Patient Engagement Advisory Panel

October 26, 2015

Washington, DC

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Agenda – October 26

8:30 a.m.	Welcome and Review Agenda
9:00 a.m.	Reflections on Annual Meeting
9:30 a.m.	Refinement of Engagement Strategy
10:00 a.m.	Break
10:15 a.m.	Q&A with Joe Selby
11:30 a.m.	Lunch
12:30 p.m.	Meaningful Engagement with Patient/Caregiver Organizations as Key Partners in PCS and Targeted Studies
2:00 p.m.	Break
2:15 p.m.	Meaningful Engagement with Patient/Caregiver Organizations as Key Partners in PCS and Targeted Studies
4:30 p.m.	Wrap-Up

Welcome, Introductions, and Review Agenda

Jean Slutsky, PA, MSPH

Chief Engagement and Dissemination Officer

Sue Sheridan, MIM, MBA, DHL

Director of Patient Engagement

Charlotte W. Collins, JD
Chair
Compensation Subcommittee

Darius Tandon, PhD
Chair
Evaluation Subcommittee

Reflections on the Annual Meeting

Darius Tandon, PhD

Co-Chair, Advisory Panel on Patient Engagement

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Engagement at Study Initiation and Execution – Some Rethinking

Jean Slutsky
Chief Engagement and Dissemination Officer
Program Director, Communication and Dissemination Research

PEAP
October 26, 2015

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Outline for Discussion

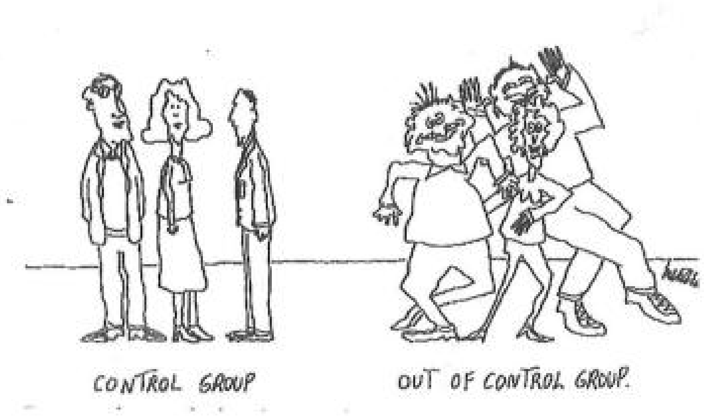
- Pragmatic Clinical Studies and Targeted Clinical Studies
  - What they are
  - How they are different
- Engagement in Research at PCORI
  - What we know
  - Where we can improve the experience
  - First implementation

Traditional Randomized Controlled Trials

- Study sample (patients under study) tends to be homogeneous (the enrolled patients look pretty much alike and not like you and me), highly motivated (and therefore more adherent), relatively free of comorbid conditions
- Research tends to take place in specialized research settings
- Research protocols are often strict and do not represent typical clinical practice

What Is a Pragmatic CER Study?

- Answers a practical, real-world comparative effectiveness research question.
- Assesses whether two or more options differ in effectiveness when administered as they are in real life
- Project is conducted in a clinical setting that is as close as possible to a real-world setting.
- Patients are NOT excluded if they have more than one health condition and tend to represent real-world patients.
- The methodological approach (including study design, outcome measures, and follow-up) is as simple as possible without sacrificing scientific rigor.



Pragmatic Clinical Studies at PCORI

Seek to produce information that can be directly adopted by providers:

- Compares two or more options for prevention, diagnosis, treatment, or management of a disease or symptom
- Addresses critical clinical choices faced by patients, caregivers, clinicians, and systems
- Often conducted in routine clinical settings
- Though often large, usually less complex protocols than traditional trials
- Topics of special interest from stakeholders

- Anticipated Awards per Funding Cycle: Six to Nine
- Funds Available per Cycle: Up to $90 Million
- Maximum Project Duration: 5 Years
- Maximum Direct Costs per Project: $10 Million; total costs: $15 million

Bottom Line

- Pragmatic clinical studies are intended to provide information that can be directly adopted by healthcare providers.
- Mostly conducted in routine clinical settings
- Large, because the expected differences in effectiveness may be small, yet important or different in patient subgroups
- Less intrusive to routine clinical practice
- Respectful of enrolled patient’s time and convenience
- Sometimes called “Large Simple Trials”
- Anticipated to have large impact

Timeline of PCORI Pragmatic Studies Initiative

- First funding announcement in February 2014
- First funded projects in mid-2015
- Competitive LOIs
- Deadline past for current (fourth) announcement
- Next LOI deadline fall 2015
- Emphasis on priority clinical topics
  - Investigator-initiated topics are also considered

Targeted Funding Announcements

- Stakeholder nominated and informed questions on specific topics
- Each targeted topic approved by the PCORI Board of Governors
- Larger dollar amounts
- Pragmatic real-world study designs so still a pragmatic clinical study

What We've Heard: Engagement Is Essential but Challenging

- Stakeholders have told us that research questions they have submitted end up looking much different once projects are awarded
- June meeting with Chief Medical Officers of health plans, Joe, Gray, Jean, Lia, and Susan
  - They want to work closely with investigators to refine questions and protocols
  - They want PCORI to be the "honest broker" to bring disparate stakeholders to the table
- Investigators tell us that pre-award intensive engagement is not financially feasible or sustainable
- Some stakeholder groups are getting multiple pre-award queries from different investigators as they prepare their LOIs and this has taxed their resources to respond
- Engaging patients and other stakeholders can be transformative

Applicants Embrace Engagement But Find the Requirements Challenging

PCORI Researcher Survey (N=508):

- Most researchers are interested in engagement (63% *very* interested)
- Researchers who applied to PCORI (N = 272) rated PCORI's requirement for engagement as more difficult than adherence to Methodology Standards and meeting other requirements
- "What could be done to encourage researchers to involve patients and/or caregivers as partners?"
    - Increase funds available (75%)
    - Train researchers on engagement (71%)
    - Train stakeholders for engagement (67%)
    - Resources for matching with partners (66%)

Pragmatic Clinical Studies and Targeted Studies and Engagement

- These studies are PCORI's biggest research investments
- Studies need to engage patients and other stakeholders to be relevant, responsive, and consistent with PCORI's mission and goals
- An alternative approach is proposed for engagement in these studies to address the financial and feasibility concerns of applicants and their potential stakeholder partners
  - Consult with stakeholders, BEFORE submitting LOI, on their evidence needs and decisional dilemma(s)
  - Intensive engagement does not need to occur BEFORE submitting LOI
  - Thoughtful discussion of engagement plans should be in the application
  - Once a project is awarded, intensive engagement is required for questions and protocol refinement and is part of the contract and budget
  - Continued engagement throughout the study as proposed and awarded
  - Done **in collaboration with PCORI** to make sure the relevant national perspectives of patients and other stakeholders are represented and engaged
  - **Budgeted under the contract with milestones and deliverables**

Language in the PCORI Funding Announcement

- In all cases, PCORI expects researchers preparing applications to have consulted with patients and other stakeholders to identify the important decisional dilemmas and evidence needs that will drive development of the research questions or to reference previously documented decisional dilemmas.

