

# The Power of Partnership: Exploring the Impact of Civil Society Involvement Throughout the Research Lifecycle

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Jessica Salzwedel

Senior Program Manager, Research Engagement

Persistence Meeting

# Learning Objectives

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- Define community stakeholders
- Understand the role of community partners in basic and clinical research
- Introduce foundational concepts of media communication
- Develop a 30-second draft elevator pitch of research

# Medical Hesitancy in the Black Community

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## 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.”

What do we mean by  
community engaged research?

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# Engagement Has Many Definitions

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“Meaningful community engagement includes a spectrum of activities, from education to relationship-building to routine partner or planning group meetings and collaboration. Increasing levels of engagement can build trust.”- **CDC**

“The myriad of ways in which the activity and benefits of higher education and research can be shared with the public. Engagement is by definition a two-way process, involving interaction and listening, with the goal of generating mutual benefit”- **National Co-ordinating Centre for Public Engagement**

“The meaningful involvement of patients, caregivers, clinicians, and other healthcare stakeholders throughout the entire research process—from planning the study, to conducting the study, and disseminating study results”- **Patient-centered outcomes research institute**

# Civil Society Member Nigeria

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“...the stakeholders are empowered enough **to understand beyond the direct issues related to the research** and then they can also sit on those tables if and when they’re engaging with the research team in a way that they can truly, **critically appraise the research** and give the necessary feedback that's at the end of the day the community's end up being better off as a result of the engagement with the trial.”

# REC/Research- Malawi

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“And the second approach that stakeholder engagement should take into account is trying **to create an atmosphere or environment that would balance the power relations**... So in trying to define good stakeholder engagement is ensuring that you are bringing in the space... people or stakeholders **who have the same power in the same room** for them to be able to provide their perspectives about that issue altogether”

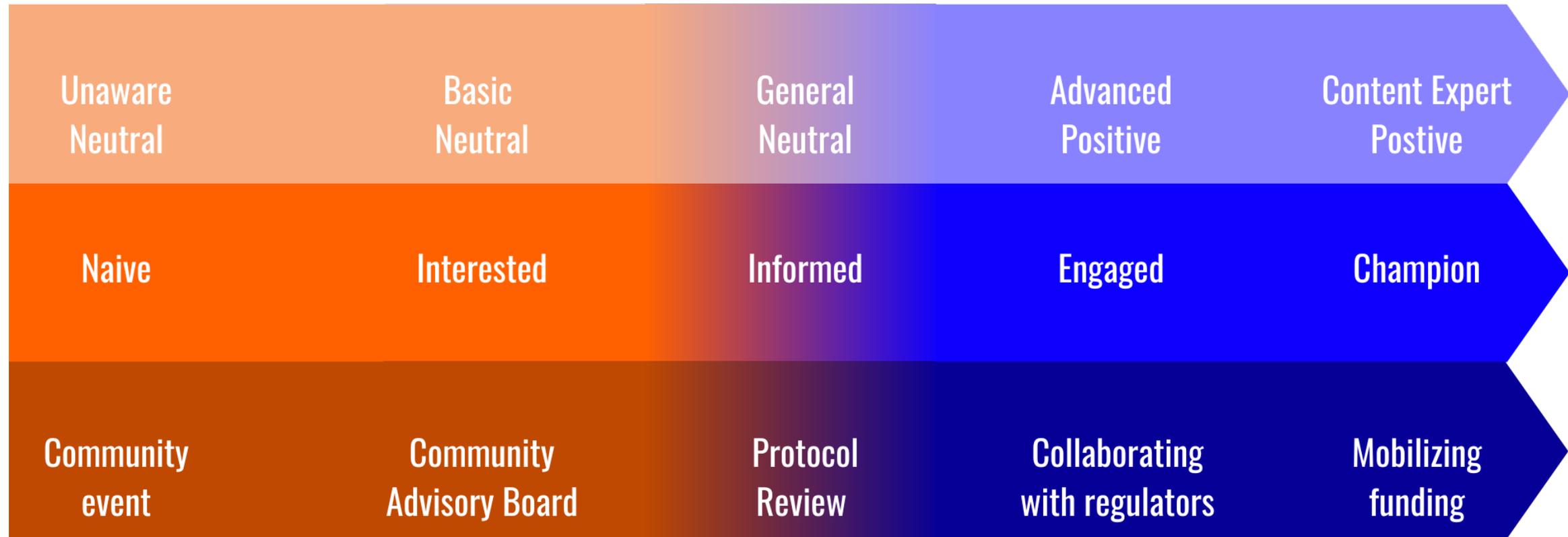
# Engagement Continuum

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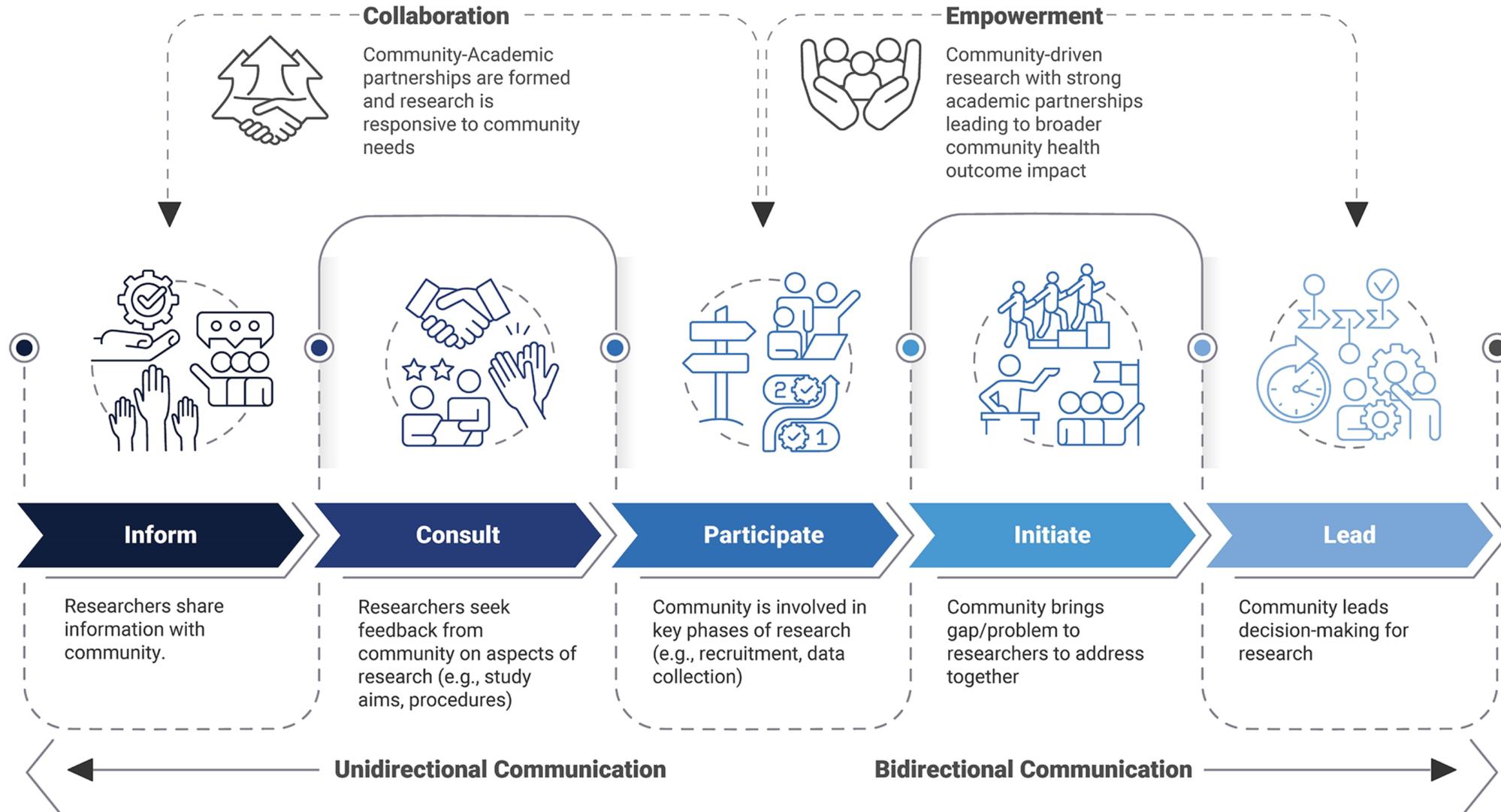
# The Benefits of Engagement

Moving through the participation pipeline



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

# Community Engaged Research Continuum



# Goals of Community Partnership

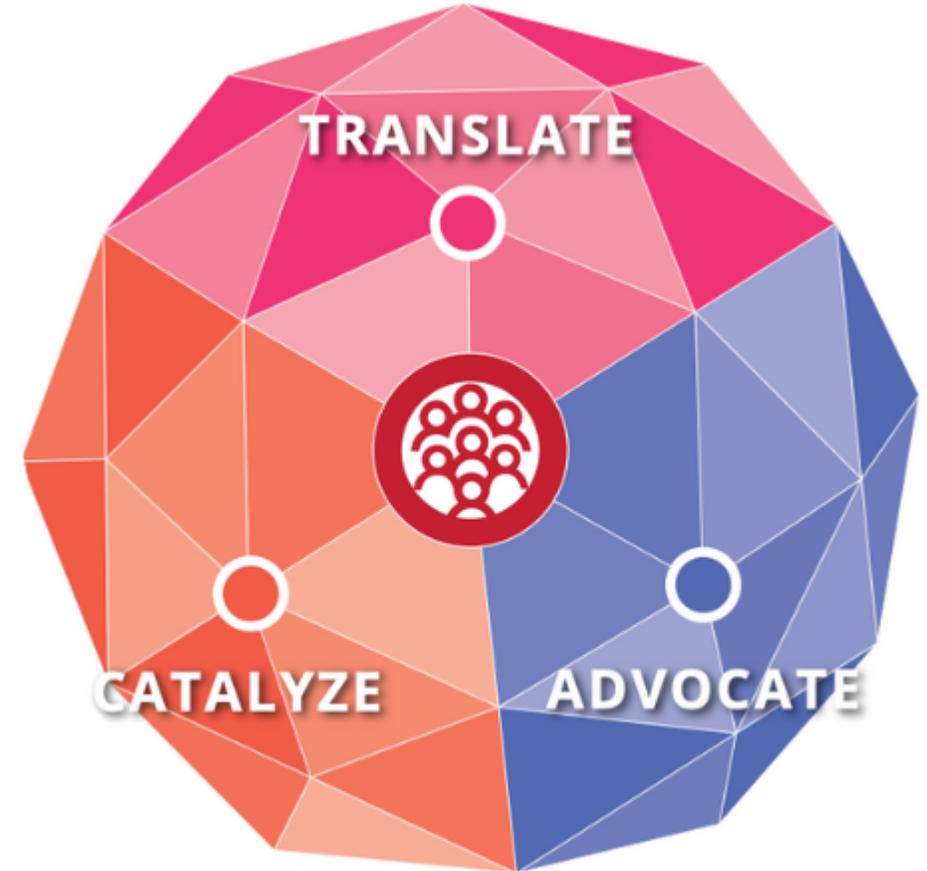
The “diamond” model- a new approach

**Goal:** Build Sustainable Relationship to Advance Public Health

**Translate:** Bridging science and community language to improve health, trust and partnership

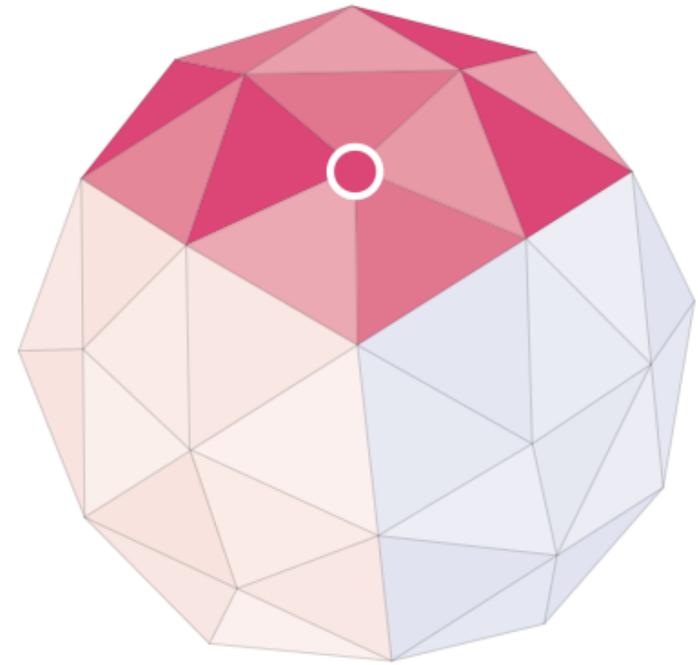
**Advocate:** Empowering communities to critically evaluate needs and mobilize for change

**Catalyze:** Promote cross-partner learning and cross-fertilization of ideas



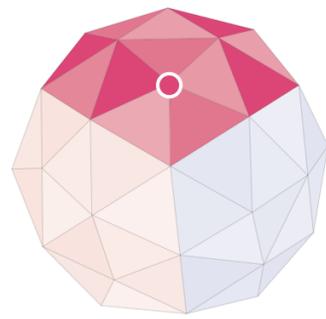
# Translate

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# Pillars of Translation

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

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

Regularly assess modes of information dissemination and participation both internally and externally

