Community & Stakeholder Engagement in HIV Cure-Related Research

CUREiculum

This research training curriculum is a collaborative project aimed at making the science of HIV cure-related research saccessible to the community and the HIV research field.

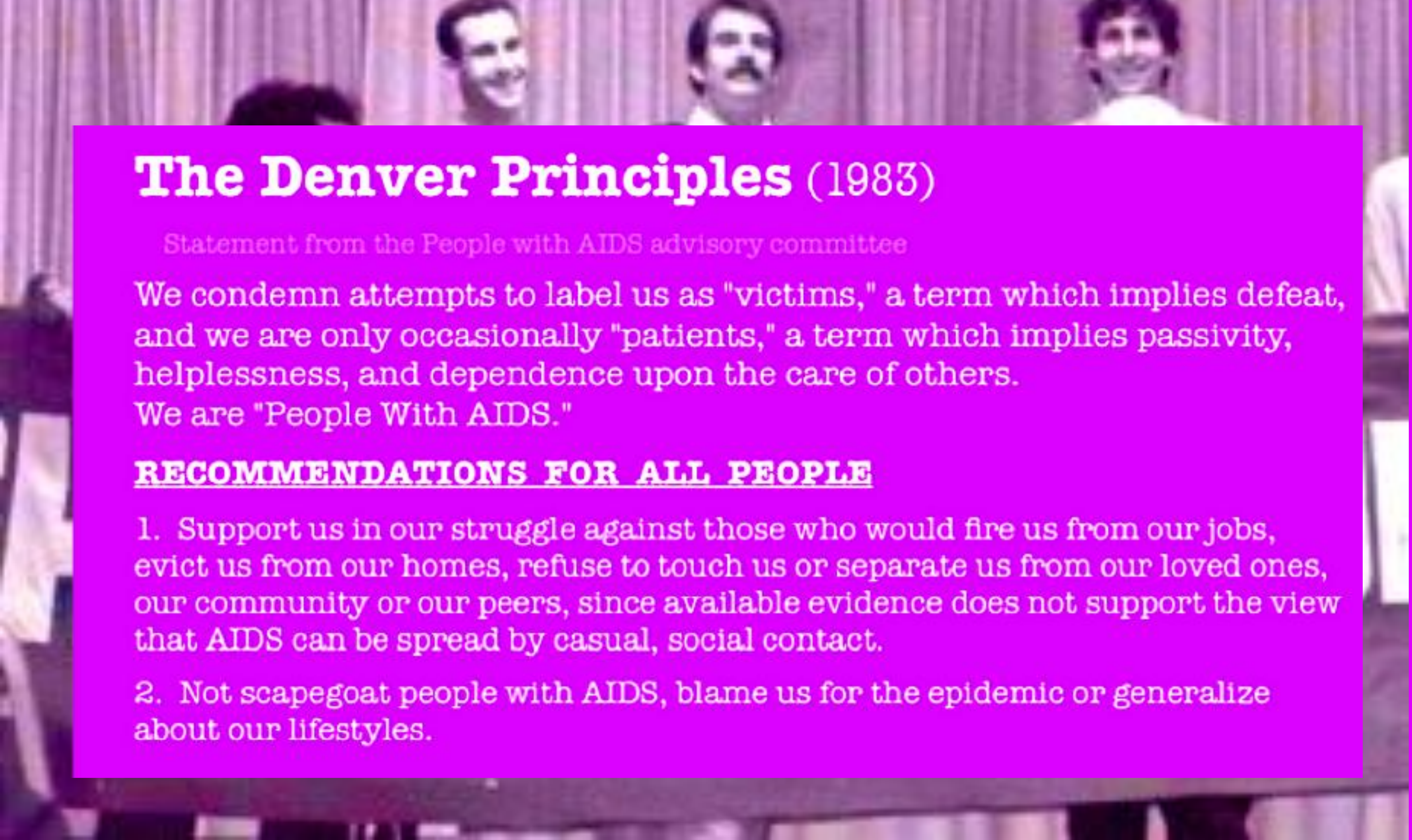
Outline

- "Nothing About Us Without Us"
- How Can We Define Stakeholders??
- How Can We Define Community?
- Where Does Engagement Fit?
- What Principles Make Good Engagement?
- Why Is Engagement Important?
- Engagement in HIV Cure-Related Research
- Why is Stakeholder Engagement Important?
- The Paramount Importance of Community-Friendly Information
- Examples and Ideas

community engagement

“Nothing About Us Without Us”

The Denver Principles, 1983



The Denver Principles (1983)

Statement from the People with AIDS advisory committee

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others.
We are "People With AIDS."

RECOMMENDATIONS FOR ALL PEOPLE

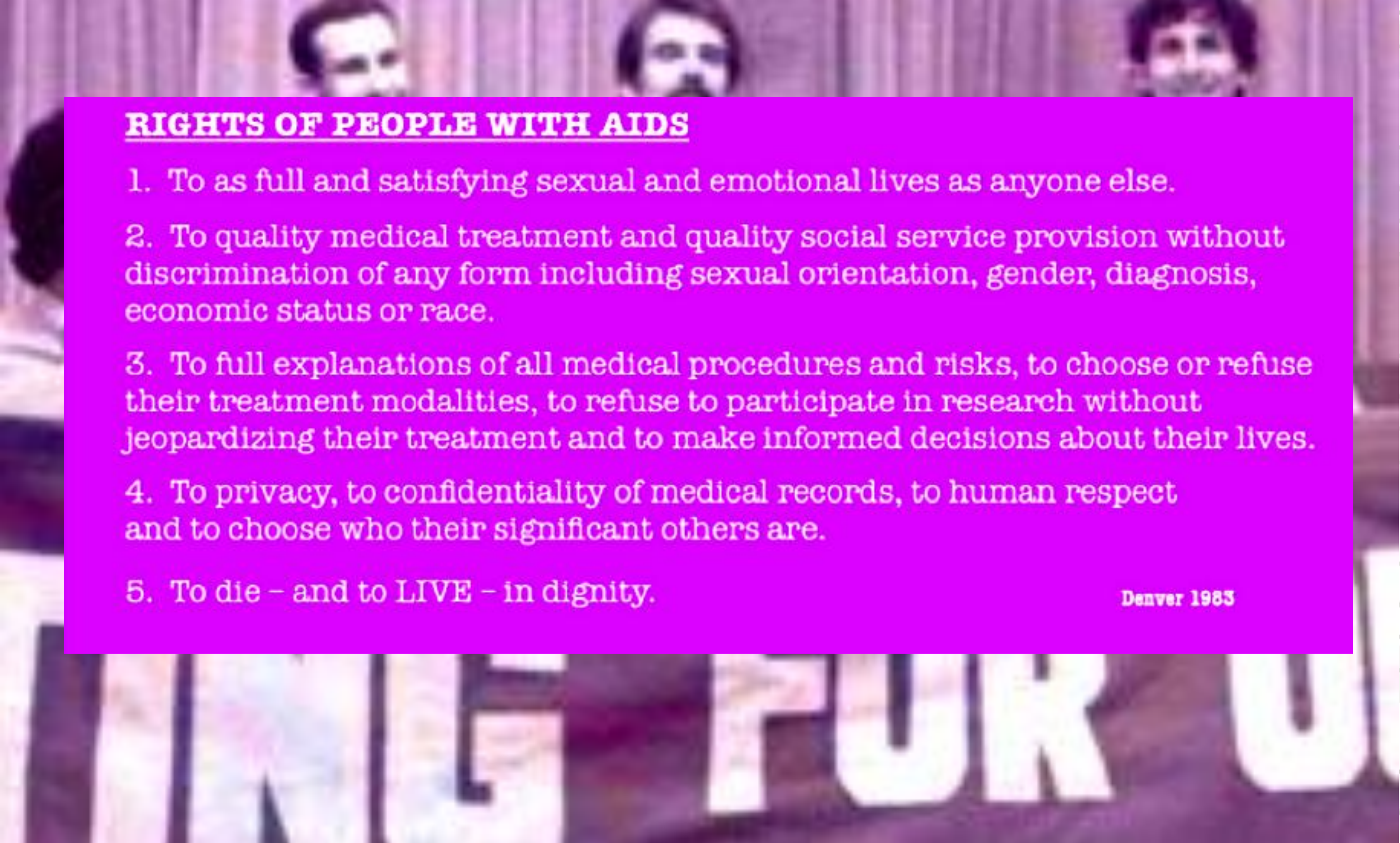
1. Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from our loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.

2. Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

RECOMMENDATIONS FOR PEOPLE WITH AIDS

1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
2. Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
4. Substitute low-risk sexual behaviors for those which could endanger themselves or their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

community engagement



RIGHTS OF PEOPLE WITH AIDS

1. To as full and satisfying sexual and emotional lives as anyone else.

2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.

3. To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.

4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.

5. To die – and to LIVE – in dignity.

Denver 1983

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The Greater Involvement of People Living with HIV (GIPA)

UNAIDS

POLICY BRIEF

The Greater Involvement of People Living with HIV (GIPA)

Context

Nearly 40 million people in the world are living with HIV.[1] In countries such as Botswana and Swaziland, people living with HIV make up a quarter or more of the population.

People living with HIV are entitled to the same human rights as everyone else, including the right to access appropriate services, gender equality,[2] self-determination and participation in decisions affecting their quality of life, and freedom from discrimination[3].

All national governments and leading development institutions have committed to meeting the eight Millennium Development Goals, which include halving extreme poverty, halting and beginning to reverse HIV[4] and providing universal primary education by 2015. GIPA or the Greater Involvement of People Living with HIV is critical to halting and reversing the epidemic; in many countries reversing the epidemic is also critical to reducing poverty.

What is GIPA?

GIPA is not a project or programme. It is a principle that aims to realize the rights and responsibilities of people living with HIV, including their right to self-determination and participation in decision-making processes that affect their lives. In these efforts, GIPA also aims to enhance the quality and effectiveness of the AIDS response.

The idea that personal experiences should shape the AIDS response was first voiced by people living with HIV in Denver in 1983.[5] The GIPA Principle was formalized at the 1994 Paris AIDS Summit when 42 countries agreed to "support a greater involvement of people living with HIV at all…levels…and to…stimulate the creation of supportive political, legal and social environments"[6].

In 2001, 189 United Nations member countries endorsed the GIPA Principle as part of the Declaration of Commitment on HIV/AIDS. The 2006 Political Declaration on HIV/AIDS unanimously adopted by 192 Member States at the 2006 High Level Meeting on AIDS also advocated the greater involvement of people living with HIV.

Why GIPA?

The participation and contribution of people living with HIV is one of the best examples of global progress in public health.

We have come from a place where people openly living with HIV were stoned to death, to a place where we have been invited to stand among the leaders of the world to shape international policies.

There is still a long way to walk but we have made historical changes and gains of which we can be proud.

- Gracia Violeta Ross

National Chair, Bolivian Network of People Living with HIV/AIDS

community engagement

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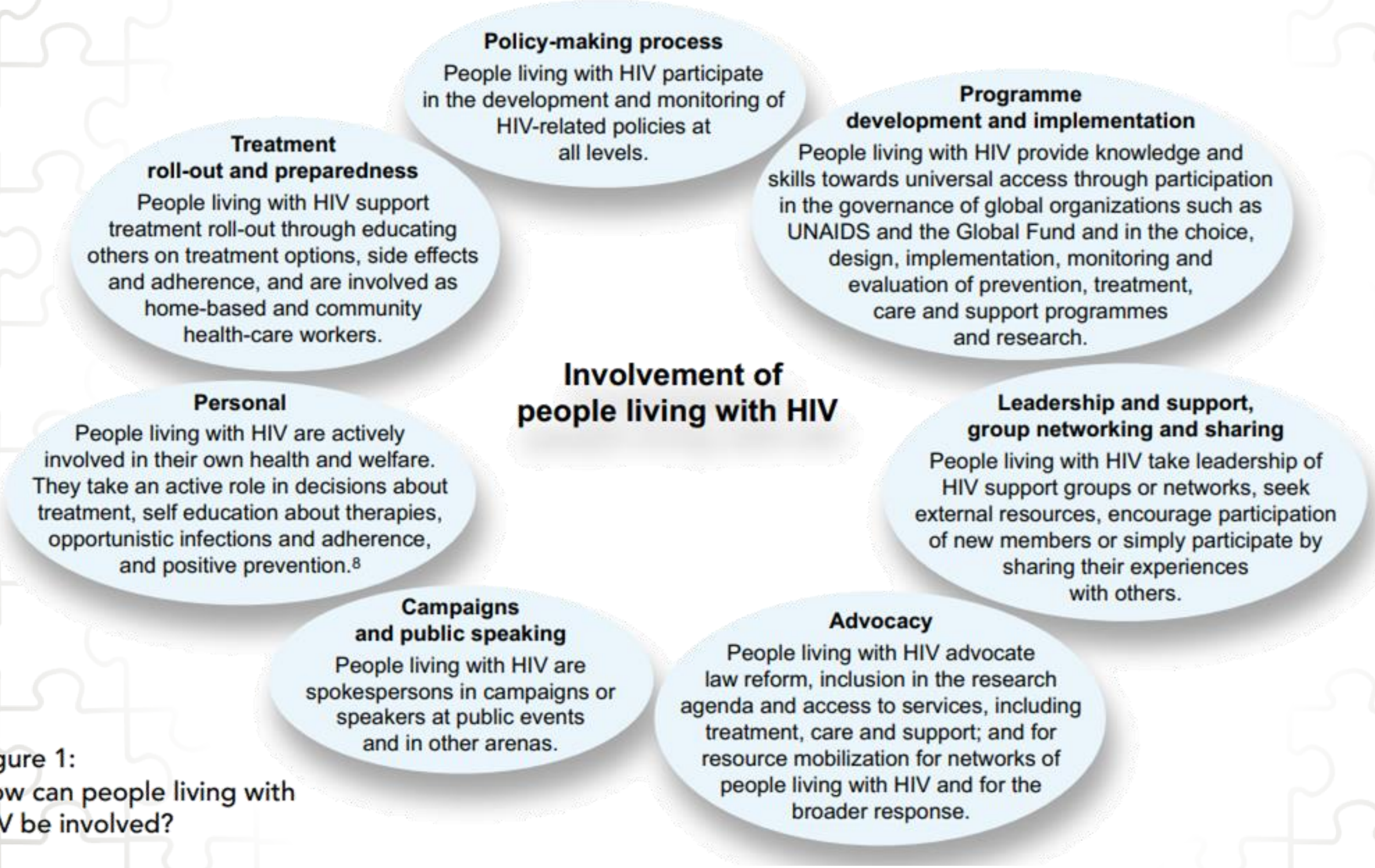
https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf

The Meaningful Involvement of People Living with HIV (MIPA)

- **intentional engagement** of people living with HIV in leadership, advisory, and decision-making roles
- **critical** to ensure that the voices of people most affected by an issue or decision are heard

https://aidsunited.org/meaningful-involvement-of-people-with-hiv-aids-mipa/

How Can People Living with HIV Be Involved?



Involvement of people living with HIV

Policy-making process
People living with HIV participate in the development and monitoring of HIV-related policies at all levels.

Programme development and implementation
People living with HIV provide knowledge and skills towards universal access through participation in the governance of global organizations such as UNAIDS and the Global Fund and in the choice, design, implementation, monitoring and evaluation of prevention, treatment, care and support programmes and research.

Leadership and support, group networking and sharing
People living with HIV take leadership of HIV support groups or networks, seek external resources, encourage participation of new members or simply participate by sharing their experiences with others.

Advocacy
People living with HIV advocate law reform, inclusion in the research agenda and access to services, including treatment, care and support; and for resource mobilization for networks of people living with HIV and for the broader response.

Campaigns and public speaking
People living with HIV are spokespersons in campaigns or speakers at public events and in other arenas.

Personal
People living with HIV are actively involved in their own health and welfare. They take an active role in decisions about treatment, self education about therapies, opportunistic infections and adherence, and positive prevention.[8]

Treatment roll-out and preparedness
People living with HIV support treatment roll-out through educating others on treatment options, side effects and adherence, and are involved as home-based and community health-care workers.

