

Diversity, Equity and Access to HIV Research

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Ending the Epidemic

May 2nd, 2024

Why is engagement important
to diversify research?

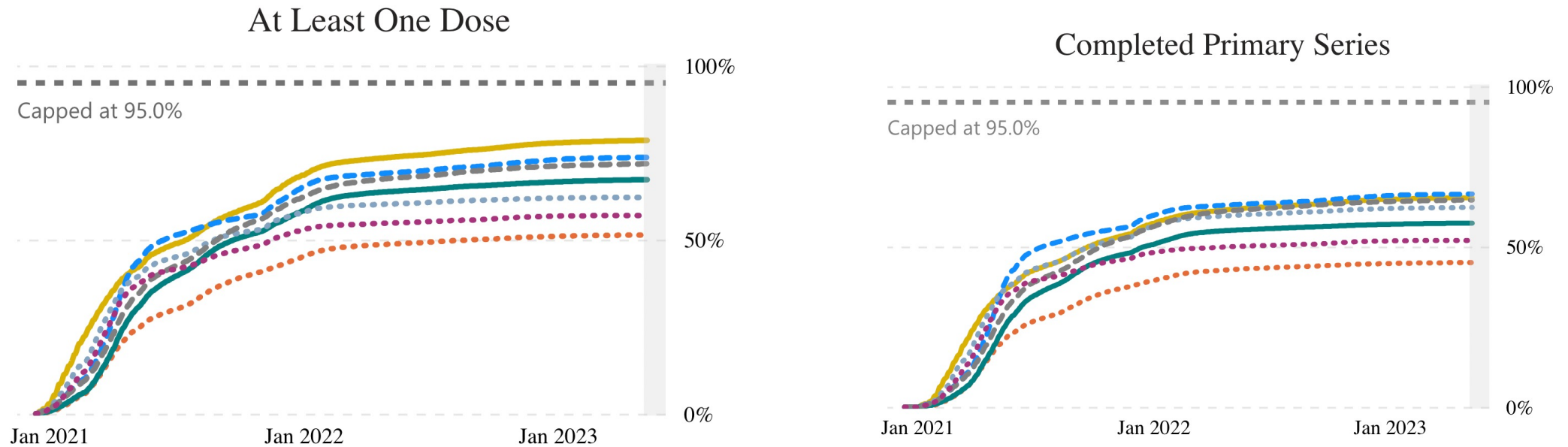
Medical Hesitancy in the Black Community

Reflections from COVID Vaccine Hesitancy

“Every day, Black Americans have their pain denied, their conditions misdiagnosed, and necessary treatment withheld by physicians. In these moments, those patients are probably not historicizing their frustration by recalling Tuskegee, but rather contemplating how an institution sworn to do no harm has failed them.”

Percent of People Receiving COVID-19 Vaccine by Race/Ethnicity and Date Administration, United States

Dec 14th, 2020- May 10th, 2023



	AI/AN, NH	Asian, NH	Black, NH	Hispanic/Latino	Multiracial, NH	NHOPI, NH	White, NH
At Least One Dose	78.5%	73.6%	51.3%	67.2%	62.1%	71.8%	56.9%
Completed Primary Series	65.2%	66.4%	45.0%	57.3%	62.2%	64.5%	51.9%
Updated (Bivalent) Booster Dose	15.5%	22.1%	9.5%	9.1%	24.4%	12.7%	16.7%

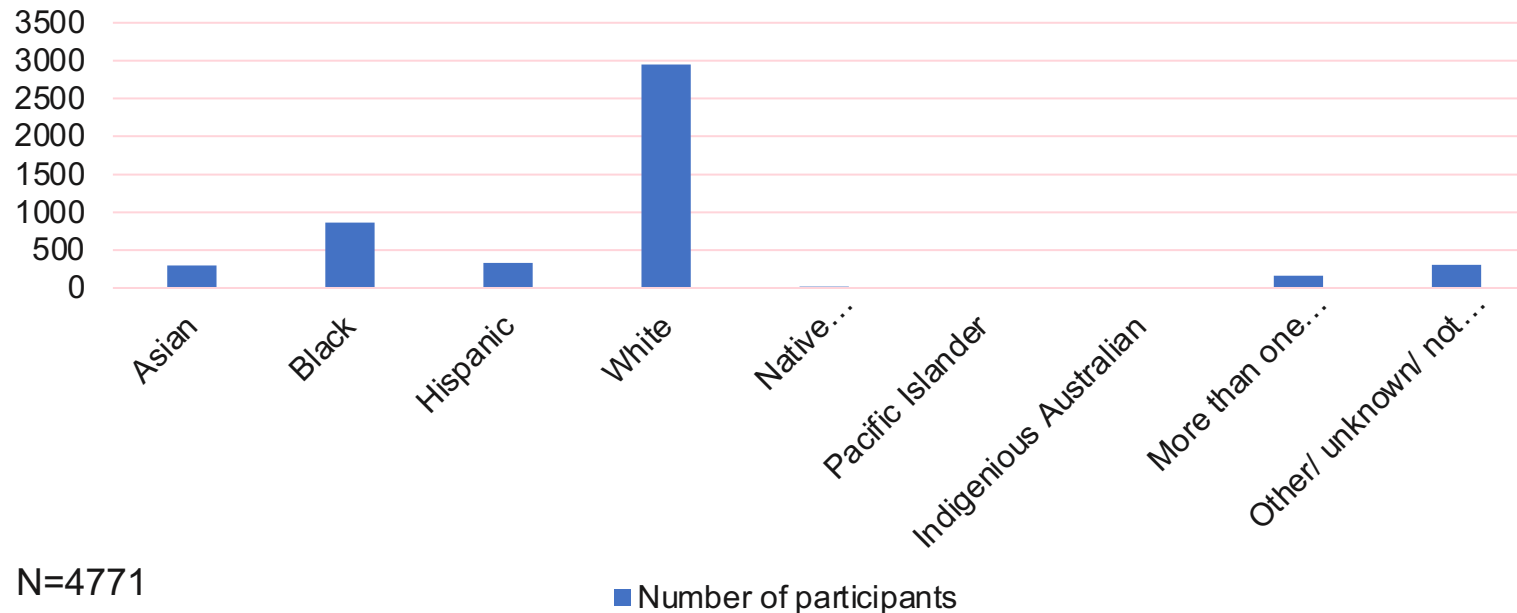
Source: CDC: Trends in Demographic Characteristics of People Receiving COVID-19 Vaccinations in the United States

Participation in HIV Cure Research

Short Communication: Population Representation in HIV Cure Research: A Review of Diversity Within HIV Cure Studies Based in the United States

[Carly Roberts](#),^{1,*} [Emma Creamer](#),^{2,*} [Cheriko A. Boone](#),³ [A. Toni Young](#),^{2,†} and [Manya Magnus](#)^{1,†}

