

Advisory Panel on Patient Engagement

Fall 2018 Meeting

October 30, 2018
9:30 – 11:30 am

Agenda

Time	Agenda Item	Discussion Lead(s)
9:30	Welcome	Kristin Carman, Dave White, and Tom Scheid
9:45	Panelist Introductions	Dave White and Tom Scheid
10:20	Public Policy Update	Andrew Hu
10:40	Contributions of Patient Engagement in PCORI-Funded Comparative Effectiveness Research	Laura Forsythe and Denese Neu
11:15	Looking Ahead- What's Next?	Kristin Carman, Dave White, and Tom Scheid
11:30	Adjourn	

Housekeeping

- Reminder: members of the public are invited to listen in on Advisory Panel meetings
- Please use the mic when speaking
- Please state your name before speaking

Welcome

Kristin Carman

Director, Public and Patient Engagement

Dave White

Chair, Advisory Panel on Patient Engagement

Tom Scheid

Co-chair, Advisory Panel on Patient Engagement

Panelist Introductions

Dave White

Chair, Advisory Panel on Patient Engagement

Tom Scheid

Co-chair, Advisory Panel on Patient Engagement

Dave White

Chair

- **Hillcrest Heights, MD**
- Health Care Consultant
- Representing: Patients, Caregivers, and Patient Advocates



Tom Scheid, MA

Co-chair

- **Columbus, OH**
- Retired
- Representing: Patients, Caregivers, and Patient Advocates



Jennifer Canvasser, MSW

- **Davis, CA**
- Founder and Director, NEC Society
- Representing: Patients, Caregivers, and Patient Advocates



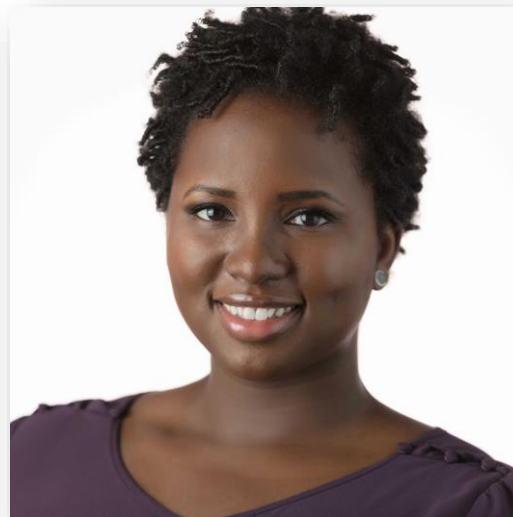
Katherine Capperella

- **Raritan, NJ**
- Global Patient Engagement Leader, Janssen Pharmaceutical, Johnson & Johnson
- Representing: Industry



Anita Roach, MS

- **Arlington, VA**
- Director, Sleep Population Health Research, National Sleep Foundation
- Representing: Patients, Caregivers, and Patient Advocates



Jill Harrison, MS, PhD

- **Derby, CT**
- Director of Research, Planetree International
- Representing: Patients, Caregivers, and Patient Advocates



Norah Schwartz, MPA, PhD

- **San Diego, CA**
- Professor and Researcher, El Colegio de la Frontera Norte
- Representing: Researchers



Matthew Hudson, MPH, PhD

- **Greenville, SC**
- Director of Comparative Effectiveness Research and Cancer Care Delivery Research, Greenville Health System
- Representing: Patients, Caregivers, and Patient Advocates



Freddie White-Johnson, MPPA

- **Greenwood, MS**
- Program Director, Mississippi Network for Cancer Control and Prevention, University of Southern Mississippi
- Representing: Patients, Caregivers, and Patient Advocates



- **Washington, DC**
- Executive Vice President, Patient Advocacy, Patient Advocate Foundation
- Representing: Patients, Caregivers, and Patient Advocates



Sonya Ballentine

- **Chicago, IL**
- Project Manager, Illinois Institute of Technology College of Psychology
- Representing: Patients, Caregivers, and Patient Advocates



