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College of Public Health

**Participatory Praxis and
Stakeholder Engagement**

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**“Go in search of people.
Begin with what they know.
Build on what they have.”**

Old Chinese Prover



What is Participatory Praxis?

- A collection of research methods that document, acknowledge, and respect local knowledge
- An approach to negotiating differences between researchers and community members such that the research perspective does not supersede community perspectives or subordinate the community in its intent or its outcomes
- Participatory methods take their starting point from the strengths and assets inherent in a community, rather than from a weakness and deficit perspective

Sprague L, Afifi R, Ayala G, El-nasoor ML. (2019). Participatory praxis as an imperative for health-related stigma research (Commentary). BMC Medicine; 17:32

What is community-engaged research?

→ “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.”

Centers for Disease Control and Prevention. Principles of Community Engagement. 2. Washington, DC: NIH Publication; 2011.

Ontology

→ Ontology: beliefs about the nature of reality. What exists, what is true? Realism vs. Relativism

→ **Realism:**

- Belief in one truth
- Truth does not change
- Truth can be discovered using objective measurements
- Truth can be generalized

→ **Relativism:**

- Multiple realities/truths
- Shaped by context
- Evolves and changes based on experiences
- Not generalizable but transferable to similar contexts

→ Beliefs about reality influence every decision we make about how we practice and how we do research and influence the relationship of the researcher to what is being studied (epistemology)

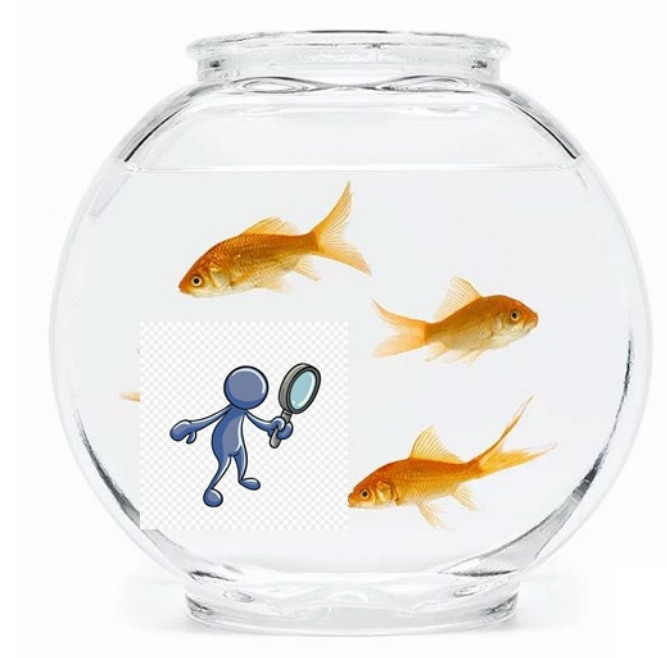
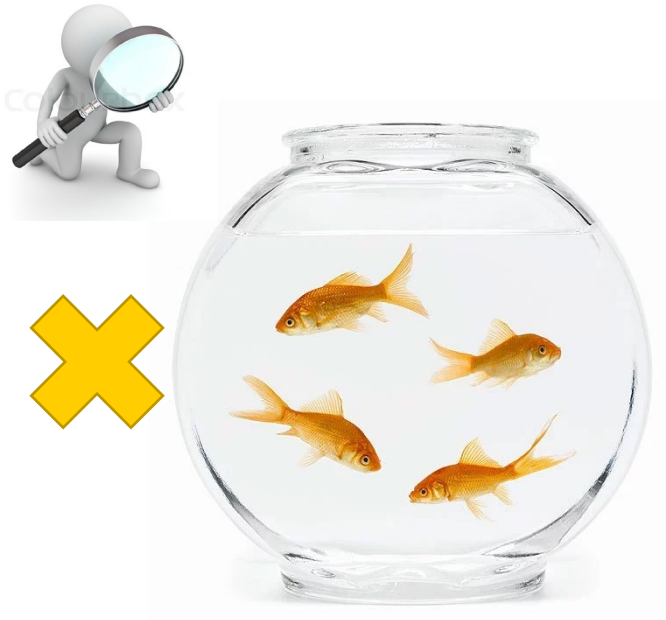
Epistemology

- Epistemology: how we should gather new knowledge... how we come to know what we know. How objective the relationship between the researcher and what can be know is. What relationships the researcher has with the research.
- **Etic approach**: 'taking an outsider's view'
- **Emic approach**: 'taking an insider's view'
- <https://www.youtube.com/watch?v=hCOsY5rkRs8>

What research ontology and epistemology is participatory praxis grounded in?

