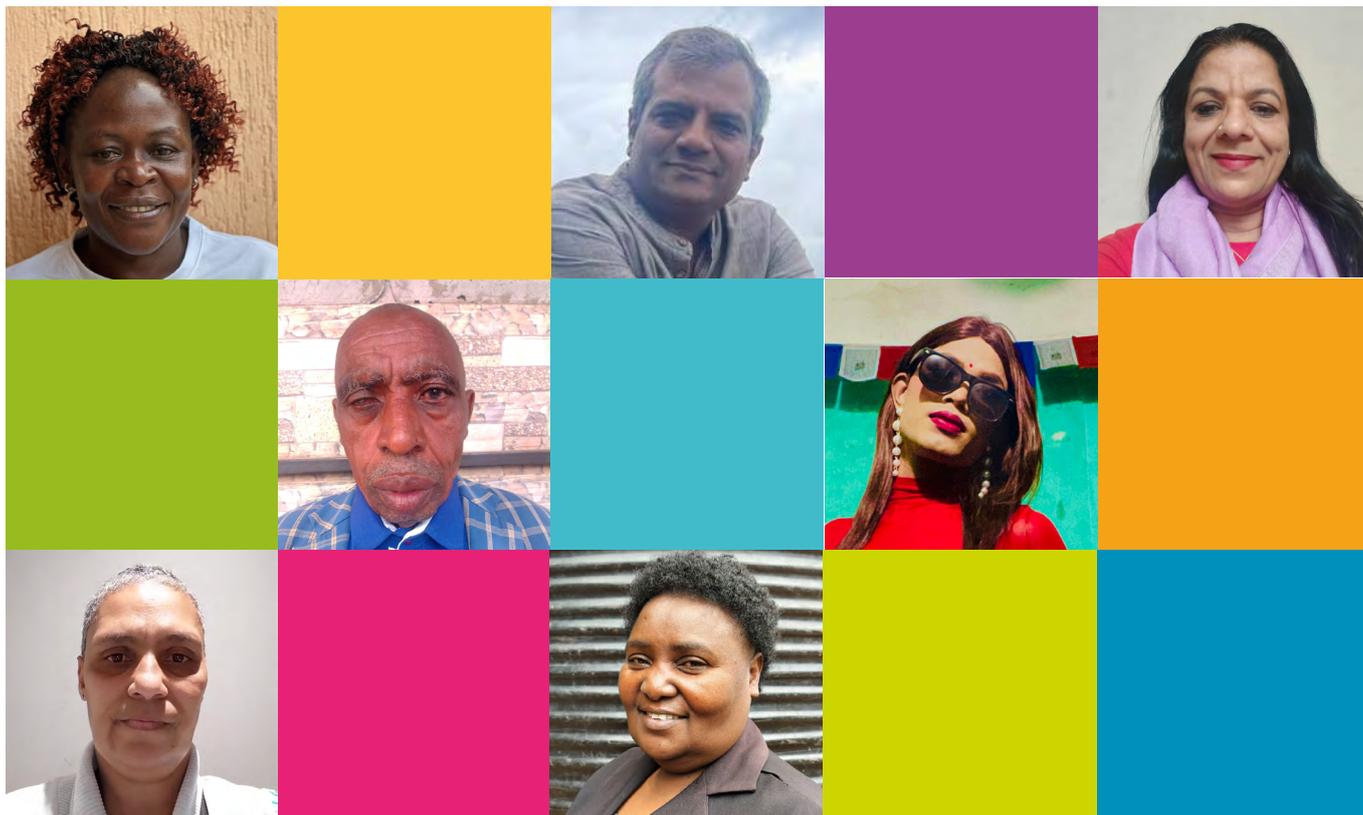


A CASE FOR INTEGRATION

A collection of the lived experiences of people living with NCDs and HIV



Acknowledgements

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Executive summary

Significant progress has been made in the HIV response over the past few decades, with people living with HIV experiencing improved life expectancy and greater access to treatment. However, their health and quality of life has been impacted due to the increased risk of noncommunicable diseases (NCDs), including mental health and neurological conditions. People living with HIV have a two-fold increased risk of cardiovascular disease (CVD) compared to people without HIV. People living with HIV may also have greater exposure to NCD risk factors. Integrated, person-centred NCD and HIV health services are the solution to addressing this double disease burden. Integrated care provides streamlined healthcare delivery by simultaneously addressing risk factors, management of all conditions, and continuity of care. It can also optimise resources in the healthcare system.

Advocacy towards NCD/HIV service integration has increased over the past decade, with commitments, recommendations and strategies on how to effectively integrate and upscale services for both. NCD Alliance has played a part in this advocacy, contributing to knowledge and evidence on integration with various publications (referenced in this publication). These have aimed to support implementation of existing recommendations, bring new findings to the advocacy environment, and spotlight initiatives that are working well. Some key publications have included [15 transformative solutions to realise better health in people living with and affected by HIV and NCDs](#), [Long, full, healthy lives: Delivering on the commitment to integrated NCD care for people living with HIV by 2025](#), and [Spending wisely: exploring the economic and societal benefits of integration HIV/AIDS and NCDs service delivery](#).

