Community-Led Research: The Role of Communities in Successful Biomedical HIV Research

Asa Radix. MD, PhD, MPH
Callen-Lorde Community Health Center

Outline

- Definitions: what is community-led research?
- Why is community engagement essential for HIV biomedical research?
- When/how should a partnership be developed?
- What are the roles of researchers & community stakeholders?
- What issues need to be addressed at the beginning of this partnership?

Language matters

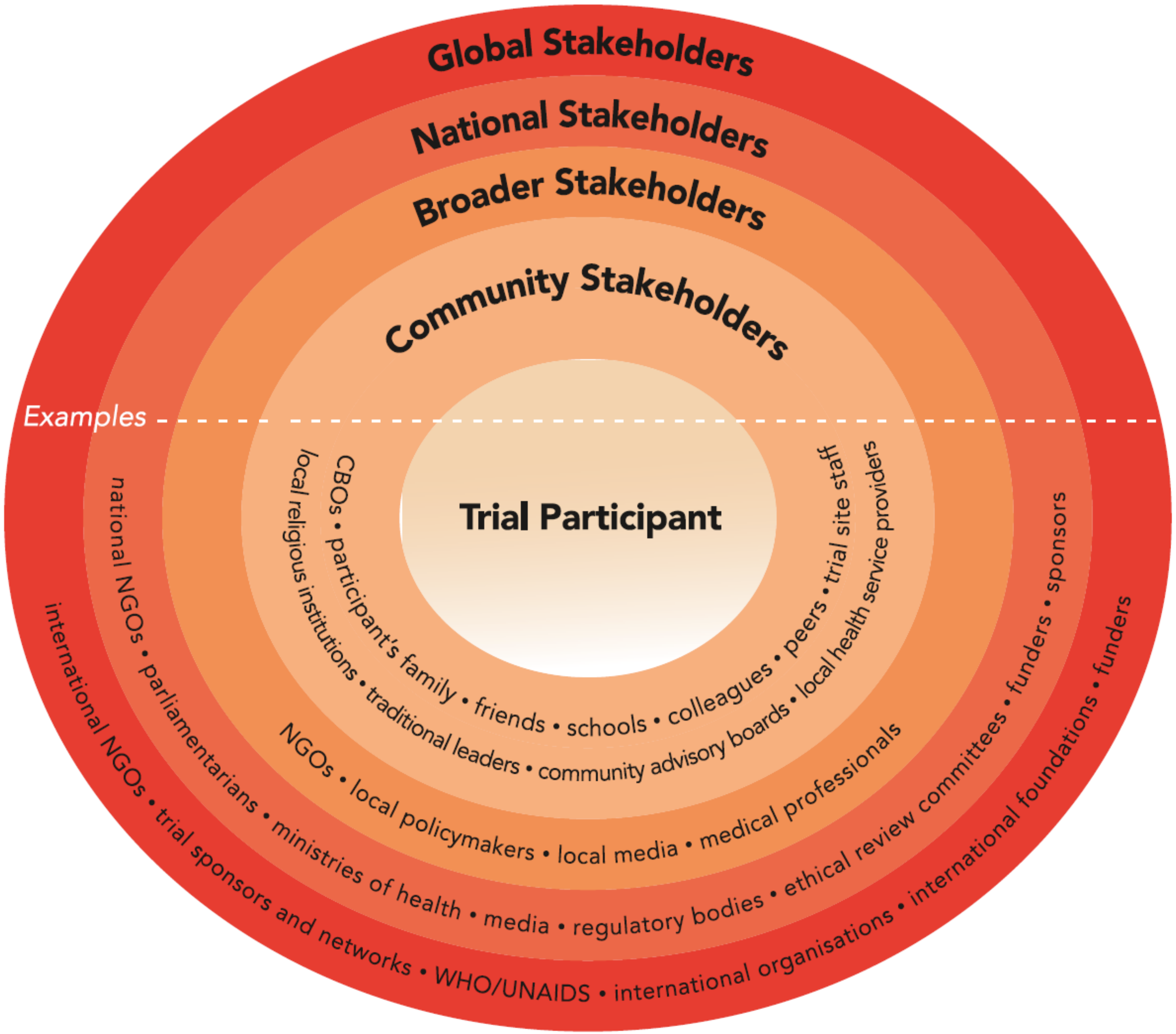
- Community-led research
- Community-based research
- Community-informed research
- Community-engaged research
- Community-based participatory research/practice

Community-led research does not just mean “research done in community settings” or “community based interventions”

Community Engaged Research

“The process of working **collaboratively** with and through **groups of people affiliated by geographic proximity, special interest, or similar situations** to address issues affecting the well-being of those people.”

