

# Advisory Panel On Patient Engagement

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*Fall Meeting*

September 17, 2019

8:30am-12:00pm

# Public Policy Update

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*Closed Session*

**Andrew Hu**  
Director of Public Policy and Government  
Relations



# Webinar Housekeeping



- Webinar is available to the public and is being recorded
- Members of the public are invited to listen to this teleconference and view the webinar
- Anyone may submit a comment through the webinar chat function, although no public comment period is scheduled
- A meeting summary and materials will be made available on PCORI's website following the meeting
- Visit [www.pcori.org/events](http://www.pcori.org/events) for more information on future activities

# Welcome

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**Kristin Carman**

Director, Public and Patient Engagement

**Tom Scheid**

Chair, Advisory Panel on Patient Engagement

**Gwen Darien**

Co-chair, Advisory Panel on Patient Engagement



# Agenda



## Today's Meeting:

- 8:45 – 9:30 Introductions
- 9:30 – 10:15 Patient/Participant-Driven Research Community Learning Network
- 10:15-11:45 Optimizing Stakeholder Engagement through the Lens of Diversity, Equity, and Inclusion
- 11:45 – 12n Reflections, Closing Remarks

## Immediately Following (Optional):

- 12n – 1:00 Lunch
- 1:00 – 5:45 Ambassador Pre-conference Event\* (Location: Salon 3)
- 6:00 – 8:00 Ambassador Reception (Location: Roosevelt 1 Foyer)
- 7:30 PEAP dinner (Location: Lebanese Taverna)

\* PEAP Participation

# 2019 PCORI Annual Meeting: Engagement Sessions



- **Thursday, September 19<sup>th</sup>**
  - **Breakfast and Poster Session**
    - 8:00am – 9:00am
  - **Improving Care and Outcomes for People with Anxiety Disorders**
    - Breakout Session (9:00am – 10:30am)
  - **Patient Perspective: Learnings and Strategies for Partnership in Research\***
    - Breakout Session (9:00am – 10:30am)
  - **How Engagement is Making Research More Useful**
    - Plenary Session (1:00pm – 2:30pm)
  - **The Potentials and Challenges for Telehealth to Improve Access to Care**
    - Breakout Session (3:00pm – 4:30pm)
  - **Reception and Poster Session**
    - 4:30pm – 6:30pm

\* PEAP Participation

# 2019 PCORI Annual Meeting: Engagement Sessions



- **Friday, September 20<sup>th</sup>**
  - **Breakfast/Poster Session**
    - 7:30am – 8:30am
  - **PCORnet in Action**
    - Breakout Session (10:00am – 11:30am)
  - **Reducing the Burden of Chronic Conditions on Patients, Families, and the Healthcare System**
    - Breakout Session (10:00am – 11:30am)

# Introductions

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Advisory Panelists



# PEAP Advisory Panel Members



- **Tom Scheid - Chair**  
*Patient Advocate*
- **Gwen Darien - Co-Chair**  
*National Patient Advocate Foundation*
- **Jennifer Canvasser**  
*Necrotizing Enterocolitis Society*
- **Katherine Capperella\***  
*Johnson & Johnson*
- **Anita Roach**  
*National Sleep Foundation*
- **Jill Harrison**  
*Brown University*
- **Matthew Hudson**  
*Prisma Health – Upstate*
- **Freddie White-Johnson**  
*University of Southern Mississippi*
- **Sonya Ballentine**  
*Illinois Institute of Technology College of Psychology*
- **Marilyn Geller**  
*Celiac Disease Foundation*
- **Sarah Donelson**  
*BioMarin Pharmaceuticals*
- **Sandy Sufian**  
*University of Illinois at Chicago, College of Medicine*