Assessing operational readiness

# Defining “Diversity” in Data Collection & Partners

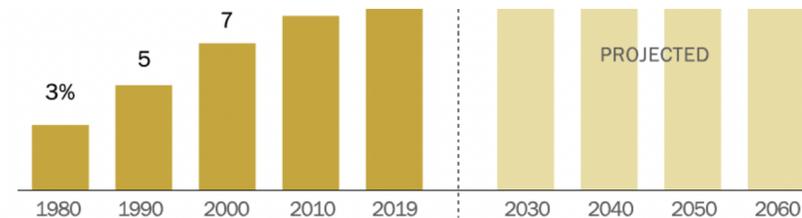


## Medical News in Brief

April 26, 2024

# US Updates Race, Ethnicity Categories for First Time Since 1997

Emily Harris



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



# Investing in Community Experts

## Community Program Incentives

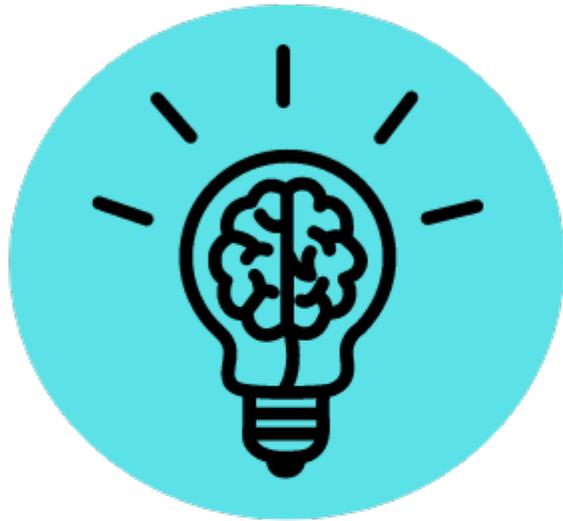
- Closed monthly literacy seminars for CAB members
  - Template for researchers to support translation
  - Support Early Career Investigators and provide networking opportunities
  - Building sufficient time for questions
- Investing in essential skills
  - Media/communication training
  - Abstract and proposal writing
  - Presentation development
- Support publications and provide authorship when possible





# Translation Metrics

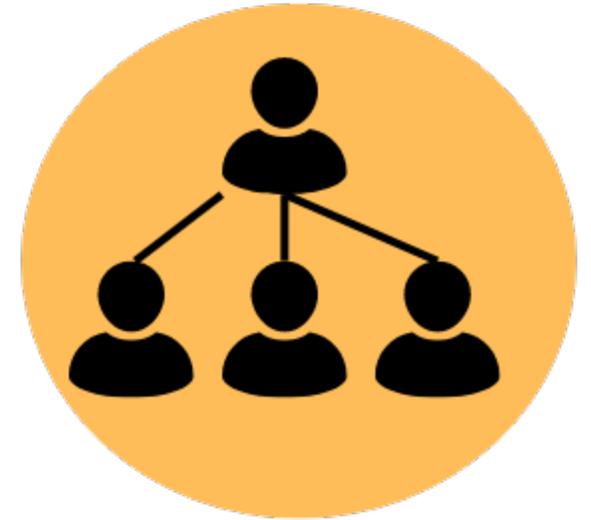
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Knowledge/  
Skills



Synthesis of  
Information



Infrastructure

# Measuring Translation

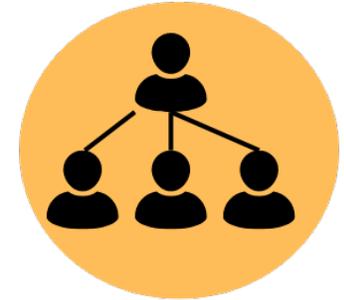
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- Knowledge assessments with increased retention of material
- Knowledge of health systems



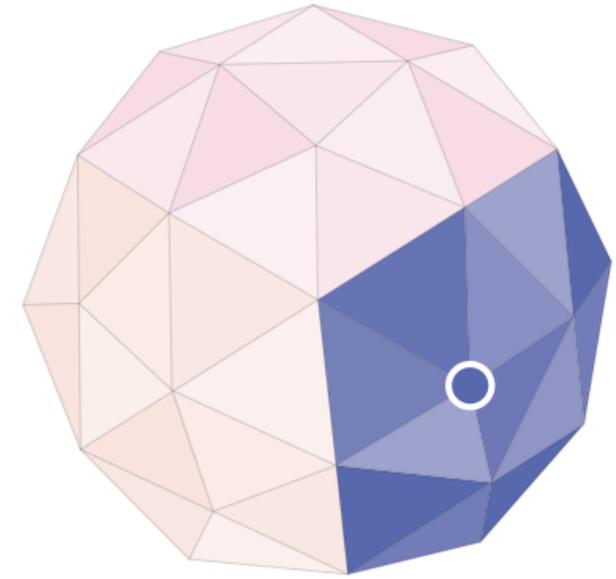
- Quality of questions over time
- Partner invitations on panels, advisory committees, meetings, etc.
- Reduction of rumors/myths/misinformation (e.g. headline quality)



- Regular staff assessments on community engagement competencies
- Number and quality of pathways to receive/evaluate community proposals

# Advocate

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# Advocate Pillars

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Identifying joint priorities  
and areas for  
collaboration

Understanding  
capabilities and  
establishing roles and  
responsibilities

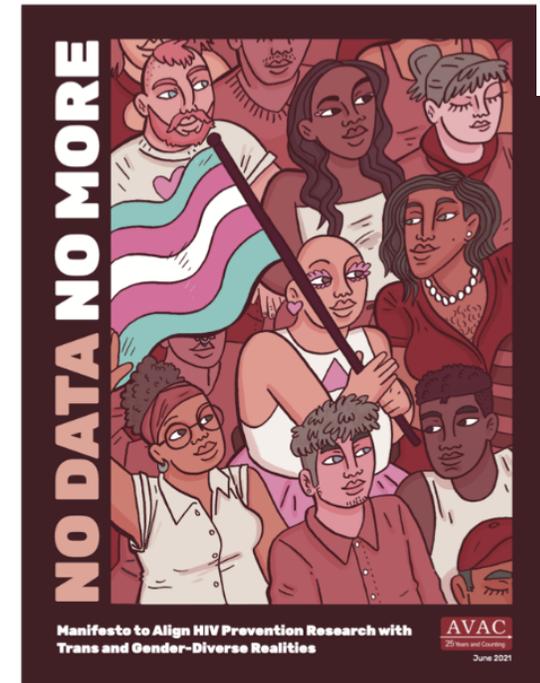
Regularly assess  
stakeholder partnership  
capacity

# 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





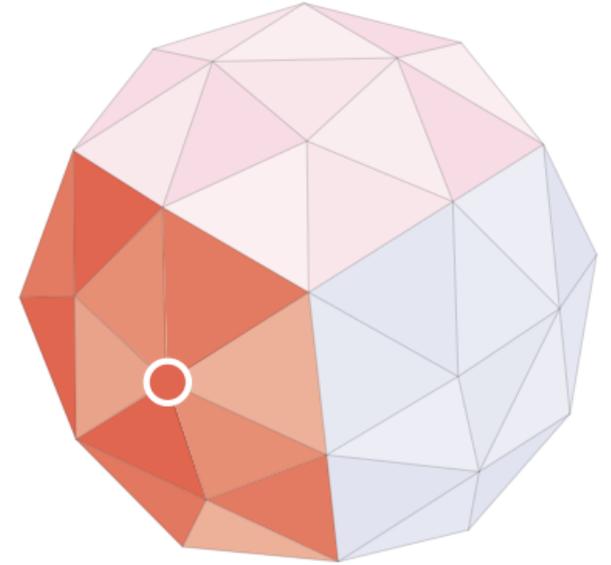
# The Potential Role of FSW in Research Involving an ATI



- **Access to Healthcare Concerns:** Many sex workers face challenges accessing HIV treatment due to stigma, discrimination, or financial constraints. Stopping ARVs temporarily can lead to worsened health and increased HIV transmission risk
- **FSWs identified potential roles in research conduct:**
  - Engaging with their communities to increase literacy about ATIs
  - Advocating for inclusion and representation in HIV cure research
  - Provision of peer support and counseling to fellow participants
  - Advocating for policies and programs that prioritize the health and well-being of sex workers in the context of HIV cure research and ATIs

*Courtesy of Josephine Achieng*

# Catalyze



# Catalyze Pillars

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Focus on the  
ecosystem/enablers of  
research

Expanding  
understanding of  
community leadership

Reflecting on internal  
behavioral/system  
changes

# Connecting Bench to Clinic

- May 2023 held a community event at African Services in Harlem
  - Target population Black NY residents
- Rockefeller's Community Coordinator Jonathan Berardi in attendance but not on the agenda
- Jonathan began attending support groups of a Black transwoman in attendance who was interested in enrollment
  - Supported presentation and engagement efforts for these meetings
  - Participant screened but not eligible
- Connection supported at least one enrollment into trans care study

**HIV Cure Research and  
The Black Diaspora**

Reaching Critical Voices

**Wednesday, May 3rd**  
6:30pm-8pm  
African Services  
429 W127th

**Food and  
Drinks  
Served!**

**Brad Jones, PhD** Weil Cornell Medicine  
**Marina Caskey, MD** Rockefeller University  
**Micheal Igodharo** Prevention Access Campaign  
**Michelle Lopez** Einstein CAB

Join the REACH collaborative for a conversation on the importance of engaging diverse populations at every stage of HIV cure research!

**REACH**  
For the Cure  
Research Enterprise to Advance a Cure for HIV

# Operationalizing Partnership in HIV Research

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

## FUNDERS

- What is the upfront cost of building these networks and how long will they be viable resources?
- What is the cost-effectiveness of investing in engagement infrastructure?
- Can engagement decrease enrollment time or increase product uptake?

## PROGRAMS

- What type of training do study/research staff need to ensure equity?
- What type of training & support do non-study providers need?
- What policies need to be reviewed/adjusted to ensure research can move forward?
- How can we clearly define the roles to avoid duplication and increase speed?

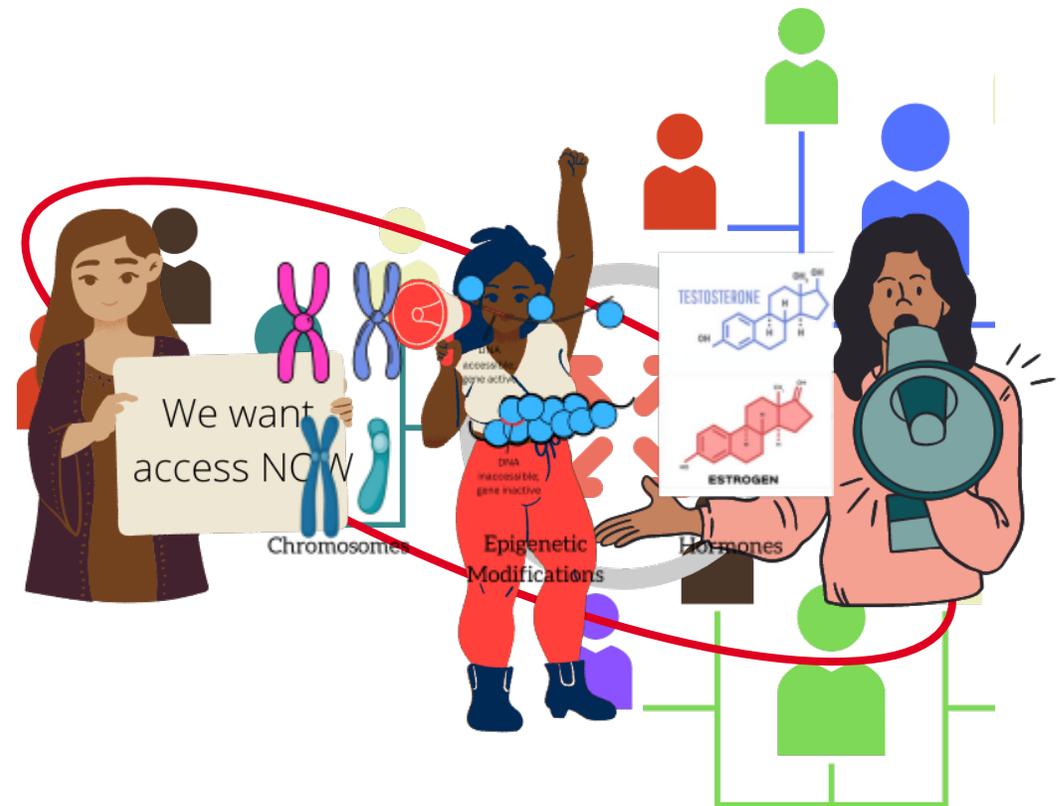
## USERS

- 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 at all levels?
- How can peer groups/influencers be leveraged to support participation/engagement?
- How can providers be supported to have more knowledge and empathy?

