Patient and Clinician Views on Comparative Effectiveness Research and Engagement in Research: A Panel Discussion on PCORI Survey Results
Introductions

Moderator and Presenters

- Lori Frank, PhD, Director of Engagement Research, PCORI
- Laura Forsythe, PhD, Program Officer, Engagement Research, PCORI

Panelists

- Marc Boutin, JD, Executive Vice President & Chief Operating Officer, National Health Council
- Barbara Doty, MD, FAAFP, Primary Care Physician and Board of Directors Member, American Academy of Family Physicians
- Susan Rawlins, RN, WHNP-BC, Director of Education, National Association of Nurse Practitioners in Women’s Health (NPWH)
PCORI’s Mission and Vision

Mission
The Patient-Centered Outcomes Research Institute (PCORI) helps people make informed health care decisions, and improves health care delivery and outcomes, by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community.

Vision
Patients and the public have the information they need to make decisions that reflect their desired health outcomes.
Survey Purpose and Methods
Purpose of the Survey

Assess attitudes of chronic disease and rare disease patients toward
- Health Research
- Engagement in Research

Assess attitudes of primary care clinicians toward
- Health Research
- Comparative Effectiveness Research (CER)
- Engagement in Research
Methods: Survey Development

- Identify Existing Survey Items
  - Health information sources
  - Trust in health information

- Develop New Survey Items
  - Perceived value of engagement
  - Interest in engagement
  - Barriers and facilitators for engagement

- Partner with Patients and Clinicians for Feedback
  - Survey concepts
  - Item wording
  - Survey layout
  - Dissemination
Methods: Crowdsourced Survey

- Recruitment from existing opt-in panels based on pre-supplied profiled information
- Web-based survey
- Rapid data collection
- Limited generalizability
**Methods: Instrument Example**

### InCrowd Question

**12. How much do you agree with the following statements:**

<table>
<thead>
<tr>
<th>Strongly disagree</th>
<th>Somewhat disagree</th>
<th>Neither agree nor disagree</th>
<th>Somewhat agree</th>
<th>Strongly agree</th>
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- a. Patients working directly with researchers can improve the value of medical research.
- b. Patients working directly with researchers can improve health care.

**Comments:**

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[Submit]
Survey Respondents
Respondents: Patients (N=900)

Disease Group
- Chronic disease patients: 80%
- Rare disease patients: 20%

Primary Language
- English: 89%
- Spanish: 11%
Serve as the primary decision-maker for…

- Parent: 53%
- Spouse or partner: 18%
- Another family member: 17%
- Child (<18 years old): 11%
- Friend or coworker: 6%
- Child (>18 years old): 4%
Respondents: Primary Care Clinicians (N=750)

**Type of Provider**
- Physicians: 53%
- Nurse Practitioners: 27%
- Nurses: 12%
- Physician Assistants: 8%

**Years in Practice**
- < 3 Years: 10%
- 3 to 9 Years: 23%
- 10 to 19 Years: 25%
- 20 to 29 Years: 35%
Primary Care Clinicians Report Low Familiarity with CER

- Not at all familiar: 45%
- Slightly familiar: 34%
- Moderately familiar: 17%
- Very familiar: 5%
Primary Care Clinicians Report High Perceived Value of CER

"CER should be used to develop clinical practice guidelines"
- Strongly / Somewhat Agree: 72%
- Neutral: 39%
- Strongly / Somewhat Disagree: 21%

"CER can improve the quality of patient care"
- Strongly / Somewhat Agree: 76%
- Neutral: 39%
- Strongly / Somewhat Disagree: 19%

"CER will be used to restrict my freedom to choose treatments for my patients"
- Strongly / Somewhat Agree: 29%
- Neutral: 39%
- Strongly / Somewhat Disagree: 32%
Primary Care Clinicians Report Infrequent Use of CER to Provide Information to Patients

- Screening recommendations: 33% for Physicians, 28% for Nurses and PAs
- Pharmacotherapy recommendations: 30% for Physicians, 27% for Nurses and PAs
- Non-pharmacotherapy treatment recommendations: 41% for Physicians, 33% for Nurses and PAs
- Advice for chronic disease management: 35% for Physicians, 26% for Nurses and PAs

*p < 0.05
Patient and Clinician Views on Health Information and Research
Patients, Caregivers, and Clinicians Agree that Research Helps Patients Make Better Treatment Decisions

- **Patients**: 72%
- **Caregivers**: 72%
- **Clinicians**: 77%

*p < 0.05

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*Patient-Centered Outcomes Research Institute*
Patients, Caregivers, and Clinicians Value Research That Measures Things Patients Care About

- Patients: 87%
- Caregivers: 89%
- Clinicians: 87%

*p > 0.05*
Research for Clinical Decisions: Relevance to Patients’ Needs is Important to Clinicians

- Relevance to my patients’ specific needs and preferences: 66%
- Research study design: 50%
- Translation into clinical practice guidelines: 47%
- Study funding source: 22%
Clinicians Frequently Use General Internet Searches and Colleagues to Obtain Information to Diagnose and Treat Patients

