

Patient and Stakeholder Engagement

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Welcome!



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*Director,
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Our Discussion for Today

- How does PCORI operationalize patient engagement and patient centeredness?
- How can you prepare to conduct patient and stakeholder engaged research?
- How can you clearly explain your plans for patient and stakeholder engagement in your PCORI proposal?



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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



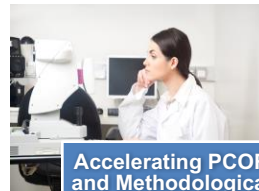
Improving
Healthcare Systems



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



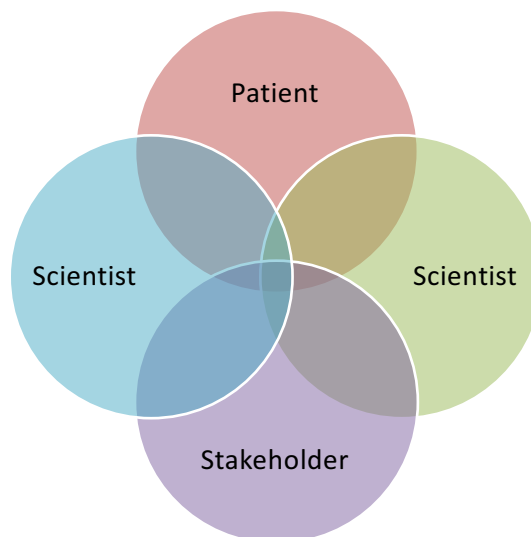
- 1: Potential for the study to fill critical gaps in evidence**
Is associated with a *significant burden in the US population* (prevalence, mortality, morbidity, individual suffering, or loss of productivity)
- 2: Potential for the study findings to be adopted into clinical practice and improve delivery 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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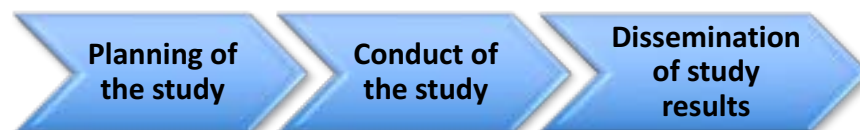
Partnering in Research



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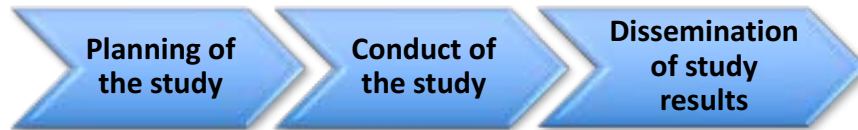
Partnering in Research



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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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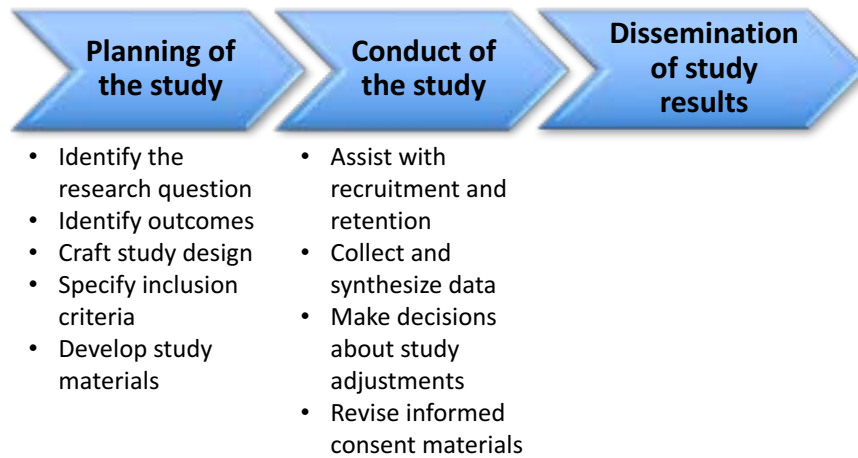
Patient Influence on Planning



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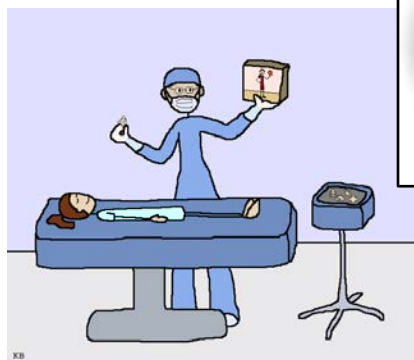
Partnering in Research



