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I apply medical anthropology to understand health challenges and use mixed-methods research to help implement community-engaged, evidence-based solutions



Using Community Engagement to Strengthen the HIV Care Continuum in South Africa



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Presentation Outline

- Key Definitions
- Brief Description of Context
- Two Examples From Experience with Community-Engaged Research

Definitions

Community Engagement

The ongoing process of working together

- **Two-way conversations:** talking *to* people, LISTENING to their needs, and acting together
- **Shared ownership:** community members help shape the plans instead of having decisions imposed on them
- **Building trust:** regular contact and mutual respect

Community-Based doesn't equal **Community-Engaged**

An HIV strategy can be **community-based** without being **engaged**

Feature	Community-Based HIV Strategies	Community-Engaged HIV Strategies
Core Focus	**Setting and access** (bringing services closer to people).	**Partnership and power** (sharing decision-making control).
Who Decides?	Usually outside experts, doctors, or researchers who design the program.	Local residents, advocates, and patients co-design the program.
The Goal	To lower logistical barriers like travel time, cost, and hospital stigma.	To build long-term trust, equity, and culturally accurate solutions.

The most effective public health initiatives combine both–delivering services **in** the community while building them **with** the community

Community Based & Engaged: How They Look in Practice

1. HIV Testing

- **Community-Based:** A hospital parks a mobile health van in a high-traffic neighborhood to offer free rapid testing.
- **Community-Engaged:** Local advocates work with health officials to decide where the van should go, what hours it should operate, and how to train local peers to deliver the tests safely to reduce stigma.

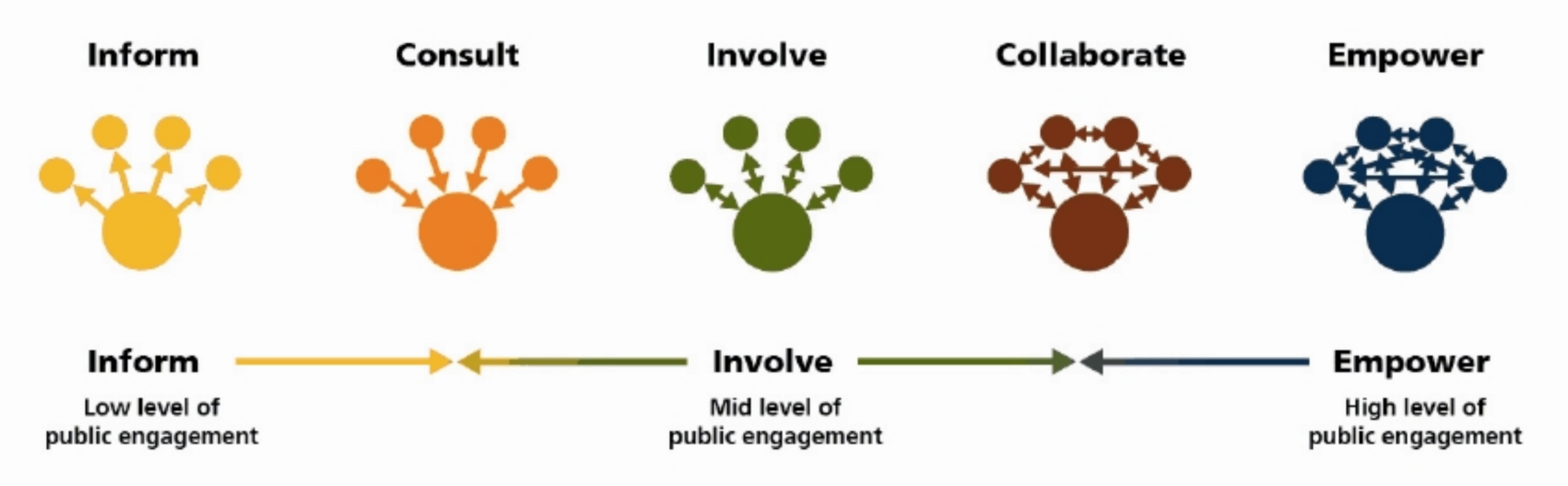
2. Clinical Research & Medication Trials

- **Community-Based:** Researchers open a trial clinic inside a neighborhood health center to make it easier for local participants to show up for blood draws.
- **Community-Engaged:** Researchers form a Community Advisory Board (CAB) made up of people living with HIV. This board reviews the study's rules, protects participant rights, and helps rewrite the trial protocols to ensure they are ethical and respectful.

3. Prevention Campaigns

- **Community-Based:** A health department mails PrEP (HIV prevention medication) brochures to specific zip codes or hands them out at community centers.
- **Community-Engaged:** The health department hosts workshops where community members actively rewrite the brochures using language, images, and strategies that actually resonate with their peers.

