Board of Governors Meeting

Via Teleconference/Webinar

September 7, 2018
9:00 AM – 3:15 PM ET

pcori
PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Welcome and Introductions

Grayson Norquist, MD, MSPH

Chairperson, Board of Governors

Joe Selby, MD, MPH

Executive Director

Agenda

9:00 AM	**Call to Order and Welcome**
9:00 – 9:05	**Consider for Approval:** Minutes of the August 21, 2018 Board Meeting
9:05 – 9:30	**Executive Director's Report**
9:30 – 10:00	**Consider for Approval:** Policy for Data Management and Data Sharing
10:00 – 10:30	**Consider for Approval:** PPRN Limited Competition Engagement PFA Development
10:45 – 12:15	**Strategic Plan 2018 Update**
1:15 – 2:45	**Panel Discussion with Outgoing Board Members**
2:45 – 3:15	**Public Comment**
3:15 PM	**Wrap up and Adjournment**

Board Vote

Call for a Motion to:	• **Approve** the Minutes of the August 21, 2018 Board Meeting
Call for the Motion to be Seconded:	• **Second** the Motion • If further discussion, may propose an **Amendment** to the Motion or an **Alternative** Motion
Voice Vote:	• Vote to **Approve** the **Final** Motion • Ask for votes in favor, opposed, and abstentions

Executive Director's Report

Joe Selby, MD, MPH

Executive Director

Celebrating Their Service
Founding Board Members 2010-2018

Debra Barksdale

Chair of the Engagement, Dissemination, and Implementation Committee

Kerry Barnett

Board Vice Chairperson
Chair of the Finance and Administration Committee and the Governance Committee

Allen Douma

Vice Chair of the Research Transformation Committee

Leah Hole-Marshall

Vice Chair of the Selection Committee

Harlan Krumholz

Member of the Program Development Committee and the Research Transformation Committee

Richard Kuntz

Founding Chair of the Program Development Committee

In Just 8 Years, PCORI has

Committed >$2.3 Billion to Research Studies and Research Support

- **$1.84B to research studies**
- Portfolio of 595 research studies
- **$471M** to Research Infrastructure, Dissemination and Implementation, and Engagement Projects

Approved Projects Through Dozens of Funding Cycles

- 19 **Research Award** cycles
- 11 **Engagement Award** cycles
- 5 **Dissemination & Implementation Award** cycles

Built PCORnet

- **National Patient-Centered Clinical Research Network**
- 13 Clinical Data Research Networks
- 20 Patient-Powered Research Networks
- 2 Health Plan Research Networks
- 14 Demonstration projects
- 63 Externally funded and 8 co-funded research projects using PCORnet infrastructure

Established Standards and Resources To Support Research

- **Methodology Standards** provide guidance in 13 topic areas for a total of 54 standards
- **Engagement Rubric** developed and published to show how engagement can occur in research

Generated Results

- Over 1,300 publications associated with PCORI-funding
- 174 research projects with **results in the public domain,** either in publications or results posted to PCORI.org

Public Reporting of PCORI Peer-Reviewed Results

242 draft final research reports submitted

144 completed reviews of draft final research reports

101 peer-reviewed research findings posted

16 full final research reports posted

Numbers as of August 20, 2018

Early Results Already Being Taken Up Into Practice

Cited at least **29 times** in evidence-based clinical recommendations (decision tools, clinical guidelines, standards of care)

Evidence-based clinical recommendations

Cited **28 times** in policy documents (Assistant Secretary for Planning and Evaluation, National Academy of Medicine, and others)

Policy Documents

Cited as a **notable example of a shared decision making tool** in a Centers for Medicare and Medicaid Services **national coverage decision** for implantable cardiac defibrillators

National coverage decision

Cited as **influencing** Commission on Accreditation of Rehabilitation Facilities **accreditation standards**

Accreditation of standards for rehabilitation facilities

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Review of Agenda

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Policy for Data Management and Data Sharing

Jason Gerson, PhD

Senior Program Officer

PCORI's Open Science Initiatives

Process for Peer Review of Primary Research and Public Release of Research Findings

(Approved by the Board February 2015)

Public Access to Journal Articles Presenting Findings from PCORI-Funded Research Policy

(Approved by the Board April 2016)