Language in the PCORI Funding Announcement

- To describe the decisional dilemma, state the specific clinical decision(s) and/or treatment choice(s) confronted by the decision makers and how the findings from the proposed research will inform those decisions. State why this decision—such as choosing a specific medication, surgical approach, intervention, or care delivery strategy to treat a condition or manage a specific population—is important to patients and their caregivers. Document the uncertainty faced by patients, clinicians, and other decision makers in making this decision. Identify the stakeholders you consulted in determining that the proposed study addresses their evidentiary needs for decision making, and indicate your commitment to continuing to engage them actively in the conduct of the study.

Language in the PCORI Funding Announcement

- Successful applicants will be required to work in collaboration with PCORI staff upon award of the proposed studies to establish a project Study Advisory Committee (SAC) that is comprised of national or regional organizations that represent, at a minimum, patients and/or families with lived experience, relevant clinicians, payers, and health plans. Other representation may be recommended in collaboration with PCORI, including individual patients with lived experience and other relevant stakeholders, including scientific and methodological experts. The SAC serves to advise and assist the research team with further refinement of the study questions, outcomes, and protocol. It is expected that the SAC will meet regularly in person at least two times per year and may use virtual communications at other times. These are to be budgeted activities and represented in the project milestones.

Timeline and Monitoring

- This alternative approach is reflected in the October 12 release of the Pragmatic Clinical Studies PFA and the Targeted PFAs
- Would require collaboration with PCORI staff and monitoring through milestones and evaluation to make sure there are no unintended negative consequences

Thank You!

15-Minute Break

Update to PCORI's Patient Engagement Advisory Panel

Joe Selby, MD, MPH

Executive Director, PCORI

October 26, 2015

What Do We Mean by Patient-Centered Outcomes Research?

- Compares two or more options for screening, diagnosis, treatment <u>that matter to patients</u>

  (one option may be "usual care")

- Considers the range of outcomes <u>that are important to patients</u>
- Conducted in real-world populations and real-world settings
- Actively engages patients and other stakeholders in the research process
- Attends to differences in effectiveness and preferences across patient subgroups

Patient-Centered Outcomes ≠ Patient-Reported Outcomes

1) Patient-centered outcomes are <u>outcomes that matter to patients</u>
2) Usually multiple for any comparison
3) Not necessarily suggested by patients, but must be vetted and supported by patients

√ Survival
√ Repeat events
√ Complications
√ Hospitalizations or days

√ Symptoms
√ Quality of Life
√ Function
√ Out-of-pocket costs

Blood pressure levels ?
Hb A1c levels ???

PCORI Study: Involving Patients in the Selection of Outcomes

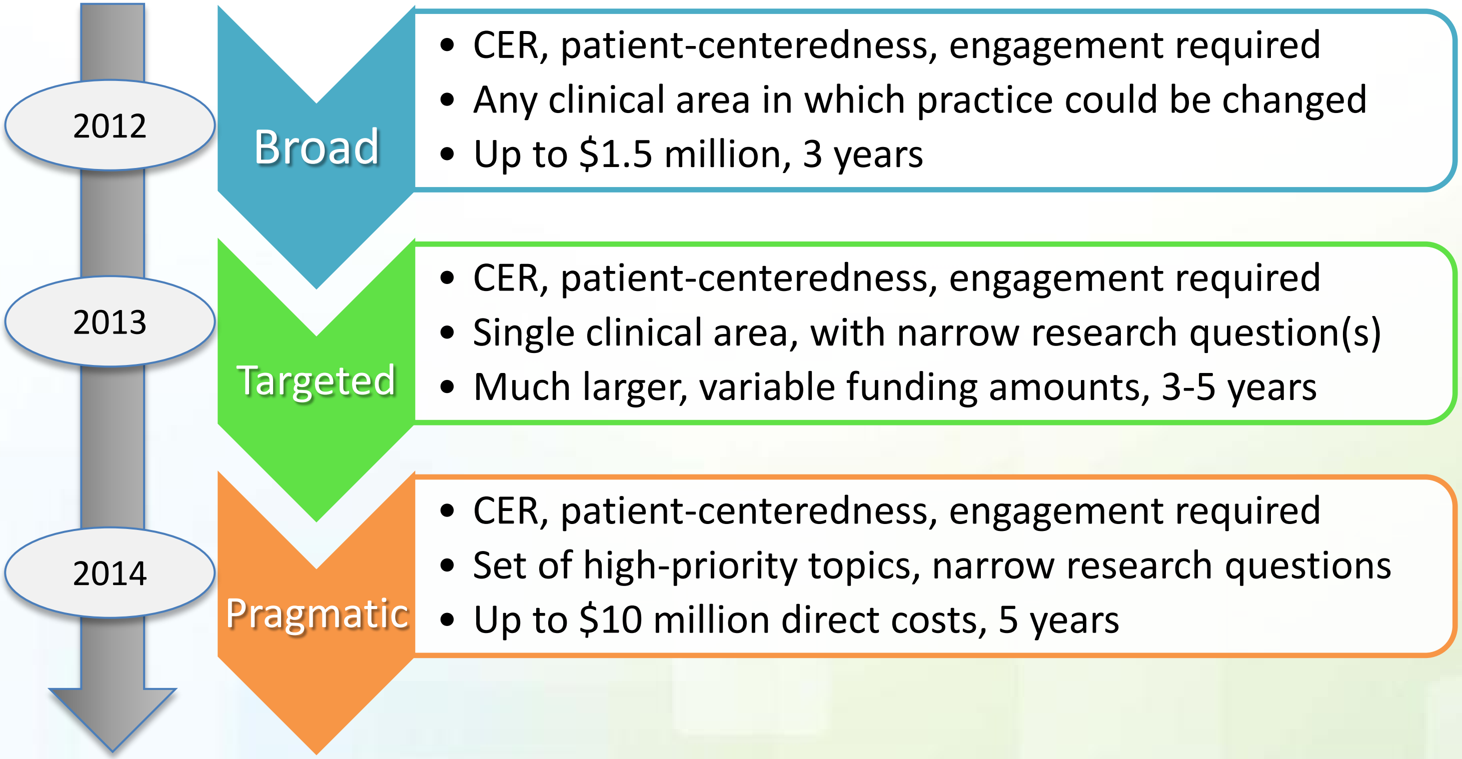
- **Principal Investigator:** Adrian F. Hernandez, MD, MHS, Duke Clinical Research Institute
- **Study Design:** Observational cohort CER study; national registry of 12,553 patients with ischemic stroke and atrial fibrillation
- **Comparators:** Use of warfarin post-stroke: yes vs. no
- **Outcomes:** Patients changed primary outcome from MACE (major adverse cardiovascular events) to **"Home Days: days spent at home during follow-up**."
- **Results:** Risk for MACE: HR (warfarin vs. no warfarin): 0.87 (0.78 – 0.98)

