Engagement in the Conduct of Research: Promising Practices from PCORI’s Portfolio & More

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April 22, 2015
Roadmap

• Welcome and Introductions
• Motivation for Focusing on Engagement in the Conduct Phase
• Key Questions to Consider During Webinar
• Strategies to Engage Patients and Stakeholders In the Conduct Phase of Research
  • Recruitment and Retention
  • Data Collection and Analysis
• Q&A
Introductions - The PCORI Team

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Kim Bailey, MS
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Katie Lewis, MPH
Sr. Program Associate,
Addressing Disparities

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Tomica Singleton
Sr. Administrative Assistant,
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Introductions – PCORI Asthma Awardees

• For introductions:
  • Have one designated person state the PI name and project title.
  • State who else on the research team is on the call (e.g., research staff, patient and stakeholder partners).

• Please keep to under one minute!
Introductions – PCORI Asthma Awardees (cont.)

- Team Apter
- Team Elder
- Team Federman
- Team Hamilton
- Team Krishnan
- Team Mazany
- Team Nkoy
- Team Otero
- Team Postma
- Team Stout
- Team Sumino
- Team Tap
- Team Teach
Motivation for Focusing on Engagement in the Conduct Phase

• In Summer 2014, 8 awardees funded by the Addressing Disparities Program presented their engagement plans.
  • Challenges
  • Success factors
• Common challenge mentioned: strategies to engage patient and stakeholder partners during the conduct phase of the study.
Motivation for Focusing on Engagement in the Conduct Phase (cont.)

- PCORI Addressing Disparities and Engagement staff identified and compiled a list of best, promising, and new strategies for engaging patient and stakeholder partners during the conduct phase of the study.

- Strategies and examples identified from:
  - Currently funded PCORI projects
    - Program and Engagement Officer’s interactions with awardees
    - PCORI’s WE-ENACT Tool
  - The PCORI Addressing Disparities Advisory Panel
  - Brainstorming new and creative strategies
Key Questions to Consider During the Webinar

• What strategies are you using to engage patients and stakeholders in the conduct phase that have not been mentioned?
• Where else can PCORI and awardee teams look for guidance on how to engage patients and stakeholders in the conduct of research?
• Who else should PCORI and awardee teams speak to in order to identify additional strategies for engagement in the conduct of research?
• What are the moderators and mediators/barriers and facilitators that awardees should consider with these engagement strategies in the conduct phase?
• How can PCORI help awardee teams to overcome potential challenges to successful engagement in the conduct phase?
Themes of Today’s Strategy Discussion

• Cycle of Engagement
• Strategies for Engagement in Recruitment, Accrual, and Retention
• Strategies for Engagement in Data Collection and Analysis
Cycle of Engagement: Oversimplified

Intensity of Engagement

Study planning & protocol development  Study implementation  Recruitment  Follow-Up  Data Analysis  Dissemination

Stage of Project
Cycle of Engagement: One Study’s Strategy

- Team divided engagement into five phases, meeting with stakeholders at a different frequency in each:
  - Intensive Design Phase – meet every 1-2 weeks
  - Recruitment Ramping Phase – meet every month
  - Recruitment Steady Phase – meet every quarter
  - Analysis Ramping Phase – meet every 2-3 months
  - Intensive Analytic Phase – meet every 3-5 weeks
Strategies for Engagement in Recruitment, Accrual, and Retention (RAR)
Strategies for Engagement in Planning RAR

• Seek guidance from partners on how, when, and where to recruit.
  • Develop relationships with official and unofficial leaders of the patient community.

• Engage your partners in thinking through non-traditional recruitment channels (e.g., radio, community newspapers, barber shops, etc.).

• Ask who the trusted messengers in the community are.

• Examples
  • Prevention project – Barber shop champion
  • Infection project – Earned media through community channels
  • Maternal health project – Social media and other channels
Strategies for Engagement in Planning RAR (continued)

• Build the capacity of your partners: Invest in human subjects protection and privacy training.
  • Example: Many projects – CITI training for partners

• Ask your partners to review and user-test all recruitment materials.
  • Example: Contraception project: Partners helped to ensure that materials appeal to the target population and are culturally and socially appropriate

• Think through potential barriers and address them.
  • Example: Developmental delay project – Data mining for a diverse sample
Engaging Partners in RAR

- Enlist your partners as study ambassadors.
- Leverage online communities and social media.
- Use your partners’ community connections.
- Examples:
  - Older adults study – Empowered patient partners to become community ambassadors
  - Cardiac study – Enlisted health bloggers/e-patient leaders
  - Breast cancer study – Book club model of recruitment at support groups, etc.
Troubleshooting RAR Challenges

• Seek the insight of partners on RAR challenges.
• Revisit the questions of when, where, and how to recruit.
• Make small tweaks to project to increase retention and completion.
• Examples:
  • Pediatric project – Revisiting who does the initial approach
  • Substance abuse project – Modifying reminder techniques, timing of intervention, and incentives for follow-up
  • Surgery project – Creative incentives for sites to recruit
Strategies for Engagement in Data Collection and Analysis
Engagement in Planning for Data Collection

- Seek patient and stakeholder partner guidance on what data to collect and how to explain data being collected to study participants.
- Ask your partners to review all questionnaires and data collection tools.
- Brainstorm potential barriers to data collection (e.g. participant burden, incentives for completion of follow-up tools, etc.) and develop a plan to address them ahead of time.
- Examples:
  - Prevention project – Cultural sensitivity and translation
  - Chronic pain project – Method of collecting follow-up data
  - Joint replacement study – Sequencing of follow-up appointment activities to reduce participant burden
Engagement in Collecting Data

• Explore the possibility of partners assisting with focus groups.
• Explore the possibility of partners assisting with other qualitative data collection efforts.
• Examples:
  • Pediatric psychiatry study – Parents of children with psychiatric diagnoses are administering part of the intervention and assisting with data collection
  • Breast cancer study – Patient partners co-led focus groups with research team
Engagement in Analyzing Data

• Ask your patient and stakeholder partners to review initial data runs – they frequently spot trends in the data that others miss.
• Have your partners help to identify mediators and moderators, and frame parameters for additional analyses.
• Use your partners’ lived experience to think through how to frame findings in ways that lay audiences can understand and relate to.
• Examples:
  • Breast cancer imaging project – Modification of inclusion criteria
  • Post-hospital discharge project – Trends in care delivery identified by patient and stakeholder partners informed analytic plan
  • Stroke project – Patient partners drafted a perspectives piece on the patient view of care delivery
Q&A
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Thank You

Contact your project Program Officer and/or Engagement Officer if you have any questions related to engagement in your project.

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