Best Practices for HIV Research Community Advisory Councils

Arryn A. Guy, Ph.D.
Investigator
Brown University
School of Public Health

Paul Goulet
Chair
Providence Boston CFAR
Community Engaged Research Council
Agenda

- Defining Community Engaged Research
- Core Principles
- Building Trust
- Equity
- Mutual Benefit
Poll Question 1

Which best describes your current role?

- Community member, person with lived-experience
- Healthcare provider
- Researcher
- Student
- Something else not listed
Poll Question 2

Which statement best describes your current experience with community-engaged research approaches?

- I would like to try, but I don’t know how
- I’m a beginner and need to learn the basics
- I tried but was not successful
- This doesn’t fit my research/advocacy interests
- I am currently doing community-engaged research and would like to improve my skills
Defining Community Engaged Research
“Community engagement in research is a process of inclusive participation that supports mutual respect of values, strategies, and actions for authentic partnership of people affiliated with or self-identified by geographic proximity, special interest, or similar situations to address issues affecting the well-being of the community of focus.

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, creating a unique working and learning environment before, during, and after the research.”

-The NIH Director’s Council of Public Representatives
**Continuum of Community Engagement in Research**

**Equity Indicators**

- Power & control
- Decision-making
- Influence
- Mutual benefit
- Ownership
- Responsibility
- Resource-sharing

**Contextual Factors**

- History
- Trust
- Relationship Building
- Respect
- Transparency

No Community Involvement → Community Informed → Community Consultation → Community Participation → Community Initiated → Community Based Participatory Research → Community Driven/Community Led

---

Continuum of Community Engagement in Research

Community involvement

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

Researcher involvement

- Community Informed: Researchers consult with community and includes community in the research. Researchers respond to specific needs or asks from community.
- Community Consultation: Researchers consults with community and includes community in the research in a defined role.
- Community Participation: Researcher responds to specific needs or asks from community.
- Community Initiated: Researcher shares equally in decision-making and ownership with community.
- Community Shares Equally in Decision-Making and Ownership: Researcher supports community identified research efforts or serves no role.
- Community Driven/Community Led: Researcher supports community identified research efforts or serves no role.

Poll Question 3

What aspects of community engaged research do you most need support with?

• Finding appropriate research partners
• Structuring an academic/community partnership
• Budgeting so all parties are fairly compensated
• Concerns about ethics or IRB
• Building and maintaining a mutually beneficial relationship
• Creating a community advisory council
Core Principles
Core Principles

- Trust
- Mutual Benefit
- Equity
Trust

academic members to become part of the community and community members to become part of the research team
Building Trust Key Examples

Ask community first
- What programs would you like to see? What do you need?
- What kind of research would excite you?
- What services would you like more evidence about?
- What concerns do you have about research?

Connection to the work
- Get personal
- How does your training & career path influence how you see the world? Your core values?
- What lived experiences do you share & which do you not?
- Share this with your community partners

Start small
- Demonstrate trustworthiness
- Pilot project first
- Larger project, longer commitment later
Core Principles

- Trust
- Mutual Benefit
- Equity
Equity

mutual respect of values, strategies, and actions for authentic partnership
## Equity Key Examples

### Establishing roles
- Who leads?
- How often will you meet?
- How do you make decisions?
- Actionable decisions

### Education
- Meaningful shared-decision making
- Education on research process
- Human Research Protection Program/Institutional Review Boards
- Data interpretation
- Psychometrics

### Budget
- Prioritize partnership building into the budget
  - Community advisory council meetings
  - Trips to visit community partners or community-based organizations
- Thinking of community partners as co-investigators
Equity Key Examples

Flexibly implement feedback
- Build flexibility at grant writing stage
- Be honest about limitations and responsibilities
- Try something new…
  - May lead to another grant idea/project

Sharing credit
- Authorship role on…
- Publications
- Presentations, etc.

Longevity
- Who owns the work
- Sustainability
- Maintaining relationships
Core Principles

- Trust
- Mutual Benefit
- Equity
Mutual Benefit

research provides resources and funding to train, employ, and build capacity of community members in all aspects of the research process
Mutual Benefit Key Examples

- **Policy change/support**
- **Creating permanent job openings for peers/community**
- **Mentorship/support professional goals Employment Continued involvement in future research projects**
- **Connection to university resources and networks**
- **Increasing access to services Research supporting study positions at CBO's for peers**

**Levels:**
- **Individual**
- **Interpersonal/Network**
- **Community**
- **Institutional/Health System**
- **Structural**
Audience participation

Write in the chat:

• What examples of mutual benefit have you seen in your work?
• What ideas do you have about how community engaged research can create mutual benefit?
Thank You

Contact us!
Paul Goulet: pbgoulet@hotmail.com
Arryn A. Guy, PhD: arryn_guy@brown.edu
Twitter: @aguywithaphd

This work was facilitated by the Providence/Boston Center for AIDS Research (P30AI042853) and the NIAAA Alcohol Research Center on HIV at Brown University (P01AA019072)