Engaging with Health System and Community Partners

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NIH PRAGMATIC TRIALS COLLABORATORY

Learning goals



- Describe the breadth of individuals to engage as partners and approaches for engaging them through all phases of the study
- Understand the real-world priorities and perspectives of healthcare system leaders and how to obtain their support
- Identify engagement practices to obtain patient and community perspectives
- Highlight challenges of partnering across diverse health systems

How researchers approach partners in traditional RCTs

Researcher reviews the literature

Researcher presents idea to researchers who understand the theory and can see how study fills gap

Researcher designs and conducts study, prepares manuscripts



ePCTs work differently.



The purpose of the healthcare system is not to do research, but to provide good healthcare. Researchers often have a tailwagging-the-dog problem. We assume if we think something is a good idea, the healthcare system will too... We need to remember that we're the tail and the healthcare system is the dog.

– Greg Simon, MD, MPH (SPOT)



Important things to know 66

- Start engagement early, even before you have a research question or study design
- Be patient: Relationships take time to build and nurture
- Consider whether your intervention will add value
- Expect changes and disruptions
- Engage partners continuously



Who will be impacted? Who are the decision makers?

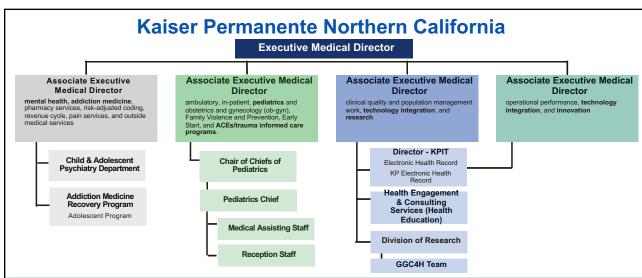


Potential partners have a variety of priorities, values, work cultures, and expectations:

- Healthcare delivery organization leaders
- Clinicians
- Operational personnel
- Patients, caregivers, patient advocacy groups

- Payers, purchasers
- Policy makers, regulators
- Research funders
- Researchers
- Product manufacturers





Guiding Good Choices for Health: The study team engaged with all of these partners within the The Permanente Medical Group at Kaiser Permanente Northern California. These partners represent a small fraction of the many relevant stakeholders in large, complex healthcare systems. Most systems are comprised of several different entities – e.g., medical group, health plan, hospitals/facilities, etc. + labor partners

Roles of partners

- 1. Designing the trial
- 2. Successfully conducting the research
- 3. Disseminating the results



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Choosing a salient question

We want to know what you need. What research should we be doing?



Source: Greg Simon, MD, MPH

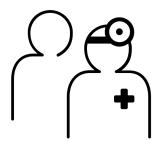


Designing the intervention for sustainment



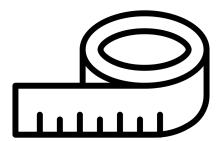


Designing the intervention to minimize burden for patients and clinicians



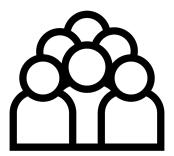


Selecting outcome measures





Determining inclusion and exclusion criteria





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Develop recruitment strategies





Example: Community Advisory Board

- Feedback from OPTIMUM's Community Advisory Board
 - Make materials more diverse and visually appealing
 - Include more "mindfulness" theme in recruitment materials
 - Highlight benefits of participating in study
- Response from Study Team
 - New posters and updated study website
 - Quarterly newsletter
 - Study animation video



Example: Patient Advisory Panel

- Old name
 - LS7 Bot and Backup: Using artificially intelligent text messaging technology to improve American Heart Association's Life's Simple 7 Health Behaviors
- New name, suggested name by patient
 - Chat 4 Heart Health



Serve as study champions





Track challenges and adaptations





Interpret study results





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Determine key messages for different groups and identify avenues for dissemination





Support implementation or de-implementation





Consider changes to policies and guidelines





Roles of ePCT partners

1. Design

- Question
- Intervention
- Outcomes
- Population

2. Conduct

- Recruitment
- Advocacy
- ChallengesInterpretation

3. Dissemination

- Messaging
- Venues
- Implementation
- Guidelines





Important things to do



- Engage partners early and often
- Set expectations to work collaboratively and build trust from the beginning
- Use familiar language that partners understand
- Get to know your partners' values, priorities, and expectations
- Assess health system partners' capacity and capabilities
- Track goals reached, challenges, and adaptations throughout the life cycle of your ePCT
- Show appreciation and celebrate accomplishments early and often to have sustained partnerships



Resource: The Living Textbook

Visit the Living Textbook of Pragmatic Clinical Trials at www.rethinkingclinicaltrials.org





Question & Answer

