

PCORI in Practice Webinar Series

Patient and Stakeholder Engagement in Research: Strategies for Initiating Research Partnerships

July 19, 2017



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

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
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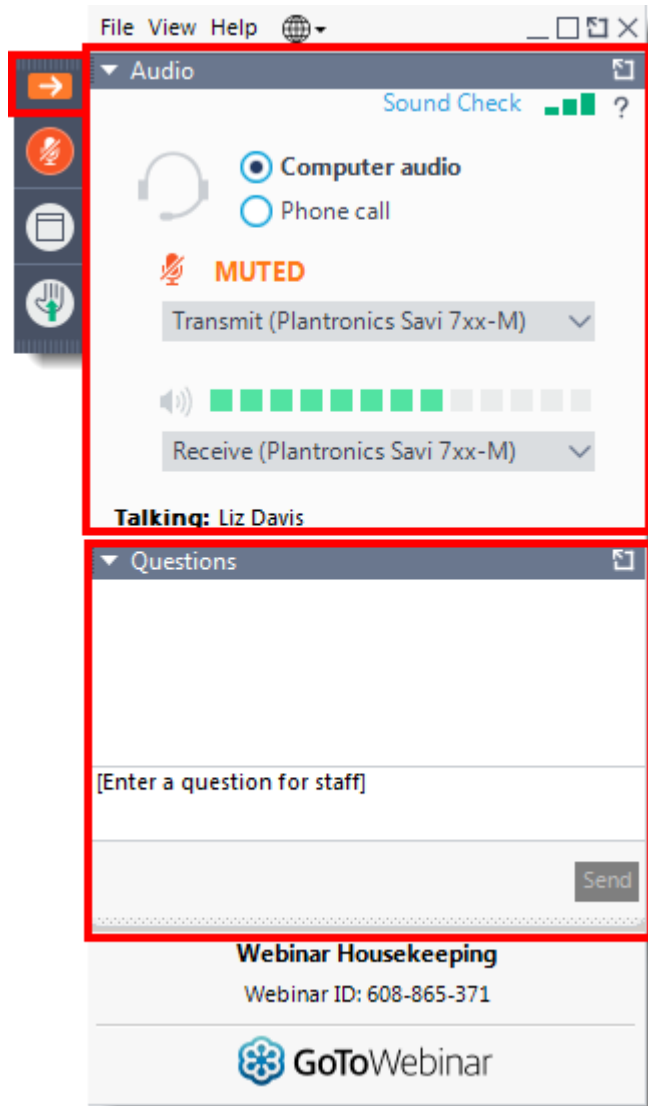
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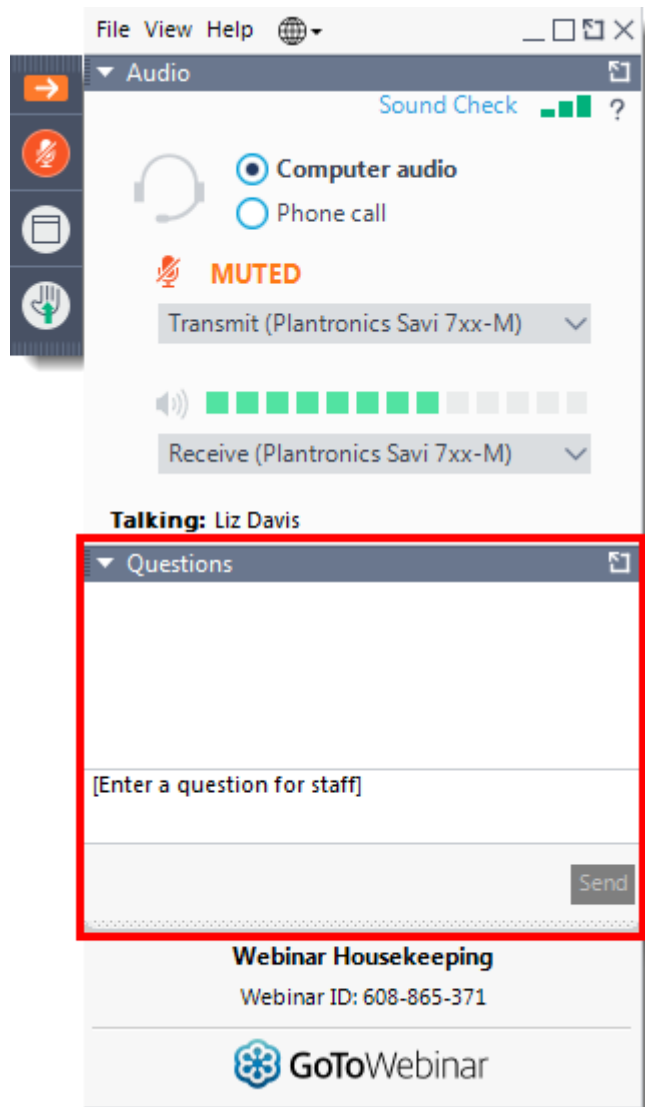
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An archive of this webinar will be posted to <http://www.pcori.org/events/2017/patient-and-stakeholder-engagement-research-strategies-initiating-research-partnerships> following this event.