  Home Days: + 47 days (27 – 68 days) over 2 years

"These findings support the routine use of warfarin for eligible ischemic stroke patients with atrial fibrillation, including those over 80 years of age, women, those with more severe strokes, and those with comorbid conditions"

Y Xian et al., BMJ 2015

PCORI's Research Funding Is Evolving Toward Greater Focus



2012

Broad

- CER, patient-centeredness, engagement required
- Any clinical area in which practice could be changed
- Up to $1.5 million, 3 years

2013

Targeted

- CER, patient-centeredness, engagement required
- Single clinical area, with narrow research question(s)
- Much larger, variable funding amounts, 3-5 years

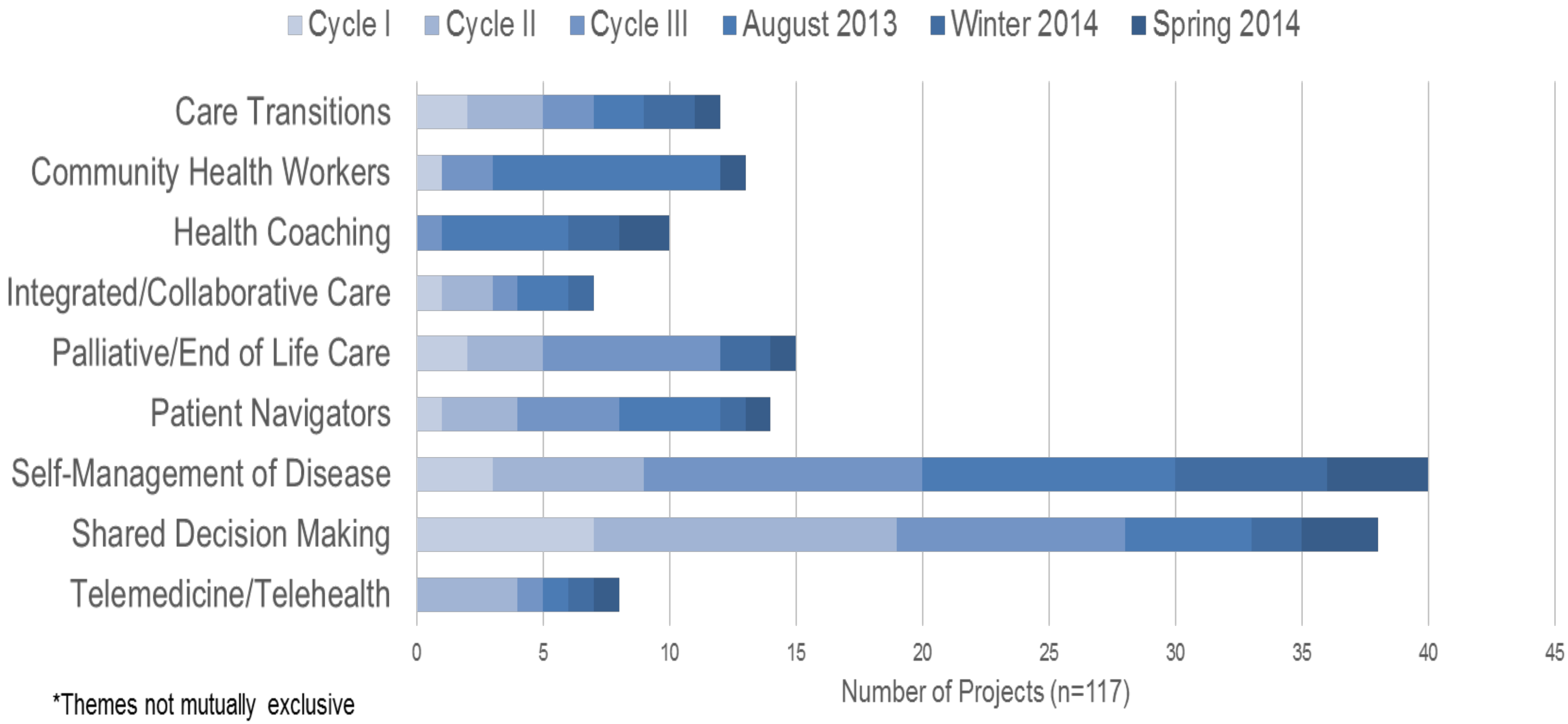
2014

Pragmatic

- CER, patient-centeredness, engagement required
- Set of high-priority topics, narrow research questions
- Up to $10 million direct costs, 5 years

Research on Patient-Centered Care from Broad Announcements

From First 6 Cycles of Broad Funding Announcements



*Themes not mutually exclusive

PCORI's Pragmatic Clinical Studies

- Must address critical clinical choices faced by patients, caregivers, clinicians, systems
- Topics of special interest identified by PCORI Advisory Panels, Institute of Medicine, Agency for Healthcare Research and Quality
- Typically conducted in routine clinical settings
- Though often large, protocols usually less complex than traditional trials
- Requires engagement of major stakeholder organizations

- Two funding cycles per year
- Number of Anticipated Awards Per Cycle: Six to Nine
- Funds Available Per Cycle: Up to $90 Million
- Maximum Project Duration: 5 Years
- Maximum Direct Costs Per Project: $10 Million

First 14 PCORI Pragmatic Clinical Studies

- **Breast cancer screening tailored to individual risk and preferences vs. annual mammography** for detecting breast cancer and minimizing screening-related harms in women 40-80.
- **Annual vs. biennial surveillance CT scanning** in patients found to have small, potentially cancerous growths on initial CT scan.
- **Standing order entry system for guiding use of colony stimulating factor vs. usual oncology practice** for reducing over- and underuse of this medication and preventing complications in patients with breast, lung, colorectal cancer.
- **Comprehensive transitional care program of early discharge and in-home support services vs. usual care** in improving functional status and preventing hospital readmissions and mortality in stroke survivors.
- **Primary care plus prompt referral to physical therapy and cognitive behavioral therapy vs. usual primary care** to prevent acute back pain from becoming chronic.

