Virtual Grand Rounds
ENGAGING PATIENTS AND STAKEHOLDERS IN DISSEMINATION AND IMPLEMENTATION RESEARCH

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Engaging Patients and Stakeholders in Dissemination and Implementation Research

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Presentation Overview

• Community Engagement Definitions: What is it and Who are Stakeholders?
• Ways Community Engagement Can Provide Value to D&I Research
• Strategies for Engaging Stakeholders
• Feedback / Q&A
Dissemination and Implementation Research: Definitions

- **Dissemination research**: focus on strategies to increase awareness and understanding of innovative, effective policies and practices to facilitate their widespread adoption

- **Implementation research**: systematic study of approaches to increase uptake of effective practices
Community Engaged Research: Definition

• ...the process of working **collaboratively with and through groups of people** affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people. It is a powerful vehicle for bringing about environmental and behavioral changes that will improve the health of the community and its members. It often involves partnerships and coalitions that help mobilize resources and influence systems, change relationships among partners, and serve as catalysts for **changing policies, programs, and practices** (Centers for Disease Control & Prevention, 2011)
Community Engaged Research’s Integration with D&I

• Early calls by community engaged researchers to engage stakeholders as way of bridging the efficacy to effectiveness gap in research
  – Reason for limited effectiveness because of limited engagement with stakeholders in “real world” settings?
• More recently, growing emphasis placed on engaging stakeholders in D&I efforts that facilitate translation of evidence-based practices/interventions into everyday use
  – CTSA programs one structure driving this integration
The Engagement Continuum

• Spectrum of engagement ranging from simply giving feedback to stakeholders (i.e., least engaged) to active, ongoing collaboration with researchers and other stakeholders as equal partners throughout research trajectory (i.e., most engaged)

• Most engaged end of spectrum often referred to as community-based participatory research (CBPR)
Stakeholder Engagement Continuum

1. Inform
   - We will keep you informed
2. Consult
   - We will consider your input and give feedback about how it informed our decisions
3. Involve
   - We will ensure that your input is considered among the choices we implement
4. Collaborate
   - We will work together to decide and ensure everyone’s views are incorporated as much as possible
5. Empower
   - We will implement what you decide

Source: International Association for Public Participation, 2007
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The Engagement Continuum

- As the field of community engagement has developed, growing emphasis on encouraging investigators across the translational spectrum to identify ways to engage stakeholders even if not the most intensive form of engagement
- Even if not undertaking most intensive form of engagement, effective and meaningful stakeholder engagement can occur
Who Are Stakeholders?

Stakeholders are individuals or groups who are responsible for or affected by health- and healthcare-related decisions that can be informed by research evidence (Concannon et al. 2012)
Who are Stakeholders to be Engaged?

- **Patients**: current and potential consumers/users of patient-centered healthcare
- **Providers**: Individuals & organizations providing care to patients
- **Purchasers**: individuals underwriting costs of healthcare (e.g., employers)
- **Payers**: those responsible for reimbursement of healthcare
- **Policy makers**: those responsible for shaping policy (including policy advocates)
- **Product makers**: Drug & device manufacturers
- **Principal investigators & other researchers**

WAYS STAKEHOLDER PERSPECTIVES CAN PROVIDE VALUE FOR D&I RESEARCH
Issue in D&I Research:
D&I “Comes After Everything Else” (Chambers & Norton, 2016)

• **Issue**: Interventions developed without consideration of whether they can broadly delivered fail to be scalable

• How Engaging Stakeholders Can Help:
  – Involvement of stakeholders on the front end to help design intervention as a means of promoting scalability
    • EX.) Development of intervention that can be delivered by agency staff while minimizing disruption to patient flow or adding undue burden on interventionist
Issue in D&I Research: Permanence of Evidence Base (Chambers & Norton, 2016)

• **Issue**: Although intervention/program may have “evidence base”, number of individuals and settings participating in trials are small and not necessarily representative of those who could benefit from intervention

• How Engaging Stakeholders Can Help:
  – Illuminate new knowledge, which can guide future adaptations & implementation

  • EX.) Many interventions adapted for use with different a) racial/ethnic groups, b) cultures, and c) organizational contexts that have varying levels of resources
Issue in D&I Research: Intervention Adaptation Requires an Ecological Focus