Figure 1:
How can people living with HIV be involved?

https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf

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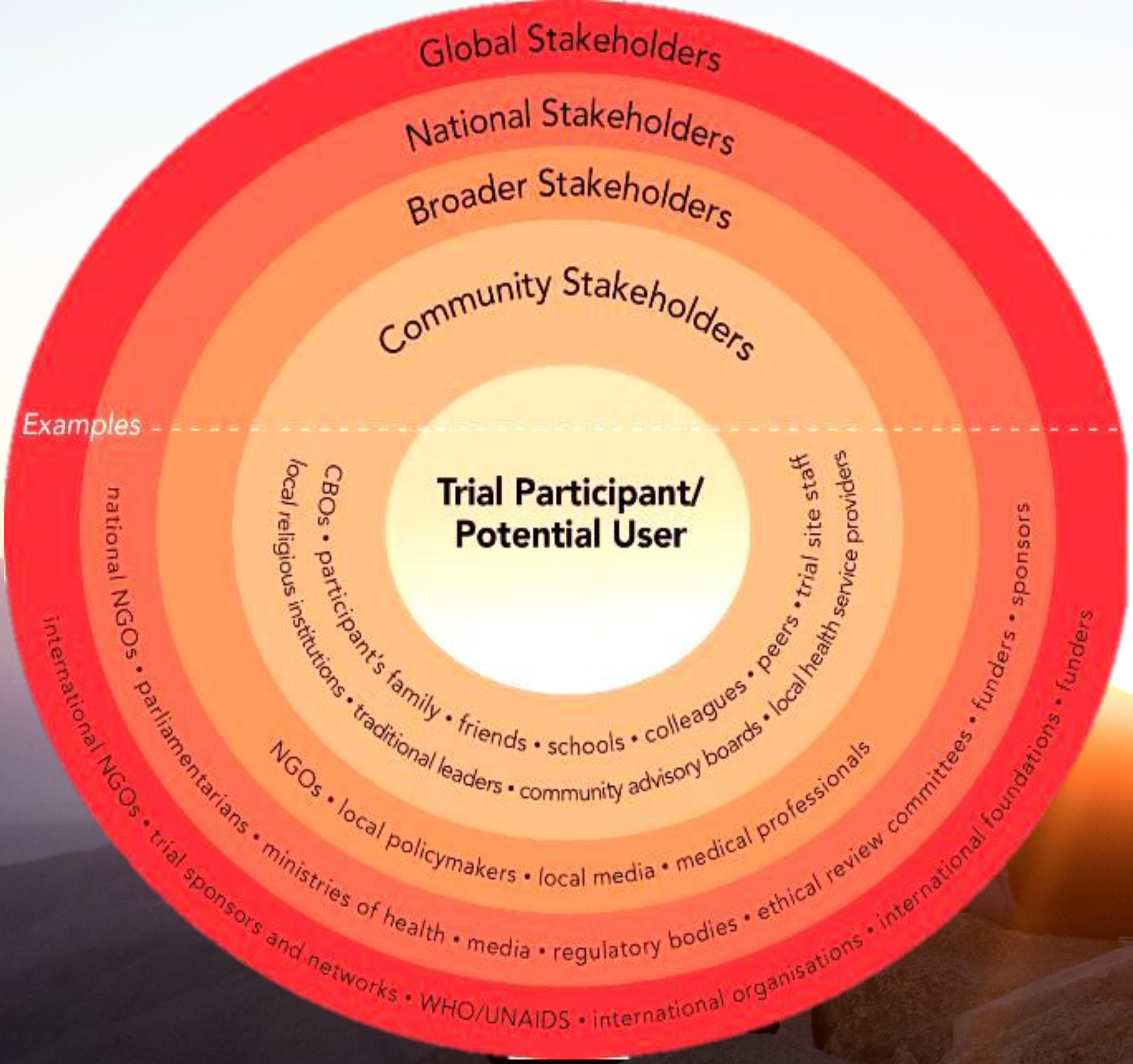
How Can We Define Stakeholders?

How Can We Define Stakeholders?

- Global Stakeholders
- National Stakeholders
- Broader stakeholders
- Community Stakeholders
- Trial Participants/Potential Participants

community engagement

community engagement



Global Stakeholders

National Stakeholders

Broader Stakeholders

Community Stakeholders

Examples

Trial Participant/ Potential User

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

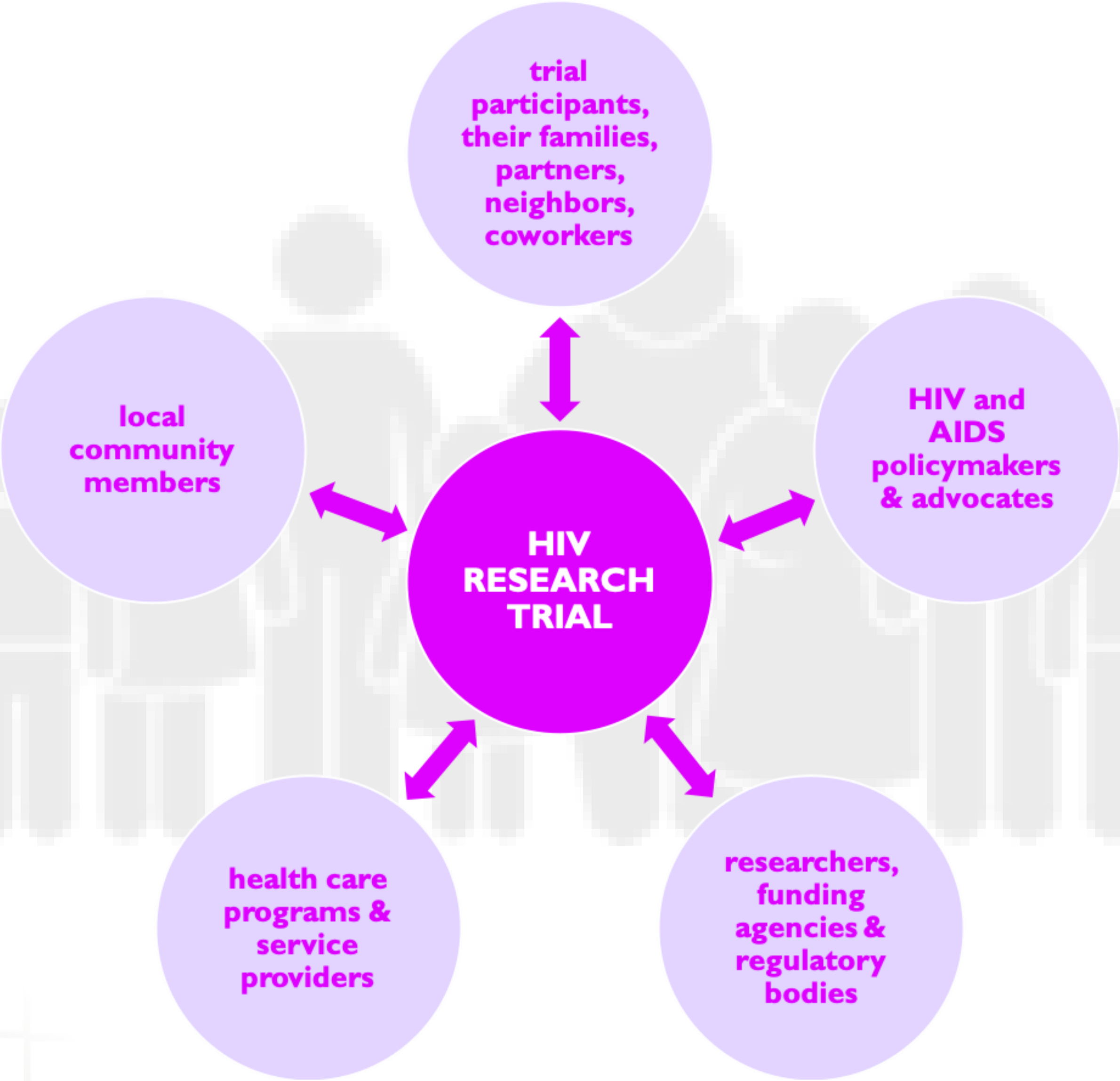
CBOs • local religious institutions • traditional leaders • community advisory boards • local health service providers

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

...WHO ARE YOU *'ENGAGING?'*



trial participants, their families, partners, neighbors, coworkers

local community members

HIV RESEARCH TRIAL

HIV and AIDS policymakers & advocates

health care programs & service providers

researchers, funding agencies & regulatory bodies

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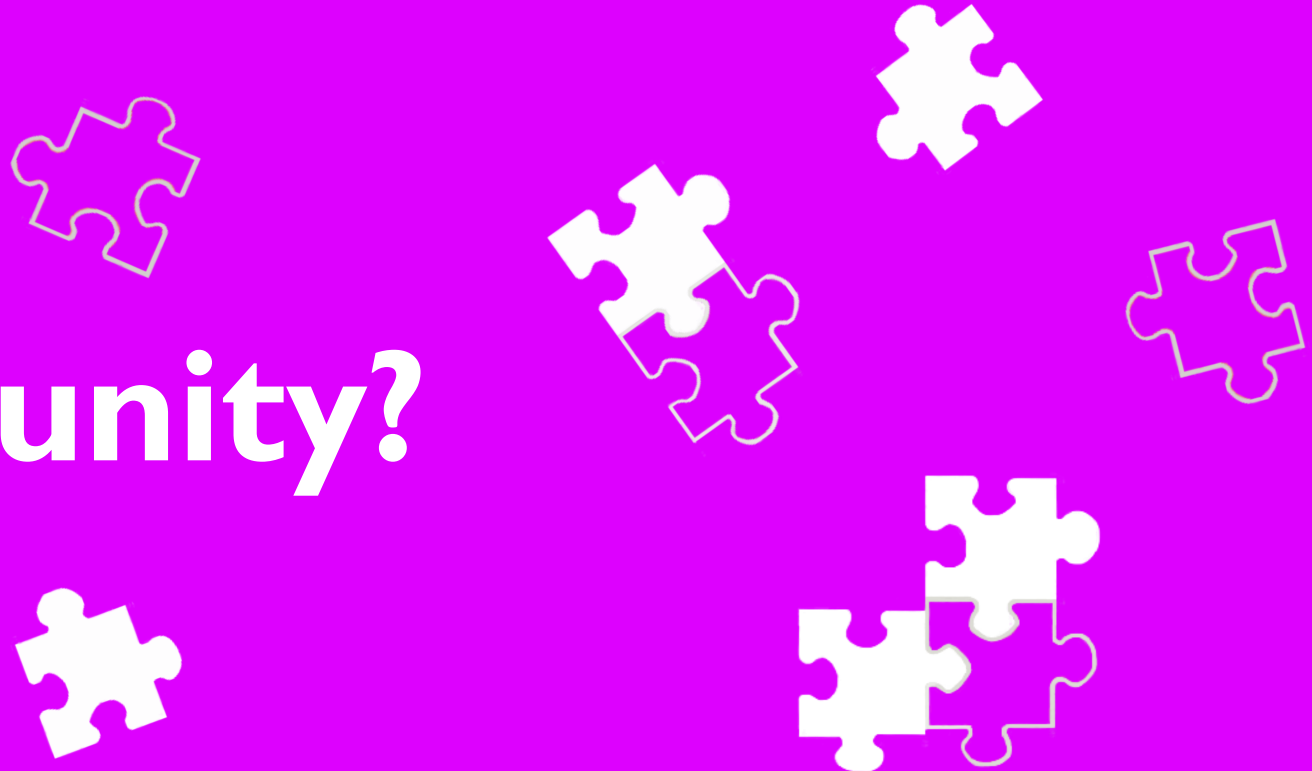
Adapted from Stakeholder Engagement Toolkit for HIV Prevention Trials

How Can We Define Community?



How Can We Define Community?

"A group of people with diverse characteristics who are linked by social ties, share common perspectives, and engage in joint action in geographical locations or settings."

(MacQueen, 2001)

"who is included and who is excluded from membership"

(Institute of Medicine, 1995)

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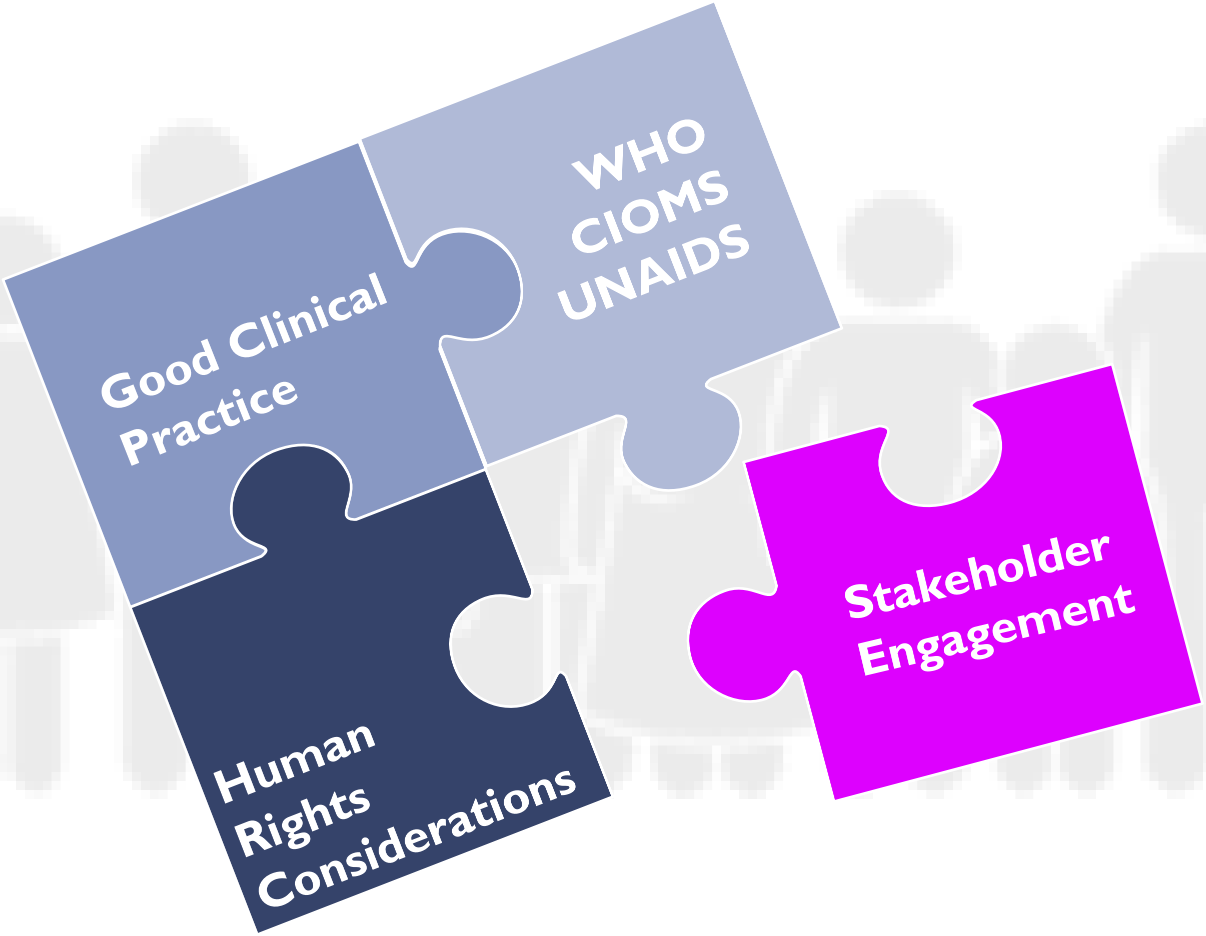
Where Does Engagement Fit?



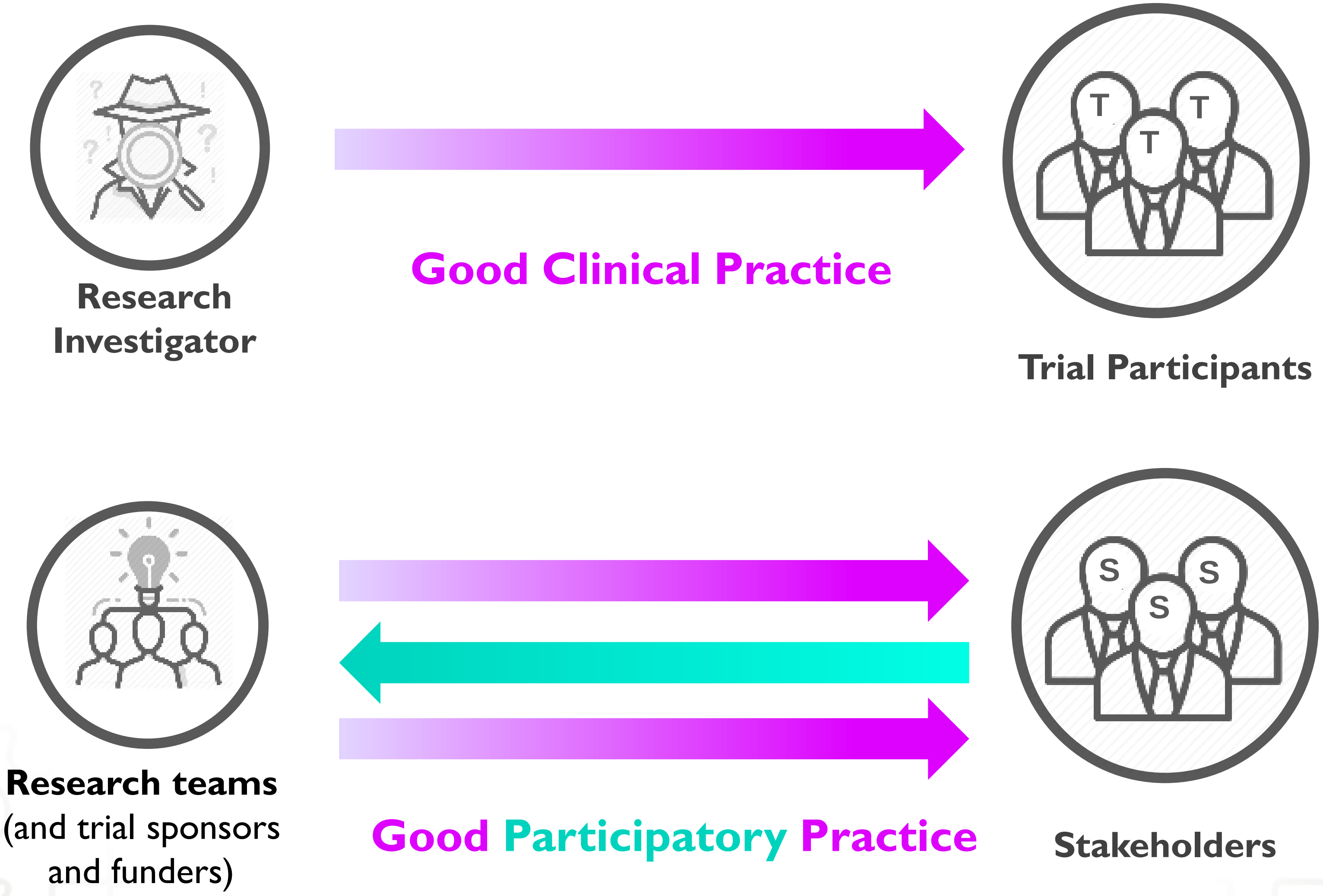
Good Clinical Practice

WHO
CIOMS
UNAIDS

Human Rights Considerations

Stakeholder Engagement

Good Clinical Practice is NOT Good Participatory Practice



Research Investigator

Good Clinical Practice

Trial Participants

Research teams (and trial sponsors and funders)

Good Participatory Practice

Stakeholders

community engagement

Why Do We Engage Beyond the Participant?