Introductions



Rachel Hemphill, PhD
Program Officer
Evaluation & Analysis



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Engagement Officer
Public & Patient Engagement



**Sunbo Igho-Osagie, MHSA,
PMP, CSSGB**
Program Associate
Public & Patient Engagement



Agenda

- Introduction to PCORI
- Key Findings: Initiating Research Partnerships
- Presentations by PCORI Awardees and Community Partners
 - ❖ Karen Wernli and Dianne Johnson
 - ❖ Giana Davidson and Nathan Shapiro
- Q&A
- Wrap-up



Learning Objectives

At the conclusion of this webinar, participants will be able to:

- Describe strategies for finding potential patient and stakeholder partners and initiating partnerships for research projects
- Identify challenges that may arise when establishing partnerships between researchers, patients, and stakeholders
- Understand the value patient and stakeholder partners bring to research projects



Introduction to PCORI



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Our Mission and Strategic Goals

PCORI helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from **research guided by patients, caregivers, and the broader healthcare community.**

Our Strategic Goals:



Increase quantity, quality, and timeliness of useful, trustworthy research information available to support health decisions



Speed the implementation and use of patient-centered outcomes research evidence

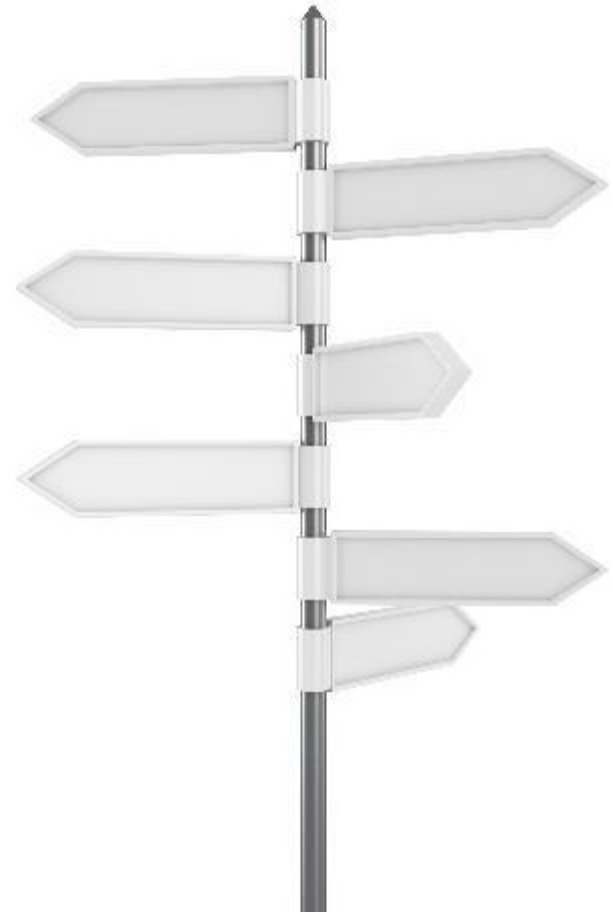


Influence research funded by others to be more patient-centered



How Is Our Work Different?

- We fund research on which care options work, for whom, under which circumstances.
- We focus on answering questions most important to patients and those who care for them.
- We aim to produce evidence that can be easily applied in real-world settings.
- We engage patients, caregivers, clinicians, insurers, employers, and other stakeholders throughout the research process.
- This makes it more likely we'll get the research questions right and the study results will be useful and taken up in practice.



PCORI's Approach to Research

“Patient-centeredness”

- The project aims to answer questions or examine outcomes that matter to patients within the context of patient preferences
- Research questions and outcomes should reflect what is important to patients and caregivers



“Patient and stakeholder engagement”

- Patients are partners in research, not just “subjects”
- Active and meaningful engagement between scientists, patients, and other stakeholders
- Community, patient, and caregiver involvement already in existence or a well-thought-out plan



PCORI's Approach to Engagement-Our Engagement Rubric



POTENTIAL ACTIVITIES
<ul style="list-style-type: none"> • Developing research questions • Selecting relevant outcomes • Define study population characteristics

POTENTIAL ACTIVITIES
<ul style="list-style-type: none"> • Drafting or revising study materials • Participating in study recruitment • Participating in data analysis

POTENTIAL ACTIVITIES
<ul style="list-style-type: none"> • Identifying partners for dissemination • Participating in dissemination efforts • Presenting information about the study

REAL-WORLD EXAMPLES
<ul style="list-style-type: none"> • Patient organization surveys members on treatment preferences • Clinicians suggest a third arm to study based on variability in practice

REAL-WORLD EXAMPLES
<ul style="list-style-type: none"> • Patients develop informed consent to make it understandable to participants • Patient representative serves on data safety monitoring board

REAL-WORLD EXAMPLES
<ul style="list-style-type: none"> • Research team holds stakeholder summit to speed implementation of findings • Research team introduces study at a patient advocacy conference to inform community of the research

	<h2>PCOR Principles</h2> <p>Reciprocal Relationships • Co-Learning • Partnerships • Transparency, Honesty, Trust</p>
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Reciprocal Relationships: Demonstrated when roles and decision-making authority of all research partners are defined collaboratively and clearly stated

Co-Learning: Researchers help patient partners better understand the research process, and researchers will learn about patient-centeredness and patient/stakeholder engagement

Partnerships: The time and contribution of patient and other stakeholder partnership is valued and demonstrated through compensation, cultural competency, and appropriate accommodations

Transparency, Honesty, Trust: Major decisions are made inclusively and information is shared readily among all research partners

Key Findings: Initiating Research Partnerships



Information Sources and Methods

Ways of Engaging-ENGagement ACtivity Tool (WE-ENACT)



PCORI Research Awardees

N=179 awardees
from PCORI's early
funding cycles



Patient & Stakeholder Partners

N=246 partners
from PCORI's early
funding cycles

Applicant Survey



PCORI Applicants

N=893 applicants
across 9 funding
cycles



Who engages as partners in PCORI research projects?

PCORI projects engage with partners from many communities.