Policy for Data Management and Data Sharing

Benefits of Responsible Data Sharing

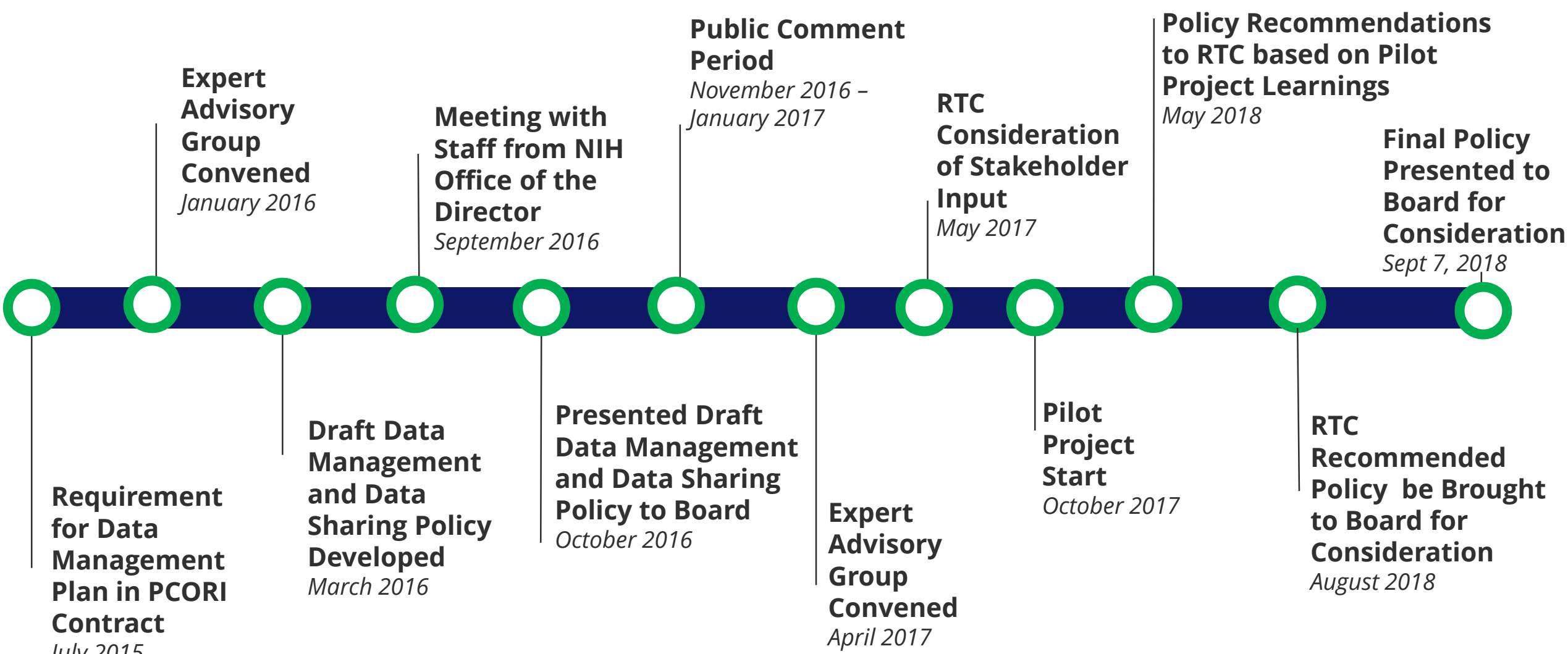
- Responsible sharing of clinical research data is in the public interest
  - Maximizes contributions made by clinical research participants to scientific knowledge that benefits future patients and society as a whole
- Data sharing can accelerate new discoveries through conduct of additional analyses, analyzing unpublished data, reproducing published findings, and conducting exploratory analyses to generate new research hypotheses
- Sharing clinical research data also presents challenges
  - Need to protect the privacy/honor consent of clinical research participants
  - Guard against invalid secondary analyses, which could undermine trust in clinical trials or otherwise harm public health

-- Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk (IOM 2015)

Guiding Values Statement

The Patient-Centered Outcomes Research Institute (PCORI) is committed to the principles of open science, particularly **maximizing the utility and usability of data collected** in research projects that PCORI funds. PCORI seeks to **encourage scientifically rigorous secondary use of clinical research data** to foster scientific advances that will ultimately improve clinical care and patient outcomes. As such, PCORI believes it is important for our research awardees to **systematically create and preserve research data and data documentation** in order to facilitate data sharing

Timeline of Policy



Policy Development: Learning By Listening and Doing

- We gathered input from a variety of sources and through a number of activities, including:
  - Expert advisory group
  - Public comment period
  - Pilot project
  - Peer funders and regulatory agencies
  - PCORI's Research Transformation Committee

Features of the Policy: Overview

- Specifies data and data documentation to be shared
- Articulates expectations for data management and data sharing to Awardees
- Provides funding to support Awardees' time and effort to prepare data
- Specifies when data would be made available for third-party requests
- Describes third-party data request review process
- Articulates criteria and review process regarding exemptions from Policy requirements

Features of the Policy: Privacy and Ethical Protections

- Thorough scientific vetting of requests for data
- De-identified data only (in accordance with the HIPAA Privacy Rule (45 C.F.R. § 164.514(b))
- Prohibition against reidentification of individuals
- Prohibition against redistribution of data to those who are not party to the Data Use Agreement
- Data must be from participants whose informed consent permits data collected as part of the research project to be de-identified and to be used for secondary research purposes and shared with researchers not affiliated with the institution

Data Deposition: Overview

- Full Data Package: Analyzable Data Set, Full Protocol, metadata, data dictionary, full statistical analysis plan, and analytic code
  - Alternatively, specified data elements may be deposited in lieu of the Full Data Package if contractual or legal restrictions apply
- Awardees depositing full data package (or applicable data elements) will work with PCORI-designated repository(ies) to curate it
- Data will be hosted by designated repository(ies), not PCORI
- Awardees will enter into a Data Contributor Agreement (DCA) with the repository. DCA governs the data deposition and establishes the Awardee's rights and obligations

Data Deposition: Requirements for Research Awardees

Targeted and Pragmatic Clinical Studies Research Awards	PCORnet Research Awards	Broad Research Awards
• Deposit Full Data Package (or required data elements, as applicable) in a PCORI-designated repository	• Deposit specified data elements such as the full protocol, analytic code used to query PCORnet data, and aggregate level datasets in a PCORI-designated repository	• Maintain Full Data Package for 7 years • PCORI may notify Awardee of its intent to provide funds for the deposition of the full data package in a PCORI-designated repository

Timeframe for Data Availability

- The Full Data Package will be made available for third-party requests when the

Final Research Report is made available on PCORI's website

- OR -

Research project's primary results are published in a peer-reviewed journal

<u>WHICHEVER COMES FIRST</u>

Data Requests: Review Process

- Review will help ensure data request has scientific merit by evaluating whether:
  - Scientific purpose is clearly described
  - Data requested will be used to develop or contribute to generalizable knowledge to inform science, medicine and/or public health
  - Proposed research can be reasonably addressed using the requested data
  - Requestor team has the appropriate expertise to conduct the proposed research
  - Questions and outcomes are relevant to patients
- Approved requestors will enter into a Data Use Agreement (DUA) with a PCORI-designated repository. DUA specifies the terms and conditions of data use, as well as the responsibilities and obligations of data requestors