PrEP research trial **controversy**

- 2004 – Cambodia trials were not initiated
- 2005 – Cameroon and Nigeria trials discontinued

ACT UP PARIS

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What Principles Make Good Engagement?

Guiding Principles of Engagement

Integrity

Transparency

Mutual Understanding

Accountability

Good Participatory Practices

Respect

Community Stakeholder Autonomy

Effective Stakeholder Engagement

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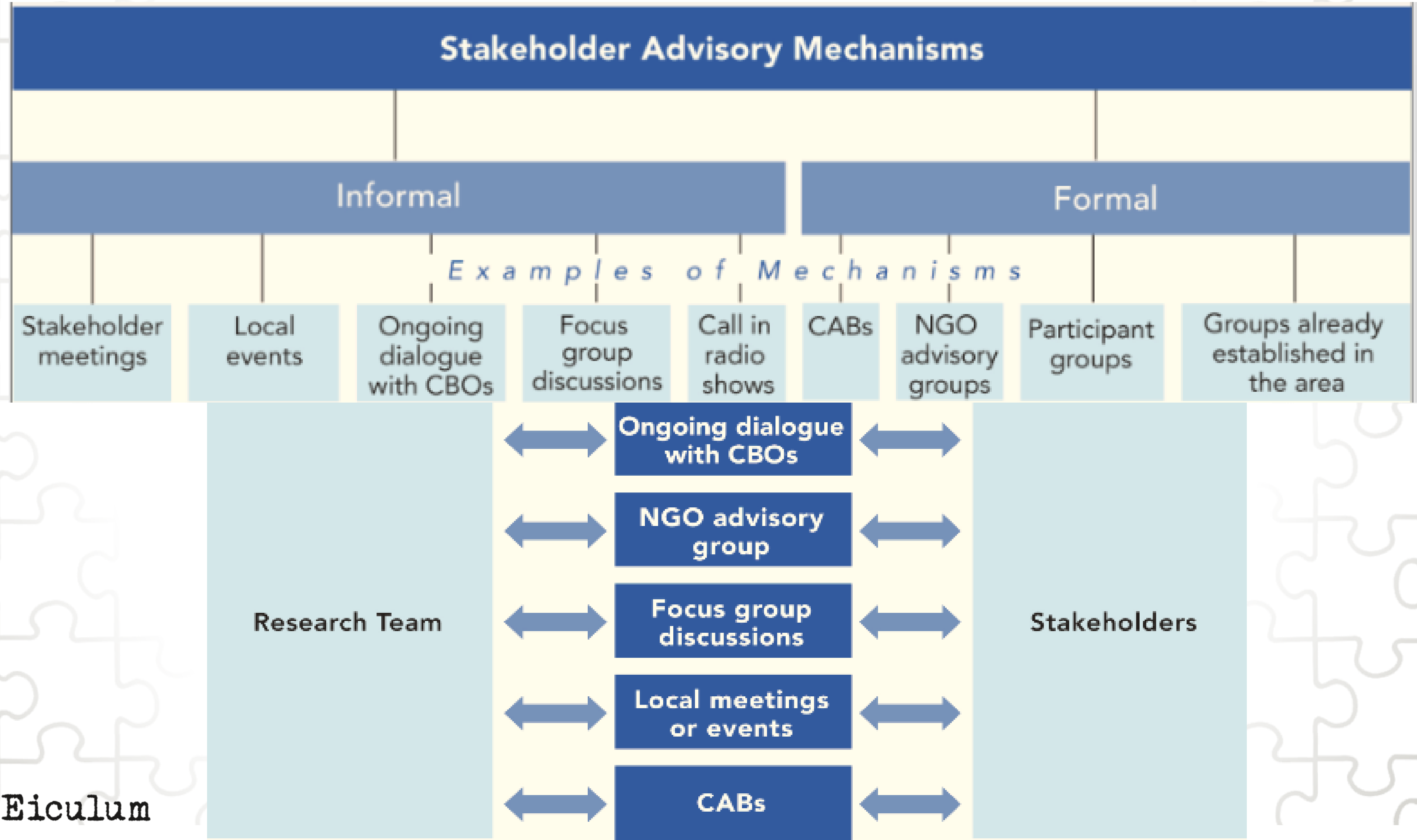
How Do We Engage?



Stakeholder Advisory Mechanisms

Informal

Formal

Examples of Mechanisms

- Stakeholder meetings
- Local events
- Ongoing dialogue with CBOs
- Focus group discussions
- Call in radio shows
- CABs
- NGO advisory groups
- Participant groups
- Groups already established in the area

Research Team ↔ Ongoing dialogue with CBOs ↔ Stakeholders

Research Team ↔ NGO advisory group ↔ Stakeholders

Research Team ↔ Focus group discussions ↔ Stakeholders

Research Team ↔ Local meetings or events ↔ Stakeholders

Research Team ↔ CABs ↔ Stakeholders

Understanding how community engagement with research works

Research Engagement activities

Meet, Talk, Discuss

Interactions

Show respect, wide consultation, listen, understand each other

When this goes well

Exchange of understandings in regular meaningful interactions increases sense of **being heard and respected** and **builds trust**

Wide consultation builds **acceptance of research as having social value** and a sense that it responds to community needs and concerns

Responsiveness of research process increases **motivation to engage**

Meaningful involvement increases **community ‘buy-in’,** willingness to participate in the research, and sense that it is partly theirs

Leads to

Address community concerns

Community support for and participation in research

Better, more relevant research

Research contributes to better health in future

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Adhikari B et al. A Realist View of Community Engagement with Health Research. *Wellcome Open Research* 2019; 4:87.

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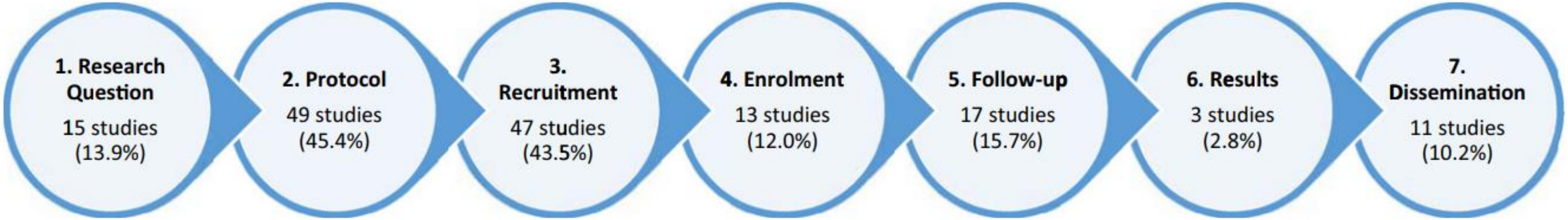
Engagement Throughout Entire Study Cycle

Day S et al. *Journal of the International AIDS Society* 2018, **21**(S7):e25174
http://onlinelibrary.wiley.com/doi/10.1002/jia2.25174/full | https://doi.org/10.1002/jia2.25174



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%)

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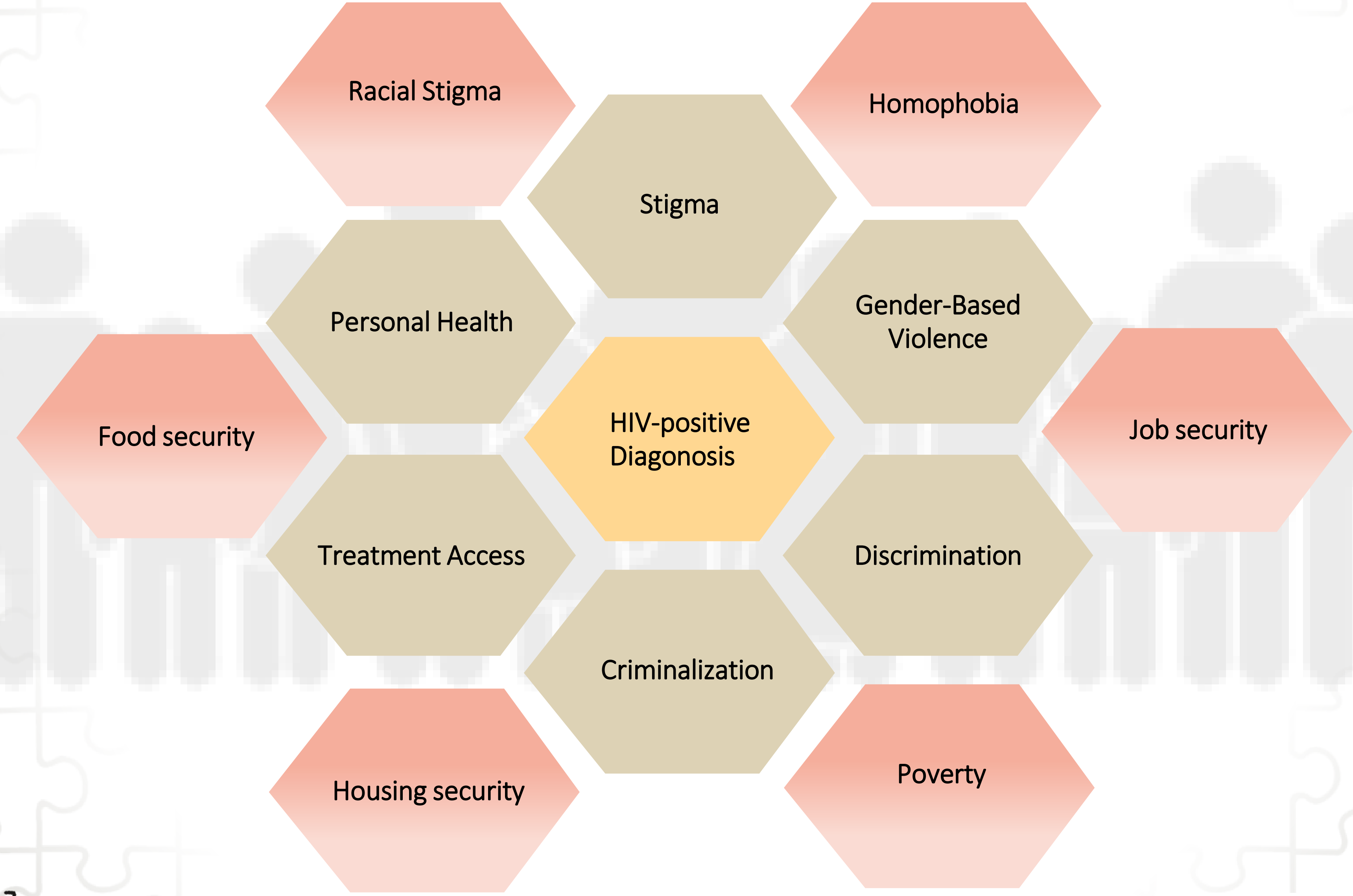
Day S et al. Stakeholder Engagement to Inform HIV Clinical Trials: A Systematic Review of the Evidence. *JIAS* 2018; 21(S7): e25174.

Why is Engagement Important?

Landscape of Engagement



Racial Stigma

Homophobia

Stigma

Personal Health

Gender-Based Violence

Food security

HIV-positive Diagonosis

Job security

Treatment Access

Discrimination

Criminalization

Housing security

Poverty

Adopted from Joe Amon

Research in the Age of **Fast Media**

- Headlines aren’t always accurate
- Potential to spread rumors
- Potential to erode trust

> *“Cure for HIV possible within three years as scientists snip virus from cells”*
>
> *-Telegraph, 2016*

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Engagement in HIV Cure-Related Research

Engagement in HIV Cure-Related Research

- **Education and transparency** are key goals that stakeholder advisory mechanisms must strive to incorporate
- Critical that all stakeholders, **including health care providers**, understand how early phase cure related research can benefit future populations
- **Developing comprehensive engagement plans** that reflect sociocultural norms and stakeholder needs are crucial to advancing research aims

Formative Research Activities

Allows the research team to understand:

- Informed understanding of local populations
- Socio-cultural norms
- Local power dynamics
- Local perceptions
- Channels of communication
- Site selection

Stakeholder Engagement Plan

- **Communication component**
  - Policies and strategies to increase broad awareness of the trial and facilitate accurate dissemination of research

- **Education component**
  - Key to building research literacy and empowering community stakeholders as decision-making agents

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Policies on Trial-Related Harm

How research teams will treat and compensate trial participants

- **Physical harms**: include any negative physical event
- **Social harms**: non-medical consequences such as
  - Social isolation
  - Stigma or discrimination
  - Employment or housing loss
  - Difficulties in personal relationships

Why is Stakeholder Engagement Important?

Four Common (MIS)CONCEPTIONS in HIV Cure-Related Research

1. **Community engagement is not recruitment for clinical research.**

2. Community engagement and community advisory boards serve related but different purposes.

3. Community engagement and education is not merely community service.

4. Community engagement.
is not research or ethics.

ENGAGEMENT IS...

the creation of relationships

individuals & groups

local, national & international

ALIGN INTERESTS → **CO-CREATION**

FOLLOWING THESE PRINCIPLES:

RESPECT

MUTUAL UNDERSTANDING

INTEGRITY

Good participatory practice
guidelines for
biomedical HIV prevention trials
2011

UNAIDS

AVAC

www.avac.org/gpp

TRANSPARENCY

ACCOUNTABILITY

AUTONOMY

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community engagement

Community & Patient Engagement

- Creation of relationships
- Management of expectations
- Sharing of information
- Meaningful dialogue
- Mutual literacy and understanding

Community Advisory Boards

- Input into research process
- Sounding board
- Protocol or research review
- Critical safeguard in research process

Recruitment for Clinical Research

- Populations of interest
- Eligibility screening
- Enrollment in clinical research
- Meaningful dialogue

Research

- Systematic work
- Generalizable knowledge
- Research methods
- Informed consent

Trust, Mutual Respect, Transparency, Autonomy

CUREiculum

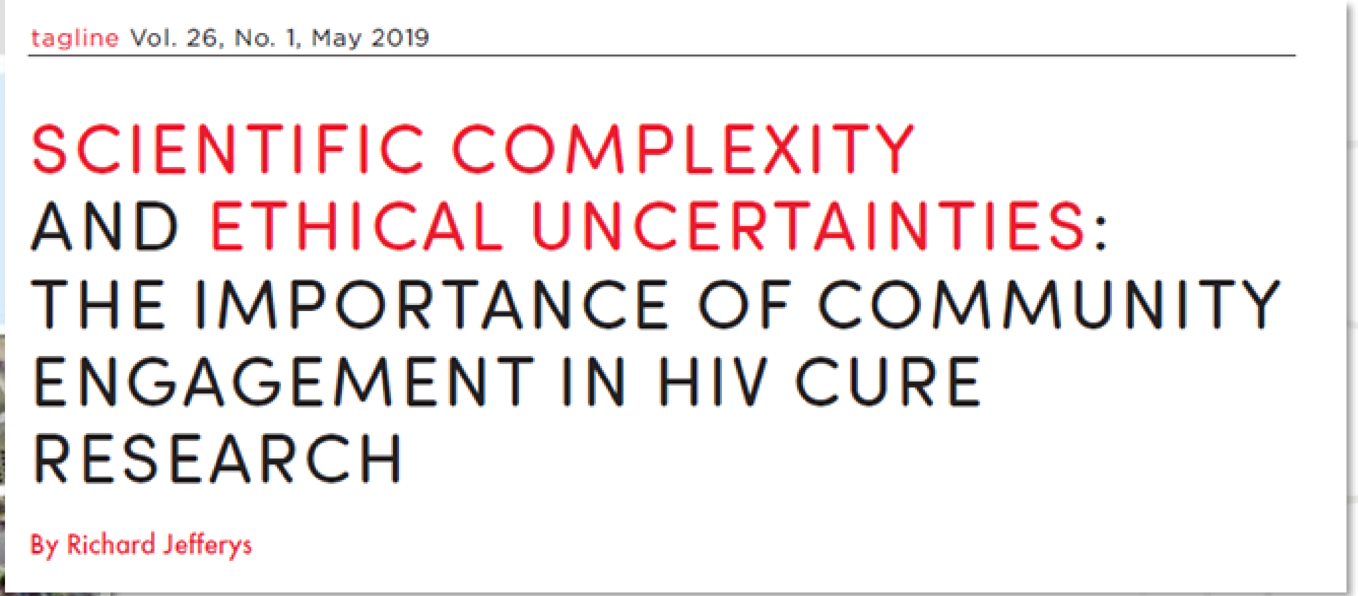
Credit: Karine Dubé

The Need for Consensus on Best Practices for Community and Stakeholder Engagement in Early-Phase (HIV Cure) Research

