Community Engagement efforts at NIH: examining best practices to bridge community and research agendas

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Objectives

- To define CBPR – what it is and not
- Review NIH example of community engagement model

Overview of the IOM recommendation on Community Based Participatory Research (CBPR)

- Definition of CBPR

“ A Partnership approach to research that equitably involves community members, organizational representatives and researchers in all aspects of the research process”

Israel, BA et al. (2001)

How are academic researchers perceived?

"They're harmless when they're alone, but get a bunch of them together with a research grant and watch out."

Getting Started…

- **What is CBPR**?
  - "community based", "community placed", "community focused", "community centered", "community engagement", "participatory"

- **Key strategies of CBPR**:
  - Active engagement and shared decision-making of community members, academic researchers and funders,
  - Integrated sources of knowledge (e.g., formal & informal)
  - Iterative data collection and analysis using multiple methods (e.g., qualitative and quantitative etc.)
  - Utilization of multiple channels for knowledge dissemination
  - Achievement of common goals: social change, improved health and well-being etc.

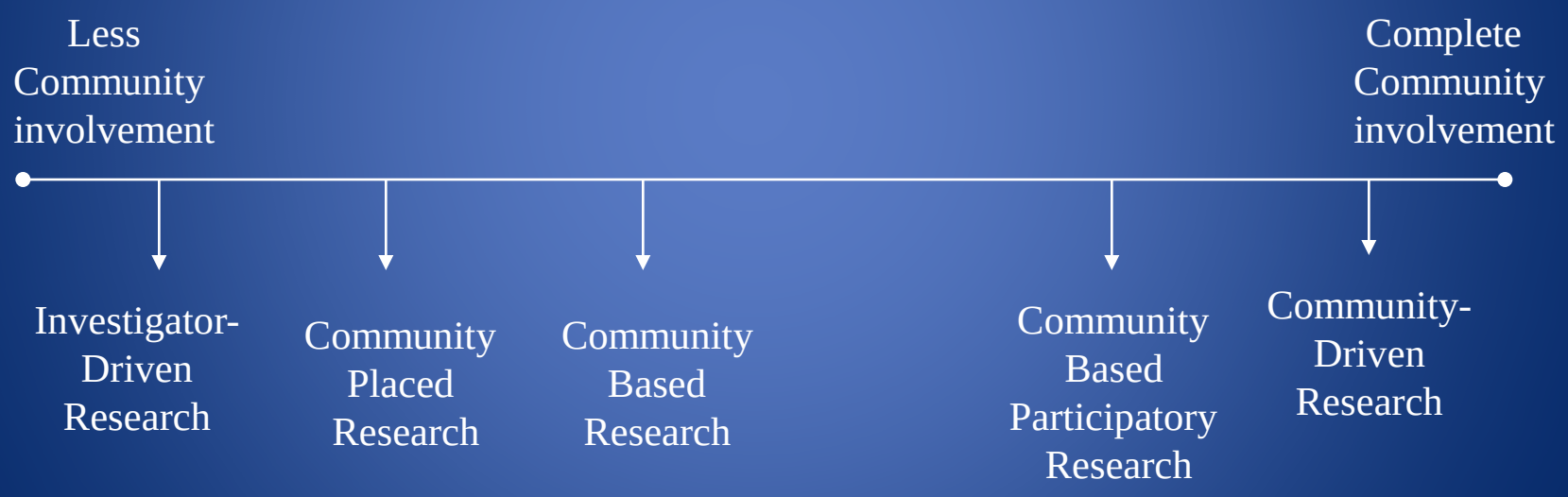
CBPR

- Not simply a *strategy*, but an *ideology*

- People should be able to determine what is happening to their community
  - They will have to live with it! (compatibility)
  - Research dollars run out, so what will happen later on? (sustainability)
  - Not a laboratory in the traditional sense (fidelity)

Community Engaged Research Continuum

(clinical & social/behavioral)



Is CBPR always the best approach?

- Not necessarily
- BUT, very popular approach
- Many are conducting research under the title of CBPR, but are not
  - Simply forming coalition to inform what is going on is NOT enough

CBPR is an everyday occasion

Benefits of using a CBPR approach: Contributions to communities & science

- Enhances relevance & use of data
- Enhances intervention design & implementation
- Increases quality & validity of research/findings
- Has potential to translate research findings to guide development of further interventions & policy change