→ **Relativism**

→ **An Emic approach**



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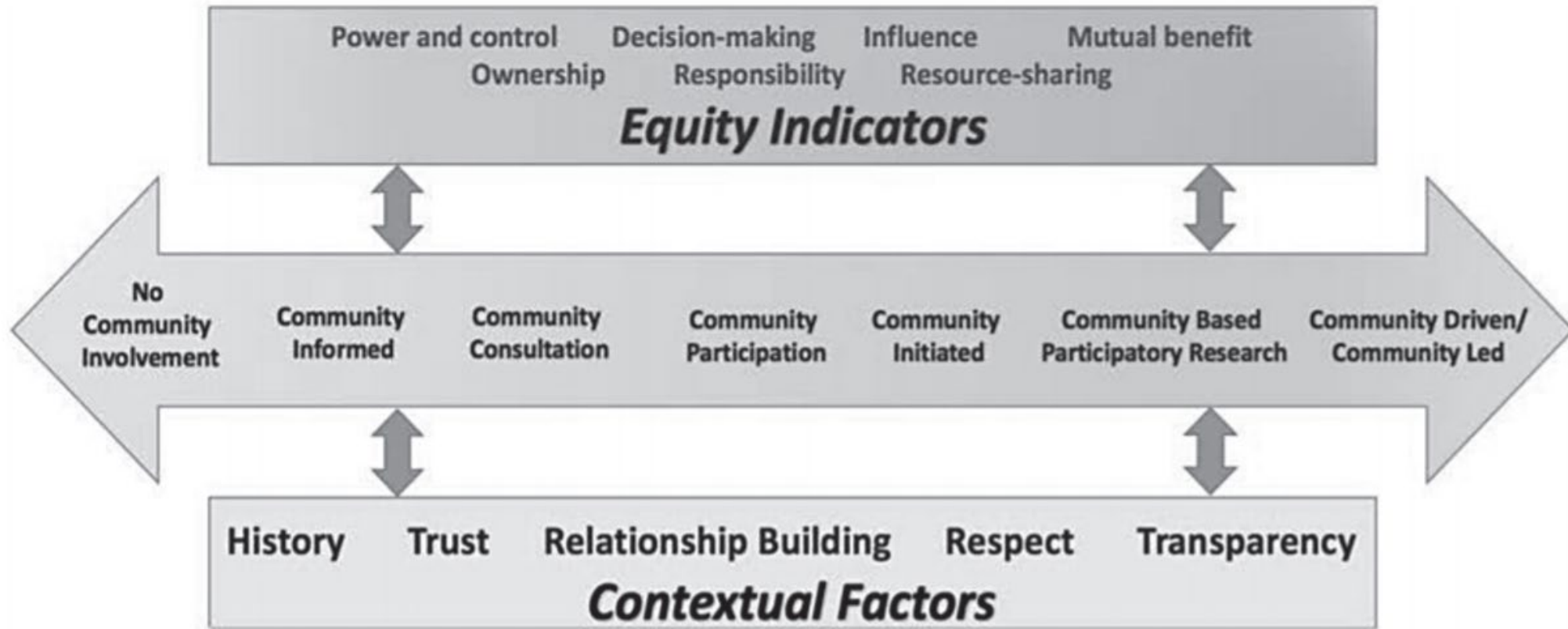


Figure 1. Continuum of Community Engagement in Research

Key, K.D., Furr-Holden, D., Lewis, E.Y., Cunningham, R., Zimmerman, M.A., Johnson-Lawrence, V., ... Selig, S. (2019). The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Progress in Community Health Partnerships: Research, Education, and Action* 13(4), 427-434. doi:10.1353/cpr.2019.0064. (Figures 1,2,3 from this article)

