

from the beautiful HIV+ community

MARCH 2023

# BEAU



№ 4

# BEAU

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LETTER

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by Marc Thompson

Hello world and welcome to issue 4 of BEAU.

After a long winter we are moving slowly into spring. A time for new growth and renewal, both things we champion here at BEAU.

Every issue of our magazine means a lot, but this issue particularly resonates with me.

Following on from our conversations about migrant men, older men, and young guys living with HIV, we turn our lens onto the lives of Black queer men.

First the facts: Black gay, bi, and queer men are disproportionately affected by HIV globally. In the United States the risk of acquiring HIV is one in two if you are a Black gay, bi or queer man. Once we are diagnosed, we also face more challenges around being engaged in care and support and we are more likely to have lower rates of viral suppression (being undetectable). In the UK the situation isn't as dire as the United States, but things are far from perfect.

Discrimination, homophobia, and stigma are well documented as challenges that put communities at

risk of HIV. For Black queer men the added impact of racism is a very real factor. COVID 19 shone a light on the health inequalities in the UK faced by people from racially minoritised communities and Black queer men are not immune from these. It should come as no surprise that we see this disparity in HIV and sexual health.

As a Black gay man living with HIV, for many years I felt I was the only one. I rarely saw people that looked like me in the spaces I went for help and support. When I looked at the stories being told about people living with HIV, Black queer men were certainly missing from the narrative.

I'm so pleased and proud that in our main feature our cover star, actor and activist Taofique Folarin, shares his story and speaks to other Black queer men to uncover what being "Black, Queer, and Positive" means to them and how they thrive and survive.

Black queer men are connected across the diaspora. So, what happens to our lives here in the UK is impacted by what happens to our brothers around the world. In our second feature Kenyan born and South African based, Human Rights lawyer and activist, Anthony Oluoch tells us what it means

to live as a gay man with HIV on the African continent.

Continuing the conversation, I'm delighted that one of my personal heroes, Rev. Jide Macaulay features in This Much I BEAU. Jide has been involved in HIV activism since the 1990s and as an openly queer and HIV positive Anglican priest he has used his platform to challenge HIV stigma and homophobia across the globe.

For our regular features in this issue, Simon Collins provides all the latest news from the Conference on Retroviruses and Opportunistic Infections (CROI), in The Basics we break down clinical research and explore the history of some of the most significant studies into HIV since the start of the epidemic and we have a coffee date with the very lovely Carl.

We'll be taking a short break over Spring but will be back in the summer with more great content from our Beaus.

If you'd like to share your story in a future issue of BEAU, we'd love to hear from you. Get in touch and tell us about being part of our beautiful HIV community.



# News with Simon Collins Round-up

## The latest in HIV treatment & news

Simon Collins is an HIV positive treatment advocate at [i-Base.info](http://i-Base.info) which he co-founded in April 2000. i-Base supports HIV positive people to take an active role in their own health care.

### Future ART: looking forwards

The most important news about HIV treatment and prevention every year is presented at the Conference on Retroviruses and Opportunistic Infections (CROI). Highlights for BEAU from this year's meeting in February are summarised below.

Many more detailed reports are linked here:

[i-base.info/htb/keyword/croi-2023](http://i-base.info/htb/keyword/croi-2023)

### CROI opening talks

Webcasts for the whole CROI conference are open access from the end of March. This makes it easy for anyone to see the presentations.

The opening talks are already online and include a dynamic and moving presentation from South African activist Yvette Raphael. A 30-year review of HIV research by Anthony Fauci is at the same link:

<https://www.croiconference.org/>

### Twice-yearly ART: taken once every six months

The newest HIV drug - lenacapavir - is so potent that it only needs to be given as a small injection under the skin once every six months. It is already approved, but so far, only for people with extensive drug resistance.

Lenacapavir needs to be used in combination with other HIV drugs, ideally that also use 6-monthly dosing. CROI included first results using lenacapavir with two long-acting immune-based drugs called bNAb's.

In a small study, 20 people who had been undetectable on oral ART for at least two years, switched to a single injection or infusion of each of these drugs. In 18 of the 20 people, viral load stayed undetectable without any other treatment for six months. One person stopped early (even though their viral load was still undetectable) and one person went back to oral meds because their viral load rebounded. These results were impressive and larger studies are already running.

### New ways to take ART and PrEP

Several studies looked at easier ways to take meds:

- Injecting long-acting cabotegravir and rilpivirine into the thigh muscle rather than the buttocks: This might mean being able to give yourself these injections, rather than having to go to the clinic every two months.

- Being able to take PrEP as a suppository (putting a pill in your bum) rather than as an oral pill: Advantages might be personal preference and getting good drugs levels in genital and rectal tissue more quickly. Do not try this with current PrEP as different drugs were used in this study.

- A new combination that only involves taking one pill a week: This will use doravirine and islatravir and studies are due to start shortly. Islatravir is another very potent drug. The daily dose is 0.25 mg and the weekly dose will be only 2 mg.

### PEP for STIs

HIV PEP involves taking a combination of three HIV drugs every day for a month. If started early enough after sex PEP can prevent someone becoming HIV positive.

Several studies at CROI showed that the antibiotic doxycycline can work in a similar way against some STIs.

French and US studies showed that a single dose of doxycycline (doxy), taken within 72 hours of sex dramatically cuts the risk of syphilis and chlamydia. This is called DoxyPEP. In some countries it can also reduce the risk of gonorrhoea but not in France (or likely the UK) because of high rates of drug resistance in Europe.

The French DoxyVAC study showed that a vaccine against meningitis (4CMenB) also halved the risk of catching gonorrhoea. People taking DOXY in this study were also roughly 90% less likely to catch chlamydia and 80% less likely to catch syphilis.

The study planned to randomise 720 gay men but was stopped early in August 2022 after the first 502 participants because the results were so good.

Participants had been using HIV PrEP for over three years. They had an average of 10 partners in the previous three months and all had had at least one STI in the previous year.

This is the same research group that ran the IPERGAY study using 2:1:1 on-demand dosing for HIV PrEP.



# Coffee date

with  
Carl Chandler

Each issue, we profile 'regular' positive guys and highlight how they live well, and beyond their HIV status.

61 year old Carl has been living with HIV since 2004. He's a former IT programme manager working for major corporates, and now enjoys travel and his motorbike. He's London born and bred and loves its cosmopolitan life.

**Hello Carl!****Tell us a bit about what you do and what you enjoy about it.**

Hi, I'm 63 and live in Vauxhall, London. I was diagnosed on 30th April 2004. I took early retirement about five years ago after a stressful job in IT management, and I'm loving life now - having the time to enjoy the little things in life is great for my mental health. It's also great for those who had to live with the ogre I was before!

**How does HIV impact your daily life?**

My HIV doesn't affect me day to day. I take one pill among the many others I take to stay healthy including vitamins and pills for hereditary high blood pressure.

**What do you know now that you wish you'd known when you were first diagnosed?**

When I was first diagnosed, I genuinely thought I was going to die - I'd had a partner and many friends who died in the early nineties. Thankfully some good friends who also have HIV pulled me out of that pit, so having positive and happy role models meant everything. However, I wish I'd kept up to date on how medication had radically changed the world for people living with HIV.

**How do you 'live well' with your HIV?**

Living well for me means staying healthy as I get older, watching my diet (well - I try!) and getting enough exercise. I want to enjoy my

retirement - there's lots to do and see. I've had a motorbike since I was 21, and I still enjoy going for a ride with friends or by myself - there's a kind of zen 'being-in-the-moment' that you have on the bike, an awareness of your surroundings, of everything that's happening on the road as well as the countryside around you. I got a car during lockdown to visit friends, and though it's a luxury to have in London it also gives me lots of pleasure to just get out of town when going on the bike is impractical. Warmer too in this weather!