# PEAP Advisory Panel Members



- **Beverly Rogers**  
Bev J Rogers Enterprises, LLC
- **Maureen Fagan**  
*University of Miami Health System*
- **Brendaly Rodriguez**  
*University of Miami, and FL Community Health Worker Coalition*
- **Umair A. Shah**  
*Harris County Public Health*
- **James Harrison**  
*University of California San Francisco*
- **Norah Schwartz**  
*El Colegio de la Frontera Norte*
- **Beth Careyva**  
*Lehigh Valley Hospital, Inc.*
- **Tracy Carney**  
*Community Care Behavioral Health, UPMC*
- **Crispin Goytia**  
*Icahn School of Medicine at Mount Sinai*
- **Simon Mathews**  
*Johns Hopkins Medicine*
- **Danny van Leeuwen**  
*Health Hats*
- **Neely Williams**  
*Community Partners' Network, Inc.*

# Patient/Participant-Driven Research Community Learning Network

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**Michelle Johnston-Fleece**

Senior Program Officer, Public & Patient Engagement

**Claudia Grossmann**

Senior Program Officer, Research Infrastructure



# PCORI Co-Leads



Claudia Grossmann  
Senior Program Officer  
Research Infrastructure

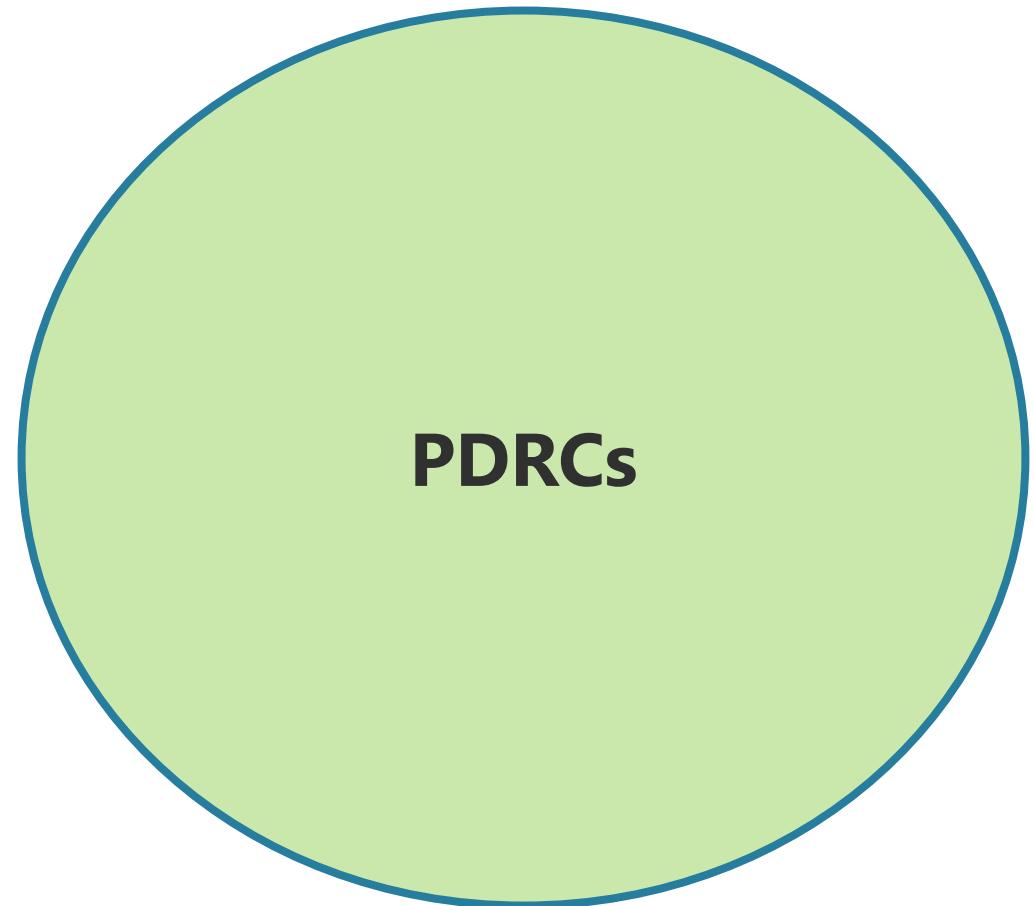


Michelle Johnston-Fleece  
Senior Program Officer  
Patient and Public Engagement

# Patient/Participant Driven Research Communities (PDRCs)



PDRC = groups whose primary focus is to enable research that is a priority to their community