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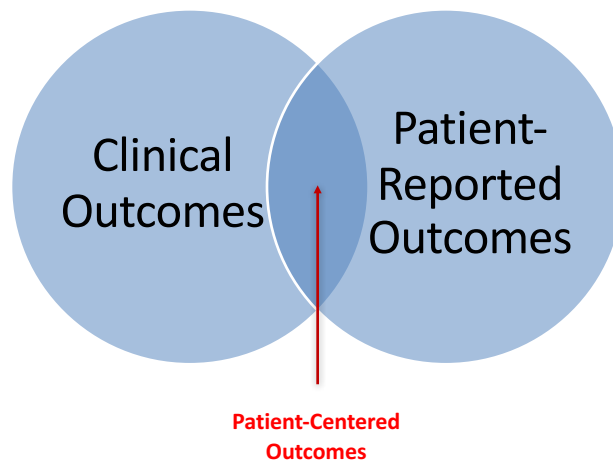
Patient Influence on Conduct



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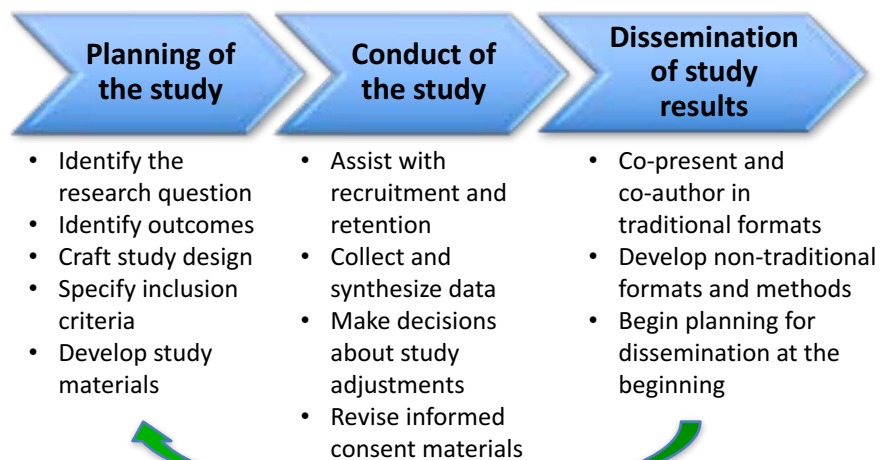
Patient-Centered Outcomes



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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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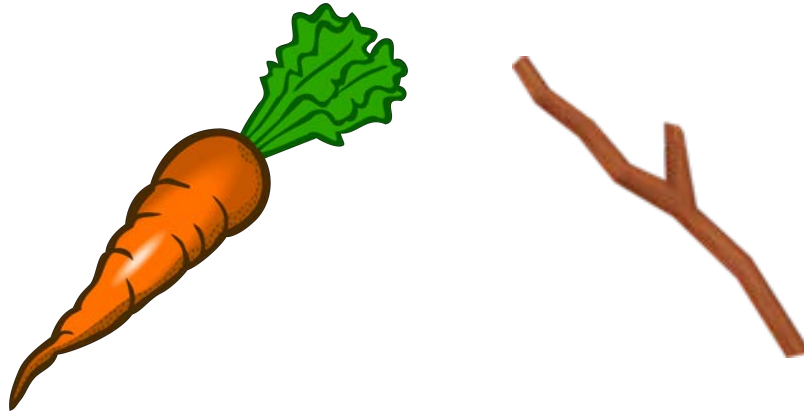
How Do We Facilitate Patient Engagement in Research?



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Engagement Tools



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Engagement Tools

- Engagement Rubric



Planning the Study



Conducting the Study



Disseminating the Study
Results



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Engagement Tools

- Engagement Rubric
- Sample Engagement Plans



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Engagement Tools

- Engagement Rubric
- Sample Engagement Plans
- Compensation Framework
- “Budgeting for Engagement” guidance document



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Engagement Tools

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- Programmatic Funding (Pipeline to Proposal Awards and Eugene Washington Engagement Awards)



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Engagement Tools

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- Other application assistance (Partner Biosketch, Applicant Training, Engagement FAQs, Applicant Town Halls)



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- Post Award: Engagement Officers



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How is this 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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