Participants in Cure Research Where Race Was Reported



Data Source: Treatment Action Group

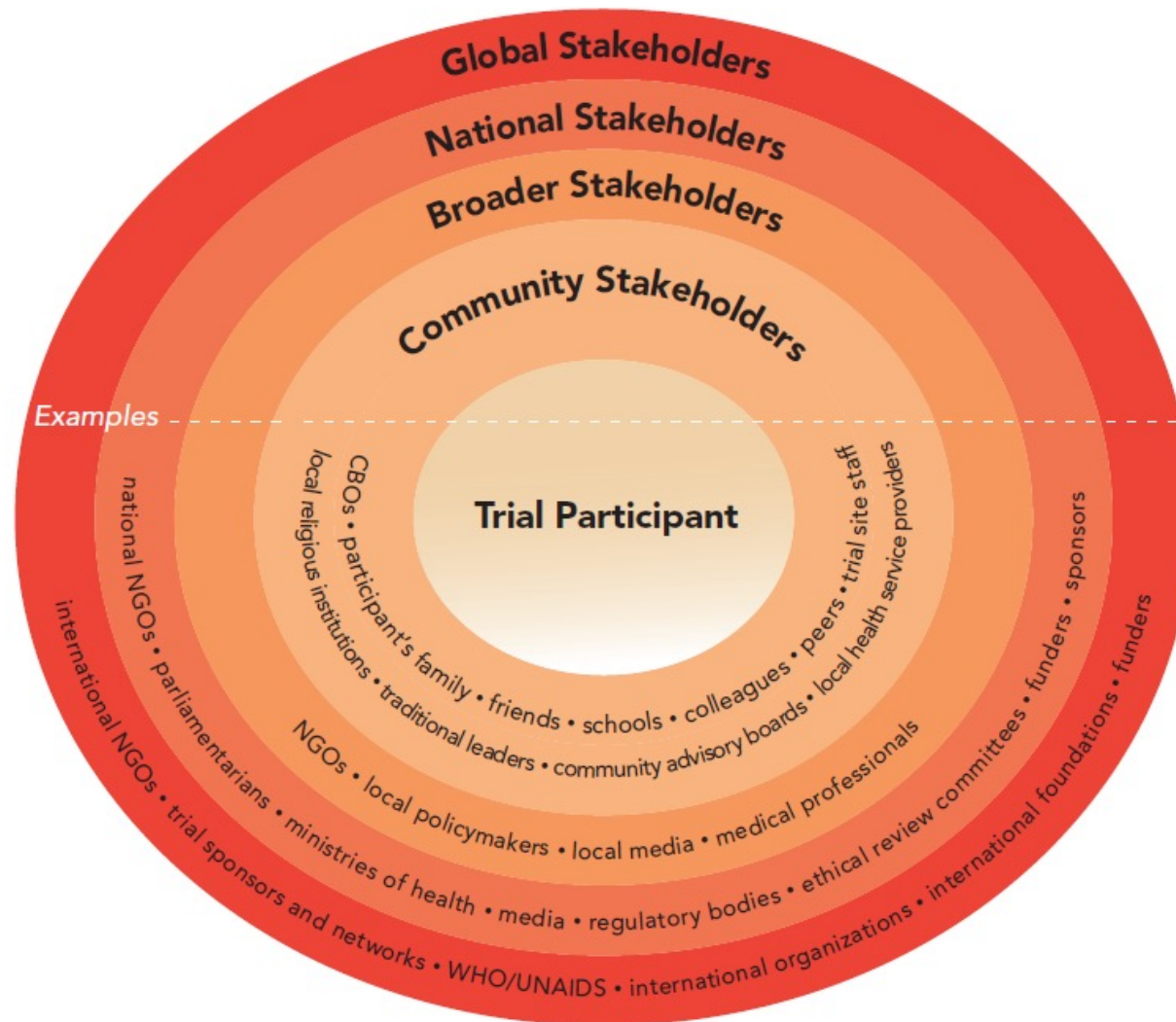
What do we mean by
“stakeholder engagement”?

Good Participatory Practice

- To facilitate building effective partnerships among all research stakeholders
- Set global **standard practices** for stakeholder engagement
- Provide trial funders, sponsors, and implementers with **systematic guidance on how** to effectively engage with stakeholders in the design and conduct of biomedical HIV prevention trials

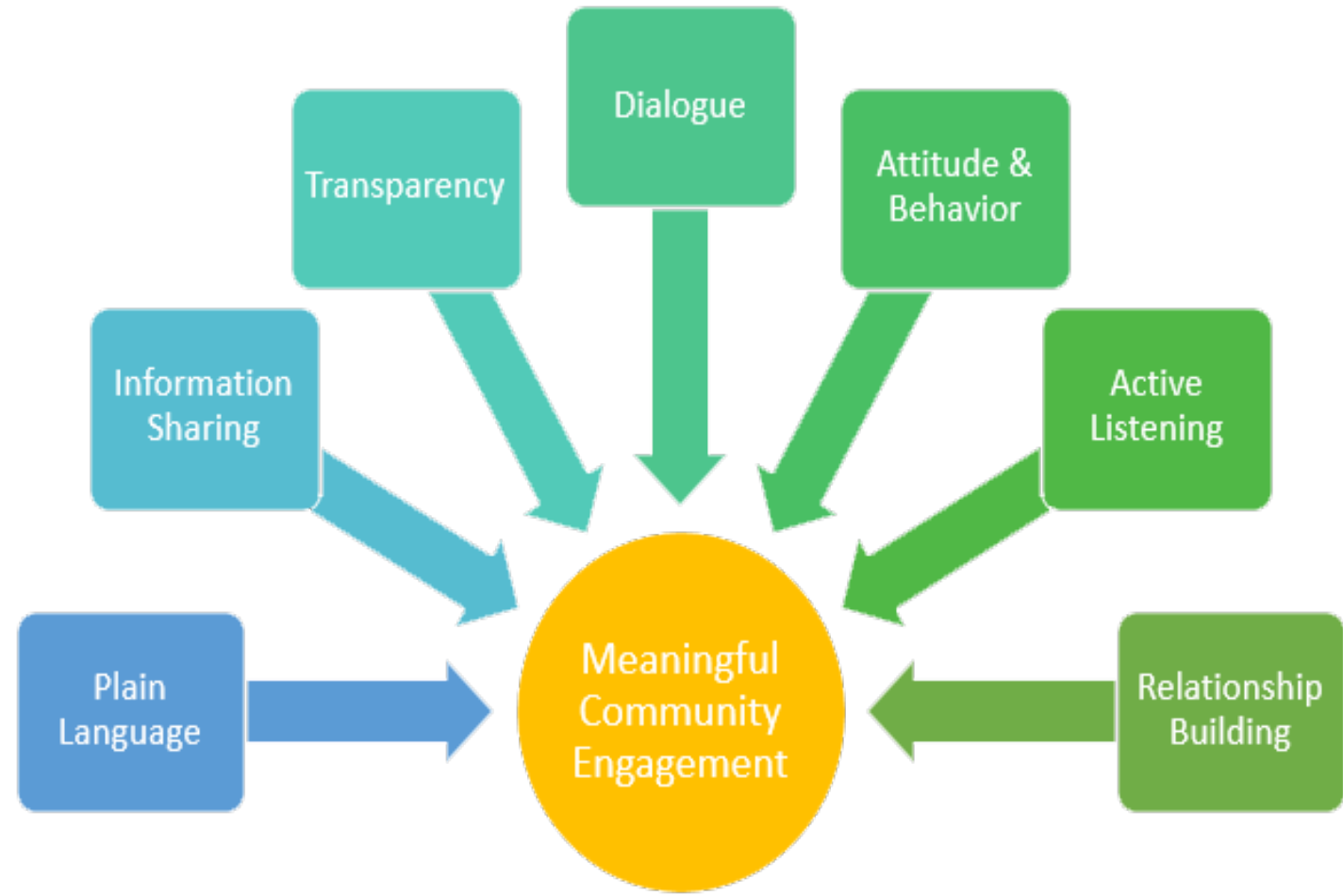


What Do We Mean By “Stakeholder”