Good participatory practice
guidelines for biomedical HIV prevention trials

UNAIDS

AVAC



tagline Vol. 26, No. 1, May 2019

SCIENTIFIC COMPLEXITY AND ETHICAL UNCERTAINTIES: THE IMPORTANCE OF COMMUNITY ENGAGEMENT IN HIV CURE RESEARCH

By Richard Jefferys

community engagement

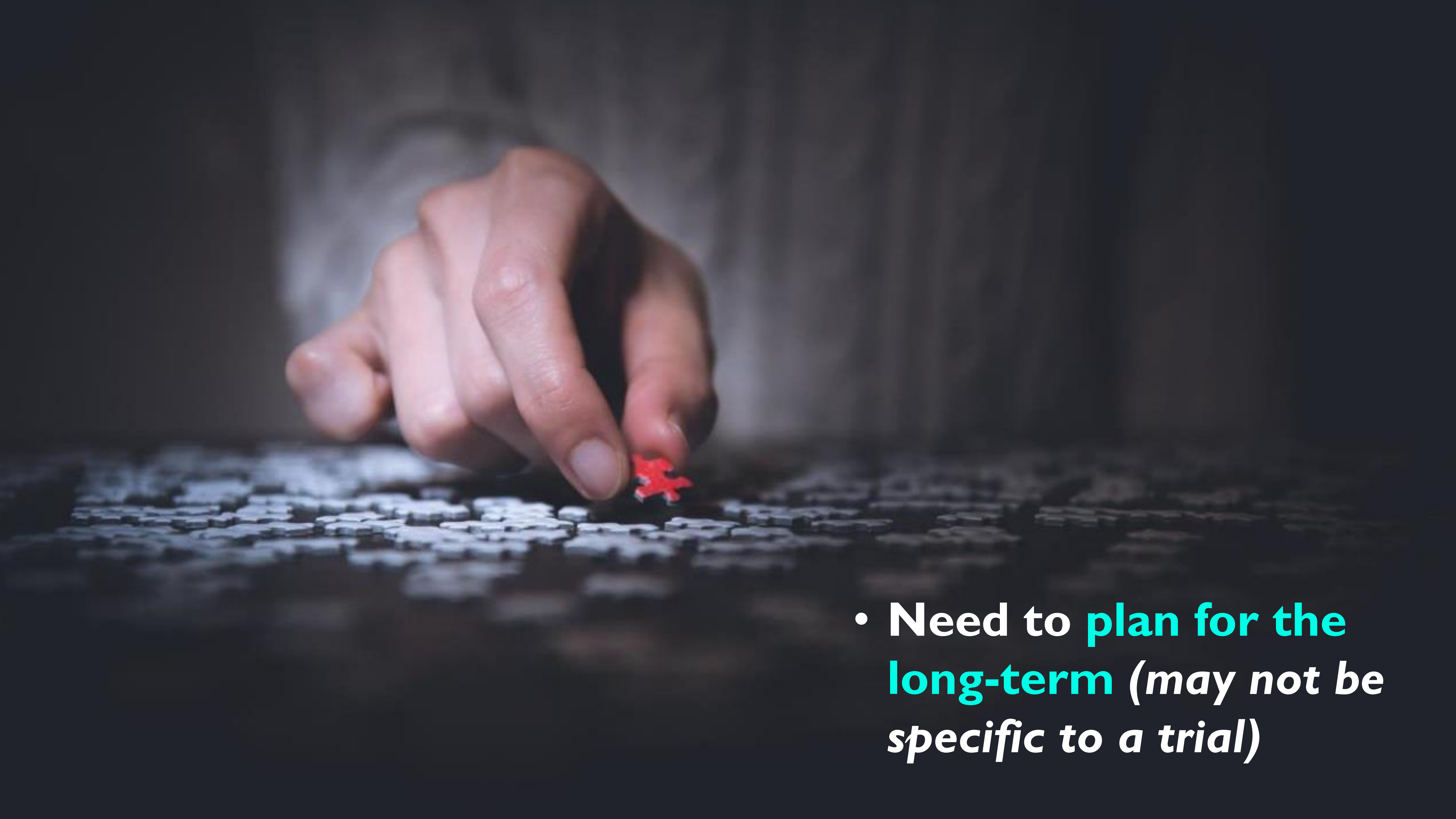
What should community & stakeholder engagement look like in the context of early-phase, basic and translational HIV cure research?

- May need deliberative process to define best practices

- **Need practical, applied model for engagement**

- **Make people living with HIV and community feel comfortable giving input**

- May also mean **building capacity of researchers** to value community input



- **Need to plan for the long-term** *(may not be specific to a trial)*

The Paramount Importance of Community-Friendly Information

The Paramount Importance of Community-Friendly Information

- **Need to invest in community scientific literacy and in scientific literacy around community concerns**

The Paramount Importance of Community-Friendly Information

- Pay attention to language choice

The Paramount Importance of Community-Friendly Information

- **Engage former study participants**, as this can be a powerful way to share information about studies and build trust

Lessons from U = U

The Research:	**HPTN 052**
The Implementation:	**Treatment as Prevention**
The Translation:	**U = U**
The Policy:	**End the Epidemic (U.S.), 95 95 95**

Credit: Dazon Dixon Diallo, SisterLove, Inc.

Minority Participation in Clinical Research

Dialogues on
Diversifying
Clinical Trials

Successful Strategies for Engaging Women and
Minorities in Clinical Trials

Whites account for 66.9% of the total U.S. population, but make up 83.3% of trial participants.[32]

Between 1985 and 2008, the percentage of AIDS cases increased in African-Americans by 30%.[26]

"How do we know that research that's primarily done on young, White, healthy males can be extrapolated to women?"

Phyllis Greenberger,
President and CEO of the
Society for Women's Health
Research

65-80% of African-Americans and Hispanics would be willing to provide essential biological samples such as blood and DNA.[28]

Minority patients more often seek care from physicians of their own race.[37]

Finding a Clinical Research Study

ClinicalTrials.gov is a database of privately and publicly funded clinical studies conducted around the world.

Explore 365,419 research studies in all 50 states and in 219 countries.

See listed clinical studies related to the coronavirus disease (COVID-19)

ClinicalTrials.gov is a resource provided by the U.S. National Library of Medicine.

Find a study (all fields optional)

Status
○ Recruiting and not yet recruiting studies
● All studies

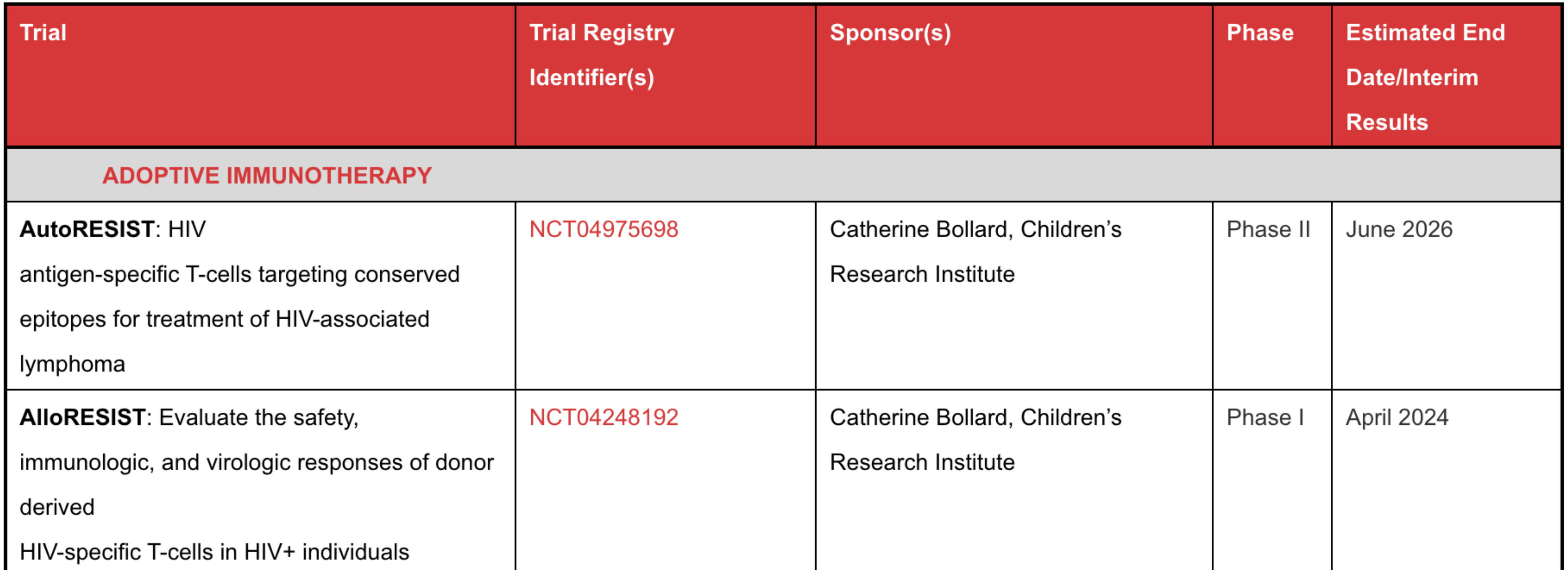
Condition or disease (For example: breast cancer)

community engagement

Finding a Clinical Research Study

Treatment Action Group

TAG's **Research Towards a Cure** webpage: https://www.treatmentactiongroup.org/cure/trials/



Trial	Trial Registry Identifier(s)	Sponsor(s)	Phase	Estimated End Date/Interim Results
ADOPTIVE IMMUNOTHERAPY				
AutoRESIST: HIV antigen-specific T-cells targeting conserved epitopes for treatment of HIV-associated lymphoma	NCT04975698	Catherine Bollard, Children's Research Institute	Phase II	June 2026
AlloRESIST: Evaluate the safety, immunologic, and virologic responses of donor derived HIV-specific T-cells in HIV+ individuals	NCT04248192	Catherine Bollard, Children's Research Institute	Phase I	April 2024

Finding a Clinical Research Study

The ACTG conducts offers a wide range of studies for people with HIV: https://actgnetwork.org/studies/

AIDS CLINICAL TRIALS GROUP

Questions?

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ACKNOWLEDGMENTS

AIDS treatment
ATAC
activists coalition

AIDS ACTION BALTIMORE

MARTIN DELANEY COLLABORATORIES
COMMUNITY ADVISORY BOARD

TAG
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Their caring support of the CUREiculum 2.0. will make a difference in the lives of thousands. of people living with HIV

We would like to thank **Jessica Salzwedel (AVAC)** for contributions to developing the initial CUREiculum module on community and stakeholder engagement.

community engagement

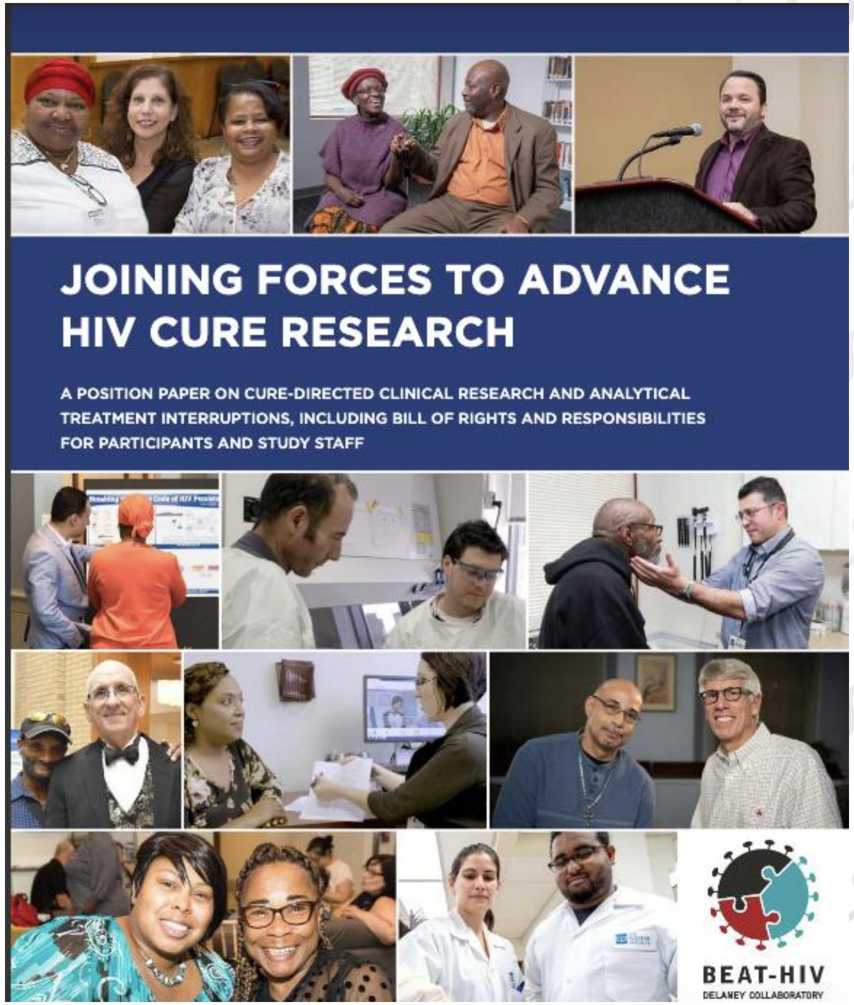
Examples and Ideas

Publications

BEAT-HIV CAB POSITION PAPER

The product of a partnership among the BEAT-HIV Community Advisory Board (CAB), BEAT-HIV principal investigators, clinical researchers, and pioneering community health center Philadelphia FIGHT, this paper is written with the community in mind.

It's meant to clarify and demystify HIV cure-directed studies, especially those that employ an analytical treatment interruption (ATI).



JOINING FORCES TO ADVANCE HIV CURE RESEARCH

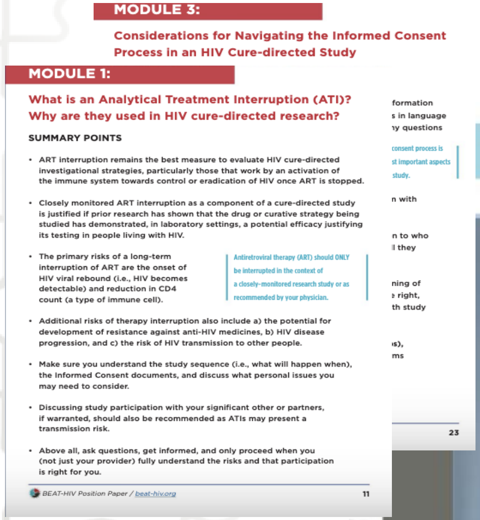
A POSITION PAPER ON CURE-DIRECTED CLINICAL RESEARCH AND ANALYTICAL TREATMENT INTERRUPTIONS, INCLUDING BILL OF RIGHTS AND RESPONSIBILITIES FOR PARTICIPANTS AND STUDY STAFF

BEAT-HIV
DELANEY COLLABORATORY

DOWNLOAD THE PAPER: https://beat-hiv.org/ati-position-paper/

BEAT-HIV CAB POSITION PAPER

They took a **"trauma-informed approach"** in developing this paper, because many people living with HIV are impacted by lifetime individual- and community-level trauma.



MODULE 3:

Considerations for Navigating the Informed Consent Process in an HIV Cure-directed Study

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MODULE 1:

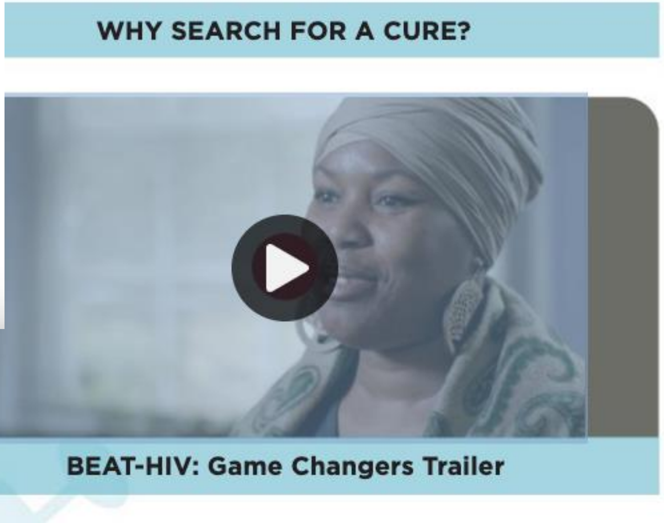
What is an Analytical Treatment Interruption (ATI)? Why are they used in HIV cure-directed research?

SUMMARY POINTS

- ART interruption remains the best measure to evaluate HIV cure-directed investigational strategies, particularly those that work by an activation of the immune system towards control or eradication of HIV once ART is stopped.
- Closely monitored ART interruption as a component of a cure-directed study is justified if prior research has shown that the drug or curative strategy being studied has demonstrated, in laboratory settings, a potential efficacy justifying its testing in people living with HIV.
- The primary risks of a long-term interruption of ART are the onset of HIV viral rebound (i.e., HIV becomes detectable) and reduction in CD4 count (a type of immune cell).
- Additional risks of therapy interruption also include a) the potential for development of resistance against anti-HIV medicines, b) HIV disease progression, and c) the risk of HIV transmission to other people.
- Make sure you understand the study sequence (i.e., what will happen when), the Informed Consent documents, and discuss what personal issues you may need to consider.
- Discussing study participation with your significant other or partners, if warranted, should also be recommended as ATIs may present a transmission risk.
- Above all, ask questions, get informed, and only proceed when you (not just your provider) fully understand the risks and that participation is right for you.

> Antiretroviral therapy (ART) should ONLY be interrupted in the context of a closely-monitored research study or as recommended by your physician.

BEAT-HIV Position Paper / beat-hiv.org 11



The paper contains five **educational modules** with linked videos featuring community members and researchers.

community engagement

To advance **research literacy**, you must engage potential **study participants** and **their communities**, **HIV researchers**, **healthcare providers**, **funding agencies**, and others looking to support HIV cure research.