Community Engagement Continuum

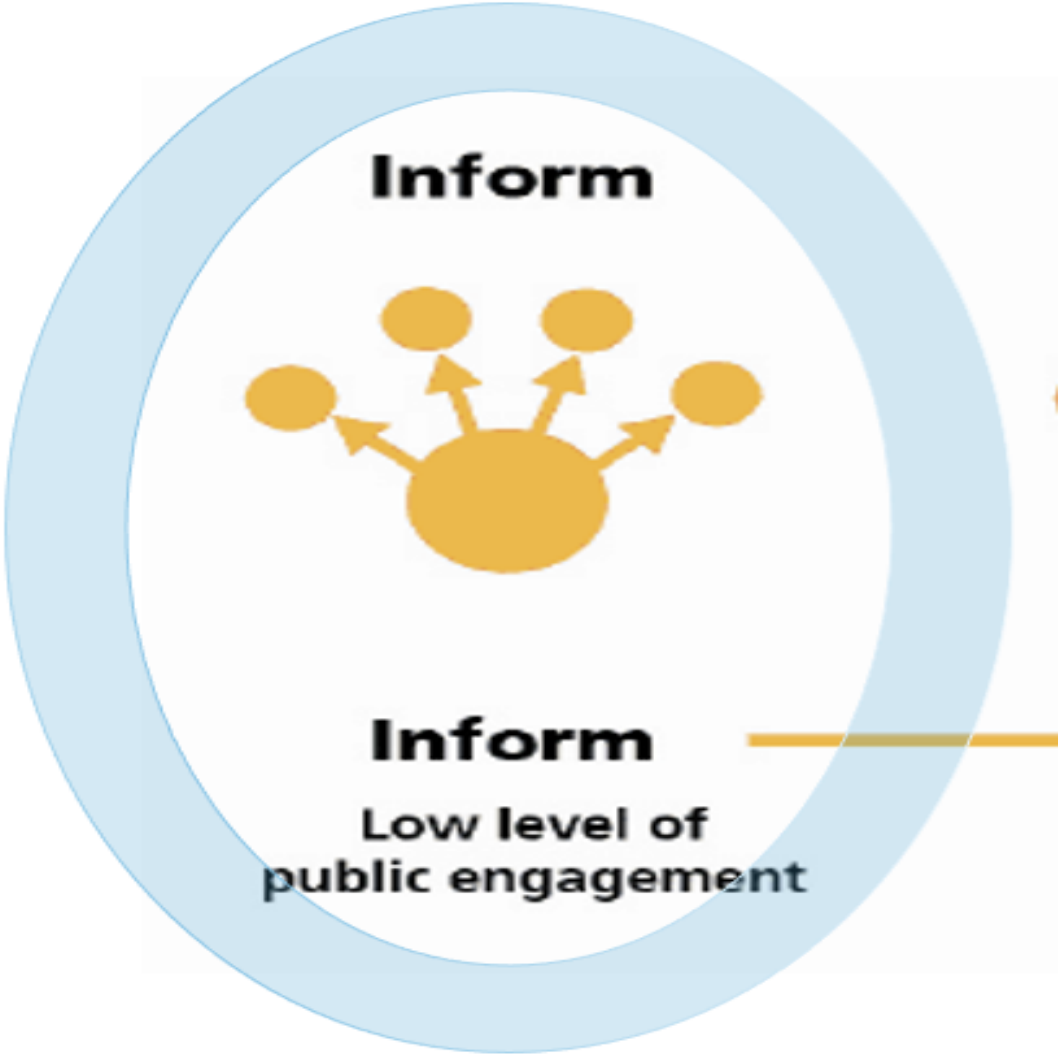


Graphic Source: https://www.bangthetable.com/blog/defining-community-engagement/

Community Engagement as an Implementation Strategy: Moving Beyond Outreach

Traditional approach:

- Community engagement as outreach



Definitions

Community-Engaged Research (CEnR) in Health Care

Community- Engaged Research: *a "collaborative approach that equitably involves all partners in research...with the aim of combining knowledge and action for social change to improve health and eliminate health* disparities" (Kellogg Foundation)

Not simply a set of research methods, **CEnR fundamentally changes the relationship between researchers and researched.**

Definitions

Community-Engaged Research (CEnR)

Treats community members and academic or public health researchers as equal partners throughout every stage of a study:

- Co-definition of problems
- Co-development of alternatives
- Co-implementation of solutions (Action)

HIV Care Continuum & Context

Using Community Engagement to Strengthen the HIV Care Continuum in South Africa

Can community engagement be viewed not as an activity, but as infrastructure for HIV care?

Community engagement is a core implementation strategy for improving retention, adherence, viral suppression, and program sustainability.