Israel, et al., 1998

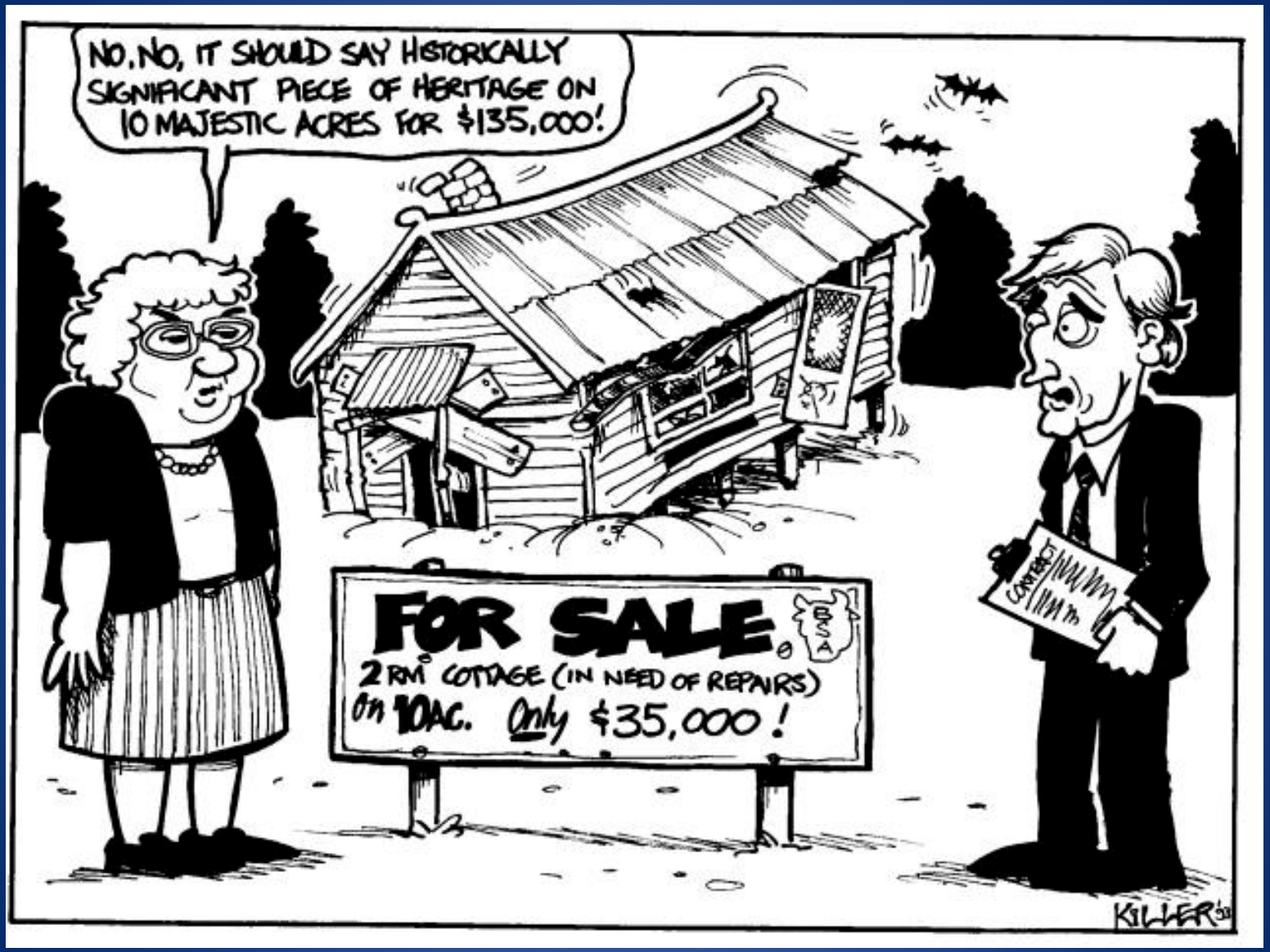
Challenges in CBPR

- Balancing the demands of process with the need for outcomes
- Engaging in continuous conversation with community partners maintaining a willingness to change – "*many moving parts*"
- TIME INTENSIVE!!!
- Flexibility in implementation
- Maintaining high expectations

Israel, et al., 1998; Lopez, 2005

Pitfalls of CBPR

- Applying for grants as a researcher before the community partner(s) is engaged
- Using the community to confirm priorities rather than provide direction (design and implementation) or expansion of research
- Not using community partners to help interpret findings
- Assuming that community cannot understand complex research challenges


NO, NO, IT SHOULD SAY HISTORICALLY SIGNIFICANT PIECE OF HERITAGE ON 10 MAJESTIC ACRES FOR $135,000!
FOR SALE
2 RM COTTAGE (IN NEED OF REPAIRS) ON 10AC. Only $35,000!
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Key Points

There are emerging practices but no single “best “ way to conduct CBPR

CBPR is an ideology

The concept of CBPR has implications for high expectations and standards

NIH Approach to community engagement

Why the Emphasis on CBPR now?