BEAT-HIV
DELANEY COLLABORATORY

THE BEAT-HIV POSITION PAPER'S TOP TEN POINTS

1. Participation in a clinical study takes time and commitment. It is very important for potential participants to understand the time required for study visits and procedures and the length of the study. Joining a clinical trial may affect a participant's life schedule and may impact their relationship(s) or family, so it is important that when considering whether to join an HIV-cure directed study, potential participants discuss their decision with family and friends and their health care providers.
2. Both sex and gender matter in HIV cure-directed research. Study participant distribution must be sex and gender balanced, and data to be collected must address relevant emotional and social factors.
3. There are multiple barriers women face when participating in research, including competing life demands, i.e. scheduling, childcare, transportation, and access to information about HIV cure-directed clinical trials. Researchers should take these barriers into consideration as they design studies to facilitate the inclusion of women and meet women where they are in their lives.
4. Inclusion of cis- and trans-gender women is imperative for HIV-cure research so that when a cure is found, it will be both accessible and affirming for all people.
5. The informed consent process is one of the most important aspects of any clinical study. The informed consent process provides information about a research study, explains participants' rights and responsibilities in plain language, provides the space to raise any and all questions that potential participants may have about the study. The informed consent form should also clearly state that you participate only because you want to and that you are free to leave the study at any time.
6. Potential clinical study participants should understand that if they consent to enroll in a cure-directed study, the hope and the expectation is that they will be able to complete the study. However, this does not mean that they give up their right to stop participating in the study at any time without any consequences. Their ongoing participation in any clinical study is completely voluntary.
7. When reviewing the informed consent form, potential participants should pay special attention to who is sponsoring the study, what potential side effects could be expected and how those side effects will be addressed.
8. Analytic treatment interruption (ATI) is a closely monitored pause of antiretroviral therapy as part of a research study. The purpose of the pause in treatment is to determine the effect of the intervention on viral load compared to standard antiretroviral therapy.
9. ATIs remain the best way to evaluate HIV cure-directed strategies, particularly those that work with the immune system.
10. Any interruption of therapy may result in viral rebound, which must be carefully monitored. Viral rebound also carries risks of HIV transmission. Be sure to know how to protect your partner(s) and what laws cover the sexual transmission of HIV in the localities where you have sex. Remember study staff are there to help you answer any questions you have.

BEAT-HIV Position Paper / beat-hiv.org 3

community engagement

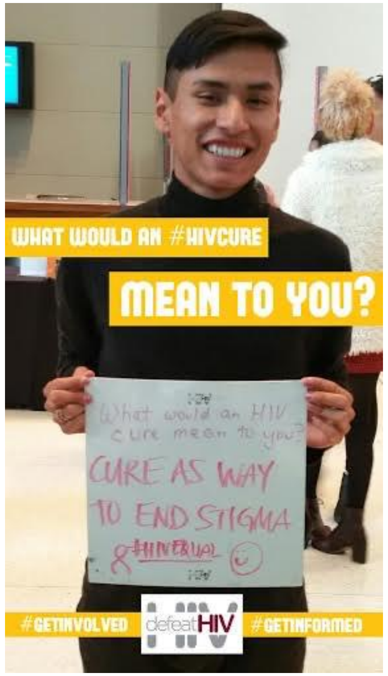
Amplify community voices

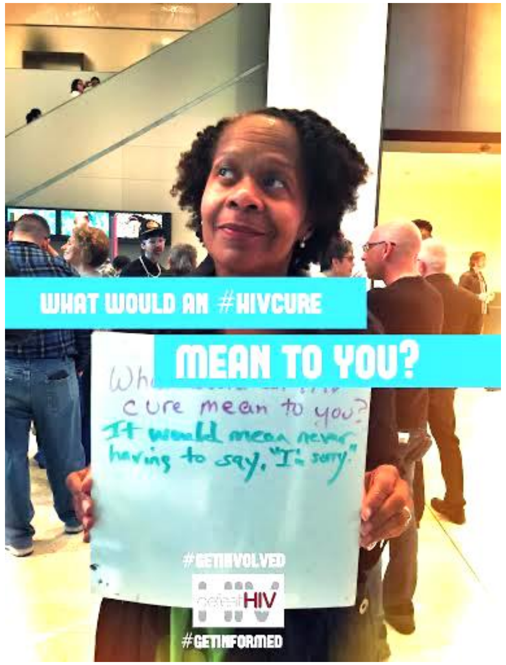
AMPLIFY THE VOICES IN YOUR COMMUNITY

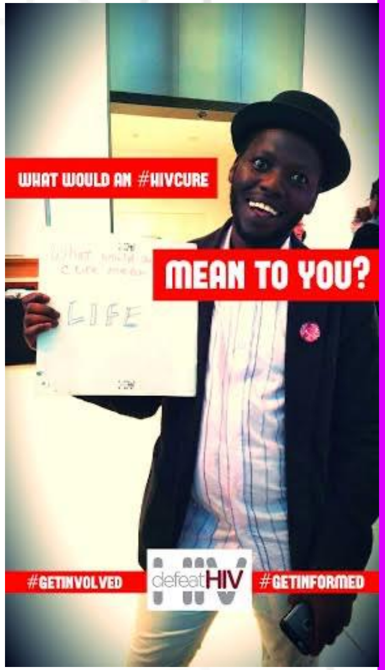
Create activities that allow people to express their thoughts about an HIV cure.

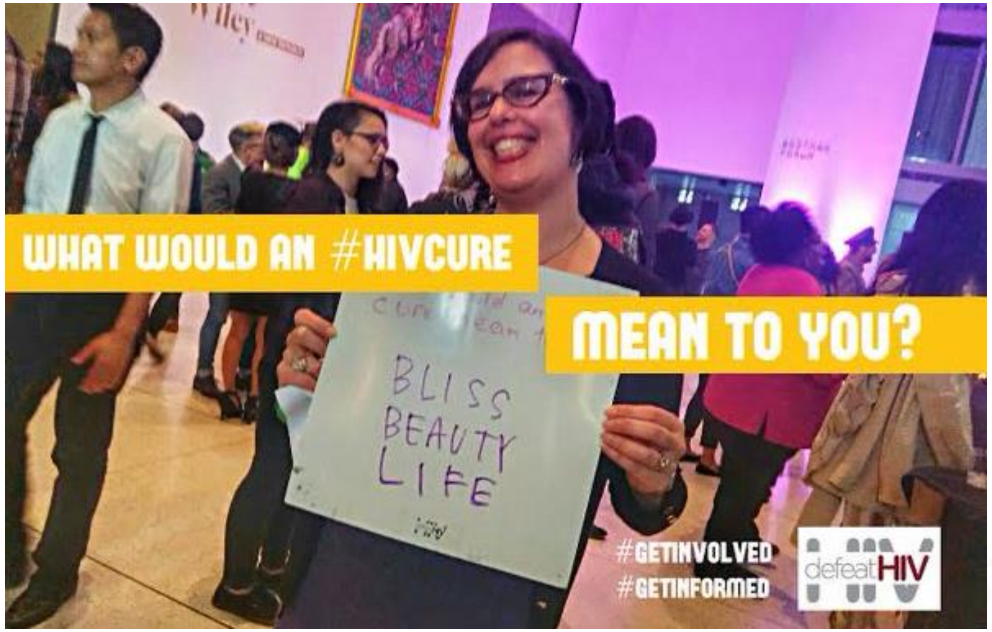
- collect anonymously
- or feature the person as well as what they say
- can be shared in many ways

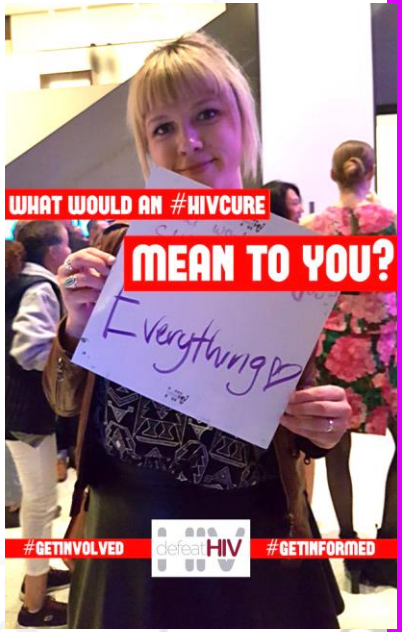
- newsletters
- emails
- websites
- social media
- posters
- abstracts
- magazines



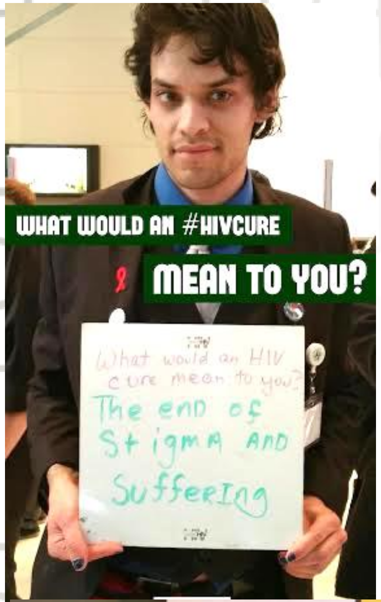


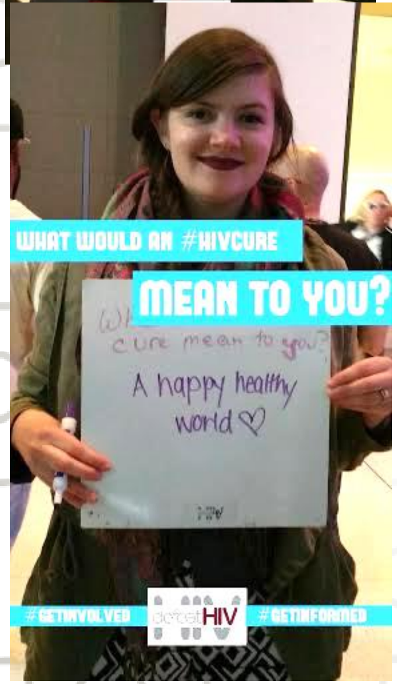


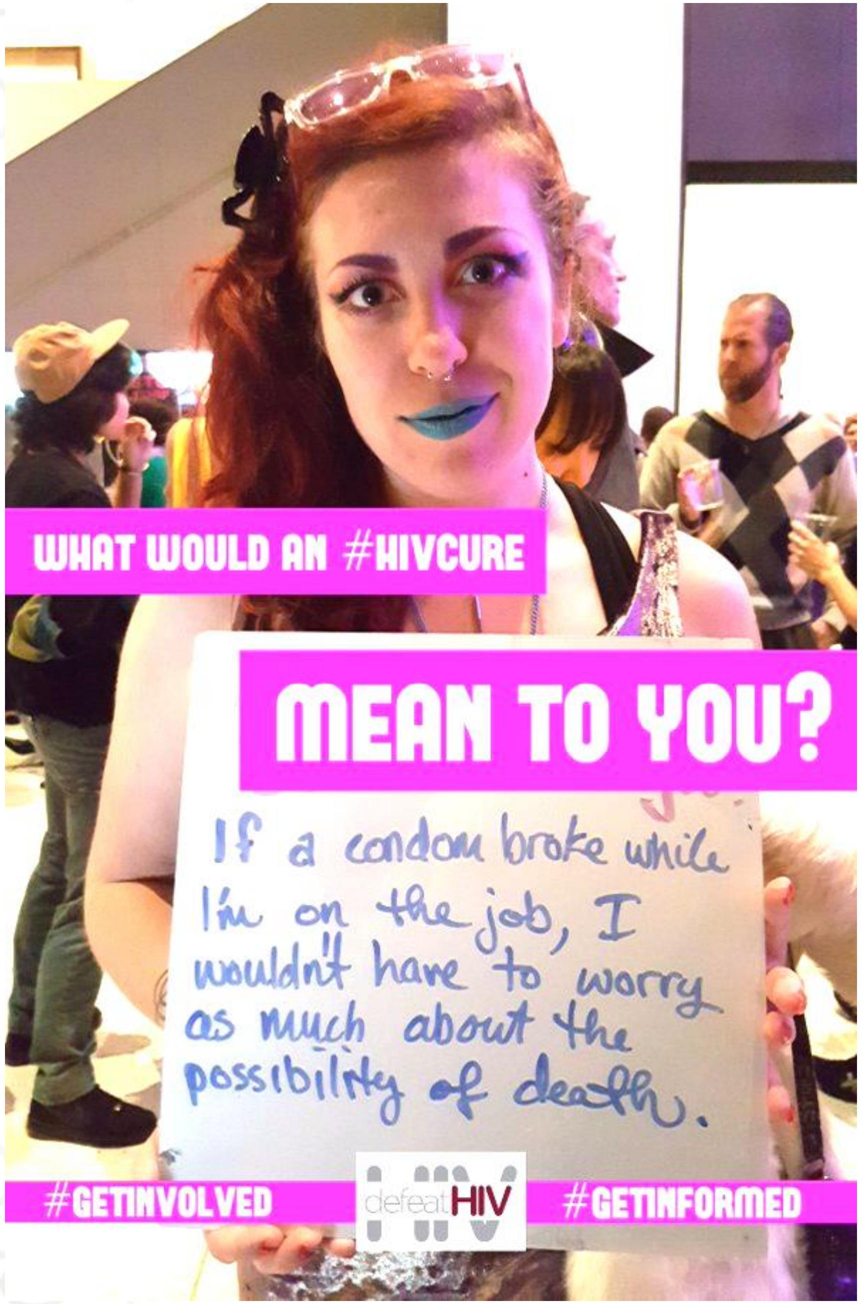


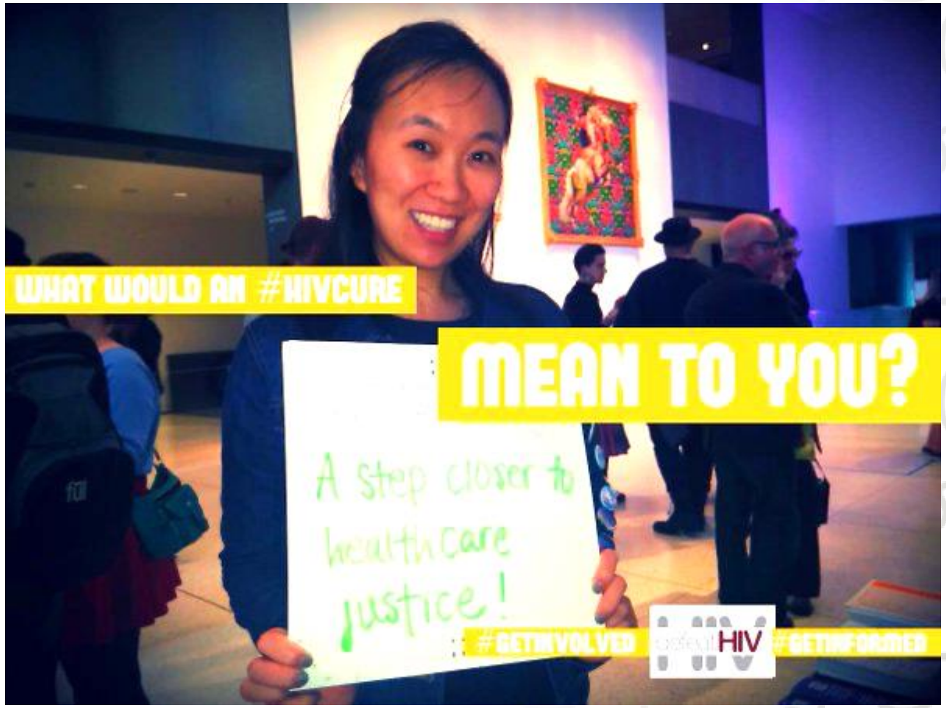


community engagement







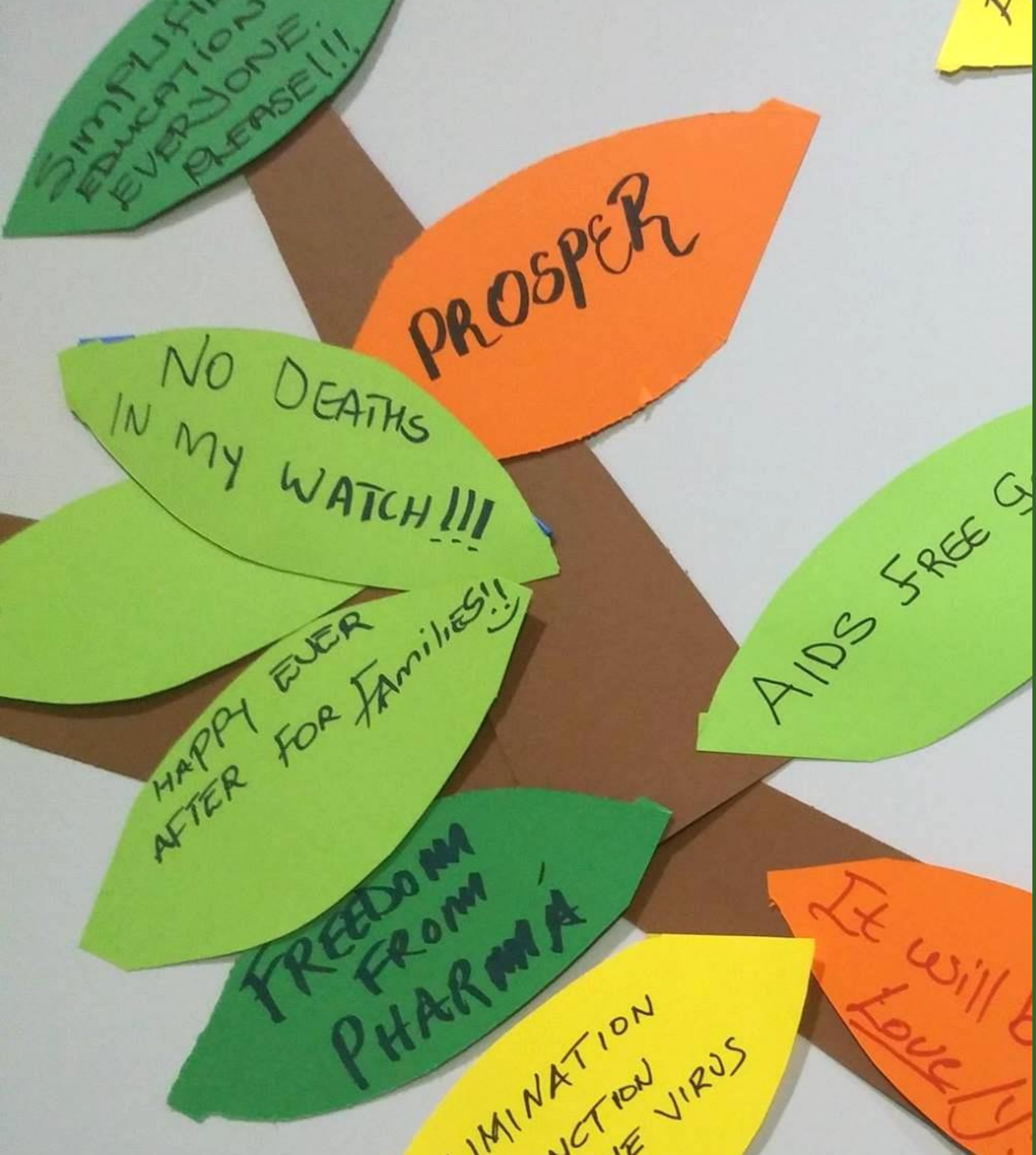


WHAT WOULD AN HIV CURE MEAN TO YOU?