Data Requests: Independent Review Committee

- All data requests will be reviewed by an independent committee. Committee will be comprised of 5 individuals:
  - Representative from the PCORI-designated repository
  - Data scientist
  - Clinical researcher with expertise germane to the data request
  - PCORI staff member
  - Patient representative
- A member of the Awardee research team that generated the requested data will be invited to attend the review as a non-voting participant

Exemptions and Waivers

- The Policy allows for PCORI Awardees to seek a full or partial exemption from the Policy requirements due to the type of data included in the research project, or if informed consent sufficiently broad to share data has not been obtained

- It is the responsibility of the Awardee to provide a written explanation to PCORI with supporting documentation to demonstrate why it would not be feasible to comply with part or all of the Policy

- PCORI will review such requests on a case-by-case basis

Next Steps: Policy Implementation

- PCORI plans to implement the specific requirements of this Policy in stages
- We will hold a Town Hall in early October 2018 for current Awardees and include information about the Policy in all Town Halls for applicants
- We will work directly with individual Awardees to facilitate compliance with the Policy
- We will make resources (e.g., FAQs) available on PCORI's website

Board Vote

Call for a Motion to:	• **Approve the Policy for Data Management and Data Sharing**
Call for the Motion to be Seconded:	• **Second the Motion** • **If further discussion, may propose an Amendment to the Motion or an Alternative Motion**
Roll Call Vote:	• **Vote to Approve the Final Motion** • **Ask for votes in favor, opposed, and abstentions**

PPRN
Limited Competition Engagement PFA

Debra Barksdale, PhD, RN

Chair, Engagement, Dissemination, and Implementation Committee

Freda Lewis-Hall, MD

Chair, Research Transformation Committee

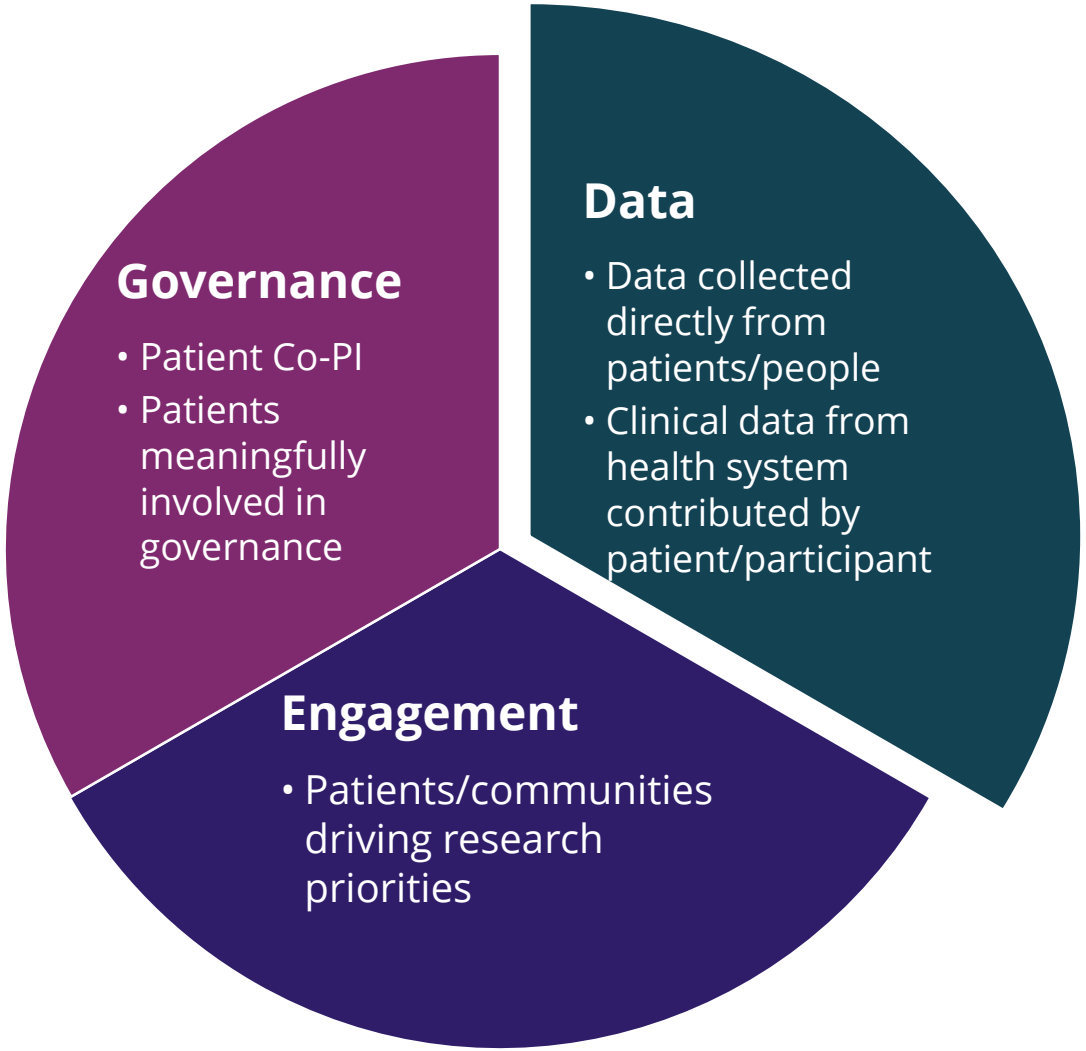
Joe Selby, MD, MPH

Executive Director

PCORnet® embodies a "network of networks" that harnesses the power of partnerships

