

## What PCORI Means By Engagement

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## Welcome

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*Director,  
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## Our Discussion for Today

- Share the importance of patient and stakeholder engagement in research and how this supports PCORI's mission of patient-centered research
- Review how PCORI evaluates engagement practices
- Provide an overview of tools PCORI created to help researcher ensure the meaningful engagement of patients and stakeholders within research teams



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## About PCORI

- An independent research institute authorized by Congress in 2010. Governed by a 21-member Board representing the entire healthcare community.
- Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process.
- Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns.



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## The Research We Fund is Guided by Our National Priorities for Research



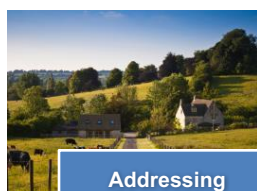
Assessment of  
Prevention, Diagnosis,  
and Treatment Options



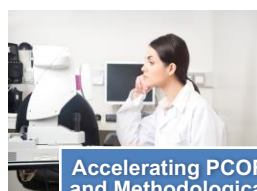
Improving  
Healthcare Systems



Communication &  
Dissemination  
Research



Addressing  
Disparities



Accelerating PCOR  
and Methodological  
Research



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## Why Engage?

To influence research to  
be patient-centered,  
relevant, and useful

To establish trust and  
a sense of legitimacy  
in research findings

To encourage  
successful uptake and  
use of research results



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## Why Engage?



Well, after having insurance coverage I made the decision along with that of my surgeon to have the surgery and the type of surgery that I had was Roux-en-Y. That landed me slap dad as they would say in the middle of the process being you know a patient and having always been a health advocate person.

And from that perspective of being a patient when the opportunity came along for me to work on projects related to obesity, it was just a natural fit. When I started this process, I was really centered on the outcomes for patients, but I am recognizing that these outcomes really are for all the stakeholders...for the clinicians who vest their time and energy in doing this work as well as for those who the services from the clinicians. Everybody wins if we are able to develop a better process and that's my hope for this project.



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## What Makes Us Different?



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## Merit Review



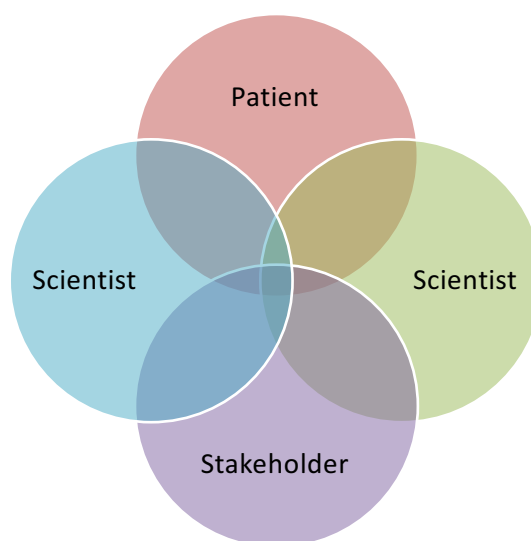
- 1: Potential for the study to fill critical gaps in evidence**  
Is associated with a *significant burden in the US population* (prevalence, mortality, morbidity, individual suffering, or loss of productivity)
- 2: Potential for the study findings to be adopted into clinical practice and improve delivery of care**  
Has the potential to lead to *meaningful improvement in the quality and efficiency of care* and to improvements in outcomes important to patients
- 3: Scientific merit (research design, analysis, and outcomes)**  
Has a research design of sufficient technical merit to ensure that the *study goals will be met*
- 4: Investigator(s) and environment**  
Assess the appropriateness (e.g., qualifications and experience) of the investigator(s)/team and the environment's capacity (e.g., resources, facilities, and equipment) to support the proposed project.
- 5: Patient-centeredness**  
Focuses on questions relevant to *outcomes of interest to patients and caregivers*
- 6: Patient and stakeholder engagement**  
Includes patients and other healthcare stakeholders as *partners in every stage of the research*



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## Panel Composition



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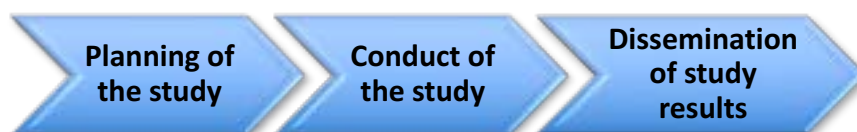
## Partnering in Research



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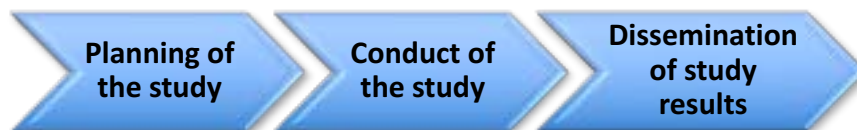
## Partnering in Research