89%

PATIENTS



89%

CLINICIANS



59%

HEALTH SYSTEMS



58%

ADVOCACY ORGS



53%

CAREGIVERS

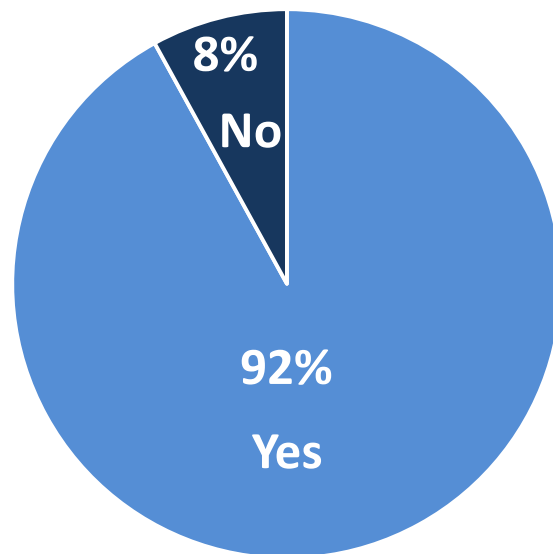
PCORI projects also engage with community-based organizations (24%), payers (15%), policymakers (14%), training institutions (14%), industry (6%), and purchasers (2%)



When do research partnerships begin?

Most applicants for a PCORI research award form partnerships before submitting their applications.

“Did you establish a patient/stakeholder research partnership prior to applying for PCORI funding?”



“How long before submitting your application did you establish a partnership?”

- Less than 6 months: 32%
- Between 7 months and 1 year: 26%
- Between 1 and 5 years: 24%
- More than 5 years: 9%



How do PCORI applicants and awardees connect with potential partners?

Organizations

- Patient/family support groups or advocacy organizations
- Community organizations (eg, senior centers, cultural centers, churches), community leaders, and events
- Existing institutional advisory councils (eg, hospital's patient and family advisory council)

Individuals

- Patients receiving clinical care and their families
- Participants and partners from previous research studies
- Patients and stakeholder recommended by colleagues or existing partners

Note: data from open-ended responses collected via voluntary surveys of PCORI research awardees (N=179), PCORI patient/stakeholder research partners (N=246), and applicants to PCORI research awards (N=454).



Some lessons learned from PCORI awardees and partners

Engage early.

- Engage patient and stakeholder partners early in the process, preferably while developing your research proposal.
- Use a variety of methods to connect with patients and other stakeholders.

Plan ahead.

- Keep in mind that it takes time and effort to establish partnerships and build trust.
- Plan ahead to manage proposal deadlines and funding for engagement activities when engaging partners during proposal development.

Note: data from open-ended responses collected via voluntary surveys of PCORI research awardees (N=179) and PCORI patient/stakeholder research partners (N=246).



Some lessons learned from PCORI awardees and partners

Foster positive relationships.

- Ensure that the work is a good fit with partners' interests and abilities.
- Create a welcoming environment for partners by encouraging, listening to, and valuing their input.
- Be open with partners about the research process and the likelihood of funding.

“Trusting your researchers is hugely important...Transparency and explaining “why” often goes a long way in developing this trust.” – Patient/Stakeholder Partner

Note: data from open-ended responses collected via voluntary surveys of PCORI research awardees (N=179) and PCORI patient/stakeholder research partners (N=246).



Panelist Presentations



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Comparative Effectiveness of Surveillance Imaging Modalities in Breast Cancer Survivors (SIMBA Study)

Karen Wernli, PhD
Associate Investigator
Kaiser Permanente Washington Health
Research Institute



Dianne Johnson
Patient Partner
Kaiser Permanente Washington Health
Research Institute





Solutions and Challenges in Patient Engagement

Lessons from SIMBA

Karen J. Wernli, PhD – Principal Investigator

Dianne Johnson – Patient Partner

July 19, 2017



Our SIMBA goal

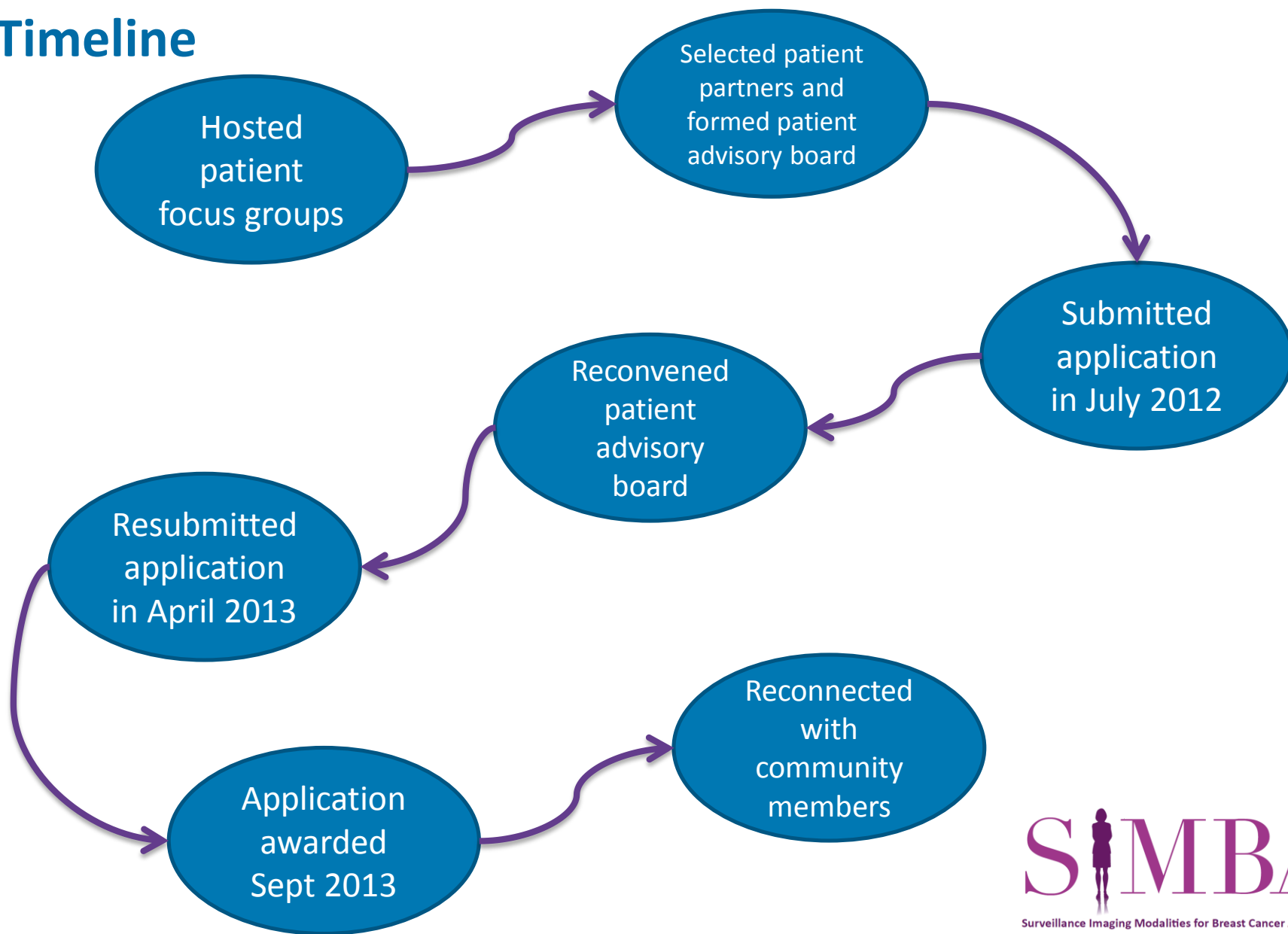
Fill the **clinical gap in knowledge** about how well breast MRI in adjunct to mammography works compared to mammography alone in women after treatment for breast cancer