- Centers for Disease Control and Prevention



Global Stakeholders

National Stakeholders

Broader Stakeholders

Community Stakeholders

Examples

Trial Participant

CBOs • participant's family • friends • schools • colleagues • peers • trial site staff

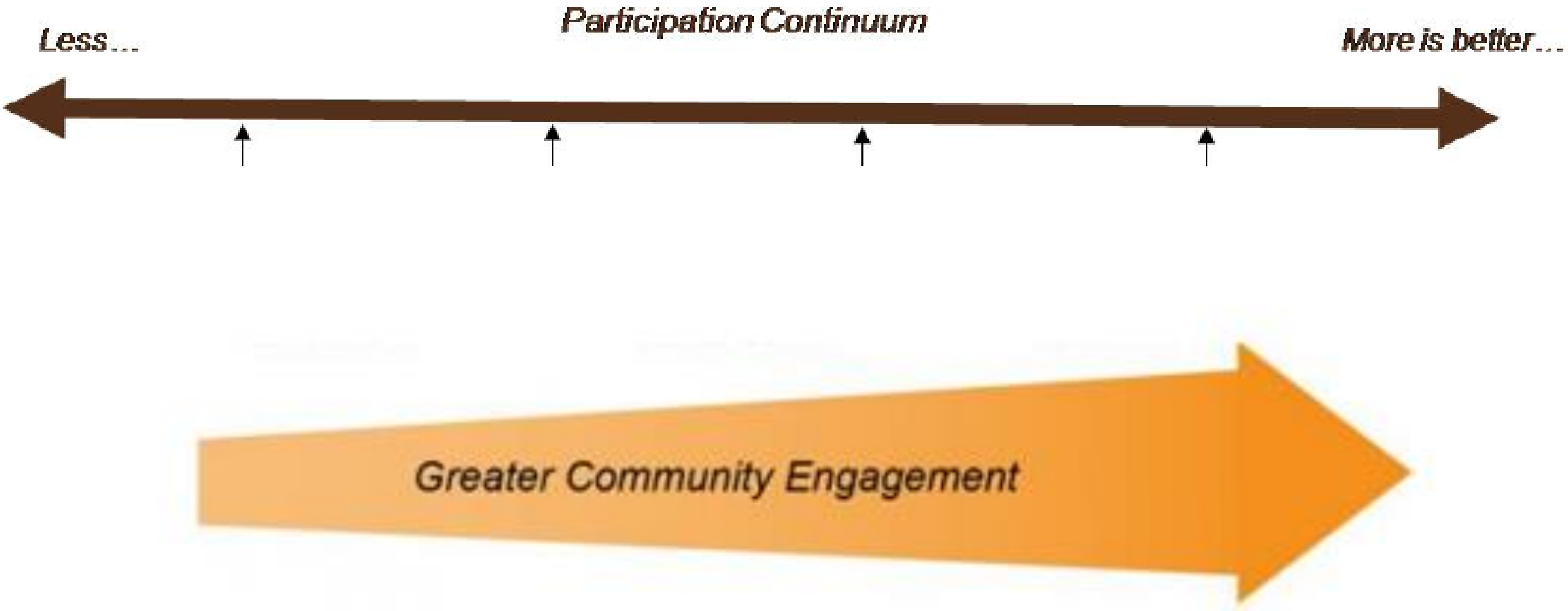
local religious institutions • traditional leaders • community advisory boards • local health service providers

NGOs • local policymakers • local media • medical professionals

national NGOs • parliamentarians • ministries of health • media • regulatory bodies • ethical review committees • funders • sponsors

international NGOs • trial sponsors and networks • WHO/UNAIDS • international organisations • international foundations • funders

UNAIDS/AVAC 2011



SHORT GUIDE TO COMMUNITY BASED PARTICIPATORY ACTION RESEARCH

Adapted from Wilder Foundation https://www.wilder.org/articles/using-framework-community-engaged-research