First 14 PCORI Pragmatic Clinical Studies

Surgical vs. antibiotic therapy for uncomplicated appendicitis for complications, subsequent appendectomy, safety, patient experience

Integrated vs. Referral Telecare for Complex Psychiatric Disorders in Rural Federally Qualified Health Centers (FQHCs) for patient self-reported health-related quality of life, access to care, therapeutic alliance with providers, appointment attendance, medication adherence, self-reported clinical symptoms, medication side effects.

Uncoated aspirin vs. low intensity warfarin vs. rivaroxaban for prevention of venous thrombosis after hip or knee replacement for aggregate clinical pulmonary embolism/deep vein thrombosis and all-cause mortality, bleeding, and patient-reported outcomes.

Full integration of primary care and behavioral care vs. co-location in primary care patients with physical or behavioral problems for self-reported anxiety, depression, fatigue, pain, physical function, sleep disturbance, social participation (via PROMIS-29)

First 14 PCORI Pragmatic Clinical Studies

Healthy lifestyle intervention plus metformin therapy vs. healthy lifestyle intervention alone for reducing weight gain and metabolic problems associated with certain antipsychotic medications in youth with bipolar disorders.

Anti-TNF factor vs. anti-TNF plus low dose of methotrexate in children with Crohn's disease for induction, maintenance of remission, patient-reported outcomes, and adverse events.

Nerve blocking regional anesthesia vs. general anesthesia in older adults undergoing surgery for hip fracture on acute post-operative pain, satisfaction with care, inpatient morbidity, and ability to walk without assistance at 60 and 180 days, health and disability, pain, ability to return home after fracture, and mortality.

Exercise coaching program vs. usual care for older adults who have experienced a low-impact fracture as a result of a fall for preventing further injuries and improving health.

Proton-beam vs. photon-beam radiation therapy post-mastectomy in women with Stage II or III for outcomes of recurrence, mortality, and cardiovascular disease complications of radiation therapy.

Targeted Research Funding Awards

- PCOR treatment options in uterine fibroids*
- Multifactorial fall injury prevention strategy in older persons**
- Effectiveness of transitional care
- Treatment options for African-American and Hispanic/Latino patients with uncontrolled asthma
- Obesity treatment options set in primary care for underserved populations
- Hypertension disparities reduction awards in African-American and rural populations**
- Comparative effectiveness of new treatment options for hepatitis C

*Project administered by AHRQ

**Projects administered by NIH

Newly Announced Targeted Funding Announcements

up to
$30M

Treatment-Resistant Depression

Clinical Strategies for Managing and Reducing Long-Term Opioid Use for Chronic Pain