Provide **evidence needed** to assist patients and providers with clinical decision-making

Disseminate results effectively for **implementation** in practice



Timeline



Hosted patient focus groups

Primary purpose: to identify 2 patient partners

Goal was to find women with general experience of breast cancer outside of my institution and to represent varying perspectives in breast cancer care.

Recruited from:

- workplace intranet

- young survivor listserv

- flyers distributed at Race for the Cure



Invited patient partners and advisory board members

Criteria of selection: different ages and cancer stage and willingness to be open to study results

Sent an email request with a copy of the abstract to patient partner for invitation.

All women not invited to be patient partners were asked to be members of patient advisory board and provided letters of support



Preparing to partner

- Listen to others and bring more than your story to the research
- Be open to learning
- Be bold and speak up
- Be patient, everyone is learning a new way of conducting research



Reconvened patient advisory board

- Several comments in critiques about the role of the patients in the research
- We used a reconvened patient advisory board meeting to discuss the questions and comments.
- Helped with a compelling argument
- All women provided a letter of support again



How to get involved

- Connect with organizations that support your area of interest
- Participate in focus groups
- Visit web sites that provide resources for your area of interest
- Consider Twitter



Reconnected with community members when funded

- Our focus group participants reflect the community we live: fairly educated Caucasian women
- With funding, we had more time to involve women of color and other diverse backgrounds in our patient advisory board by:
 - Sending Patient advisory board recruitment materials to
 - African American women support group
 - Listservs distinct to particular racial/ethnic backgrounds
 - Posting within cancer support groups, ie Cancer Lifeline
 - Attended play focused on breast cancer in African American women
 - All new members were met in person by PI and project manager



Tips for starting off

- This is cross cultural work – to be successful people need to be flexible and willing to change
- Be prepared – partners and research staff might not agree on what is of value from the study
- Engage all parties and listen carefully before crafting processes or conclusions.



Considerations and Challenges

- Working together is like working with any colleague—Or picking your college roommate!
- Pace of research compared to the real world
- Research culture and communication



SIMBA
Surveillance Imaging Modalities for Breast Cancer Assessment

Thank You

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@WernliKarenJ

@diannej84



Comparing Outcomes of Drugs and Appendectomy (CODA Study)

Giana Hystad Davidson, MD, MPH, FACS
University of Washington
Assistant Professor, Division of General Surgery
Medical Director, Post-Acute Care UW Medicine



Nathan Shapiro, MD, MPH
Vice Chair of Emergency Medicine Research
Associate Professor of Emergency Medicine
Beth Israel Deaconess Medical Center & Harvard Medical School



Stakeholder Engagement in Protocol Development & Implementation: Building a Village



Comparing Outcomes of Drugs & Appendectomy

Giana Davidson, MD MPH

Nathan Shapiro, MD MPH

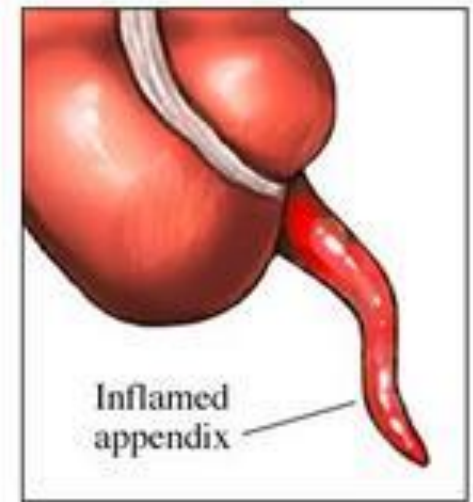
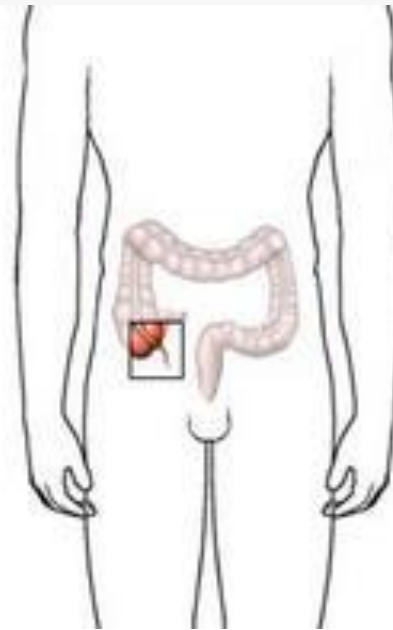
Patient and Stakeholder Engagement in Research:

Strategies for Initiating Research Partnerships

July 19, 2017

Appendicitis: Significance and Background

- Lifetime risk is 7-12%
- Appendectomy is most common urgent general surgical procedure
 - Performed in nearly 300,000 Americans each year (97.5% of appendicitis patients)



Why Appendectomy?

