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The Ethical Value and Challenges of Community-engaged Research

Frank Robinson

Partners for a Healthier Community

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The Ethical Value and Challenges of Community- engaged Research

3rd Annual Symposium...
Community-Engaged Research:
Exploring the Reach, Impact and Value
Frank Robinson, PhD



Authenticity in C-E Research = Ethics

- What do we mean by community?
- Who speaks for the community?
- What is the base for the research relationship?
- How do we truly achieve maximum involvement and ownership in the collaboration?
- What makes C-E research ethical?



What Do We Mean by Community?

It depends on what community you are talking about



Defining Community

- ...Or No Definition At All
 - Too often people talk about “the community” without defining what they mean or who they are specifically referring to
 - When we talk about community, it is important to frame the discussion in terms of:
 - Who is included in the particular “community” we are discussing
 - And distinguish which “level” we are referring to



Is the community the people?

General Description

“A group of people who are linked by social ties and share common perspectives and interests and may share a common geographic location.” (MacQueen et al. 2001)

Target/Sample

... separate and overlapping groups of people who are infected and affected by in various ways

... trial participants, their families and partners, providers, and community groups within the geographic parameters....

... the group of people who will participate in or are likely to be affected by or have an influence on the conduct of the research

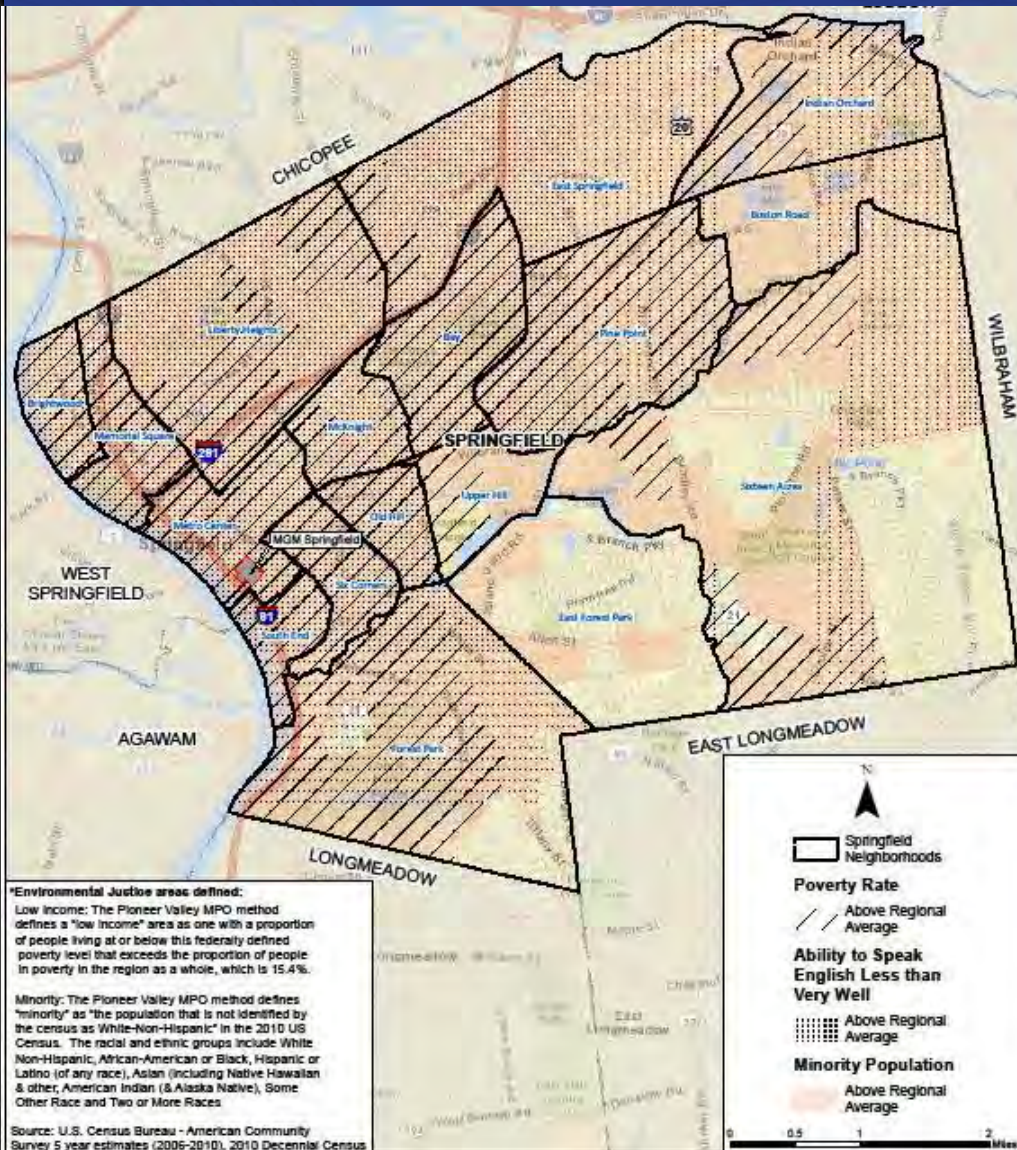


Is community the place where people live?

EJ Communities

... those neighborhoods that have rates of poverty or racial/ethnic minorities. above the regional/state average.

... areas with above average number of residents who self-identify as speaking English "less than very well" - criteria for immigrant populations.





Who speaks for the “community”?

Who do you talk to about your research interests?

Stakeholder analysis



Who speaks for the community?

