

# Measuring Patient Engagement in the Planning and Conduct of Clinical Pain Research

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# Plan for Today

Explore 4 questions about the **measurement of engagement**:

Why is it important?

How is it complex?

Where are we now?

What does it mean for us?

# Work in Progress: Landscape Review and Gap Analysis



What  
measures are  
needed?  
For and by  
whom?

What is the  
current state of  
available  
measures?

How should we  
address  
measurement  
gaps?

Supported by: Tom Concannon, RAND

<https://www.pcori.org/blog/pcori-and-rand-project-evaluate-measures-patient-and-stakeholder-engagement>

# How We Are Learning About Measures

## Key Informant Interviews

N=19 diverse stakeholders  
e.g., patients, researchers,  
policy makers, etc.

## Literature Review

83 articles

- Through 2017: literature reviews of engagement measurement
- 2018 - June 2021: studies of engagement measurement
- Reference mining

## Synthesis

Coming soon!



**Patient and stakeholder engagement throughout**



# Measurement of Engagement

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Why is it important?



# Measurement of Engagement is a Critical Tool

## For Engagement **Science**

Expanding evidence about the **most effective, acceptable, user-centered approaches** to engagement

Understanding the impact of engagement on **research, the people involved, healthcare, and health outcomes**

## For Engagement **Practice**

Helping teams understand **how well they are engaging** and where they can improve

Making engagement **easier and more widespread**

# Measurement of Engagement

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How is it complex?



# How Is It Complex?

**Wide variation** in engagement terms, definitions, approaches, requirements, and assumptions



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Engagement is affected by factors at multiple levels

Measurement of engagement, like engagement, is a **multi-stakeholder process**

# Different Stakeholder Groups Have Different Priorities

## Patients

Can I have a meaningful impact on research?

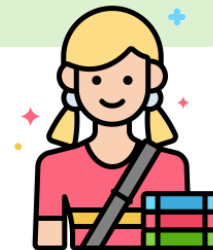
Was I supported and prepared to engage as I desired?



## Researchers

How do I engage effectively and efficiently?

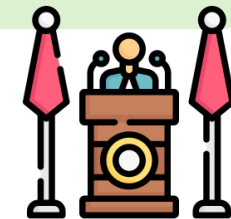
How will engagement affect my research?



## Policymakers

How inclusive is engagement?

What is the impact of engagement on research and health?



# Perspective Matters



# Measurement of Engagement

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Where are we now?



# Where Are We Now?

Lack of shared language and measurement frameworks

[Redacted content]

[Redacted content]

[Redacted content]

# Developing Shared Terms: Engagement Domains and Example Concepts (draft)

<b>Content</b> <i>Who, What, Why?</i>	<b>Context</b> <i>When, where?</i>	<b>Process</b> <i>How?</i>	<b>Outcomes</b> <i>So what?</i>
<p><b>Stakeholders</b> and <b>researchers</b> involved</p> <p>Underlying <b>ethical principles</b>: equity, inclusion</p>	<p><b>Community</b>: culture, language, population</p> <p><b>Research team</b> and <b>organization structures</b></p>	<p><b>Group dynamics</b>: power sharing, inclusion, diversity</p> <p><b>Engagement intensity</b>: consultation, collaboration</p>	<p><b>Patient and partner experience</b></p> <p><b>Impacts on research</b>: better questions, useful evidence</p>

# Where Are We Now?

Lack of shared language and measurement frameworks

**Limited measures of engagement in research**



# Measures of Engagement in Research

Approximately 35-40 published instruments

- Majority are drawn from the community engagement literature
- Most focus on engagement processes and contexts, relatively few focus on outcomes

Limits of published instruments

- Few report validity testing, most that do focus on face validity
- Reliability testing is rare
- Limited grounding in conceptual frameworks

# Illustrative Example: PCORI-Funded Measure of Community Engagement



## The Research Engagement Survey Tool (REST)

- 32 items
- Based on 8 engagement principles (e.g., sustainability, co-learning)
- Measures overall engagement and adherence to each principle
- Strong internal consistent, content validity
- Involved stakeholders throughout development

## REST-short form

- 9 items
- Strong internal consistency and correlation with the full REST
- Convergent validity with other related measures



### **Melody Goodman**

Associate Dean for Research and Associate Prof. of Biostatistics, New York University School of Global Public Health

# Where Are We Now?

Lack of shared language and measurement frameworks

Limited measures of engagement in research **that engaged patients and stakeholders throughout the conceptualization, design, validation, and implementation process**

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# Where Are We Now?

