6 Strategies for an Effective Patient-Engaged Meeting/Conference

July 29, 2016
Presentation Objectives

• To provide ideas, examples and strategies for effective and meaningful patient participation
• Serve as a guide for anyone looking to plan a research or scientific meeting involving non-technical attendees
• Help increase patient and caregiver engagement in scientific meetings
Roadmap

• Introductions
• Eugene Washington PCORI Engagement Award Program
• Why Patient Engagement in Meetings/Conferences
• Effective Strategies
• Engagement Awardee Examples
• Q&A
Introductions

Muriel Konne
Eugene Washington PCORI Engagement Awards

Shivonne Laird, PhD, MPH
Eugene Washington PCORI Engagement Awards

David Longnecker, MD
Project Title: Summit on Advanced Illness: Driving Changes through Leadership, Evidence, and Action
Organization: Coalition to Transform Advanced Care (C-TAC)

Julia Kohn, PhD, MPA
Project Title: PCOR & Reproductive Health Summit
Organization: Planned Parenthood Federation of America

Debra Michaels, MS
Project Title: Patient Engagement in Benefit-Risk Assessment throughout the Life Cycle of Medical Products
Organization: Drug Information Association (DIA)
About Us

• An independent research institute authorized by Congress in 2010
• Funds comparative clinical effectiveness research (CER) that engages patients and other stakeholders throughout the research process
• Seeks answers to real-world questions about what works best for patients based on their circumstances and concerns
Eugene Washington PCORI Engagement Award Program
Engagement Award Program

• A programmatic funding opportunity, launched in February 2014
• $20.5 million in FY 2016
• Support projects that will build a community better able to participate in PCOR/CER as well as serve as channels to disseminate study results
• Engagement Award projects will produce deliverables that are useful to awardees, PCORI, and the broader PCOR community for increasing patient and stakeholder engagement in PCOR/CER
Engagement Award Funding Opportunities

**Engagement Award (EA) projects**

- build our knowledge base about how patients and other stakeholders want to participate in PCOR/CER or receive research findings;
- implement training or skill development initiatives to build capacity for engaging in PCOR/CER; and/or
- strengthen channels for disseminating PCOR/CER findings.

**Engagement Award Initiative Notice (EAIN) meetings/conferences**

- align with PCORI’s mission and strategic plan, and facilitate expansion of PCOR/CER in areas such as:
  - research design and methodology
  - research development
  - dissemination and implementation

Awards of **up to $250,000** per project, **up to two years** in duration
Why Engage Patient and Caregivers in Conferences?

To influence event to be patient-centered, relevant, and useful to patients and caregivers

To facilitate meaningful interactions between patients, scientists and other stakeholders

To establish trust and a sense of legitimacy in event proceedings and encourage use of information

Project Lead: Nia Aitaoto
Project Title: The Gathering for Pacific Islander Health
Effective Strategies
STRATEGY #1

Create a planning and/or advisory COMMITTEE made up of PATIENTS and other relevant STAKEHOLDERS to inform conference/meeting agendas
Why is this Helpful?

- Provides viewpoints that are representative
- Provides feedback on past and current conferences
- Aid in drafting of session content
- Serve as community liaisons and spread the word
- Can serve as panelists, speakers, presenters

Community-Campus Partnerships for Health

Project Lead: Alan Richmond
Project Title: Facilitating Patient and Stakeholder Engagement Through Partnerships
STRATEGY #2

Develop PARTNERSHIPS with community GROUPS who serve as a GATEWAY to reaching potential meeting participants
Why is this Helpful?

- These partnerships can expose organizers to innovative recruitment ideas to reach patient population
  - Increase recruitment of patient participants
- Can provide organizers with activities that are meaningful to patients which can be incorporated into the conference agenda
  - Ensures that the needs and interests of patient participants are met
- Examples include patient advocacy groups and faith-based community
STRATEGY #3

Administer pre-conference SURVEYS to inform conference planning
Why is this Helpful?

• Provides information on specific patient needs to organizers by identifying gaps within the agenda
• Can address potential issues gathered from the pre-conference surveys
• May result in increased dialogue and interaction by tailoring the meeting to patient participant interest
• Helps in focusing on research priorities of the patient community
STRATEGY #4

Utilize various discussion APPROACHES, including large group ROUNDTABLES, panel DISCUSSIONS as well as smaller BREAKOUT sessions
Why is this Helpful?

- Encourages discussion and feedback
- Fosters an environment for patients to learn about each other’s experiences
- Creates a space for patients to voice any response they may have to the topic
- Increases patient partner interactions with different stakeholders

Project Lead: Rebecca Allen, PhD
Project Title: Sharing Opinions and Advice about Research (SOAR) in the Deep South
Various Approaches Used

- Large group roundtables
- Panel discussions
- Small breakout sessions
- Pre-assigned groups can ensure equal representation of views
- Incorporate livestream component to engage online audience
STRATEGY #5
Include patients as CO-PRESENTERS during conference and ADVISE presenters to use non-technical language
Why is this Helpful?