# 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





Marc Franke – DZIF, German Center for Infection Research, Germany Patient Advisory Board for HIV

**"I once had HIV" - The story of a cure**

# **Marc Franke, The Düsseldorf Patient**

—

**the personal story  
behind the cure**



# List of all people who have been cured of HIV – sorted by year of transplantation

Location	Name	Year of Transplantation	Type of cancer	Stopping ART	Presentation at CROI/IAS	IciStem number	Gene mutation
Berlin	Timothy Ray Brown	2007 + 2008	AML	2007	2008 + 2009	"00"	CCR5Δ32/Δ32
Düsseldorf	Marc Franke	2013	AML	2018	2016 +2019 + 2020	#19	CCR5Δ32/Δ32
New Berlin	?	2015	AML	2018	2024		CCR5Δ32/WT
London	Adam Castillejo	2016	Hodgkin's lymphoma	2017	2019	#36	CCR5Δ32/Δ32
New York	?	2017	AML	2021	2022		cord blood CCR5Δ32/Δ32 + WT/WT
City of Hope	Paul Edmonds	2018	AML	2021	2023		CCR5Δ32/Δ32
Geneva	Romuald	2019	biphenotypic sarcoma	2021	2023	#34	WT/WT

# Timeline

## Marc Franke

- 1969/04 Birth
- 2001/01 Coming out
- 2008/01 HIV diagnosis (fresh)
- 2010/10 Start ART
- 2011/01 Acute Myeloid Leukemia (AML)
- 2012/10 Relapse of AML
- 2013/02 Stem Cell Transplant
- 2018/11 Discontinuation ART
- 2023/02 Article in Nature Medicine



# 2008/01

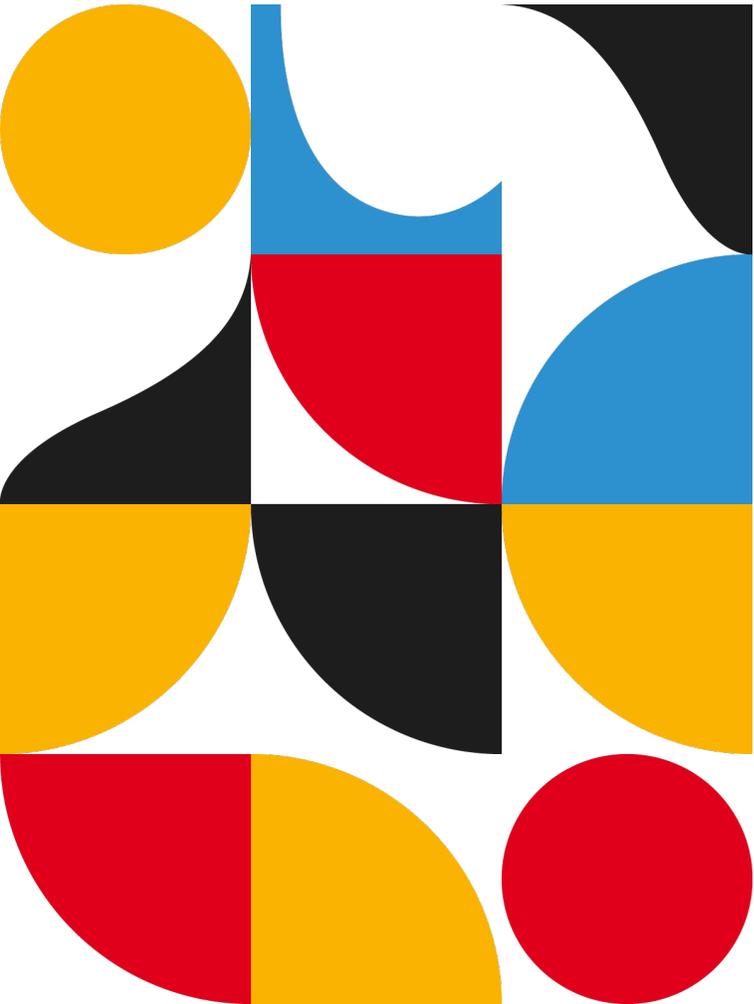
## HIV diagnosis

- The values clearly showed that I had only been living with HIV for a short time.
- The infection must have taken place in the last 3 months.
- During that time, I had condomless sex only with my boyfriend.
- We broke up before the diagnosis.
- In retrospect, I remember that he complained of fever, night sweats, and exhaustion....



# 2011/01

## Pneumonia + Leukemia



- A friend drove me to the emergency room with suspected pneumonia. It was pneumonia.
- My blood values were not within the normal range - suspicion of leukemia.
- The pneumonia was cured in 2 weeks.
- To confirm the leukemia, a bone marrow puncture was performed.
- Acute Myeloid Leukemia (AML) was diagnosed.
- My version was dangerous, but if diagnosed early it could be treated with chemo.
- Since I was living with HIV I could not participate in any study

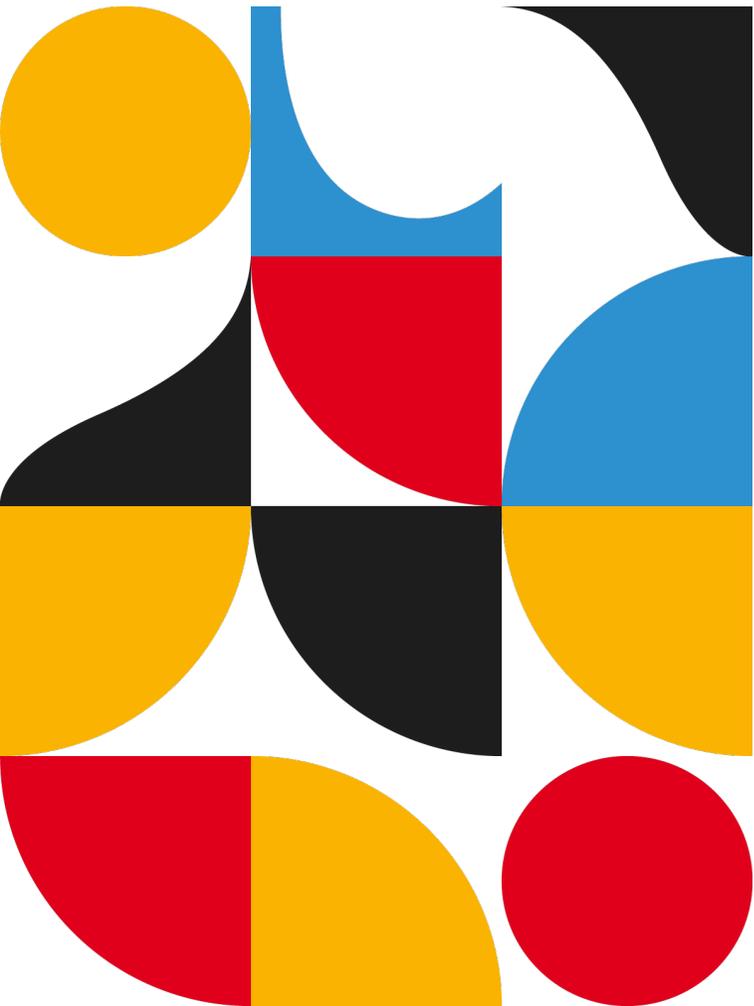
# 2011/01 Acute Myeloid Leukemia (AML)

My oncologist said when I was diagnosed with AML that although I have a serious form of AML, it is very treatable with chemotherapy if detected early.



# 2011/01

## Ingo



- The reason why I look so optimistic in the previous photo is Ingo.
- I met Ingo on a gay dating platform during my first week at the university hospital.
- He visited me the next day.
- Then he came every day.
- I wore rose-colored glasses and had to look good in the evening.
- So no time to let yourself down.
- Besides, I wanted to get to know Ingo better.

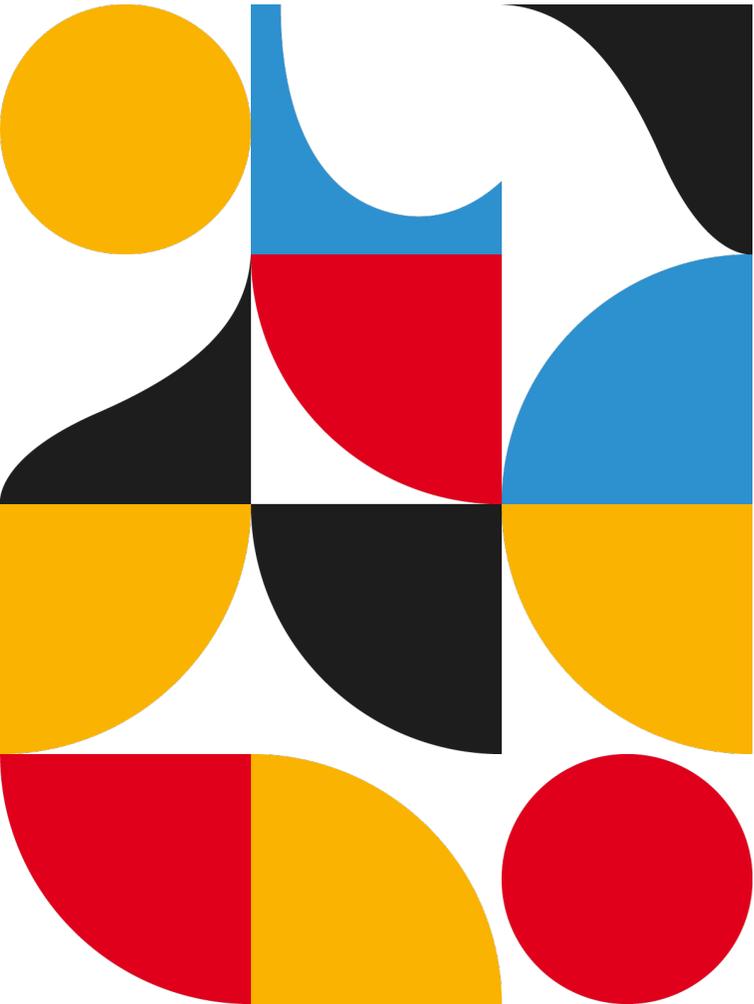
# 2011/04 Birthday, together with Ingo

- In 2011 I had 6 chemo cycles.
- I went into rehab.
- At the end of the year, I did a reintegration.
- By the end of the year, I was working full-time again.



# 2012/10

## Relapse of leukemia

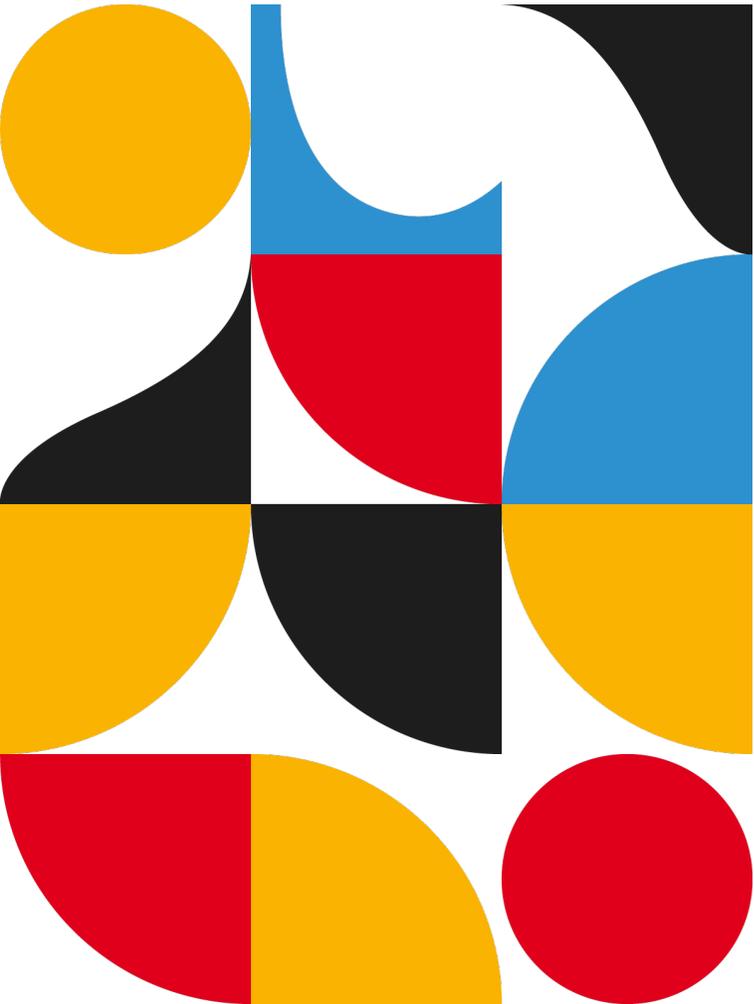


- I had a check-up appointment with my oncologist.
- Blood values were suspicious. So I went to the leukemia outpatient clinic.
- The result of the bone marrow puncture showed a relapse of the leukemia.
- Another round of chemo didn't work - a stem cell donation was necessary.

# 2012/10 – 2013/02

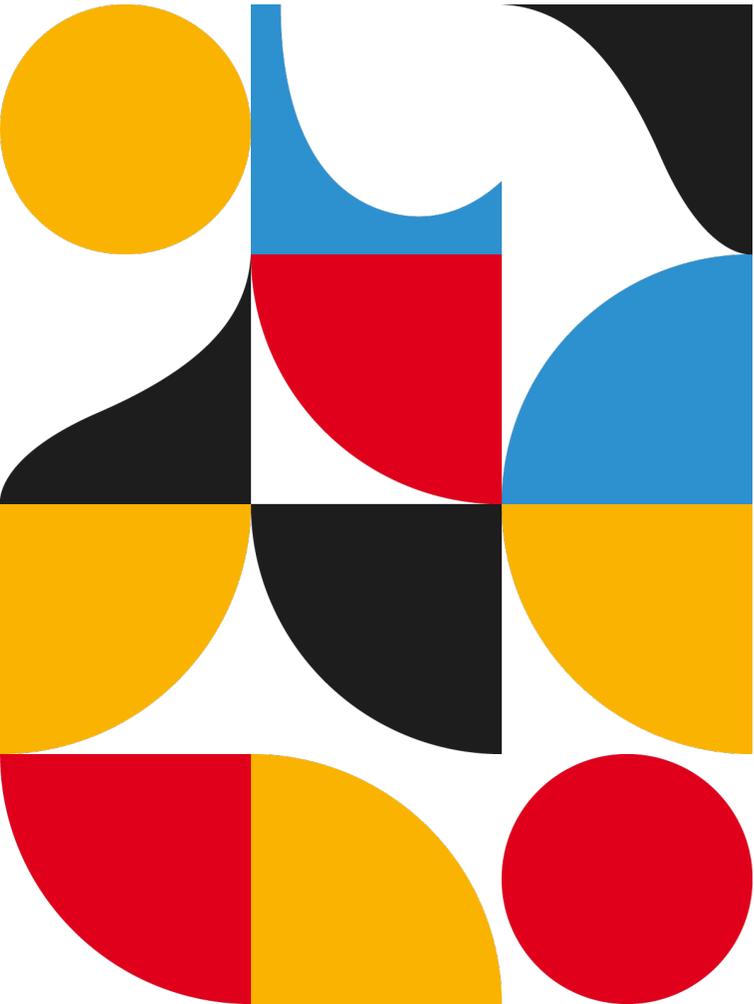
## Waiting for the transplant

- My doctors do not only want to look for a suitable donor for me.
- This donor should also have the CCR5 $\Delta$ 32/ $\Delta$ 32 (homozygous)
- Therefore, all donors that were considered had to be screened for this genetic variant.
- My doctors informed me that the search would take some extra time.
- I agreed anyway.