- Perceived safety
- Payment
- Antibiotic resistance
- Variability in outcomes
- Research focus in U.S. on technique

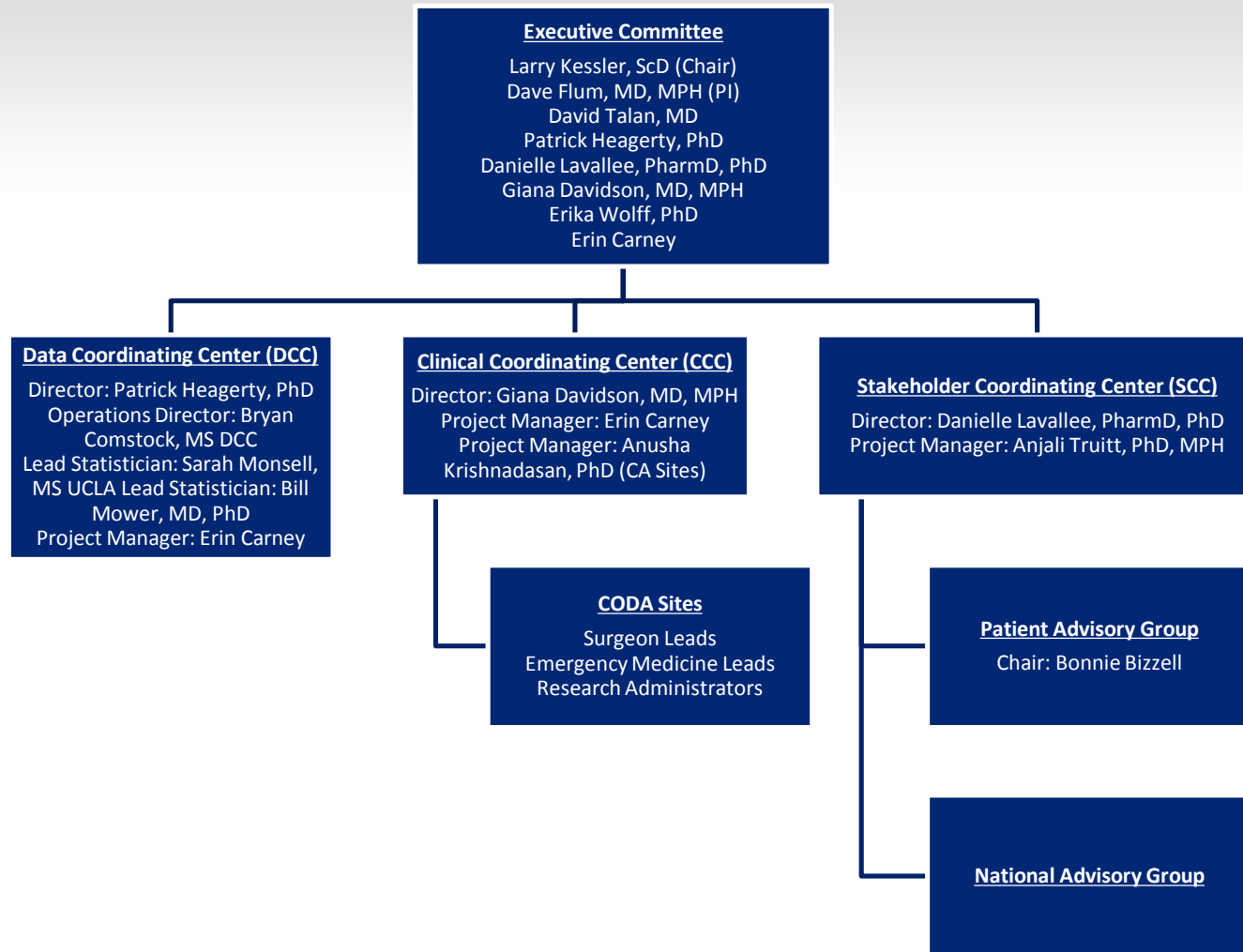


Stakeholder Perspective: Why Rock the Boat?

- Patients
- Hospital
- Surgeon
- Payer



Colleagues & Collaborator: Org Structure



Emergency Medicine: Surgery: Primary Care



Risk/Benefit of Appendectomy vs. Antibiotics: Multiple Perspectives

- **Emergency Medicine:**
 - Throughput in the ED
 - Repeated imaging
 - Who can I send home vs who needs to be admitted?
- **Surgeons:**
 - Do patients that “fail” antibiotics have more complex surgery
 - Who is more likely to be successful in each treatment arm?
 - Missed appendiceal neoplasms
- **Primary Care Providers:**
 - Burden of long-term pain, antibiotic resistance
- **Patients:**
 - I have finals/single parent/income relies on tips...
 - How can I go back to work quicker?
 - How long until this pain goes away?