Engagement Should Be Meaningful

- Collaborative, reciprocal processes that recognizes, respects and values the knowledge, perspective, and resources shared among partners
- Builds **trusting relationships** that facilitate individuals, groups, and organizations involved to understand and collaboratively address issues of concern



Features of Good Engagement

What ethics guidance say

Broad & Inclusive



Early & Sustained



Dynamic & Responsive



The Power of Choice

Engagement is about choice

- **Options**

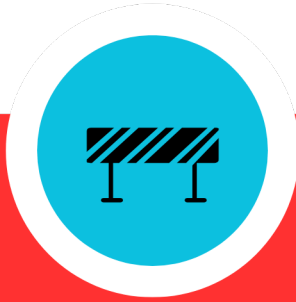
- Different mechanisms to get information about research and opportunities for input
- Requires infrastructure to identify new approaches for engagement

- **Choice**

- The ability for an individual to select from an array of participation options
- Requires researchers, institutions, funders to create available, accessible & affordable

How do we improve equity in
research?

A Framework for Implementing Equity in Research



**Barriers
to
Research**



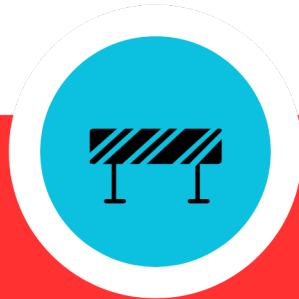
**Tools
to Address
Barriers**



**Financial &
Structural
Changes**

A Framework for Implementing Equity in Research

A focus on formative research



Barriers to Research



Tools to Address Barriers



Financial & Structural Changes

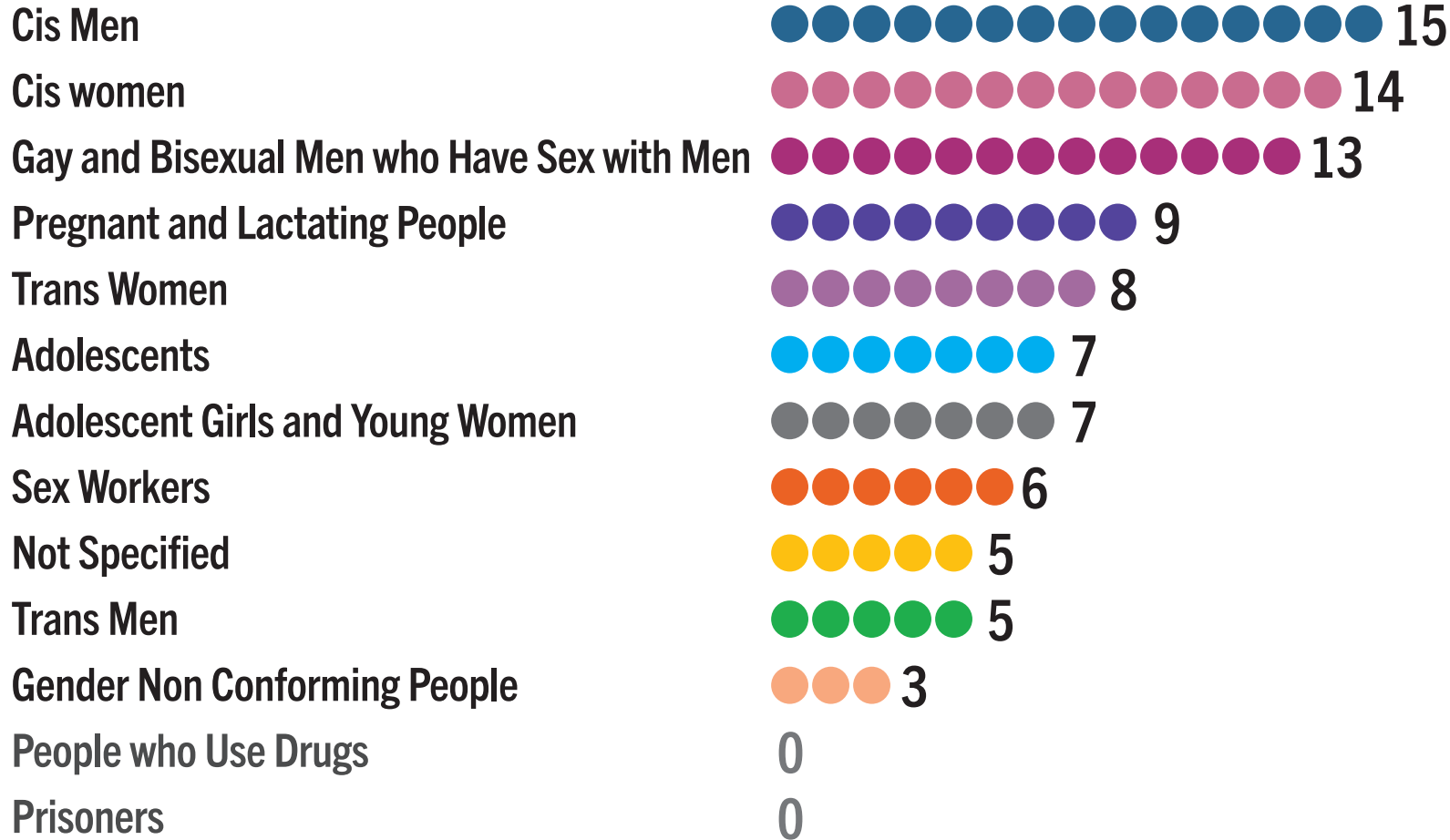
Define and map diversity objectives that match the scientific objectives and reflect the target population for the product

Consult intended users and civil society groups to understand potential barriers to participation at all levels

Regularly assess modes of information dissemination and community participation

Assessing operational readiness

Defining “Diversity”



- Cis men, cis women, and gay and bisexual men who have sex with men well represented
- Sex workers, trans men, and gender non conforming people less well represented
- No studies planned for people who use drugs or prisoners
- Inclusion of diverse populations is key to gather evidence around safety, adherence, etc.