• **Issue**: Complexity of intervention adaptation that may need to address multiple aspects of service system and organization (Aarons et al., 2012; Damschroder et al., 2009)

• **How Engaging Stakeholders Can Help:**
  – Stakeholders at the patient, provider, and/or policy-levels can all provide guidance on aspects of intervention adaptation
    • EX.) Adaptation of Mothers and Babies intervention that engaged clients, staff, managers, and home visiting model developers (Tandon et al., under review)
Issue in D&I Research: Collection of High Quality Implementation Data

• **Issue**: Development and use of implementation measures must minimize burden on setting in which implementation research is occurring

• How Engaging Stakeholders Can Help:
  – Stakeholders can provide insight on a) ways in which data are already collected/available; b) strategies to minimize respondent burden; and c) measures that are most relevant and useful to an agency/organization
    • EX.) Are certain types of adoption/sustainability data needed for an agency to provide justification for an intervention’s continued use?
Issue in D&I Research: Promoting the Use of More Effectiveness-Implementation Hybrid Designs

• **Issue**: Lag time between intervention efficacy and uptake to routine practice; blending of effectiveness and implementation trials can facilitate quicker uptake

• **How Engaging Stakeholders Can Help:**
  – Implementation strategies that may be tested in Hybrid 2 or 3 designs can be shaped/recommended by stakeholders with an understanding of strategies that will be most viable in their setting
STRATEGIES/CONSIDERATIONS FOR ENGAGING STAKEHOLDERS
Selecting Key Stakeholders

• Not all stakeholder categories will be relevant for a given project (e.g., drug/device manufacturers)

• Considerations in selecting:
  – Funder requirements (e.g., PCORI, NIH)
  – Objectives of project
  – Type of input needed
  – Importance of obtaining broad spectrum of perspectives
  – What type of input is needed pre-award, during project, and post-award
Mechanisms for Facilitating Stakeholder Engagement

• Clearly define roles & responsibilities of stakeholders
• Clearly articulate what stakeholders will gain/being responsive to why stakeholders would want to participate
  – Promoting access to new treatments or therapies (patients, providers)
  – Determining feasibility and sustainability of an intervention (providers, policy-makers)
• Develop sound bites to recruit stakeholders
  – Linked to project goals, roles/responsibilities, and what members will gain
Mechanisms for Facilitating Stakeholder Engagement: Roles & Structures

• Roles for patients & stakeholders
  – Consultants
  – Project staff
  – Project investigators (Co-PI, Co-I)
  – Advisory board members
Stakeholder Engagement Should Start at the Beginning of the Intervention Development Cycle

- Community engaged research often notes that planning for dissemination needs to occur at the outset of a project
  - Who are the stakeholders that can advise on developing a new intervention?
Stakeholder Engagement Should be Ongoing and Meaningful

• Engagement should be meaningful NOT symbolic
  – Including program managers in study as advisory board member, etc. instead of merely obtaining a support letter

• Engagement should be ongoing NOT sporadic
  – Stakeholders should ideally be collaborators throughout a project
    • EX.) Program staff and managers can provide feedback on appropriate tools and approaches for measuring fidelity AND be engaged throughout project as fidelity data are collected, analyzed, and interpreted
Stakeholder Engagement Should Benefit both Academic and Community Stakeholders

• Data collected during D&I studies should:
  1. Inform the scientific community about an evidence-based intervention and/or the science of D&I research, and
  2. Benefit community stakeholders

• Synergy between 1 & 2, as data can provide benefit for community stakeholders by:
  – Providing evidence to sustain a program/intervention
  – Facilitating the translation of an intervention into a community/clinical agency
  – Building organizational capacity to implement an intervention
Stakeholder Engagement Should Foster Capacity Building for Community Stakeholders

• Can stakeholders learn new ways to assess domains of implementation (e.g., fidelity, feasibility) within their agency?
  – Ex.) providing stakeholders with one or more tools that can be used to measure an implementation domain

• Can stakeholders learn more about research design or data collection approaches that could later be used in their agencies?
Stakeholder Engagement Should Be a Long-Term Process/Partnership

• Movement away from researchers collecting implementation data on how an intervention works for a setting to...

• Working with a setting to integrate the intervention so that it is sustained over time (if appropriate)
Questions?

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