People with lived experience, including their care partners, are central to shaping the global health agenda, including for NCDs and HIV. The Our Views, Our Voices initiative of the NCD Alliance supports the promotion of the meaningful involvement of people living with NCDs in the NCD response, and this publication contributes to further efforts in doing so. This collection of stories by people living with HIV and one or more NCD highlights diverse, first-hand expertise of the barriers in managing conditions and accessing care, as well as resilience in the face of such challenges. Ten stories, which cover multiple countries and conditions, were selected through a submission and interview process.

The stories bring to life **three key priority areas** which stem from previous policy recommendations made by NCD Alliance:

- 1. Improve awareness** of the risks and burden of NCDs, and eliminate stigma;
- 2. Integrate HIV and NCD care;** and
- 3. Improve affordability and access** to comprehensive care and treatment for HIV and NCDs.

Integrated NCD/HIV services are in line with the principles of Universal Health Coverage (UHC) and offer better health outcomes through treating people, not specific diseases.

INTRODUCTION

HIV and NCDs

Over the past few decades, significant progress has been made in the HIV response, with millions now accessing antiretroviral therapy (ART) and experiencing improved quality of life and longer life expectancy. Efforts to meet the world's ambitious goals¹ for HIV diagnosis (95% of people living with HIV know their status), treatment (95% of those diagnosed are on antiretroviral treatment) and HIV viral load suppression (95% of those on treatment are virally suppressed) have resulted in 25 million premature deaths being averted in Africa alone. In 2022 approximately 39 million people were living with HIV worldwide, with a substantial majority (76%) taking treatment to manage their condition²

STATISTICS



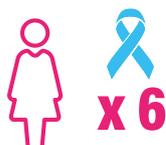
2019
REVIEW

A 2019 systematic review reported the prevalence of **depression among people living with HIV globally as**

31%



People living with HIV have nearly a **two-fold increased risk of CVD** compared with HIV negative individuals.



Women living with HIV have nearly a **six-fold increased risk** for cervical cancer.



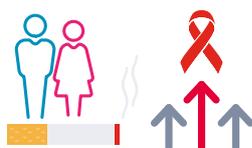
Cardiovascular disease is now one of the **leading causes** of non-AIDS-related morbidity and mortality in **people living with HIV**.



The global burden of CVD among people living with HIV has tripled over the past two decades, the large majority being in **sub-Saharan Africa** and the **Asia Pacific region**.



86% of **premature NCD deaths** occur in **low- and middle-income countries**.



The prevalence of tobacco smoking is significantly higher among HIV-positive men and women than HIV-negative men and women, respectively. This is the case in almost all world regions.

1 UNGA (2021) Sustainable Development Goals; UN General Assembly 2021'Political Declaration on HIV and AIDS: Ending Inequalities and Getting on Track to End AIDS by 2030.'

2 UNAIDS (2023) Global HIV & AIDS statistics — Fact sheet.

As people age they are more susceptible to developing NCDs, and it is a cruel irony of the success of the HIV response in many parts of the world that people living with the virus are now faced with a higher prevalence of NCDs than adults without HIV. People living with HIV face four main NCD co-morbidities: cardiovascular disease (CVD), depression, diabetes and cancer. This is the result of various factors, such as chronic inflammation from the virus itself, the side effects of long-term ART, and higher exposure to risk factors like smoking, unhealthy diet, and physical inactivity³. Health systems are faced with the challenge of providing care for this double burden.

Integrated HIV and NCD health services support people living with HIV to live long, full, and healthy lives⁴, and make sense for a number of reasons. Integration can enhance the continuity of care, a crucial factor for managing chronic conditions like NCDs and HIV. Integrated services can streamline healthcare delivery and improve patient adherence to treatment regimens. Importantly, integrated services optimise resources in the health system, and for those seeking care⁵. Integrated care also addresses the overlapping risk factors and shared socioeconomic determinants impacting both HIV and NCDs, providing more effective person-centred approaches to health management and supporting global efforts to achieve Universal Health Coverage (UHC).

The World Health Organisation's (WHO) Global Action Plan for the Prevention and Control of NCDs and the UNAIDS 95-95-95 targets both emphasise the need for integrated approaches to healthcare. In the Political Declaration on HIV/AIDS⁶ 2021, Member States pledged, among other things, full coverage of NCD services for 90% of people living with, at risk of, and affected by HIV by 2025.

Since these global commitments were made, major global health organizations like UNAIDS, the Global Fund⁷, and PEPFAR⁸ have prioritised integrated healthcare approaches in their strategies and funding efforts. WHO provided implementation guidance⁹ for the integration of NCDs in HIV, TB, and sexual and reproductive health programmes in 2023, and in the same year, the Global Fund issued a guidance note for grantees to help them include impactful interventions for managing co-infections and co-morbidities for people living with HIV and priority populations.¹⁰

Some low- and middle-income countries (LMICs) have made notable progress towards integration. For example, Kenya routinely screens people living with HIV for diabetes¹¹, and similar pilot services for cardiovascular diseases have been implemented in Kenya, Nigeria, and Zambia¹² while Tanzania has responded to Global Fund guidance in its 2024 – 2026 grant with plans to expand the screening and treatment of NCDs among the 1.7 million people receiving HIV treatment¹³.