	TRADITIONAL	COMMUNITY ENGAGED	CBPR
Selection of Research Topic	Based on epi data & funding opportunities	Community identifies relevant issues	Community identifies important issues
Study Design	Based on scientific rigor & feasibility	Community ensures acceptability	Community intimately involved with design
Recruitment & Retention	Based on literature & "best guesses"	Community consulted on strategies	Community guides and aids recruitment
Instrument Design	Instruments adopted/adapted from other studies.	Instruments adopted & tested/adapted to fit local populations	Community developed instruments
Data Collection	Conducted by academics	Community involved in some data collection	Conducted by community, if feasible; focus on capacity building
Analysis & Interpretation	Researchers own the data, analyze & interpret findings, publish in peer review journals	Results shared with community for interpretation; dissemination includes community venues	Data shared; community & researchers interpret; wider community dissemination

Transgender People and HIV

- Data gaps for almost all low and middle income countries
- Trans people can also be prisoners, sex workers, PWID…

- **25 million** transgender adults worldwide
- Estimated global HIV prevalence of **19%** among transgender women
- Transgender women are **49 times** more likely to live with HIV
- Transgender women sex workers have a **12 times** higher risk of HIV acquisition

Prisoners

- **5-10%** TW have been incarcerated (USA)
- **38%** TW prisoners have been sexually assaulted in prison (USA)

Sex Workers

- **50%** TW have been sex workers (USA)

MSM

- **20-30%** transgender men have sex with cis men (USTS 2015)
- Often excluded from MSM programming or programs don't include reproductive health concerns/cancer screening

PWID

- High rates of substance use, few data on # trans PWID
- Needle sharing for silicone/hormones – data gap

Sources: WHO; UNAIDS; Baral S, 2013; Winter S, 2016

HIV and Transgender People in the US

Prevalence

- USA (all adults): 0.39%

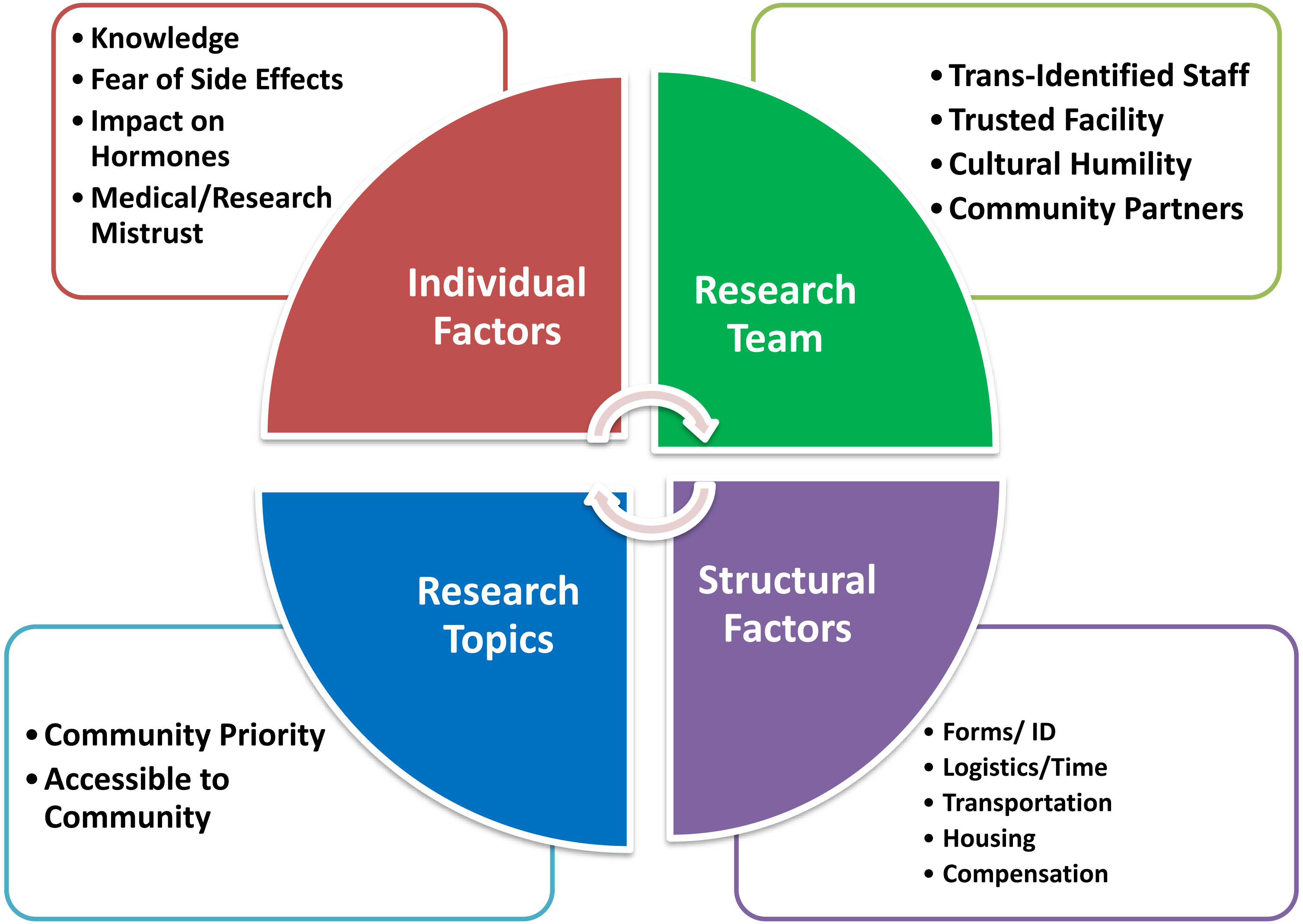
- Transgender women 14.1% (8.7%, 22.2%)*
  - Black 44.2%
  - Hispanic 25.8%
  - White 6.7%

