

THE ROLE OF COMMUNITY VOICES IN A CHANGING RESEARCH LANDSCAPE

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The Changing Landscape for HIV Research

- Sharply reduced funding in general, making it more and more difficult to compensate people and organizations fairly in the context of research
- Sharply reduced funding especially for stand-alone behavior change research: Emphasis has shifted to biomedical strategies coupled with behavior change as a supportive element (e.g., for product adoption and adherence) rather than behavior change as a central focus
- Elevated tensions regarding biomedical vs. behavioral approaches; traditional community based organizations are not as well positioned as clinically based research settings to implement intervention studies, creating tensions in community and research institution partnerships
- Emphasis on evidence-based prevention, treatment, and care – which is generally a good thing - but necessitates attention to internal validity and results in ways that can tip the balance towards academic-led research
- Some inertia around innovation, whereby exciting new approaches are first tested elsewhere (e.g., sub-Saharan Africa) rather than in the U.S.

Some Definitions of Community Engaged, Community Based and Participatory Research

- These approaches to research involve mutually respectful collaboration between researchers and community members that involve full recognition of the unique strengths and expertise that each brings to the table.
- These approaches involve engagement and partnering with those being studied, rather than distancing from them and the problem as a form of scientific objectivity.
- These approaches generate systematic inquiry that involves bi-directional, co-learning processes and focuses on local capacity building, systems building, sustainability and empowerment as research goals

Why Use Community Engaged / Participatory / Community Based Approaches to Research?

- ***These approaches bring rigor to research efforts that serve community-identified needs:***
- Traditional research is often viewed as more objective, unbiased and as yielding more generalizable findings than applied and community-based/community engaged/participatory approaches to research.
- However, academic-community partnerships can both organize around and address community-identified questions and needs and bring rigor to applied “project based” research in ways that both create real change and generate scholarly results.

These approaches facilitate conducting research focused on unexplored issues and populations:

- They are useful for addressing issues that might otherwise fly under the academic radar.
- They are valuable for giving voice to especially marginalized, disenfranchised or silenced communities and individuals
- They are well suited for investigating issues that academics might not be able to thoroughly and appropriately address using only their own expertise

These approaches offer powerful tools for serving the needs of local and regional communities:

- They can empower communities to organize and take control of what matters to them and, through partnerships with scholars, provide needed resources to address the issues and needs communities view as important.
- They enhance researchers' ability to understand community problems, to address community priorities, and to develop culturally sensitive research approaches.
- They serve the community both immediately and long term by providing education, since both the academic and community partners typically learn new information and develop new skills during the course of a CBPR project.

Implementation Science (IS)

The study of methods to improve the uptake, implementation, and translation of research findings into routine practice

→ IS bridges the “evidence to program” gap

Impact Evaluation (IE)

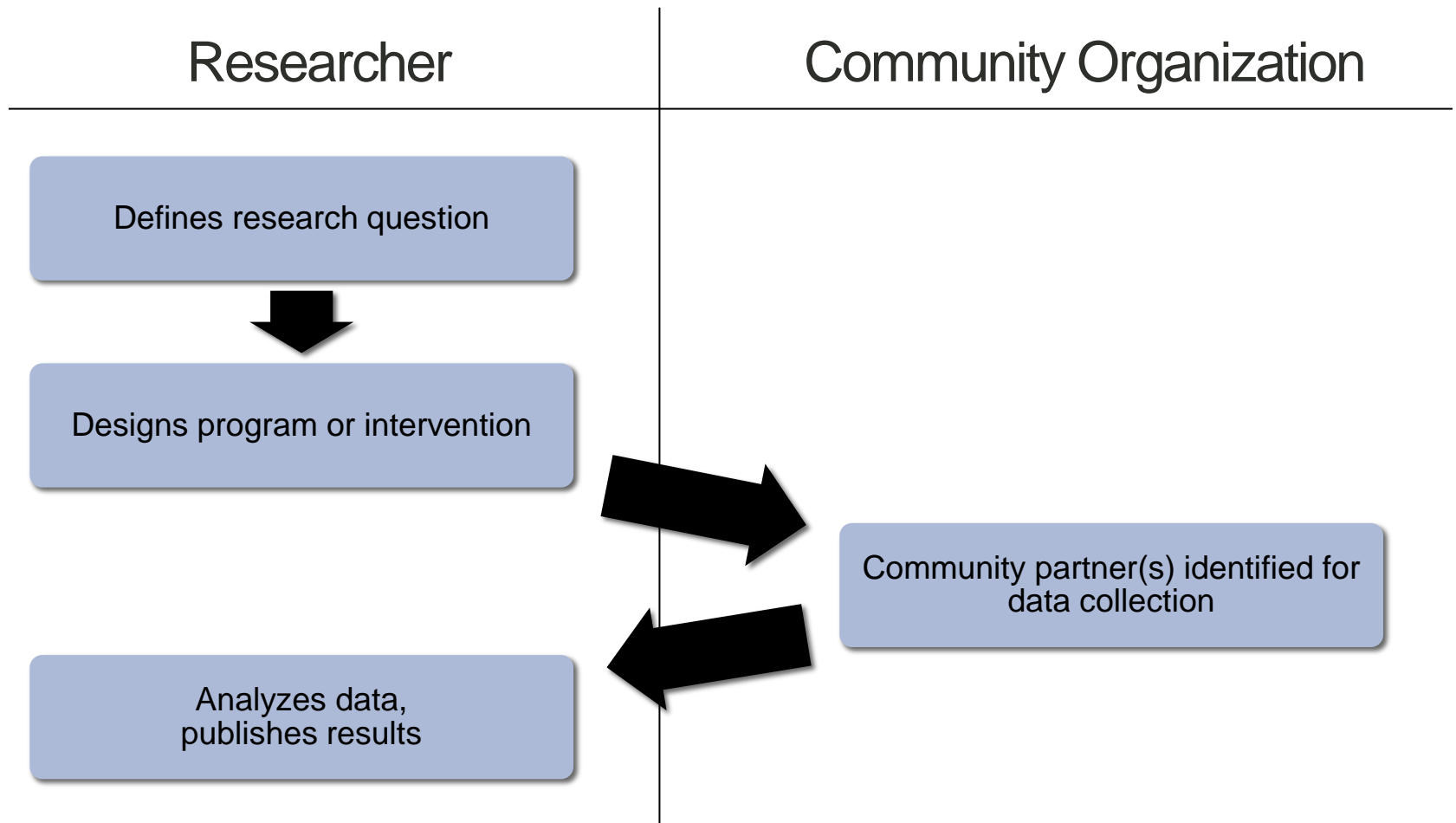
Impact evaluation studies whether changes in well-being are due to the program or intervention and not due to other factors