up to
$40M

Targeted PFAs

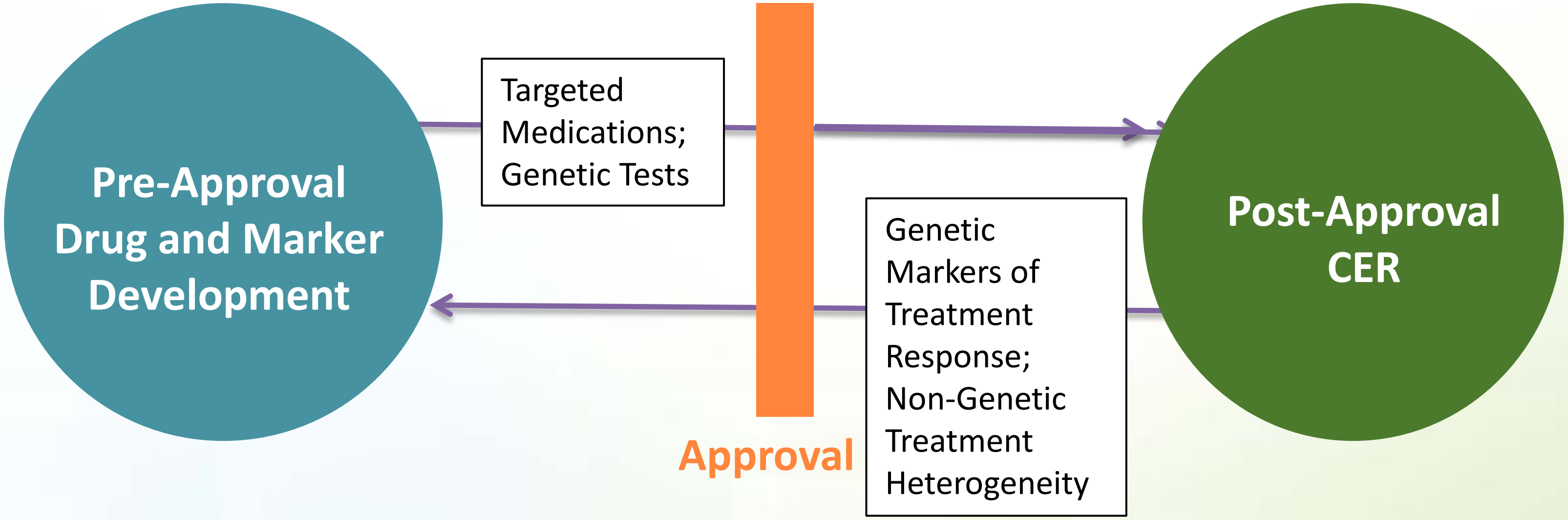
up to
$30M

New Oral Anticoagulants

Treatment of Multiple Sclerosis

up to
$50M

PCOR Is a Key Part of Precision Medicine Research



Pre-Approval Drug and Marker Development

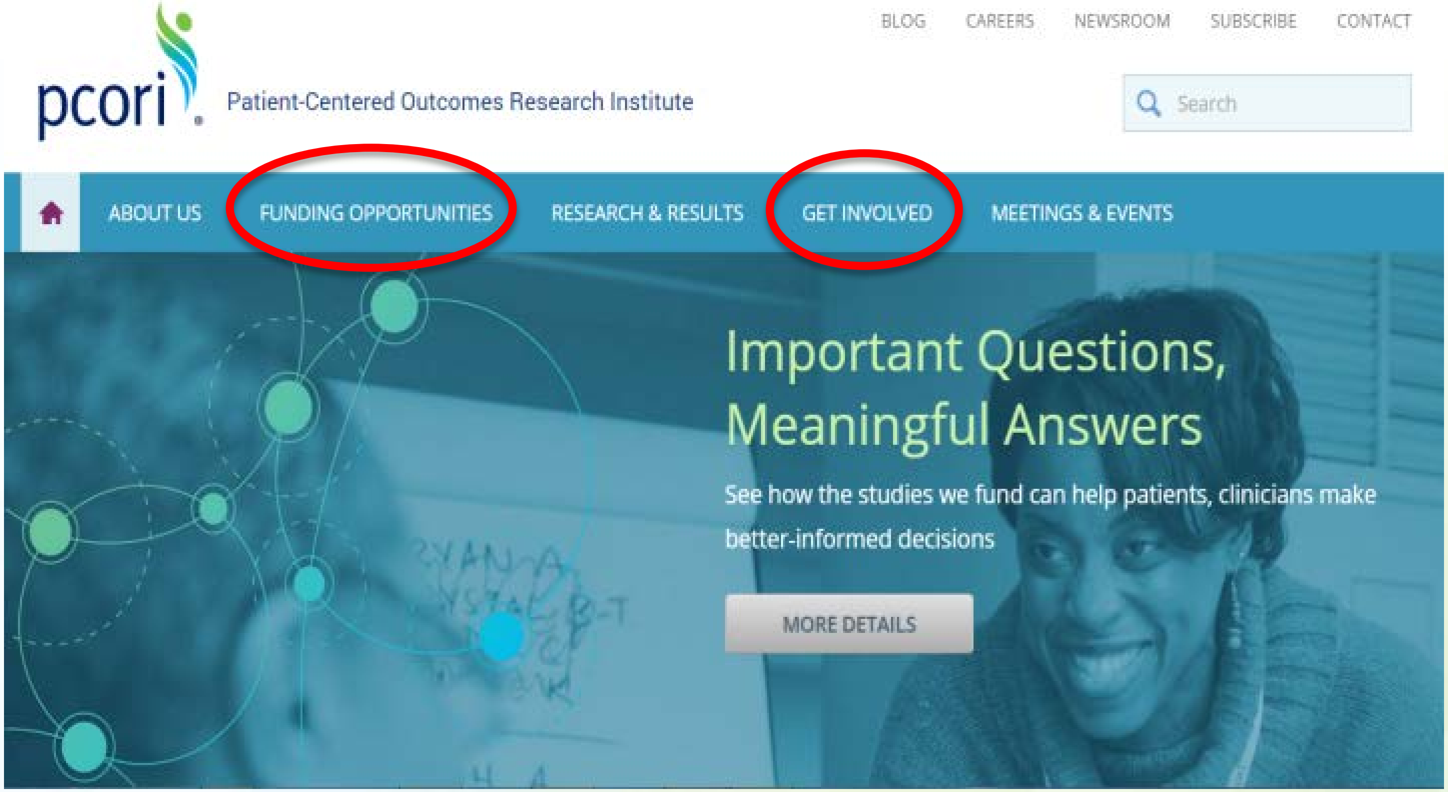
Targeted Medications; Genetic Tests

Approval

Genetic Markers of Treatment Response; Non-Genetic Treatment Heterogeneity

Post-Approval CER

And of Course … www.pcori.org



Important Questions,
Meaningful Answers

See how the studies we fund can help patients, clinicians make better-informed decisions

Lunch

Meaningful Engagement with Patient/Caregiver Organizations as Key Partners in PCS and Targeted Studies

Sue Sheridan, MIM, MBA, DHL
Director of Patient Engagement

Michelle Johnston-Fleece, MPH
Engagement Officer

Jaye Bea Smalley, MPA
Engagement Officer

Lisa Stewart, MA
Engagement Officer

Laurie Davidson, MLIS, Med
Medical Librarian

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Examples of Patient and Caregiver Engagement in Pragmatic Clinical Studies (PCS) and Targeted Studies Currently Funded by PCORI

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Jaye Bea Smalley, MPA

Engagement Officer

October 26, 2015

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Governance Structure

Committees

- Family Advisory Committee*
  - Chaired by advocacy organization representative
- Stakeholder Engagement*
  - Chaired by other advocacy organization representative
- Recruitment and Retention*
- Data Safety Monitoring Board*
- Data Management and Biostatistics
- Outcomes Assessment/QOL*
- Dissemination*
- Steering Committee*
  - Two advocacy organization representatives

Decision-making bodies – Steering Committee and Family Advisory Committee.

* These committees include patient representatives.

Patient Organization and Patient/Caregiver Partners

- Representative from a national office of an advocacy organization is chair of Stakeholder Advisory Committee.
- Regional chapter representative from another national advocacy organization is chair of Family Advisory Committee.
- 14 individuals who are patients or caregivers.
- Patients and caregivers are representative of the two regions where the trial is being deployed.

Promising Engagement Practices

- Following invitation to submit the application, the research team deployed a survey to patients, caregivers, and clinicians to ensure research question and aims were priorities and to inform protocol design.
- Patient organizations partnered to deploy survey to patient and caregiver partners, researchers deployed survey to clinicians in respective health systems.
- Trial decisions include Family Advisory Committee in addition to the steering committee.
- Plans to evaluate adherence to engagement principles throughout the course of the study.

Lisa Stewart, MA

Engagement Officer

October 26, 2015

Governance Structure

- Co-Investigator Team
  - 3 institutions
- Study Team
  - Research institutions + staff of local primary practices
- Patient Advisory Panel
- Health Systems Stakeholder Group
  - PCPs, NCQA, AAFP, state health plan, and disease management organization
- Community Interest Stakeholder Group
- DSM-EC

Patient Organization and Patient/Caregiver Partners

- 10 patient advisors representative of four states
- Four local and regional patient advocacy groups, plus state department of health and county health services
- Contributed to:
  - Development of intervention
  - Defining eligibility criteria and outcome measures
  - Shaping content of website, patient manuals, self-monitoring tools, healthy eating and budgeting tips

Promising Engagement Practices

- Patient advisors involved with recruitment of clinical practices.
- Team designed an eight-domain engagement rubric that is used as a project assessment tool.
- Select study participants will be involved with process evaluation as they roll off study.
- Dissemination Planning Meeting to occur in year 5 with all partners and stakeholders.