# 2012/10 – 2013/02

## Waiting for the transplant



- At that time, I watched the documentary about Timothy Ray Brown – The Berlin Patient.
- I was sure that the transplantation would lead to an HIV cure for me, too, if a suitable donor could be found.
- It was like a needle in a hay bale in a huge field of hay stacks.
- Before Christmas 2012, a donor was found.
- On Valentine's Day 2013, the time had finally come!

# 2012/10

# Timothy Ray Brown



**Aired on TV**

**arte TV, rbb 2012**  
**Der Berliner Patient**  
**Geheilt von AIDS**

**A movie by**  
**Mira Thiel**  
**Benjamin Cantu**



# 2012/12 Waiting for the transplant

- By Christmas 2012, a donor was found.
- The best Christmas gift ever
- 1 out of 5 donors had the gene variant!
- As you can see, nurses also make snowmen as plasters for the central venous catheter (CVC).



# Valentines day 2013 Stem Cell Transplant



The transplant was only 2 250ml bags.

Fun fact:

- You have tomato taste in your mouth.
- You smell tomato too.
- Because the transplant is protected from the cold with glycol.

# 2016/08 Anna, my donor



 **AIDS 2024**

Thanks to:

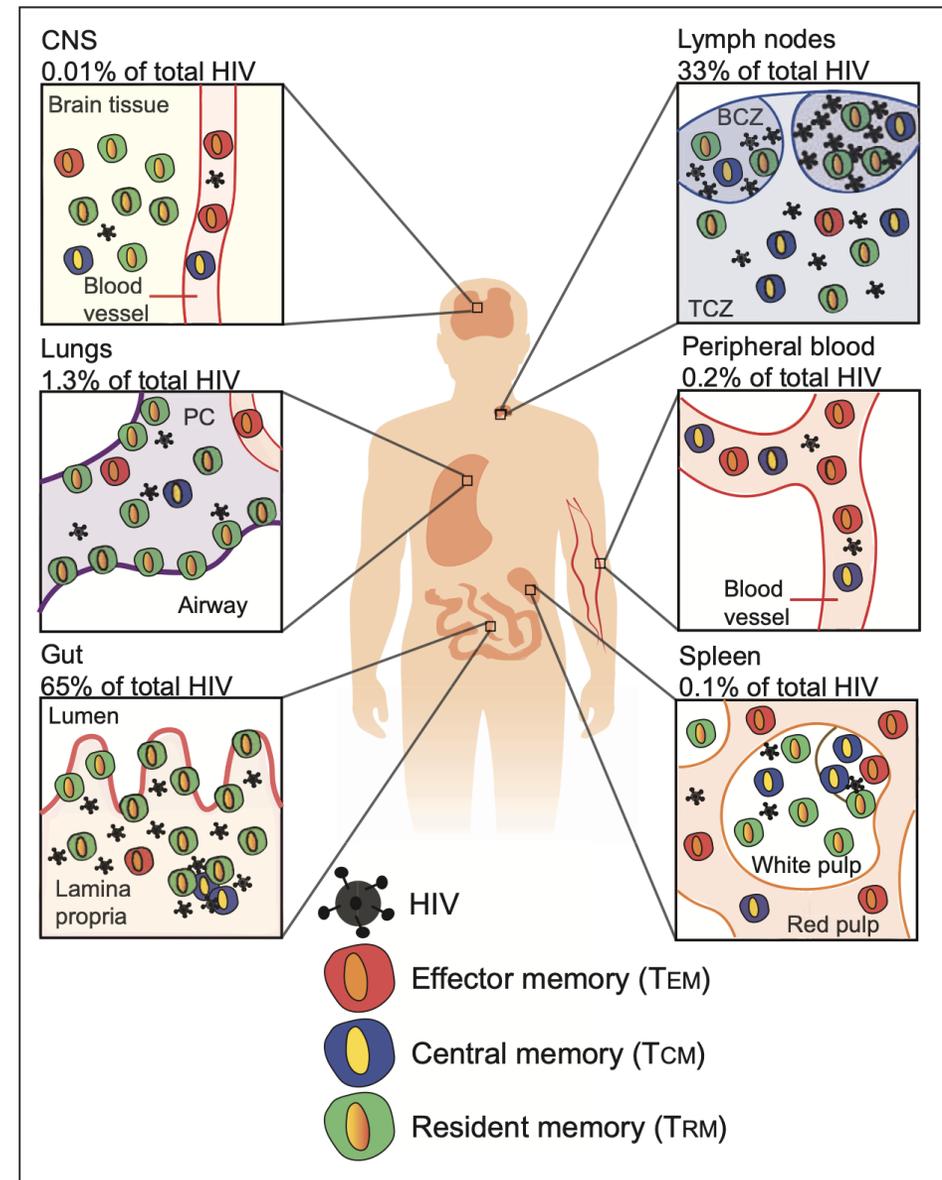
**DKMS**   
WE DELETE BLOOD CANCER

Advocacy. Access. Equity. 

# 2014-2018... Searching the HIV reservoir

Percentages of HIV in the body

- 0,2 % Blood
- 60 % Gut
- 33% Lymph nodes



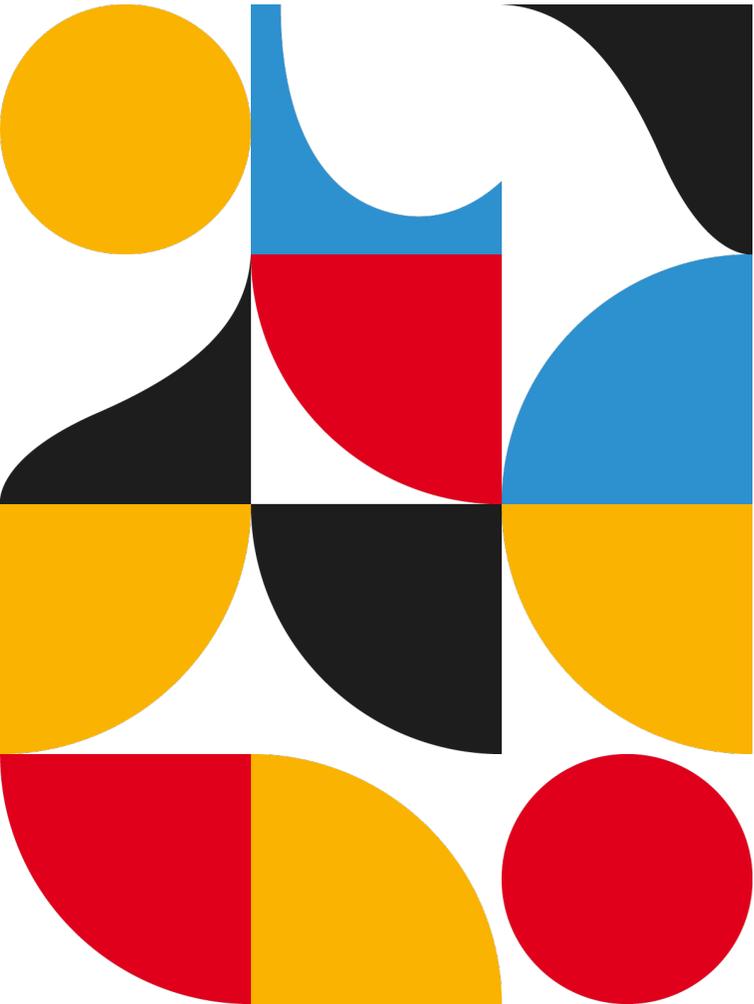
# 2014-2015 Searching the HIV reservoir - Blood

Bloodletting was carried out regularly over several months to lower the blood iron.

The iron level was very high due to the many blood transfusions during the chemotherapy.

Very sensitive PCR tests were carried out on the blood.

Immune cells were also collected by apheresis and transplanted into humanized mice.

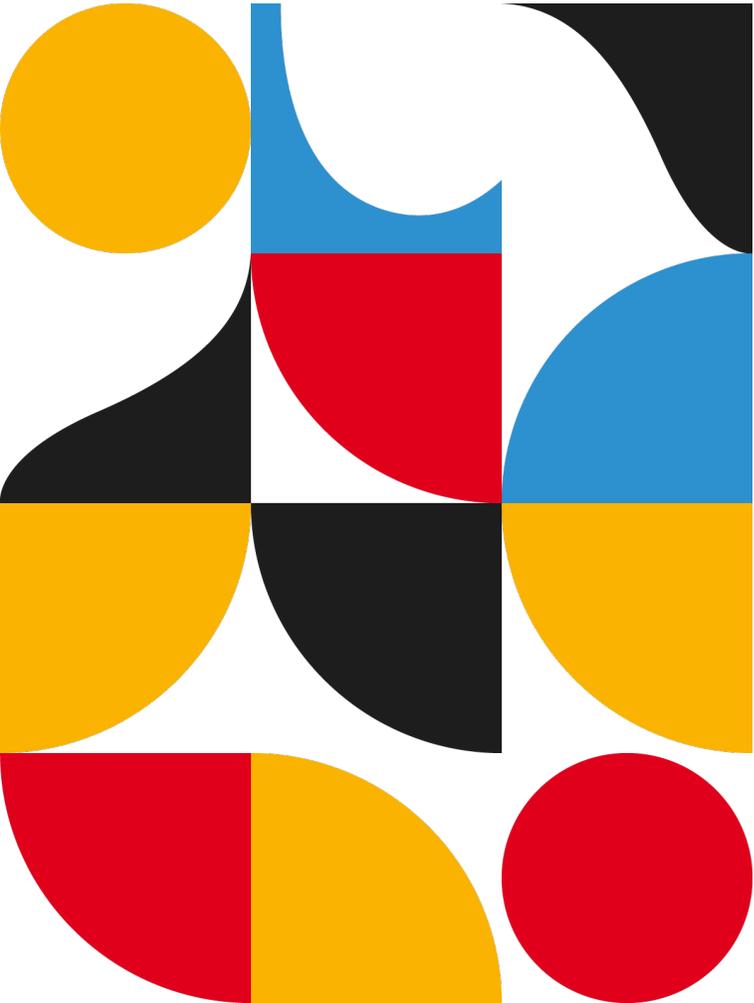


# 2014 Searching the HIV reservoir - Gut

I was due to have a gastroscopy/ileocolonoscopy anyway.

My doctor asked me if I would be willing to have tissue samples taken from my intestinal wall.

The samples have been sent all over the world to carry out very sensitive tests.



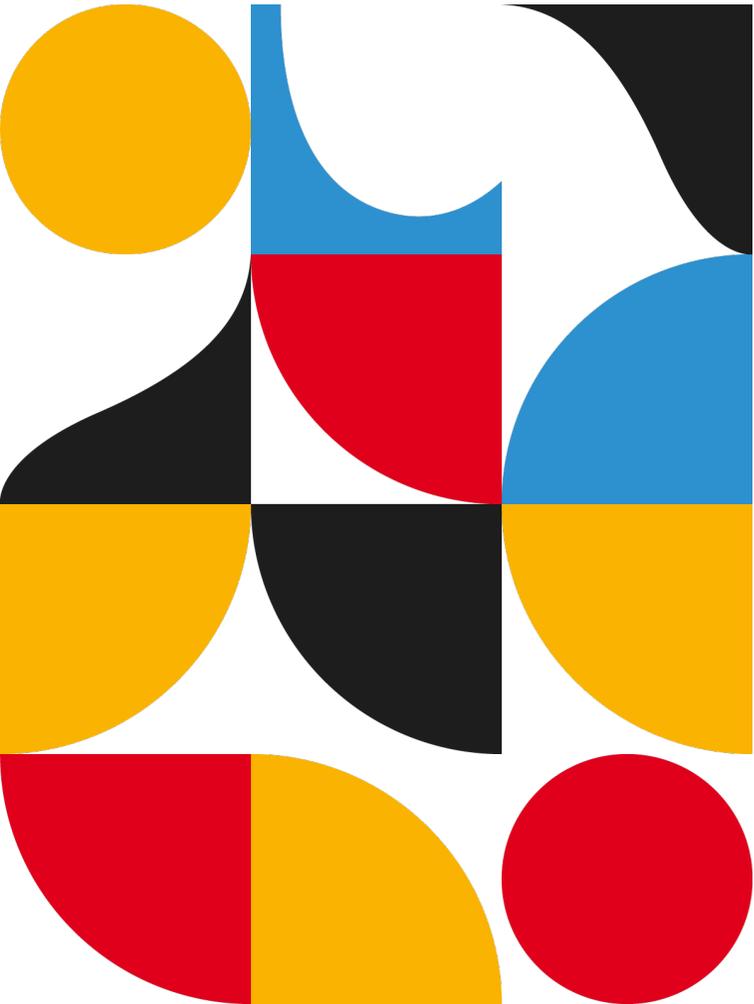
# 2017 Searching the HIV reservoir – Lymph node

All tests to date had only shown HIV virus fragments, but these had proved to be inactive.