20 Patient-Powered Research Networks (**PPRNs**) + 13 Clinical Data Research Networks (**CDRNs**) + 2 Health Plan Research Networks (**HPRNs**) + 1 Coordinating Center = A national infrastructure for patient-centered clinical research

PPRN Vision


Governance
• Patient Co-PI
• Patients meaningfully involved in governance
Data
• Data collected directly from patients/people
• Clinical data from health system contributed by patient/participant
Engagement
• Patients/communities driving research priorities

20 PPRNs

ABOUT Patient Powered Research Network (ABOUT Network)
University of South Florida

ARthritis patient Partnership with comparative Effectiveness Researchers (AR-PoWER PPRN)
Global Healthy Living Foundation

Collaborative Patient-Centered Rare Epilepsy Network (REN)
Epilepsy Foundation

Community and Patient-Partnered Research Network
University of California Los Angeles

Community-Engaged Network for All (CENA)
Genetic Alliance, Inc.

COPD Patient Powered Research Network
COPD Foundation

DuchenneConnect Registry Network
Parent Project Muscular Dystrophy

Health eHeart Alliance
University of California, San Francisco (UCSF)

IBD Partners Patient Powered Research Network
Crohn's and Colitis Foundation

ImproveCareNow: A Learning Health System for Children with Crohn's Disease and Ulcerative Colitis
Cincinnati Children's Hospital Medical Center

Interactive Autism Network
Kennedy Krieger Institute

Mood Patient-Powered Research Network
Massachusetts General Hospital

Multiple Sclerosis Patient-Powered Research Network
Accelerated Cure Project for Multiple Sclerosis

National Alzheimer's and Dementia Patient and Caregiver-Powered Research Network
Mayo Clinic

NephCure Kidney International
Arbor Research Collaborative for Health

Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Consortium
Duke University

Phelan-McDermid Syndrome Data Network
Phelan-McDermid Syndrome Foundation

PI Patient Research Connection: PI-CONNECT
Immune Deficiency Foundation

Population Research in Identity and Disparities for Equality Patient-Powered Research Network (PRIDEnet)
University of California San Francisco

Vasculitis Patient Powered Research Network
University of Pennsylvania

Accomplishments of PPRNs

- Established participant governance
- 405,226 consented participants across all PPRNs
- 27 externally funded studies (non-PCORI)
- Participate in all 9 Collaborative Research Groups; lead 4
- 4 recently awarded Partnering to Conduct Research with PCORnet (PaCR) awards, bringing in $6M in co-funding
- Substantial collection of participant-generated data (e.g., Patient Reported Outcomes)
- Developing capabilities to extract EHR data, both participant-driven and in collaboration with CDRNs

PPRNs and PCORI

- PCORI recognizes the continuing strategic importance and value of the PPRNs as distinctive, relatively mature patient/participant- and caregiver-driven research organizations
- PCORI Research Infrastructure and Engagement staff have been working to consider options for continuing the PPRNs
- We see opportunity for PPRNs to engage with PCORI more broadly, as well as with PCORnet, and PCRF

Defining PPRN Opportunities

- There is an opportunity to:
  - Capitalize on accomplishments and developed expertise
  - Further develop strengths and areas of demonstrated value
  - Build on lessons from PCORnet Phases 1 and 2

- It is time to take a fresh, thoughtful approach to understanding the opportunities and potential
  - Critically important to engage the PPRNs in that dialogue
  - There is value in engaging outside assistance in gathering information and moderating discussion among the PPRNs
  - Continue to partner with PCRF

Approach

1. PPRNs have been offered the opportunity for modestly funded Phase 2 contract extensions
   - Will allow all PPRNs to engage in future-facing discussions with PCORI to develop a longer-term approach
   - Extends all contracts to March 31, 2019
   - Up to $84k total costs per award
   - 18 out of 20 PPRNs are participating thus far

2. Limited competition Engagement Award opportunity
   - Open to all Phase 2 PCORnet PPRNs, expected release late October 2018
     - Expect up to 10 awardees
   - FY2019 Research Infrastructure funds
   - 18-24 months beginning as early as April 2019
   - Up to $350k total costs per award

Goals for Engagement Awards Limited PFA

- Grow research portfolios of the successful PPRN applicants

- Better position PPRNs to engage both with PCORnet and PCRF
  - Strengthen research idea generation and prioritization
  - Strengthen dissemination capacity for study results
  - Form and participate in a PPRN learning network
  - Continue to explore opportunities for PPRN-CDRN collaborations
  - Monitor learnings from PPRN demonstration projects and PaCR awards

- Drive increased research participation within the patient/participant community

- Further develop their expertise in area of participant-driven research (e.g., patient-preference studies, patient reported outcome standardization, meaningful health outcomes)

Proposed PFA Processes

- Approved by both RTC and EDIC Strategy Committees
- PFA scope will be developed in collaboration between Research Infrastructure and Engagement staff, with substantial input from PPRNs
- Follow Board-approved Engagement Award review process:
  - Review process by internal staff
  - Slate approved by Chief Engagement and Dissemination Officer

Board Vote

Call for a Motion to:	• **Approve Development of PPRN Limited Competition Engagement Award PFA up to $4M**
Call for the Motion to be Seconded:	• **Second the Motion** • **If further discussion, may propose an Amendment to the Motion or an Alternative Motion**
Roll Call Vote:	• **Vote to Approve the Final Motion** • **Ask for votes in favor, opposed, and abstentions**

BREAK

We will return at 10:45 am ET

Join the conversation on Twitter via @PCORI

Strategic Plan Update 2018

Toward Greater Specificity in PCORI Funding Announcements and Research Portfolio

Joe Selby, MD, MPH

Executive Director

From February 2018 Board of Governors Meeting - Proposals for Updating PCORI's Strategic Plan