**How do you stay connected to your community?**

I've been into leather since I was about eleven. When I was a teenager, I would even go to motorbike shows just so I could 'innocently' brush against guys in full leather; these days there's lots of social activities for guys into gear - the monthly leather social held at Comptons and the monthly London Leathermen events at the Duke of Wellington pub, both in London's Soho. Of course, we all regret the closing of Backstreet, London's oldest and last leather bar. I've made some great lifelong friends on the leather scene.

I also sing with the London Gay Men's Chorus. When people say there's no real gay community in London I point to the Chorus. There's people from all walks of life but you're not defined by what you do, only by who you are.





And there's something about singing that really brings people together. If I'd had a crap day at the office, I could go to rehearsal thinking 'I don't wanna do this' and by the end of the evening I'd forgotten all the work worries and I'd had a great time. It's also very social; with so many members you can find like-minded people, and also people you wouldn't have thought you'd click with, but you end up loving.

**What advice would you give to your 17-year-old self?**

If I could talk to my seventeen-year-old self I'd tell me that being gay isn't the frightening thing I thought it was. I'd also tell myself to take more chances; I've often been risk averse and sometimes wonder how things would have turned out if I'd taken a few different paths rather than being Captain Sensible. Life is for living, so grab it by the throat - I'm trying to live like that now.

*Carl's favourite things*

**Books**

Two of my all-time favourites are *Dancer from the Dance* by Andrew Holleran, a story of life and love in New York in the 70s. The description of

clubbing and how they reacted to those perfect tunes on the dancefloor echoes my own clubbing days at Trade - very different music but a similar vibe.

The other is Felice Picano's *Like People In History*, a novel spanning three decades of gay life in New York and Fire Island. I found many echoes of my own life in this book.

**Films**

As a young gay man I was expected to be familiar with the 'gay classics' which unfortunately don't seem to get passed down the line these days, so at the risk of sounding like an old fart I'm going to recommend *The Women* - not the ghastly remake but the glorious 1939 original. Featuring only women on screen, it has cracking one liners, Joan Crawford being a superbitch, as well as Rosalind Russell, Paulette Goddard and Joan Fontaine. Yes, it's in black and white, but trust me it's worth it.

Also shout-outs for *Now Voyager* (Bette Davies as an old maid turned glamorous society hostess having a steamy affair on a cruise) and *The Lion in Winter* (Katherine Hepburn and Peter O'Toole battling it out in the 12th century. Oscars for Hepburn and for the screenplay - sizzling dialogue).

Right ... having recommended it, I'm going to re-watch *The Women* - it's been a while since I saw it. *Jungle Red!*



SPOTLIGHT

# Alex Muto



aniamo  
MUTO



All photos: MUTO

**Alex Muto, 32, artist/designer.**

Alex was born in Leicestershire to a British mother and an Italian-born father. He has an identical twin brother who is 57 minutes older than him, which he tells us is quite a long time for twins! Growing up you could always find them immersed in their own little world, encouraged to be creative with whatever they could get their hands on. 'It feels like creativity is in my DNA' he says and that's always provided a safe space for him to express himself, enabling him to share the way he experiences the world.

He studied Fashion Design at Westminster University and graduated with a BA in 2014. This was followed by design positions at Tom Ford, Gucci and Burberry. During this time he really struggled in these environments, recognising that his values and beliefs didn't align with the culture of the industry. He began to feel more and more unhappy and found himself in a dark place.

A deep depression combined with his HIV diagnosis in April of 2018 caused him to take a step back and re-evaluate the direction his life was taking. With

the help of a fantastic therapist and the support of those closest to him, he made the decision to bring about some big changes. With the goal in mind of creating a simpler existence, he left his job and relocated to the peaceful countryside where he slowly began to reconnect with who he was.

A big part of his rehabilitation was about reclaiming that creativity for himself. From a little studio setup in the corner of his bedroom - making sure to stay true to the idea of keeping things small and simple - he carefully began crafting his own vision of a brand he could feel proud of.

To Alex, MUTO is so much more than just a fashion clothing brand. It's an online shop space where he can showcase all of his personal designs and creations. From hand painted t-shirts and printed shadow-stripe shorts to specially sourced vintage jewellery and one-of-a-kind artworks.

All his designs are inspired by his Italian heritage with a nod to retro sportswear and a hint of playful nostalgia. It's so important to him that



SPOTLIGHT

I feel so fortunate to be living in a time where my HIV diagnosis *doesn't define who I am* and that this can be viewed as one of the *least interesting things* about my life.

the brand be inclusive, joyful and not take itself too seriously.

He has a lot of fun screen printing and painting every item himself. 'After working more digitally in the corporate world, it feels so creatively fulfilling to get back to being more hands on again' he tells BEAU.

He's come to appreciate how every human has their unique personality, and how handmade products can reflect that. He believes there's an undeniable magic and beauty that can only be achieved through the imperfect human touch.

Rediscovering his love for creativity and reconnecting with his younger self has been such a healing experience for him. 'It feels wonderful to be back in a place where I feel healthy and inspired again' he adds and he's looking forward to seeing where his creativity leads him next.

To see more of Alex's work visit:  
[www.alexmuto.com](http://www.alexmuto.com)  
[@mutoitalia](https://www.instagram.com/mutoitalia)





FEATURE

# Black, queer, & HIV+

despite the disparities

by Taofique Folarin

We are born into this world without labels or attachments. It's not long before we are placed in categories of nationality, race and gender, then subjected to the schemas of humanity. Race undeniably becomes a significant part of our identity, whether actively or subconsciously, and when the time comes this is followed by sexuality.

The intersectionality for Black, Queer and HIV Positive Men (BQPM) is tenfold. We travel through life as Black queer men, already belonging to two marginalised minority groups, with their unique complexities to navigate and barriers to overcome. We learn to stand tall in the face of adversity and keep moving forward, holding onto our joy despite the racism, discrimination, homophobia and hate that in varying degrees is sure to come our way. The addition of living with HIV in the 21st century makes my journey - our journey - unique, sensitive, and complex and brings with it the challenge of overcoming HIV stigma. This itself intersects with racism, homophobia, and transphobia, making it much harder to decipher and resolve.

For this feature I had the honour of talking with two Black queer men who are living with HIV. Peter Fleming, 55, is a Social Enterprise Board member and South-West London HIV Representative. Peter has been living with HIV for over twenty years. And Topher Campbell, who was diagnosed over five years ago, identifies as Afro-Queer, is an artist, filmmaker, theatre-maker, and founder of the Rukus! Archive. Both openly and

authentically shared their story, experiences, hopes and fears with me. Our unique stories speak of strength, resilience, and courage. I salute them both and all my fellow positive Beau Black kings.

Contrary to depictions in the media, Black queer men and Black queer men living with HIV in particular, are not a homogenous group and should not be treated as one. Peter and I were both diagnosed in our twenties, Topher later in life. Topher told me that when he was diagnosed, he was not a young person trying to find himself interrupted by HIV, but a grown man who needed to respond to a sudden shift in identity and outlook.

As someone who identifies as BQPM, it has been a roller coaster journey to get to a place of loving all these aspects of myself, and today I can proudly say that I do. Although they do not define me, over time they have given me purpose and facilitated self-discovery and a deeper understanding of who I am. Topher too spoke of how his diagnosis enabled him to be more compassionate and introspective in ways he would not have experienced.