- 3 Webel AR, Schexnayder J, Cioe PA, Zuñiga JA. (2021). State of the Science. *J Assoc Nurses AIDS Care*. May-Jun 01;32(3):322-346. A Review of Chronic Comorbidities in Adults Living With HIV: doi: 10.1097/JNC.0000000000000240. PMID: 33595986; PMCID: PMC8815414. See also: UNAIDS (2019) Responding to the Challenge of NCDs (<https://www.unaids.org/en/resources/documents/2019/responding-to-the-challenge-of-non-communicable-diseases>).
- 4 NCD Alliance (2021) Long, full, healthy lives: Delivering on the commitment to integrated NCD care for people living with HIV by 2025.
- 5 NCD Alliance (2023) Spending Wisely: Exploring the economic and societal benefits of integrating HIV/AIDS and NCDs service delivery.
- 6 UNAIDS (2021) Political Declaration on HIV and AIDS 2021. https://www.unaids.org/en/resources/documents/2021/2021_political-declaration-on-hiv-and-aids.
- 7 The Global Fund (2023) Guidance Note Prioritization Framework for Supporting Health and Longevity Among People Living With HIV Allocation Period 2023-2025.
- 8 PEPFAR (2024) Addendum to Fiscal Year 2024, Technical Considerations <https://state.gov/wp-content/uploads/2023/12/PEPFAR-Addendum-to-Fiscal-Year-2024-Final.pdf>.
- 9 World Health Organisation (2023) Integrating the prevention and control of noncommunicable diseases in HIV/AIDS, tuberculosis, and sexual and reproductive health programmes: implementation guidance <https://www.who.int/publications/i/item/9789240061682>.
- 10 The Global Fund (2023) Prioritization Framework for Supporting Health and Longevity Among People Living With HIV Allocation Period 2023-2025.
- 11 NASCOP (2022) Ministry of Health, National AIDS & STI Control Program. Kenya HIV Prevention and Treatment Guidelines, 2022 Edition. <https://www.differentiatedservicedelivery.org/wp-content/uploads/Kenya-ARV-Guidelines-2022-Final-1.pdf>.
- 12 NCD Alliance, Integrating NCDs in the HIV response to protect decades of progress. <https://ncdalliance.org/why-ncds/universal-health-coverage-uhc/integrating-ncds-in-the-hiv-response-to-protect-decades-of-progress>.
- 13 The Global Fund (2024) Tanzania and Global Fund Launch New Grants to Accelerate Progress Against HIV, TB and Malaria. <https://www.theglobalfund.org/en/updates/2024/2024-01-30-tanzania-global-fund-new-grants-accelerate-progress-against-hiv-tb-malaria/>.

However, progress in achieving the 90% NCD coverage goal for people living with HIV has been uneven, with one study finding that only eight among a total of 49 countries in Sub-Saharan Africa (SSA) have integrated healthcare systems¹⁴. This is despite growing evidence on the effectiveness of integrated health systems, and of integrating NCD services with HIV care at primary health care levels¹⁵. Integrating HIV and NCD services can also support progress towards achieving UHC. For example, in Zambia, a cervical cancer prevention pilot project launched in 2006 targeting women beginning HIV treatment, was the catalyst for routine cervical cancer screening for all Zambian women, irrespective of their HIV status¹⁶. In 2019 Zambia began human papillomavirus (HPV) testing at existing HIV clinics which has expanded to all 10 provinces with more than 40,000 women screened in 2023 alone¹⁷. The HPV test detects the presence of the virus that can cause cervical cancer.