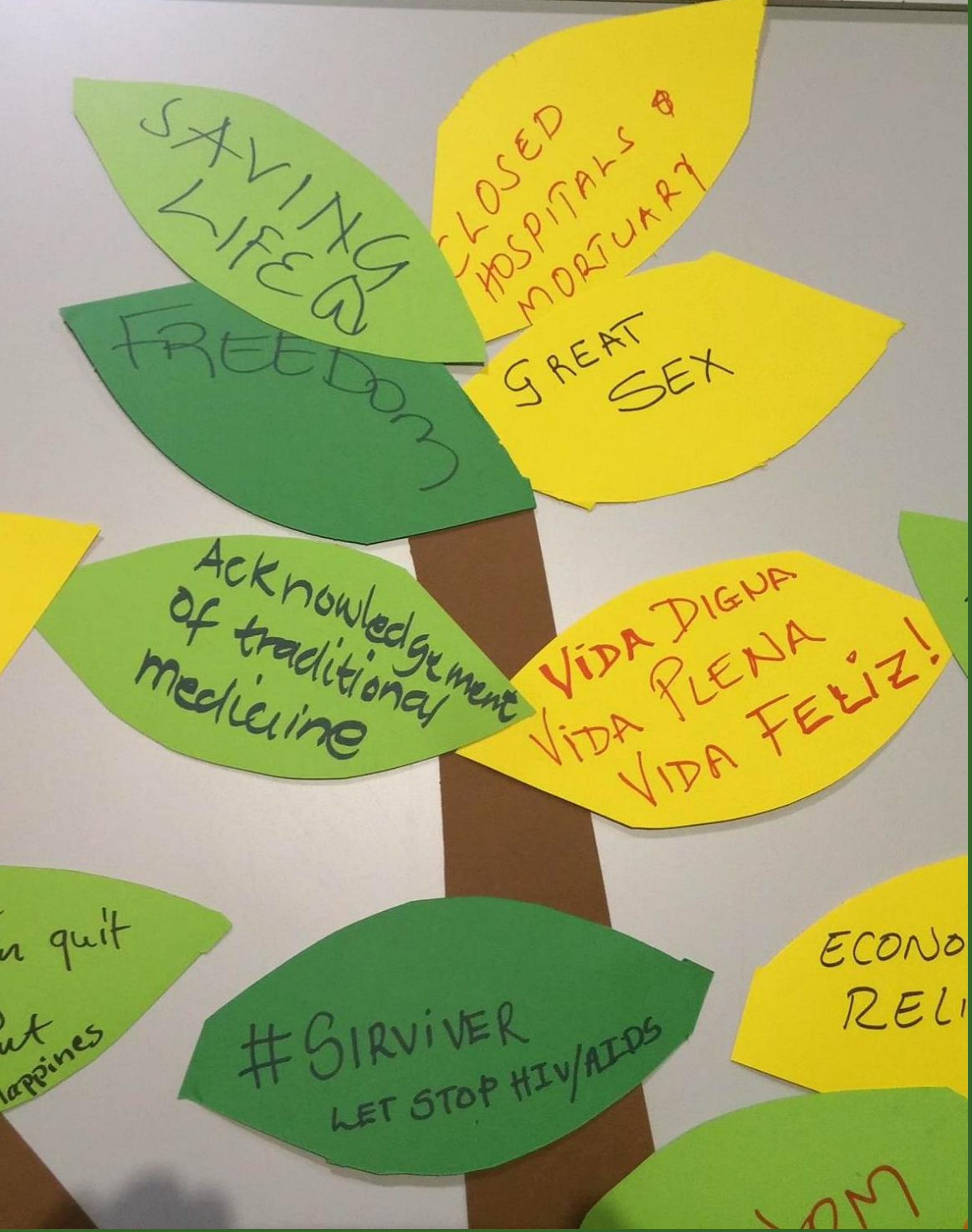
Volunteers from the Martin Delaney Collaboratories (MDC) Community Advisory Board (CAB) created an **“HIV Cure Tree”** at the 2016 IAS Conference Global Village in Durban, South Africa.

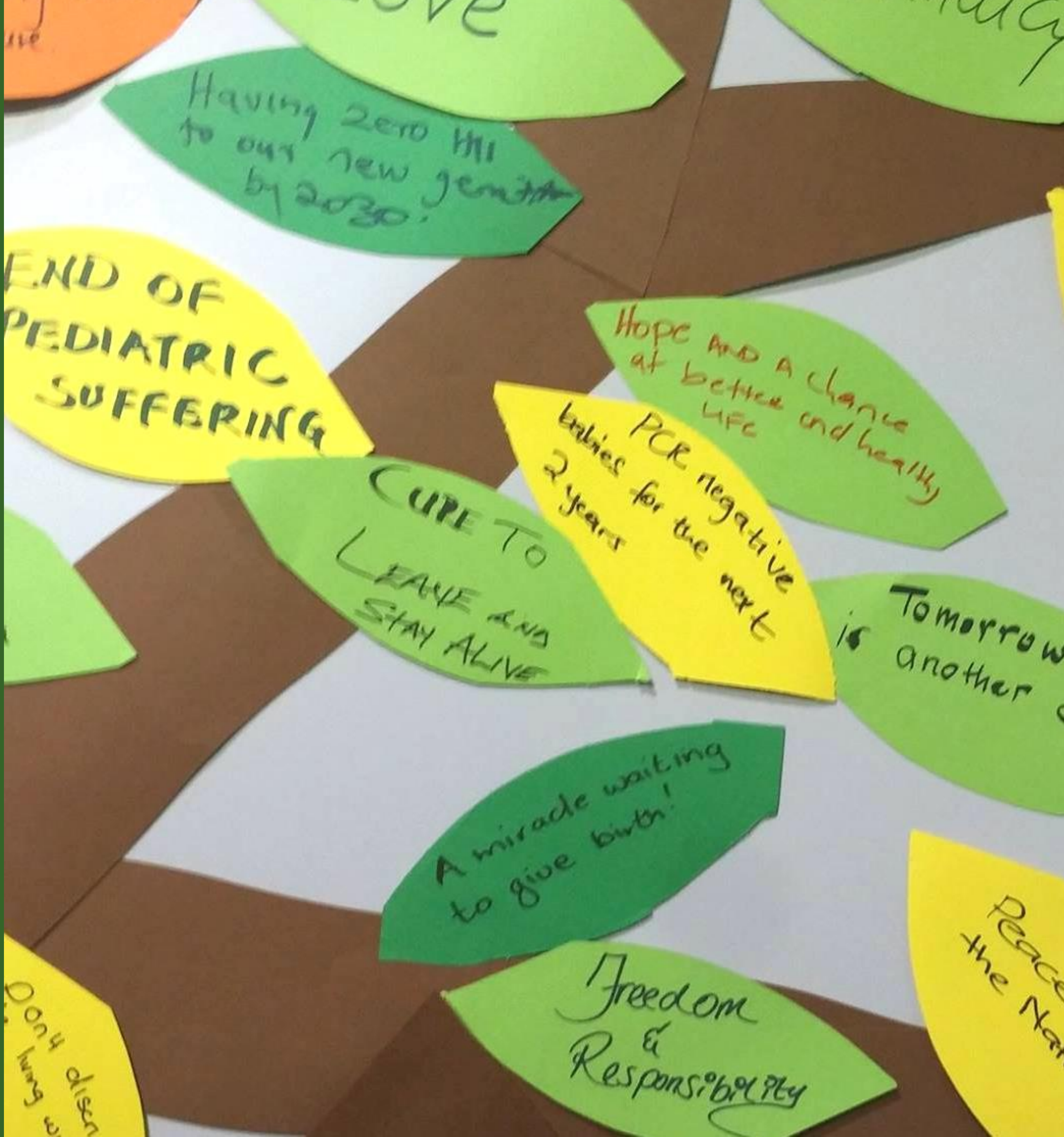
They asked Global Village attendees from around the world. to write on paper leaves their answers to the question, *“What would an HIV cure mean to you?”*

Respondents included clinicians, researchers, policy-makers, people with HIV, activists, and others.


SIMPLIFI EDUCATION EVERYONE PLEASE!!!
PROSPER
NO DEATHS IN MY WATCH!!!
AIDS FREE G
HAPPY EVER AFTER FOR FAMILIES!! :)
FREEDOM FROM PHARMA
MINATION NCTION E VIRUS
It will b Lovel


SIRVIVER LET STOP HIV/AIDS
FREEDOM
Beginning of Life
TO LIVE freely!!
IS H BEST THINK.
COMUMCATIO About STAT is the Best C
A Found Cure is the start of a new struggle to cure all access is needed
* Acce * stay No m
THERE is HOPE
A cure to me means never having to take meds again!
Accepting your


SAVING LIFE@
CLOSED HOSPITALS & MORTUARY
FREEDOM
GREAT SEX
Acknowledgement of traditional medicine
VIDA DIGNA VIDA PLENA VIDA FELIZ!
n quit
ut
appines
ECONO
RELI
#SIRVIVER LET STOP HIV/AIDS
OM


LOVE
Having zero HI to our new generation by 2030!
END OF PEDIATRIC SUFFERING
Hope and a chance at better and healthy life
PCR negative babies for the next 2 years
CURE TO LEAVE AND STAY ALIVE
Tomorrow is another
A miracle waiting to give birth!
Freedom & Responsibility
Peace the Na
Don't discr living w

What Would an HIV Cure Mean to You?
Ascribing Meaning Through an HIV Cure Tree

Laurie Sylla[1], Michael Louella[1], David Evans[2,3], Jeff Taylor[4], Richard Jefferys[5], Karine Dubé[6]

1 defeatHIV Community Advisory Board (CAB), Seattle, Washington; 2 Project Inform, Los Angeles, California; 3 Delaney AIDS Research Enterprise (DARE) CAB, Los Angeles, California; 4 Collaboratory of AIDS Researchers for Eradication (CARE) CAB, Palm Springs, CA; 5 Treatment Action Group, New York, NY; 6 UNC Chapel Hill, Chapel Hill, NC.

Background

Interest and investment in HIV cure research has been increasing since the apparent cure of Timothy Ray Brown 10 years ago through a bone marrow transplant from a donor homozygous for the CCR5-delta 32 mutation. While his experience has not yet been replicated and is still not fully understood, it spawned the burgeoning field of HIV cure research. An HIV cure holds the possibility of being transformative societally as well as medically. Little has been explored about the meaning and value individuals ascribe to a cure.

Methods

Volunteers from the national Community Advisory Board (CAB) of the Martin Delaney Collaboratory (MDC), a US National Institutes of Health initiative funding multiple HIV cure research collaboratories created an “HIV Cure Tree” at the 2016 IAS Conference Global Village in Durban, South Africa. MDC CAB volunteers asked a convenience sample of Global Village attendees from around the world to write on paper leaves their answers to the question, “What would an HIV Cure Mean to You?” Respondents included clinicians, researchers, people living with HIV, activists, and others. Upon return to the US, a demographically diverse group of members of the Seattle-based defeatHIV Community Advisory Board, an MDC local site, broke into small groups and engaged in a pile sort activity to group the leaves into themes.. This was supplemented by creation of a word cloud using the words from the leaves.

CHARACTERIZATION OF LEAF THEMES (n = 244); 2016

GROUP 1		GROUP 2		GROUP 3		GROUP 4		GROUP 5		GROUP 6	
Freedom	34	Hope	48	Freedom	47	Life/hope	64	Freedom	71	Social	91
Hope	16	Freedom	44	Hope	24	No more!	42	Life	71	Individual	90
Economics/Cost	14	Health	39	Life	23	Freedom	34	Future	65	Altruist future	34
Happiness/Fulfillment	14	Love	18	Cure	19	Treatment	26	???	33	Science	17
Stigma	14	Dedication	16	Removal of stigma	19	Stigma	22			Science process	7
Life	13	Relief	16	Optimism	17	Family	14			Altruist science	1
Relief	12	Peace	13	Prosperity	13	Intersectionality	14				
Victory	12	Misc	10	Future	11	Funding	9				
HIV/AIDS free	11	Research	9	???	10	Language	9				
Children	10	Educational	6	Happiness	9						
Future	10	Money	6	Societal benefit	9						
Unity	9	Fears	3	Determination	7						
End of Death	8			Family/Kids	7						
End of illness/suffering	8			Religious	6						
No more meds	7			Peace	5						
Peace	7			Pessimism	3						
Policy	7										
Prevention	6										
Time	6										
Faith/Values	5										
Love	4										
New beginnings	4										
Research	3										
Sex	2										

Results

We collected 244 leaves. The most dominant themes were freedom, hope and life. Themes related to peace, relief, stigma, happiness and the future were also significant, Examples of leaves related to freedom included freedom from the virus, freedom from stigma, freedom from medication, and freedom from worry.

Conclusions

People see an HIV cure as liberating for both individuals and societies. Many perceive it as the best route to ending stigma and a key element contributing to ending AIDS. Personal and social meanings connected to cure were of paramount importance to individuals. Cultural context contributes to the meanings people ascribe to a cure. There is significant global support for continuing to search for an HIV cure.

Acknowledgements

We would like to thank all the people who visited our booth in The Global Village at AIDS 2016. We also thank Moses Supercharger for giving us the seed of this idea to engage people around HIV cure research and David Palm for his help in our planning process. As well, we thank members of the Martin Delaney Collaboratories Community Advisory Board (CAB), including the members of the CABs for the Collaboratory of AIDS Researchers for Eradication (CARE), Delaney AIDS Research Enterprise (DARE) and defeatHIV.

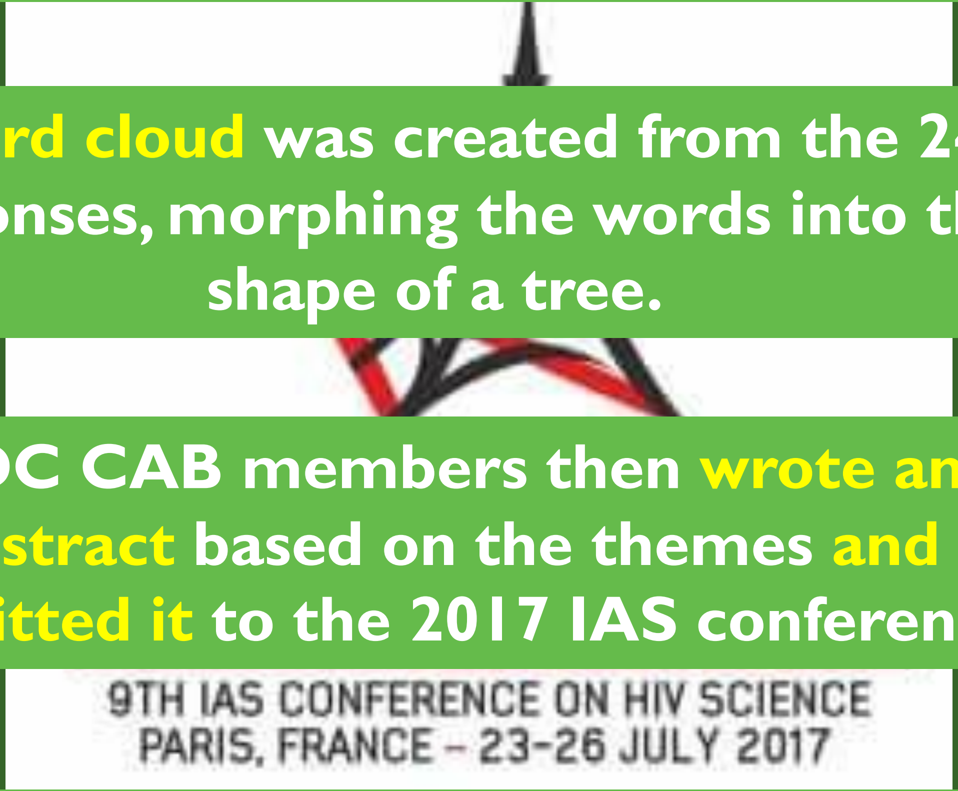
The authors would like to acknowledge funding support from NIH CARE: U19 AI096113 and UM1AI126619; DARE: U19 AI096109 and UM1 AI126611; and defeatHIV: U19 AI096111 and UM1 AI126623.