Defining “Diversity”

- In 2022 there were 695 new infections among Black New Yorkers and 651 among Latinos.
 - No data about nationality

Medical News in Brief

April 26, 2024

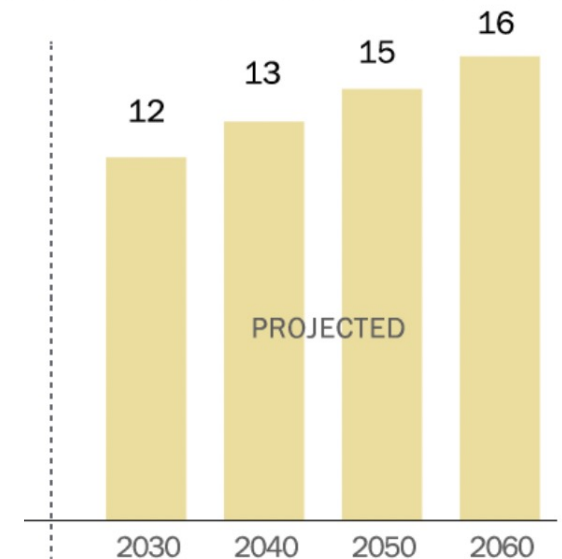
US Updates Race, Ethnicity Categories for First Time Since 1997

Emily Harris

One-in-Ten Black People Living in the U.S. Are Immigrants

Immigrants – particularly those from African nations – are a growing share of the U.S. Black population

BY CHRISTINE TAMIR AND MONICA ANDERSON



Source: *One-in-ten Black People in the U.S. Are Immigrants*
Pew Report, 2022

The Message and the Messenger

The power of language

- Language is a powerful tool that helps establish a relationship with participants
- The method of communication is critical (webinar, whatsapp, in-person, etc.)
- Messengers need to be reliable narrators with training
- Communication is a pathway not an activity



Language for HIV Cure

Community preferred language to describe cases of HIV Cure

HIV cure research is in a heightened moment with lots of new research, discussion and debate happening. This document shares the most up-to-date community preferred terminology about the cure space to help those in discussions, in covering or in translating new research. It was developed with the input of the Martin Delaney Collaboratories Community Engagement Coordinators and Community Advisory Boards.

Defining HIV Cure

Classic cure

DEFINITION: Removal of all replication-competent virus. This term is used to describe:

1. An individual who has received a stem cell transplant with a donor who has a natural immunity to HIV
2. An individual who has cleared the virus through immune mechanisms in the absence of antiretroviral therapy

Remission is an acceptable term to use when it is uncertain if a classic cure has been achieved. If virus is detectable, the community preferred terminology is "viral control".

PREFERRED ALTERNATIVE PHRASES

"classic cure", "cure", "eradication", "spontaneous cure", "traditional cure"

PHRASES TO AVOID

"Sterilizing cure", "Natural cure"

EXAMPLES

- Stem cell transplantation**
 Timothy Brown ("Berlin Patient")
Remained cured with non-detectable virus for ~ 12 years until his death from a recurrence of cancer in 2020.
 Adam Castillejo ("London Patient")
ART interruption was initiated in September 2017 and there is no evidence of viral rebound or detectable intact virus. HIV-specific antibodies have waned.
 "Düsseldorf Patient"
ART interruption was initiated in November 2018 and there is no evidence of viral rebound or detectable intact virus. HIV-specific antibodies have waned.
 "New York Patient"
ART interruption was initiated in 2020 and there is no evidence of viral rebound or detectable intact virus. HIV-specific antibodies have waned.
 "City of Hope"
ART interruption was initiated in 2021. Viral load remains undetectable and there is no evidence of viral rebound. HIV-specific cellular immune responses have waned.

EXAMPLES

- Immune clearance**
 Loren Willenberg
Elite controller diagnosed in 1992. Never taken ART. No detection of viral DNA in blood and tissue.
 Esperanza Patient
Diagnosed in 2013. No intact viral DNA detected in blood and tissue.

October 2022

avac.org

NYC HIV Research Symposium
 May 11th, 2022 1pm-530pm
 Doors open for lunch at 1230pm
 The LGBT Center
 208 W 13th St, New York, NY 10011 • Rm 110 & Rm 101

Time ET	Title	Speaker
1pm-330pm	HIV Cure Research as a Tool to End the Epidemic	Brad Jones, PhD, West Cornell Medicine
130pm-215pm	HIV Vaccine Pipeline & HIV Prevention Pipeline	Megala Szlezewski, MD, Columbia University Walea Bi-Sade, MD, MPH, MPA, Columbia University
215pm-245pm	Exploring Clinical Trial Design for HIV Prevention and Cure	Richard Jefferys, Treatment Action Group Stacey Hannah, MHS, AVAC
215pm-245pm	Cure Strategies Under Investigation	Jessica Satzweil, MA, AVAC
3pm-4pm	Promoting Equity, Diversity and Access to Research	Jorge Solor, PhD, MPH, New York Blood Center Kerensa Boud, EdD, MPH, CDEB, City College of New York Dafreem Usher, MEd, MSW, MPH, MA, Treatment Action Group Adam Ward, MSK PhD Candidate, West Cornell Medicine Moderator: Jorge Benitez, Columbia University John Heald, MPH, AVAC
415pm-5pm	CAB to Prevention: What Communities Need to Know About Research to Introduction	Hong Van Thu, MD, MS, New York Blood Center Jessica Rodriguez, MS, AVAC
415pm-5pm	Exploring Diversity in Cure Research: Sex, Class and the West	Adam Ward, MSK PhD Candidate, West Cornell Medicine
5pm-530pm	Introduction to REACH Collaboratory	Melina Canay, MD, Rockefeller University Brad Jones, PhD, West Cornell Medicine
530-630pm	RECEPTION	