Community Involvement/Activity						
Community is not included in any aspects of the research	Community informs the research and may or may not be informed or included (or know they're informing)	Community provides input and feedback to researchers to inform the research	Community has some active role in the research	Community initiates the research agenda/priorities	Community shares equally in decision-making and ownership	Community leads and owns the research
No Community Involvement	Community Informed	Community Consultation	Community Participation	Community Initiated	Community Based Participatory Research	Community Driven/Lead
Researcher works independent of community	Information is gleaned from the community which informs the research 'ear hustling'	Researcher consults with community and includes community in the research (front end or back end)	Researcher includes community in the research in a defined role	Researcher responds to specific needs or asks from community	Researcher shares equally in decision-making and ownership with community	Researcher supports community identified research efforts or serves no role
Researcher Involvement/Activity						

Figure 2. The Continuum of Community Engagement in Research: Involvement and Activity

Key, K.D., Furr-Holden, D., Lewis, E.Y., Cunningham, R., Zimmerman, M.A., Johnson-Lawrence, V., ... Selig, S. (2019). The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Progress in Community Health Partnerships: Research, Education, and Action* 13(4), 427-434. doi:10.1353/cpr.2019.0064. (Figures 1,2,3 from this article)

<i>Community Perspective/Experience</i>						
We do not know about this project	We may or may not be aware of this project but our information informed it	Researchers met with us to present the project and asked for our input	Researchers provided opportunities for us to participate (e.g., recruitment, community advisory board)	We told researchers what questions we need answers for	We participated in all aspects, equitably	We fully own the research
No Community Involvement	Community Informed	Community Consultation	Community Participation	Community Initiated	Community Based Participatory Research	Community Driven/Lead
We had no contact with the community	We sat in on a meeting and learned a great deal	We met with several community organizations, they shared their concerns and gave us suggestions	We have a defined role(s) for community to participate in the research	We created the research in response to community identified issue(s)/question(s)	We developed the project together with community partners	The community is in charge and we support their efforts when asked
<i>Researcher Perspective/Experience</i>						

Figure 3. The Continuum of Community Engagement in Research: Perspective and Experience

Key, K.D., Furr-Holden, D., Lewis, E.Y., Cunningham, R., Zimmerman, M.A., Johnson-Lawrence, V., ... Selig, S. (2019). The Continuum of Community Engagement in Research: A Roadmap for Understanding and Assessing Progress. *Progress in Community Health Partnerships: Research, Education, and Action* 13(4), 427-434. doi:10.1353/cpr.2019.0064. (Figures 1,2,3 from this article)

