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BEST PRACTICES in COMMUNITY-ENGAGED RESEARCH

Section 3.1

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LEARNING OBJECTIVES

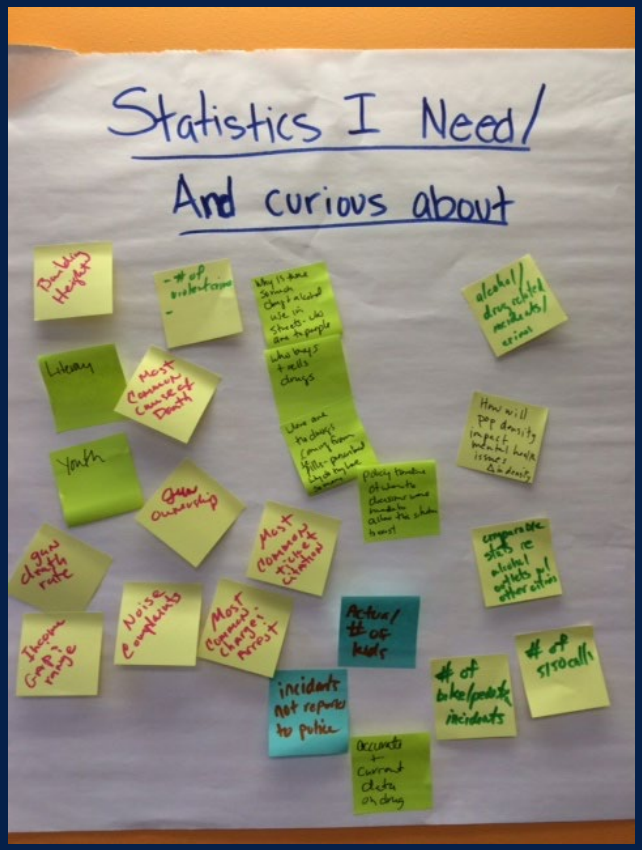
After this lecture, learners will be able to:

- Name rationales for, benefits and challenges of community/stakeholder engagement in research.
- Describe the continuum of engagement, and principles and best practices in community/stakeholder engagement in research.
- Understand why health equity framing is necessary for health research in general and essential to stakeholder engagement.
- Recognize their potential to be in solidarity with and/or join the movement for liberation, using research as a tool.

What Do We Mean By "Community?" and "Stakeholder?"

These are my people. We belong to each other. They know me. I know them. We share a common history. We understand one another's beliefs. I can feel comfortable with them. I believe in them. This is my home. This is where I come from. We enjoy the same things. We share memories. These are my people. We belong to each other. They know me. We argue We work together We have a shared vision of the future. We share a common history. We understand one another's beliefs. I can feel comfortable with them. I believe in them. We know how to fix this. This is where I come from. We. Us. Them. In common. We share memories. We are certified the same way. Together. We have common struggles and goals and meanings for strength, risk and vulnerability. We are we. We are perceived to be the same. We show up together. We benefit the same ways.

WHY DO COMMUNITY-ENGAGED RESEARCH?



"**Engagement with stakeholders** makes research translation maximally *efficient*, *focused*, and *relevant*." – UCSF CTSI

And impactful.

WHO ARE YOUR STAKEHOLDERS?
And how can you engage them?

1) Your patients and their families

2) Your colleagues

3) Community-based clinics or organizations (service orgs, faith-based orgs) that serve your patients or the communities they belong to

4) Public agency employees

5) Policy makers

UCSF COVID-19 Research Patient and Community Advisory Board (PCAB)

RESEARCH MILESTONES

Research Activities	Research Administration
Define topic of interest and impacted population(s)	Secure basic resources (time and money)
Identify stakeholders	Develop budget and timelines
Define the problem and research question	Meet with stakeholders
Determine desired impact(s) of research	Draft and sign agreements
Determine methodology	Set up finance administration
Develop instruments	Check and recheck activity timelines and deliverables
Plan dissemination	Process payments
Implement inquiry activities, incl. analysis	Plan budget and logistics for activities, including dissemination

