STAKEHOLDER ENGAGEMENT IN RESEARCH

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There is an “I” and an “us” in “genius.”
ASSIGNMENT

You are a researcher with all the grants, publications, and academic advancement you need.

- What is the change in health behavior or outcome that you want to have achieved to consider your research career a success?

- How long are you willing to wait for this change?

- Who are the people who need to know, understand, and/or care about your work to make this change possible?
WHY STAKEHOLDER ENGAGEMENT IS NECESSARY

The Pipeline Fallacy of Producing & Vetting Research to Get Evidence-Based Practice*

A PRELIMINARY TAXONOMY OF TYPES OF HUMAN RESEARCH AND OTHER ACTIONS FOR CHANGE
WHO ARE STAKEHOLDERS?

“individuals, organizations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavor”


- Patients and the public
- Providers
- Purchasers
- Payers
- Public policy-makers and policy advocates in non-governmental sector
- Product makers
- Principal investigators

HOW DOES STAKEHOLDER ENGAGEMENT INFLUENCE RESEARCH?

Forsythe et al.
PATIENT-CENTERED OUTCOMES RESEARCH LOGIC MODEL

PCOR Principles
Trust, honesty, co-learning, transparency, reciprocal relationships, partnership, and respect

FOUNDATIONAL ELEMENTS
- Awareness of
- Methods for PCOR
- Valuing of the patient
- Perspective Interest in PCOR
- Ways for patients and researchers to partner
- Resources and infrastructure
- Policies and governance

ACTIONS
- Initiate and maintain partnerships between researchers and stakeholders
- Facilitate cross-communication among research stakeholders
- Capture, use and optimize patient perspective across phases of research
- Ensure meaningful influence on research
- Train for partnering
- Share and use learnings

OUTCOMES
Near-term
- Culture of patient-centeredness in research
- Meaningful & effective partnerships

Intermediate
- Research relevant to patients/other stakeholders
- Questions and outcomes are meaningful to end users
- Use of research results in health decisions
- Quality health decisions
- Satisfaction with health care experiences

Long Term
- Optimal health

Forsythe et al.
SECONDARY DATA ANALYSIS AND STAKEHOLDERS

- To identify the most relevant questions from the data
- To obtain the data
- To analyze the data
- To interpret the data
- To disseminate the data
- To implement policies as a result of the data
- To help obtain funding for next step or intervention to address data
PRACTICAL ADVICE ABOUT STAKEHOLDER ENGAGEMENT

- If you need a letter of support for this grant, that person should be involved as a stakeholder (and vice-versa).
- If you need a letter of support for the follow-up grant, that person should be involved as a stakeholder.
- Ask mentors, navigators, and community leaders for additional referrals to other stakeholders.
- Pay your stakeholders commensurate to the cost of their time, especially patients and community members/leaders.
Genuine stakeholder engagement takes time—have faith that it will make the research better.

Try to have some meetings NOT at your research office.

Share meeting agenda early to get feedback.
  - People are more likely to come to a meeting whose agenda they shaped.

Provide food.

Your job at the stakeholder meeting is not to talk or to defend. It is to listen, to acknowledge, and to respond with immediate or future actions.

Stakeholder engagement work is fun and regenerative.
FOR MORE INFORMATION

- UCSF CTSI Community Engagement and Health Policy Program:
  - Community-Engaged Research Guides and Resource Manuals: https://accelerate.ucsf.edu/research/community-manuals
  - Community-Engaged Research Consultation https://accelerate.ucsf.edu/consult/community-engaged-research
- PCORI Engagement in Health Research Literature Explorer https://www.pcori.org/literature/engagement-literature
- Center for Participatory Research at University of New Mexico: CBPR Engage for Equity https://cpr.unm.edu/research-projects/cbpr-project/index.html