CODA Research Proposal Development

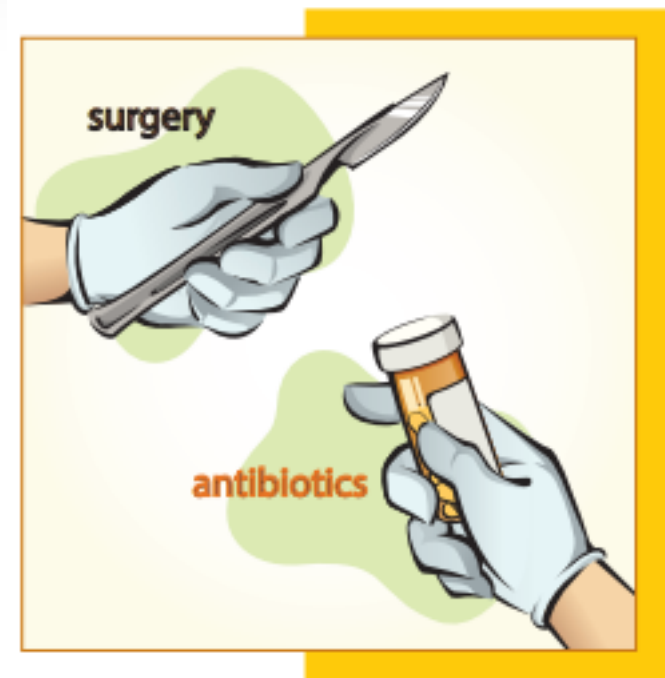
- Engaged patients, clinicians (ED, surgery, primary care), healthcare administrators, funders and researchers across WA state
- Used multi-modal approach to engagement
- Planning took place over 9 months
- Non-funded work
- 6:30 a.m. Friday morning conference calls

Clinical Stakeholder Engagement

- Identified **Clinician Partners** from 10 hospitals in WA
 - Weekly meeting on proposal development
 - Advise on study protocol and patient-facing materials
 - Serve as study champions at their hospitals
- Clinicians from Europe (ASGBI) surveyed in how they use antibiotics in practice.

CODA: Research Questions

1. Are antibiotics as effective as appendectomy for uncomplicated appendicitis?
2. Which patients are most likely to have a successful outcome with antibiotics-first?



What Matters to Patients

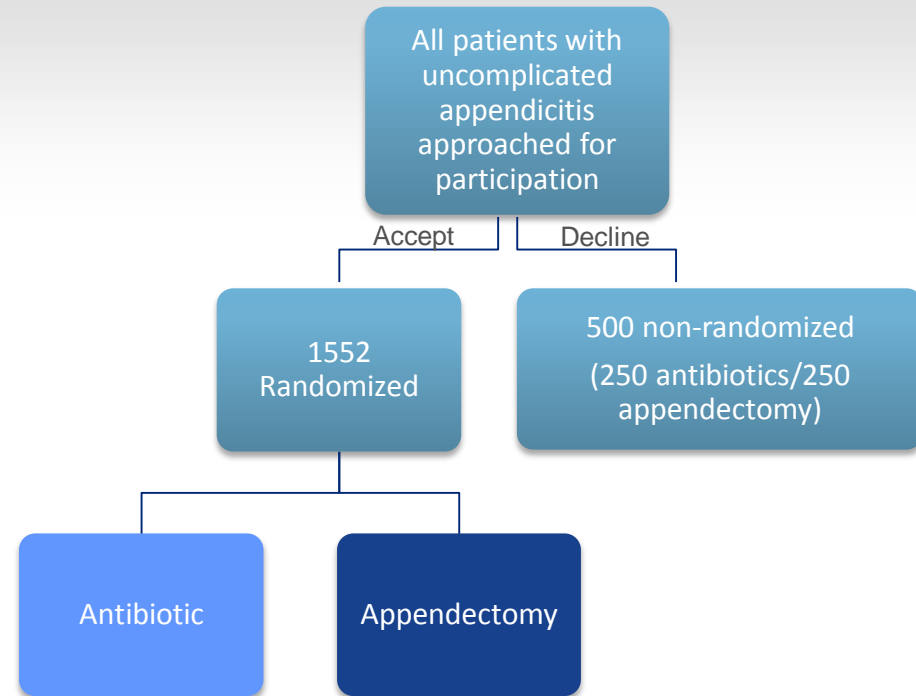
Are the benefits of avoiding surgery outweighed by the potential burdens?

- Recurrence of appendicitis and eventual surgical intervention
- Lingering symptoms
- Anxiety and uncertainty impacting quality of life and return to work/school
- Long-term antibiotics



CODA Study Design

- Randomized controlled trial
 - Large-scale (n=1,552)
 - Non-inferiority based
 - Antibiotics “just as good as” appendectomy
 - Pragmatic
 - Routine clinical practice settings, heterogeneous population
- Parallel observational cohort (n=500)



Collaborative Implementation

There is a critical need for collaboration at design and implementation

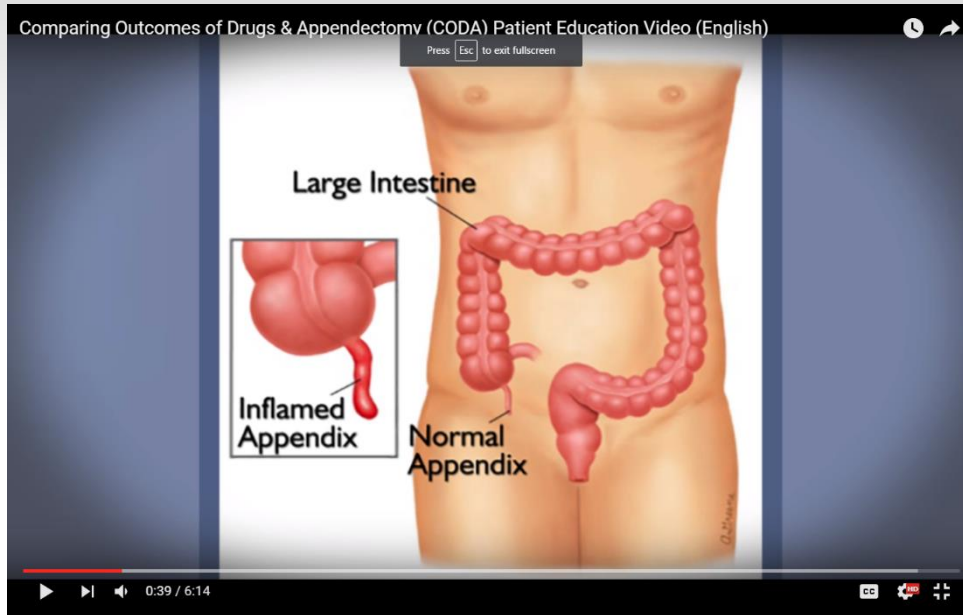
- Run-in period
- Messaging to Primary Care Providers
- Consistent messaging to patients