- **Elected officials** formally represent the entire community
- **Public agencies** such as the local health, mental health, and housing departments
- Community level **organizations of residents around common interests**; these may be neighborhood associations, advocacy groups, or unions
- **Non-profit service organizations and other community-based organizations**, with a governance structure, leadership and members
- **Coalitions** - victims of domestic violence, environmental health, tenant organizations, advocate for fair treatment (such as the NAACP or NCCJ)
- **Faith based community organizations** such as churches, synagogues and mosques also represent the interests and values of their members.



People support what they help to create!
A shared understanding and balanced relationship

What is the base for the research relationship?

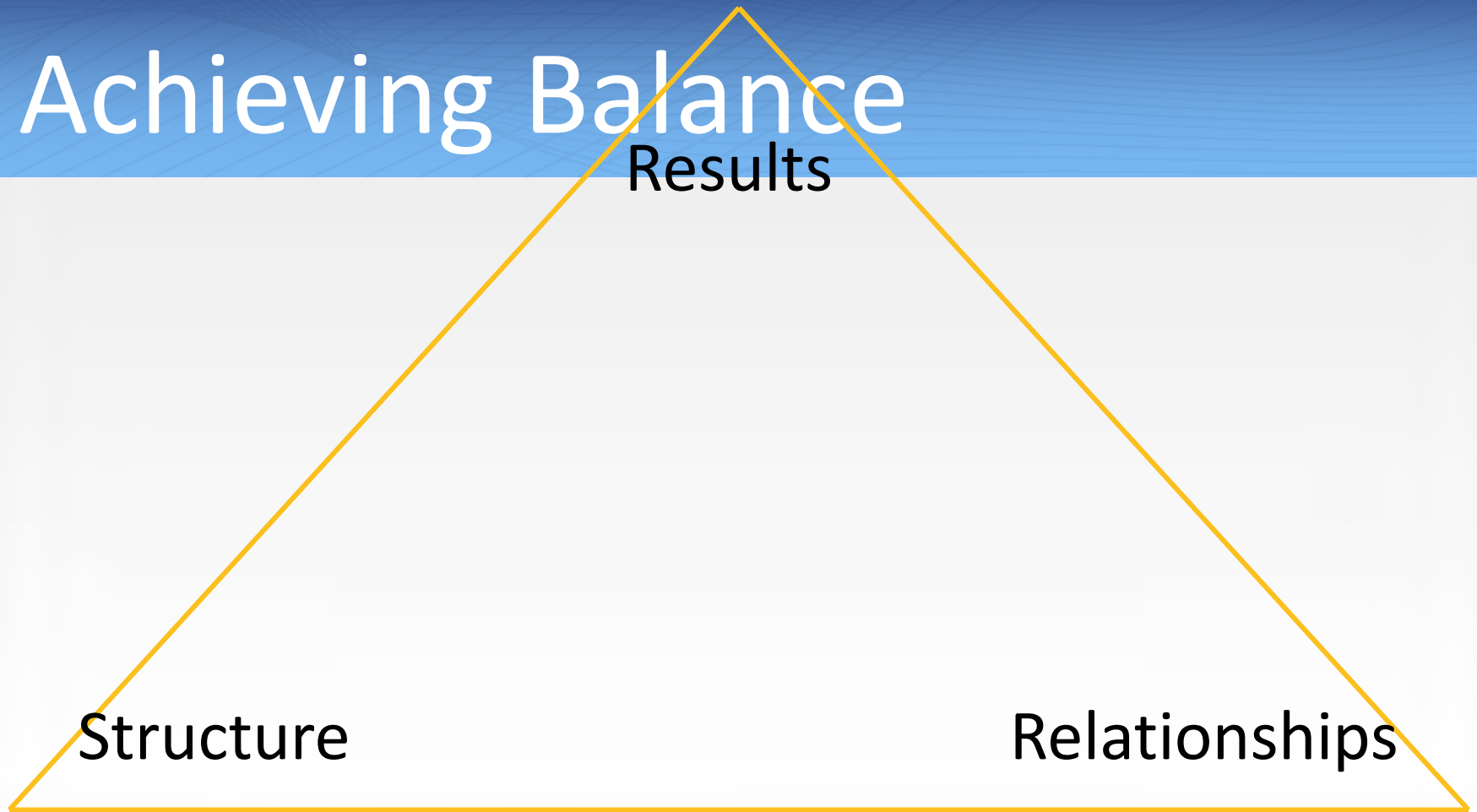


Achieving Balance

Results

Structure

Relationships



Maximum Ownership &
Maximum Involvement

Level of Ownership

Decide
and
Announce

Gather input
from
individuals
and decide

Gather input
from group
and decide

Consensus

Delegate with
constraint

Fallback*

**Fallback can be to any other level*

Level of Involvement



What makes C-E research ethical

Authentic community participation



Authentic Community Participation

- A working **Relationship** between Researcher and Community that:
 - Assures the ethical principle of **beneficence**
 - Maximizes **benefits** and minimizes risks for participants and for host communities.
 - Minimizes exposure to **controversy** and risk of **disruption**
 - Increases the **transparency and accountability** of the research to the community
 - Improves **quality of trials**, participant retention, adherence and accurate self-reporting: ensuring trial procedures are acceptable to participants and other decision-makers
 - Strengthens local **capacity and infrastructure**



Authentic Community Participation

- There is a **Structure** for shared responsibility and ownership for the process
 - Agreement about how and whose priority issues are addressed.
 - Community input in or review of the study design to optimize the chances of generating useful knowledge and protecting subjects. Project review by the community and relevant institutions
 - There are mechanisms for assuring that the study is culturally responsive and respects the rights of the subjects
 - The community provides input in the analysis and interpretation of the results



Authentic Community Participation

- The **Results** reduced inequities
 - The results are published and disseminated
 - The findings have been translated to policy and action