CONTINUUM OF ENGAGEMENT

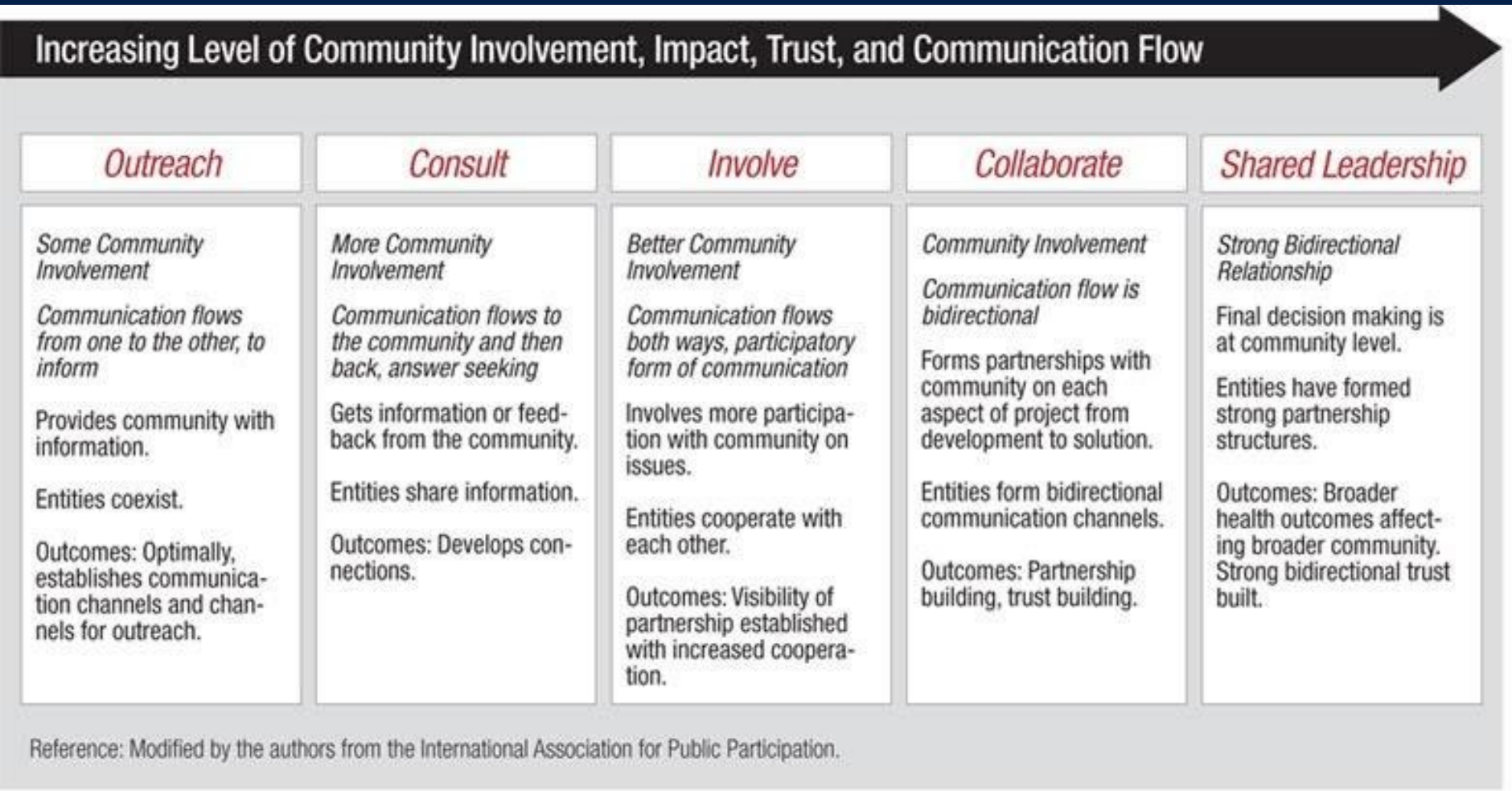


Figure 1.1. Community Engagement Continuum

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STOP COVID-19 CALIFORNIA

Community-engaged and participatory:

- Recruitment of partners and participants
- Priority setting
- Data collection & analysis/ production of findings
- Dissemination

Development and implementation of applied research/ action agenda, including Policy Briefs and COVID Vaccination Efforts

Deep engagement: translation of findings into action at the community level in terms of how COVID vaccination efforts were being implemented, modeled

CHALLENGES to STAKEHOLDER ENGAGEMENT

- Mistrust: harms (historical and current) are real
- Under-representation in medicine (URM) of minoritized groups increases likelihood of mistrust, miscommunication, misinterpretation
- Stakeholders often are engaged merely for recruitment purposes
- Most dissemination misses opportunity for lay audiences
- Academic researchers can be perceived as participating in and perpetuating a colonial power
- Variation in knowledge types and the value and power of those types
- Variation in definitions of health, and the value and power of those definitions


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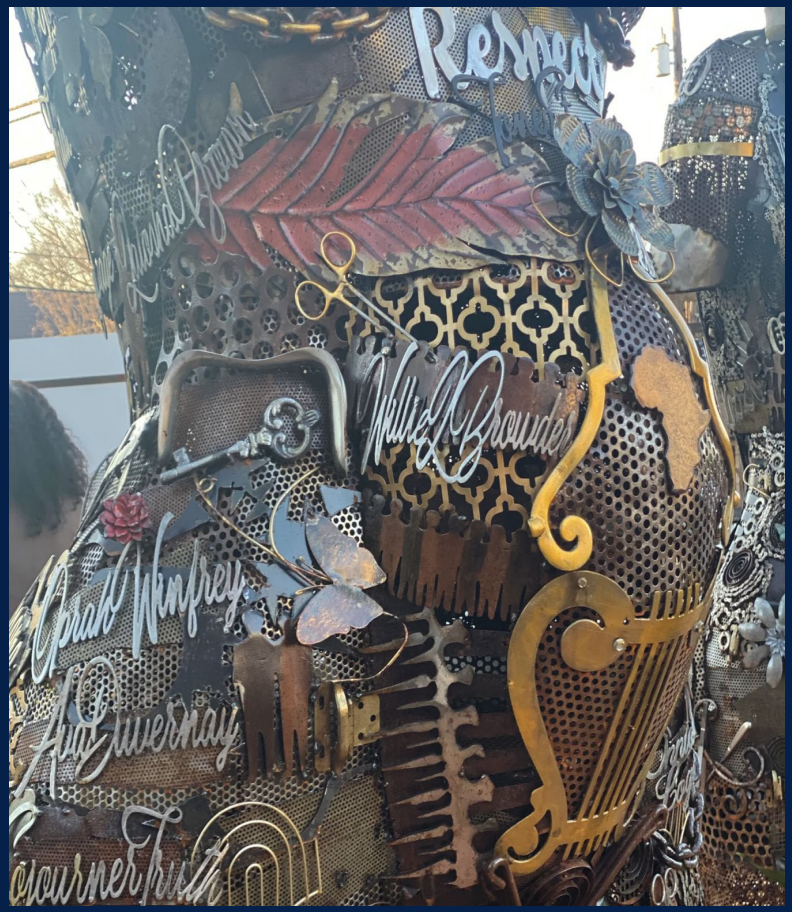
The Mothers of Gynecology
By Michelle Browder