#1: Balance Our Efforts Across 3 Main Lines of Work (funding research, dissemination and implementation, influencing how research is done) – but keep focus squarely on Research

#2: Address issues related to assessing new high-cost treatments – new evidence products

#3: Expand our options for supporting CER for health decision making

#4: **Continue to work toward greater specificity in all PCORI solicitations and more focus in research portfolio**

#5: Greater Emphasis on Dissemination including Shared Decision Making

#6: Find ways to include and use PCORnet in organizational activities

#7: Re-visit our National Priorities and Research Agenda, with public engagement

Despite marked progress, we can do better in getting to specific stakeholder-driven research questions

- Even our targeted processes continue to follow more of an "investigator-driven" process, with relatively long proposal development and merit review components, rather than processes oriented to stakeholders – emphasizing fidelity to original questions and rapid initiation of research
- When an idea is identified and approved, it may then be written up as a Targeted PFA, or placed on a PCS priority list or mentioned as a special emphasis area in a Broad PFA – from the stakeholders' view, the research question then drops from view for a year or more during the solicitation and merit review processes
- There is a sense that what we get in response to solicitations sometimes fails to match up well with the stakeholder's original question and concern
- PCORI's aim is to have a robust list of targeted, specific research questions to be posted in the immediate post-reauthorization period

Working Proposal #4: Continue to work toward greater specificity in all PCORI solicitations and focus in portfolio

Potential Approaches to Getting More Specific <u>in our Topic Identification and Solicitation</u>:

1. Increase the specificity of our topic pipeline processes, in part through greater involvement of key stakeholders throughout the process
2. Sequence research: PCORI should fund some rapid-cycle studies and evidence-syntheses to help refine research questions and lead to more definitive CER
3. Consider focusing our targeted portfolio on a set of key research areas, while remaining open to new, emerging needs through our Broad and PCS funding mechanisms, and/or through designating additional areas of interest over time

Revitalizing Our Topic Pipeline – 3 Main Foci

A cross-PCORI working group has been examining each aspect of our pipeline:

Increase ***Sources*** for and ***Approaches*** to Topic Capture and Generation

Consider strengthening outreach, transparency, and responsiveness; more systematic landscaping; and

Developing a prioritized list of topical areas for targeted research

Increase and Speed-up the ***Channels/Pathways*** within the Pipeline for Development and Refinement of the Topics and Research Questions

Use a variety of evidence synthesis and rapid-cycle research to refine topics

Increase ***Options*** for Types of Research Funding Mechanisms to Best Answer Highly specific Questions

Consider developing study protocols, greatly reduced application requirements, and pre-vetting of capable research entities

Potential Activities to Support the Pipeline Process

- Ensure that the level of development and refinement of the topic or research question is appropriate and directed to the right kind of research to answer it

Topic Refinement Activities:

- Horizon Scans
- Rapid-cycle Studies
- Topic Briefs
- Evidence Updates
- Evidence Maps
- Systematic Reviews and Meta-analyses
- IPD Meta Analyses

Primary Research:

- Special Emphasis in Broad Research
- PCS Priority Topic
- Single Targeted Study
- Multiple Targeted Studies
- Vanguard Studies
- Landmark Trial

Potential Advantages of Specifying an Initial Set of High-Priority Areas

- Priorities would be based in part on patient and stakeholder voices from PCORI's first 9 years
- Priorities could build in part on the accumulated expertise within PCORI staff
- With a narrower number of priority topics, PCORI could cultivate deeper, more continuous relationships with key stakeholders and other funders in each area, leading to accumulating expertise and better CER questions
- Contributions to practice change and improved outcomes could be more reliable because of improved specificity, buy-in and dissemination/implementation
- New areas would be prioritized over time through stakeholder engagement and the Broad/PCS mechanisms; older areas could also be retired if critical evidence gaps are being filled

Selecting Initial Set of Priority Research Areas: Potential Criteria

Possible Criteria for an Initial Set of 10 to 15

- PCORI currently has a concentration of studies and portfolio development work in this area
- Strength of stakeholder and Board interest and enthusiasm
- Agreement between stakeholders on research question
- Burden – societal cost, individual suffering
- Compelling opportunity to make a difference through extension of portfolio
- Unlikely to be studied by others
- "Right" for PCORI: e.g., critical comparisons; patient-centered questions, treatment heterogeneity questions
- Provides collaboration opportunities
- Leverages PCORnet