# Research and Implementation Continuum



## Discovery

*Pre-clinical*

## Safety and Efficacy

*Pre-market*

## Effectiveness and CER

*Post-market*

*Outcomes*

## Dissemination

*Implementation*

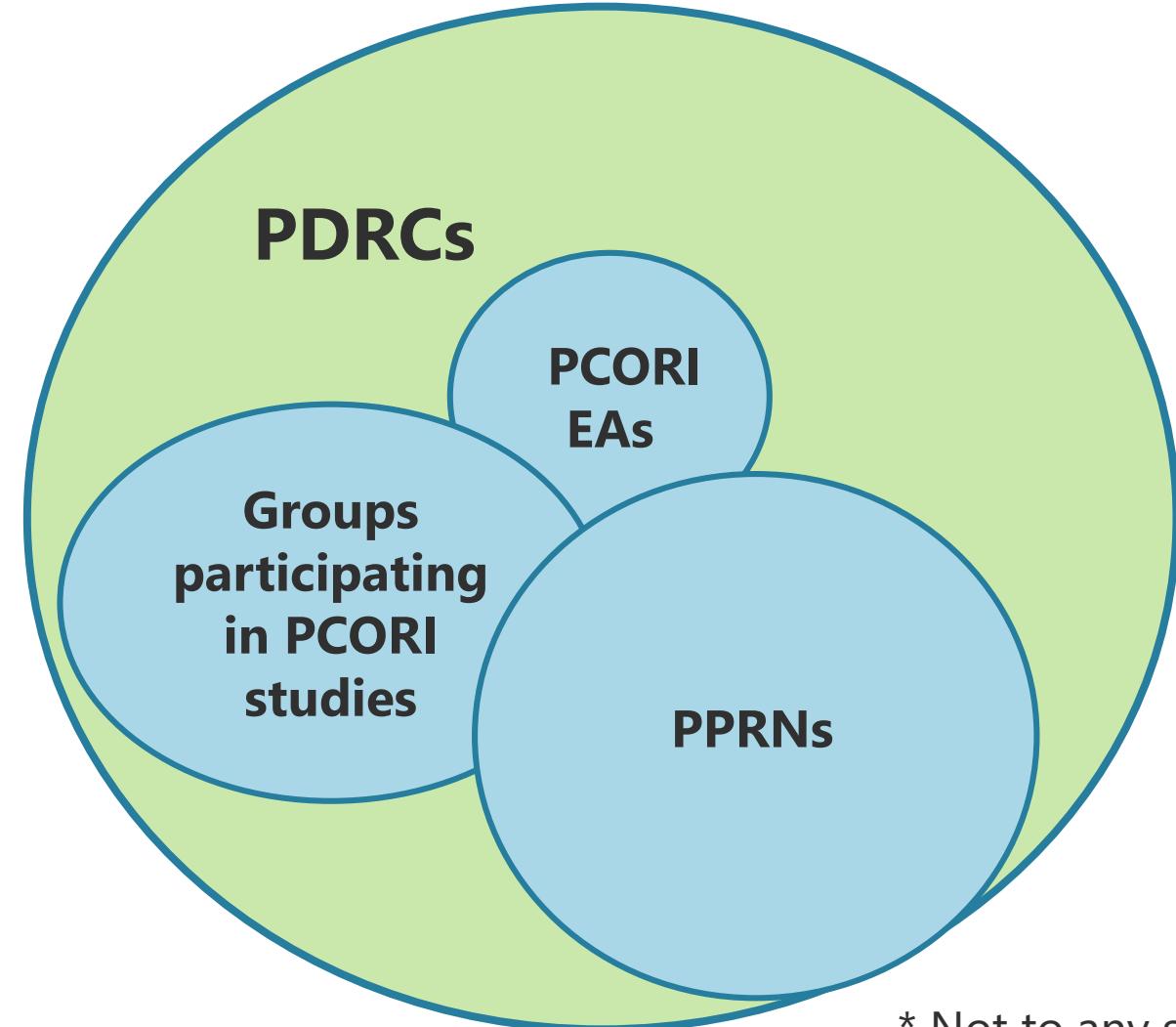
*Coverage/Payment/  
Reimbursement*

## Policy and Practice

# PDRCs and PCORI



- **PPRNs** = PDRCs led by patients/participants and organized around the evidence needs of their communities originally funded by PCORI as part of PCORnet
- **EAs** = Engagement Awards