Why Community Engagement Matters Now

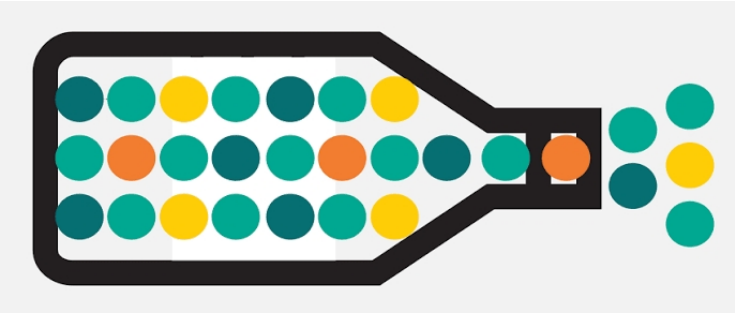
South Africa's Current HIV Care Context

- Significant gains in testing and treatment
- Remaining challenges:
  - Retention in care
  - Adherence
  - Sustained viral suppression
- These gaps increasingly require implementation solutions

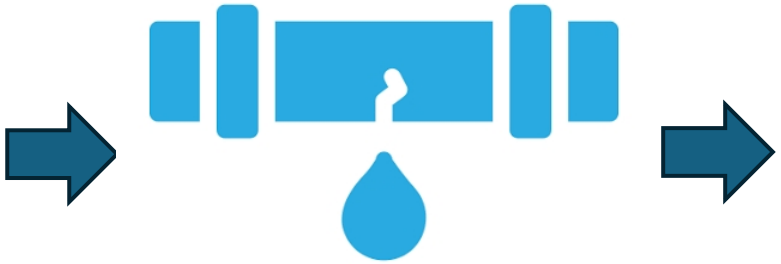
UNAIDS South Africa Fact Sheet (latest edition)

The HIV Care Continuum: South Africa 2026

Linkage to Care

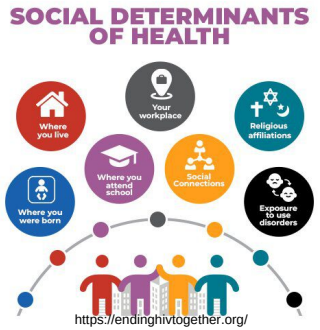


Retention in Care



Adherence





The HIV Care Continuum: A clinical **and social** pathway

Every step depends on:

- Trust
- Relationships
- Communication
- Community context
- Structural realities

The South African HIV Care Cascade Breakdown

Cascade Step	National Performance Status	Key Dynamics & Bottlenecks
1. Diagnosis	**~96% of all PLHIV know their status**	**Target Exceeded.** Strong universal testing programs exist. However, gender disparities persist; men are less likely to test and frequently get diagnosed late.
2. Linkage to Care	**~82% of diagnosed individuals are on ART**	**The Primary Bottleneck.** Despite high initial entry to clinics, the country falls short of the 95% target. The "1.1 Million Close the Gap" campaign specifically targets the millions missing from treatment.
3. Retention in Care	**45% to 56% long-term retention**	**High Care "Leakage."** While short-term linkage is high, long-term retention (12 to 60 months) drops severely due to treatment interruptions, mobility, and economic factors.
4. Adherence	**Varies heavily by subpopulation**	**Adolescents & Young Adults (AYA)** and young males struggle most with daily pill adherence due to stigma and lack of targeted support systems.
5. Viral Suppression	**~92% to 94% of those on ART**	**Target Achieved.** For individuals who remain retained on their antiretroviral regimen, South Africa's public sector clinical outcomes are excellent.

AI-generated table. Main data sources: *National Strategic Plan for HIV, TB and STIs, 2023-2028*, and Marcus Low, 2026, "SA's ARV *programme* hardly grew in 2025, according to latest estimates." *Spotlight*

Are there successful examples of using CE to address HIV Care Continuum Gaps?

A robust body of peer-reviewed literature demonstrates that community-engaged HIV strategies significantly improve health outcomes.

Community engagement succeeds because it fixes structural blind spots. Outside researchers often guess at what a community needs, whereas a Community Advisory Board, for example, can point out that a clinic's hours are wrong, its wording is stigmatizing, or its location is physically unsafe for vulnerable groups