Black Queer Men are still at higher risk of HIV in the UK, and globally we are disproportionately more likely to be diagnosed with HIV than white gay men. I have been living with HIV for over ten years. I am happy, healthy, and grateful. I take a pill every day to keep my viral load undetectable and my HIV does not currently impact on my physical health or my life directly. When I received my diagnosis time just froze and yet my world continued moving. For a long time, I felt I was merely a passenger, observing. There I was, sitting in front of a white middle-class doctor who, after giving me what I thought was a death sentence due to my lack of knowledge on the subject, told me that I would live a ‘normal’ life with the same life expectancy as a negative person. And that living with HIV is no different to having a long-term manageable illness such as diabetes. Hearing this prognosis did not make me feel any less fearful. Peter talked of a similar experience telling me ‘It didn’t register at the time...I was hit with denial, thinking it was a mistake until it was confirmed.’

Like Peter, I could barely process what was being said to me, what was happening and what this now meant for my life and my future. The fear of retribution from the world and my irrational mindset of not wanting to burden anyone led me to shut down and close off from people I loved. I attempted to navigate this new diagnosis alone. Topher expressed a feeling of loss and disorientation upon

his diagnosis, with the compounded effect of previous trauma ‘because all the old memories and grief resurfaced. Too many funerals, too many friends and old lovers dead.’

Black men living with HIV in the UK face numerous barriers. However, the three of us were all happy with our first point of access to care and recounted a successful experience with an outstanding job from our clinics, which certainly helped when it came to our future engagement with HIV care. Peter recounted that ‘I found the people at the clinic treated me in a satisfactory way. If my needs [had] been more complex, then it’s likely it would not have seemed so clear to me, as a matter of simply trusting the process’.

During our formative and adolescent years, all three of us were provided with an armour of tools, and we learnt behaviours to lean on, especially when navigating hyper-masculine, homophobic environments, music, and interactions. For survival, it may have been necessary to hide parts of ourselves, speak up for ourselves, and in some circumstances, destroy ourselves. We’ve endured racism, micro-aggressions and fetishisation. All this alongside the losses, peaks and troughs that are inevitable in life. But as Topher rightly points out, ‘the culminated trauma of racism and homophobia contributed to issues of self-esteem, guilt, loneliness, abandonment, and abuse’.

We know HIV stigma has a real impact on people's lives, but it can also hinder access to healthcare and support. When I was first diagnosed, I used to dread my doctor’s appointments. I was scared someone I knew seeing me and finding out. Like many Black queer men, I was proficient at hiding parts of myself, and this became a valuable tool for not disclosing my HIV status. The skills and tools we develop as Black queer men to survive have been valuable in helping us to live with HIV. As Peter noted, ‘I have developed skills as second nature that served to help me deal with challenges that otherwise would have been more difficult to navigate around and adapt to’.

There was a time when it seemed impossible to tell family or friends. The idea of coming out for a second time was unfathomable. I know it was an unhealthy decision for my wellbeing not to reach out and talk to someone. I can trace back my insistence to go it alone to my childhood. I grew up in a single-parent household with a successful, ambitious, and strong mother. From a young age, I decided my goal was to make her life easier. I had already witnessed the harsh world Black women have to navigate. It was at this time that my self-actioned responsibility and the unwarranted burden that I took on to be the man of the house was embedded. Eventually, I realised that carrying the weight of my diagnosis alone and maintaining an external

image that everything was OK only served to damage my mental health. The moment I started living for myself again, making decisions to reclaim my power and control my narrative, I found community, bringing purpose, love, and more understanding than I ever imagined. I discovered that we are part of a massive community, and we are not alone. Telling my family, like my sexuality, was one of the most challenging but beneficial things I have ever done. The effects of stigma can be subtle, making forming meaningful relationships and building social networks challenging. I became very good at keeping people, old and new, at arm’s length, never letting them close enough. The effects manifest themselves today as social anxiety and low self-esteem.

Telling others about our HIV is a very personal thing and should always be down to the individual. We all discussed the main barriers to telling family, friends, and work. Topher commented, ‘I know stigma exists; therefore, I do not disclose my status in questions about health conditions or long-term conditions, on monitoring forms and so on. There is no room given to the sensitivity of disclosure about HIV. It is not like saying one is diabetic or has cancer. In this respect, I self-censure’.

Even though I have worked in sexual health for some time, this article will be the first time I have openly discussed my status in the public



"Like many Black queer men, I was proficient at hiding parts of myself, and this became a valuable tool for not disclosing my HIV status. The skills and tools we develop as Black queer men to survive have been valuable in helping us to live with HIV."

sphere. As an actor and a figure in the public eye, I also agree with Topher's approach to telling others. He told me that he wanted to be able to position his experience in a way that benefited others whilst also shedding light on the very serious personal consequences. I often wonder about the empowering and reassuring impact that seeing BQPM in HIV awareness campaigns would have had on my journey, had they existed at the time.

In terms of dating, Topher informed me that his more intimate romantic relationships have not suffered because of his HIV status adding 'My partners have had a consistent and intelligent approach to their sexual health and wellbeing. They've been so clued up, which has been a relief and a revelation that has helped me regain confidence and self-worth considerably'. Peter recounts a similar narrative: 'I refused to let my dating life suffer and was upfront with sex partners that my viral load was undetectable, and I could not pass on the virus. I found the approach of conversation created a sense of respect for us which made us both more personable and appreciative of our sexual health and well-being overall'. Topher however also hinted at the more negative mental health impacts telling me that 'for some time after my diagnosis, I was convinced that I would never date or find a significant partner. I spent much energy going to the gym and focusing on being a "fuckboy" or "fuckman"'

Mental health and wellbeing were a recurring theme that emerged from our conversations, as was the importance of maintaining one's state of mind when living with HIV. Before my diagnosis, mental health was not particularly on the radar. I never questioned it, probably because I didn't have the knowledge or the vocabulary to do so. Instead, I carried around a 'I can handle anything attitude' and 'I must be strong' mentality which I developed in my childhood. In contrast it was my diagnosis that taught me that it's OK to ask for help and I discovered the true power of community and communication.

When rates of depression, anxiety, self-harm and suicidal thoughts are known to be higher in Black men, why are we less likely to seek help for our mental health problems than white men? From my experience, the reluctance to engage was due to my own lack of understanding around mental health as well as the challenge in overcoming its stigma. This was also compounded by a subtle mistrust of the system. If I feel my experiences are not understood or valued, I find engaging with services challenging.

I accessed Terrence Higgins Trust and NAZ support services. Both gave me a safe space to express my feelings and benefitted me to varying degrees. My race was not a topic of conversation in either service, and neither service was delivered by Black male practitioners or clinicians. This arguably created

a natural distance and reduced relatability between me and them. I am forever grateful for these services and the work they continue to do. However, a lack of awareness, fear of the system, and perceived or internalised homophobia can mean BQPM might struggle to access the information and support relevant to our specific needs, particularly in relation to our cultural and ethnic backgrounds.

There is also, historically, a lack of trust in the healthcare system from Black men, which may add to the lower levels of engagement on top of the lack of culturally sensitive services available. Topher told me that although he hasn't personally experienced racism in the health system, he does feel that mental health and well-being services could better cater for Black and racially marginalised people. An HIV diagnosis can be disempowering and might put us at a higher risk of developing poor mental health. This was the experience of all three of us. Peter highlighted that 'we need more of the quality space some are creating and hosting, also to keep people in care once diagnosed, more stigma-free, happier and more in control of treatment with living with the condition'.

I asked the guys what advice they would give Black men who have been recently diagnosed or are struggling with their HIV. Peter expressed it like this: 'know that there is a way through this, that [a diagnosis] is not

shameful or necessarily disruptive to how things were before. Also, it is potentially an opportunity more than an obstacle for a new insightful beginning of belonging to a unique and broad community with long interconnected experiences of friendship, backgrounds, and occupations.' For Topher, it was some salient points, perhaps even a mantra to live by: 'Stay strong. Be vulnerable. Take medication. Develop wellbeing habits and skills. Be honest with yourself. Look after your physical health. Take your time when it comes to public disclosure. Seek advice and counselling if needed. Take your time. Love yourself'.