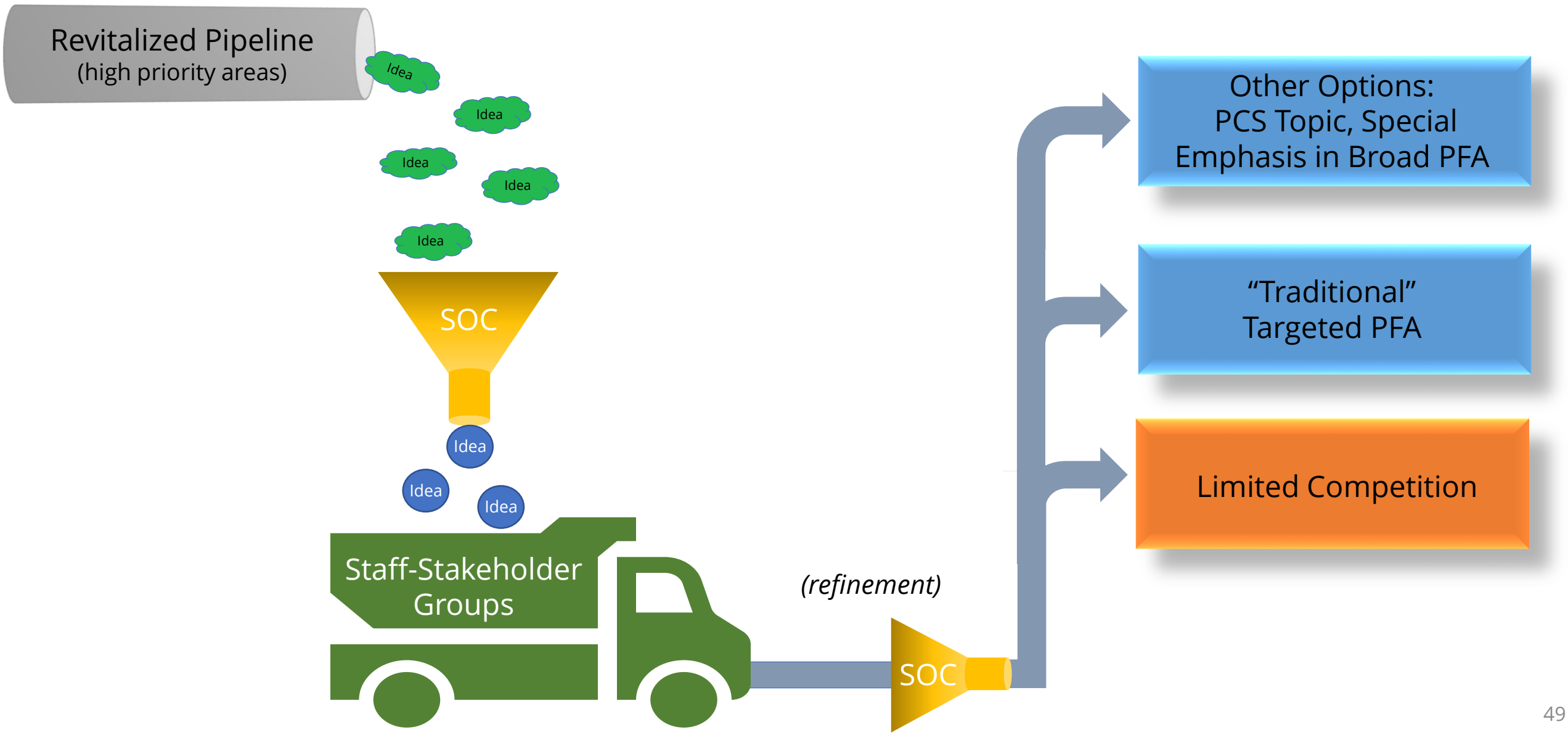
Some Examples of Topics That Would Meet Most of These Criteria

- Alzheimer's, dementia, cognitive impairment
- Autoimmune disorders (arthritis, IBD, MS, psoriasis)
- Asthma
- Cancer (selected types: Breast, lung, prostate, etc.)
- Cardiovascular disease (selected types: AFib, CHF, etc.)
- Care coordination; transitional care
- Diabetes
- Mental Health (selected types: depression, PTSD, bipolar, etc.)
- Multiple chronic conditions
- Rare diseases
- Obesity
- Pain and opioids
- Palliative care
- Shared decision-making
- Telehealth
- Additional areas to be added via stakeholder engagement and from Broad and PCS applications

Potential Advantages of Pre-vetting a set of Research Teams to Compete for selected High-Specificity Topics

- Helps to ensure that applicant teams have patient, clinician, system engagement in place, proven capacity for recruitment and follow-up, potential capacity to handle coverage of all comparators, and understanding of needs to work with stakeholder teams throughout the study
- Shortens the subsequent intervals from posting to application due date because applicants would not have to arrange engagement, systems, during application preparation; applications would be shorter, not needing to prove patient-centeredness or clinical relevance of question or describe engagement
- Shortens review time requirements because there would typically be fewer, shorter applications to review
- Could have a major influence on research community by pushing researchers toward preparing engaged teams for large-scale, patient-centered, pragmatic research

Possible Revised Pipeline for Targeted Topics



Bringing the Two Ideas Together – What If:

- Our Topic Pipeline could generate more specific research questions because we focused on a finite number of areas of interest for targeted research (e.g., 10-15), spend more time with stakeholders, made greater use of rapid-cycle research, evidence synthesis and pilots to refine questions
- We pre-vetted research teams that have demonstrated expertise in large pragmatic trials and/or large observational studies, and groups could apply to be vetted at any time
- When appropriate, the PFA for these highly-specific questions would be a limited competition among pre-vetted groups
- Because the questions have been so highly developed and the groups pre-vetted, we could spend somewhat less time in the application and review period

Comments or Suggestions?

Next Steps:

- If Board agrees, these plans could be further discussed with all 3 Strategy Committees
- Continued exploration and refinement of ideas by working groups that include staff, Board and Methodology Committee members
- Discussion of next iteration with Board as a whole by December 2018

Evolving Research Synthesis Methods: Evidence Maps

Jennifer Croswell, MD, MPH

Senior Program Officer

Evidence Maps

- Definition:

  A depiction of the results of a systematic search of a broad question that can facilitate

  1. **Evidence-informed decision making or**
  2. **Identification of key research gaps for future focus**

  by making evidence available and presenting results in an accessible, user-friendly format, often a visual figure or graph

- PCORI is also using the approach to illustrate how our current investments fit into the overall body of evidence

Early Evidence Map Illustrating Gaps in Evidence

TABLE F-1 Evidence Map for Cancer/Neoplasms

Indicator	Mechanistic Data	Animal Data	Observational Studies	Randomized Trials: Primary Outcome	Randomized Trials: Secondary or Non–Pre-specified Outcomes[a]
Calcium					
All cancers	✓	✓	✓	✓[b]	✓[b]
Breast cancer	—	—	✓	—	—
Colorectal cancer	✓	✓	✓	✓[b]	✓[b]
Colorectal adenoma	✓	✓	✓	✓	—
Prostate cancer	—	✓	✓	—	—
Vitamin D					
All cancers	✓	✓	✓	—	✓[b]
Breast cancer	—	—	✓	—	✓[b]
Colorectal cancer	✓	✓	✓	—	✓[b]
Colorectal adenoma	✓	✓	✓	—	✓[b]
Prostate cancer	—	—	✓	—	—

NOTE: ✓ = evidence is published; — = no available evidence.

