Using a CBPR Approach with Health Literacy Research for Community or Patient Stakeholder Engagement
HARC VIII

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Agenda

☐ Introductory Activity –

1. Continuum of community-engaged research (CEnR) including CBPR

2. Relevance of CEnR and CBPR

3. Strategies for incorporating engaged research in traditional project designs

4. Application of CEnR to FOAs

COMMUNITY & CONTINUUM

Definition of Community

- Basic definition of community: "those who have a shared identity"
  - People with shared experience, such as gender, racial/ethnic identity, sexual orientation, disability or health condition, or online community
  - Neighborhood/geographic proximity
  - Emotional connection, shared values or norms, common interest or shared need (i.e., religious affiliation)
  - Institutions and individuals representing selves or organizations

Community Engaged Research (CER)

- APPROACH to research
- Can be incorporated into most research designs
- Done well, it adds to research strategy
- Can be used with interventions, education, clinical guideline development
- CER, CEngR, CEnR…..

Community Engagement

- Range of levels of engagement

- <u>Collaborative</u> effort between community partners and program planners/researchers

- Community members <u>involved</u> in topic selection, design of research/program development, dissemination of findings to improve use of research

- Community representatives have a <u>voice and role in the process</u>

- Work <u>benefits a community</u>

- National Institutes of Health & PCOR

Definition of Community-Based Participatory Research

- Collaborative approach to research and practice that equitably involves all partners in the research/planning and implementation process