Helicopter science to Community-Based Participatory Research

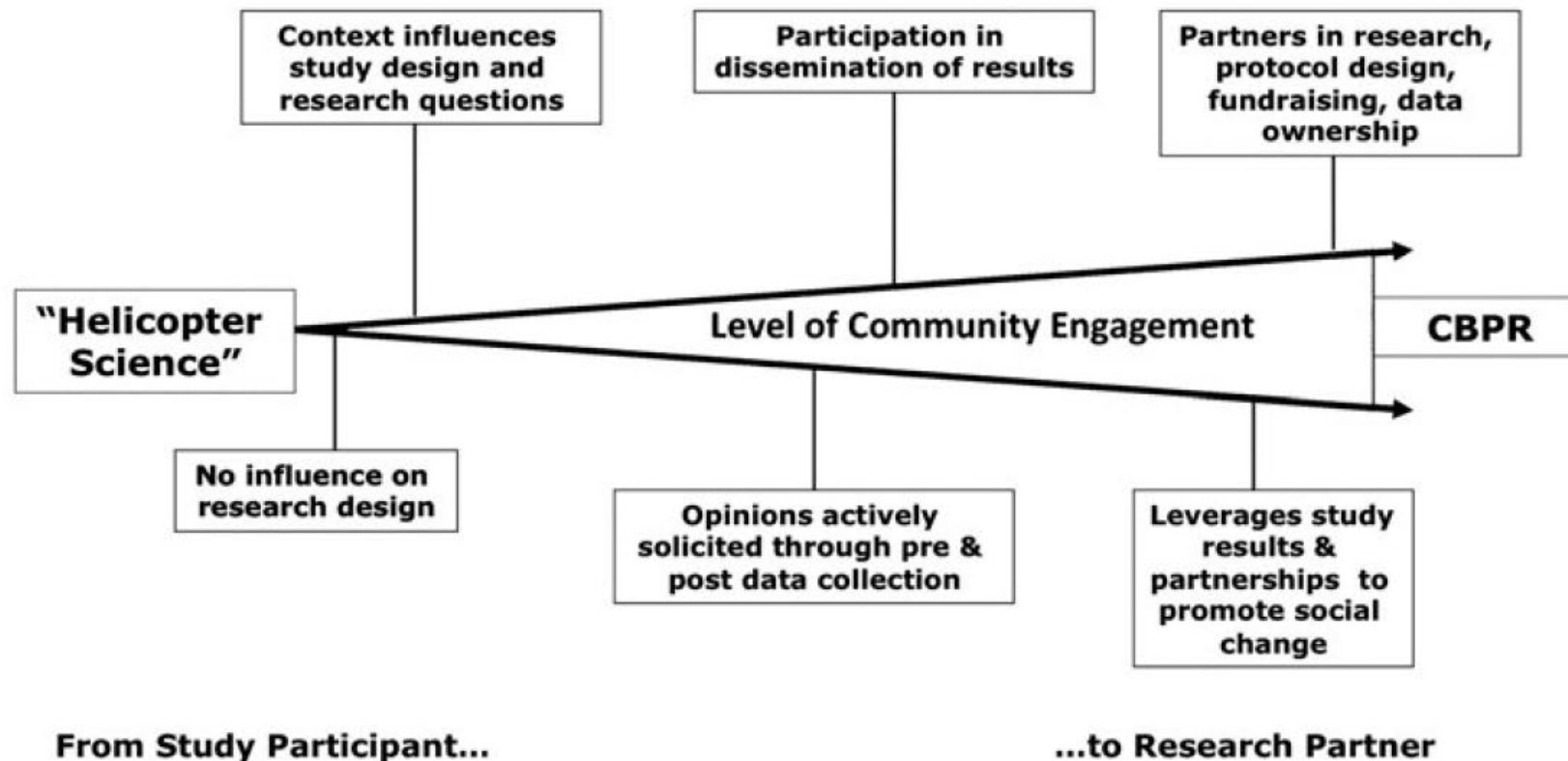


FIG. 1. Schematic of community based participatory research as a continuum of efforts, with varying degrees of community engagement. Levels of engagement increase as community members are transformed from study participants to research partners.

Balazs CL, Morello-Frosch R. The Three R's: How Community Based Participatory Research Strengthens the Rigor, Relevance and Reach of Science. *Environ Justice*. 2013;6(1):10.1089/env.2012.0017. doi:10.1089/env.2012.0017.

Foundational values for participatory praxis

Table 1 Foundational values for participatory praxis in health-related stigma research

Equity	Research is designed and conducted with the goal of social egalitarianism that improves health and well-being for marginalized groups. Researchers and communities are co-equal investigators with different sets of skills and experiences to share with each other
Justice	Research is designed and conducted with the goal of creating social change that increases access to the rights and privileges of citizenship, including access to healthcare, recourse for discrimination, and voice in decision-making and policies for marginalized groups
Dignity	The inherent worth and value of all participants is recognized at every stage of the research
Participation	The people and communities that are the subjects of research should lead the research and be meaningfully engaged at all stages, including the right not to participate
Non-othering	People and communities who are the foci of research are seen as similar to the researchers, and approached from a common base of humanity, rather than seen as essentially different, exotic, incomprehensible, or 'other'
Accountability	Communities and researchers hold themselves and each other accountable to their commitments, including to participatory praxis
Reflexivity	Researchers and communities engage in self-reflection to examine their own stigmatizing attitudes and biases and commit to rigorously seeking out and addressing their own prejudices and to refrain from acting on them
Transparency	The rules for decision-making are clear, collective, agreed in advance, and followed
Flipping power dynamics	Research is designed and conducted with the goal of creating social change that results in marginalized groups gaining greater control and self-determination over their lives and environments

Definitions created by the authors based on principles described in the literature [2, 4, 7, 9]

Sprague L, Afifi R, Ayala G, El-nasoor ML. (2019). Participatory praxis as an imperative for health-related stigma research (Commentary). BMC Medicine; 17:32



Community-based participatory research (CBPR)

→ “a partnership approach to research that equitably involves community members, organizational representatives, and researchers, and others in all aspects of the research process.”

(Israel, Schulz, Parker, and Becker, 1998).