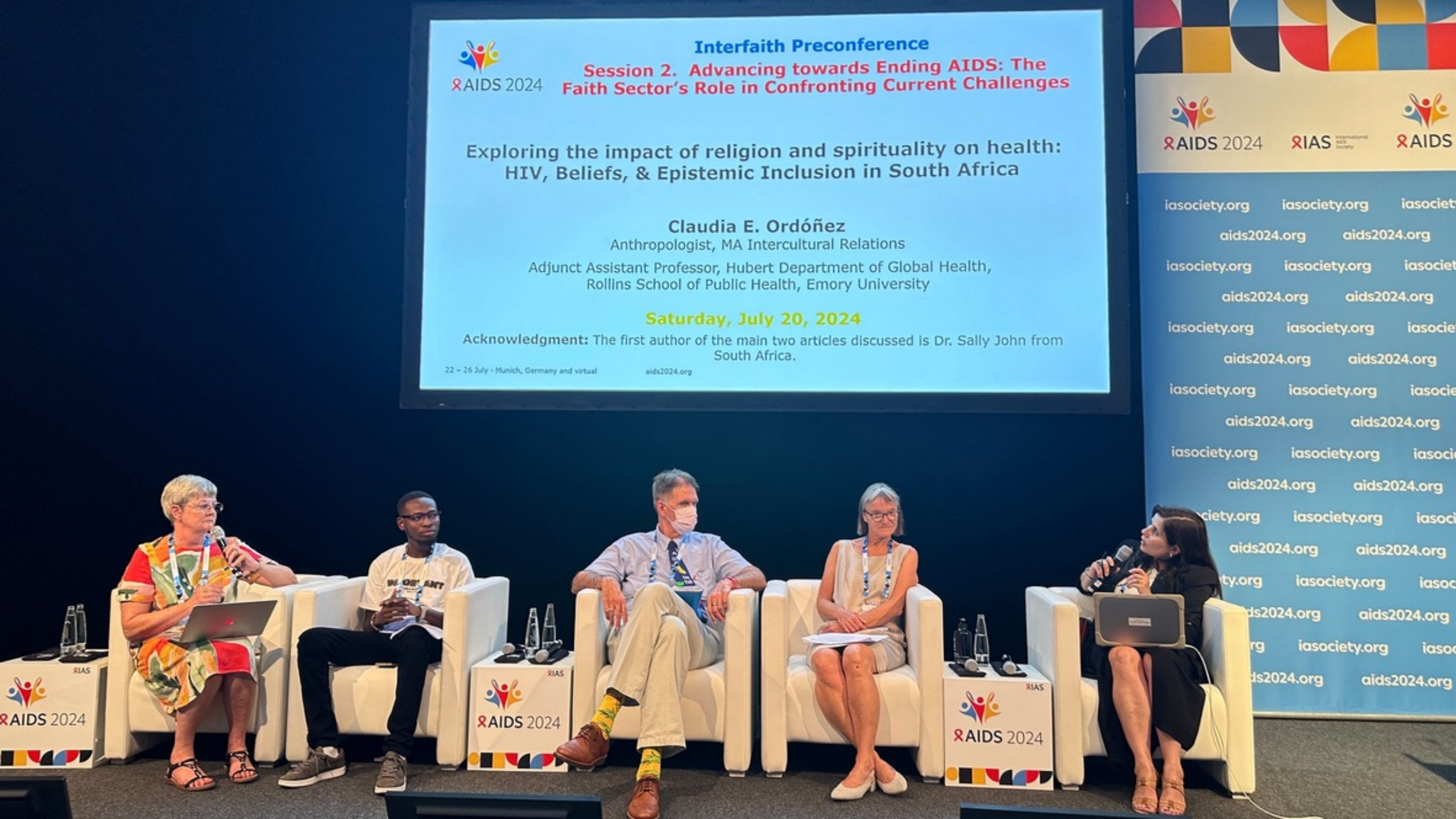
Successful examples of using CE to address South Africa's HIV Care Continuum Gaps?

To address the sharp drop-offs in **Linkage** and **Retention**, South Africa has pioneered several highly successful, community-engaged frameworks.

Direct Community Trust and Sports Events for Men

Men have historically lagged in South Africa's HIV cascade. To counter this, community NGOs (e.g., Bulungula Incubator in the rural Eastern Cape) designed culturally tailored models.

Impact on Gaps: These interventions break through the intense stigma that prevents men from entering healthcare facilities. This approach has successfully driven up the testing and linkage rates of first-time male testers in historically isolated rural populations


AIDS 2024
Interfaith Preconference
Session 2. Advancing towards Ending AIDS: The Faith Sector's Role in Confronting Current Challenges
Exploring the impact of religion and spirituality on health: HIV, Beliefs, & Epistemic Inclusion in South Africa
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Saturday, July 20, 2024
Acknowledgment: The first author of the main two articles discussed is Dr. Sally John from South Africa.
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Examples

Example 1. Implementation Science Interventions

Using community- engaged research in Implementation Science for HIV care improvements in South Africa

Community engagement provides an effective framework to address the need **to co-design, adapt, implement, and evaluate interventions** that align with national goals to address HTN and DM to lower CVD morbidity and mortality

1. Co-Designing CVD & HIV Care Integration in SA

Case Study: iHEART-South Africa

Integrating **H**IV and h**EART** health in **S**outh **A**frica (iHEART-SA): 5-year late-stage implementation science intervention adapted to the SA context, seeking to identify effective strategies to integrate HIV and hypertension care

- ***Setting:*** Region F of Johannesburg

Aim: to adapt intervention components to i) address key barriers to heart health and ii) be feasible to implement and sustainably scale in HIV care settings, given local capacity, motivation, and resources