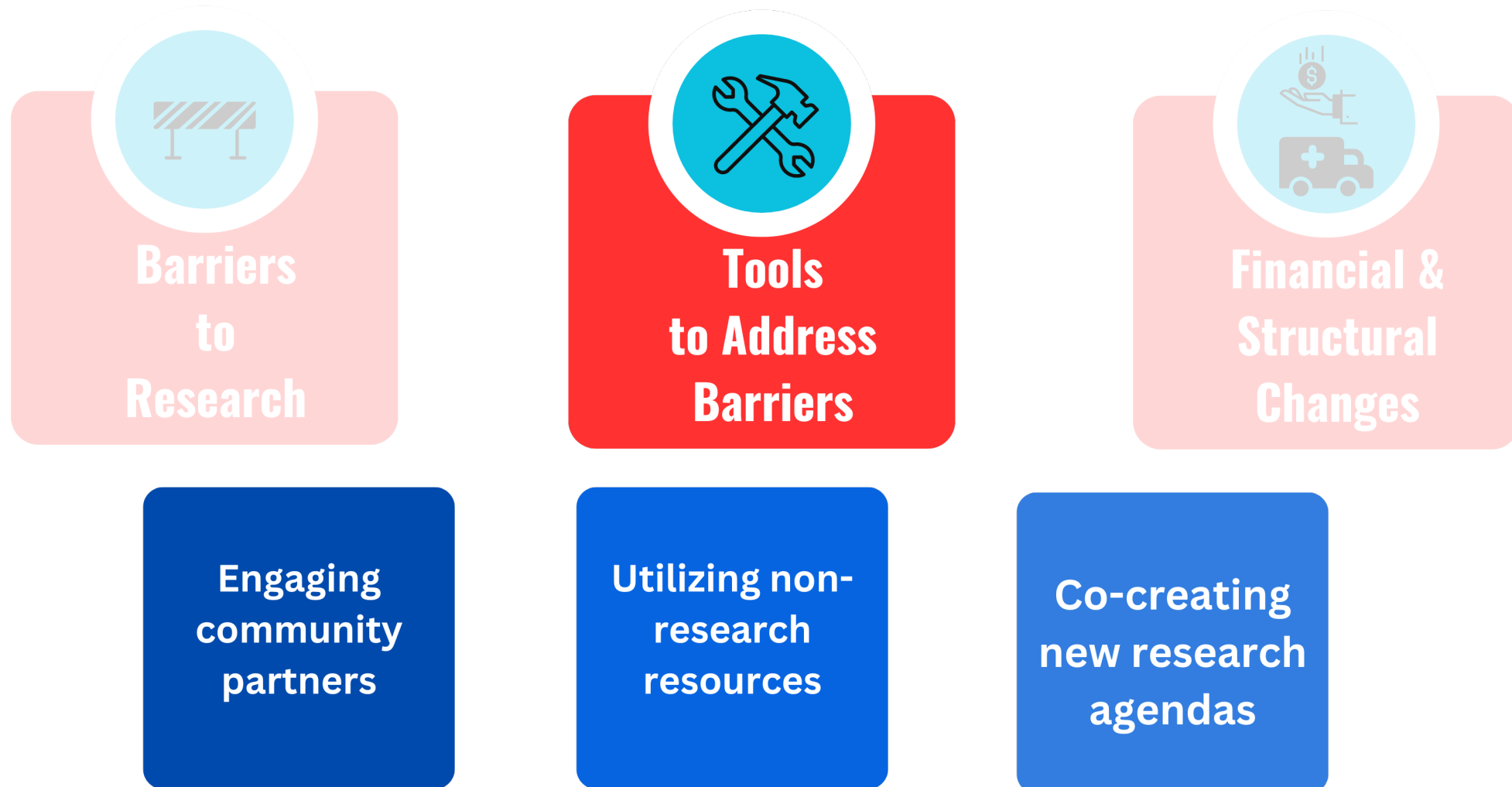


With HIV cure, we will end Stigma and Discrimination attached to infants, youths and adults living with HIV

Join the conversation online, follow @anayd_africa and #HIVCureResearch_NG on social media