- Transgender men 3.2% (1.4%, 7.1%)*

*** Lab confirmed**

Becasen, J et al. AJPH 2019; Woodring J Natl Health Stat Report. 2015

Trans People & Engagement in Research



Individual Factors

- Knowledge
- Fear of Side Effects
- Impact on Hormones
- Medical/Research Mistrust

Research Team

- Trans-Identified Staff
- Trusted Facility
- Cultural Humility
- Community Partners

Research Topics

- Community Priority
- Accessible to Community

Structural Factors

- Forms/ ID
- Logistics/Time
- Transportation
- Housing
- Compensation

Fisher, 2017; Fisher 2016; Hughes, 2016; Siskind 2016; Iribarren, 2017; Grant, 2016

What are the Benefits of Community-engagement for Researchers?

- Helps to identify community priorities
- Input into study design help to make tools and interventions culturally appropriate
- Builds trust between researchers & communities & future collaborations
- Improves communication, address community concerns
- Increases participation and retention
- Improves dissemination of results to communities

Protests at the International AIDS Conference 2004 about early PrEP trials

- Community involvement must happen at all stages of research
- Power of advocacy
- Importance of transparent communication

DOI: 10.1371/journal.pmed.0020234.g001 (Photo: Act Up–Paris)

What are Benefits for Community Stakeholders?

- Address important disparities in the community
- Ensure research conducted is culturally relevant
- Create/protect jobs
- Build research infrastructure
- Reduce power imbalance
- Identify risk associated with participation and help develop appropriate ways to protect participants
  - ethical, political, and logistical concerns
- Research may be more likely to lead to improvements in community health

How to Build Authentic Community-Researcher Partnerships

Respect

Community Stakeholder Accountability

Mutual Understanding

Integrity

Transparency

Accountability

Considerations for Community Stakeholders

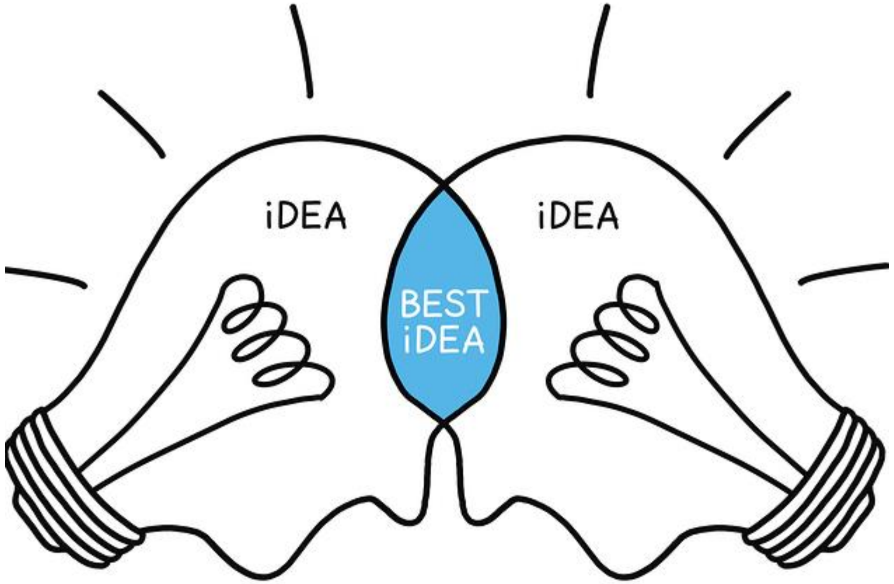
- Who are the researchers? Can we work with them?
- Have they previously worked with our communities?
- Is there a commitment/experience to community engagement?
- What will be our level of participation?
- How will it benefit us?
- How will we be compensated for our contributions?
- Do we have the bandwidth?
- What resources (time, money, space) are needed?
- What about the research burden on our community?
- How will people provide input?
- Can we maintain commitment?