→ *Are the results we observe due to our intervention?*

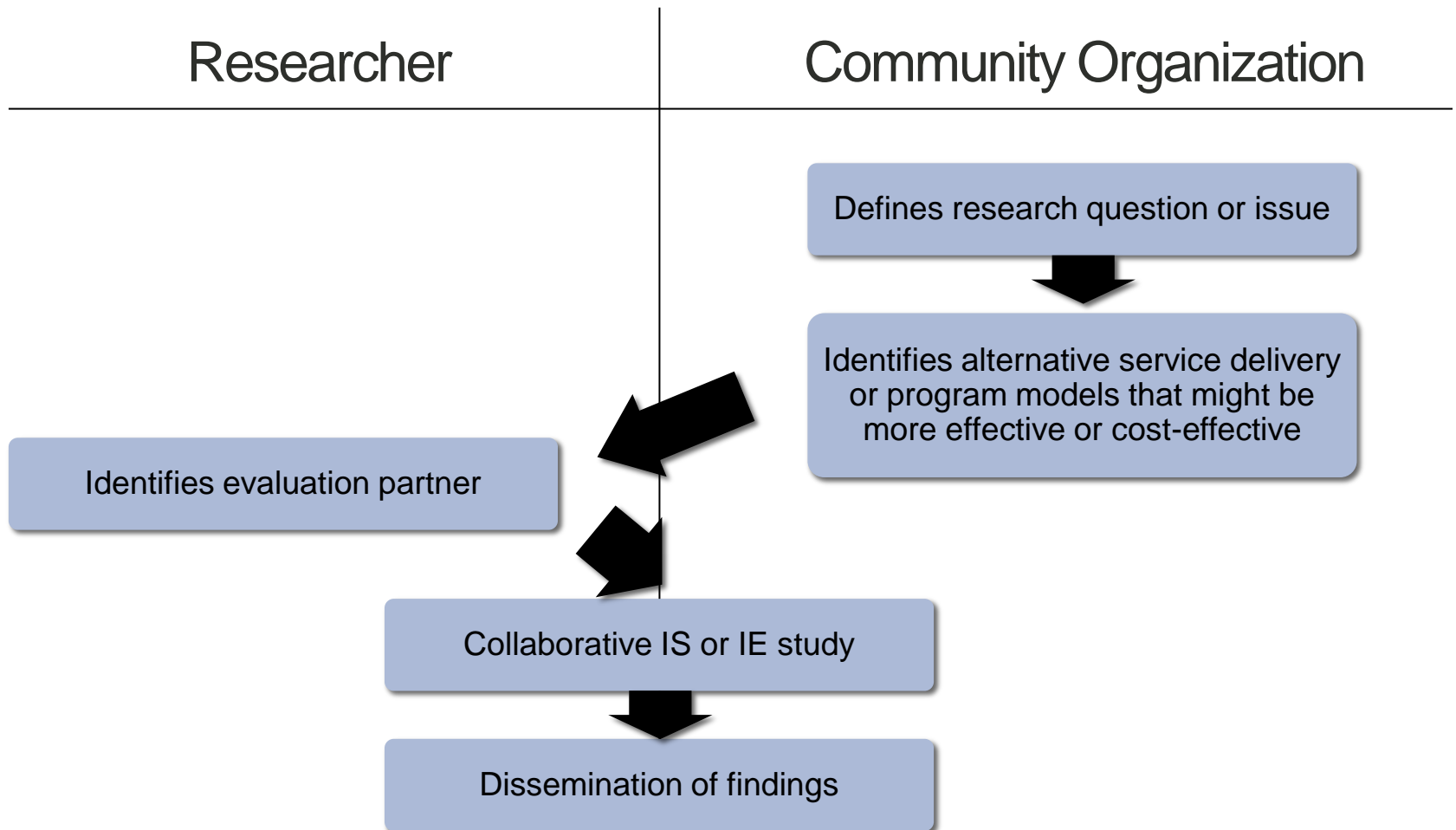
Sources: Madon T, et al. *Science* 2007;318:1728–1729

