Best Practices for HIV Research Community Advisory Councils

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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

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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

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"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

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Continuum of Community Engagement in Research

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

Equity Indicators

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

Contextual Factors

History   Trust   Relationship Building   Respect   Transparency

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Continuum of Community Engagement in Research

No Community Involvement	Community Informed	Community Consultation	Community Participation	Community Initiated	Community Based Participatory Research	Community Driven/ Community Led
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
Researcher works independent of community	Information is gleaned from the community which informs the research 'ear hustling'	Researchers 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

Community involvement

Researcher involvement

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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

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Inspiring Change

Workbook

A community-based participatory research workbook for involving African Americans with serious mental illness in research

Table of Contents

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Core Principles

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Core Principles

Trust

Mutual Benefit

Equity

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Trust

academic members to become part of the community and community members to become part of the research team

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Building Trust Key Examples
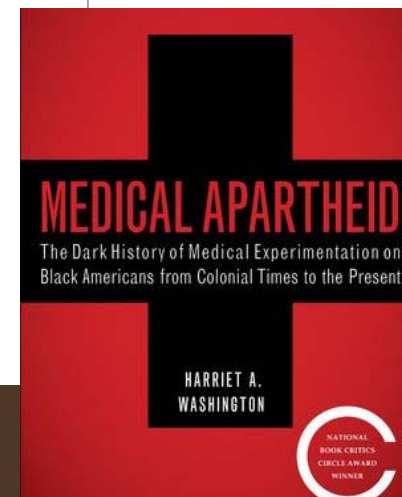
Ask community first

- 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

MEDICAL APARTHEID
The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present

HARRIET A. WASHINGTON

NATIONAL BOOK CRITICS CIRCLE AWARD WINNER

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Mutual Benefit

Equity

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Equity

mutual respect of values, strategies, and actions for authentic partnership

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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.

Engaging African Americans Living with HIV and Serious Mental Illness: Piloting Prepare2Thrive—A Peer-Led Intervention

Arryn A. Guy, Steve N. Du Bois, Nicole "Novie" Thomas, Scott Noble, Rodney Lewis, Jock Toles, Craig L. Spivey, Wren Yoder, Stephen D. Ramos, Honor Woodward

Progress in Community Health Partnerships: Research, Education, and Action, Volume 14, Issue 4, Winter 2020, pp. 413-429 (Article)

Published by Johns Hopkins University Press
DOI: https://doi.org/10.1353/cpr.2020.0048

Longevity

- Who owns the work

- Sustainability

- Maintaining relationships

Leadership
Researcher
Healthcare provider
Community member

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Core Principles
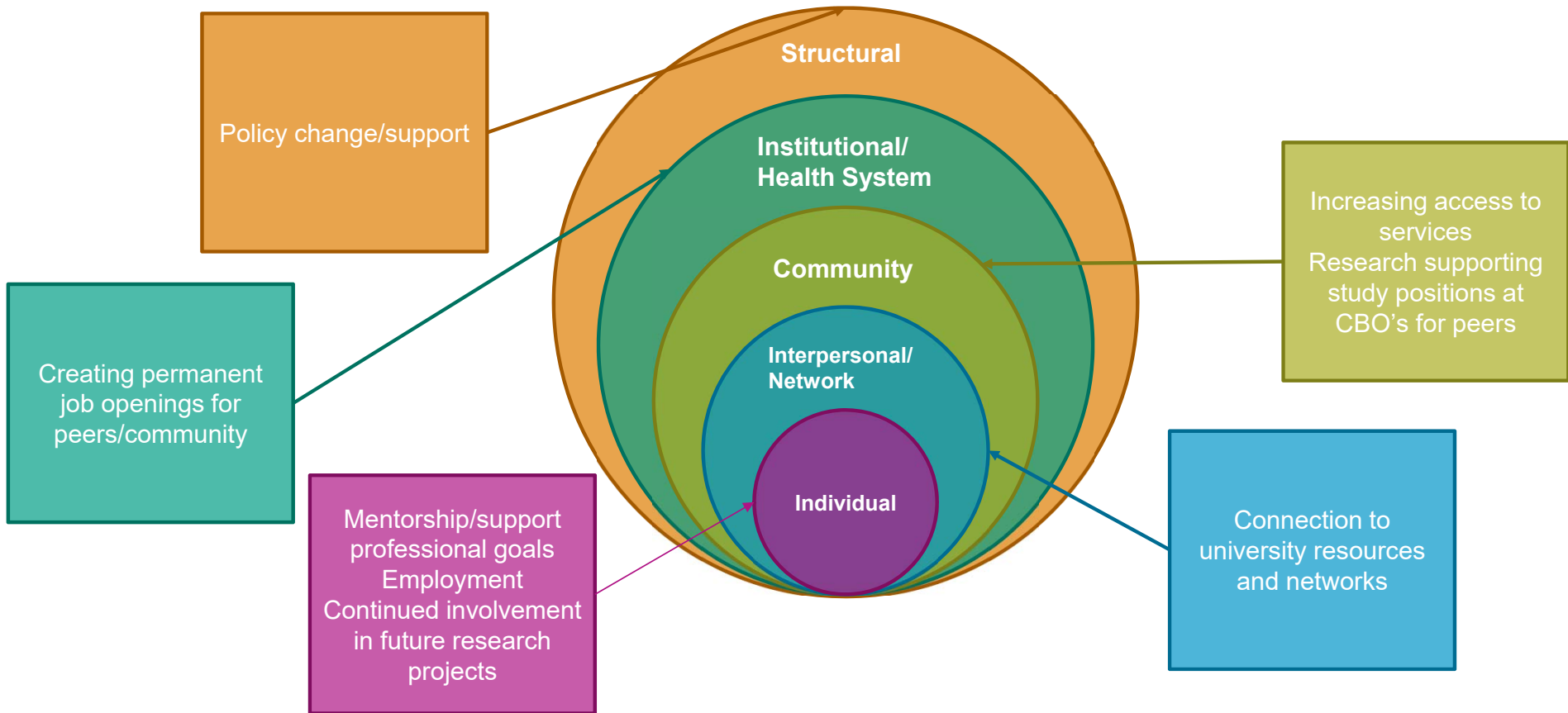

Trust

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

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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

Structural

Institutional/ Health System

Community

Interpersonal/ Network

Individual

Increasing access to services
Research supporting study positions at CBO's for peers

Connection to university resources and networks

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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?

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Thank You

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