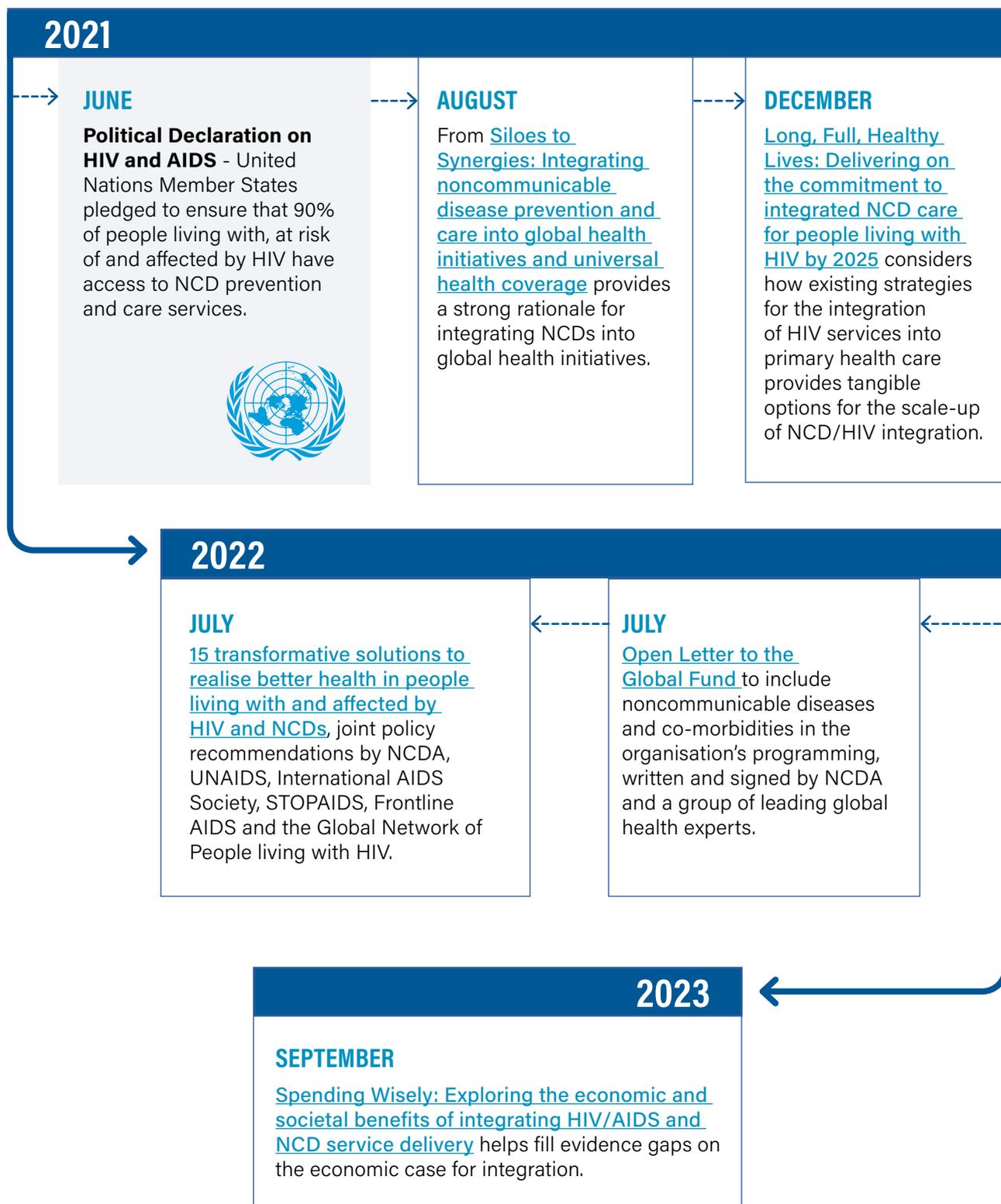
Around the world, people living with HIV are at the forefront of advocating for and shaping the HIV response. Their sustained leadership has seen huge advances in treatment, access to care and fighting stigma and discrimination. Support for the meaningful involvement of people living with HIV is now an accepted principle in global, regional, and national decision-making¹⁸. As the global burden of NCDs is increasingly recognised, so has the leadership and contributions of people living with NCDs. In 2021, the [Global Charter on Meaningful Involvement of People Living with NCDs](#) was launched which recommends 10 strategies to embed and enable the meaningful involvement of people living with NCDs in decision making at all levels. In 2023, the WHO launched a framework for the meaningful engagement of people living with NCDs, providing further guidance on operationalising the meaningful engagement of individuals with lived experience¹⁹.

As we look ahead to the UN High-Level Meeting on NCDs in 2025, NCDA will be calling for greater alignment between global health and development agendas to consolidate efforts and achieve more through integrated action.



- 14 Chireshe R, Manyangadze T, Naidoo K. (2024) Integrated chronic care models for people with comorbid of HIV and non-communicable diseases in Sub-Saharan Africa: A scoping review. PLoS One. Mar 15;19(3):e0299904. doi: 10.1371/journal.pone.0299904. PMID: 38489252; PMCID: PMC10942093.
- 15 Godfrey AK, Robert NP. (2023) The Lancet Integrating HIV, hypertension, and diabetes primary care in Africa, Comment by DOI: [https://doi.org/10.1016/S0140-6736\(23\)01884-6](https://doi.org/10.1016/S0140-6736(23)01884-6).
- 16 NCD Alliance (2021) From Siloes to Synergies https://ncdallianceorg/sites/default/files/NCD_%20LEVERAGING_GLOBAL_HEALTH_WINS_8_09_FINAL%20%281%29.pdf.
- 17 World Health Organisation, Geneva (2024) Zambia steps up cervical cancer screening with HPV testing <https://www.afro.who.int/countries/zambia/news/zambia-steps-cervical-cancer-screening-hpv-testing>.
- 18 UNAIDS (2007) Policy Brief The Greater Involvement of People Living with HIV (GIPA).
- 19 World Health Organization (2023) WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions <https://iris.who.int/bitstream/handle/10665/367340/9789240073074-eng.pdf?sequence=1>.

ADVOCACY ROAD MAP



NCDA, together with partners and people with lived experience, has produced various resources (highlighted above) to support advocacy recommendations on the road towards integrated care for NCDs and HIV.

Overview of the collection

This collection of stories aims to support advocacy for more person-centred and integrated care for people living with NCDs and HIV. The collection of stories promotes an understanding of the barriers and challenges experienced by people living with HIV and NCDs in navigating their health systems.

From the perspectives of people living with HIV and NCDs and drawing from their experiences in accessing care, three key and linked priority areas have been identified that would have transformed their healthcare journey:

1. **A lack of awareness of the risks and burden of HIV-related NCDs** by both people living with HIV and healthcare workers in the HIV and NCD responses which impact negatively on their health care journey.
2. **Fragmented and siloed health services that result in delayed diagnosis and enrolment in care** and, for many people, having to attend multiple appointments and facilities.
3. **Increased out-of-pocket expenses** as well as comparatively high costs for medicines and treatment for NCDs that make it challenging for people living with HIV and NCDs to take care of their health.