1. Co-Designing CVD & HIV Care Integration in SA

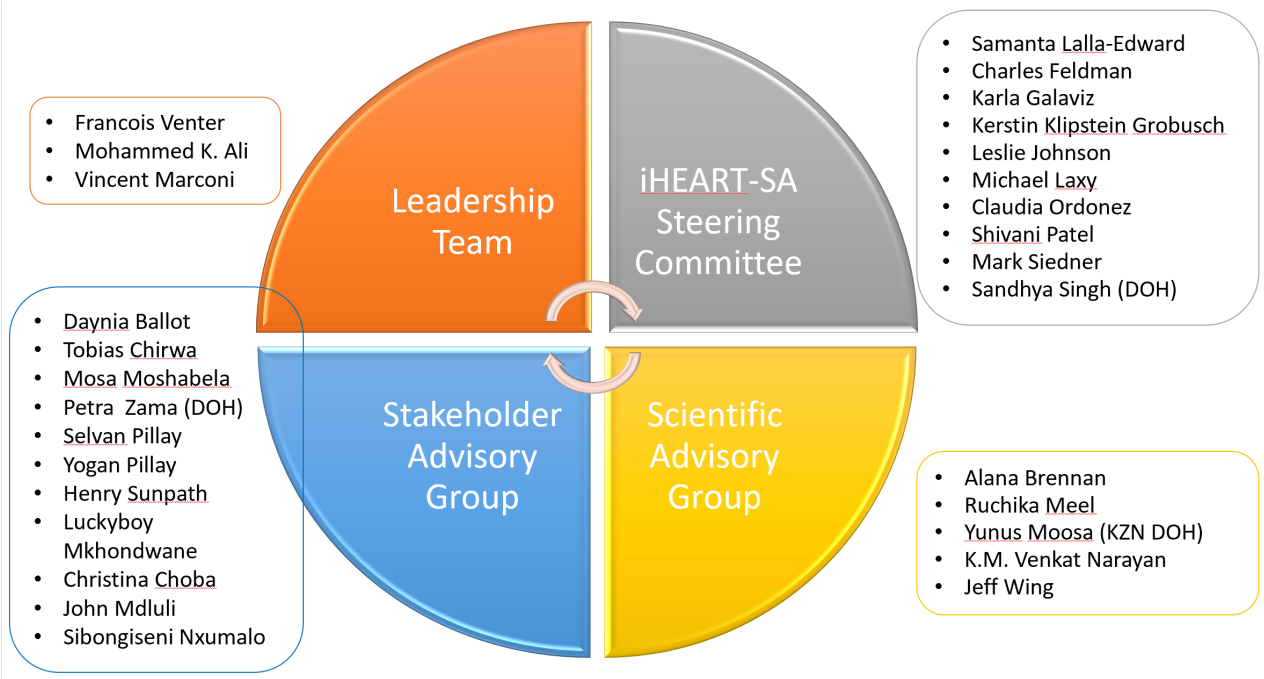
Case Study: iHEART-South Africa

Formative Research Phase for Intervention Development

A qualitative, pre-implementation study was conducted using the Behavior Change Wheel (BCW) to develop a tailored intervention to **increase cardiovascular disease risk assessment and treatment among PLWH** in Region F.

- ***Community-Engaged Strategy:*** early creation of iHEART's Community Advisory Board

iHEART-SA Team, CAB, & Collaborators





https://www.ezintsha.org/iHEART-SA

iHEART-SA CAB Composition

Stakeholder Category
Community Engagement Liaison
Health activist
Patient
Public Health Academic
South African DOH
Traditional Health Practitioner

Defined community stakeholders holistically by involving persons from relevant, interested, and impacted groups

1. Co-Designing CVD & HIV Care Integration in SA

Case Study : iHEART-South Africa

Formative Research Phase for Intervention Development

RESULTS: Through analysis of qualitative data and the Community Advisory Board ranking of results using a community-engaged research approach, the following **top barriers were identified:**

	Patient Advisory Group	Clinician Advisory Group	Community Advisory Group
Top 3 barriers	1. Wait time 2. Understanding the need for medication 3. Distance to clinic	1. Human/economic resources (Replaced by #4 role differentiation in clinics) 2. Education/training 3. Information management	1. Education/training (clinician) 2. Interactions between patients and clinic staff (clinician & patient) 3. Wait time (patient)/large patient volume (clinician)

1. Co-Designing CVD & HIV Care Integration in SA

Case Study : iHEART-South Africa

Key Lessons from the use of CE in iHEART-South Africa

Lesson 1

- Community engagement is infrastructure, not outreach

Lesson 2

- Communities contribute expertise, not just feedback

Lesson 3

- Trust is an implementation outcome

These lessons cut across retention, adherence, viral suppression, and HIV surveillance

Example 2. Surveillance and HIV Programs

Why Surveillance Requires Engagement?

Community-engaged surveillance can improve:

- Transparency
- Trust
- Interpretation of findings
- Acceptability of public health programs

People are more likely to trust public health systems when they understand them.

2. Community-Informed Surveillance and HIV Programs:

Case Study: REACCTS Study's River of HIV Network Detection & Response (HIV NDR)

Responding to HIV Clusters in **A**tlanta with **C**ulturally **C**ompetent Linkage **T**o **S**ervices (REACCTS): Early-stage IS project addressing HIV molecular cluster detection response among Black/African American and Latinx populations

- ***Setting*** : Metro Atlanta, Georgia

One of the goals of surveillance and HIV NDR is to use epidemiologic information to strengthen public health responses, including identifying opportunities for earlier diagnosis, better linkage to care, and improved engagement in services.