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## Partnering in Research



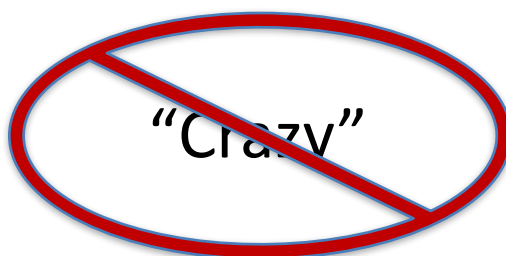
- Identify the research question
- Identify outcomes
- Craft study design
- Specify inclusion criteria
- Develop study materials



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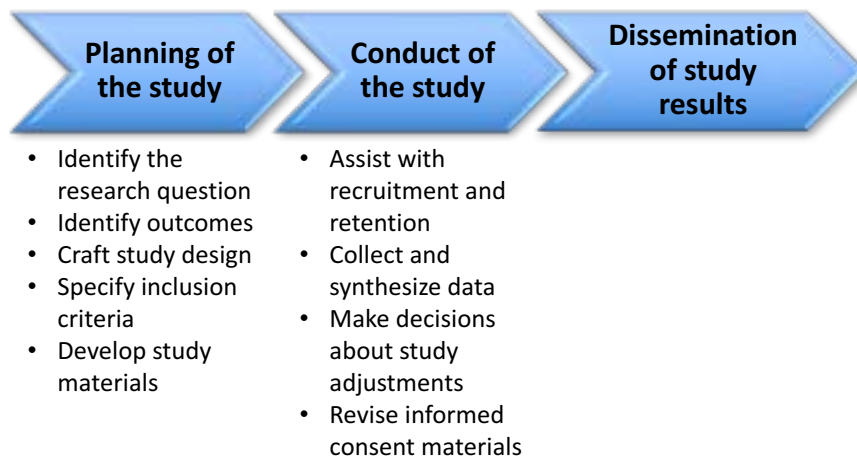
## Patient Influence on Planning



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## Partnering in Research



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## Patient Influence on Conduct

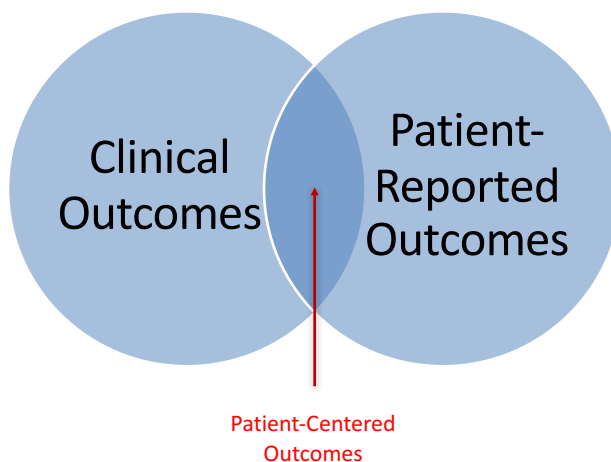


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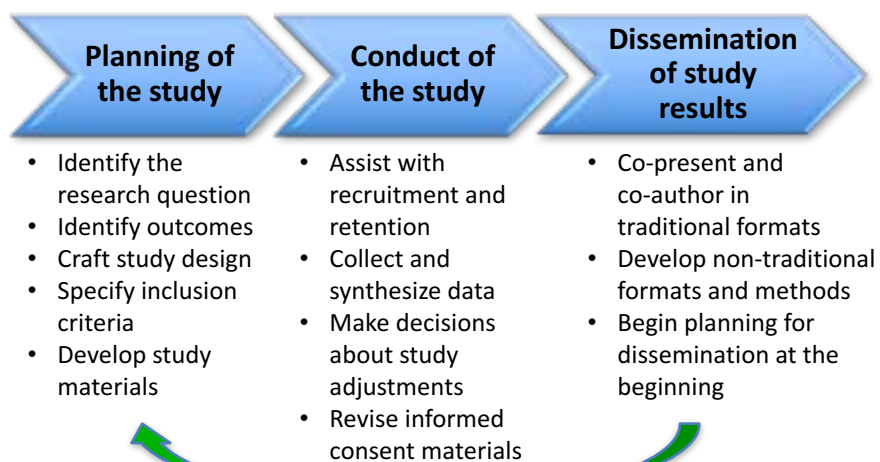
## Patient-Centered Outcomes



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## Partnering in Research



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## Patient Influence on Dissemination



It is important to include the patient voice within research because they are the ones that know the best solution for their problems. It gets them involved throughout the whole process and they are able to help us devise a solution.