Marilyn Geller, MSPH

- **Woodland Hills, CA**
- Chief Executive Officer, Celiac Disease Foundation
- Representing: Patients, Caregivers, and Patient Advocates



Sarah Donelson, MA

- **San Francisco, CA**
- Director, Regulatory Outcomes and Patient Engagement, BioMarin Pharmaceutical, Inc.
- Representing: Industry



Sandy Sufian, MA, MPH, PhD

- **Chicago, IL**
- Associate Professor, Health Humanities and History, Disability Studies, University of Illinois at Chicago, College of Medicine
- Representing: Patients, Caregivers, and Patient Advocates



Beverly Rogers

- **Country Club Hills, IL**
- CEO and Founder, Bev J Rogers Enterprises, LLC
- Representing: Patients, Caregivers, and Patient Advocates



Maureen Fagan, MHA, DNP

- **Miami, FL**
- Chief Experience Officer, University of Miami Health System
- Representing: Clinicians



Brendaly Rodriguez, MA

- **Miami, FL**
- Manager, University of Miami, and FL Community Health Worker Coalition
- Representing: Patients, Caregivers, and Patient Advocates



Umair A. Shah, MD, MPH

- **Houston, TX**
- Executive Director, Harris County Public Health
- Representing: Policy Makers



James Harrison, MPH, PhD

- **San Francisco, CA**
- Assistant Professor, University of California San Francisco
- Representing: Researchers



Emily Creek, MBA

- **Atlanta, GA**
- Senior Director, Help & Support, Arthritis Foundation
- Representing: Patients, Caregivers, and Patient Advocates



Megan Lewis, PhD

- **Research Triangle Park, NC**
- Program Director, RTI International
- Representing: Researchers



Ting Pun, PhD

- **Portola Valley, CA**
- Retired
- Representing: Patients, Caregivers, and Patient Advocates



Jack Westfall, MD, MPH

- **San Jose, CA**
- Medical Director Whole Person Care, Santa Clara Valley Medical Center
- Representing: Clinicians



Public Policy Update

Andrew Hu

Director, Public Policy and Government Relations

Contributions of Patient Engagement In Research

Early Findings From The Patient-Centered
Outcomes Research Institute

Laura Forsythe

Director, Evaluation and Analysis

Denese Neu

Engagement Officer, Public and Patient Engagement

Project contributors

Advisory Panel on Patient Engagement

- Emily Creek
- John Chernesky
- Libby Hoy
- Anjum Khurshid
- Jane Perlmutter
- Phil Posner
- Ting Pun
- Beverly Rogers

PCORI Staff Members

- Chinenye Anyanwu
- Geeta Bhat
- Robin Bloodworth
- Kristin Carman
- Laurie Davidson
- Lauren Fayish
- Courtney Hall
- Maggie Holly
- David Hickam
- Denese Neu
- Michele Orza
- Jean Slutsky
- Lisa Stewart
- Victoria Szydlowski

PCORI Board of Governors

- Robert Zwolak

PCORI Methodology Committee

- Naomi Aronson

Agenda

- Summarize the key points
- Share our methods and findings
- Hear your reactions and interpretation
- Discuss the implications

The Key Points

- PCORI teams describe contributions of engagement to all aspects of projects
- Significance of engagement contributions are in 4 key areas: acceptability, feasibility, rigor, and relevance
- Impact of engagement was achieved through both traditional and more collaborative approaches to engaging with patients and other stakeholders

Analyzing articles on PCORI-Funded CER, we sought to answer:

- What are the contributions of engagement to PCORI-funded CER?
- What engagement approaches did PCORI teams use to achieve these contributions?



Why this study?

- Many PCORI studies now have peer-reviewed articles detailing CER findings and the role of stakeholder engagement
- PCORI's funding, requirements, and evolving guidance provide a shared context for studying the contributions of engagement on a large scale
- Add to the evidence about the contributions of engagement and the significance of those contributions

How did we do this study?