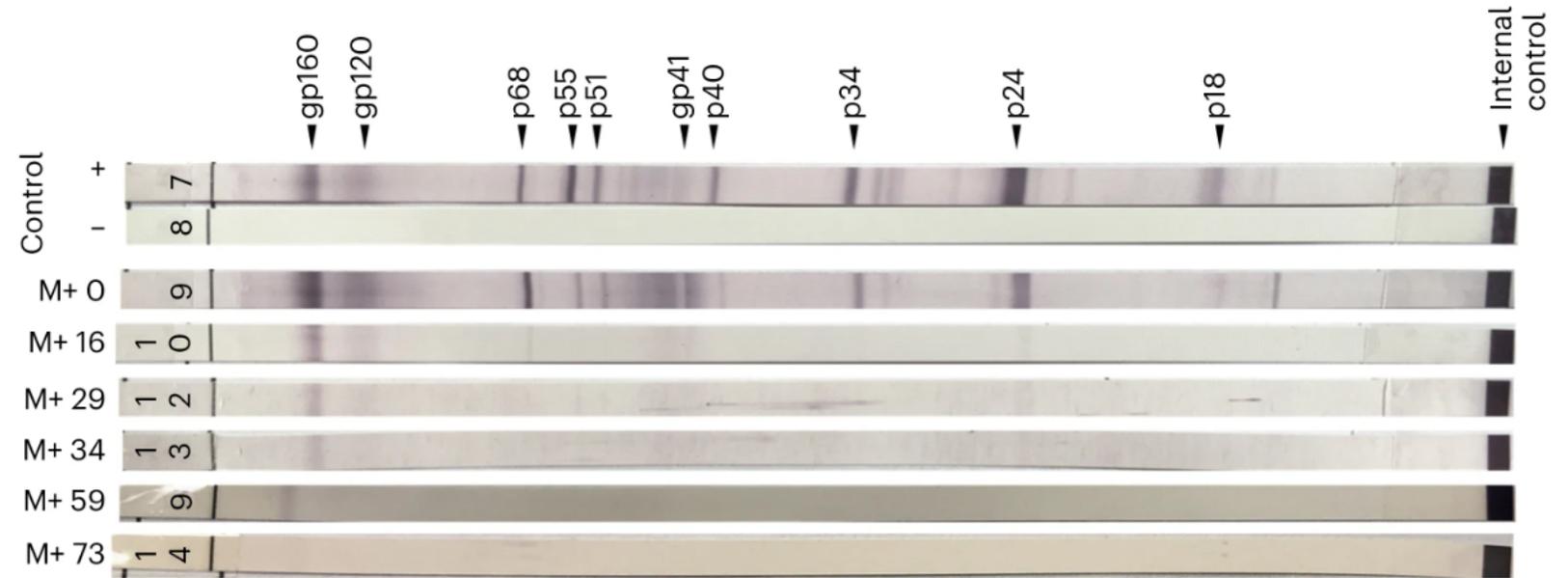
The next step was to take a lymph node sample.

The operation was done in the gynecology department. The doctors there specialize in the fine removal of tissue.

The lymph node was send to Oregon for examinaton and is still there.



# HIV test after HSCT 2013 - 2019



nature medicine  
In-depth virological and immunological characterization of HIV-1 cure after CCR5Δ32/Δ32 allogeneic hematopoietic stem cell transplantation

22 – 26 July · Munich, Germany and virtual

[aids2024.org](https://aids2024.org)

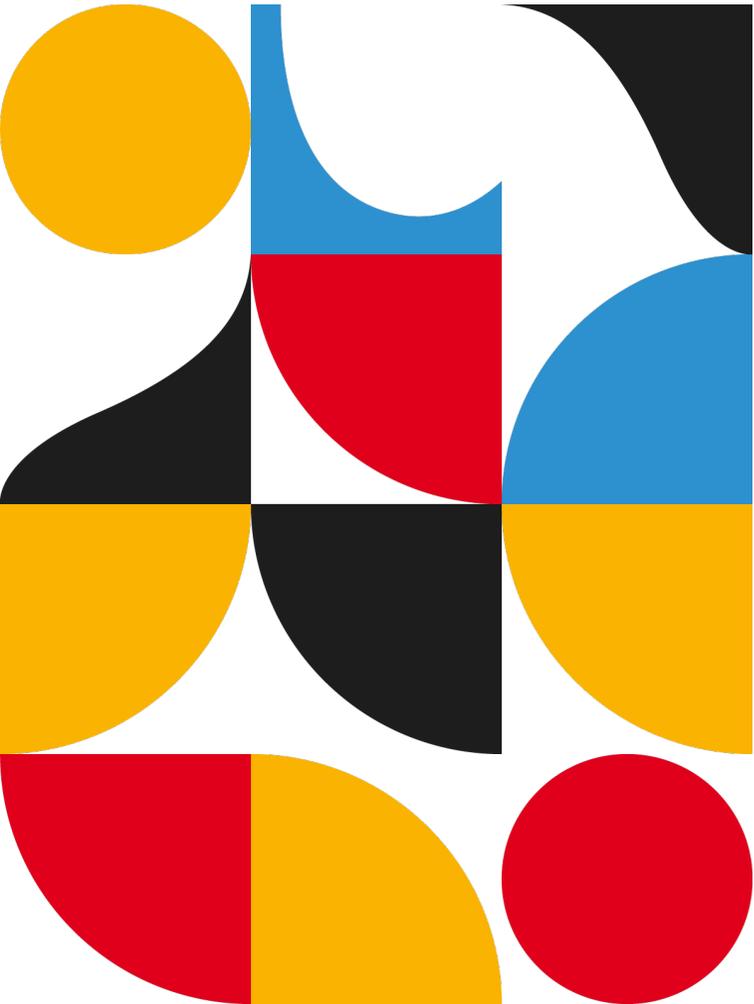


# 2018 Start ATI?

ART could only be discontinued once the immune suppression had been eliminated.

However, this was delayed because:

- Drop in chimerism
- Hepatitis
- Diabetes
- Herpes Enphazelitis
- Hip replacement
- No evidence of active HI viruses



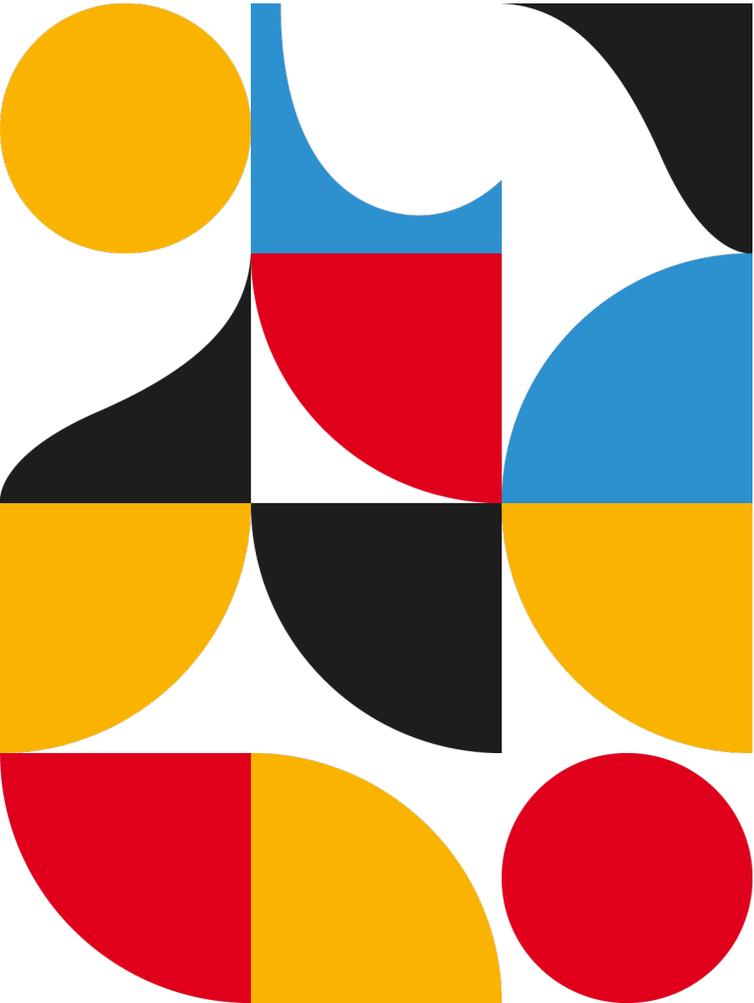
# 2018/11 Start ATI! How to make it save?

Regular HIV tests were done to safeguard the ATI:

- First 2 times a week
- Then 1 time a week
- Then every 2 weeks
- Then monthly
- Currently every 2 months

My doctor explained to me that if I relapse, the ART would simply start again.

But I had 100% confidence. After all, I had known Björn since 2011 and my ART was changed before I started chemo.



# ATI

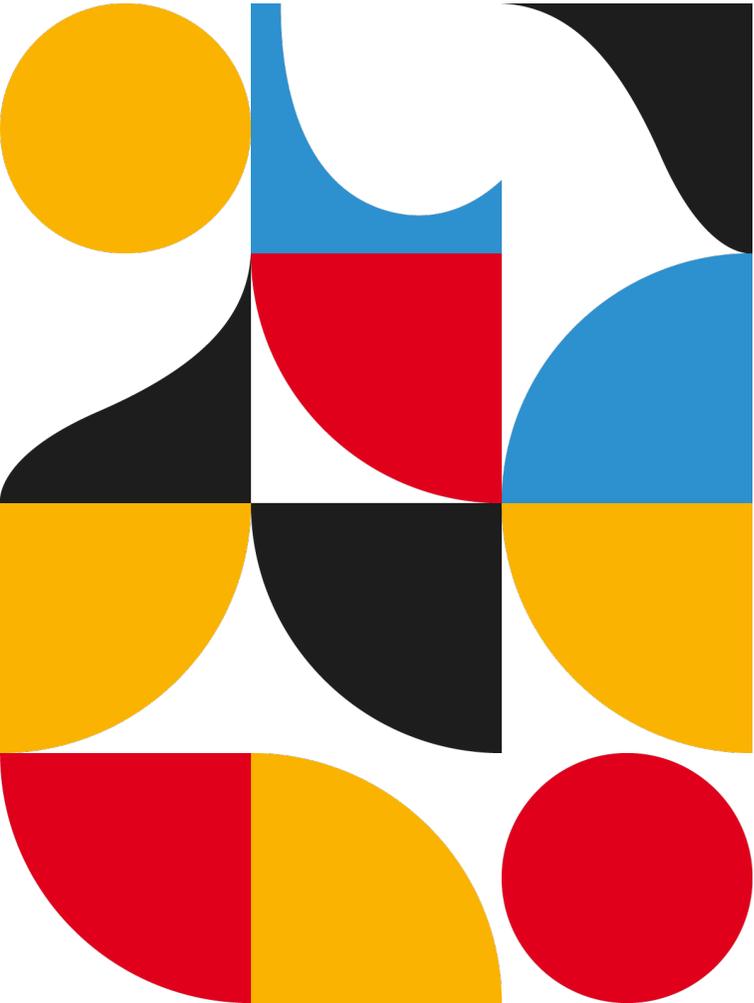
## Challenges and solutions

I initially went to the university clinic for the HIV test. One way was 120km - and 90-180 minutes driving time. To save driving time, I then went to my local GP and had my blood taken there.

I had received prepaid parcels from the university hospital. I sent the blood tubes to Cologne for examination.

I was trained to draw my own blood. I already had the stamped packets.

Fortunately, the intervals soon became longer, and I no longer had to take blood myself.



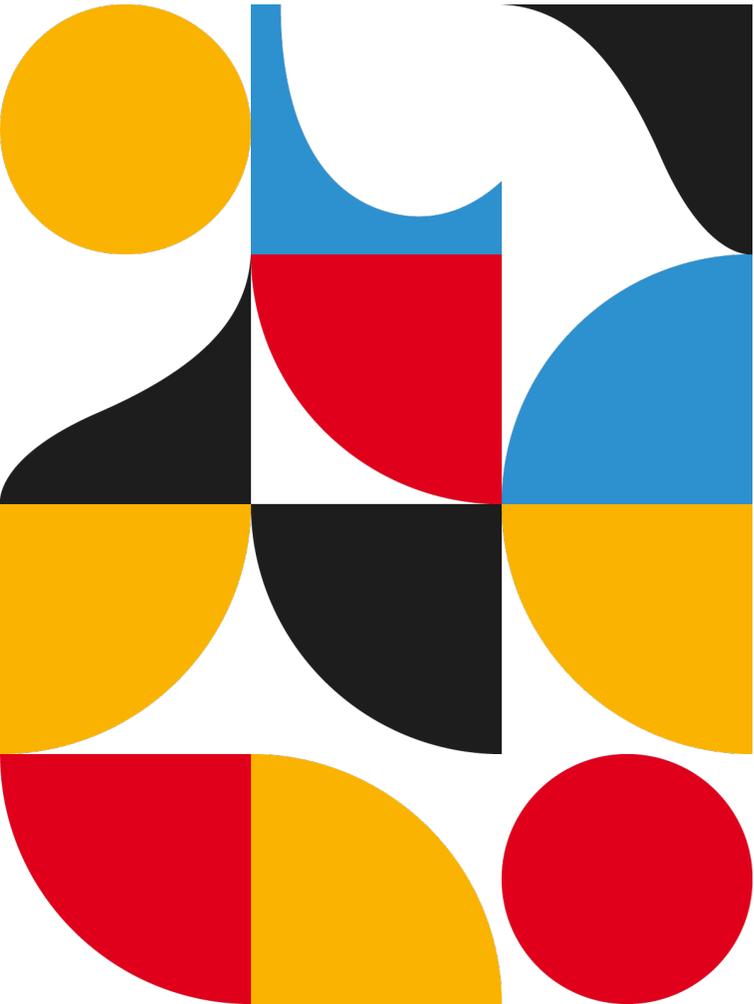
# ATI Feelings?