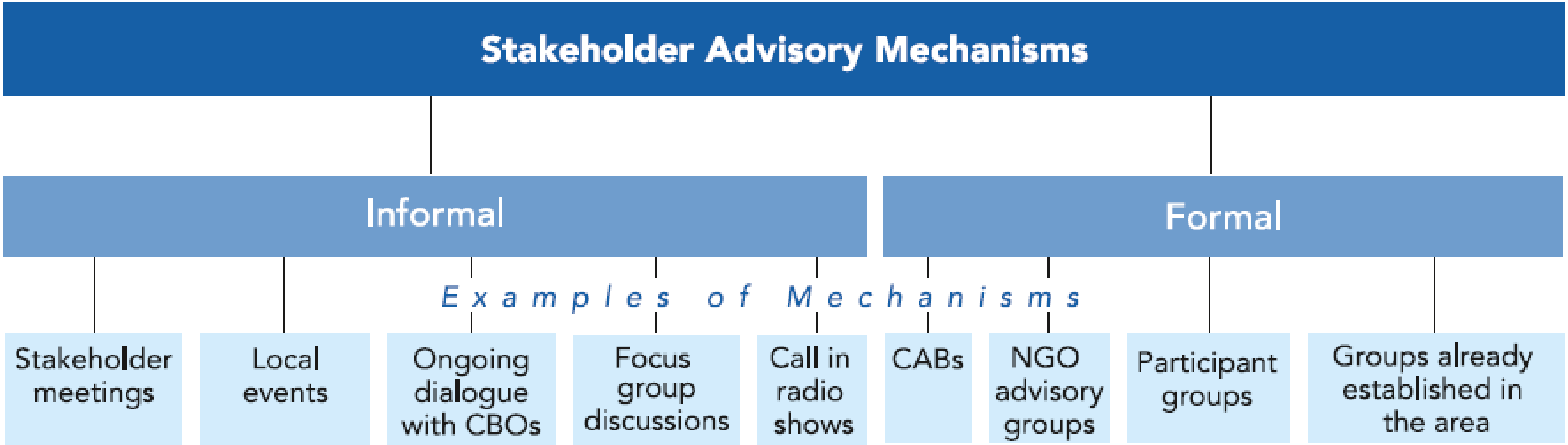
Considerations for Researchers

- Why do you think your research is aligned with community needs
- What are your research interests & why do you do this work?
- What experience do you have working with community stakeholders?
- How will stakeholders involved? Study design? Recruitment? Publications?
- Can you cope with the realities of working with community stakeholders? Conflicts of commitment, institutional capacity, Community research expertise, grassroots activism
- Are you committed to capacity building and sustainability?
- How will you value community contributions (budget)
- How will you allocate for CAB development and mangagement?