- Guided by PCORI's Advisory Panel on Patient Engagement
- Identified and extracted articles based on guidance for consistency and quality
- Thematic analysis of extracted text
- Included 127 articles that **explicitly** describe contributions of engagement to PCORI-funded **CER**



Contributions of Engagement

Research
Focus

Research
Design

Interventions:
Tailoring/
Delivery

Recruitment &
Retention

Data
Collection &
Measures

Data Analysis

Dissemination

PCORI teams describe engagement contributions
to **all aspects** of CER projects

Contributions of Engagement

Research Focus

Research Design

Interventions: Tailoring/ Delivery

Recruitment & Retention

Data Collection & Measures

Data Analysis

Dissemination

- Identification of topic or project
- Formulation or expansion of research aims or questions
- Choice of comparator(s)
- Determination of research outcomes (primary and secondary)

Contributions of Engagement

Research Focus

Research Design

Interventions: Tailoring/ Delivery

Recruitment & Retention

Data Collection & Measures

Data Analysis

Dissemination

- Identification of topic or project
- Formulation or expansion of research aims or questions
- Choice of comparator(s)
- Determination of research outcomes (primary and secondary)

“We knew regaining functional status was an important component of recovery, but we did not realize how much depression, anxiety, and fatigue weighed on many stroke survivors’ minds. So we revisited our aims, overhauled our data collection plan, and ensured that our goals were not only informed by patients but also aligned with the issues that patients cared about the most.” ¹

Contributions of Engagement

**Research
Focus**

**Research
Design**

**Interventions:
Tailoring/
Delivery**

**Recruitment &
Retention**

**Data
Collection &
Measures**

Data Analysis

Dissemination

- Practical guidance on how to carry out the research
- Choice of design (e.g. delayed start, mixed methods)
- Study participant allocation and randomization designs
- Broader inclusion and less restrictive exclusion criteria

Contributions of Engagement

**Research
Focus**

**Research
Design**

**Interventions:
Tailoring/
Delivery**

**Recruitment &
Retention**

**Data
Collection &
Measures**

Data Analysis

Dissemination

- Practical guidance on how to carry out the research
- Choice of design (e.g. delayed start, mixed methods)
- Study participant allocation and randomization designs
- Broader inclusion and less restrictive exclusion criteria

“This allowed us to reach a real-world sample of children with critical health needs, rather than be constrained by requiring a confirmed clinical diagnosis that many families may not have been able to afford or may not have wanted to pursue.” ²

Significance of Engagement Contributions

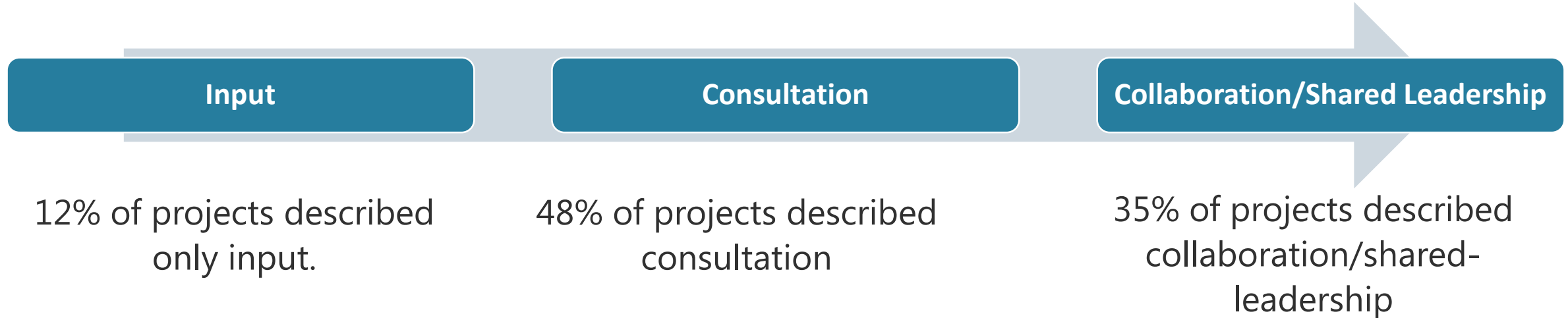
- Acceptability
- Feasibility
- Rigor
- Relevance