- General internet search engines: 40% daily, 31% a few times per week
- Online subscription services: 38% daily, 28% a few times per week
- Colleagues: 34% daily, 28% a few times per week
- Online free services: 20% daily, 40% a few times per week
- Peer reviewed literature: 18% daily, 35% a few times per week
- Cochrane Database or other systematic reviews: 4% daily, 13% a few times per week
Patients Use Internet as First Source of Health Information

- **Internet**: 60% (Chronic) vs. 32% (Rare)
- **Doctor or health care provider**: 26% (Chronic) vs. 34% (Rare)
- **Family or friends**: 11% (Chronic) vs. 27% (Rare)
- **Other source**: 2% (Chronic) vs. 6% (Rare)

*p < 0.05*
Patients Use a Variety of Internet Sources (Last 12 Months)

**Patient online community**
- Chronic Disease Patients: 37%
- Rare Disease Patients: 45%

**Website for health plan**
- Chronic Disease Patients: 34%
- Rare Disease Patients: 47% (*p < 0.05*)

**Website for government health agency**
- Chronic Disease Patients: 36%
- Rare Disease Patients: 54% (*p < 0.05*)

**Website for disease focused group**
- Chronic Disease Patients: 37%
- Rare Disease Patients: 42% (*p < 0.05*)

*p < 0.05*
Patients’ Trust in Internet is Low Compared to Other Sources

% “A lot” of trust

- **Doctor**
- **Disease focused groups**
- **Government health agencies**
- **Your health plan**
- **Internet**
- **Family or friends**
- **Online patient communities**

- Chronic Disease Patients
- Rare Disease Patients

*p <0.05*
Patient and Clinician Views on Engagement in Research
Respondents Agree that Working Directly With Researchers Can Improve the Value of Medical Research

- Patients: 83%
- Caregivers: 81%
- Clinicians: 72%

*p<0.001
Patients, Caregivers, and Clinicians are Interested in Engaging in Research

- Patients: 66%
- Caregivers: 58%
- Clinicians: 55%

*p<0.001
## Barriers and Facilitators of Engagement

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<thead>
<tr>
<th>Patients</th>
<th>Barriers</th>
<th>Facilitators</th>
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|          | • Lack of time (43%)  
|          | • Concerns about privacy (36%)  
|          | • Work, school or caregiving commitments (33%)  | • Helping others with their medical condition (68%)  
|          |          | • Learning about their health (63%)  
|          |          | • Helping the next generation (57%)  
|          |          | • Getting paid (56%)  
|          |          | • Making research more meaningful to patients (49%)  
| Clinicians | • Lack of time (79%)  
|          | • Lack of payment (47%)  
|          | • Lack of research training (35%)  | • Helping patients receive better care (79%)  
|          |          | • Getting paid (78%)  
|          |          | • Contributing to scientific knowledge (61%)  
|          |          | • Making research more meaningful for patients (61%)  
|          |          | • Improving professional satisfaction (52%)  
|          |          | • Helping researchers decide what to study (43%)  |
Barriers to Research Engagement Differ by Race/Ethnicity

- Lack of training in research
- Distrust of researchers
- Work, school, or caregiving commitments
- Concern about my privacy
- Lack of time

Whites (N=616)  
Blacks (N=71)  
Spanish-dominant Hispanics (N=97)  
English-dominant Hispanics (N=50)

*p ≤0.05
Strengths and Limitations

**Strengths**
- Exploration of understudied topic areas
- Inclusiveness of understudied populations: Spanish speakers, rare disease patients
- Ecological validity

**Limitations**
- Generalizability
- Self-reported data
- New survey items testing complex constructs
Conclusions

- Health research is valued by patients and clinicians.
- Clinicians expressed low familiarity with CER but high perceived value.
- Use of CER is relatively low in this primary care clinician sample.
- Limited CER evidence base in places clinicians seek information may explain limited use of CER.
Conclusions

Most patients, clinicians, and caregivers believe engagement can improve the value of health research.

Many patients, clinicians and caregivers are interested in engaging in research themselves.

Strategies to facilitate both patient and clinician engagement:

- Establish link between engagement and patient care
- Financial compensation
- Minimize time burden
Implications for PCORI’s work

- Expand the evidence base for CER questions of high importance to patients and clinicians
- Explore ways to get good CER data into the health information channels that patients and clinicians use
  - Plan for dissemination based on an understanding of patterns of health information use and understand differences by patient and provider type
- Raise awareness of the role of CER information in clinical and health decision-making
- Address barriers to research partnerships involving patients and involving primary care clinicians
Panel Discussion

- What factors might account for low familiarity with CER among primary care clinicians? What can PCORI do to increase familiarity?
- To what do you attribute limited use of CER in clinical decisions? What are the implications for PCORI?
- What are the consequences of engaging both patients and clinicians in research?
- How can time and financial barriers to engaging in research best be addressed? Which engagement facilitators should PCORI work to strengthen?
Thank you!

Acknowledgements

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- Panelists

Please send questions or comments to:

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