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There is a gap between what stakeholders want to measure and what they can currently measure

Limited engagement science and measurement development specifically in the context of **clinical pain research**

- What is generalizable or transferable?
- What is unique to engagement in pain research?

# Measurement of Engagement

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What does it mean for us?



# For Engaged Teams: Creating a Culture of Continuous Improvement

- Establishing shared vision of goals, roles, expectations
- Maintaining ongoing dialogue and qualitative understanding
- Closing the feedback loop by recognizing the contribution of partners

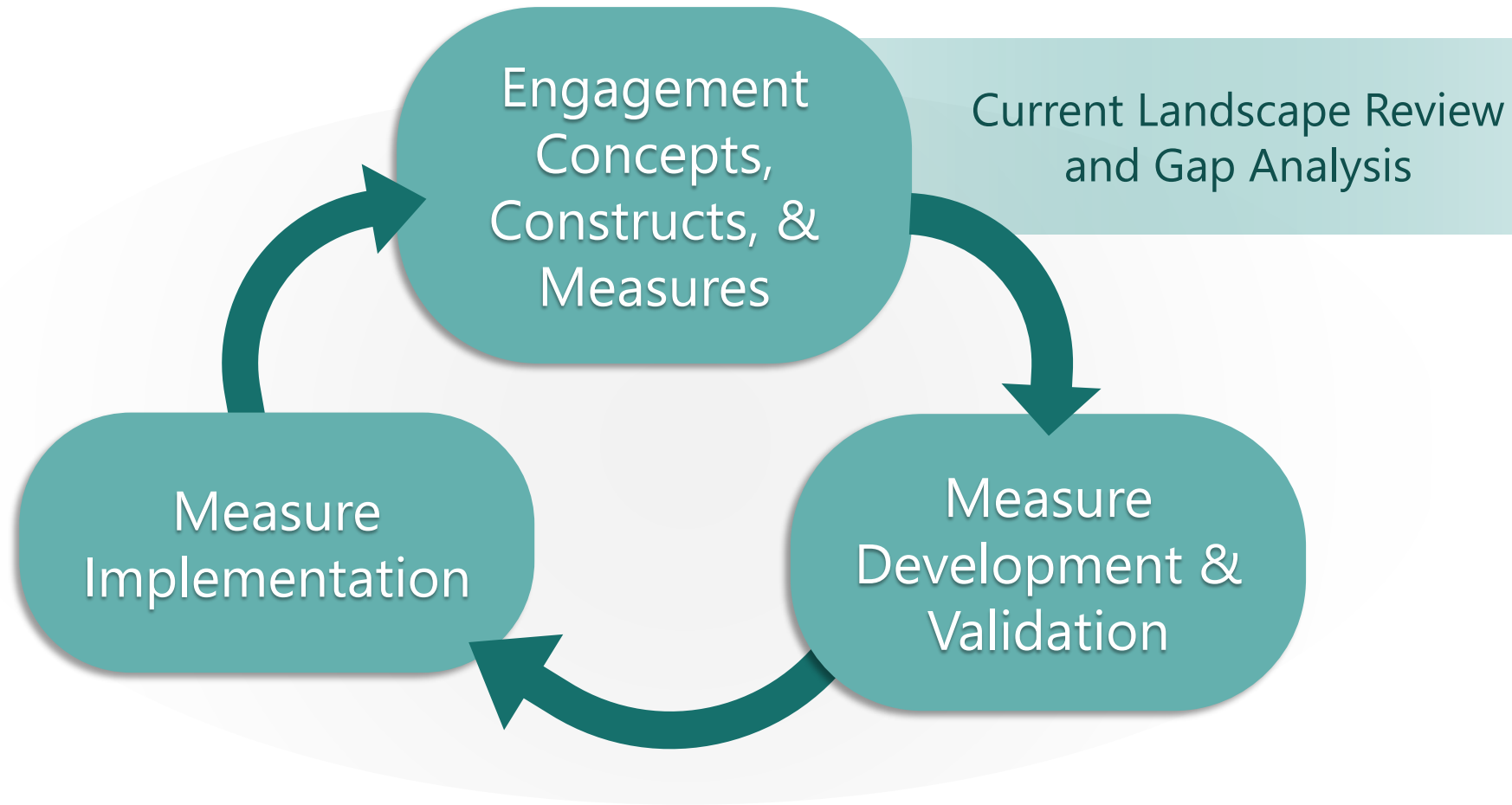
Resources from PCORI training:



## Building Effective Multi-Stakeholder Research Teams

Available at: [pcori.org/research-teams](https://pcori.org/research-teams)

# For PCORI, Other Funders, and the Field: More Work to be Done





# Invitation: Let PCORI Know Your Priorities



## Request For Information on the Science of Engagement

- Seeks input from potential applicants, patients, and other stakeholders and organizations who participate in research or engage communities
- Poses a specific set of questions on both the scientific research topic priorities (including measurement) and the process & resources needed to successfully support studies about engagement

**Responses are due by November 19, 2021 to [SOE-RFI@pcori.org](mailto:SOE-RFI@pcori.org)**

**Download the RFI at [www.pcori.org/soe](http://www.pcori.org/soe)**

# Measurement of Engagement

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## Summary & Conclusions



# Summary: Conclusions & Opportunities

- Measurement of engagement is...
  - a critical tool for both Engagement Science and Practice
  - complex – variation, multi-level, multi-stakeholder
- Different stakeholder groups want to measure different aspects of engagement and have different priorities
- There is a gap between what stakeholders want to measure and what they can measure

# Summary: Conclusions & Opportunities

- Need for more measures of engagement that...
  - Are well validated
  - Address engagement outcomes and other topics prioritized by stakeholders
  - Engage stakeholders in development, validation, and implementation
- Shared language and measurement frameworks will facilitate measure development and use

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# Measurement of Engagement – Key Summative References

REVIEW

CTS Clinical and Translational Science  
Open Access

## Systematic Review of Quantitative Measures of Stakeholder Engagement

Bowen DJ, Hyams T, Goodman M, West KM, Harris-Wai J, Yu JH. Clin Transl Sci. 2017 Sep;10(5):314-336.

ORIGINAL RESEARCH PAPER

Health Expectations  
Open Access

## Patient and public engagement in research and health system decision making: A systematic review of evaluation tools

Boivin, A, L'Espérance, A, Gauvin, F-P, et al. *Health Expect* 2018; 21: 1075– 1084.



EDITORIALS

## Evaluating patient and public involvement in research

If we are serious about involvement, we need to be equally serious about evaluation

Boivin A, Richards T, Forsythe L, Grégoire A, L'Espérance A, Abelson J, Carman KL. BMJ. 2018 Dec 6;363:k5147.

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# Supporting References From PCORI: Science of Engagement



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# Engagement Resources on PCORI website



- [Engagement Plan \(Updated Template\)](#)
- [PCORI Engagement Rubric](#)
- [Engagement in Health Research Literature Explorer](#)
- [Engagement Tool and Resource Repository for Patient-Centered Outcomes Research](#)
- [Compensation Framework](#)
- [Budgeting for Engagement Activities](#)
- [Methodology Report](#)
- [Guidebook: Engaging with Research Partners about Data and Analysis](#)

# Continue the Conversation



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