2. Community-Informed Surveillance and HIV Programs:

Case Study: REACCTS Study's River of HIV Network Detection & Response (HIV NDR)

Study Aim: Making HIV Surveillance Knowledge Accessible and Transparent

Challenge

HIV surveillance and HIV NDR can be:

- Complex
- Misunderstood/Suspicious
- Difficult to explain

2. Community-Informed Surveillance and HIV Programs:

Case Study: REACCTS Study's River of HIV Network Detection & Response (HIV NDR)

CEnR Used for Making HIV Surveillance Knowledge Accessible and Transparent:

Community-Centered Approach

Community members and partners helped to:

- Identify information needs
- Co-create messages
- Shape visual narratives
- Improve transparency
- Address data misuse concerns

Products of CEnR

- Bilingual website
  - Infographic
  - Animation
- Innovative methodological adaptation of the River of Life

Communities become informed participants rather than passive subjects

River of HIV NDR Project (2026)
Presented at USCHA 2026 and IDWeek 2026

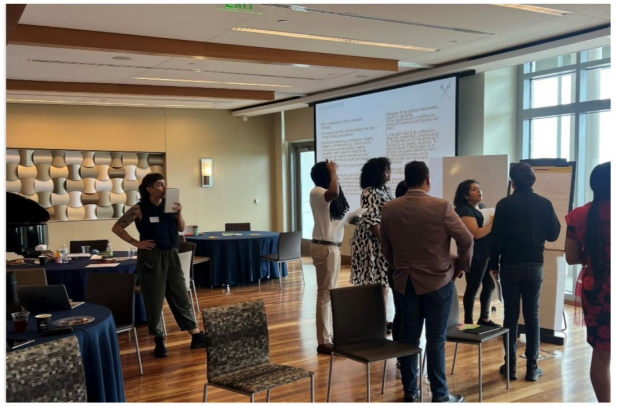
Defining “Community” for River of NDR

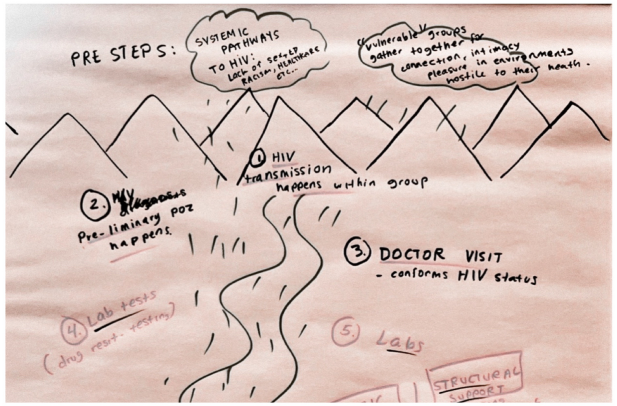
“Community partners in the REACCTS Study are individuals who participated in all or part of the study through meaningful collaboration. ***Some have lived HIV experience, including anonymous PLWHIV*****.** They represent diverse perspectives, including ***community leaders, activists, advocates, community engagement specialists, certified community-based researchers, public health officials, clinicians, academic researchers, and graduate students***.

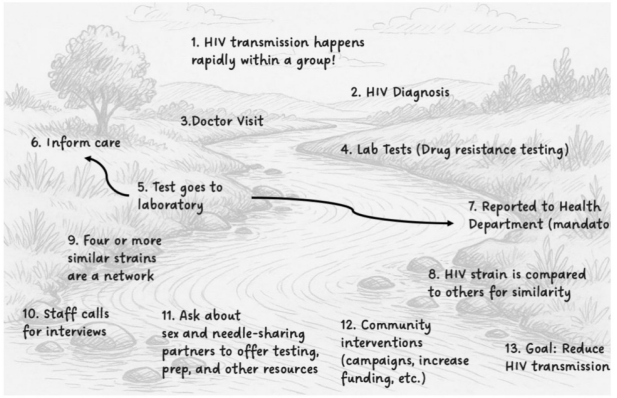
Meaningful Involvement of People with HIV/AIDS was applied.”

How do community- engaged research results look?