Standardized Information & Informed Consent

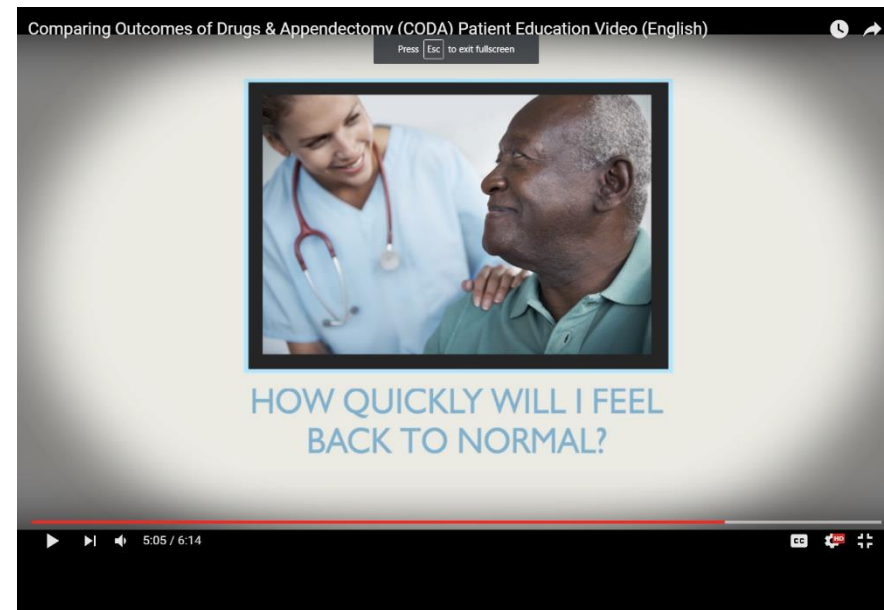
- Improves communication to patients
 - Clear message regarding treatment
- Need to normalize options
- Improve patient expectations
- Decrease operating on the antibiotic arm

Standardizing Patient Information



- English and Spanish
- Collaborative development: surgeons, ED docs, media team, patient advisors

- **Challenge:** Deliver standardized patient information across all sites
- **Solution:** 6-minute video given to all patients diagnosed with appendicitis



Clinician Engagement: Weekly Newsletter



In This Issue:

- [Recruitment Summary](#)
- [Appendectomy Treatment Outcomes in Older Adults](#)
- [Stakeholder Engagement Twitter Chat Transcript Now Available](#)
- [Intern Presents CODA Poster at Research Symposium](#)
- [Appendicitis in the News](#)
- [Save the Date: 2017 PCORI Annual Meeting](#)
- [CODETTA Ancillary Trial: Thank You for Your Support!](#)

Clinical Team Coordination with Research Team

Your CT scan confirms you've got appendicitis. We are participating in an important research project that is trying to figure out the best treatment for appendicitis.

I think you're a great candidate for this national appendicitis study we're participating in.



Can I invite a research coordinator in to show you a video and talk to you about this ground breaking study?

Real Time Feedback:

Research Coordinator -- Clinical Leadership

- Site:
- Research Coordinator:
- What went well/success stories:
- What challenges did you have/lessons learned:
- Who was most helpful to you during this experience:
- How much total time did you spend recruiting and enrolling this participant? (identification-->enrollment via portal + baseline survey completed)?
- How long did the baseline survey take?
- Reason(s) for declining randomization OR factors that facilitated randomization:
- Times of page, screening call-back, arrival to ED, in-person eligibility confirmation, approach:



Collaboration across research specialties

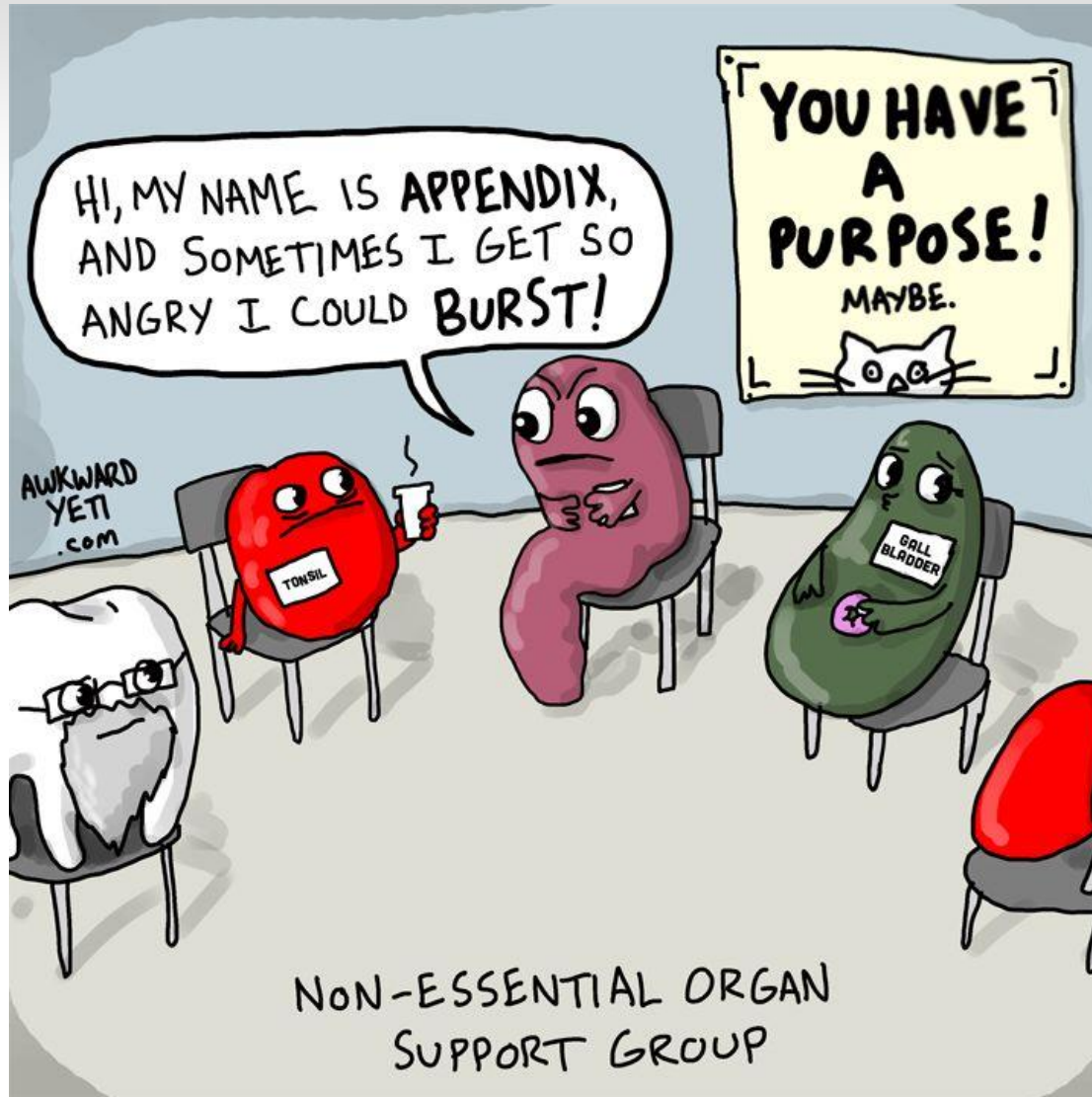
Basic Science : Health Services Research



Acknowledgments

- CODA is led by investigators at the Comparative Effectiveness Research Translation Network (CERTAIN) in collaboration with surgeon and EM researchers from across 12 hospitals
- ClinicalTrials.gov Identifier: **NCT02800785**
- Funding
 - Research reported in this presentation was funded through a Patient-Centered Outcomes Research Institute (PCORI) Award (1409-24099)

Questions and Information



codastudy.org

Q&A



PATIENT-CENTERED OUTCOMES RESEARCH INSTITUTE

Reference Articles

Johnson et al. *Research Involvement and Engagement* (2016) 2:6
DOI 10.1186/s40900-016-0020-4

Research Involvement
and Engagement

COMMENTARY

Open Access

The patient voice in research—evolution of a role



Dianne S. Johnson, Mary T. Bush, Susan Brandzel and Karen J. Wernli*

* Correspondence: wernli@ghc.org
Group Health Research Institute,
1730 Minor Ave, Suite 1600, Seattle,
WA 98101, USA

Plain english summary: Engaging patients in research studies is becoming more common because it makes research and its results more relevant for patients. It is important to understand the best ways for patients and researchers to work

Research Involvement and Engagement.

2016 2:6. doi: 10.1186/s40900-016-0020-4.

<http://www.pcori.org/research-results/2013/comparative-effectiveness-surveillance-imaging-modalities-breast-cancer>

Annals of Family Medicine.

Sheridan S, Schrandt S, Forsythe L, Hilliard TS, Paez KA; Advisory Panel on Patient Engagement (2013 inaugural panel). [The PCORI Engagement Rubric: Promising Practices for Partnering in Research](#). *Ann Fam Med*. 2017 Mar;15(2):165-170. doi: 10.1370/afm.2042. PubMed PMID: 28289118.

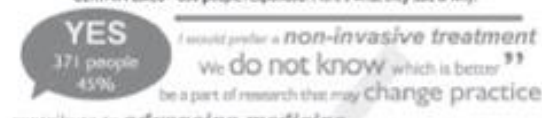
Engaging Stakeholders in Surgical Research: The Design of a Pragmatic Clinical Trial to Study Management of Acute Appendicitis

Evidence from randomized clinical trials in Europe within the past 20 years suggests that antibiotics alone may be used to treat acute appendicitis as an alternative to appendectomy, the standard of care for more than 100 years.¹ Despite this, there are concerns about long-term outcomes, especially with regards to quality of life and safety.² To answer these questions, we designed a pragmatic clinical trial to be conducted

Figure. Subjective Information Obtained From Patient Stakeholder Engagement Through Crowdsourcing, Social Media, Blogs, and Surveys

Appendectomy Vs. Antibiotics: Would YOU Randomize?

CERTAIN asked—830 people responded. Here's what they said & why:



JAMA Surgery.

2016 151(6): 580-582. doi:
10.1001/jamasurg.2015.5531

<http://www.pcori.org/research-results/2015/comparing-outcomes-drugs-and-appendectomy-coda>



Thank you!

- Acknowledgements:
 - Survey respondents
 - Webinar panelists
- Slides and a recording of this webinar will be posted to <http://www.pcori.org/events/2017/patient-and-stakeholder-engagement-research-strategies-initiating-research-partnerships> following this event.
- Send any questions or comments to surveys@pcori.org
- Upcoming Engagement webinars:
 - September 2017 - Topic: Engagement Activities and Impacts
 - September 2017 - Topic: Challenges and Facilitators of Engagement



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