You will see these challenges reflected in the stories below. The final section of this publication gives a more in-depth explanation of these three challenges, together with guidance on how the powerful stories of lived experience can be used to strengthen advocacy towards integrated care for NCDs and HIV.



MY STORY, MY VOICE

From the perspective of people with lived experience

The lived experiences featured in this publication have been selected from over 30 stories generously shared by people living with HIV and NCDs from around the world. A total of ten stories were selected for inclusion in this collection. The stories were selected to ensure a balanced representation across conditions, regions, genders and ages and to reflect a diversity of experiences in navigating stigma, seeking care and managing multiple conditions.

We need more than ARVs

Sara, 44 years old, Cambodia. Living with HIV and hypertension.

I have been living with HIV since 2002, and started taking ARVs in 2004. For the past 4 years, I have suffered a lot. In 2020 I became very depressed due to stomach pain. In addition, I also had gynaecological issues. After I was diagnosed with these conditions I had to take more medications and it was difficult to tolerate the side effects. I suffered a lot.

One day while riding my motorbike, I felt dizzy and had to stop for a while to rest. If I had been dizzy and passed out, I would have had an accident! Another time I fainted, fell slowly and prayed shakingly. People nearby saw me and helped me. I was unconscious for about 30 minutes. When I woke up my tears flowed as I thought I was going to die and that my children wouldn't be able to see me at my last breath. Following this I was also diagnosed with having high blood pressure. **I started to get depressed and I worried about my health. At the same time I have to adhere to my medications for all these issues.**

Before this, I only took my ARV pills once a day and had no other illnesses but over the past four years my health has deteriorated. Sometimes I feel like I want

to quit my work as a community representative. I am so sick and I wonder, is it because I have been taking ARVs for so many years now?

I want communities living with HIV to receive additional services beyond ARVs. These additional services mean that when a patient comes in, they receive their ARVs and can also be diagnosed with NCDs like high blood pressure and they can be given medication for it as well. **We also need to spread information to the community so they are not left behind.**

As a community representative, I help my community by assisting people to get an IDPoor card (Identification of Poor Households Programme). If they do not have this card, they are unable to access social health protection. When attending meetings with stakeholders, as a community representative and a person living with HIV, I always mention that there are community members who do not have IDPoor cards and I advocate for ways to help them to get the cards, so that they can access social assistance when they need it.



My beautiful scars – mental health support matters

Luthando, 25 years old, Zambia. Living with HIV and depression.

How I became aware of my status is a crazy story. I was in the ninth grade when my two friends and I noticed that an organization that did outreaches were setting up tents outside my school. We decided to go test. I was 14 years old. Pre-counselling was done, and we were told about HIV. When the results came, my friends were given their status there and then. But the counsellor told me that they needed my mother to be present. My mother came and we returned home with the counsellor. They told me my status was positive. The counsellor asked if I was sexually active, I wasn't, and at some point, I think she didn't believe me. I didn't know about mother-to-child transmission. At this time my mother disclosed her status to me and my older sister.

I was okay then, but when I completed secondary school the reality of my status hit me. It was such a difficult time. I began to blame my mother. In my mind I asked, "why did you choose to be careless with my life?" Even if I seemed okay on the outside, inside I wasn't okay. I would break down and cry, I didn't talk to my mum some days and I became rude in our conversations. It took connections with people for me to make a change and come to terms with my status. I connected with someone at the clinic who became my mentor – she was open about her status and encouraged me. I became active in support groups, and I got to understand more about HIV, mother to child transmission and I accepted this is my life and this is my future.

I had many dreams when I was young, and I thought that my journey of life was going to be cut off by my HIV status. But, engaging in support groups at my clinics, and talking about my status has helped me. I am proud to say that at this time, I am leading these support groups, and I can stand up and tell young people about my status and my experience. I also benefited from group therapy with my friends at the clinic.

Looking at our local clinics here in Zambia, people take their treatment and go. They might not know that there are these mental health services.

“

I would like to see all clinics give information to patients, in their languages, about mental health support. I also want to see healthcare providers asking their patients more questions about how they are coping and what their needs are. They should be trained to offer this support and information on mental health.”

For my future, I would like to be really confident to challenge our policymakers about things that are not working for our people connected to HIV, SRHR and menstrual health. If there is something that is needed on these issues, you can count me in. I called my story *Beautiful Scars* because while HIV remains part of me, I am beautiful in all aspects.



Me and my koala bear – universal health coverage for all

Ashleigh Nikki Bezuidenhout, 48 years old, South Africa. Living with HIV, cancer survivor

My name is Ashleigh and I am originally from Zimbabwe, I came to South Africa as an HIV patient in 2015. I was diagnosed with HIV in July 2014 and it broke my heart because I really couldn't believe that for 7 years I carried the virus from my now ex-husband. It was hard but I overcame all the stumbling blocks with being HIV positive and being on treatment.