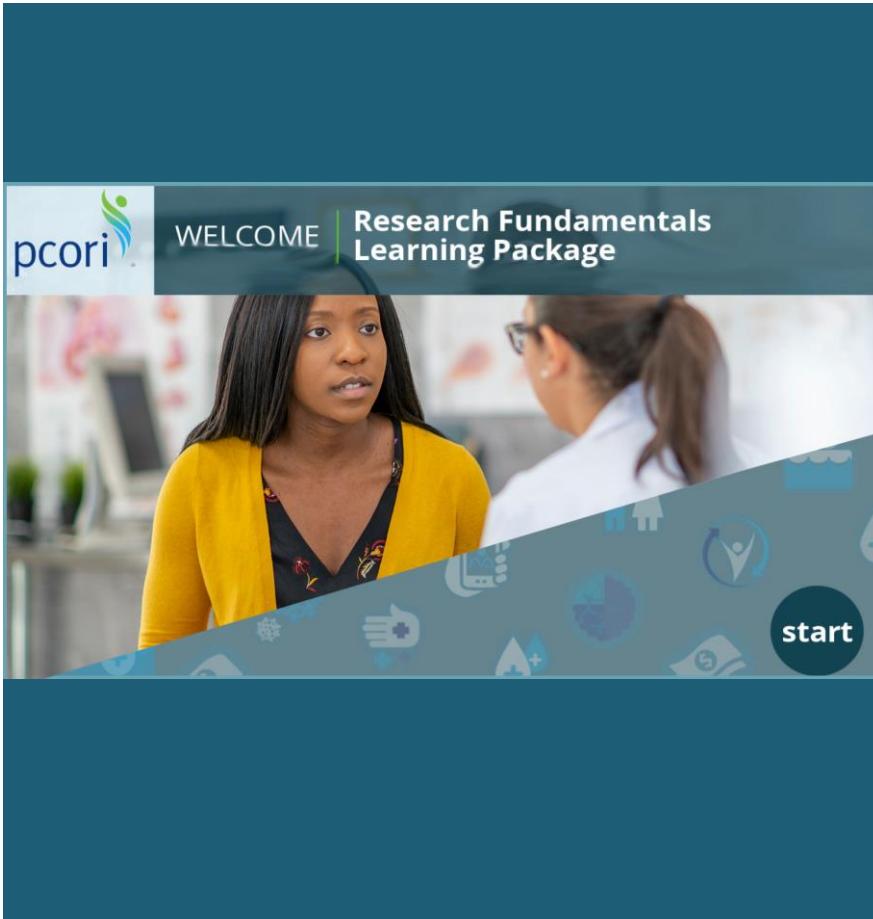
\* Not to any scale

# PDRCs and PCORI



- Lots of requests for opportunities to exchange lessons and learn from each other
- Done in a limited way among PPRNs in PCORnet and among Engagement Awardees
- PCORI has been thinking a lot about how to better support PDRCs, including access to tools and resources
  - [Engagement in Health Research Literature Explorer](#)
  - [Engagement Tool and Resource Repository](#) (this week!)
  - PCORI-produced tools and trainings
    - Research Fundamentals
    - Working as a Team

# Research Fundamentals Learning Package



For **stakeholder partners** who are new to research, this package uses plain language to **understand the language and logic of the research process**.

The ultimate goal of the package is to help all stakeholders, regardless of experience conducting research, to engage with confidence and contribute individual experiences to shape studies from start to finish.

# Intended Outcomes of Research Fundamentals Learning Package



Provide **foundational knowledge in PCOR/CER to non-scientist participants** on research and other projects, and to patient and other stakeholder merit reviewers, peer reviewers, and PCORI Ambassadors.