Principles of CBPR - 1

1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community (an asset rather than deficit approach)
3. Facilitates collaborative, equitable partnerships in all research phases and involves an empowering and power sharing process that attends to social inequalities
4. Promotes co-learning and capacity building among partners
5. Integrates and achieves a balance between research and action for mutual benefit of all partners

Israel BA, Schulz AJ, Parker EA, Becker AB, Allen AJ, Guzman JR, Lichtenstein R. (2018) Critical Issue in Developing and Following CBPR Principles. Chapter 3 in Wallerstein et al. (eds). Community-Based Participatory Research for Health. 3rd Edition. San Francisco: Jossey-Bass.

Principles of CBPR - 2

- 6.Emphasizes PH problems of local relevance and ecological perspective that attend to the multiple determinants of health and disease
- 7.Involves system development through a cyclical and iterative process
- 8.Disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process
- 9.Requires a long term process and commitment to sustainability
- 10.Addresses issues of race, ethnicity, racism and social class and embraces cultural humility

Israel BA, Schulz AJ, Parker EA, Becker AB, Allen AJ, Guzman JR, Lichtenstein R. (2018) Critical Issue in Developing and Following CBPR Principles. Chapter 3 in Wallerstein et al. (eds). Community-Based Participatory Research for Health. 3rd Edition. San Francisco: Jossey-Bass.

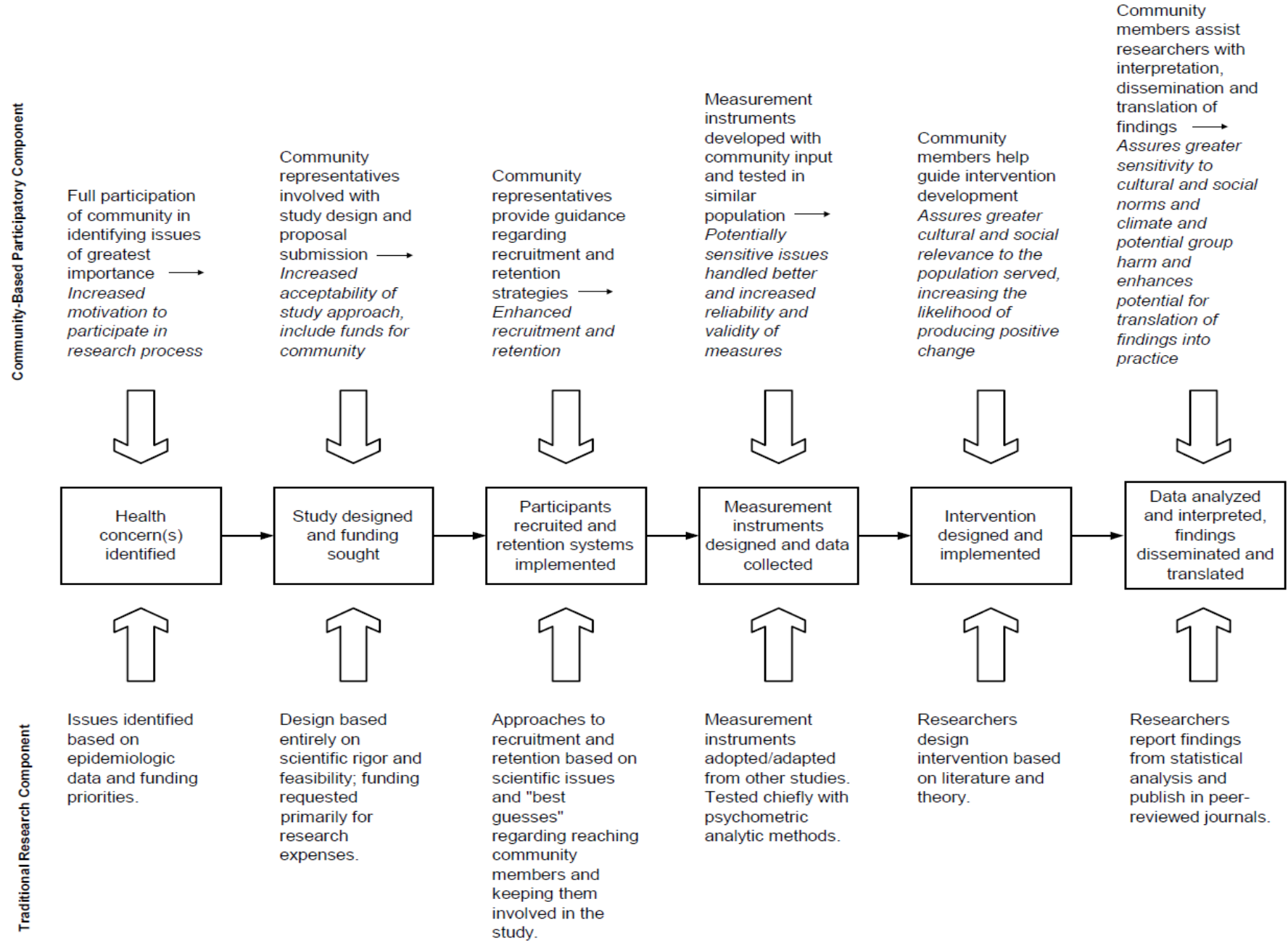
Distinguishing Community-Based from Community-Placed Research