After chemo, I had to take up to 40 tablets a day. One tablet less a day didn't make much difference. I also never saw the tablet as an enemy before. It was a daily routine.

I also had a lot more respect for leukemia.

Today I can say that I am cured of HIV - the leukemia is only in remission.

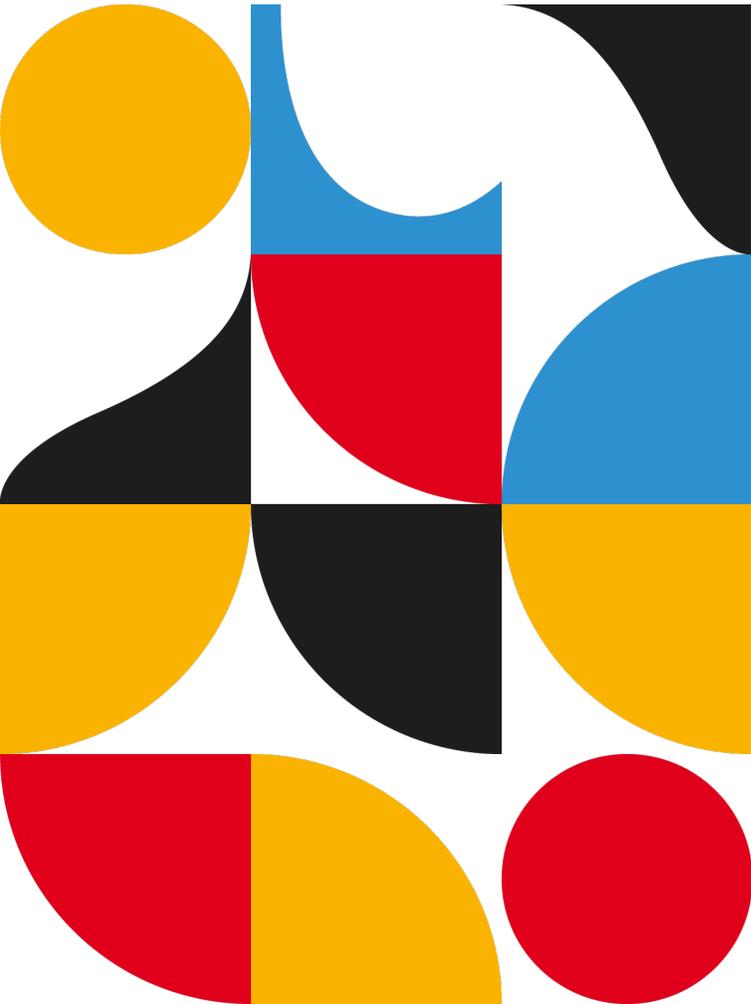
Because I knew my doctors over the years and all the steps in the course of treatment were always explained to me well and I was involved in the decisions, I never felt like a guinea pig.



# 2022 Amsterdam Dinner

## Dr. Shringar Rao, Erasmus MC, Rotterdam

Dr. Rao is researching the HIV reservoir



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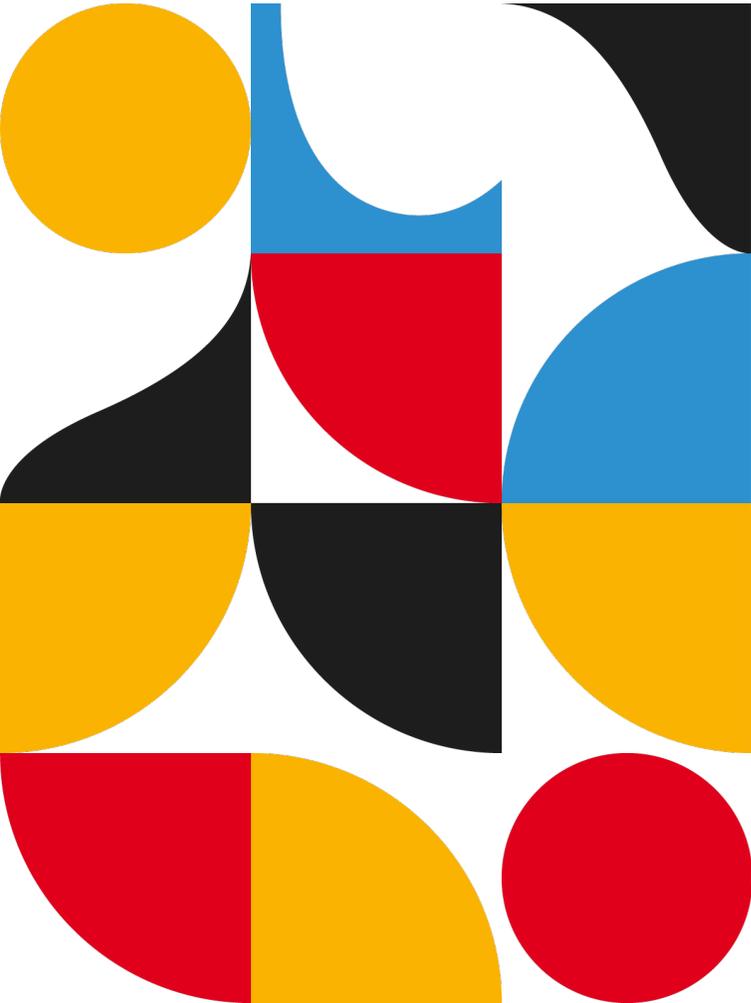
2023/02

Prof. Annemarie Wensing, IciStem Utrecht



2023/04

Dr. Björn-Erik Ole Jensen, Düsseldorf



22 – 26 July · Munich, Germany and virtual

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2023/08

Dr. Nadine Lübke, UKD



 AIDS 2024



# 2023/09 Honolulu



**AIDS 2024**

## The 3 Musketeers Paul, Adam and Marc with Lish and Jonah

- We have to rename our WhatsApp group...

**2023/09**  
**Stuttgart**  
**Marc, Motte**  
**and Ingo**

Family complete 😊



**2023/10 Berlin**  
**Preis der Deutschen Hochschulmedizin 2023**



# 2024/07 at AIDS 2024

## Dr. Björn-Erik Ole Jensen



 AIDS 2024



**HIV Sverige - YouTube channel**

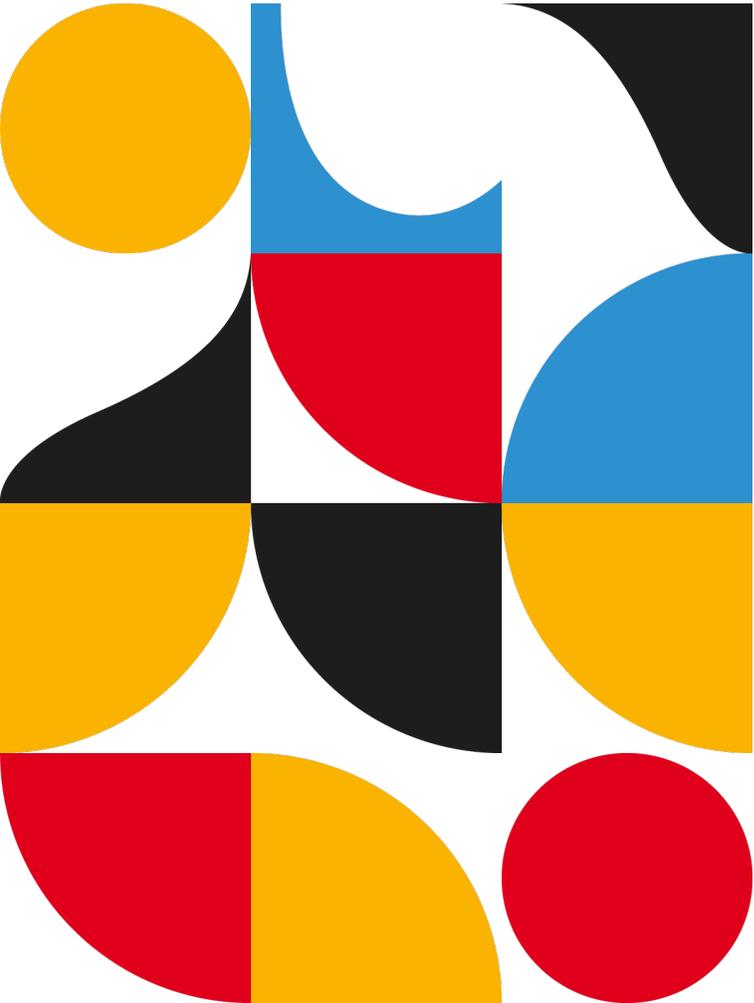
**Björn talks about:**

- Team effort
- Why are there so many cured people in Germany?
- Why this way is not for everyone.
- Strategies for the future.

# Things to be done...

- Fight against HIV stigma!
- Make HIV tests easily and inexpensively available – anonymously!
- Know your status!
- Tell everyone about U=U and PrEP!  
This is a game changer!
- Make people realize that HIV doesn't just affect MSM. Over 50% of positive people worldwide are women!
- Keep searching for a cure for HIV!
- Connect with other researchers – worldwide!

**I hope for a single shot solution to end HIV worldwide!**



# Personal thoughts/wishes:

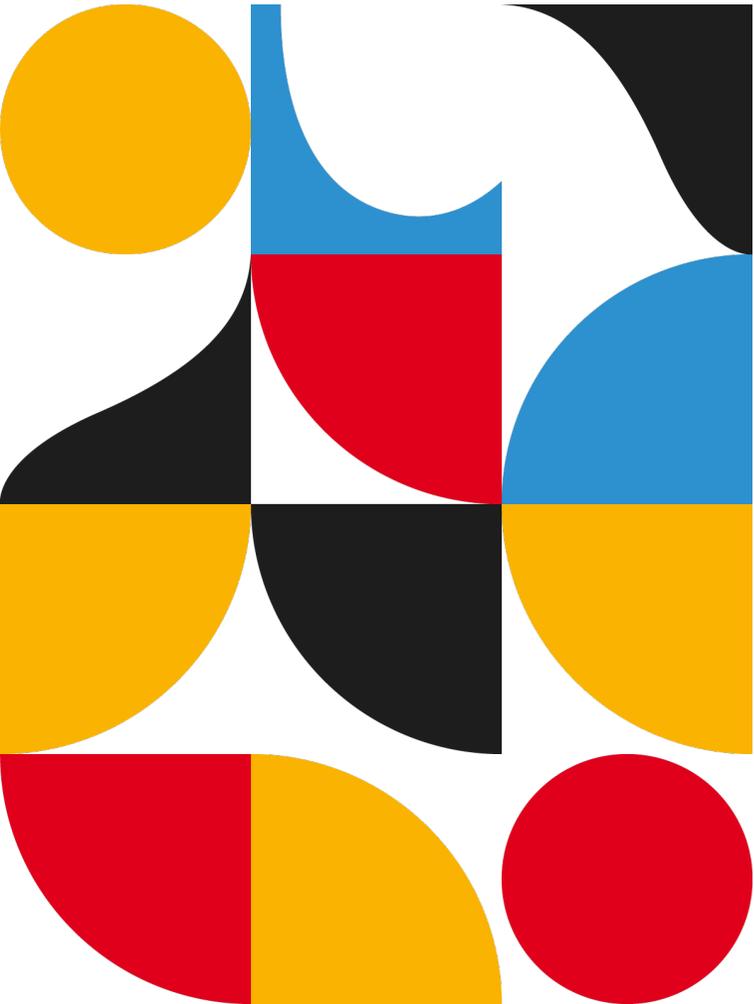
- **Please try to avoid the 4 letter word!**

Many people don't know the difference between HIV and AIDS.

The press has repeatedly referred to me as a former AIDS patient in reports – this is not correct and has hurt me very much.

- **Language matters!**

- Check the People First Charter
- Check the UNAIDS TERMINOLOGY GUIDELINES



## Contact Marc:

Marc\_DP@gmx.com

Marc\_QandA@gmx.com

[https://linktr.ee/Marc\\_DP](https://linktr.ee/Marc_DP)



# SCAN ME

# List of all people who have been cured of HIV – sorted by year of transplantation

Location	Name	Year of Transplantation	Type of cancer	Stopping ART	Presentation at CROI/IAS	IciStem number	Gene mutation
Berlin	Timothy Ray Brown	2007 + 2008	AML	2007	2008 + 2009	"00"	CCR5Δ32/Δ32
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City of Hope	Paul Edmonds	2018	AML	2021	2023		CCR5Δ32/Δ32
Geneva	Romuald	2019	biphenotypic sarcoma	2021	2023	#34	WT/WT

# Communicating HIV Cure Science

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When I say I live in Downtown Eastside, ‘A’ they think I’m a user, “B” they want to know if I have any diseases. **They’re the stereotype questions that people think of from the outside. Listening is one of the hardest things to do** down here because a lot of people [that] got here [i.e. to the Downtown Eastside] have already formed their opinion. Just like a lot of people live down here have already formed their opinion from outsiders.