THE UNIVERSITY of NORTH CAROLINA at CHAPEL HILL MDC CAB HIV CARE Collaboratory of AIDS Researchers for Eradication DARE defeatHIV

Afterwards, members of the Seattle-based defeatHIV Community Advisory Board sorted the paper leaves into themes.

A **word cloud** was created from the 244 responses, morphing the words into the shape of a tree.

MDC CAB members then **wrote an abstract** based on the themes **and submitted it** to the 2017 IAS conference.



The abstract was accepted for poster presentation at the conference, and the word cloud was used as a central image.

community engagement

no virus
love
relief + love
life worth living!!
we would be out of work YAY!
it will be a great thing for me!!
freedom
my precious time with my children
human rights
saving life
extinction of the virus
well-being
hope
relief
equity
life
equality
love
behavior change
self acceptance
it can be prevented
is the best thing
my parents & brother
peace
no virus
increase employment rate
saving life
peace
health
a free generation
together we can fight HIV
AIDS free generation
hope for our children
death is finished
low flow of tears
everything I guess
we will be born again
bring HIV cure and
a world full of happy people
future
end to illness
a big relief as I take ARVs daily!!
no more pills!
excitement
it will mean so much for my kids
life no discrimination
liberation
saving lives
good future
paradise
success
sexual health
humanity restored
HIV no more
peace
tolerance
elimination
increase of economy
fewer orphans
no stigma
to be free in life
peace for all
it will be great
better life
so happiness
HIV free society
excitement
behavior change!!!
freedom
light
the end
no job
out of a job
equity
more hope
happy
funding
joyfulness
a fresh start
completed
normalcy
happiness
children who don't need to worry about becoming HIV-infected
AIDS free world
cure for all
fulfillment of my dreams!!
less co-morbidities
prosperity
higher economic growth rates
free from worry
integrity
happy families
hope
end AIDS forever
peaceful sleep
Lovely!!!!
end of suffering
stress free
closed hospitals & mortuaries
happy ever after for families!!
a future
Love
justice
live freely
end of stigma
no more criminals making $$$ selling fake cures
HIV cure end to travel restrictions
saving life
no more death
no deaths on my watch!!!
acknowledgement
benefits the life of person
there is hope
better care for children
no nightmares
mind free of HIV
survivor
goodbye pain and sickness
life
hope
a better future
only the beginning
better life
I can quit taking my treatment
no stigma
achievement
huge relief from a debilitating epidemic
would be peace & relax
more productive populations
the nation will benefit
morals
being happy with who you are
restart development for Africa
working together we can beat HIV/AIDS
economic relief
ability to love and be loved
we will praise and thank God
solidarity with all!
fulfilled lives without stigma
health
an optimistic way of living
prolonging life
no more loss of loved ones
satifaction
finished
no worries
prosper
the end of stigma
morals
restoration
freedom from pharma
acceptation
victory
freedom! hurray!!!!
great sex
I would be happy too much if we can cure HIV
not so special
no stigma
less stigma
living life without medicines coursing through our blood
free from stigma & discrimination
journey to long life
self love
happiness
liberation
ending of suffering
free country without HIV
better future
free from taking treatment
the future is certain
renew freedom
future
no more heartaches personal + professional
ecstatic
no fear
more lives saved
mental health
more research
prosperity
less dead!!
HIV free generation
second chance
no school yeah!
hope
relief
a better tomorrow
relief
stress-free life
freedom
prolong life expectancy

FREEDOM
LIBERATION
HOPE
NO FEAR
What Would an HIV Cure Mean to You?
Ascribing Meaning Through an HIV Cure Tree
DEATH HAS COME TO AN END
No stigma
love
freedom
hope
peace
freedom
life
hope
no stigma
morals
health
happiness
future
no fear
relief
AIDS FREE GENERATION
NO STIGMA
THERE IS HOPE


hope
freedom
peace
peace
life
hope
saving lives
equality
freedom from pills
love
tomorrow is another day
life
bright futures for my grand
liberation from donors with motives
together we can fight HIV
AIDS free generation
death is finished
low flow of tears
everything I guess
bring HIV cure and we will be born again
HIV free generation
no discrimination
hope for our children
future
a world full of happy people
life no discrimination
saving lives
end to illness
liberation
we will live long
peace to the nation
social justice
peace
a big relief as I take ARVs daily!!
no more pills!
AIDS free generation
it will mean so m
hard work pays off
lack of responsible behavior
good future
better life
a free generation
so happiness
faithfulness
behavior change!!!
death has come to an end
more lives saved
HIV free society
excitement
medicine that will totally end AIDS
a better tomorrow
the future is certain
achievement in research
light
the end
better future
completed
freedom to enjoy love making
normalcy
happiness
intersectional collaboration
end AIDS forever
funding
joyfulness
a fresh start
end of psychological suffering
access is needed
no job
out of a job
equity
more hope
happy
better life
children who don't need to worry a
AID
journey to long life
more years 2 live
AIDS free world
turning hope into reality
Love
justice
end of stigma
Lovely!!!!
end of suffering
stress free
closed hosptials & mortuaries
ARV treatment free of charge
peaceful sleep
protecting black life
a safer future for my kids
mind free of HIV
no nightmares
survivor
goodbye pain and sickness
freedom
no more death
no deaths on my watch!!!
benefits the life of person
acknowledgement
there is hope
better care for children
no more death
to get rid of stigma
a better future
only the beginning
I can quit taking my treatmen
no more criminals making $$$ selling fake cures
no stigma
coordinated efforts
huge relief from a debilitating epidemic
would be peace & relax
HIV free society
travel restrictions
morals
a healthier & positive world
py with who you are
development for Africa
together we can beat HIV/AIDS
more productive populations
the nation will benefit
no worries
prosper
freedom from pharma
I would be happy too much if we can cure
achievement
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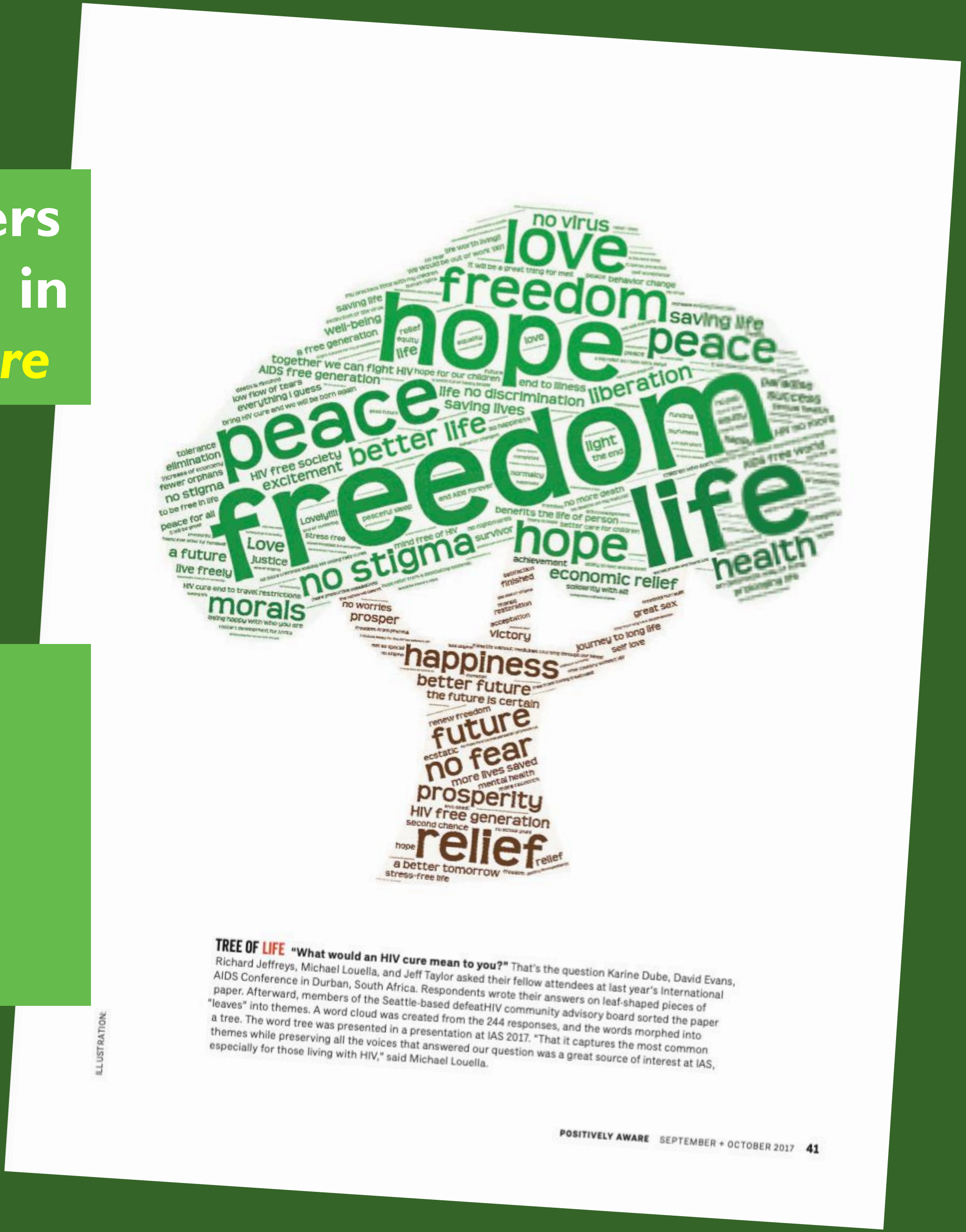
finished
the end of stigma
morals
restoration
acceptation
economic relief
victo
hope
prolonging life
ability to love and be loved
economic relief
solidarity with all!
fulfilled lives without stigma
we will praise and thank God
hea
an optimistic w
prolong
no more loss of
freedom! hurray!!!!
great sex
stigma & discrimination

After the conference, MDC CAB members submitted the word cloud for publication in the 2017 Sept-Oct issue of *Positively Aware*

The resulting article, "Tree of Life", appeared in print and online on Sep 6, 2017.

https://www.positivelyaware.com/articles/tree-life



TREE OF LIFE **"What would an HIV cure mean to you?"** That's the question Karine Dube, David Evans, Richard Jeffreys, Michael Louella, and Jeff Taylor asked their fellow attendees at last year's International AIDS Conference in Durban, South Africa. Respondents wrote their answers on leaf-shaped pieces of paper. Afterward, members of the Seattle-based defeatHIV community advisory board sorted the paper "leaves" into themes. A word cloud was created from the 244 responses, and the words morphed into a tree. The word tree was presented in a presentation at IAS 2017. "That it captures the most common themes while preserving all the voices that answered our question was a great source of interest at IAS, especially for those living with HIV," said Michael Louella.

ILLUSTRATION:

POSITIVELY AWARE SEPTEMBER + OCTOBER 2017 41

community engagement

Poster presentations

Barriers to HIV Cure Research Participation Among Persons Living With and Without HIV

THE GEORGE WASHINGTON UNIVERSITY
WASHINGTON, DC

Cheriko A. Boone, MSW, MPH[1,3]; Amanda D. Castel, MD, MPH[2]; A. Toni Young[3,4]; Eleanor Sarkodie, MPH[3,5]; Richard Strange[3]; Thomas J. Villa[3]; Nancy Caballero-Suarez, PhD[3,6], Evelyn Rodriguez-Estrada, MD[3,6]; Jon Fenech[3]; Daniel Barros, MPH[3,7]; Terry Howard, MScPPH[3]; Andre Ceranto[3]; Jane Kanyinda, MPH[2]; Manya Magnus, PhD, MPH[2]

[1]The George Washington University, Department of Psychology; [2]The George Washington University, Milken Institute School of Public Health; [3]Community Advisory Board (as of June 2019), BELIEVE Collaboratory for HIV Cure Research at Weill-Cornell Medicine; [4]Executive Director, Community Education Group [5]Whitman-Walker Health; [6]Centro de Investigación en Enfermedades Infecciosas (CIENI) - Instituto Nacional de Enfermedades Respiratorias (INER); [7]University of Sao Paulo

Milken Institute School of Public Health
THE GEORGE WASHINGTON UNIVERSITY

BACKGROUND

Functional and sterilizing HIV cures are on the horizon, with early trials of curative approaches underway. The majority of research on attitudes about HIV cure has focused on persons living with HIV (PLWH) and has not included HIV-negative persons, thereby limiting our understanding of other communities who may influence the willingness of PLWH to enroll in current and future safety or efficacy clinical trials. In order to inform clinical trial recruitment strategies, we sought to characterize knowledge, attitudes, and perceptions of HIV cure research among PLWH and HIV-negative individuals.

METHODS

- Data were collected from an anonymous online convenience sample of adults (N = 185) between 9/2017 and 7/2018.
- Correlates of barriers to study participation were examined using logistic regression.
- Factor analysis was used to construct a 7-item scale of HIV cure pessimism; and linear regression was used to assess predictors of HIV cure pessimism, stratified by HIV status.

RESULTS

While the perception of what an HIV cure meant and willingness to participate in invasive and/or high risk cure trials differed by HIV status, there were no differences (p<0.05) in what motivated willingness to participate (WTP).

Table 1: Characteristics of Survey Participants (N=185)	%
Age (median) [IQR]	(37) [28-49]
Self-identified male	55.9
Self-identified female	41.8
Self-identified transgender (female-to-male)	0.5
Self-identified other gender	2.7
Lives in East Coast, United States	41.8
Lives in Southern United States	9.9
Lives in Midwest, United States	6.6
Outside the United States	7.7
Living with HIV [44% > 20 years]	27.0
Family or friends living with HIV	32.4
Self-perceived risk for contracting HIV	14.0
Black/African American	24.3
College degree or higher	79.7

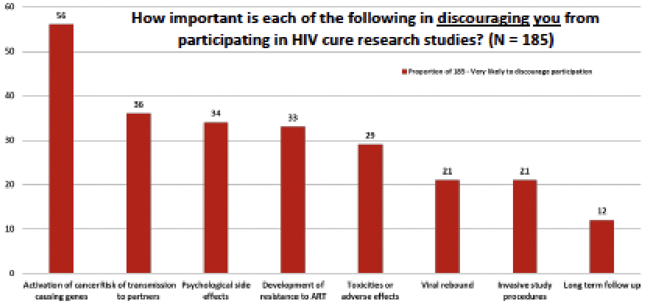
Table 2: Perceptions of HIV Cure Research and Eventual Cure Uptake | HIV Pessimism Scale (N = 185)

Survey Item	Strongly Agree/Agree		Strongly Disagree/Disagree	
Scale: 1 = Strongly Agree 2 = Agree 3 = Neutral/Not sure 4 = Disagree 5 = Strongly Disagree	HIV negative (n = 135) N (%)	HIV positive (n = 50) N (%)	HIV negative (n = 135) N (%)	HIV positive (n = 50) N (%)
Cost will prevent people from taking it*	101 (82.1)	39 (81.3)	14 (11.4)	1 (2.1)
The dangers of a new cure may be too high*	27 (22.0)	19 (39.6)	36 (29.3)	7 (14.6)
Current ARV is very good; we do not need a cure	7 (5.7)	4 (8.3)	102 (83.6)	38 (79.2)
If a cure were available for HIV, people will not use PrEP and other methods to stay HIV negative	32 (26.0)	15 (31.3)	66 (53.7)	19 (39.6)
More education is needed before HIV cure will be accepted by the community*	80 (65.0)	30 (63.8)	13 (10.6)	12 (25.5)
I do not think there will ever be a cure	10 (8.1)	5 (10.4)	89 (72.4)	29 (60.4)
A cure that would stop the need for all HIV treatment is desirable (reverse-coded)	114 (93.4)	44 (91.7)	3 (2.5)	1 (2.1)
I can trust my healthcare provider's decision on which medical treatments are best for me**	70 (57.4)	40 (83.3)	22 (18.0)	2 (4.2)
All things considered, I completely trust my healthcare provider***	54 (43.9) [Not sure: 39 (31.7)]	38 (79.2) [Not sure: 6 (12.5)]	30 (24.4)	4 (8.3)

Chi-square comparing strongly agree/agree vs not sure vs strongly disagree/disagree:
*p<0.05 **p<0.01 ***p<0.001
Bold items included in *HIV Cure Pessimism Scale (Cronbach's alpha = 0.59, standardized)*
For each %, denominator excludes missing responses and "neutral/not sure" responses

Negative perceptions of HIV cure differed significantly based on HIV status: HIV-negative respondents more likely to perceive cost (p<0.05) and lack of trust in healthcare providers (p<0.01) as barriers; and PLWH were more likely to perceive risks of treatment (p<0.05) and lack of community education as barriers (p<0.05) (see Table 2).

After adjusting for confounders, HIV-negative persons identifying as Black/Asian/multiracial/Latinx had higher HIV cure pessimism scores than persons who identified as White (p<0.05). Among PLWH, women had higher HIV cure pessimism scores than men (p<0.05).



CONCLUSIONS

- Understanding barriers to HIV cure research participation is critical as we develop novel curative therapies.
- Knowledge of barriers and facilitators of HIV cure research participation is essential to preemptively prepare for social and behavioral implications of eventual dissemination.
- Salient differences between PLWH and HIV-negative persons deserve consideration when developing strategies for recruitment and community engagement in cure research.

FUTURE DIRECTIONS

- Examine willingness to participate (WTP) in HIV cure-related research using the HIV Cure Pessimism Scale in conjunction with other validated instruments measuring **psychosocial correlates**, **barriers** and **facilitators** to research participation (e.g., Barriers to Research Participation Questionnaire, Kibler & Brisco, 2006).
- Ensure that ongoing research examines both HIV cure pessimism and WTP among populations that are often underrepresented in HIV cure-related research (e.g., women; racial/ethnic minorities; sexual & gender minorities; younger populations; older adults; long-term HIV survivors (all ages); persons with education level of high school diploma or less; persons living in rural areas, the Southern and Midwest United States; and international populations).
- Through quantitative and qualitative methods, assess attitudes toward analytical treatment interruption (ATI), including as they relate to WTP in HIV cure-related research.
- Future research, recruitment, and retention strategies may benefit from knowledge and best practices in the HIV prevention and HIV vaccine clinical trial arenas.