All Types of Contributions can Have an Impact

	Example
Some contributions influence the entire course of the research	Partner input drives primary outcomes and comparators
More narrowly focused contributions can substantially impact research	Changing an enrollment script increased enrollment by 30 percent ³
Not all stakeholder recommendations can be implemented	Study duration (3 years) too short to measure stakeholder preferred outcome 'maintaining independence' ⁴
Some recommendations introduce trade-offs	Using an unvalidated measure to assess outcome prioritized by stakeholders ⁵

Engagement Approaches on a Continuum



Putting this study in context

Limitations

- Analysis represents these authors' perceptions of engagement
- Variable levels of detail
- Likely under reporting projects with truly integrated partners
- Based on PCORI's earliest studies

Strengths

- Near real-time look at real-world experiences in likely the largest US sample
- Experiences authors' compelled to write about despite article word limits
- Focus on PCORI articles increases confidence that we found and all relevant published information on engagement

Impact of engaging stakeholders

- PCORI funding is driving change in research
- Engagement
 - can influence research value, relevance, and utility
 - cannot address all challenges facing the conduct of CER, but it can improve core aspects
 - has value far beyond input and validation of existing research ideas
- Engagement can help balance the inherent tradeoffs affecting research conduct while also responding to end-user needs

Implications for practice and research

- Increased emphasis and resources devoted to engagement will likely accelerate adoption and value of engagement
- Potential to catalyze a stronger shift to the culture of engagement and generate more useful findings
- Prioritizing inclusion of information on engagement in peer review articles is critical
- Investment in additional research and translation of findings into guidance is needed

Next steps

- More rigorous understanding of:
 - how engagement influences research conduct as well as influence on uptake and use in decision-making
 - what are the critical elements of optimal (and sub-optimal) engagement practices and circumstances
 - what are the key characteristics of engaged partners beyond the type of stakeholder group they represent
- Developing of an expanded and robust return on investment on engagement

Where are we heading?

- Make engagement easier, routine and efficient with evidence-based guidance
- Make the benefits of engagement clear and aligned with stakeholder and PI needs
- Explore the use of alternative approaches that draw on broader reach for input

References

1. O'Brien EC, Xian Y, Fonarow GC, Olson DM, Schwamm LH, Hernandez AF. Clinical commentary on "certain uncertainty: life after stroke from the patient's perspective". *Circ Cardiovasc Qual Outcomes*. 2014;7(6):970.
2. Ratto AB, Anthony BJ, Pugliese C, Mendez R, Safer-Lichtenstein J, Dudley KM, et al. Lessons learned: engaging culturally diverse families in neurodevelopmental disorders intervention research. *Autism*. 2017;21(5):622-34.
3. Brach JS, Perera S, Gilmore S, VanSwearingen JM, Brodine D, Wert D, et al. Stakeholder involvement in the design of a patient-centered comparative effectiveness trial of the "On the Move" group exercise program in community-dwelling older adults. *Contemp Clin Trials*. 2016;50:135-42.
4. Minneci PC, Nacion KM, Lodwick DL, Cooper JN, Deans KJ. Improving surgical research by involving stakeholders. *JAMA Surg*. 2016;151(6):579-80.
5. Lindquist LA, Ramirez-Zohfeld V, Sunkara PD, Forcucci C, Campbell DS, Mitzen P, et al. PlanYourLifespan.Org - an intervention to help seniors make choices for their fourth quarter of life: results from the randomized clinical trial. *Patient Educ Couns*. 2017;100(11).

Looking Ahead- What's Next?

Kristin Carman

Director, Public and Patient Engagement

Dave White

Chair, Advisory Panel on Patient Engagement

Tom Scheid

Co-chair, Advisory Panel on Patient Engagement

Thank you for coming!