Michelle Johnston-Fleece, MPH

Engagement Officer

October 26, 2015

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Governance Structure

- **Core Engagement Group**
- **Statewide Patient and Stakeholder Engagement Committee**
- **Steering Committee**
  - *Includes Patient and Stakeholder Engagement Committee Co-Chairs*
- **Executive Committee**
- **Intervention Committee**
- **Dissemination and Implementation Committee**
- **Assessment and Outcomes Committee**
- **Community Coalitions for Improving Post-Acute Services**

Governance Structure (cont.)

- **Hospital and Community Partner Committee**
- **Statewide Care Collaborative**
- **QI Improvements and Analytics Committee**
- **Data Management/IT Platform Committee**
- **Data Analysis Committee**

- **For All Committees:**
  - *70% Consensus rule*
  - *"Engagement Advocate" identified*

Patient Organization and Patient/Caregiver Partners

- State policy lead for large national advocacy organization (who is also a family caregiver)
- 2 Patients, 2 Family Caregivers on Core Engagement Group
- External Advisory Board members being identified (including national stakeholders); will likely convene in Year 2 of study

Community Involvement

- Community coalitions to be developed; to be led by care coordinator who manages intervention at each site
- AAAs involved in intervention development
- AAAs, AHECs, and university expert in disparities involved to foster community relationships

Promising Engagement Practices

- Dedicated Co-I to lead engagement
- “Engagement Advocate” in all meetings
- REDCap Engagement tracker
- Engagement processes included in Manual of Operations
- Annual evaluation of engagement
- Quarterly check-ins with stakeholders by Engagement Committee Co-Chairs

PCS Engagement Questions Identified by Engagement Officers

- How can patient organizations ensure transparency and co-learning to constituency given the unique issues that present in pragmatics? *Example: Consideration of contamination and selection bias if outreach too broad.*
- What guidance might PCORI give on local vs. national patient and patient organization representation?
- What guidance might PCORI give on individual patient vs. patient organization representation?
- What guidance might PCORI give on ensuring adequate patient population representation? *Example: age group, racial/ethnic representation*
- What considerations and activities should PCORI consider and address so that patient and caregiver organizations are engaged throughout the entire lifecycle of a five-year trial?

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15-Minute Break

Breakout Sessions

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Report Back from Breakouts

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Listening to Stakeholders: Learning from PCORI Surveys on CER and Engagement

Lauren Fayish, MPH
Laura Forsythe, PhD, MPH
Lori Frank, PhD

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Today’s Presentation

- Stakeholder survey objectives and methods
- Key findings on research engagement
  - Patients and caregivers
  - Clinicians
  - Researchers

Stakeholder Survey Objectives

- To understand attitudes toward CER
- To understand the use of health information in decision making
- To understand awareness of and attitudes toward engagement in research
- To evaluate the potential for engagement in research to enhance the uptake of research results in clinical practice
- **To inform methods to facilitate use of CER and the engagement of patients and stakeholders in research**

Survey Development

- Partnership with American Institutes for Research (AIR)
- Guided by an overarching multi-stakeholder advisory panel and four survey-specific working groups
- Survey development included literature review and cognitive testing
- Surveys fielded September 2014 – January 2015

Patients

Caregivers

Clinicians

Researchers

Survey Samples and Recruitment

Sample	Methods for Recruitment	
PATIENT	Rare Conditions Convenience samples obtained through Genetic Alliance liaising with relevant advocacy organizations to survey their members (N=560 patients, 609 caregivers)	Chronic Conditions Nationally representative samples obtained via probability-based online panels (GfK Knowledge Panel®) (N=762 patients, 776 caregivers)
CAREGIVER		
CLINICIAN	Nationally representative sample of primary and specialty physicians, physician assistants, and nurse practitioners drawn from the American Medical Association MasterFile (N=638)	
RESEARCHER	Convenience sample of clinical researchers invited via 23 professional organizations and the PCORI mailing list (N=508)	

Selected Findings:

Patient and Caregiver Views on Engagement in Research


Patients

Caregivers

Clinicians

Researchers

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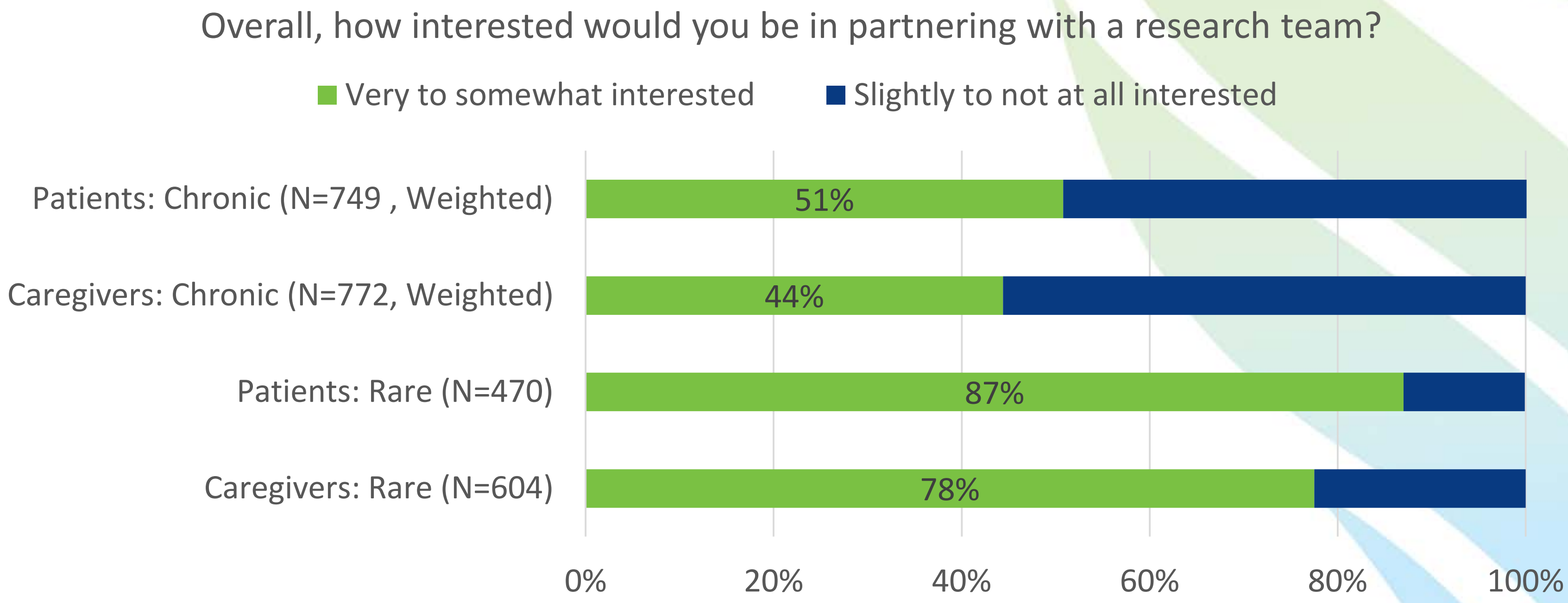
Patient and Caregiver Views on Interest in Engagement



Interest in engagement in research was highest among rare disease patients and rare disease caregivers.