- Recognizes the unique strengths that each brings

- Combines knowledge with action and achieving social change to improve health and eliminate disparities
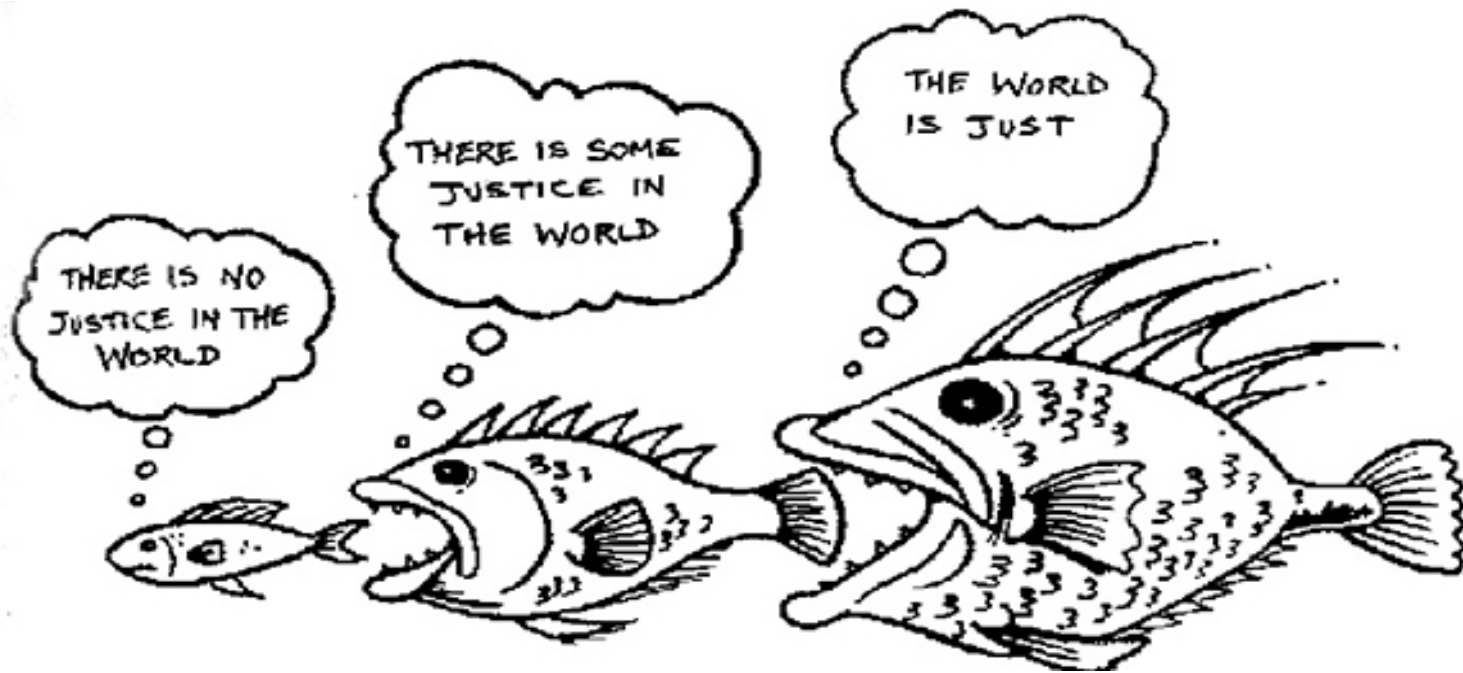
Communication Flow for Ladder of Participation
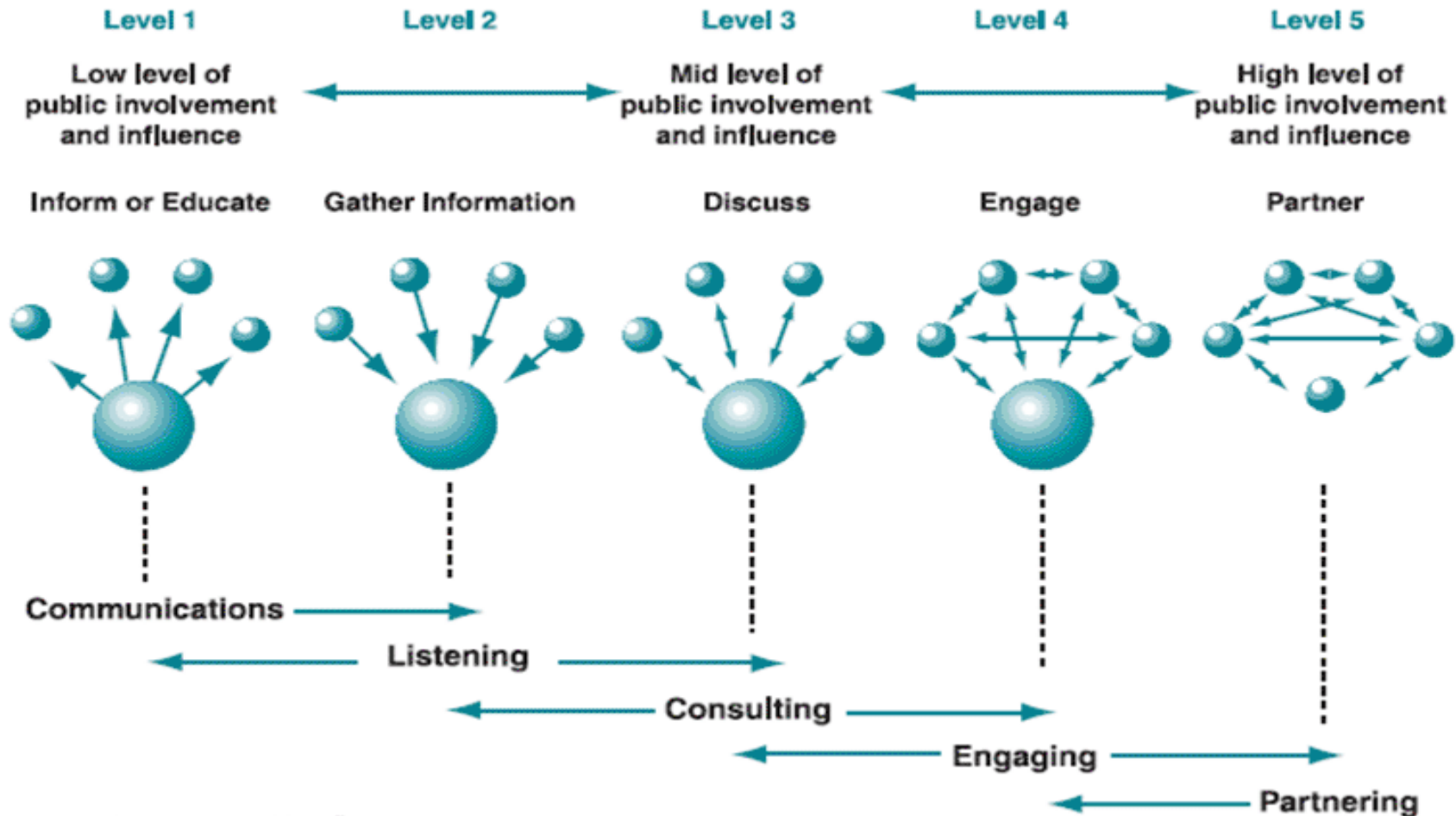
Adapted from Patterson Kirk Wallace