- Who chose the problem to be studied?
 - Is there an intervention or service component?
 - Who designed the intervention?
 - Who made the research policy decisions?
 - Who writes papers/makes presentations?
 - Where are the results disseminated?
- “Where does power lie?” (Wallerstein & Duran chapt. 2, 2018)

http://www.med.umich.edu/csp/Course%20materials/Fall%202005/Lichtenstein_Community-Based%20Participatory%20Research%20Workshop.ppt#262,8,
Key Principles of Community-Based Participatory Research

Viswanathan M, Ammerman A, Eng E, Gartlehner G, Lohr KN, Griffith D, Rhodes S, SamuelHodge C, Maty S, Lux, L, Webb L, Sutton SF, Swinson T, Jackman A, Whitener L. Community-Based Participatory Research: Assessing the Evidence. Evidence Report/Technology Assessment No. 99 (Prepared by RTI—University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016). AHRQ Publication 04-E022-2. Rockville, MD: Agency for Healthcare Research and Quality. July 2004.

Figure 1. Analytic framework for community-based participatory research



Equity-oriented Collaborative Community-Based Research – 4 questions

- Are we collaboratively developing critically conscious knowledge?
- Are we authentically locating expertise?
- Are we conducting race-conscious research and scholarship?
- Is our work grounded in asset-based understandings of community?

Gordon da Cruz C. (2017) Critical Community-Engaged Scholarship: Communities and Universities Striving for Racial Justice, Peabody Journal of Education, 92:3,363-384, DOI: 10.1080/0161956X.2017.1324661.

Reflections on Researcher Identity and Power

→ Positionality/Power/Privilege

- insider-outsider continuum
- “social determinants of health ... explanatory models for communities of color, the particular histories of genocide, forced migrations, appropriation of lands, and attempted assimilations of indigenous cultures and languages...hegemonic discourse that reinforces internalized oppression.”

→ Epistemology of power/ construction of knowledge

Muhammad M, Wallerstein N, Sussman AL, Avila M, Belone L, Duran B. Reflections on Researcher Identity and Power: The Impact of Positionality on Community Based Participatory Research (CBPR) Processes and Outcomes. Crit Sociol (Eugene). 2015;41(7-8):1045-1063.

Role of the ‘researcher’