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Patient and Caregiver Views on Preferred Roles for Engagement

- Helping researchers understand what information they need
- Helping researchers make findings easy to understand
- Helping researchers get results out

Top Factors in Determining Whether to Partner with Researchers

- Belief that participation can result in meaningful findings
- Feeling respected by the researchers
- Having an interest in the research
- Having meetings at a time that doesn’t interfere with other commitments
- Receiving information about research and how it is conducted
- Working for a team or organization that you know and trust

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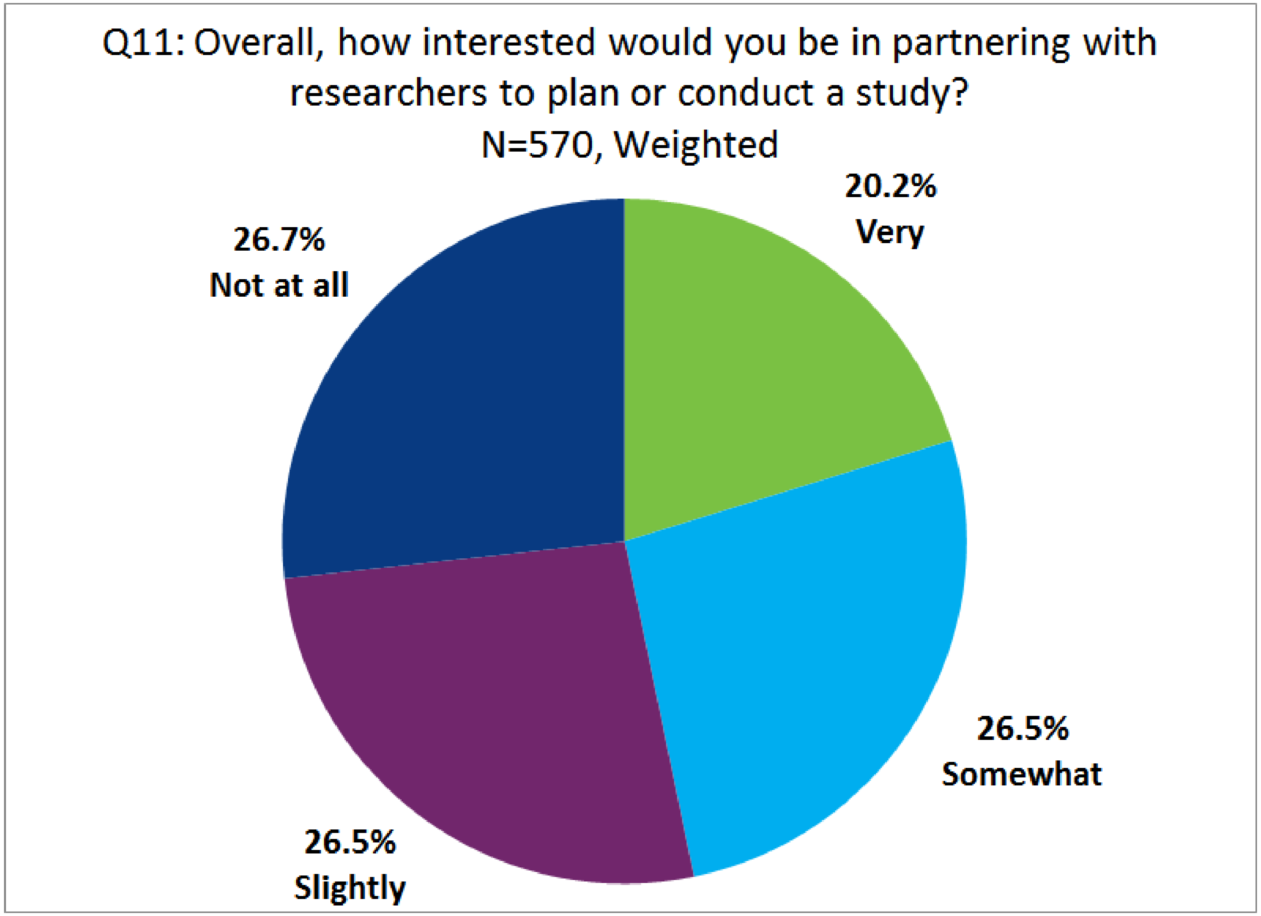
Summary: Patient and Caregiver Views

1. Familiarity with research engagement is low, but interest in engagement is high, particularly for translating results and sharing findings.
2. Rare disease patients and caregivers may be particularly enthusiastic about partnering in research.
3. For patients and caregivers, key facilitators of research partnership were a belief that participation in research can result in meaningful findings, feeling respected by researchers, and having an interest in the research.

Selected Findings:

Clinician Views on Engagement in Research

Clinician Views on Interest in Engagement



Many clinicians expressed interest in engaging with researchers as partners.

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Areas of Interest for Partnering with Researchers: Clinicians (% “Very Interested”)

Most Interest

- Helping decide which interventions to compare (30%)
- Identifying key implications of study findings for clinical practice (30%)
- Communicating findings to other clinicians (25%)

Least Interest

- Helping researchers analyze the data (12%)

Factors for Determining Whether to Partner with Researchers: Clinicians (% “Very Important)

Highest Importance

- Helping patients receive better care (75%)
- Contributing to scientific knowledge (57%)
- Making studies more meaningful to patients (56%)

Lesser Importance

- Improving professional satisfaction (36%)
- Helping researchers decide what to study (31%)
- Getting paid for my time (30%)
- Learning more about how research works (23%)

Factors Preventing You from Partnering with Researchers: Clinicians (% “Very Important”)

Highest Importance

- Lack of time (67%)

Lesser Importance

- Lack of training in research (29%)
- Lack of compensation for time/effort (26%)
- Lack of interest in research (19%)
- Lack of access to researchers (19%)
- Belief that research will have minimal impact on patients (6%)
- Distrust of researchers (4%)

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Summary: Clinician Views

1. Clinician familiarity with research engagement of patients and clinicians is low, but interest in engagement is high.
2. Clinicians see value for partnership (particularly clinician partnership) to improve the value of research.
3. Clinicians expressed most interest for working with researchers to decide comparators, identify key findings, and communicate findings for other clinicians.
4. Key facilitators were helping patients receive better care, contributing to scientific knowledge, and making studies more meaningful to patients. Lack of time is a key barrier.