- Helps patients better identify with and relate to the topic matter
- Easier for all participants to follow presentation
- Ensures that patient voices are represented throughout the presentation

Project Lead: Sarah Verbiest, MPH, MSW, DrPH
Project Title: Defining Unmet Patient-Centered Health Care Needs in the 4th Trimester
STRATEGY #6
Create a LEVEL playing field for ALL conference attendees
Why is this Helpful?

- Organizers are more likely to observe a higher level of participation by patient partners by removing any potential opportunity for intimidation or discomfort
- Show participants that you care about their input
- Helps ensure that patient participants have a positive experience

Cerebral Palsy International Research Foundation

Project Lead: David Roye, MD
Project Title: A Workshop to Transform the Healthcare of Women with Disabilities
Some Examples

- Ensure conference is physically accessible by all members
- Distribute conference materials prior to the meeting
- Administer pre-calls for patients to orient them to meeting content in advance
- Provide navigators/meeting buddies to assist individuals
- Use first and last names on nametags – no degrees or titles necessary
- Encourage different stakeholder groups to interact
BEST PRACTICES
2015 National Summit on Advanced Illness Care:
Driving Change through Leadership, Evidence, and Action

EAIN- 1259
Project Lead: David Longnecker, MD
Hosted by The Coalition to Transform Advanced Illness Care (C-TAC)
Coalition to Transform Advanced Care (C-TAC)

• National, non-partisan, non-profit coalition of 130+ organizations representing consumer groups, faith-based organizations, policy makers, providers, payers, academic institutions, and others.

• Mission: *All Americans with advanced illness, especially the sickest and most vulnerable, receive comprehensive, high-quality, person- and family-centered care that is consistent with their goals and values and honors their dignity*

• 2016 National Summit on Advanced Illness Care
  – Sept 20th - 21st, 2016, [Register Now](#)
  – 2015 National Summit
C-TAC’s Guiding Principle:

Serve People, not just Patients

“In the midst of this battle with cancer, purpose, meaning and dignity keep me on the battlefield. There may not be a cure, but it is well with my soul.”

Accomplishments in engaging participants

• Participants from 32 states, the District of Columbia and Canada

• 75% increase in community, faith-based, patient and caregiver participation since the 2013 National Summit.

• Over 40% of programming focused on community and patient engagement.

• Participants reported their two topics of greatest interest were forming community partnerships and clinical partnerships
C-TAC’s Approach to Participant Engagement

• **Support** your community
  – Travel awards, token registration fees, etc.

• **Listen** to your community
  – Community workgroup; Pre-meeting survey; pre-meeting community workshop (included Dr. Joe Selby)
  – Community leaders, persons with illness, and caregivers

• **Follow up** and after event

• **Integrate** community voice into ongoing effort
Integrate community in your program

- Improved Shared Outcomes (e.g., person-centered care; reduced unwanted hospitalizations)
- Person/Family Decision-Making with coordinated input from clinicians and trusted advisors
- Clinical Interventions (e.g., symptom management)
- Community and Social Support (e.g., respite care for caregiver)
PCOR & Reproductive Health Summit

Julia Kohn, PhD, MPA, National Director of Research

Planned Parenthood Federation of America
Research & Clinical Quality Improvement
July 29, 2016
Project Goals & Objectives

**Goal:** To translate the principles of PCOR into patient-centered reproductive health research priorities and increase our ability to engage patients in reproductive health research.

- **Objective 1:** Convene a group of stakeholders
- **Objective 2:** Increase awareness of emerging practices in patient engagement
- **Objective 3:** Disseminate research priorities for PCOR in reproductive health
Convene a Group of Stakeholders

In October 2015, 45 stakeholders from 32 organizations attended the PCOR & Reproductive Health Summit.
Increase Awareness of Emerging Practices

• Four PCORI award recipients shared experiences with engaging patients and other stakeholders in reproductive health research

• AcademyHealth staff shared lessons from PCORI Pilot Projects Learning Network (PPPLN)
Patient and Consumer Survey Ads
<table>
<thead>
<tr>
<th>What matters most to you about your sexual and reproductive health?</th>
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<tbody>
<tr>
<td>• birth control/contraception</td>
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<tr>
<td>• staying healthy</td>
</tr>
<tr>
<td>• sexually transmitted infections</td>
</tr>
<tr>
<td>• safety</td>
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<tr>
<td>• autonomy/choice</td>
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<tr>
<td>• affordability</td>
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<tr>
<td>• pregnancy prevention</td>
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<td>• access to birth control</td>
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<tr>
<td>• access to health care</td>
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<td>• abortion</td>
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<th>What do YOU think researchers should study?</th>
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<tbody>
<tr>
<td>• birth control/contraception</td>
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<tr>
<td>• male birth control</td>
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<tr>
<td>• cancer</td>
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<td>• sexually transmitted infections</td>
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<td>• sexual health</td>
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<td>• long-acting reversible contraception</td>
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<td>• pregnancy</td>
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<td>• mental health</td>
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<td>• fertility</td>
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<td>• abortion</td>
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Conclusions

• We must hear directly from patients
  – Suggested topics we would not have necessarily prioritized (i.e., male birth control)
  – Opportunities for improved dissemination of research (i.e., effectiveness of birth control methods)

• Stakeholders are willing to engage

• Social media can be a tool for engagement (and dissemination)

• Reproductive and sexual health is a big tent
Thank you!