For three years between 2018 and 2021 I suffered severe stomach cramps and constipation. Each time I told my doctor, I was just given laxative medication and sent home. **The focus was on treating us for HIV and not on our overall health.**

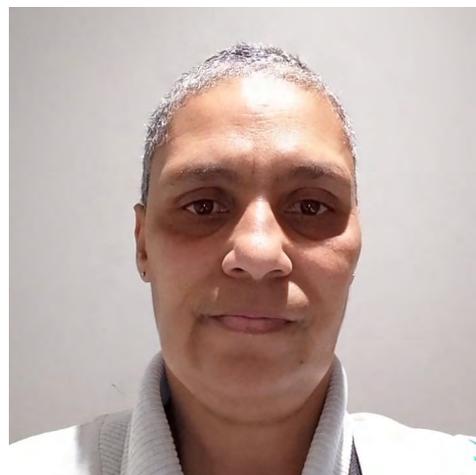
It broke me all the time leaving the clinic or hospital and always being told that there was nothing serious, when each x-ray or scan showed lumps on my ovaries and all I got was numerous types of pain meds which helped just for a short time. It was on the 15th of February 2021, that I fell very sick. The pain was unbearable, and once again I went to my nearest government clinic only for the doctor to send me home with laxatives. It was too much and I told my boss that I needed help immediately, I was in pain, constipated for 5 days, vomiting and couldn't even walk straight up. I went to the hospital that afternoon and was in casualty for 5 hours before being seen as it was during the COVID-19 pandemic.

A scan detected a mass and the doctors had to put a draining tube through my nose to help relieve the swelling and pain in my stomach. It was the scariest time of my life. I was alone with my family far away, and I was scared I was going to die alone. I was transferred to Charlotte Maxeke Hospital and was told there that I needed an emergency operation which took place a few days later. They removed a big mass the size of an orange, 12 small tumours and 30cm of my small colon which was badly infected. I tested positive for cancer of the colon, and ended up with a stoma bag, which I still have today. My world shattered when I was given this diagnosis and told I needed to have chemotherapy.

When Charlotte Maxeke hospital burnt down in April 2021, the other patients and I really struggled to access chemotherapy. I reached out to CANSA Association of South Africa who put me in touch with the right people to get my chemotherapy. I'm now in remission for 3 years.

My highs were when the nurses at the chemo clinic at Charlotte Maxeke Hospital were supportive and made sure I was comfortable and relaxed. My lows were when chemotherapy was delayed because of the high number of patients and the COVID-19 pandemic. I am where I am today because of my partner and my mum's support, and my dad and my brother who are now here in South Africa with me. My heartfelt thanks go to Zodwa Sithole of CANSA and her team for all the help they have been giving me throughout my journey.

I would like to see more people reaching out to be advocates for HIV and cancer because the stigma is bad here. I'm especially appealing to the Department of Health to help patients get medications, especially for colon cancer patients to get our bags which are in very short supply. Thirty bags over 30 months is not enough and it's a painful experience trying to keep a bag on for 4 days at a time. I want to see everyone treated equally and I hope I can be a part of raising awareness of these challenges for all cancer patients. Today I can proudly say: I'm a colon cancer survivor!



My HIV and hypertension journey: We are more than HIV

Domitilah Anyango Okeymo, 50 years old, Kenya. Living with HIV and hypertension

I tested positive 28 years ago. I had a sister-in-law who was very ill, she was kind and very good to me, I loved her so much. When she was ill I had a responsibility to take care of her. I was advised to take her to the HIV testing centre. There, the person doing the testing told me that I should also take an HIV test, he said he had a target of 10 people and people were not testing because of stigma. He wanted to get to his target so that he could get paid.

The doctor who tested me insisted I come back to the testing centre. I went the following day and he told me about my results. I couldn't believe it. My sister-in-law was the one who was sick. I thought they labelled it incorrectly. He denied this, but I did another test in Uganda where services were available. It came out positive and I sank into depression. I was a teenage mother with 2 children under 3 years old. I had not completed high school yet. I tried to end my life, but my neighbour saved me and my children.

At the time, ARVs were not available for free and I could not afford them.

I met an 18-year-old young woman who was born with HIV and there began my healing journey. This was a turning point for me. I thought: she has lived with HIV for 18 years, and so can I. I realised that I could live to see my children grow up. She took me to TASO (The AIDS Support Organization) to get a CD4 test and my medication was sponsored. I owe that young woman my life. I really wanted to have my children tested but the fear of not being able to afford their drugs made me shun testing. I later got the courage to take my children for testing, and got to know I had a positive child, my second-born. She started treatment and she became well.

In 2004 medication to prevent mother-to-child transmission of HIV came to Kenya and I decided to have my third and last baby at 32. I started experiencing nosebleeds that made me anaemic. One day while travelling I experienced a nosebleed and a fellow passenger advised me to check my blood pressure. On alighting, I went to a facility where I was admitted because my blood pressure was high and I was started on antihypertensives which I still take today.

Previously, my hypertension was managed in the same facility as my HIV, and they had a lab outside the facility, so it was comfortable for us. But in 2020 I lost my job and I had to come back to my home area further away from the city.

“

Here, they have an HIV clinic, but I have to go to another facility for hypertension and then explain everything there again. It is not comfortable having to explain to different people and disclose my status each time. So, I check my blood pressure myself.”