Despite advances in HIV prevention and treatment, HIV stigma seems harder to budge. It can have severe consequences and takes many forms, including discrimination, prejudice, and social exclusion. Societal stigma and self-stigma are something I have been working through since my diagnosis to get to a place today where I can take ownership of my health and my status without fear. That's not to say I don't still struggle, but with organisations such as the Love Tank, House of Rainbow, NAZ, and Terrence Higgins Trust, I now know there is support for me and a network to access. Peer support has played a crucial role in my health. There was a time I felt isolated and lonely, but through access to support services, I found commonality alongside a welcoming community. They provided



the opportunity to connect with others in similar situations, which massively reduced feelings of isolation and improved my mental health. Community-based organisations like these can play an essential role in ending HIV stigma by providing support, education, and advocacy.

Ending HIV stigma in the UK and specifically in the Black community requires a multi-faceted approach. We, as Black men, are stigmatised from general society and within our communities. Peter commented, 'the HIV negative public need to understand that living with HIV is a treatable health condition that doesn't discriminate. Role models from our community would help too!' That's true and it is essential to educate the public and our Black communities about HIV: how it is transmitted, how it can be prevented, dispelling myths and misconceptions about it and reducing the fear and stigma that surrounds it. The media has a significant role to play, too, in shaping public attitudes which is why BEAU is so important. By promoting positive, diverse, and accurate representations of people living with HIV, the media can help reduce stigma and encourage empathy and understanding from all communities.

I asked the guys what thriving with HIV meant to them. Peter: 'Thriving with HIV to me looks like living one's life contrary to narrow perceptions and self-limiting beliefs with a real and

growing sense that any possible good can come through grabbing it by the horns and making the journey with others an open book.' Topher: 'I am not sure what thriving with HIV means but living with it means being honest with yourself and your body and taking care of your physical health, taking care of your mental health, and living as much of a "normal" life as possible. Thriving means the same as if one is HIV negative. Seek to thrive in life as a human being.'

Together, I believe we can break down the barriers that prevent Black men from accessing the care and support they need. We can build a world where we can all live healthy and fulfilling lives, free from stigma and discrimination. By coming together, we have the power to create lasting change and ensure that everyone has access to the resources and support they need to reach their full potential. Let us join forces and work towards a brighter future where all people, regardless of race, gender, sexual orientation, or any other identity, are valued and celebrated for who they are. Let's turn hope into action so that, despite the disparities, we may live.

Our lives matter.



# BEAU Basics: Clinical research

Across the last issues of Beau, we've looked at the history of HIV treatment and explained how it works to keep us healthy and prevent the replication of the virus.

It's a long journey from discovering the treatments that help to manage our HIV to getting the drugs into our bodies.

We also know that living with HIV goes beyond taking medication. HIV can impact our mental health, our behaviour and how we engage with the world.

Since the start of the HIV epidemic research has been central to understanding how medications might work, the impact they have on our bodies and lives, and how HIV impacts our well-being.

HIV research over the past 40 years has helped identify the virus, developed the range of treatments available to us, helped us better understand when to start treatment and the role of treatment in the prevention of HIV, U=U - Undetectable=Untransmittable and PrEP.

In this issue we explore what clinical research is and why it's important, what getting involved in research might mean for you and the stories of some of the most important trials that have got us to where we are today and will inform the future of HIV treatment and care.

## What is clinical research?

Clinical research is the study of health and illness in people.

Researchers and scientists may have many reasons for doing a clinical study, such as:

- To explore the cause of a disease or a set of symptoms
- To test if a treatment will help with a symptom or condition
- To learn how a certain behaviour affects people's health

There are two types of clinical research: **observational studies**, and **clinical trials**.

**Observational studies** observe people in normal settings. Researchers gather information, group volunteers according to broad characteristics, and compare changes over time. For example, researchers may collect data through medical exams, tests, or questionnaires about a group of older adults over time to learn more about the effects of different lifestyles on cognitive health.

**Clinical trials** are research studies performed in people that are aimed at evaluating a medical, surgical, or behavioural intervention. They are the primary way that researchers find out if a new treatment, like a new drug or diet or medical device (for example, a pacemaker) is safe and effective in people. Often a clinical trial is used to learn if a new treatment is more effective and/or has less harmful side effects than the standard treatment. Other clinical trials test ways to find a disease early, sometimes before there are symptoms. Still others test ways to prevent a health problem. A clinical trial may also look at how to make life better for people living with a life-threatening disease or a chronic health problem. Clinical trials sometimes study the role of caregivers or support groups.

A well-designed clinical trial is the gold standard for proving that a treatment or medical approach works, but clinical trials can't always be used.

## Clinical research: Explained (continued)

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For example, scientists can't randomly assign people to live in different places or ask people to start smoking or eat an unhealthy diet.

### Why is clinical research important?

Modern medical care is based on evidence. This means using treatments or strategies that have been proven to work in research studies. Before clinical research, medical care was based on guesswork, expert opinion, and traditional practices. Evidence from well-run studies helps to overcome this.

### Why is it important that people and communities get involved in clinical studies and research?

HIV activists have always argued for active people living with HIV (PWHIV) to be involved at all stages of our health care, including research.

This includes being involved in which studies are needed and how they are designed.

The involvement of PWHIV helps make sure:

- That the studies are run properly.
- That all participants receive at least current standard-of-care treatment.
- That enrollment runs well.
- We are included in monitoring and following early results.
- As patients and advocates we have a good idea on how latest treatment advances may affect the standard of care in the future.

People may choose to join a clinical trial for various reasons. Some people join a trial because the treatments they have tried for their health issue did not work. Others participate because there is no treatment for their health issue.

By taking part in a clinical trial, participants may find out about new treatments before they are widely available. Some studies are designed for or include people who are healthy but want to help find ways to prevent a disease, such as one that may be common in their family.

## Key studies in HIV research

### FIRST REPORTS OF SYMPTOMS - DECEMBER 1981

This was the first study that identified an outbreak of *Pneumocystis carinii* (pneumonia) amongst gay men and drug users (including gay men who were drug users). Testing revealed that the occurrence of this infection that is usually easy to fight off was caused by a suppressed immune response, which suggested these communities might be dealing with an unknown disease that attacked the immune system. This would later be defined as AIDS and, by 1983, it would be understood that this was caused by untreated infection with a new virus called HIV.

For more info, see:  
<https://www.nejm.org/doi/full/10.1056/NEJM198112103052402>

### AZT: ACTG 019 STUDY

In 1987, after AZT was approved for use in the USA - because it was shown to increase the likelihood of survival in patients with AIDS - there was some debate about how early on patients should be given the drug. This was until the AIDS Clinical Trials Group ran a study (ACTG 019) on 3200

patients living with HIV but who had no symptoms and found that a low dose of AZT (500mg per day) significantly delayed the progression of AIDS in patients who had T-cell counts of below 500 cells per cubic millimetre. This was used as an argument for early treatment (even in patients without symptoms), although there was some concern about whether AZT could become toxic if used by patients for a prolonged period of time.

For more info, see:  
<https://www.nejm.org/doi/full/10.1056/NEJM199307293290510>

### DELTA

The use of AZT alone in PWHIV only had a small benefit so the Delta trial - the results of which were published in 1996 - tested whether combinations of AZT with other available antiretroviral medications - didanosine (ddl) and zalcitabine (ddC) - would be better at improving the chances of survival of PWHIV. The study found that a combination of AZT and either ddC or ddl improved survival in patients compared to AZT alone. These findings would mark the

## Clinical research: Explained (continued)

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beginning of the kind of combination antiretroviral therapies we receive today.