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86c.—YEW.

UPDATED: MAR 11, 2019 · ORIGINAL: MAY 9, 2018

The First Birth Control Pill Used Puerto Rican Women as Guinea Pigs

Eugenics and unethical clinical trials are part of the pill's legacy.

ERIN BLAKEMORE

STAKEHOLDER ENGAGEMENT & HEALTH EQUITY

STAKEHOLDER ENGAGEMENT & HEALTH EQUITY

Individual Health = Population Health

Population Health = Social Determinants of Health

Social determinants of health illuminate inequities

Stakeholder realities, priorities and analysis are

Flip the Script: Research for Health Equity

Minimum: Be aware of and acknowledge historical abuse by health researchers

Maximum: Commit to actively addressing the social determinants of health and redressing harms. Conduct research and change research infrastructure to advance health equity.

BEST PRACTICES

- Engage partners in design, well before conducting research, if possible
- Identify and communicate potential benefit(s) for each partner
- Share resources and decision-making
- Be clear about possible impacts of the research
- Don’t be a colonizer: don’t impose & don’t take without giving
- Agree on communications methods (how, how often, who)

Best Practices - Transparency & Self-Reflection

- Why do you care?
- Be clear about what you hope to learn, gain. Describe benefit you bring
- Be clear about what you can share. Share as much as you're able
- Don't think you're going to save anyone, except maybe yourself
- Be yourself
- Stakeholders can help provide insight, entree, proxy trust

Best Practices - Practicalities

Relationships with Research Partners

- Carefully define roles for all partners in the project
- Define and share leadership opportunities
- Plan for your relationship after the project

Budget

- Adequately compensate partners and participants for their time and expertise - participants are not just “subjects”
- Practice transparency, equitable sharing of resources

Time

- Define aims and timelines
- Be flexible with competing priorities of community partners

Community Partners Provide Project Consultation, Advising & Guide Institutional Change

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Principles of Partnership for Equity (draft)

- Partners agree on mission, values, goals, measurable outcomes and accountability for the partnership.
- Partners work toward mutual trust and respect, practicing genuineness, transparency and commitment.
- Partners build capacity, building upon strengths and assets, and working to address needs & increase capacity of all partners.
- Partners work toward a balance of power, enabling resources among partners to be shared.

Principles of Partnership for Equity (draft cont'd)

- Partners embrace co-designed and multi-directional evaluation. Give & receive feedback, toward improving both the partnership and its outcomes.
- Partners commit to liberation. Working to overcome racism, sexism, homophobia, classism & other barriers to equity, leveraging privilege to defend & assist.
- Partners own privilege, acknowledging how they contribute to, benefit from, or suffer from oppression.

Partnership Fundamentals: How To

Partners make clear and open communication an ongoing priority, developing a common language.
Principles and processes for the partnership are established with the input of partners
There is feedback among partners, iterative improvement
Partners share benefits, accomplishments
Partnerships can dissolve and need to plan a process for closure

Adopted by the CCPH Board of Directors October 1998

THE MOVEMENT:
Health Equity & Anti-Oppression

We all have opportunity to contribute to efforts against health inequity and oppression

CBPR--- also referred to as “Participatory Action Research” proposes we commit to action to change conditions that harm

Research can be anti-oppressive-- giving voice to the voiceless, providing evidence towards change, especially when applied to changing policy, systems and environment

Stakeholder Involvement Helps:

Eg. undocumented populations fear revealing themselves; we gained participation through trusted partners in multiple studies; undoc. staff helped interpret findings

Lived-experience shapes worldview:

- African American and US-born Latinx participants were mostly incensed that soda corporations marketed to them specifically
- Asian and Latinx immigrants thought Soda corporations marketing to POC was smart, tailored marketing

Research staff who understood differences in immigration experience and generation helped interpret the nuanced perspectives from what otherwise might be seen as a homogeneous ethnic group

Contact Us:

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