I volunteer as a support person for people living with HIV, and I have seen that when people complain about their symptoms their concerns are dismissed, and they are told “This is about HIV or your treatment it will pass”. People stop saying anything because they don't want to keep complaining. Many people consult me, and I tell them to seek another opinion. On top of that, **it is difficult to make the time to go to another place for screening for things that we as people living with HIV, might be at higher risk of.**

My wish is that healthcare workers and even clinicians themselves at HIV clinics are trained to recognise diseases like hypertension and diabetes. I would like NCDs to be integrated into HIV clinics, from labs for screening to just checking blood pressure. This will mean that everyone, including young people, can access screening and take care of their health.



From diagnosis to now – advocating for holistic treatment

Serah Mbovi Makau, 58 years old, Kenya. Living with HIV, hypertension and diabetes.

I was first tested for HIV in 1996 and confirmed HIV positive. I didn't enrol for care due to stigma. I was in denial for about ten years until I became unwell due to multiple opportunistic infections, like TB among others. Due to my situation, I accepted I had to start treatment in 2006. My response to TB treatment was good, so I was put on ARV's which I also responded well to, despite the side effects. My drugs were changed by my health provider to address their side effects.

All was fine until 2018 when I discovered that I was hypertensive. I went to a regular clinic, where they tested my blood pressure and realising that it was high, and they put me on medication. **Now I had another medication, which I had to take daily, another appointment and another clinician I had to see. Taking both medications was not easy, the timings of the medication didn't match. I also felt that each clinician had their own interest - HIV only or hypertension only.**

Sometimes, I was not able to adhere to my medication, I would forget to take my ARVs, and my viral load increased. Things were complicated and it was a burden to adhere to the medication and attend two different clinics.

I adjusted, I was doing well and had a suppressed HIV viral load. But in 2023 toward the end of the year things changed. I had a wound that would not heal, and so I went to the hospital. While I was there, I fainted. The doctor at the hospital suspected that I had another issue and tested my blood sugar.

“

When I woke up, the doctor disclosed to me that I had very high blood sugar. They did not have my history and did not know my HIV status, so I had to start again. Now I had a third clinician, and a third appointment and new medication to adhere to.”

This became my worst nightmare. I now had three different clinicians, three clinics and three different appointments - and they weren't speaking to each other and didn't tell me about drug interactions or explain things to me holistically.

Now I have to spend more time managing the three conditions and consulting with different health professionals, and I have to pay for my hypertension and diabetes medication myself, which can be costly. It is also not easy getting time out from my work as a teacher.

My wish is that my conditions can be treated and monitored in one clinic, with one clinician, and one appointment. I want to be treated holistically, and to be given information about these conditions and my medications so that I am empowered to manage them.

I am a member of the National Network of People Living with HIV and an active member of the Kenya Network of HIV-Positive Teachers (KENEPOTE). I am open about my status and I advocate for my community. I love my work as a Deputy Head Principal and teacher. What motivates me is the fact that each medication prescribed to me is working fine, despite the burden and my condition is stable. My fear is that I don't know what my future will look like with NCDs. I am hoping things will change for the better.



My triple challenges – ageing with HIV

Isaac Lonzi, 69 years old, Kenya. Living with HIV, hypertension and a disability.

I am Isaac Lonzi now aged 69 years old. I am a retired teacher since 2016. This is my true story written from the bottom of my heart. I will begin with my short history. I was born in a well-to-do family, my father was the richest in the area and I was brought up as a son of a rich man. I began going to sex workers and I started smoking like a chimney and drinking at an early age. I suffered from severe depression but thanks to a psychiatrist I recovered. My faith then led me to stop drinking and smoking. But in 2007 I tested HIV positive.

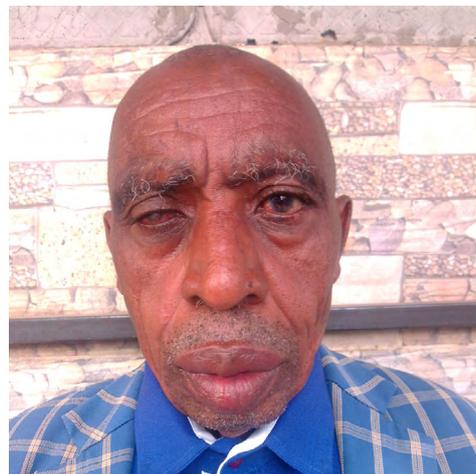
I had no choice but to accept living positively. I started a new life and with courage and determination I was able to create a conducive environment in my family and this is how my wife became supportive. In 2010 I went public during World Aids Day and this was reported in the media. From that time I became a national figure for people living with HIV. I was among the pioneers of the Kenya Network of HIV-Positive Teachers (KENEPOTE) and I crisscrossed all parts of Kenya doing advocacy on living positively with HIV. True disclosure was almost a cure for me.

In 2018 I was diagnosed with high blood pressure. I was almost paralyzed but thanks to quick action, I survived. Today I take 2 medications for blood pressure daily. These medications are costly, unlike my HIV medications that are provided to me without cost. Although I am a retired teacher, I used to do some driving to make money, but in 2020 I lost an eye, and as I am now living with a disability, I can no longer drive.

