

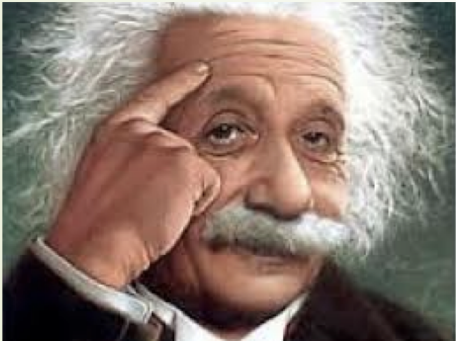
Patient Engagement in Practice Improvement and Practice-Based Research

Tung Nguyen, MD

Professor of Medicine, UCSF
Dean's Diversity Leader, Differences Matter Initiative

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There is an “i” and an “us” in “genius”!

Stakeholder Engagement

- Stakeholders: individuals, organizations or communities that have a direct interest in the process and outcomes of a project, policy or research endeavor
- Stakeholder engagement is an iterative process that:
 - Solicits knowledge, experience, judgment and values of stakeholders
 - Creates shared interests, values, and mission
 - Uses a relevant, transparent, and effective decision-making process
 - Builds on the interests and strengths of the stakeholders to implement actions for change

Who Are Stakeholders in Research on the Care of Individual Patients?

- Patients
- Caregivers
- Healthcare providers
- Healthcare staff
- Healthcare systems
- Health insurers
- ???

Who Are Stakeholders in Research on “Population Health”?

- Patients, caregivers, families
- Healthcare providers, staff, and systems
- Home health agencies, medical interpreters, etc...
- Health insurers
- Public health department
- Patient advocacy groups
- Community-based organizations
- Faith-based organizations
- Employers
- Media
- Government
- ???

Why Stakeholder Engagement?

Who should decide:

- What diseases matter or problems that should be prioritized?
- What settings are important?
- What are appropriate processes of care?
- What health outcomes matter?
- How should these processes and outcomes be achieved?
- How are corrective measures determined and applied?
- What level of evidence should be used to make decisions and priorities?
- How might findings be applied?
- How to disseminate and sustain effective change?

Levels and Types of Stakeholder Engagement

- Levels of engagement/partnership: Advisory, Steering, Executive
- Types of engagement:
 - Prioritization
 - Design
 - Implementation
 - Assessment
 - Dissemination
 - Sustainability

Tips for High Impact Stakeholder Engagement for Health Equity

- Partner with diverse patients and community members
- Be humble!
- Share power with the people!
- Pay the people!
- Go where the people are and work outside of usual office hours!
- Any problem in stakeholder engagement is an opportunity for change!
 - Question and address barriers: institutional, traditional research paradigm

Accelerating Systematic Stakeholder, Patient, and Institutional Research Engagement (ASPIRE)

- Stakeholders: UCSF patient-centered outcomes research (PCOR) investigators, patient advisory board members, community organizations
- Needs assessment and asset map
- Develop toolkit for training, recruitment
- Annual convening and symposium
- Plan and advocate for institutional changes
- Disseminate through national CTSA channels

Institutional Infrastructure for Stakeholder Engagement in Health Research for Equity

- Training for academic and community partners
- Funding and finance administration
- Increasing number of underrepresented researchers
- Staffing for partnership building and support
- Language interpretation/translation services
- Academic roles for community experts
- New professional incentives for research partnership and collaboration
- New communications practices, incl. hub for exchange of information
- Engagement in policy development

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>

“Tell me and I'll forget, show me and I may remember, involve me and I'll understand.”
Chinese proverb

Twitter

@ARCHDrNguyen

@UCSF_CCE

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