Julia Kohn, PhD, MPA, National Director of Research
julia.kohn@ppfa.org

Visit our project page and view our recent webinar at:
http://www.pcori.org/research-results/2015/pcor-reproductive-health-summit
Patient Engagement in Benefit-Risk Assessment through the Medical Product Life Cycle

September 16 – 18, 2015
Debra L. Michaels, PI

Partially funded by a PCORI Conference Engagement Award
Patient Engagement in Benefit-Risk Assessment through the Medical Product Life Cycle

► A 2-day conference on how and when to best engage patient partners in benefit-risk assessment and decision-making
► For patient partner, industry, academic, and regulatory stakeholders
► Objectives:
  • Establish consensus on points for patient engagement/input on B-R assessment/decision-making
  • Identify current status of practices, challenges, & gaps (needs for new information and practices)
  • Identify next steps for addressing the gaps to improve engagement practices among all stakeholders
Patient Engagement in Benefit-Risk Assessment through the Medical Product Life Cycle

Dimensions of Patient Input in Product Development

1. Patient Perspective
   - Unmet Needs: Asthma, Diabetes, etc.
   - FDA: role
   - Usability issues

2. Patient Preference
   - Patient Voice Needs
   - Indications: Considered
   - Indications submitted

3. Patient Choice
   - Life Stage/Disease Stage
   - To Achieve
   - Not to Achieve
   - Choice: prescriber, healthcare system, informal caregiver

Other Methods or Tools: Informative Carcinogen, Continual Monitoring, Ongoing Awareness, Purchasing, Decision to be Made, Ways to Decide, Patient Participation, Integrated Process, Benefit Stack.
Patient Engagement in Benefit-Risk Assessment through the Medical Product Life Cycle
Patient Engagement in Benefit-Risk Assessment throughout the Life Cycle of Medical Products: Current and Future States

COLOR KEY

- **Green**: denotes aspects of patient engagement in benefit-risk assessment of medical products that are in place, with efforts begun
- **Yellow**: denotes aspects that are not now in practice but should be implemented in the medical product life cycle for effective and meaningful patient engagement in benefit-risk assessment. Yellow may also denote aspects that are sometimes practiced but need to be applied more widely/consistently or improved upon.
Patient Engagement in Benefit-Risk Assessment: Integrating Patient Stakeholders

- **Connecting with interested patient partners:**
  - DIA Patient Engagement Community
  - Patient stakeholders working on related issues
  - Patient stakeholders responding to engagement practices survey
  - Patient participants in previous engagement workshop

- **Involve patients in formulating conference questions:**
  - Informal brainstorming – issues and how to address them
  - All stakeholders bring expertise to the conference topic

- **Conference planning and delivery:**
  - Patient stakeholders on program planning committee
  - Patient stakeholder – researcher/regulator teams as Session Co-Chairs
Patient Engagement in Benefit-Risk Assessment: Integrating Patient Stakeholders

- **Conference planning and delivery (continued):**
  - Poll/survey additional patient stakeholders for content ideas
  - Invite patient stakeholders as speakers

- **Getting patient stakeholders to the conference:**
  - Networks developed through the planning process help with outreach
  - “Why you should attend” messages are better with patient stakeholder input

- **Working on the conference output:**
  - Collaboration doesn’t end when the conference is over
  - Sharing drafting/writing responsibilities
  - Sharing review and feedback responsibilities
  - Ongoing communication of messages to those who can use them
Patient Stakeholders as Session Co-chairs

- **Role of session chairs:**
  - Flesh out the details of session content
  - Identify speakers
  - Moderate the session during conference

- **Patient stakeholders teaming with researchers or regulators as co-chairs:**
  - Ensures the patient perspective will be brought to the topic
  - Ensures that patient stakeholders are invited as speakers
  - Ensures that patient stakeholder committee members are actively involved on conference day(s)
  - Encourages patient stakeholder attendees to participate in dialog
  - Establishes/strengthens good working relationships among stakeholders
Thank you!
For More Information about Engagement Award Program

Web Page: [www.PCORI.org/eugene-washington-awards](http://www.PCORI.org/eugene-washington-awards)
Email Address: ea@pcori.org
Contact Number: 202-370-9312

Team Members:
- Lia Hotchkiss, MPH - Program Director
- Muriel Konne - Intern
- Shivonne L. Laird, PhD, MPH - Program Officer
- Yasmeen Long, MA - Program Officer
- Rachel Mosbacher, MA - Program Officer
- Alicia Thomas, MHS - Program Officer
- Ivey Wohlfeld - Program Associate
Questions?
Thank you!