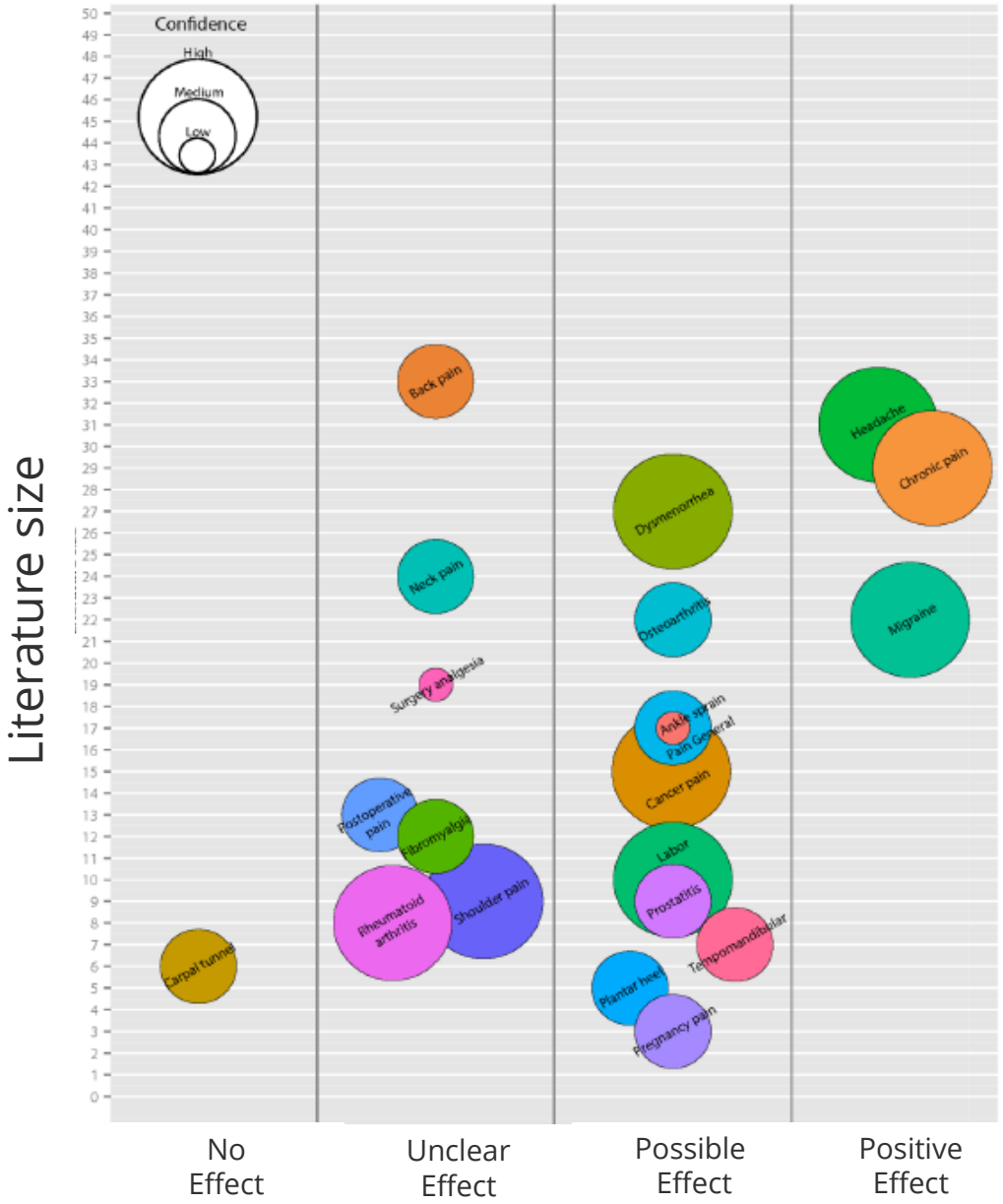
[a]Secondary outcomes often were not pre-specified by the investigators.

[b]Limited data.

IOM. 2011. Dietary Reference Intakes for Calcium and Vitamin D. Washington, DC: The National Academies Press.