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community engagement

community engagement

The defeatHIV Community Advisory Board

OUR MISSION

To serve as a communication link and mobilize HIV cure researchers, their institutions and our communities to work together to cure HIV

OUR PRIORITIES

- **Social Justice** – inclusion, access, equity
- **Messaging** -- Being intentional and attentive to **language impact** regarding cure research
- **Aligning** researchers and community members to achieve research success
- Building **trusting relationships** with communities
- Developing **science/research literacy, development of skills** and **personal growth** among CAB members
- Creating **a diverse CAB** that ensures that input from people living with HIV is accounted for in all CAB decisions

Engaging Community

OUR EFFORTS

- Host **community forums** with HIV cure **research experts**
- Provide opportunities for community members to meet **Timothy Ray Brown**, the only person to be considered cured of HIV
- **Outreach at events** such as gay pride, AIDS fundraising events, health fairs, etc.
- **Outreach to targeted community groups** *we go to them*
- **Webinars** highlighting gene therapy and stem cell transplantation research
- Extensive use of **social media** for advertising and posting event recordings
- **Open door** invitation for community members to come to CAB meetings

Bringing Community to Cure

Laurie Sylla[1], Erick Seelbach[1], Arjun Jay Kumar[1], Thomas Andrus[2] and Michael Louella[1,2]

[1]defeatHIV Community Advisory Board [2]defeatHIV, Fred Hutchinson Cancer Research Center, Seattle, WA

Influencing Research

OUR MEMBERS

- Are **integrated members** of collaboratory **executive** and **scientific core** committees
- Provide **feedback to researchers** on study protocols, consents, recruitment and compensation policies
- Engage in **advocacy** on timely issues: materials transfer agreement (to obtain medications for animal studies); need for nonhuman primate research; appropriate funding for cure research; community involvement as required structural component of cure research collaboratories in new federal funding cycle
- Engage in **CAB self-education** – attend scientific meetings; bring speakers to CAB meetings to assure we are **informed advocates**
- Obtain corporate support for community members to attend scientific meetings
- Nurture and maintain a **valued partnership** between researchers and community

Acknowledgments

We would like to thank the members of the defeatHIV CAB, both past and present, who have taught us that nobody can do everything, but everyone can do something: Arjun Jay Kumar; Abe Gaston III; Bill Hall; Brandon Aguirre-Rendon; Erick Seelbach; Gavin Green; John Sigala; J.T Munny; J. Wong; Kellan Desper; Kim Louis; Kyon Saucier; Larry Pike; Laurie Sylla; Lindsay Saenz; Manuel Venegas; Michael Barnes; Michael Louella; Mitch Arnone; Paris Mullen; Robert Reinhard; Stephanie Deyo; Tranisha Arzah.

Results

OUR IMPACT

Reached **thousands of community members** with **accurate and responsible** cure information

FROM JULY 1, 2014 TO JUNE 30, 2015

56,597*

ENGAGEMENTS WITH HIV CURE RESEARCH

*ESTIMATED BY ATTENDANCE, FOLLOWERS, SUBSCRIBERS & AD PLACEMENTS

DUPLICATIONS ACROSS MEDIA FROM UNQIUE INDIVIDUALS NOT ACCOUNTED FOR IN THIS TALLY

IN THEIR WORDS….

> I must admit I dream of a cure too, so I'll always be here for my little girl. Who is 6 now, and I am 30 and terrified. I am sorry to speak like this, but I never talked to anyone that had the science and hope behind it…. You don't know me but I'm forever grateful for this day and your knowledge. Thanks again. - **Melissa M.**, *community member*

> Due to its commitment to welcoming as members local stakeholders as well as any person drawn by news about cure research happening in Seattle, the defeatHIV CAB proves time and again invaluable to our team, our institution and to their own communities, thereby helping everyone navigate new, unfamiliar territory to avoid misunderstandings, communicate effectively and, most importantly, to listen to each other.
>
> - **Keith R. Jerome, MD, PhD** and **Hans-Peter Kiem, MD**, *co-Principal Investigators, defeatHIV*

YOU DON'T HAVE TO WEAR A LAB COAT TO HELP US FIND A CURE FOR HIV

defeatHIV COMMUNITY ADVISORY BOARD

FRED HUTCH CURES START HERE

WE'RE SCARED…. AND BRAVE: Potential Trial Participant Expectations of HIV Cure Researchers

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1 defeatHIV Community Advisory Board; 2 Delaney AIDS Research Enterprise (DARE) CAB; 3 Collaboratory of AIDS Researchers for Eradication (CARE) CAB; 4 UNC Chapel Hill

Abstract

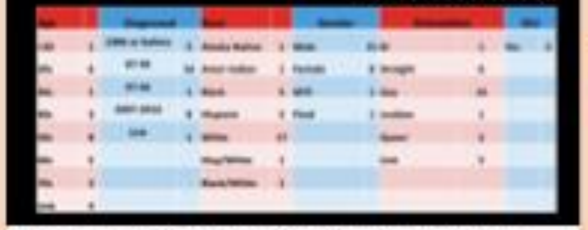
Background: Clinical studies exploring methodologies leading to a functional or an eradicating cure are a new field in HIV research, with unique physiological and psychological risks and potential benefits to participants. This study endeavored to learn about potential participants' motivations to participate in these studies, barriers to participation, perceptions of what an HIV cure would mean, and expectations related to participating in HIV cure research.

Methods: A cross-sectional survey of 400 HIV+ adults was conducted, followed up by nine focus groups in California, North Carolina and Seattle, Washington. Focus group discussions included questions specific to what individuals expected of HIV cure researchers and what they wanted researchers to know.

Results: These results are from a subset of questions from the four Seattle focus groups that included 31 participants. Participants wanted research teams to understand the psychological trauma experienced by many people living with HIV, particularly past and ongoing stigma, to be respectful of them as whole human beings, to "get them," to be honest and transparent about all study risks and procedures, to compensate them fairly, and to have study team members and visits available to them after hours. Participants also endorsed having someone with a mental health background as part of the study team. Non-white participants expressed desire for study teams to include members who were reflective of participants. Participants expressed significant concerns about risk to their health, study procedures, side effects, and lack of durability of a functional cure. Women had specific concerns related to reproductive health and the impact side effects might have on their responsibility to care for others. Some wanted researchers to be mindful that they were as essential to the research as the researchers.

Conclusions: Honest, respectful relationships between participants and researchers, with transparency, appropriate compensation, and safety planning will be necessary for recruiting and retaining cure trial participants. Taking participant concerns and expectations into account will contribute to the success of HIV cure research.

SEATTLE FOCUS GROUP DEMOGRAPHICS



As part of a larger study, four focus groups of people living with HIV were conducted in Seattle, WA, with a total of 31 participants. Separate groups were conducted for **women**, **long-term survivors** (20+ years), **Latino gay men**, and **young adults** (<30 years old.) Stigma interfered with recruitment for an intended **transgender women**'s group. The long-term survivor group was largest, resulting in half of our participants being over 50, and more than 2/3 diagnosed pre-HAART. Group focus impacted participant demographics, which are not a representative sample. IDU prevalence in Seattle/King County is <5%.

WHAT PARTICIPANTS SAID THEY EXPECT/WANT FROM HIV CURE RESEARCHERS

EXPERTISE/PROFESSIONALISM EXPECTATIONS

- Professional
- Scientifically competent
- Culturally aware/competent/reflective
- Trauma-Informed Care competence
- Researcher/institution reputation
- Knowledgeable
- Researcher stability
- Knowledgeable about hormones and their interplay

INFORMATIONAL EXPECTATIONS

- Full, thorough disclosure
  - Procedures, risks, benefits
  - What you do and don't know about potential risks
- Update participants on research progress
- How will you compensate me/my family (survivors) if something bad happens to me?
- "I want Spanish-speaking researchers who can explain everything in Spanish - not translated."

RELATIONAL/INTERACTIONAL EXPECTATIONS

- Treated with RESPECT
- Team members able to make participants feel comfortable
- Able to establish TRUST
- Make me feel comfortable
- Culturally sensitive
- Respect my time
- Take time with me
- Be patient, especially if I don't understand questions or treatments
- Be sensitive to impact of STIGMA
- EMPATHY
- I'd want someone who could help you, comfort you if something bad happened
- Someone should be available 24/7 - a live person
- They should talk to you in terms you understand
- They should be open and honest. Second informed consent

EXPECTATIONS RE: RESEARCHERS' VIEWS OF PARTICIPANTS

- See participants as unique, whole individuals
- Researchers should not be stigmatizing
- They should be thankful you're there
- They should understand what the community needs. They need to "get the community."

"They need to remember that they need us at least as much as we need them."

"WE'RE SCARED… AND BRAVE…."

It takes courage to participate in cure research. Participants want empathy. They want to feel seen, understood and respected. They want to be seen as partners in research.

"HOW MANY OF THEM HAVE BEEN RESEARCHED? NOT JUST DOING IT FOR OTHERS, BUT HOW MANY OF THEM HAVE BEEN DOING IT, HAVE BEEN IN RESEARCH?"

BE AWARE OF MENTAL HEALTH CONCERNS

- Baseline screening for mental health and periodic screening for changes would be useful - mental health is as important as cardio health
- What is potential impact of interventions on psychoactive medication?
- Will mental health history and substance abuse history be exclusionary?
- Understand treatment changes are stressful
- Be aware changes in depression, anxiety, etc., could be an intervention response
- Don't expect us to be happy
- Understand impact of stigma on participants- be aware of stigmatizing language

SOME OPERATIONAL SUGGESTIONS

- After hours availability of study staff
- Optional support group for study participants
- Have referrals available for mental health, substance abuse practitioners
- Mental health specialists available as consultants to researchers
- Social workers/counselors available
- Provide incentives to keep people engaged, like a chance to win free groceries
- FREE PARKING would make a difference

AND FURTHERMORE….

- Want to be culturally and linguistically understood by researchers
- Don't want the cure to be worse than what we have now (side effect concerns)
- LTS, heavily treated, concerned about being excluded
- The cure should be worth it, quality of life
- We appreciate what they are doing
- Keep up the good work

Discussion

Participants are making themselves vulnerable to researchers- physically and emotionally. They are inconveniencing themselves and taking time out of their lives. They are trusting the study team and want to feel personally connected to them. They want to be treated with the dignity, respect, and support they deserve for putting themselves on the line.

Significance

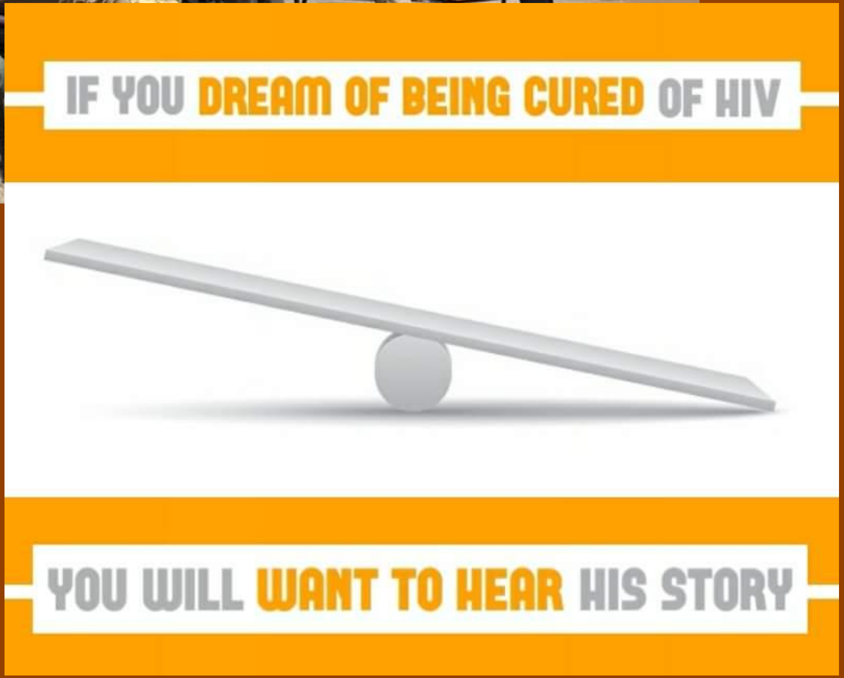
Studies that recognize community member concerns and meet their needs and that are carried out with respect and empathy will be more likely to be successful with recruitment and retention of all people living with HIV, and thus more likely to bring us closer to a cure more quickly.

Acknowledgements: defeatHIV CAB members: Bill Hall, Manuel Venegas, Tranisha Arzah; Host Sites: Madison Clinic, HEYO Lifelong, AIDS Healthcare Foundation, Entre Hermanos; Most Importantly: Focus Group Participants

Assessing Factors Affecting Participation in HIV Cure-Related Research: Implications for Effective and Ethical Implementation, UNC IRB 14-672

Events

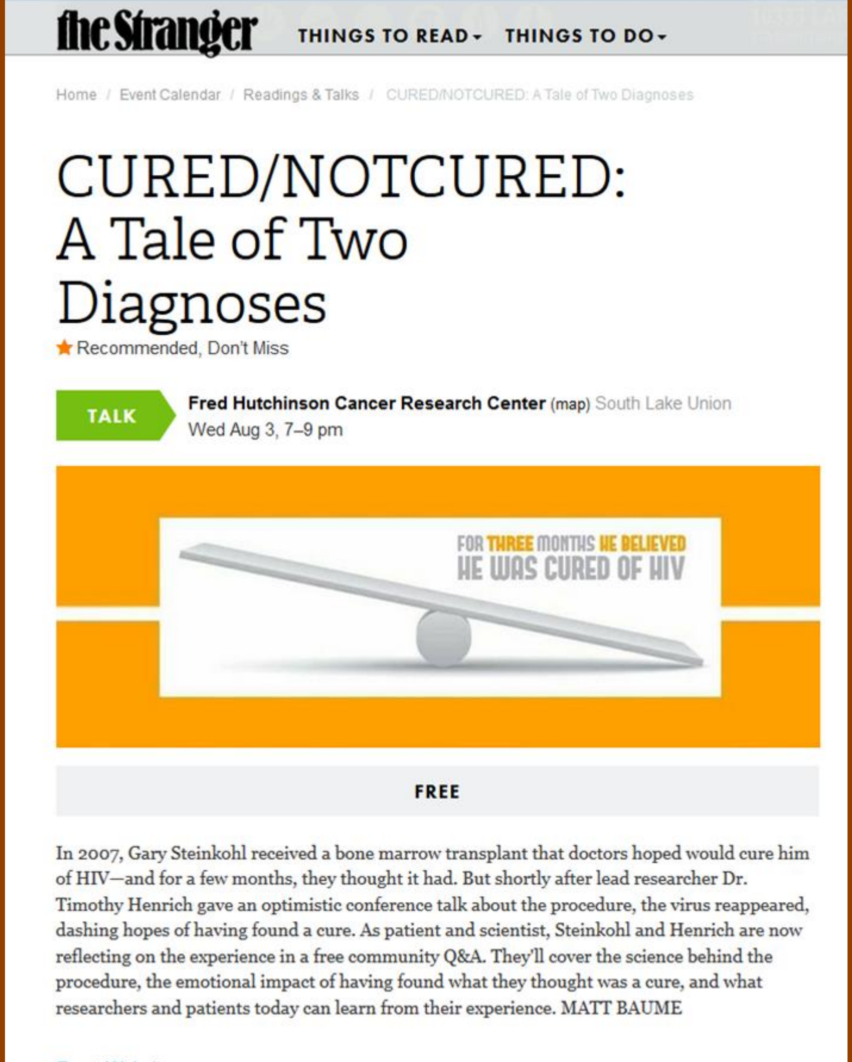
COMMUNITY FORUMS:
CURED/NOT CURED: A TALE OF TWO DIAGNOSES



Click on the underlined text to get other ideas for your events.

- A community forum with Dr. Timothy Henrich and Gary Steinkohl to discuss the research around Boston Patients and its implications for people living with HIV
- Hosted by 3 advocate representing the spectrum of experience of living with HIV who led the conversation
- 89 people attended

COMMUNITY FORUMS:
CURED/NOT CURED: A TALE OF TWO DIAGNOSES



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CURED/NOTCURED: A Tale of Two Diagnoses

★ Recommended, Don't Miss

TALK

Fred Hutchinson Cancer Research Center (map) South Lake Union
Wed Aug 3, 7–9 pm

FREE

In 2007, Gary Steinkohl received a bone marrow transplant that doctors hoped would cure him of HIV—and for a few months, they thought it had. But shortly after lead researcher Dr. Timothy Henrich gave an optimistic conference talk about the procedure, the virus reappeared, dashing hopes of having found a cure. As patient and scientist, Steinkohl and Henrich are now reflecting on the experience in a free community Q&A. They'll cover the science behind the procedure, the emotional impact of having found what they thought was a cure, and what researchers and patients today can learn from their experience. MATT BAUME

EVENT PLANNING TIP: Create a press release for your event and send it to your local media, including newspapers, radio and TV news.

- KING 5 TV NEWS segment
- KOMO Radio interviews with Dr. Henrich and Mr. Steinkohl
- Entry into The Stranger Suggests calendar (a popular Seattle publication)
- Recorded by the Seattle Channel and posted to the defeatHIV YouTube channel