Re-Assessment & Feedback

Co-learning
Researchers   Informants

4

Focus on standards: Elements to consider

- Standards or principles?

- "Minimum"

- Levels: supra- vs. subordinate

- Prioritization

- Actionable

- Strength of evidence

- How to communicate?

- Knowledge gaps

Standard Comparison Exercise

An opportunity to compare proposed standards across research teams…

Across all proposed standards

- ***Which proposed standards should be nominated for inclusion?***

- Is there a hierarchy that emerges from the full set of standards?

- Is this set of standards comprehensive for the PCWG component of the Report?

- What is the relationship between strength of evidence and recommendation for inclusion for this set?

  - Do PCWG standards differ on this dimension relative to other standards that will be nominated?

Take out your pencils!

	Mayo	OHSU	UMd
Pre/early engagement	X	X	X
• agenda setting	X	X	X
Trust/relationship	X	X	X
• Communication	X	X	X
• cultural sensitivity		X	X
• Transparency	X	X	X
Co-learning	X		X
• equality	X	X	X

Comparing standards across subjects

	Mayo	OHSU	UMd
Give back/report back	X	X	X
Evaluate engagement impact	X	X	
Resources/allocation	X	X	X
Document patient voice	X	X	

- inclusion by point in process

	Mayo	OHSU	UMd
Pre/early engagement	X	X	X
• agenda setting	X	X	X
Trust/relationship	X	X	X
• Communication	X	X	X
• cultural sensitivity		X	X
• Transparency	X	X	X
Co-learning	X		X
• equality	X	X	X

	Mayo	OHSU	UMd
Give back/report back	X	X	X
Evaluate engagement impact	X	X	
Resources/allocation	X	X	X
Document patient voice	X	X	
• inclusion by point in process			

Discussion Questions - 2

- Discuss PCOR as culture change. How does the work completed by these groups inform us about opportunities to shift the research culture toward patient-centeredness?

  - Discuss specific ways in which patients can be engaged. Discuss specific ways in which clinicians and health systems can be engaged.

  - Consider incentives and disincentives for participation by stakeholder. What do the research team findings discussed here suggest for changing system incentives to enhance PCOR?

- Discuss variability within each stakeholder group of interest. Does the variability along multiple dimensions within the clinical research community matter for implementing PCOR? How should variability of "patients" be addressed?

Discussion Questions - 3

- What can we learn about implementing standards from the work so far? What do the findings discussed during this workshop suggest about communication strategies for the proposed standards? Who are the target audiences?

- Do any of the findings address differences between patient activism and patient advocacy? Is this distinction a helpful one to make in PCOR?

- Summarize findings related to the role of caregivers in PCOR. From the idea of culture change discussed earlier, what is applicable to caregivers? Do the proposed standards adequately address the role of caregivers or proxies in PCOR?

Day 1 Adjourn
Thank you!