- Help patients and public stakeholders understand PCOR, CER, basic research principles, and other content areas relevant to the conduct of stakeholder engaged research
- Help patients and public stakeholders be involved in PCOR

**Piloting expected late 2019; Full release expected early 2020**

# Research Fundamentals Learning Package



## Research Fundamentals Learning Package

### Learning Need Navigation Tool

Interactive PDF: The  
PCORI Approach to  
PCOR/CER

Screencast: Engaging  
in Stakeholder-Driven  
Research

MODULE 1:  
Developing  
Research  
Questions

MODULE 2:  
Designing  
the Research  
Study

MODULE 3:  
Planning  
Consent &  
Study  
Protocols

MODULE 4:  
Recruiting &  
Retaining  
Study  
Participants

MODULE 5:  
Analyzing &  
Disseminating  
Findings

# Working as a Team Learning Package



## Coming Spring 2020!

For **new and experienced researchers and stakeholder partners**, this package offers **practical guidance on how to work successfully as a unified team** where everyone is engaged and contributes confidently throughout the research process. From conducting meetings to resolving conflict, the package helps team members in any role to work collaboratively during a study.

# Working as a Team Learning Package



**Multi-media website**  
that offers resources in  
an array of modalities

- Text content
- Illustrations
- Podcast-style audio
- Videos
- Animations
- Online interactive practice activities
- Downloadable tools (checklists, tip sheets, best practice summaries, and activity guides)