For more info, see:

[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(96\)05387-1/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(96)05387-1/fulltext)

### **START**

The Strategic Timing of Antiretroviral Treatment (START) study, was a 2012-2015 large-scale randomised clinical trial that tested whether there was a benefit to starting ART sooner. The study found that people who started ART when their T-cell count was above 500 cells per cubic millimetre had better health outcomes than those who started when their T-cell count was 350 or below - a 53% reduction in the risk of serious illness or death.

For more info, see:

<https://www.aidsmap.com/news/may-2015/start-trial-finds-early-treatment-improves-outcomes-people-hiv>

### **THE SWISS STATEMENT**

The Swiss Statement was a statement for doctors issued in 2008 by the Swiss National AIDS Commission that stated that PWHIV on effective

HIV treatment cannot transmit HIV through sex. It was informed by, among other things, studies of serodiscordant couples that showed PWHIV with a low viral load count on ART did not pass the virus on to their partner. This statement would lead to the campaign we know as U=U (Undetectable = Untransmittable) and was an important intervention in legal cases where PWHIV were being criminalised for having consensual sex with people who were HIV negative.

For more info, see:

<https://i-base.info/qa/factsheets/the-swiss-statement>

### **PROUD STUDY**

The PROUD study was a 2014 randomised trial run across 13 sexual health clinics in England among queer men who had had sex without condoms in the last 90 days. One group of HIV-negative participants were given HIV PrEP to take daily immediately, and another group were given it after a deferral period of 1 year. The study found a drastic reduction in HIV infections in the group taking PrEP compared to the deferred group, which was important evidence that proved the efficacy of PrEP.

### **PARTNER STUDY**

The PARTNER study was an international study that ran from 2010 to 2014, which recruited 1166 sero-discordant couples (gay and straight) to assess the risk of HIV transmission with an undetectable viral load. The study found no linked HIV transmissions from the HIV positive to the negative partner and firmly concluded that the risk of HIV transmission through sex from someone who is undetectable is always zero (even for sex that is usually high risk, like cumming inside someone).

For more info, see:

<https://i-base.info/partner-study/>

### **ATLAS AND FLAIR**

The ATLAS study and FLAIR study were both studies about injectable ARV that reported in 2020. The ATLAS study compared the effectiveness of long-acting ART injections to oral ART in participants who were already on treatment, while the FLAIR study compared efficacy in individuals who were starting treatment for the first time. Both studies found high rates of viral suppression and few side effects from long-acting injections, as well as strong satisfaction from

participants with injections as a method of administration. Injectable HIV treatment has been approved for use by the NHS since April 2022.

For more info on the ATLAS study, see:

<https://www.nejm.org/doi/full/10.1056/NEJMoa1904398>

For more info on the FLAIR study, see:

<https://www.nejm.org/doi/full/10.1056/NEJMoa1909512>

### **SOURCES:**

<https://i-base.info>

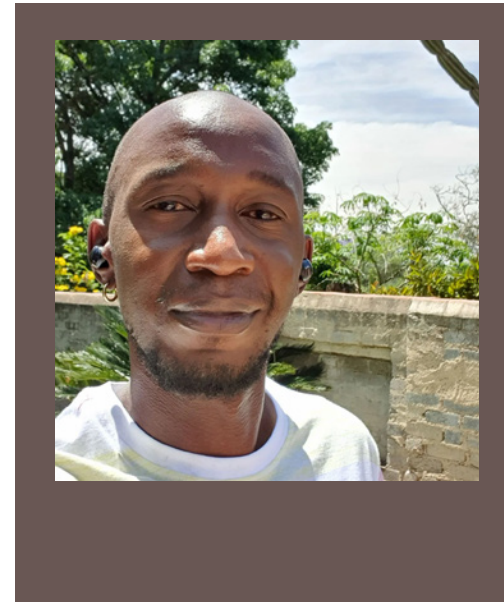
<https://www.nia.nih.gov/health/what-are-clinical-trials-and-studies>

# So, let's get back to my friend asking me that question:

Musings on HIV and coming out, from a conversation between two men who grew up together in a very small town in Kenya.

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He is a former Program Manager at Pan Africa ILGA in Johannesburg, South Africa, and also worked as the Executive Director of Gay Kenya Trust, an organization that works towards equality and non-discrimination for all including gay and lesbian individuals in Kenya.



by Anthony Oluoch

A friend and I were recently talking about mental health. This is a topic my friends and I often discuss and it's something I believe friends need to be able to talk more openly about. Our conversation about mental health soon veered into one about HIV, but before I go on let me give you some context. He is one of my oldest friends. We grew up together in a very small town in Kenya. At the time, of course, I was not an out gay man. One simply couldn't be. Not in that town, conservative as it was and still is. But we remain friends to this day. I have not come out to him about being HIV positive. It is just not something we have ever talked about. I suppose then, that this piece for BEAU is my coming out story to him.

When our conversation moved from mental health to HIV, he asked me a question "What is the right reaction when you learn that someone is HIV positive?" The question immediately triggered in me the thought of my being a gay, Kenyan man living with HIV. Dissociating the two is almost impossible.

The Penal Code in Kenya criminalises same-sex relations. It states that any person who has carnal knowledge of any person against the order of nature or permits a male person to have carnal knowledge of him or her against the order of nature, is guilty of a felony and is liable to imprisonment

for fourteen years. The language of the law is in, and of itself, discriminatory and has been challenged in the country, albeit unsuccessfully, over the years. The most recent failure in challenging the law was in 2019 where the High Court of Kenya ruled that these clauses in the Penal Code were not discriminatory and therefore not unconstitutional.

Of the 54 countries in Africa, 34 of them still have anti-homosexuality laws like the one in Kenya. I bring up this discrimination through the law to underline the persistence of stigma: state-sponsored stigma. This has remained codified long after independence and long after the decriminalisation of homosexuality in former colonial powers.

According to UNAIDS in 2022, the risk of acquiring HIV is 28 times higher among gay men and other men who have sex with men compared with adult men (15–49 years) in the general population globally. It should come as no surprise therefore that, as the world was beginning to be confronted with the virus and as statistics began to paint a particular picture, HIV began to be referred to as a "gay" disease. The "gay plague". It killed hundreds of thousands of gay men at the beginning of the epidemic and it continues to disproportionately kill many gay men today.

Now, in a continent where most countries criminalize same-sex relations, one where society largely deems homosexuality to be a western import and considers gay men an abomination, it is easy to see why the prevalence of HIV in gay men is so high.

It is also the reason why my HIV diagnosis as a gay man in Africa was an incredibly difficult thing to deal with. I was already dealing with the fact that my loving another man is a crime. I was dealing with a society that was so fixated with and disgusted by the way in which I engage in the very personal act of sex. I was dealing with the fact that my family might disown me. I was dealing with religious leaders constantly telling me that I would go to hell. I was dealing with societal pressure to marry a woman and sire children to maintain my family's bloodline. I was dealing with the fear of losing everything and everyone if my love for a fellow man was known to anyone.

So, let's get back to my friend asking me that question.