Decide on level of participation

- How much/little do stakeholders want to be involved?
  - Research question
  - Research design
  - Data collection
  - Analysis
  - Dissemination





Stakeholder Advisory Mechanisms

Informal

- Stakeholder meetings
- Local events
- Ongoing dialogue with CBOs
- Focus group discussions
- Call in radio shows

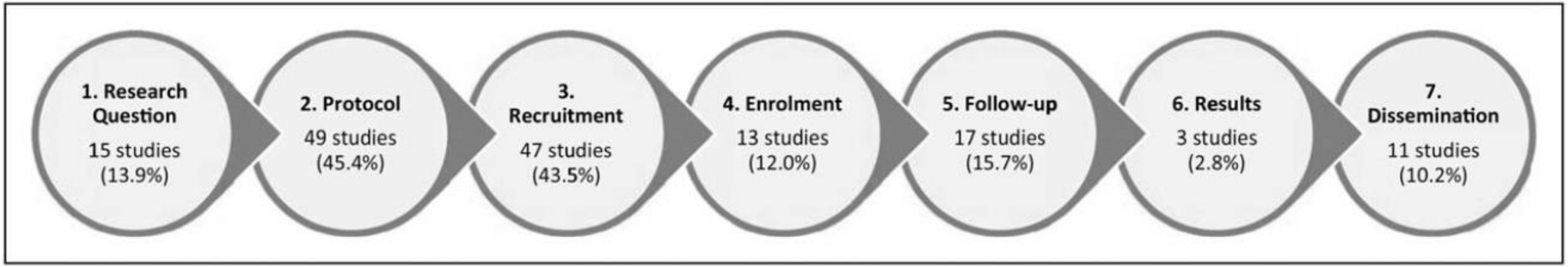
Formal

- CABs
- NGO advisory groups
- Participant groups
- Groups already established in the area

Examples of Mechanisms

UNAIDS/AVAC 2011

Purpose of stakeholder engagement by clinical research stage



1. Research Question
15 studies
(13.9%)

2. Protocol
49 studies
(45.4%)

3. Recruitment
47 studies
(43.5%)

4. Enrolment
13 studies
(12.0%)

5. Follow-up
17 studies
(15.7%)

6. Results
3 studies
(2.8%)

7. Dissemination
11 studies
(10.2%)

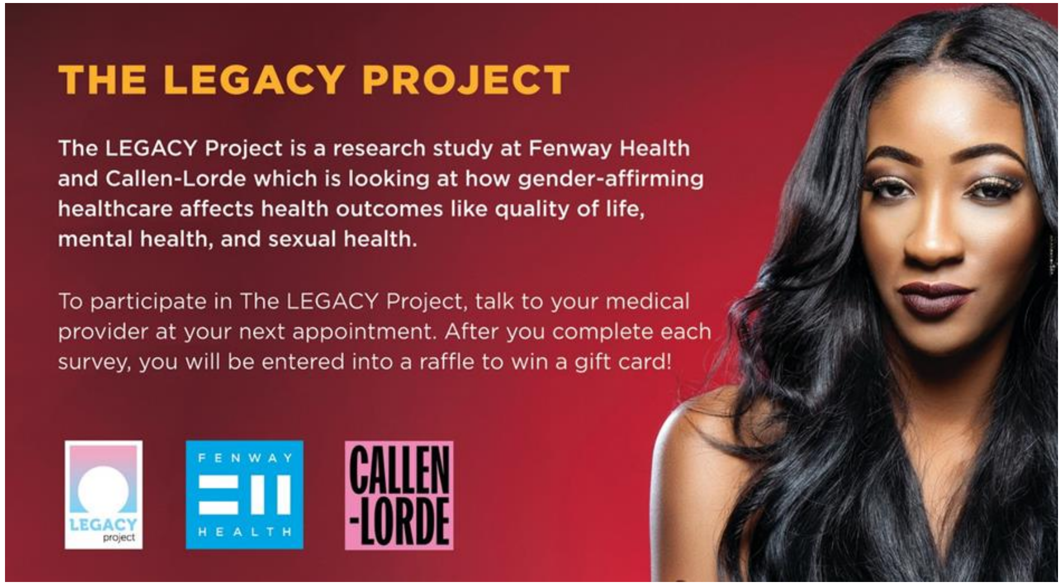
Day S. J Int AIDS Soc 2018; 21:e25174

Expect Difficulties

- There are different cultures & priorities (community vs. academia)
- Anticipate & address power imbalances (where to meet)
- There will be trust issues, work on buy-in at all levels
- Anticipate training needs
  - Research methods, Human subjects training, analyses
- Different languages, timeline
- Budgets

LEGACY: Transgender cohort study of gender affirmation and HIV-related health

- Aim: to evaluate medical gender affirmation delivered in primary care as an intervention to reduce disparities in HIV-related outcomes
- “first community-based cohort of trans people”
- 4,500 transgender adults ages 18+
  - Gender affirmation
  - HIV viral suppression
  - PrEP uptake
  - STIs
  - HIV incidence