Khandker SR, Koolwal GB, Samad HA. *Handbook on Impact Evaluation*. World Bank, 2010.

Research Model A:



Research Model B:



Opportunities and Challenges

- Leverages the strengths of both partners
 - CBO expertise with community
 - Researchers can increase rigor and objectivity
- Addresses real-world problems and solutions
 - Rather than one-off experiments with unknown practical value
 - Studies are often designed to compare alternatives head-to-head
- May enhance dissemination of successes and failures
- Incentives must align
 - Academics must “publish or perish”
 - CBOs must be recognized for scientific contributions and compensated fairly (financial and non-financial)

Oakland Example: CRUSH Study

- CRUSH: Connecting Resources for Urban Sexual Health
 - Multi year collaborative study part of statewide CHRP's Epidemiologic Interventions Initiative
 - Integration of TLC+ and PrEP Services for MSM of Color

Aims

- Test & link >400 young MSM of color to sexual health services
- Enhance & evaluate engagement & retention strategies for young HIV+ MSM of color
- Engage & retain HIV- young MSM of color in sexual health & preventive services, including PrEP

We know that: PrEP works...What we STILL need to learn: uptake, acceptability, implementation, retention, integration modalities- in clinical and community settings, etc, etc.

CRUSH Project Partners



Gladstone Institute
of Virology and Immunology



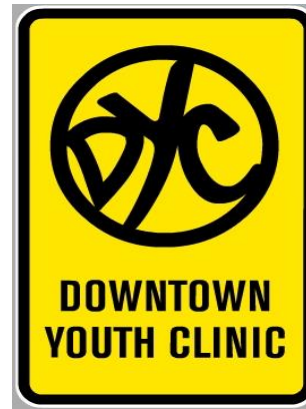
Pangaea
Global AIDS Foundation

UCSF

University of California
San Francisco



HEPPAC



ASIAN HEALTH SERVICES



Building Stronger Communities

 **La Clínica.**

Critical Lessons Learned so far...

Community and Partner “buy in” is a MUST

- Lots of time to develop language and tools
- PrEP is new to ASOs...and non-ASO (i.e. AHF PrEP controversy raised questions about partnership/need for training
- Re-imagining HIV prevention with PrEP means diving into universal messaging, cultural norms around sex and sexuality, gender identity and expression
- Multiple outreach attempts at the provider and person level needed to engage community

CRUSH CAB *Influences the Science and Practice*

- Original RFA stated that CABs were essential for all funded studies, and required 2 meetings/year....
 - **Our CAB meets 1/month!!!**
 - **Our CAB functions are directly linked to our Aims**

CAB Functions include

- Research tools/instruments: review/refined questionnaires, beta pilot tested instruments
- Advisory: Best Practices for Promotion, Recruitment and Retention of YMSMC
- Participation in Project Implementation Process: CQI & Troubleshooting
- Facilitation of Inter-Agency Collaboration: Youth Outreach Corp & Media Relations Working Groups

Decision Based Partners in research

- **CAB Members assigned leadership roles:**

- Scientific Liaison attends monthly research review meeting
- Director of Education organizes in-services, training opportunities
- Director of Media Affairs Coordinator active in speaking about CRUSH
- Director of Internal Affairs- spearheads the monthly agenda

- **Examples:**

- Struggled with outreach: Director of media affairs featured on NPR
- Clinical messages around condom use: Scientific Liaison feedback helped changed provider interactions with participants

Recommendations for Research Studies

- Changing research paradigms: Make CBPR practices a required element of grant funding (CHRP Community Collaborative mechanism as an example...)
- Actively EMPOWER community members to have leadership and decision making powers as part of studies
- Create opportunities for long term, sustained community training, education, and access to programming
- Directly link community engagement strategies to research aims
 - Community Advisory Boards
 - Community forums and agency trainings
 - Data analysis and interpretation