I should have taken his curiosity as a cue to tell him that my reaction was days of dissociation, tears, and complete desperation. I should have said that I was convinced I was going to die because, at the time, that was

all I could think of. I should have said my reaction was shock, anger, and the inexplicable urge to end it there and then. I should have said that it did come as a shock. I should have said that it was a burden, not only to me, but to him as my friend, and to my family. That I considered myself to be a disappointment. A disappointment for allowing myself to contract the "gay disease" and become another stereotypical statistic. I should have told him that I was afraid. Afraid of living with HIV. Afraid of having to take medicine daily. Afraid of my family finding out. I should have said that I was angry at the world for allowing this to happen. I should have told him that I felt disgusted and not worthy of love. That I felt sad. That I was depressed. That I was heartbroken and miserable. I should have told him that after my diagnosis, as a gay man in Africa, I was broken.

I should have done all of that. But I didn't. What I did instead was what we often do when confronted with a situation like that: think only about the stigma and hyper fixate on what society would think of us.

Societal perception brings with it the trauma of stigma. It is the anticipated stigma that causes most, if not all, of the emotional reaction I just described. It is this same stigma, the criminalisation of same-sex

relations, and the criminalisation of HIV that prevents many gay men from getting tested. And if they test positive, it also stops them from seeking treatment and care. Not many years ago, warnings on billboards and in newspaper headlines proclaimed, “Don’t Die of Ignorance” and “AIDS: The Bubonic Plague of the 21st Century”. Today, in some parts of Africa, people still believe that HIV is a death sentence. And that if you share a spoon or a cup or a toilet with someone who is living with HIV, you too will contract it. Some countries in Africa still criminalize HIV. Many countries still don’t have laws preventing discrimination on the grounds of HIV status and even for those that do, the fear of disclosing one’s status prevents people from seeking redress when they are victims of discrimination. Many countries have, however, taken that first step in recognising us as key populations in their national health strategies.

While we already face an incredible amount of stigma in wider society as gay men, within the Black and gay community there still exists stigma towards people living with HIV. You find dating websites and apps with profiles that still use the word “clean” to mean HIV negative. This is especially prevalent in countries where we are criminalised for engaging in same-sex relations.

These same websites and apps are often the only way gay men can connect considering the scarcity of social spaces that welcome a diversity of sexual orientations and gender identities. And even with the great advances in science around HIV, we still have people explicitly stating that they would never date a person who is HIV positive because they do not want to die!

But despite all of this, we are proudly here, living positively with HIV, attempting to make a difference in our communities in the African continent and beyond. People like David Deo in Kenya, Reverend Jide Macaulay from Nigeria, Cameron Kakande from Uganda and countless other brave and beautiful people shining a light in an otherwise dark and dreary world.

Lately, the world’s attention has been focused on another pandemic, Covid 19, which much like the HIV pandemic, has its own stigma attached to it. Covid has also shown, once again, how health is closely interlinked with and impacts on other crucial issues including mental health. Addressing a lot of this I think comes down to education. As human beings, we need to learn more, read more, understand more. Not only about what HIV is, but also what it means to those of us who live with it every day of our lives. Science has proven that as someone living

with HIV adhering to my medication, my viral load will be undetectable which means that I have zero chance of transmitting the virus to any of my sexual partners. It also means that someone else has a higher chance of contracting HIV from a person who does not know their status than from someone who does and is taking care of themselves.

We share the responsibility of educating our friends and family about the fact that people living with HIV live long healthy lives. Lives that can be full of love and light and laughter and purpose. Lives not defined by the virus we live with, but by what we do in the world. We all share the responsibility of ending the stigma attached to homosexuality and HIV. And we all share the responsibility of ensuring that we know our status and if we don’t, to get tested. If we then test positive, we know that there is a world of support for us wherever we are. If we adhere to our medication we will live a long, beautiful, wholesome life. And if we are fortunate to test negative, we know there are ways in which we can eliminate our chances of contracting the virus including a drug known as PrEP. Isn’t science amazing? Together, we can end this epidemic. But first, we must end the ignorance and stigma. And we must tackle the criminalisation of our existence as gay men in order to address the

inequalities we face as a result of societal attitudes, including pushing for the provision of health services for gay men living with or at risk of contracting HIV.

My heart melts when I see the revolutionary act of a Black man loving a Black man. My spirits are lifted when I witness the revolutionary act of a Black man living with HIV loving a Black man living with HIV. My love for humanity grows when I see a Black man living with HIV loving a Black man not living with HIV. We have come a long way from the death sentence days. We have grown, we have morphed, we have evolved. I believe that all we have is love. Love and kindness. Love for ourselves. Kindness for who we are. Love for our bodies. Kindness for our souls. But most of all, love and kindness for one another.



THIS MUCH I BEAU

Interviewed by: Scott Agnew

# This much I BEAU

by Revd  
Tide Macaulay

Founder & CEO of House of Rainbow,  
HIV activist, and human rights campaigner

As a priest, as a pastor, and as a minister I take LGBT people on a journey and take the word abomination and turn it around to say that what G.A.Y. stands for is an acronym: God Adores You, God Accepts You and God Accommodates You.

I'm 57 years old, I'm Nigerian, I'm British, I'm Gay, I'm a Christian, I'm living with HIV and all of this is part of God's love for me. So, I say to people who are struggling with their faith, their sexuality and their HIV that we are genuinely loved children of a living God. And that's so important to hear

when you have had to live out a level of condemnation within your own religious community, within your own cultural community and within your country of origin.

By default, I created my own family because I felt rejected, especially by my dad and some of my siblings. I became estranged and I found my own friends and family in the LGBT community.

Unfortunately, the two people who understood me have both passed away. The first, my mother accepted me as a gay child. It wasn't what she said but



what she did. I was literally covered with love. She covered me in love regardless of the sexual orientation of her child. The second, my brother, said that when I came out, they didn't know what to do but they have never stopped loving me. And that was really important for me to hear.

For me it's important within the LGBT community that we have an understanding that not everybody is out to get us, not everyone is our enemy and to recognise that we have come from a place of great resource and that we can give nurture and love not just to LGBT people but to others as well. It's not every family that's homophobic, some just don't know how to approach or address the matter.

My father, however, is still alive and is a religious leader like myself. He's very homophobic and very conservative - to the point that he actually supported the Nigerian Government introducing anti-gay laws in my country. How in all authenticity can I have a relationship with somebody who wants me and millions of LGBT people behind bars and subjected to conversion therapy? If my father can go to that extremity with a law that will punish his own child, let alone other people's children, as a minister

of the Christian faith what is his understanding of grace and the love of God and all of God's children? Coming out was not an easy thing for me but I think I found my strength knowing that there are millions of LGBT people like me, so I am not alone. There are also millions of people with HIV, so again I am not alone.

House of Rainbow (Nigeria's first LGBT Church) is still active but homosexuality in Nigeria is illegal so even though we have Pride and House of Rainbow and a community that's inclusive, it has become a challenge for us to hold those spaces without violence and attacks on LGBT people. The physical ministry therefore is on hold for as long as it takes but with the advent of social media, we have been able to find a space online and come together there. I've met remarkable people around the world: in Jamaica, Uganda, South Africa, Ghana, Nigeria - who have been courageous and bold to speak out that they're gay, lesbian, trans and queer, and that they love God despite what their society is saying.