Power

Community Collaboration must Recognize Power

- Disenfranchised and marginalized populations

- Community organization exists to facilitate a way of life that affects people and social systems

- Privileged provide access to power and wield it to reproduce structures of control

Discussion

How do you think health literacy and power are related?

How does power impact your health literacy work?

How does power influence your work with communities?

Power Comes into Play

- Interpersonal communication

- Access to resources

- Definition and acquisition of knowledge

Definition of Stakeholders

- Persons with past/current illness experience, family/caregivers/ advocacy groups (PCORI)

- People with vested interest at various levels; constituents; "Representative" of a sub-group

- Are those most affected by the research involved?

- Are those who have a stake in the research/problem involved?

  - Consideration of who impacted by research or issue addressing
    - Community leaders- informal or formal
    - City Council members or staff, faith leaders/ organizer or advocate/nonprofit or school leaders/staff

RELEVANCE & RATIONALE

CBPR for Cultural Tailoring and Sensitivity

- Learned patterns of thought, communication, beliefs and behavior shared
- Norms and expectations
- Professional and organizational culture
- Family and social group culture

- Cultural liaison
- Identify and include in research and intervention

Direct Benefits to Research

- Gain unique knowledge and skills (form of researcher empowerment)

- Improve participation

- Refine recruitment protocols

- Improve adherence to treatment

- Tailor materials and programs to culture and community

- Identify new potential relationships between independent and dependent variables

Direct Benefits to Research

- Identify innovative research or program evaluation questions and ethical considerations

- Ideas for mediators or different outcome measures

- Improve interpretation of and meaningfulness of findings

- Improve translation and feasibility

- Sustainability

- Dissemination- relevance to patients & community members

Direct Benefits to Research and Clinical Practice

- Patient satisfaction and trust

- Community ownership or buy-in

- Reduction in medical errors

- Belief that programs are important and therefore should be attended and funded

Benefits to Broader Community

- Capacity for managing health issue

- Improvements in knowledge, understanding of importance of topic

- Skill building

- Medical/health care knowledge

- Empowerment

- Social networking

- Satisfaction with care

- Greater dissemination to local community

Discussion

Do you think CBPR can help build health literacy skills of the community? If yes, how?

What about other related literacies, such as research literacy?

Challenges of CBPR

- Time to build relationships

- Different skills than how PhDs and MDs are trained

- Concern about introducing bias

- Managing conflicting agendas

- Determining which stakeholders

- Worries about null results or

- Inconvenient findings

- Sustainability

Group Activity #1

Discussion at tables

What types of community partners could you engage in your project?

What are some of your challenges and some benefits to an engaged process?