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Selected Findings:

Researcher Views on Engagement in Research


Patients

Caregivers

Clinicians

Researchers

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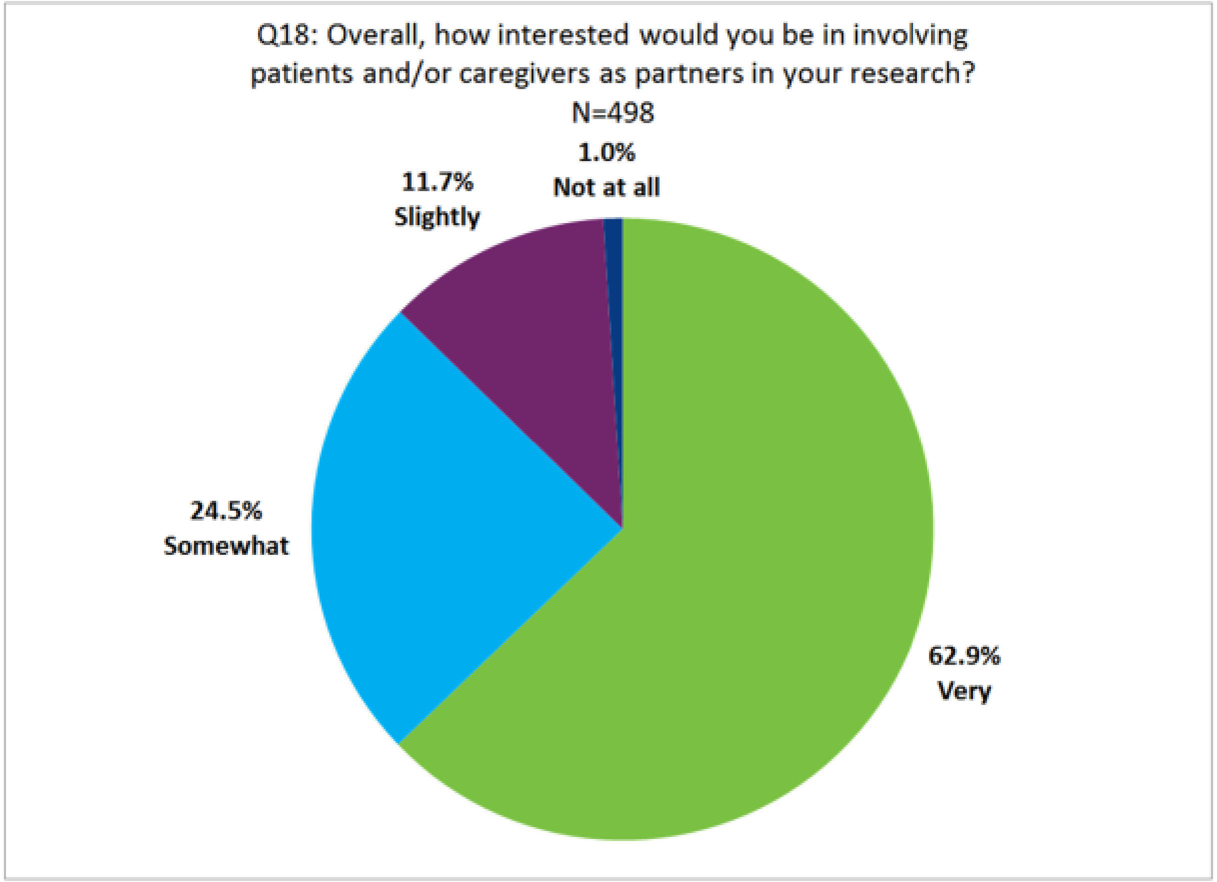
Researcher Views on Interest in Engagement



The majority of researchers are interested in partnering with patients and caregivers in their research

Researcher Views on Preferred Roles for Engagement

How valuable do you think involvement of patients and/or caregivers in the following activities could be to your research? (% "Very Valuable")	
	%
Participant recruitment or data collection	62
Identifying research topics or agenda	59
Dissemination of findings	57
Developing the research questions	48
Results review, interpretation or translation	36
Proposal development	27
Study design: identifying comparators, measures, and interventions	24
Data analysis	6

Factors Facilitating Involvement of Patients or Caregivers in Research (% "Very Important")

- Resources to assist in the training and coordination of patient and/or caregiver partners (63%)
- Guidance in successfully applying for funding that requires patient and/or caregiver partners (58%)
- Empirical evidence showing the value of patient and/or caregiver partners in research (45%)
- Training for me and other staff in co-leading research with patient and/or caregiver partners (39%)

Factors that Would Hinder Engagement for Researchers (% “A Great Deal”)

Top Endorsed Barriers

- Lack of infrastructure to support partners in research (48%)
- The potential increased resources to work with partners (37%)
- Regulations (HIPAA, IRB concerns) (34%)

Summary: Researcher Views

1. These researchers, who were relatively familiar with engagement, expressed interest in partnering with patients and caregivers.
2. Researchers see most value for engagement in:
   - Participant recruitment/data collection
   - Identifying research topics/research questions
   - Disseminating findings
3. Key facilitators for research engagement include additional resources and training to support engaged research.

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Webinar Series

- Listening to Patients, Caregivers, and Clinicians: Meeting Stakeholder Needs for Comparative Effectiveness Research- A PCORI Survey
  - November 4: 11am

- Listening to Researchers: Meeting Stakeholder Needs for Comparative Effectiveness Research - A PCORI Survey
  - November 18: 11am

Thank You!

Lauren Fayish, MPH

Program Associate, Evaluation and Analysis

Patient-Centered Outcomes Research Institute (PCORI)

For additional questions, please email surveys@pcori.org

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Questions?

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Wrap-Up

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Day 1 Conclusion