Evidence Map Facilitating Informed Decision-Making

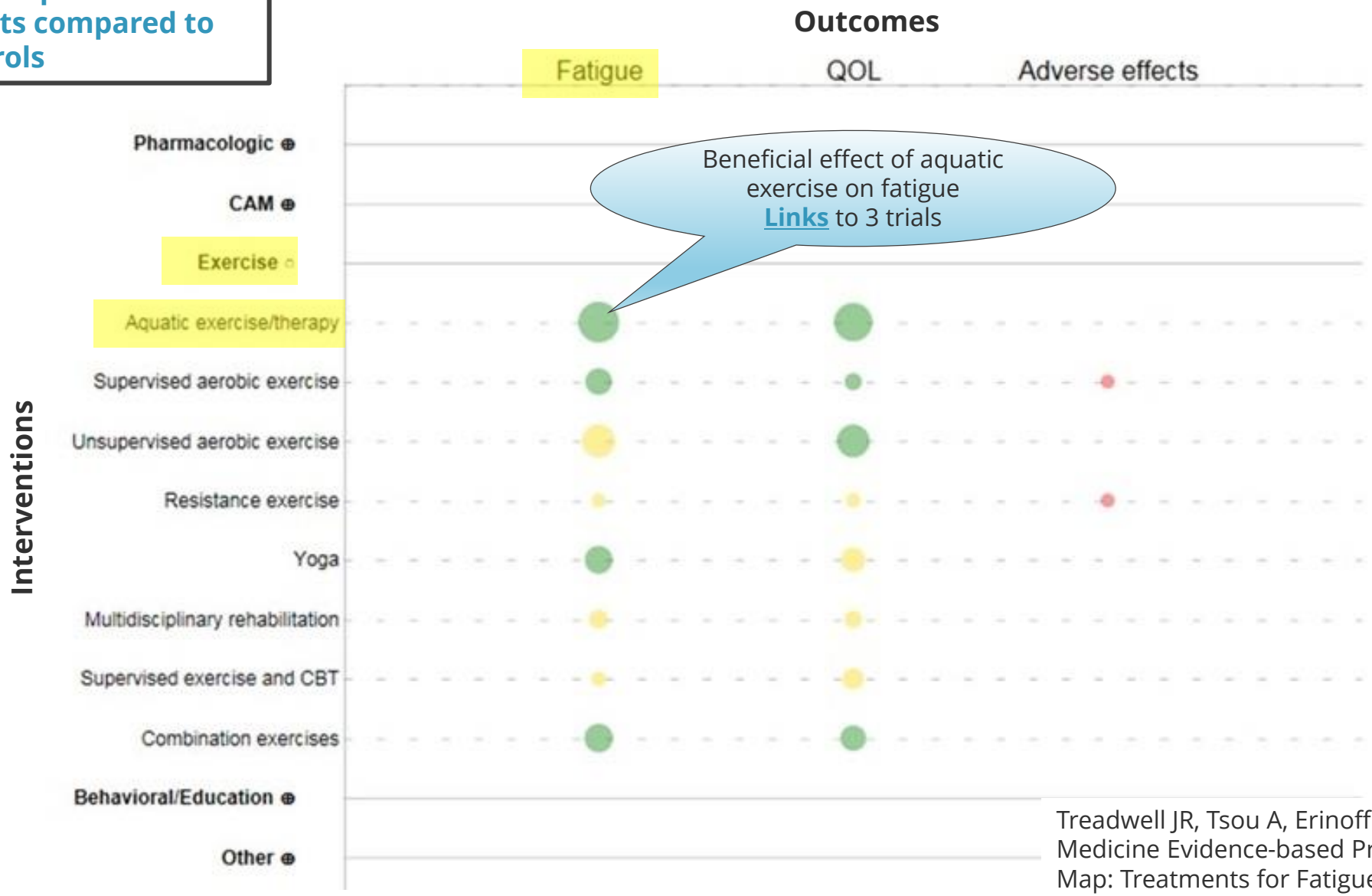
- Evidence map of acupuncture for pain conditions
- Estimates the evidence base using systematic reviews as unit of analysis
- Plot shows:
  - Estimated size of the literature (y-axis, number of RCTs included in largest systematic review)
  - Effect (x-axis)
  - Confidence in the estimate (bubble size)



Hempel, et al. Evidence map of acupuncture. VA-ESP Project #05-226; 2013.

PCORI's First Evidence Maps: Informed Decision-Making for Fatigue Interventions in Multiple Sclerosis

This map shows results compared to controls



- Effective intervention
- Insufficient evidence
- Adverse events

No bubble – No studies found

Treadwell JR, Tsou A, Erinoff E, Schoelles K. (ECRI Institute-Penn Medicine Evidence-based Practice Center.) Draft PCORI Evidence Map: Treatments for Fatigue in Multiple Sclerosis. Feb 2018.

PCORI's First Evidence Maps: Impact of mHealth for Self-Management Of Chronic Disease on Patient-Centered Outcomes

Prepared by the ECRI Institute-Penn Medicine Evidence-based Practice Center:

J Reston, J Kaczmarek, E Erinoff, K Schoelles

Objectives

- Identify evidence gaps:
  - Describe the evidence landscape of mHealth interventions (e.g., text messages, mobile applications, wearable devices) for self-management of chronic disease
  - Highlight the potential for PCORI's funded research to address identified evidence gaps
- Assist evidence-informed decision-making:
  - Document where the evidence supports (or doesn't) the use of mHealth technologies to enhance patient self-management of chronic diseases

Demo of mHealth Maps

Summary

- Evidence maps synthesize large amounts of information in an accessible visual format
- They can be conducted in less time than the traditional systematic evidence review, while using many of the same processes
- They facilitate informed decision-making
- They allow for identification of key research gaps
- PCORI has been advancing the method by moving into interactive, online formats with manipulatable variables

Questions and Comments

BREAK

We will return at 1:15 pm ET

Join the conversation on Twitter via @PCORI

Panel Discussion
Outgoing Board Members 2010-2018

Debra Barksdale

Chair of the Engagement, Dissemination, and Implementation Committee

Kerry Barnett

Board Vice Chairperson
Chair of the Finance and Administration Committee and the Governance Committee

Allen Douma

Vice Chair of the Research Transformation Committee

Leah Hole-Marshall

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Harlan Krumholz

Member of the Program Development Committee and the Research Transformation Committee

Richard Kuntz

Founding Chair of the Program Development Committee

Public Comment Period

Kristin Carman, MA, PhD

Director, Public and Patient Engagement

Wrap Up and Adjournment


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