STRATEGIES

Structures for Engagement

- Advisory

- Boards

- Workgroups

- Co-Investigators

- **Meeting people where they are…

CAC or Project focused Workgroup

- Committee structure

- Define roles

- Decision making process

- i.e. Community Advisory Board

Principles for Participation

1. Community recognized as having a <u>unique identity</u>
   - Acknowledge multiple cultures in community and social and economic factors

2. Emphasizes <u>local</u> <u>relevance</u> of public health issue and <u>ecological perspective</u>

   - Policy, organizational, and community factors; family and individual knowledge, behaviors, and beliefs all influence health.
   - Unique characteristics help or make it difficult for families to stay healthy

Principles for Participation

3. <u>Builds</u> <u>on</u> <u>strengths</u> <u>within</u> community

   - All communities, cultures, and organizations have strengths. They need to be leveraged

4. Facilitate <u>collaborative</u> and <u>equitable</u> partnership in all phases

   - Active listening, shared decision-making

Principles for Participation

5. Promotes <u>co-learning</u> and <u>capacity</u> <u>building</u> for researchers and partners

   - Community has expertise; Researchers and community learn from each other

   - Participation can lead to new abilities, skills or opportunities for organization and individuals

6. Participatory process is a cyclical and <u>iterative process</u>

   - Strategy for flow of communication

Principles for Participation

7. Broad <u>dissemination of findings/knowledge</u> gained

    - Findings of research and curriculum available beyond academic journals and written in an understandable format

8. Acknowledge <u>long-term</u> process and <u>commitment</u> <u>to process</u>

    - CAB members need to be at meetings to share in decision making for the duration of the work

Facilitating Participation

- Incentives

- Child care

- Provide food

- Cultural sensitivity

COMPENSATION

Strategies for Engagement

World Café

- Working meetings

- Qualitative methods modified for feedba

- World Cafes

- Delphi Method (for building consensus)

- Concept Mapping

**Consider including capacity building- facilitate networking

**Recognition (and discussion) of power differentials

Discussion

Do you think CBPR can be applied to…

…all types of research ?

…all types of settings, even online?

CBPR: Clinical Trials and Evaluation

- Protocols more:

  - inclusive of family and support networks

  - feasible for consistent participation

- Processes for design (RCT, Stratifications)

- Recruitment materials

- Interpretation of findings

- Communication of findings in non medical terms disseminate to wider audience

- Recommendations for scale up

CBPR: Assessment and Evaluation

- Define purpose

- Interpret literature for tailoring evidence-based programs to local cultural context

- Introduction and length of a survey

- Identify theoretical concepts and help choose measures

- Order of survey questions

- Translation

- Administration strategies

- Program design- curriculum design and implementation

- Discuss relationships between measures

- Interpret finding

- Write or present findings

Burning Questions?

USING IN PROPOSALS

Group activity #2

At tables, review project summaries

Discuss specific ways to incorporate CBPR or CEnR

Come up with specific ways to incorporate CBPR or CEnR in different sections of grant proposal.

- *Background, Innovation, Research Strategy, Budget, Human Subjects*

RESOURCES

CBPR

- Community Campus Partnerships for Health: *Community-Based Participatory Research*
  - https://depts.washington.edu/ccph/commbas.html

- UCSF Accelerate: *Community-Engaged Research Presentations and Tools*
  - https://accelerate.ucsf.edu/research/community-tools

- AAPCHO: *CBPR Toolkit*
  - http://www.aapcho.org/resources_db/cbpr-toolkit/

Health literacy and CBPR

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- Gillis, D.E. (2004). A Community-Based Approach to Health Literacy Using Participatory Research. *Adult Learning*, *15*(1-2), 14-17.
    - http://eric.ed.gov/?q=A+Community-based+approach+to+health+literacy+using +participatory+research&id=EJ768235

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- Poureslami, I., FitzGerald, JM., Madeleine, M., & Waters, D. (2011). Using Community-Based Participatory Research (CBPR) To Develop Culturally And Linguistically Appropriate Educational Materials To Assess Asthma Patients" Knowledge And Health Literacy In Ethno-Cultural Groups. *American Thoracic Society Journals*. A1429-A1429.