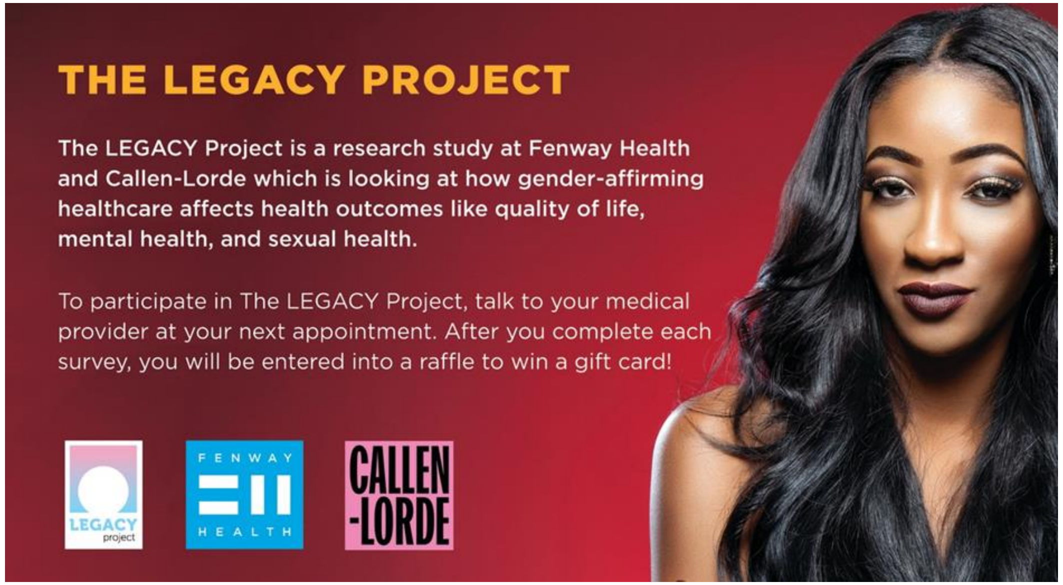
THE LEGACY PROJECT

The LEGACY Project is a research study at Fenway Health and Callen-Lorde which is looking at how gender-affirming healthcare affects health outcomes like quality of life, mental health, and sexual health.

To participate in The LEGACY Project, talk to your medical provider at your next appointment. After you complete each survey, you will be entered into a raffle to win a gift card!

LEGACY: Transgender cohort study of gender affirmation and HIV-related health

- Community-based, community-informed research
- 4 Focus groups (N=28) to identify research priorities and concerns with study design
- Community advisory board
- Stakeholder advisory group
- Research team: predominately trans/gender diverse



THE LEGACY PROJECT

The LEGACY Project is a research study at Fenway Health and Callen-Lorde which is looking at how gender-affirming healthcare affects health outcomes like quality of life, mental health, and sexual health.

To participate in The LEGACY Project, talk to your medical provider at your next appointment. After you complete each survey, you will be entered into a raffle to win a gift card!