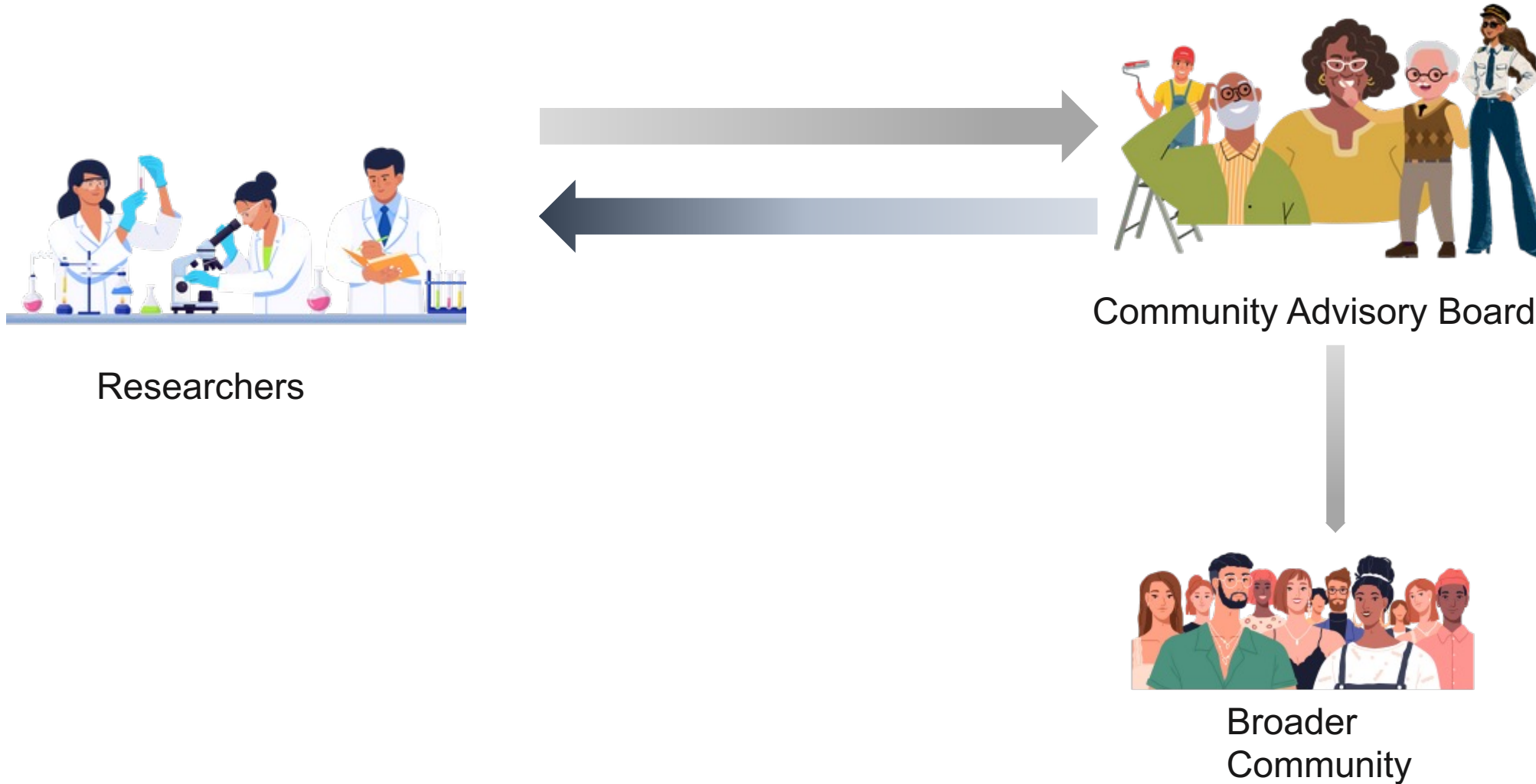


A Framework for Implementing Equity in Research



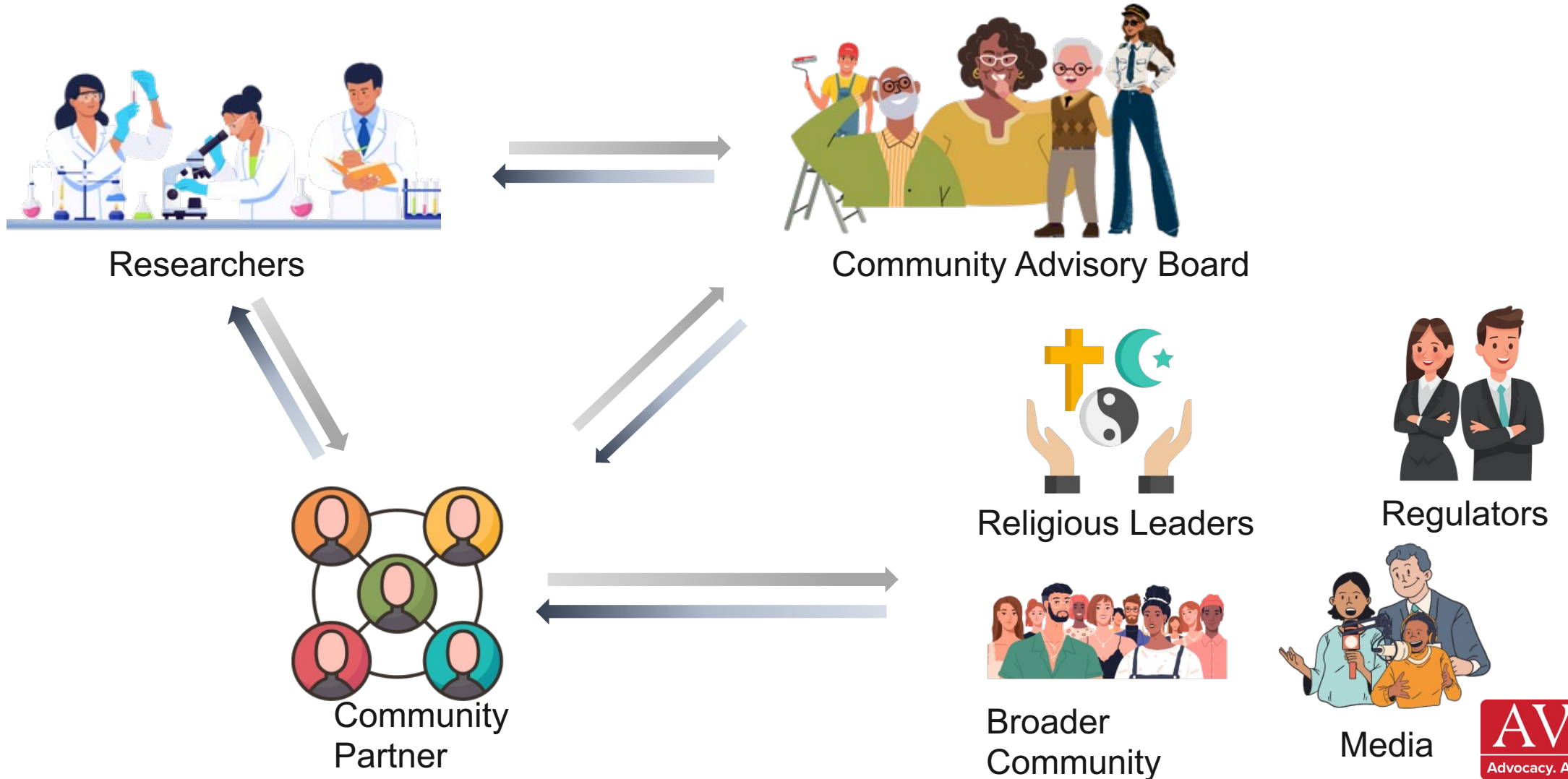
Standard Engagement vs. Partnership Models

Consult intended users



Standard Engagement vs. Partnership Model

Learning from the Martin Delaney Collaboratories



Example of Community Partnership Models

Treatment Advocacy Literacy Campaign in Zambia developed community engagement monitoring tools during PoPART study

Trained local community groups and network leaders on Good Participatory Practice

Developed and regularly administered a Community Score Card to assess engagement from the trial site

Provided regular updates to trial leadership on engagement methodology and effectiveness of messaging strategies



Setting a Diverse Agenda

An example of trans leadership

- Employed trans consultants to conduct focus groups and lead data sharing
- Developed tools to support trans and nonbinary inclusion in addition to research questions
- Created indicators to ensure inclusion was on track
- Connecting sponsors, researchers and clinical trialists with trans leadership to ensure trans priorities are reflected in new research projects