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*(Participant #1, Man, Black)*

# A Word About COVID

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The global pandemic disrupted everything, including media

- COVID has dominated the media landscape for almost two years.
  - Many journalists who never reported on health became COVID reporters.
  - Lots of worthy news stories never got coverage because COVID took all the space.
  - It's better now, but COVID is often still dominating news coverage in many places.
- Media houses downsized so working journalists are more stretched than ever.
- Mis/disinformation about science has become a major problem, but....
- More people know more about the research process now.

# Four Goals of Media Engagement

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- Minimize inaccurate, bad or confusing coverage
  - And know how to respond to it when it happens
- Reach our target audiences with high quality, accurate information they can use
- Develop lasting and respectful relationships with media practitioners
- Give journalists and advocates information they can understand and report accurately on

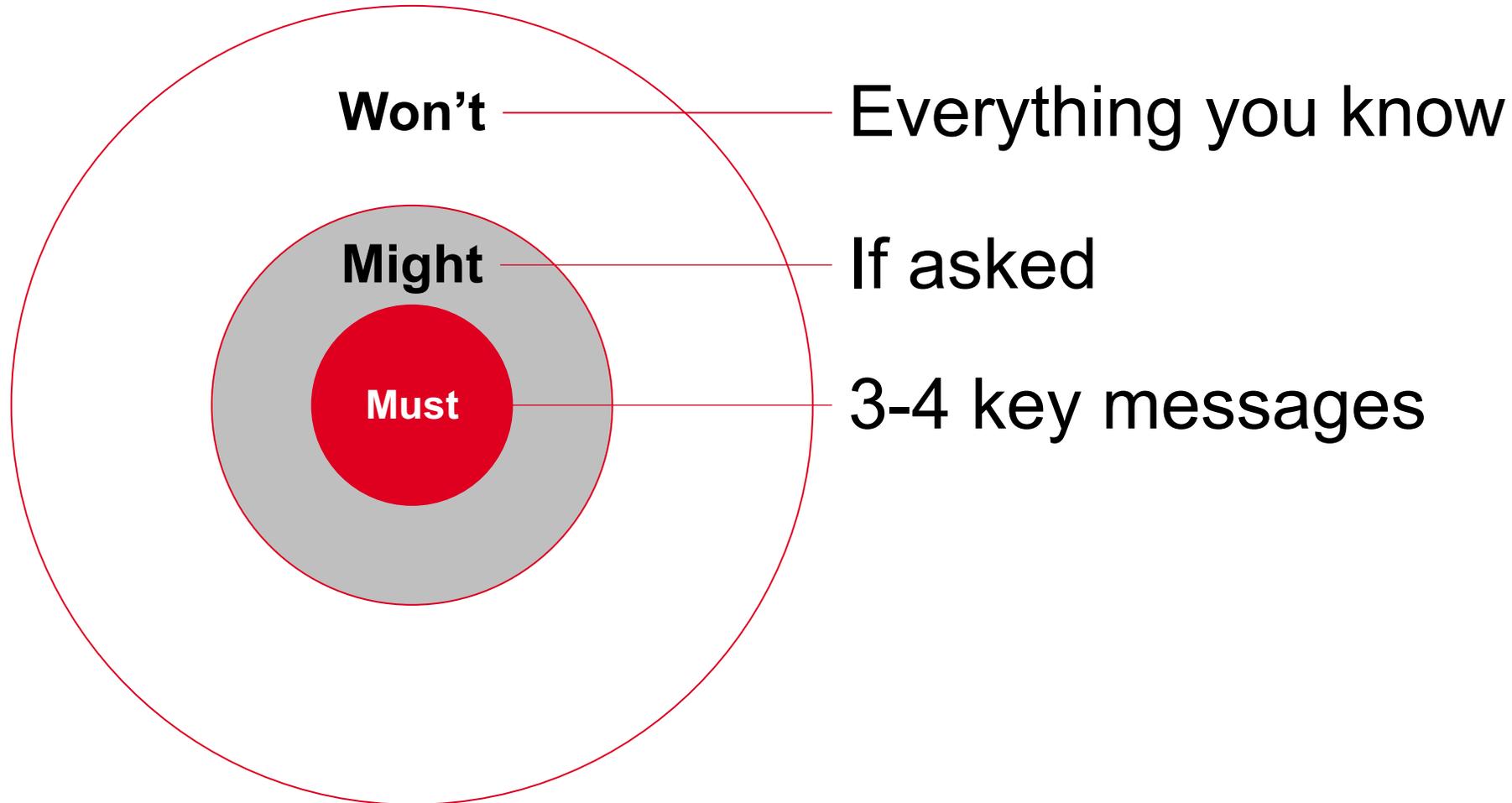
# Rules for Communication

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- Once information becomes **public**, you lose some control over it.
  - You can't control what reporters write about public information.
- BUT
- You can control:
    - **What** you say and **how** you say it
    - **What** information and context you provide
    - **How and if** you respond to inaccurate or inflammatory media coverage, social media memes, rumors, etc.
    - **Where and who** you make your response

# Message Target

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# Responding to Misinformation

- Do not panic.
- If a journalist publishes a misleading article or a social media personality misinterprets your data, *reach out* to him/her first to try to correct it.
- Respond quickly in form of a letter to the editor, opinion piece etc. Offer to go on a livestream platform.
- Build and generously use connections with local newsrooms/reporters/influencers.
- When the editor/publication doesn't respond to your first request, reach out again. Be persistent.
- If they don't respond...go somewhere else.



## END OF AIDS?

By [Emily Cook](#) 25/09/2009

# Responding to Misinformation

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- Carefully select your resource persons/authors to ensure that they have authority on the specific issue(s) they are responding to. *It's best to have local resource persons.*
  - *Make sure they are trained!*
- Beware that information may spread. *So always monitor multiple sources.*
- Share coverage with other research groups, advocates, policy makers and other allies. Others may benefit from it or may be able support you if a response is needed.

# Advocates, Journalists & Researchers

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- Part of your work is protecting the rights of participants, educating communities about research and doing good for your fellow humans.
  - Traditional journalists have a code of ethics and often see themselves as watchdogs for the public.
  - Advocates are watchdogs too.

Advocates and journalists:

- want to get the story right – but they need researchers to explain complicated terms and the research process and to **give them the human angle**.
- want an ongoing relationship not just a dump of information when you need them or want to get something out to the public.

# Social Media

## The good, the bad and the downright confusing

- Social media is people-powered.
  - You or your organization can share information directly with an audience, without going through a “traditional” media intermediary.
- There is a lot of “noise” on social media; sometimes it’s hard to break through that noise
- You need to build an audience and that can be difficult and time consuming.
- Social media is immediate and transitory. You can push info out quickly, but social media channels move fast, so it doesn’t always reach the right people at the right time.

Let's **unpack** The HIV Cure & Age | 12 04 2024 Instagram live 5pm EAT/10am ET

Your Host: Doreen Morocha | Jessica Salzwedel-AVAC | Dr. Allison Agwu

Towards an HIV Cure | AVAC Global Health Advocacy, Access & Equity | IAS

#women4cure

Hi, my name is Ms. Lusungu Harawa, a WomenforCure Advocate,

Currently working with the National Association for Young People living with HIV in Malawi as a Project Focal Point.

As Africa, we have not had a case of HIV Cure and yet we are burdened and with lost hope! As young people face adherence challenges with are almost non resolved., why not have a Cure to solve all these problems?

+3 548 833 916 herinblathwe@gmail.com @healthympower

Play (k) 0:32 / 4:23

/ 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

AVAC Advocacy. Access. Equity.

# 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**



**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-130pm	HIV Cure Research as a Tool to End the Epidemic	Brad Jones, PhD, Weill Cornell Medicine
130pm-215pm	HIV Vaccine Pipeline & HIV Prevention Pipeline	Maggie Sotomayor, MD, Columbia University Wafaa El-Sadr, 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 Saltzweid, MA, AVAC
3pm-4pm	Promoting Equity, Diversity and Access to Research	Jorge Sotelo, PhD, MPH, New York Blood Center Keasha Bond, EdD, MPH, CHES, City College of New York Dahshun Usher, MSW Rizzo Boone, MSW, MPH, MA, Treatment Action Group Adam Ward, MSc PhD Candidate, Weill Cornell Medicine Moderators: Jorge Benitez, Columbia University John Merade, MPH, AVAC
415pm-5pm	CAB for Prevention: What Communities Need to Know About Research to Introduction	Hong Vin Tieu, MD, MS, New York Blood Center Jessica Rodrigues, MS, AVAC
415pm-5pm	Exploring Diversity in Cure Research: Sex, Class and the West!	Adam Ward, MSc PhD Candidate, Weill Cornell Medicine
5pm-530pm	Introduction to REACH Collaboratory	Marina Caskey, MD, Rockefeller University Brad Jones, PhD, Weill Cornell Medicine
530-630pm	RECEPTION	

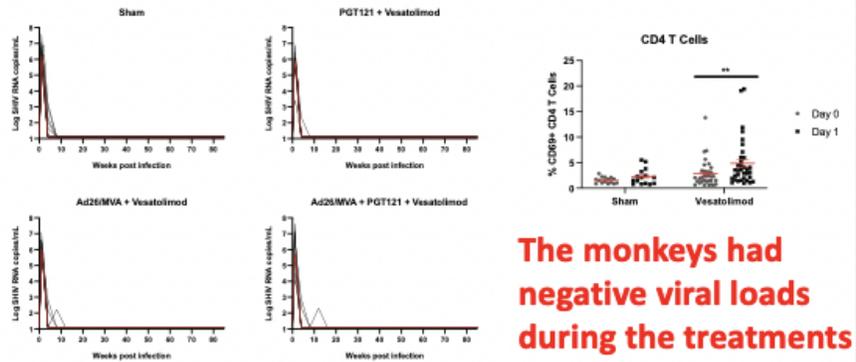


Join the conversation online, follow @anayd\_africa and #HIVCureResearch\_NG on social media

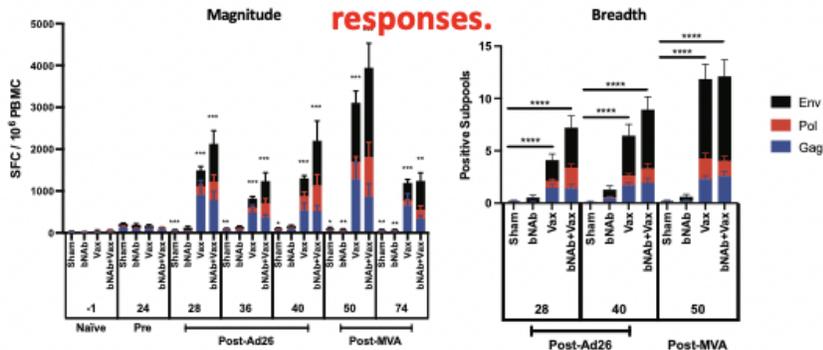


# Examples of Strong Slides

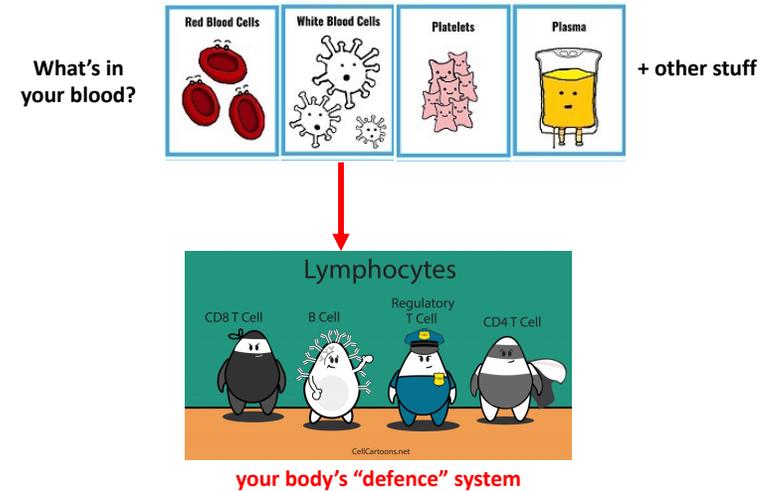
All animals were fully suppressed during treatments and prior to ART discontinuation despite significant vesatolimod-induced activation of CD4 T cells



Ad26/MVA vaccination significantly increases the magnitude and breadth of cell-associated IFNγ responses **The vaccine caused good immune responses.**



Why blood is so important (and amazing!) **Background Slide**



Courtesy of John Frater

Courtesy of Victoria Sperling-Walker

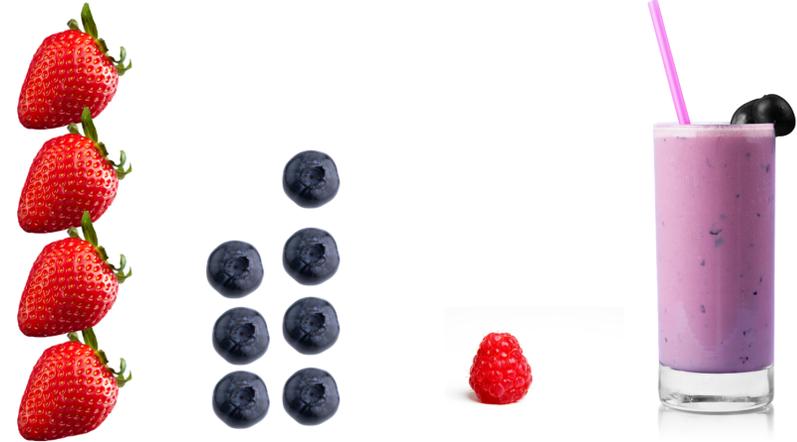
# Examples of Strong Slide Communication