# PPRN Limited Competition Engagement Awards (PPRN EAs)

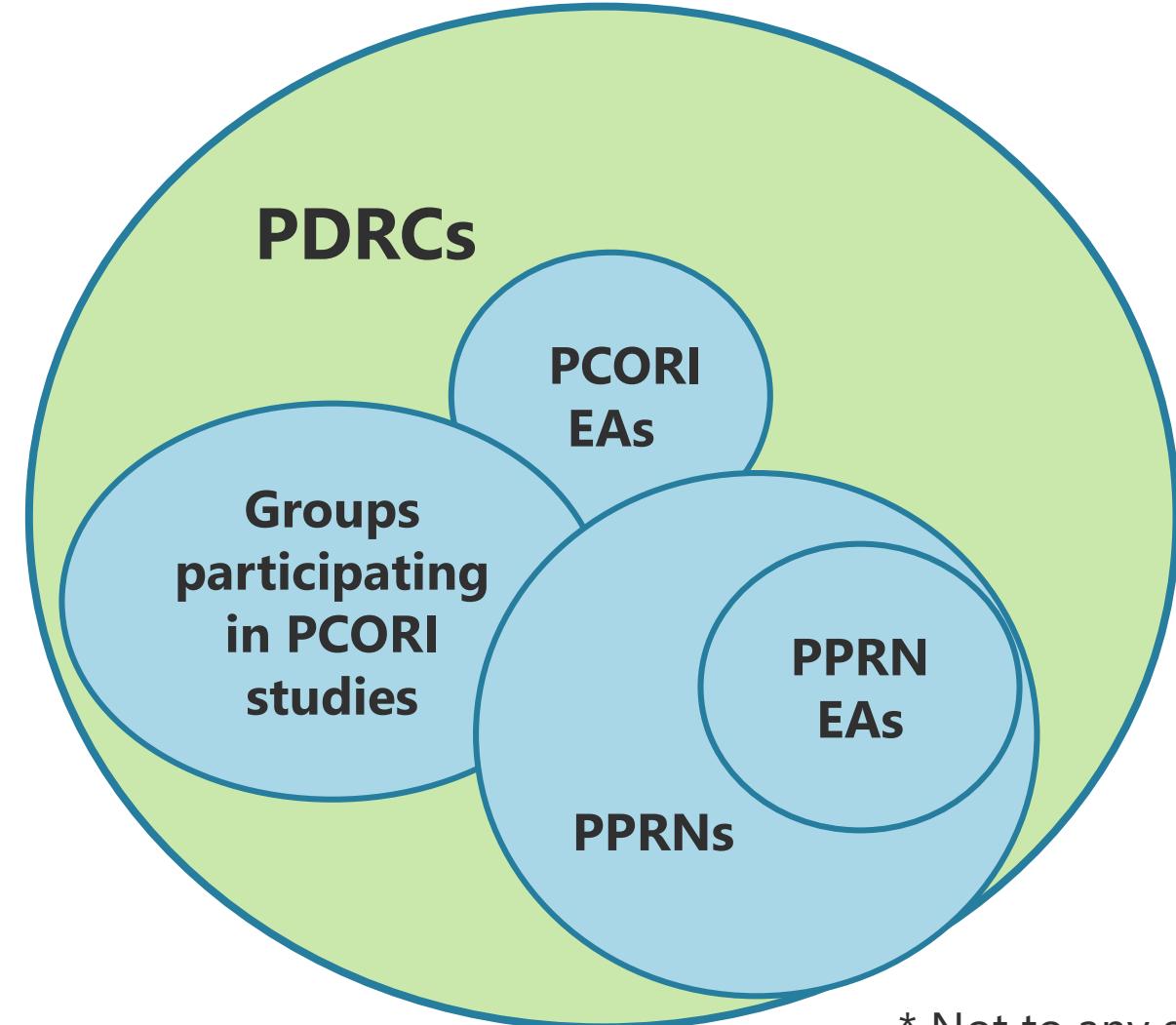


- [PPRN Limited Competition Engagement Awards](#)
- Focused on further developing engagement capacity and building towards more sustainable models
- Themes:
  - Improving use of technology to facilitate engagement
  - Addressing issues of diversity and representativeness of their populations
  - Better understanding and addressing the needs of potential research partners

# PDRCs and PCORI



- **PPRNs** = PDRCs led by patients/participants and organized around the evidence needs of their communities originally funded by PCORI as part of PCORnet
- **PPRN EAs** = Recipients of PPRN Limited Competition Engagement Award
- **EAs** = Engagement Awards



\* Not to any scale

# PDRC Learning Network



- **What:**
  - PDRC Learning Network
- **Why:**
  - Helping catalyze a future where PDRCs play a much greater role in guiding the entire clinical and care delivery research enterprise
  - Heard desire for patient-driven groups to learn and share
  - Opportunity to continue work with PPRNs
- **How:**
  - Within PCORI, a collaborative partnership between Research Infrastructure and Engagement
  - NORC contracted for coordination
- **When:**
  - 2.5 years starting July 2019
  - First meeting in September 2019

# PDRC Learning Network Goals



Contribute to and shape a national discussion on the roles of PDRCs

Generalize learnings in PDRC priority areas

Help inform PCORI in supporting PDRCs

Support learning between PDRCs

**PPRN EA Projects**

Support learning  
between PDRCs

- Provide a venue to share lessons learned and best practices
- Identify areas of common challenge
- Provide connection to tools and resources
- Provide exposure to relevant expertise outside network and/or clinical research, e.g. business processes

Generalize  
learnings in PDRC  
priority areas

- Draw out generalizable lessons from work of PPRN EAs in 4 priority areas:
  - Improving representativeness of PDRC membership and research participants
  - Elaborating on sustainable PDRC business models
  - Improving effectiveness of digitally-based engagement efforts
  - Accelerating adoption of evidence-based engagement approaches

Contribute to and shape a national discussion on the roles of PDRCs

- Conduct a landscape review of PDRCs
- Develop a conceptual model to inform the work of the network
- Create communication products to inform the work of the network
- Create products to facilitate communication of the network's progress with lay and scientific audiences