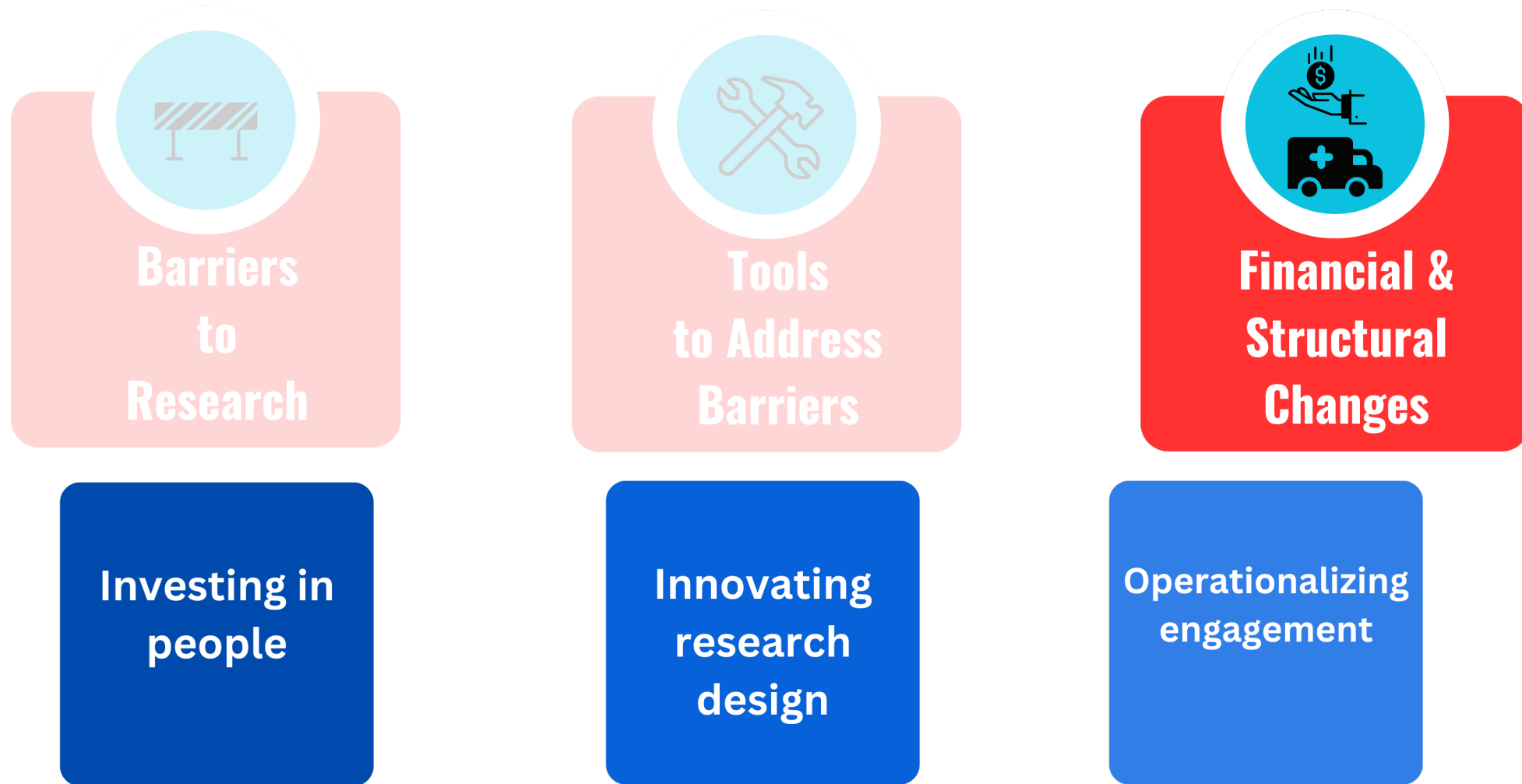


Meeting Multiple Needs

Putting research in the real-world

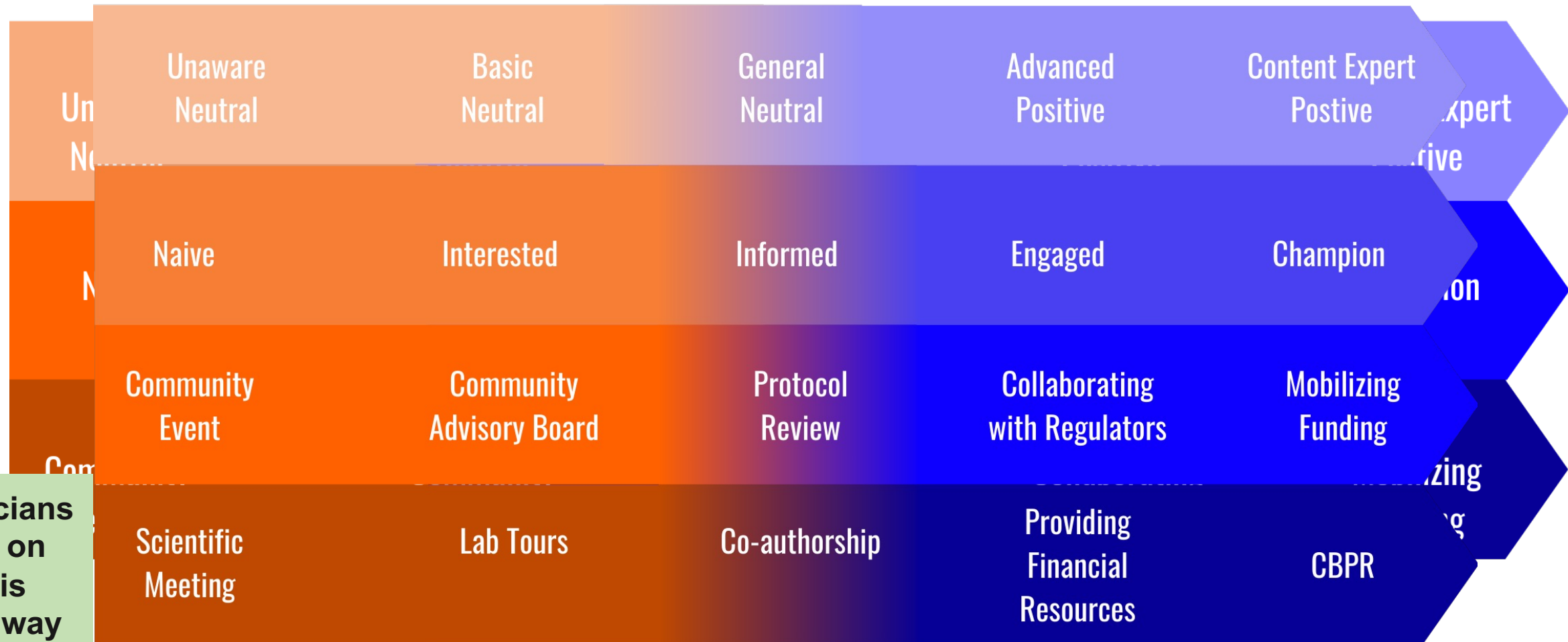
- Linking with grants management and communication departments to provide CAB members with:
 - communication (presentation and media) training to support growth and knowledge sharing
 - headshots and/or other professional development services
 - grant and abstract writing support to share best practices
- Support non-traditional lines of communication like texting or whatsapp to ensure space for everyone
- Provide data or transport stipends to recognize expertise

A Framework for Implementing Equity in Research



The Benefits of Engagement

Moving through the participation pipeline



Clinicians are on this pathway as well

Adapted from MacQueen & Cates, American Journal of Preventive Medicine, 2005

Operationalizing Engagement in HIV Research

Those who Use; Those who Choose; Those who Pay the Dues

FUNDERS

- What is the cost for clinical research and how long will a trial last?
- What is the cost-effectiveness of investing in engagement infrastructure?
- What is the market size, generally and will the approach be applicable to all?
- Can engagement decrease enrollment time or increase product uptake?

PROGRAMS

- What type of training do study staff need to ensure equity?
- What type of training & support do providers need?
- What policies need to be reviewed/adjusted to ensure research can move forward?

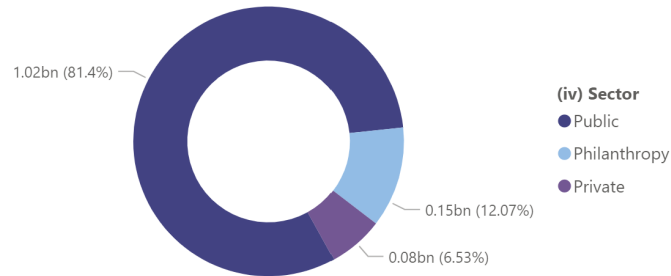
USERS

- Will participation in a clinical trial prohibit enrollment in a later trial?
- Where/from whom do potential users desire to hear about and access research information?
- How will relationships change over time?
- How can we increase & support participation adherence?
- How can peer groups/influencers be leveraged to support participation/engagement?
- How can providers be supported to have more knowledge and empathy?

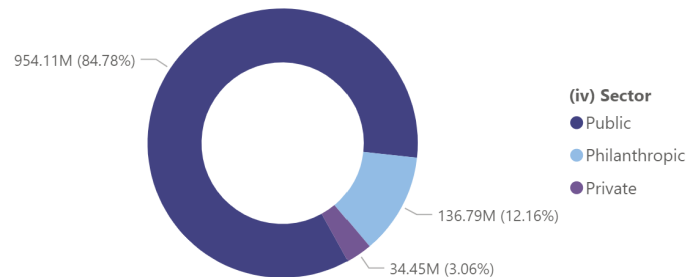
HIV Prevention Funding Trends

Breakdown of HIV Prevention R&D by Sector

2021



2022



Top 10 Funded Key Populations in HIV Prevention R&D

Population Focus	Sum of 2022 Disbursement USD
AGYW	25,343,416.78
Female Sex Workers	1,424,212.64
HIV-negative individuals	5,479,112.40
Indigenous populations	1,002,357.27
MSM, TGW	4,450,420.00
Person with HIV	1,459,366.72
PLHIV who have failed first-line therapy	1,360,678.00
Pregnant mothers and neonates	1,330,000.00
Women	18,877,277.82
Young women	4,832,668.48
Total	65,559,510.11

- The National Institutes of Health is the largest funder of HIV prevention research globally
- Growing increase in clinical research sponsored by industry and philanthropy which do not have the same definitions of diversity or equity

How can you build a pipeline
for engagement?

CureROAR Program

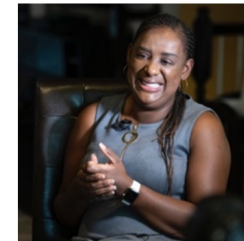
Developing Messengers

Goal: Build a cadre of research advocates able to meaningfully engage and influence the HIV cure research agenda.