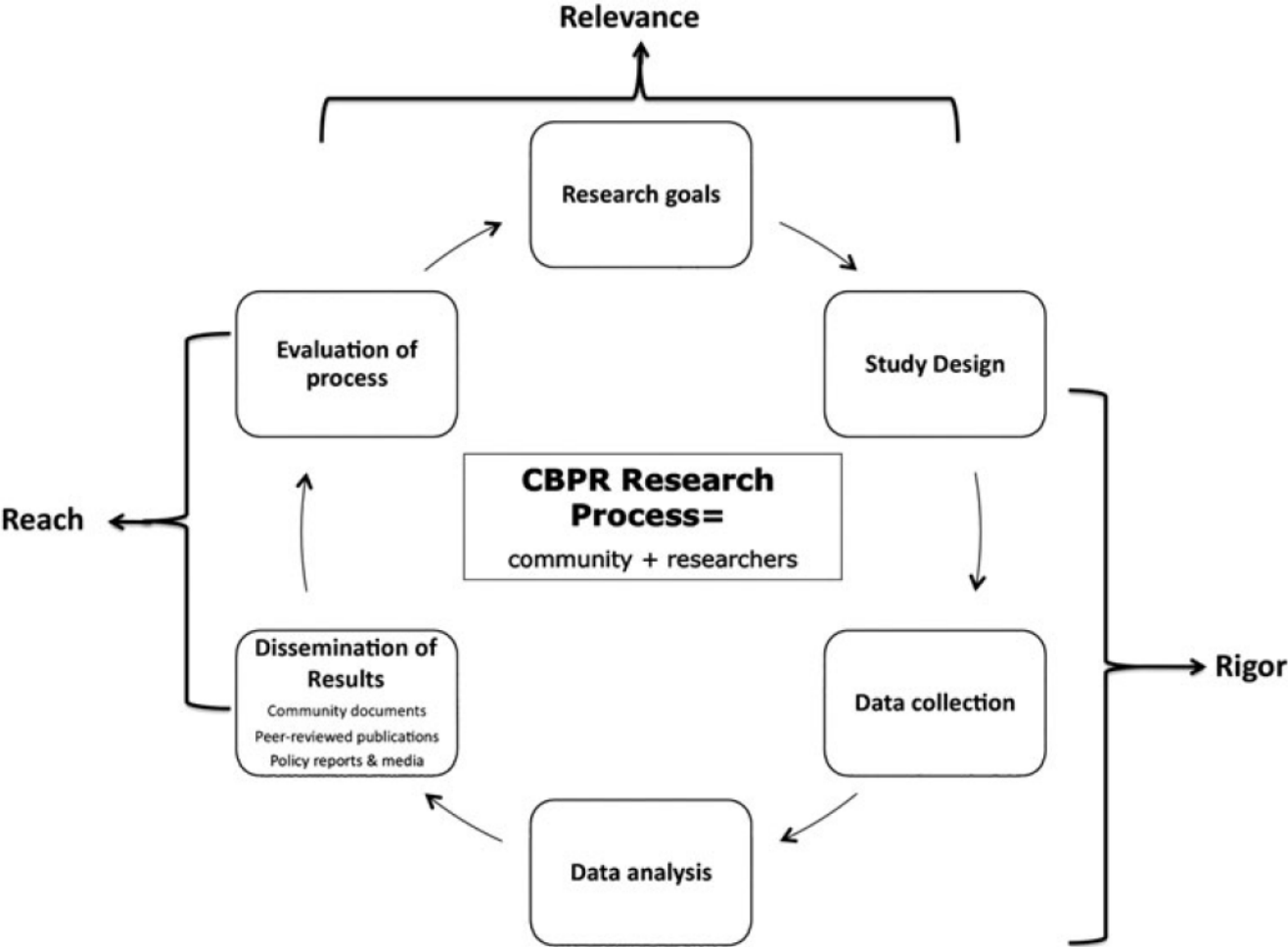
- facilitator, collaborator, enabler, participant, catalyst, co-learner, not “expert” know-it-all, ‘letting go of control’
- “It is essential that health care professionals have an investment in the success of the community, be active members, and remove the barriers that come between them and the members of the community.” (Eng and Parker, 1994)

Benefits of CBPR

- “Ensuring that the research topic reflects a major issue identified by community;
- Improving the quality, validity and sensitivity of the research by drawing upon community wisdom;
- Promoting trust between communities and researchers;
- Improving the translation of research findings into policy and practice;
- Enhancing uptake of the research findings by community members.”
- + many more (Israel et al., 1998, p.180-181)

Enhanced Relevance, Rigor and Reach

FIG. 2. The 3 Rs (rigor, relevance, and reach) in relation to generalized steps of a community based participatory research approach, where traditional researchers and community members are jointly involved at each step, though levels of participation may vary.



Balazs CL, Morello-Frosch R. The Three R's: How Community Based Participatory Research Strengthens the Rigor, Relevance and Reach of Science. Environ Justice. 2013;6(1):10.1089/env.2012.0017. doi:10.1089/env.2012.0017.

“Participatory research is fundamentally about who has the right to speak, to analyze and to act.” Minkler and Wallerstein, 2003



Minkler M, Wallerstein N. Introduction to community based participatory research, Community-Based Participatory Research for Health, 2003 San Francisco, CA Jossey-Bass

Question???



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