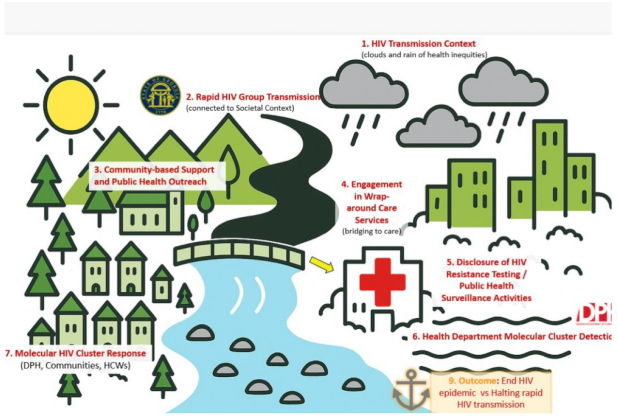
Co-creation process with Community Partners of the River of Network Detection and Response

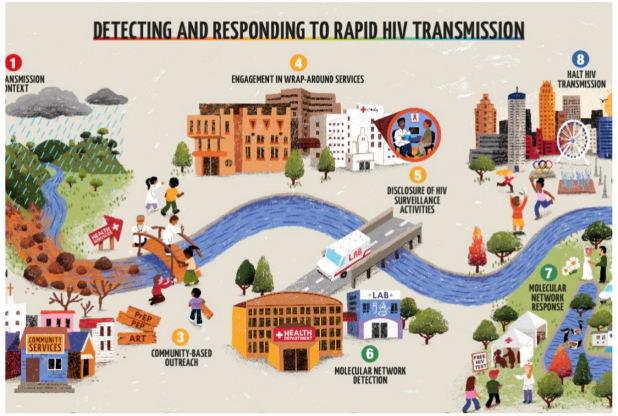












Co-Designing an HIV Network Detection and Response Process Map with Communities in the U.S. South: A Participatory Tool to Improve Implementation and Trust

Claudia E. Ordóñez[1,2], Masonia B. Traylor[3], Genesis Appiah[3], Latonia Wilkins[4], Dominiqué Cureton[3], Li Ann Sanchez[5], Nicole Fox[5], Eric Rangel[6], Michael Hutson[7], Juan David Patino-Mateus[8], Victor Samuel Diaz-Sarmiento[9], Julian Santiago Ramon[8], Olankunle Ogunbayo[1], Lenore Manderson[2,10], Aimee Rivera Solis[7,8], Jane Y. Scott[8], Carlos S. Saldana[8, 11]

[1] Emory University, Rollins School of Public Health, Atlanta, GA, USA, [2] University of The Witwatersrand, School of Public Health, Johannesburg, South Africa, [3] Lady BurgAndy, Atlanta, GA, USA, [4] Project RED Paint, Inc, GA, USA, [5] Community EsTr/El/La, Atlanta, GA, USA, [6] Latino LinQ, Atlanta, GA, USA, [7] Georgia Department of Public Health, GA, USA, [8] Emory University School of Medicine, Department of Medicine, Division of Infectious Diseases, Atlanta, GA, USA, [9] Emory University School of Medicine, Department of Medicine, Atlanta, GA, USA, [10] Monash University, School of Social Sciences, Melbourne, Australia, [11] Emory CFAR

Emory University School of Medicine — Department of Medicine

Emory Rollins School of Public Health

INTRODUCTION

- **HIV Network Detection and Response (HIV NDR)** uses HIV genetic data to identify transmission patterns and support prevention and care
- **Limited understanding of HIV NDR** can contribute to mistrust and implementation challenges among Black/African American and Latina/o communities
- **Georgia community members, practitioners, and researchers** partnered to develop tools to improve HIV NDR communication

METHODS

- **Community-Based Participatory Action Research (CBPAR)** guided iterative, consensus-building co-design process from May 2025-August 2026
- **Adaptation of *River of Life* exercise into a participatory implementation method** for understanding and communicating a complex surveillance system **and for a high HIV burden setting**
- **Early engagement of partners** with lived experience and culturally concordant backgrounds

RESULTS

Table 1. Characteristics of REACCTS Study Partners (N = 17)

Characteristic	Category	n
Role*	Lived experience	3
	Clinicians	2
	Public health practitioners/officials	7
	Community engagement specialist	1
	Researchers	7
Ancestry/Ethnicity (Self-identified)	Latina/o and Black/African American	15
	Other or not specified	2

*Roles overlapped; partners identified with more than one category

Collaboration resulted in **two communication tools:**

1. ***River of HIV NDR* process map infographic** depicting HIV NDR as a river flowing through Georgia and Atlanta
2. **English & Spanish video animations** of the River of HIV NDR process map