- Need for translational research
  - US health outcomes are no better than outcomes for other industrialized countries
  - Even though the US is a leader in biomedical research, there is a gap between this research and practice, and ultimately health outcomes

- NIH Roadmap – http://nihroadmap.nih.gov
  - Long-term plan to strengthen linkages between research and practice and practice and communities
  - One strategy – community engaged research

NIH Roadmap

- Long term plan
- Sets priorities for NIH
- Emphasizes strengthening links between research and practice
- Encourages improved communication and cooperation between researchers and communities

NIH Director's Council of Public Representatives (COPR)

Director's Council of Public Representatives - Windows Internet Explorer

http://nih.granicus.com/MediaPlayer.php?view_id=12&clip_id=62

U.S. Department of Health & Human Services

National Institutes of Health

Turning Discovery Into Health

01:15:15 / 02:08:51

Director's Council of Public Representatives

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- Acknowledgement of COPR Members John Burklow, Associate Director for Communications and Public Liaison, Office of the Director, NIH

Minutes

Meeting Agenda

Friday, November 5, 2010

1:00 p.m. **Acknowledgement of COPR Members**
John Burklow, Associate Director for Communications and Public Liaison, Office of the Director, NIH

New Members
- Donna Appell, New York
- Gardiner Lapham, Washington, D.C.
- Susan Wooley, Ohio

Retiring Members
- Naomi Cottoms, Arkansas
- Elmer R. Freeman, Massachusetts
- Beth Furlong, Nebraska
- Brent Jaquet, Washington, D.C.
- Matthew Margo, New York
- Anne Muñoz-Furlong, Virginia

1:15 p.m. **COPR Members Update on Outreach Activities**

1:45 p.m. **Director's Update**
Francis S. Collins, M.D., Ph.D., Director, NIH

2:00 p.m. **Questions and Answers**

2:15 p.m. **BREAK**

2:30 p.m. **Enhancing Public Participation: Using New Strategies and Tools**
Carlos Pavão, Co-Chair, COPR

2:45 p.m. **Discussion**

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Definitions Definition of “Public Participation”

- Public participation is based on the belief that those who are affected by a decision have a right to be involved in the decision-making process.
- Public participation is the process by which an organization consults with interested or affected individuals, organizations, and government entities before making a decision.
- Public participation is two-way communication and collaborative problem solving with the goal of achieving better and more acceptable decisions.

Ahmed, S. M, et al. 2009

Definition of "Community Engagement"

- A process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people
- Community engagement is a core element of any research effort involving communities.
- It requires academic members to become part of the community and community members to become part of the research team

Ahmed, S. M, et al. 2009

Definitions *Operating* Principle for Community Engagement

Community engagement:

- Process & power sharing
- Maintenance of equity& and flexibility
- Including the cultural context of communities
- Should operationalized in the form of partnerships
- Help mobilize resources and influence systems
- Change relationships among partners
- Serve as catalysts for changing policies, programs, and practices.

Ahmed, S. M, et al. 2009

Education Guidelines for Educating Researchers and the Lay Public

- The work group developed a template for developing guidelines: *Principles, Values, Strategies, and Outcomes for Investigators Who Want to Engage the Community in Their Research:*
- 13 values
- Strategies for achieving each value
- Outcomes of strategies

Ahmed, S. M, et al. 2009

Value → Strategy → Outcome

- Investigators and communities understand what CBPR means.
- The research goals are clear and relevant.
- The community-investigator partnership is strong.
- All partners receive equal respect.
- Communities and investigators share power and responsibility equitably.

Ahmed, S. M, et al. 2009

Value → Strategy → Outcome: Continued

- Diverse perspectives and populations are included in an equitable manner.
- The research project results in mutual benefit for all partners.
- Communities and investigators have opportunities to build capacity.
- The partners sustain the relationship and the research outcomes after the project ends.
- Communications are continuous.

Ahmed, S. M, et al. 2009

Value → Strategy → Outcome: Continued

- The monitoring and evaluation process is transparent.
- The partners establish appropriate policies regarding ownership and dissemination of results.
- The partners translate the research finding into policies, intervention, or programs.

Ahmed, S. M, et al. 2009

- PRIMR
- NIH Roadmap
- NIH Council of Public Representatives (COPR)
- IRB Community Member Resources – USC
- NIH Common Fund – About the NIH Roadmap
- University of Washington

http://www.cbprcurriculum.info

References

- Israel A, et al. *Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health.* Annual Review of Public Health. 19:173-202, 1998.
- Israel B, et al (Eds.). *Methods in Community-Based Participatory Research for Health.* San Francisco: Jossey-Bass & Co., 2005.
- López, EDS, et al. *Planning and conducting community forums to disseminate research findings using a CBPR approach: A case study from Community Action Against Asthma*. *Metropolitan Universities Journal*, 16(1): 57-76, 2005.
- Ahmed, S. M. et al. *Community Engagement in Research: Frameworks for Education and Peer Review*, 10.2105, AJPH, 2009

Thank you