



**Prevent
Blindness**

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

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Senior Engagement Officer

PCORI.org



Patient-Centeredness vs. Patient Engagement



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



**Kristen Harris Nwanyanwu, MD,
MBA, MHS**
Associate Professor of Ophthalmology and
Visual Science, Yale University



**Lauren P. Daskivich, MD,
MSHS, Director**
Ophthalmic Services and Eye Health
Programs, Los Angeles County
Department of Health Services



Priscah Mujuru, DrPH, MPH, RN
Health Scientist Administrator, Division of
Community Health and Population
Science, National Institute on Minority Health
and Health Disparities

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