RESULTS

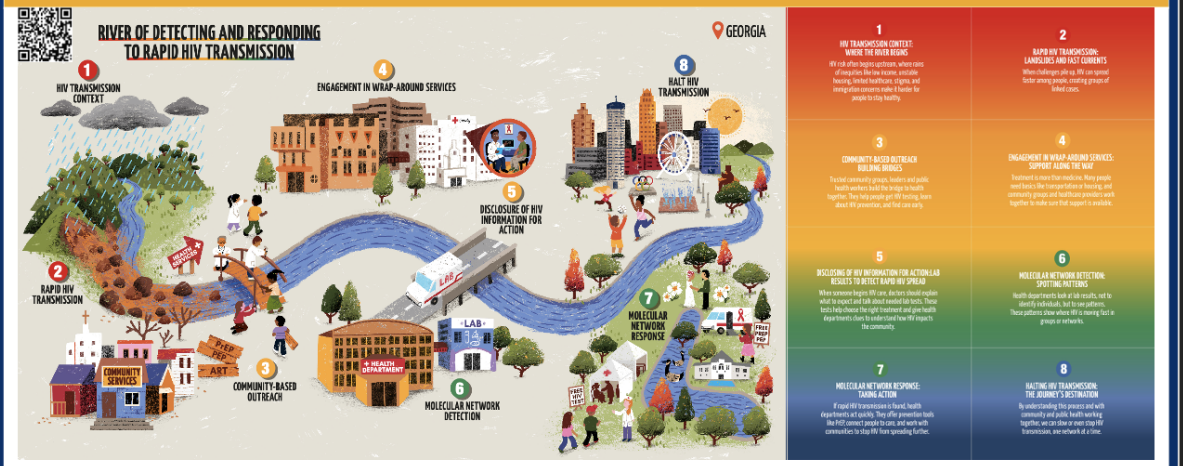


Figure 1. Visual Tool: River of HIV-NDR Process Infographic

The community co-created infographic in Figure 1 presents eight stages, from upstream social drivers of HIV risk to molecular detection, network response, and transmission prevention. Technical concepts are paired with plain-language explanations to improve accessibility. Public health staff and clinicians endorsed the tool for training and communication.

CONCLUSION

- Participatory co-design and adaptation offer a feasible, community-centered strategy for HIV NDR implementation
- Co-created visual tools may improve understanding of HIV NDR and build trust among affected communities and practitioners
- The approach has potential for adaptation and transferability across diverse public health contexts

INNOVATION HIGHLIGHT

The River of HIV NDR represents a novel adaptation of the *River of Life* exercise as a low-resource, community-engaged implementation science method for translating complex HIV molecular surveillance concepts into accessible and trusted communication resources.

ACKNOWLEDGMENTS

REACCTS Study research participants and partners, Cris Yépez – Cardenilla Design, Intercultural Productions, NIH and Emory Center For AIDS Research (P30 AI050409), Atlanta, GA.

Poster selected for presentation at ID Week 2026, Washington, DC


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Stronger HIV Continuum Outcomes

Community Engagement Strengthens the HIV Care Continuum

Community engagement helps transform:

- Diagnosis into linkage
- Linkage into retention
- Retention into adherence
- Adherence into viral suppression

The future of HIV epidemic control depends not only on biomedical innovation, but also on meaningful partnerships with the communities most affected by HIV.



Community engagement is not extra work.
It is the work.



References

South African HIV Context

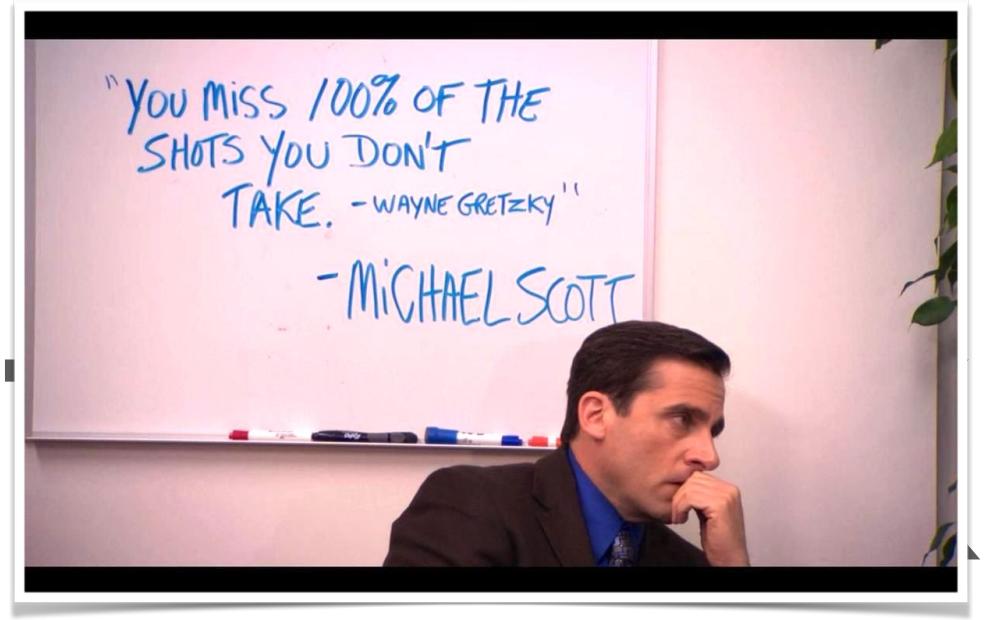
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Engagement and HIV Care

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Community-Centered HIV Surveillance and Knowledge Translation

- **River of HIV NDR Project (2026)**
  - Presented at **USCHA 2026**
  - Presented at **ID Week 2026**


"You miss 100% of the shots you don't take. -Wayne Gretzky"
-Michael Scott

YOU!