- Shaw, S.J. *Addressing minority health access through community-based health literacy research*. University of Arizona.

Grants and CBPR

- Community-Campus Partnerships for Health: *Tips & Strategies for Developing Strong Community-Based Participatory Research Proposals*
  - http://depts.washington.edu/ccph/pdf_files/cbpr-reviewf.pdf

- Community-Campus Partnerships for Health: *Examples of Funded Proposals*
  - https://depts.washington.edu/ccph/commbas.html#FundedProposals

- Community-Campus Partnerships for Health: *Tips & Strategies for Funding Community-Engaged Research (CEnR).*
  - http://www.feinberg.northwestern.edu/sites/cch/docs/arcc/CCPHGrantWritingResources.pdf

- ARCC: *Sample Proposals and Partnership/Project Cases Studies*
  - http://arccresources.net/category/sample-proposals-partnership-case-studies/

PCOR grants

- AHRQ: *Community-Based Participatory Research, Lessons for Stakeholder Engagement in Patient-Centered Outcomes Research*
  - http://effectivehealthcare.ahrq.gov/index.cfm/tools-and-resources/ehc-program-webcasts/community-based-research/

- PCORI: *What We Mean By Engagement*
  - http://www.pcori.org/funding-opportunities/what-we-mean-engagement

- PCORI: *Engagement Rubric*
  - http://www.pcori.org/sites/default/files/Engagement-Rubric.pdf

- PCORI: *Sample Engagement Plans*
  - http://www.pcori.org/sites/default/files/PCORI-Sample-Engagement-Plans.pdf

Articles of Interest

▢ Banks, Armstrong, et al., 2013. Everyday Ethics in CBPR. Contemporary Social Science. http://www.tandfonline.com/doi/pdf/ 10.1080/21582041.2013.769618

▢ Burke, J. G., Jones, J., Yonas, M., Guizzetti, L., Virata, M. C., Costlow, M., et al. (2013). PCOR, CER, and CBPR: Alphabet soup or complementary fields of health research? *Clinical and Translational Science, 6*(6), 493-496. http://ctb.ku.edu/en/table-of-contents/ leadership/leadership-functions/make-decisions/tools#tool1

▢ Coats, J. V., Stafford, J. D., Thompson, V. S., Javois, B. J., & Goodman, M. S. (2015). Increasing Research Literacy: The Community Research Fellows Training Program. *Journal of Empirical Research on Human Research Ethics: JERHRE*, *10*(1), 3–12. http://doi.org/ 10.1177/1556264614561959

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▢ Jurkowski, Janine M., et al. "Engaging low-income parents in childhood obesity prevention from start to finish: A case study." *Journal of community health* 38.1 (2013): 1-11. https://www.ncbi.nlm.nih.gov/pubmed/22714670

▢ Jurkowski, J. M., Lawson, H. A., Mills, L. L. G., Wilner III, P. G., & Davison, K. K. (2014). The empowerment of low-income parents engaged in a childhood obesity intervention. *Family & community health*, *37*(2), 104-118

▢ Lawson, H. A., Caringi, J., Pyles, L., Jurkowski, J., & Bozlak, C. (2015). *Participatory Action Research*. Oxford University Press, USA.

▢ *Muhammad, M., Wallerstein, N., Sussman, A. L., Avila, M., Belone, L., & Duran, B. (2014). Reflections on Researcher Identity and Power: The Impact of Positionality on Community Based Participatory Research (CBPR) Processes and Outcomes. Critical Sociology*, 0896920513516025. http://cura.unbc.ca/cm/DelphiBackgrounder.pdf

▢ Sandoval, Jennifer A., Julie Lucero, John Oetzel, Magdalena Avila, Lorenda Belone, Marjorie Mau, Cynthia Pearson et al. "Process and outcome constructs for evaluating community-based participatory research projects: a matrix of existing measures." *Health Education Research* 27, no. 4 (2012): 680-690.

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THANK YOU!