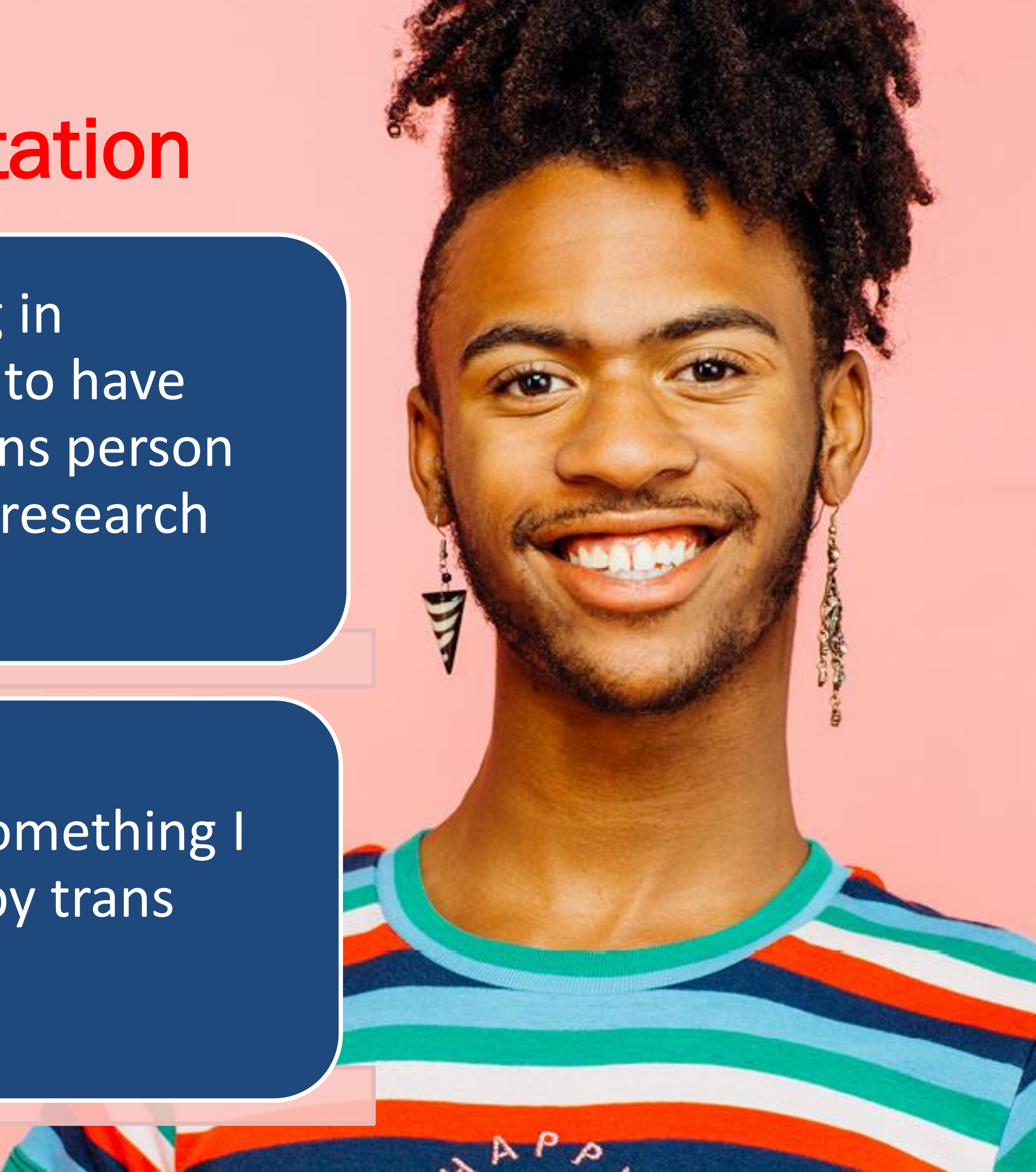
Focus Groups

1. Study design
2. Sampling
3. Recruitment and screening
4. Study implementation
5. Survey measures
5. Dissemination

Importance of Representation

“In terms of research priorities of being in research studies I feel like it’s a priority to have trans people and not just one token trans person but trans people as integral part of the research team designing it from the beginning. “

“I’ve done a few research things, and something I always appreciate is when they’re run by trans people…”



Recruitment

Participants spoke of needing to be inclusive of patients who are questioning or who do not identify as "transgender"

"I think maybe questioning folks may also not feel like they're included…under the study premises even if they would be."

Study Implementation

Participants wanted informed consent processes specific to use of biospecimens and separate from survey-related informed consent process

“at the very least say… ‘we will come back to you and ask for that specific consent,’ to say, ‘this is specifically what we’re going to do,’ instead of being like, ‘take my DNA.’ ”

Survey measures

Add resiliency measures to surveys, not just disparities and deficits

“there’s like a scale for depression…I fill out this thing when I come into my PCP… there’s no inverse of that, you know what I mean? There’s no elation. ”

Dissemination of Results

“people put in all these informations, and at the same time, you almost feel like it never reaches, like, people, so they can see us in a different light… So I feel like that’s maybe one of the reasons why they don’t want to participate.”

“ you’re left wondering, ‘what were the results of that study?’ “

Final Message

- Early and diversified stakeholder engagement has been key to advancing HIV biomedical research
- Engaging multiple stakeholders can be complicated
- Conflicts during research are inevitable

Many rewards for engaging communities

- Better quality data
- Long term relationships
- Generating data for real change

Acknowledgements

- Ali Harris
- Lauren Sava
- Sari Reisner
- Dustin Duncan
- Tonia Poteat