Help inform PCORI  
in supporting  
PDRCs

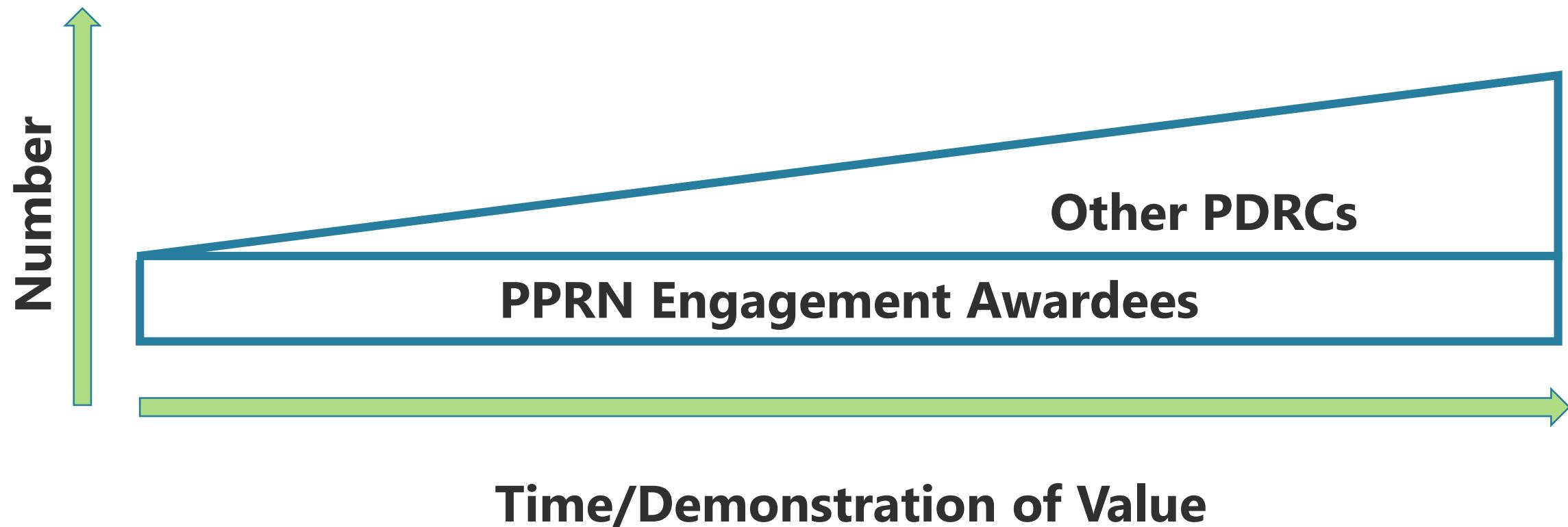
- Define priorities and needs based on network convening and workgroups
- Articulating priorities for multiple stakeholders (e.g. funders, research organizations)
- Make recommendations to PCORI and the field

# PDRC Learning Network Coordinator Scope



- **Task 1: Support of learning network activities that include exposure to learnings from organizations outside the learning network.**
  - Monthly network calls
  - Monthly online seminars
  - Annual in-person meetings
- **Task 2: Support and coordination of network workgroups in key PDRC priority areas.**
  - Improving representativeness of PDRC membership and research participants
  - Elaborating on sustainable PDRC business models
  - Improving effectiveness of digitally-based engagement efforts
  - Accelerating adoption of evidence-based engagement approaches
- **Task 3: Production of reports, manuscripts, and/or other materials or presentations that inform and reflect on the work of network.**

# Model for Learning Network Participation



# PDRC Learning Network Stakeholder Meeting

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July 12, 2019

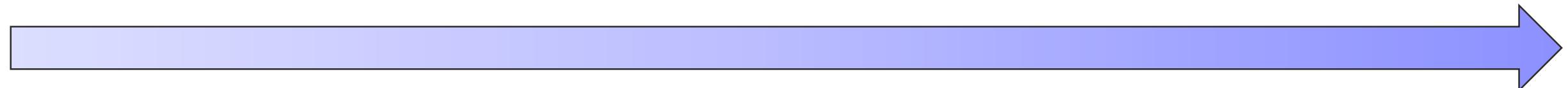


# PDRC Learning Network Stakeholder Meeting



- Participants:
  - National Health Council
  - FasterCures
  - Chan Zuckerberg Initiative
  - Parent Project for Muscular Dystrophy
  - Kith Collective
  - People-Centered Research Foundation
  - Former PPRN PI
  - PCORI Staff
- Goals:
  - Share experiences and plans for supporting patient/participant driven research communities
  - Discuss opportunities for alignment
  - Explore potential areas for collaboration in the future