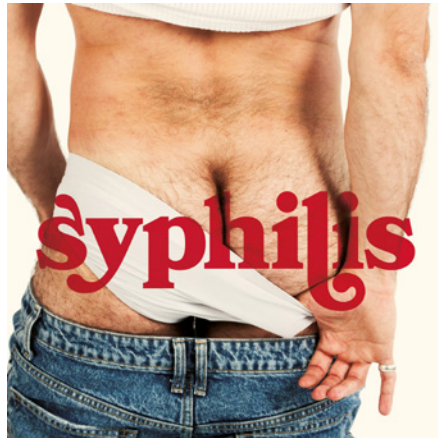
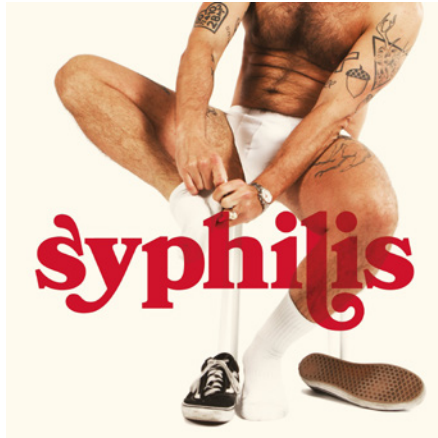
It's not just in African and Caribbean countries that work needs to be done - eastern Europe still has a lot of stigma and shame and a lack of knowledge

and education around LGBT people and HIV generally. As Chairperson of the International Network of Religious Leaders Living with HIV we can connect with religious leaders all over the world who may not know or understand the basics around HIV. If we can train and teach those religious leaders, the gatekeepers of their communities, and they then go on to educate others about HIV in their sermons then we can change whole cultures literally overnight in my opinion.

When I tested positive for HIV I couldn't tell my close friends and the first person that I told literally insulted me. I went into denial and then didn't talk to anyone. I think it took maybe the best part of 15 to 18 years before I told all of my close friends from that era. When some of them found out they were upset with me that I hadn't shared it with them at the time. I think among the Black community and among the Black gay community, culturally and religiously it wouldn't have been accepted. But now honestly things are changing, they really are and people are talking. I now come across Black gay men who have been living with HIV for more than 20 years and I never knew it until a couple of years ago.

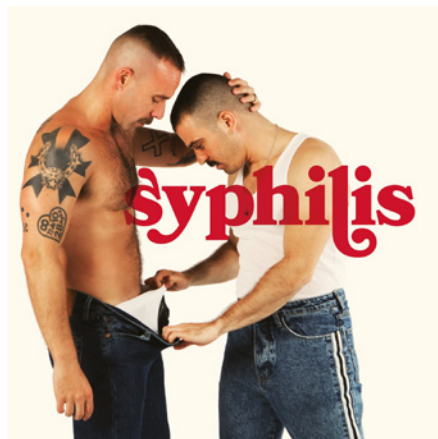
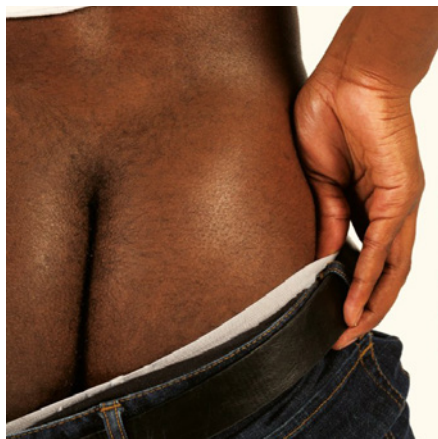
One life lesson is to be authentic regardless of the situation or the dangers because your authenticity will always remain - lies and cover ups will disappear - authenticity is engraved in you.

The more truthful I have been the more I have suffered over the years from homophobia, HIV stigma and racism but my reality is that I stayed strong. I did not allow it to push me away nor to derail me. I know unfortunately honesty does have a cost, sometimes a high one. This can be financial but also professional as well as personal. Nonetheless it is important to be absolutely authentic and the benefits will outweigh those costs.



# Long Time No Syphilis

*The comeback you weren't  
looking forward to*



All photos: Long Time No Syphilis

Did you know that syphilis is on the increase? The number of people in the UK diagnosed with syphilis has more than doubled since 2012.

Many of us haven't heard about syphilis, or know little about it. We think of it as something that was common in the 1970s and has gone away. But syphilis is back - and it's back in a big way.

If it's left untreated, syphilis can have serious implications on our health. In its later stages, it can cause serious and potentially life-threatening problems.

Testing for syphilis is free and easy in the UK, but many people with syphilis don't know they have it. Treating syphilis means that it can't be passed on to sexual partners.

As public health budgets get cut, lots of people who need to know about syphilis (and get tested or treated for it) don't know about how it is prevented, treated or cured. It's time for that to change.

The Long Time No Syphilis website is available in English, Arabic, German, Spanish, French, Italian, Portuguese, Polish, and Russian.

For more info, visit:

<https://www.longtimenosyph.info/>



**Everything you want to know about syphilis\***  
\*but were afraid to ask



# From the archives:

In every issue we choose a couple of items from the archives, to celebrate and recognise our history and the creativity of our beautiful HIV community.

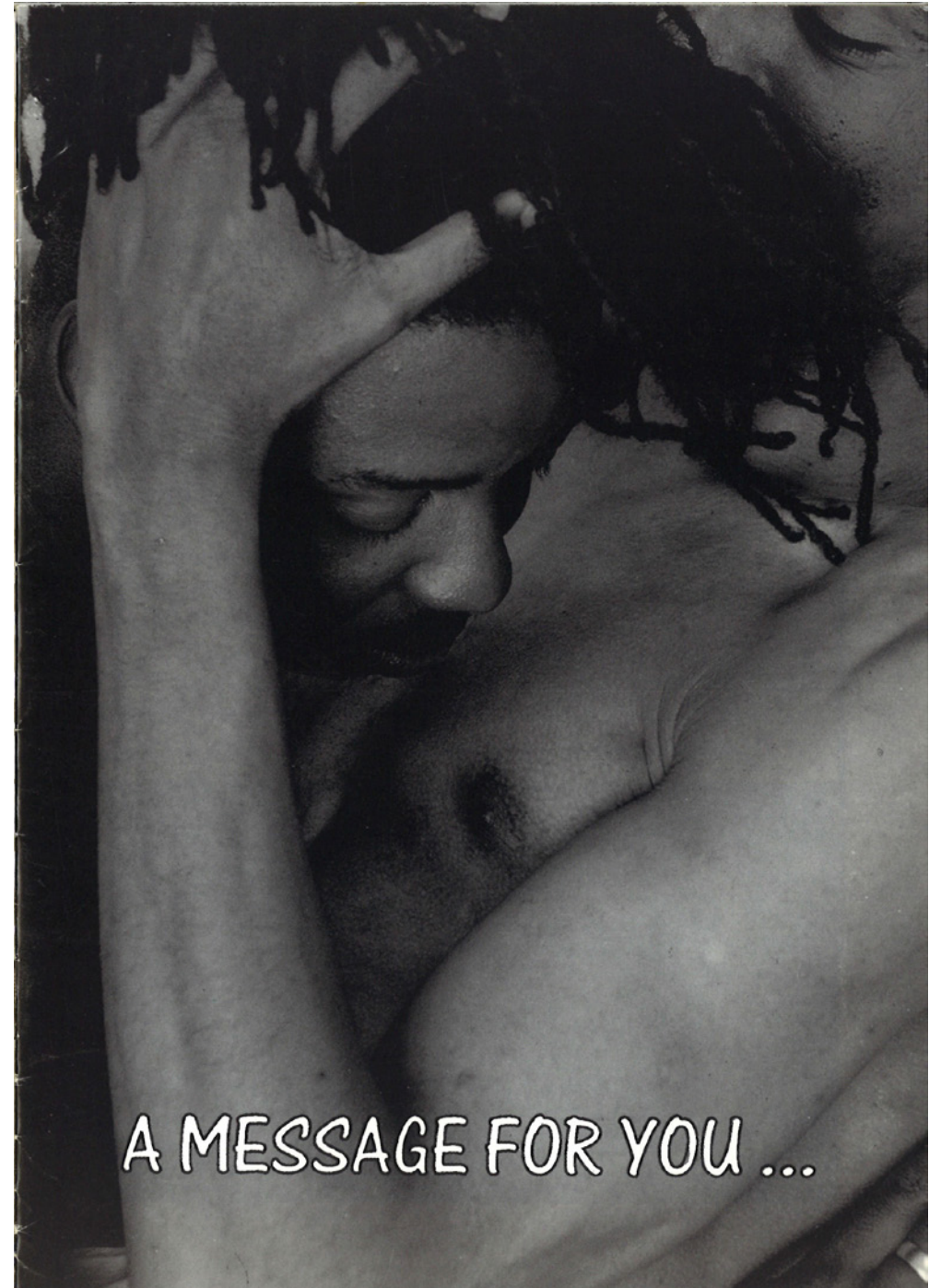
Visuals and messages have been key to shaping people's perception and understanding of HIV since the start of the epidemic.