I have been working the field for twenty-five years. I specialize in services for people with serious mental illness. I know a lot, but frankly I'm not black. I'm not Latino. I'm not homeless and if we are going to provide programs for those people for my brothers and sisters citizens then they have to be leading the charge. You know I think they have two big roles. Roles in research coming in...so in partnering with Sonia and folks coming in they hit me with questions I never thought of, but they have even bigger roles going out. Its advocates like Sonia that are going to take our wisdom off the shelf and use it. So that is even more important.



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## How Do We Facilitate Patient Engagement in Research?



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## Engagement Tools



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## Engagement Tool

- Engagement Rubric



Planning the Study



Conducting the Study



Disseminating the Study Results



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## Engagement Tool

- **“Budgeting for Engagement Activities” Guidance Document**
  - Planning
    - Compensation and recognition
    - Partner expenses
    - Project staff
    - Engagement event and/or meeting costs
    - Incorporating partner feedback.
  - Consider budgeting for engagement activities by phases of research as outlined in PCORI’s Engagement Rubric
  - Aligning a detailed budget with the activities for engagement outlined in your Engagement Plan will ensure that you have sufficient funds to support the engagement activities in your project



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## Engagement Tool

- **Compensation Framework**

Sample Model Addressing Fair Compensation for Engaged Research Partners: Engagement Spectrum with Examples: An Ideal Moving Toward Greater Collaboration

Engagement Activity Levels	I. INFORM	Simply informing	Communicating plans to the patient community	Varying Compensation Levels
	II. CONSULT	Consulting on decision	Offering opinions, advice, feedback	
	III. COLLABORATE	Deciding together Acting together	Joint decisions solicited Taking actions jointly	
	IV. STAKEHOLDER DIRECTED	Encouraging independent initiatives	Leading to patient/caregiver/organization generated research	



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## Engagement Tool

- **Sample Engagement Plans**

<i>Engagement Plan A: Effect of Glucose Monitoring on Patient and Provider Outcomes in Non-Insulin Treated Diabetes.....</i>	<i>3</i>
<i>Engagement Plan B: Sustainable Methods, Algorithms, and Research Tools for Delivering Optimal Care Study (SMART DOCS).....</i>	<i>9</i>
<i>Engagement Plan C: Peer-Driven Intervention as an Alternative Model of Care Delivery and Coordination for Sleep Apnea.....</i>	<i>14</i>
<i>Engagement Plan D: Caring for the Whole Person: A Patient-Centered Assessment of Integrated Care Models in Vulnerable Populations .....</i>	<i>17</i>
<i>Engagement Plan E: A Comparison of Treatment Methods for Patients Following Total Knee Replacement .....</i>	<i>24</i>
<i>Engagement Plan F: Improving Care Coordination for Children with Disabilities Through an Accountable Care Organization .....</i>	<i>29</i>



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## Engagement Tool

- **PCORI Methodology Standards and Methodology Standards Academic Curriculum**

The screenshot displays the PCORI Methodology Standards Academic Curriculum webpage. The sidebar on the left contains the following links: "The PCORI Methodology Report", "PCORI Methodology Standards", "Methodology Standards Academic Curriculum", "Category 1: Standards For Formulating Research Questions", "Category 2: Standards Associated With Patient-Centeredness", "Category 3: Standards For Data Integrity And Rigorous Analyses", and "Category 4: Standards For Preventing And Handling Missing Data". The main content area on the right lists the following modules: "Introductory Lecture: Prepared and presented by Jodi Segal, MD, MPH", "Learning Modules: Prepared and presented by Albert Wu, MD, MPH, and Clifton Bingle", "Module 1: Introduction", "Module 2: Objectives", "Module 3: Overview on Patient-Centeredness", "Module 4: Patient and Stakeholder Selection and Engagement", "Module 5: Ensuring Representativeness", and "Module 6a: Patient-Reported Outcomes: Introduction, Objectives, and a Case Example". Each module has links for "Watch", "Listen", and "Handout".



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## How is PCORI's Application Process Different?

- Engagement Plan
- Partner Biosketch
- Partner Compensation
- Description of research question and outcomes
- Provision of partner names
- Milestone development
- IRB approval



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## Lessons Learned from the Portfolio

- Start with the goal, not the rule
- Ask first, exclude second
- Keep the “unusual suspects” in mind
- Engagement is relational, not transactional
- For proposals: Show your work!



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## Embody the Six Engagement Principles

Partnership

Co-learning

Reciprocal  
Relationships

Trust

Transparency

Honesty



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## The Last Word...



Its hard to imagine ever doing another study where I don't start out with patients and families first. Its absolutely changes the way you look at a project and the way you do business and I hope don't ever do another one without patient and family engagement.



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## Questions?



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## Thank You

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