# Research and Implementation Continuum



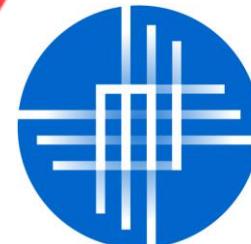
## Discovery

*Pre-clinical*



## Safety and Efficacy

*Pre-market*



## Effectiveness and CER

*Post-market*

*Outcomes*



## Dissemination

## Policy and Practice

*Implementation*

*Coverage/Payment/  
Reimbursement*



Organizational Center of Gravity

# Challenges & Opportunities for Collaboration



- Policies have built up demand for patient engagement. Can communities provide supply?
  - Supply-side needs
    - Understanding PDRC competencies needed while accounting for diversity-maturity model, self-assessments
    - Tools/templates/resources and process to adapt them locally
    - Rubrics along continuum
  - Opportunities on demand side
    - Standardize processes, data (e.g. FDA Clinical Outcomes Assessments)
    - Opportunity to help both PDRCs and stakeholders prioritize and focus the needs

# Challenges & Opportunities for Collaboration



- Retaining the “magic” of patient engagement within PDRCs as they evolve
  - Supporting both bottom-up and top-down efforts
  - Ensuring authentic connection to grassroots patients among PDRCs and true representation and engagement of diverse and underrepresented populations
  - New methods that are scalable
- Sustainability – good will only goes so far among PDRCs
- Sharing learnings and updates on our respective work in multistakeholder environments

# Timeline



- May/June: PPRN Engagement Awards started
- July: Stakeholder meeting
  - Learning Network Coordination on board
- September: First Learning Network call
- October: First Online Seminar

# Discussion



- What should we consider as we embark on this project?
- Key considerations for the landscape review and taxonomy of PDRCs?
- Would you add any other challenges or opportunities to those raised at the stakeholder meeting?

# Questions?

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# Appendix

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# 8 PPRN Engagement Awards (PPRN EAs)



1. Enhancing Engagement, Research Participation, & Collaboration through the IBD Partners Patient Powered Research Network  
Angela Dobes, Crohn's & Colitis Foundation, Inc., IBD Partners PPRN
2. An Open-Source Crowdsourcing Platform for Community-Engaged Research and Dissemination  
Mitchell Lunn, Stanford University, PRIDEnet PPRN
3. Co-producing Learning Health System Culture and process to accelerate PCOR in the ImproveCareNow Network  
Peter Margolis, Cincinnati Children's Hospital Medical Center, ICN PPRN
4. Multi-stakeholder Engagement for Enabling Patient-Driven Research  
Robert McBurney, Accelerated Cure Project for Multiple Sclerosis, iConquerMS PPRN

# 8 PPRN Engagement Awards (PPRN EAs)



5. PARTNERS - Enabling Real-time, Personalized Engagement in Research: An App-based Approach

Marc Natter, Boston Children's Hospital, PARTNERS PPRN

6. Diversifying, Expanding and Tracking Patient Engagement in Arthritis Research

Ben Nowell, Global Healthy Living Foundation, ArthritisPower PPRN

7. Bridging the GAP between Patients/Caregivers and COPD Research – The COPD PPRN BRIDGE Project

Cara Pasquale, COPD Foundation, COPD PPRN

8. Project COGENT (Customizing Consumer GENerated Tools to Engage Researchers)

Rebecca Sutphen, University of South Florida, ABOUT PPRN

# Optimizing Stakeholder Engagement through the Lens of Diversity, Equity and Inclusion

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*Closed Session*

**Facilitators:** Matt Hudson and Gwen Darien, with Debra Joy Perez, Senior Vice President, Organizational Culture, Inclusion and Equity, Simmons College (*Remote*)

**Planning Group Co-Leads:** Brendaly Rodriguez, Beverly Rogers

# **Closing Remarks**

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**ADJOURN**



# 2020 PEAP Meeting Dates



- January 30-31, 2020
- June 4-5, 2020



# Lunch

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*Available in the Foyer*

*Reserved Tables for PEAP in Salon 3*