Most people remember the Tombstones/Iceberg campaign (better known as the *Don't Die of Ignorance* campaign) or the Act Up *Silence=Death* reclaiming the pink triangle.

We want to acknowledge the role of design and creativity in changing the narrative on HIV, combating HIV and empowering people living with HIV.

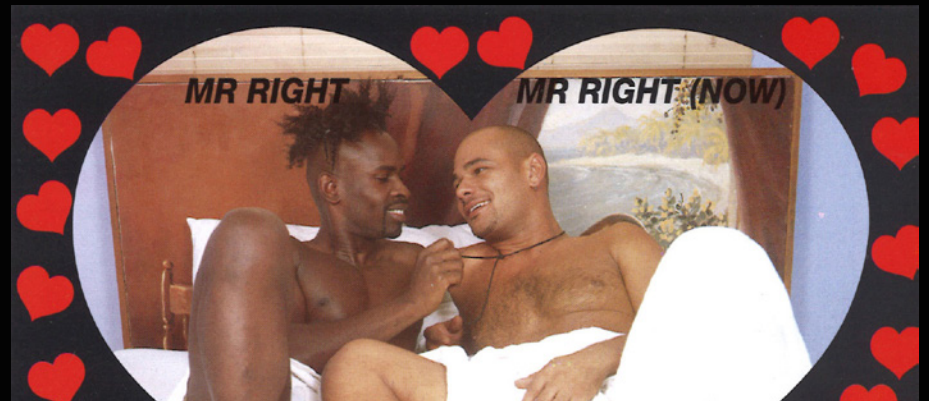
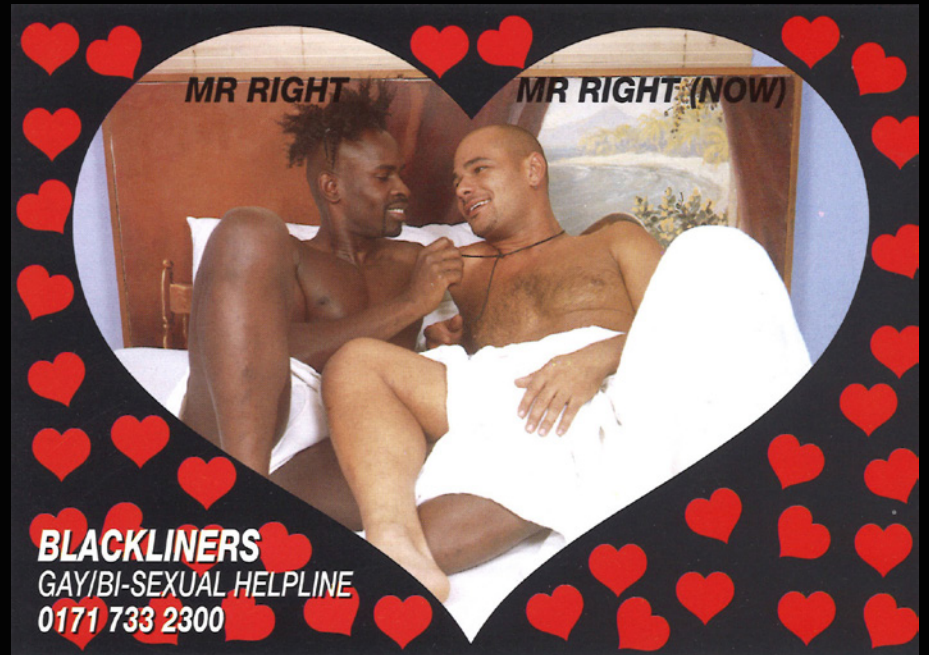
The following images are kindly provided to us by *HIV Graphic Communication* - a historic visual archive of promotional campaigns and graphic ephemera from the UK.

ACROSS: A MESSAGE FOR YOU...  
BHAN (Black HIV/AIDS Network).  
Leaflet: A5 12pp 2 col, mono inside.  
Design: Riverside Health Promotion Service.  
Photo: Robert Taylor. 1992.

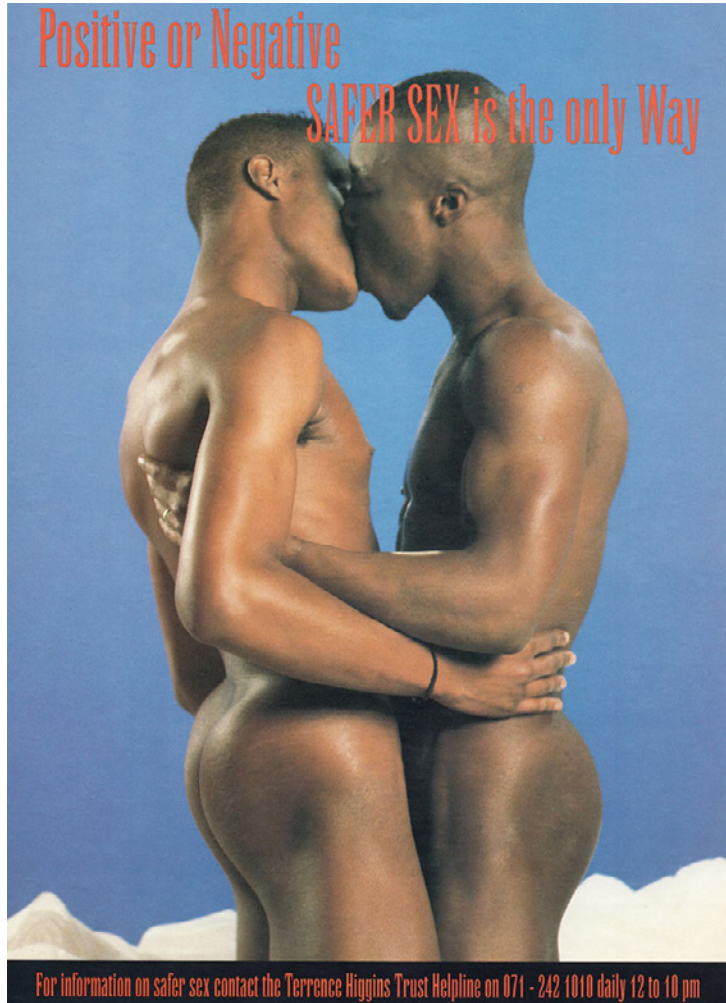




TOP: COMBINATION HIV & STI PREVENTION  
Prepster, The Love Tank. Booklet: A6 12pp, 2 col.  
Design: created.com. May 2020.



ACROSS: MR RIGHT, MR RIGHT (NOW)  
Blackliners. Postcard: A6 4 col 2 col reverse.  
circa 1995-1996.



TOP: Positive or Negative...  
The Terrence Higgins Trust.  
Poster: A4, 4 col. circa 1993.



ACROSS: #PrEP4BlackQueerMen  
iwantprepnw & Prepster.  
Vest: 2 col on black.

from the beautiful HIV+ community

MARCH 2023

# BEAN

№ 4