Dave Margolis explaining the reservoir



Marc Wagner explaining latency and reactivation



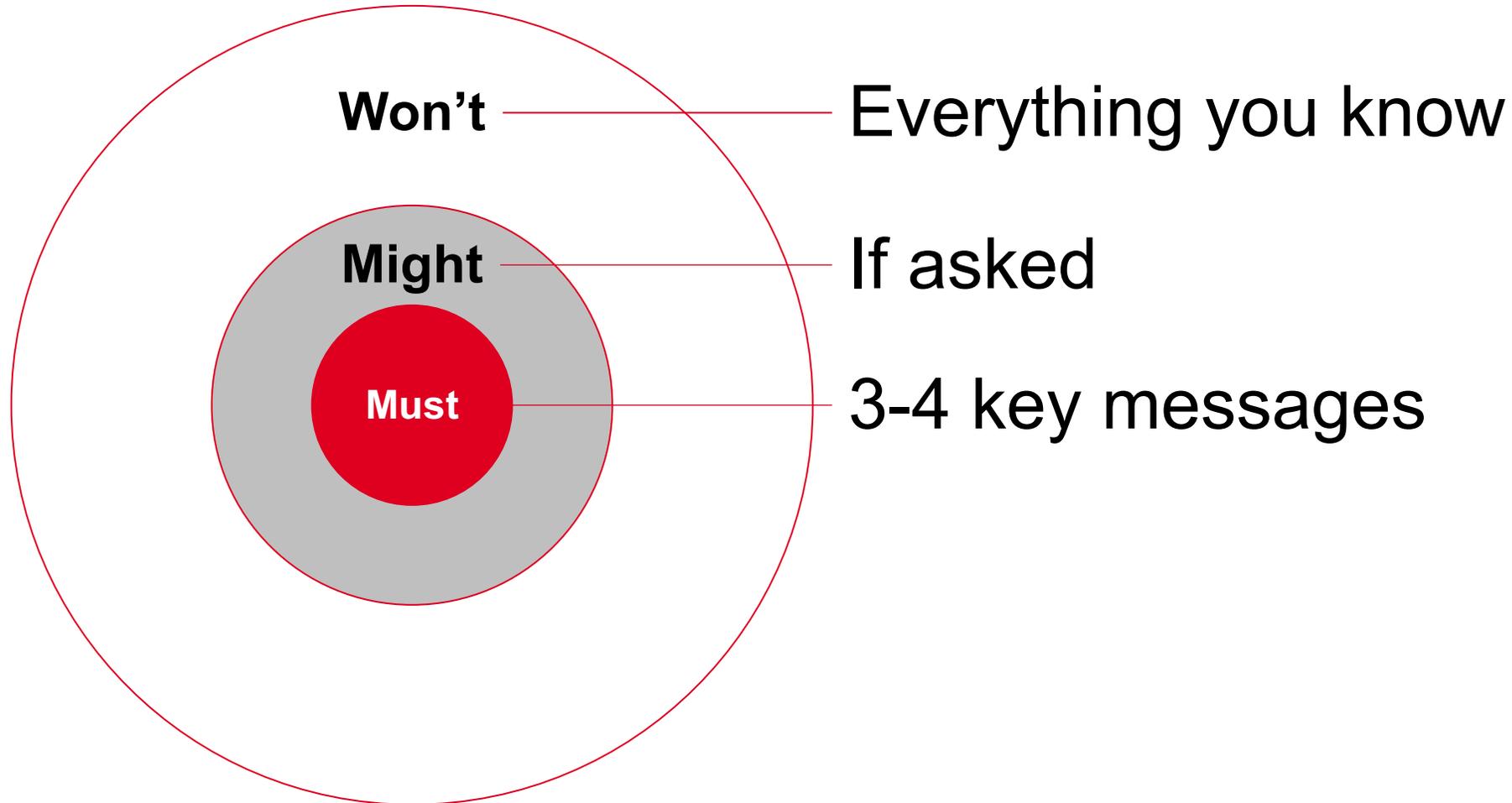
Ya Chi Ho explaining single cell analysis



Brad Jones NK-cell resistance to killing

# Elevator Message- Examples

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# The Dusseldorf Patient

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- This new case is another man who had cancer and achieved cure through a bone marrow transplant to keep his cancer. While this is really exciting and gives hope for the field, this is not a strategy being pursued for the field. Researchers are trying to learn from this case and develop more scalable approaches that can work for people without cancer. **(Flesch-Kincaid score 6.6)**
- This new case is exciting. But it is not a treatment everyone with HIV can get. Marc, the patient, had cancer and needed a new immune system to survive. The treatment to replace the immune system is dangerous, so it is only used as a last resort. The case still gives us hope because scientists can learn from it! They are working on ways to get the same results in people with HIV who don't have cancer.

**(Flesch-Kincaid score 6)**

# Plain Language

- Written and speaking materials should be at an 8<sup>th</sup> grade level or lower
- Flesch-Kincaid score
- Culturally appropriate (age and regional)
- Using person-centered language

## 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:**  
*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 Castelle** ("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**

**Loreen Wilenborg**  
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 [www.avac.org](http://www.avac.org)

Readability Statistics	
<b>Counts</b>	
Words	246
Characters	1,192
Paragraphs	24
Sentences	16
<b>Averages</b>	
Sentences per Paragraph	2.2
Words per Sentence	13.5
Characters per Word	4.5
<b>Readability</b>	
Flesch Reading Ease	73.3
Flesch-Kincaid Grade Level	6.3
Passive Sentences	6.2%

OK

# The Dusseldorf Patient- PWH

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## Key Messages

1. This treatment is NOT a viable strategy but provides a pathway for researchers to pursue.
2. Validating the excitement and hope

## If Asked

1. More details about Marc (type of cancer, duration on therapy, etc.)
2. More about the other cases
3. Introduce “natural immunity” and discuss how rare it is

## Never

1. Regimen of chemotherapy or ART involved
2. CCR5 or delta32 mutation

# The Dusseldorf Patient- Social Media (Africa)

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- This case is one of seven people, who had cancer, cured of HIV. Each person had cancer and needed a dangerous procedure called a stem cell transplant to get rid of the cancer. A stem cell transplant replaces the person's immune system with someone else's. Since the procedure can cause death, doctors use it as a last resort. There is still hope! Researchers are learning how to train body soldiers to find and fight HIV better. **(Flesch-Kincaid score 6.3 )**

# The Dusseldorf Patient

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## Social Media Interview- Africa

### Key Messages

1. This treatment is NOT a viable strategy but provides a pathway for researchers to pursue.
2. Validating the excitement and hope

### If Asked

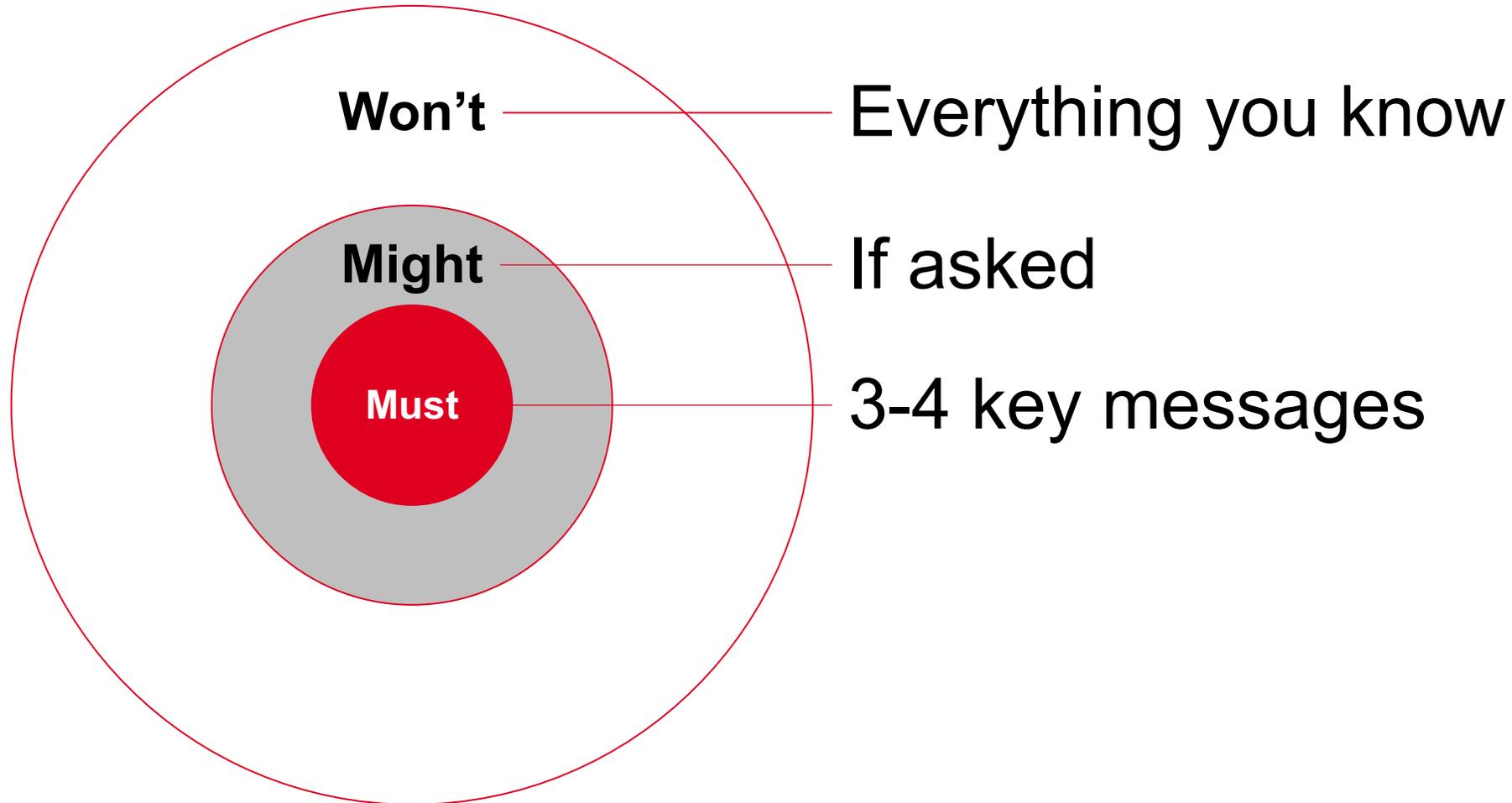
1. More details about Marc (type of cancer, duration on therapy, etc.)
2. More about the other cases noting the pediatric cases from Africa

### Never

1. Describe the process of stem cell transplantation
2. Regimen of chemotherapy or ART involved
3. CCR5 or delta32 mutation

# Message Target- Elevator Pitch!

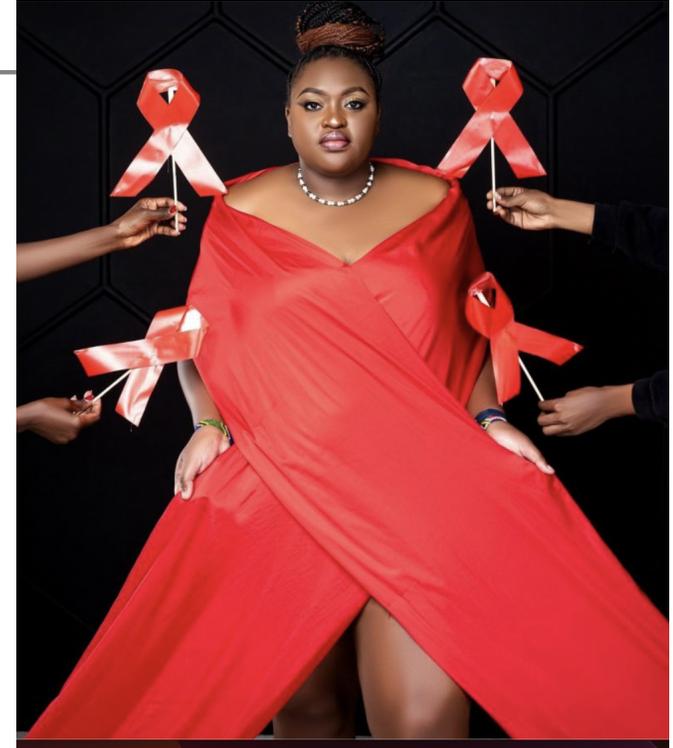
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# Get Involved!

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- MDC program works with media influencers
- Practice at CAB meetings
- Take advantage of CFAR programs
  - CABs can review slides
  - Suggest questions
- Utilize media training at institutions
- Consult with community groups



**Raif Derrazi**  
@RaifDerrazi · 42.5K subscribers · 290 videos  
In 2012, on my birthday, I was diagnosed with AIDS. Since then I've fought hard to reshape...more  
[instagram.com/raifderrazi](https://www.instagram.com/raifderrazi) and 3 more links

Subscribe

# Thank You!

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## AVAC

- Angelo Kwagga-Katumba
- Kay Marshall
- Alison Footman



Towards  
an HIV Cure  
 IAS

