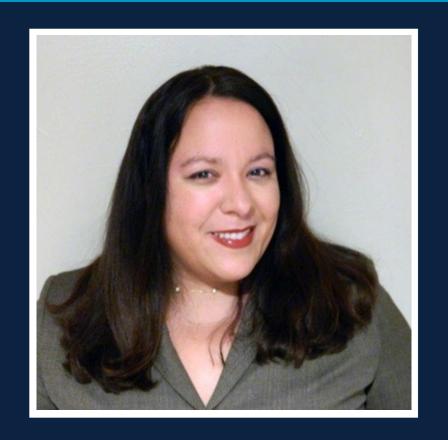
13th Annual Focus on Eye Health Summit



BEING SEEN AND HEARD





SESSION 2: Vision Research and the Citizen Scientist

Mabel Crescioni, DrPH, JD

Moderator
Senior Engagement Officer
Patient-Centered Outcomes Research Institute

Prevent Blindness

Vision Research and the Citizen Scientist

Mabel Crescioni, DrPH, JD, LLM Senior Engagement Officer *PCORI.org*



Patient-Centeredness vs. Patient Engagement pcori



Patient-Centeredness

- Addresses outcomes (both benefits and harms) that are important to patients
- The interventions proposed for comparison are currently available to patients
- Study design is low burden to participants



Patient and Stakeholder Engagement

- Patients and stakeholders are partners in research, not only "subjects" or "participants"
- Leverages the expertise of patients, clinicians and other stakeholders for the purpose of improving study design and conduct
- Includes a range of engagement approaches: input, consultation, collaboration, shared leadership
- Can occur by building upon existing relationships, or developing new ones

"Research Done Differently"



PCORI research has shown that engagement makes a meaningful differences in studies:



User-Orientation & Acceptability:

studies in which patients and clinicians will be willing to participate based on burden, usability, and alignment with preferences, values, and needs



Feasibility:

interventions, enrollment, and data collection that are more doable in real-world settings



Study Quality:

study rigor, comprehensiveness, and quality of materials and products



Relevance:

results applicable and important for decision-making



Engagement Scope & Quality:

engagement processes are effective, and stakeholders are well equipped

PCORI's Foundational Expectations for Partnerships in Research





Diversity & Representation



Early & Ongoing Engagement



Dedicated Funds for Engagement & Partner Compensation



Build Capacity to Work as a Team



Meaningful Inclusion of Partners in Decision-Making



Ongoing Review & Assessment of Engagement

SESSION 2 PANEL: Vision Research and the Citizen Scientist



Mabel Crescioni, DrPH, JD
Senior Engagement Officer,
Patient-Centered Outcomes Research
Institute



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