- Graduated interviews around the perceptions and considerations for control. Manuscript in development
- Monthly focused on advancing HIV cure science and advocacy messages
- Work with Black women, including African immigrant population, to develop HIV cure messaging for themselves and pediatric projects and advocacy efforts
- Small grants available for local literacy populations
- Conference scholarship
- Developed messages for faith community support
- Comprehensive monitoring and evaluation approach
- Developed messages for faith community support
- Held dialogue with Black women and MSM in Oakland



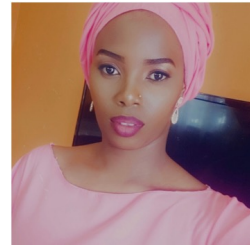
Tanzania



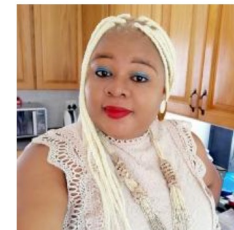
USA



Uganda



Uganda



South Africa



Malawi



Uganda



Uganda



USA



USA



USA



USA

Global South Advocacy-for-a-Cure Academy

3-day intensive program focused on building literacy and translation

15-20 participants with full scholarships to attend the meeting

Available to Global South participants exclusively

Alumni academy held every third year to deepen knowledge.

Alumni enter into a network that provides ongoing literacy and access to conference scholarships.

Partnership with IAS



US Academy currently being planned!

Reaching Broader Stakeholders

Examples From Global Partners

- Developed a media training for journalists in Zimbabwe
 - Available to media café programs in Zambia, Uganda and Kenya
- Innovative Whatsapp training to target youth
- Engagement with MoH and PEPFAR programs
- MOUs with religious leaders

With HIV cure, we will end

The Herald

with HIV in Malawi as a Project Local Point.
As Africa, we have not had a case of HIV Cure and
As young
are almost
re all

/ LOCAL NEWS
Have we

01 NOV, 2022 - 14:11

AVAC

HIV STR

Quest of an HIV cure will ease burden of daily treatment

Play (k)

HIV advocate Cathy Murombedzi upbeat about HIV cure

Octob

E get things wey we supposed torchlight unto this cure matter, and the things Na Dis na two step arrangement wey dey help to flush (shock) di virus comot for where di cells been dey rest, na one kain drug like dat wey we go need top up with anoda one wey go help kill di cells wey been don dey sick.

Join the conversation online, follow @anayd_africa and #HIVCureResearch_NG on social media

AVAC #HIVCureResearch Advocacy/Campaign

The Sunday Mail

AVAC
Advocacy. Access. Equity.

EBONI Study

Putting equity at the center

- All site PIs are Black women
 - Opened new sites
 - Diversified specialties (OBGYNs, infectious disease, family practice)
- All site staff receive EDI training



New sites, new PIs mean new contracts and additional training. This will take more time and investment from funders.

HPTN 096

Building Equity Through Advocacy

PEER SUPPORT

Serving as role models, Peer Supporters are trained and establish mutually supportive relationships to exchange knowledge, connect clients with resources, and provide education on HIV-related topics.

SOCIAL MEDIA

Leveraging digital tools and social media best practices to provide HIV-related information to Black MSM in the southern U.S. by promoting healthy behavior change and increasing awareness of study activities.

HEALTH EQUITY

Partnering with local community-based organizations to leverage or build coalitions focused on advocacy strategies to address social and structural barriers to HIV prevention and care for Black MSM in the southern U.S.

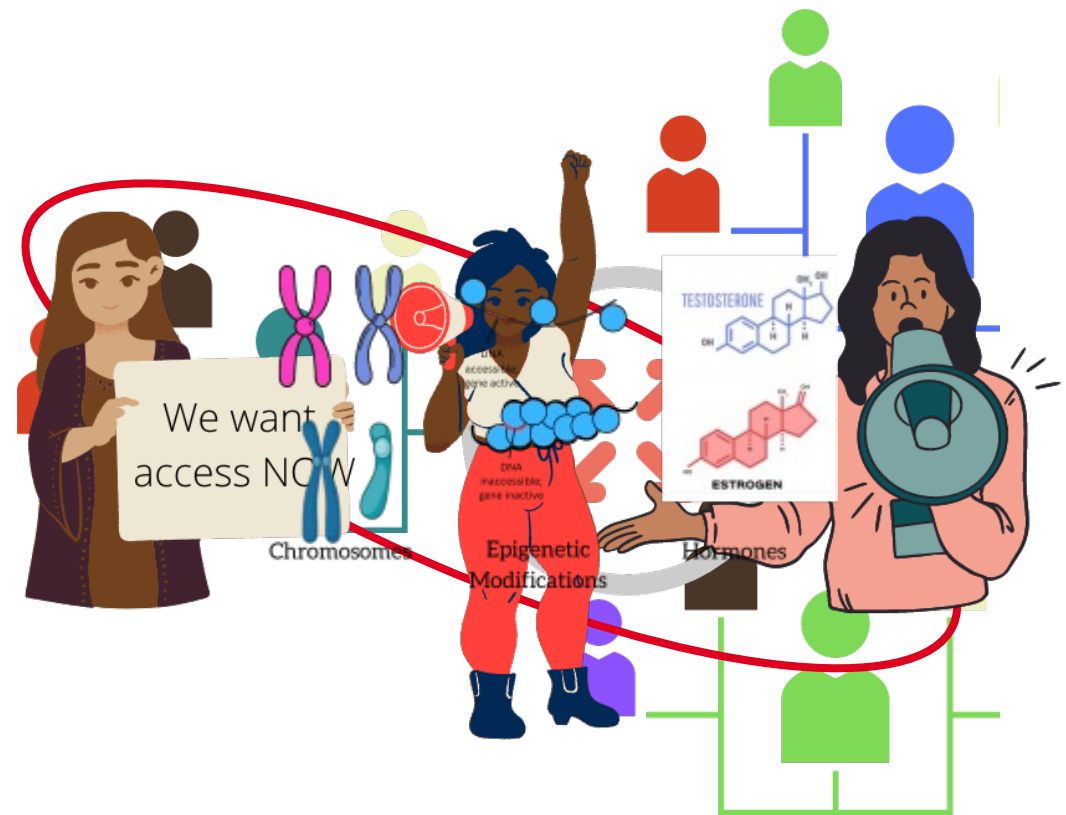
STIGMA PREVENTION

The **Culturally Responsive Intersectional Stigma Prevention (CRISP)** program is a package of training, skills building, technical assistance, and quality improvement activities designed for healthcare facilities.

Engagement in Research As a Path to Equity

A summary

- Goal: build sustainable relationships to support public health
 - Broad and inclusive
 - Early and sustained
 - Responsive and dynamic
- The approach varies:
 - Information is broad and deep
 - Expanding the network
 - Champion creation
 - Being a connector



Thank You!

REACH
For the Cure

Research Enterprise to Advance a Cure for HIV



Towards
an HIV Cure
IAS

 **aidsfonds**

 **I4C**
IMMUNOTHERAPY
FOR HIV CURE



PAVE Pediatric Adolescent
Virus Elimination

A Martin Delaney Collaboratory

CASPR

COALITION TO ACCELERATE &
SUPPORT PREVENTION RESEARCH

AVAC
Advocacy. Access. Equity.