In my country, **I receive a 6-month supply of HIV medications, but for my blood pressure medication, I must buy these myself from the chemist.** You see, for those who are ageing with HIV, many of us are getting hypertension, diabetes, and cancers, and these NCDs are not treated for free in our country. This is a problem, especially for older people without support – HIV and NCDs don't

know if you have no money. I would like to see this addressed. **Screening for NCDs must be included in the treatment of HIV and the treatment of NCDs must be treated like the medication for HIV, especially as we are ageing.**

I am one of the advocates in my country for people living with HIV. The youth need role models like me so that they can praise themselves. For ageing people living with HIV, we need support for our medications. Young people are also ageing, and they will also face these things. I am courageous, I maintain my self-esteem and although I have many challenges I find happiness being active and being a Chelsea football fan.



A father living with HIV and NCDs – harmonisation is possible

Claude Karangwa, 52 years old, Rwanda. Living with HIV, hypertension and diabetes.

I was diagnosed with HIV in 2005, when we had taken our baby for a vaccination. At the time I had small skin rashes and test results showed that I was HIV positive but my wife tested negative. We went back home and raised our baby boy, and he grew up well. Later we had a second child who tested HIV-negative, and a third baby too, who was also HIV-negative. At that time, we decided to keep that family size as the government policy suggested. I had accepted my status.

Because I was working out of the city, I would travel a lot, but I was taking my medication on time, and following treatment recommendations. I try my best to take care of myself. At first, I had a clinical visit once a month, later this shifted to two months and then to three months. Today I am on a 6-month treatment plan. My daily work would involve frequent travel and I would carry my documents always, to ensure I had access to my medications.

There was a point when I started feeling pain in my calf muscles while walking. I went for a medical check-up and I was diagnosed with diabetes. My blood sugar was extremely high and they said that I was about to die. From the health centre in Kigali, I got a transfer to the hospital where they tested my blood sugar again and the results were still extremely high. They gave me water to drink as I was very thirsty and they again confirmed that I had diabetes. Other tests revealed that I also had hypertension. My blood pressure showed that I had severe hypertension. That is how I began treatment. I would take all the medications however, the diabetes medication posed some side effects to me and I did not feel well.

I wonder if more research could be done looking at how to harmonise treatment needs for people like me. **We have community health insurance, but sometimes they tell us that drugs are not available. In that case, we need to buy from the private pharmacies and it is 100% from our pockets.** I support advocacy to ensure that we always have access to our medication – for private pharmacies to provide drugs on the community health insurance so we can go there for medication. It would also be better if we could access all our medicines in one place – this would be a great solution. It would even be more convenient if this was all provided by the same health care provider. It would save us from going back and forth to multiple places. **That back-and-forth travel affects our health and productivity. Even that frustration escalates our condition.** For HIV treatment services, you don't even spend more than 5 minutes because everything is in one place - I wonder how other services can be simplified and integrated in the same way? That is what we need! .



Echoes of resilience – stigma goes beyond HIV

Mona Balani, 48 years old, India, living with HIV and hypertension, TB survivor.

I would like to share my personal experience as a person living with multiple chronic conditions like HIV, Tuberculosis (TB) and hypertension. My journey with HIV began in 1999 when I tested HIV positive after my husband's positive diagnosis. My journey was not easy as I've encountered stigma and discrimination at both community and healthcare facility levels because of my diagnosis. I began my antiretroviral (ARV) treatment in 2006 when my health was severely compromised due to extra-pulmonary TB in my abdomen, adding to the challenges I faced.

Every time I've sought treatment for health issues other than HIV, discrimination has been my constant companion. One such incident which affected me a lot was when I had boils and deep fluid-filled sores on my legs and arms because of the stavudine regimen in my antiretroviral therapy. Instead of immediate bandaging and care, I was referred back to the ART centre following which I opted to self-manage and changed my own dressings.

Stigma and discrimination also contributed to further delay in diagnosing my extra-pulmonary TB in the abdomen, pushing me close to death. During these health crises, I also grappled with feelings of guilt and disappointment, and I was constantly questioning why I should continue living. **My condition was often judged, and many such incidents took place when healthcare providers hesitated to touch me to take my pulse or blood pressure.** Whenever I visited the ART centre, I was only prescribed medicines, and I didn't receive any counselling or extended care for my reproductive or sexual health and well-being.

In 2007 I felt panicky and anxious and I didn't know why. My doctor checked me for hypertension, and it turned out that my blood pressure was high. To help take care of my health, I started yoga and meditation and this helped lower my blood pressure. When I see this in my community I tell them to check their blood pressure. For the last 4 or 5 years I have had an annual routine check-up. I am going because I know that this should pick up any issues early. **For many of my female friends, they don't know about NCDs and their doctor doesn't bother about further tests, they are given painkillers and sent home.** I encourage my friends to go to a private doctor for further tests.

The only reason why I am alive today to write this story is because of my self-will, determination and proper adherence to my medication and treatment. Because of the never-ending support from my family and loved ones I never stopped fighting this battle.

Beyond my own story, other people living with co-morbid conditions in my community also face similar challenges, including the fact that most of the NCDs are left undiagnosed, untreated or inadequately treated due to stigma and discrimination associated with HIV and TB. With my experience, I would like to emphasise the need for HIV-NCD service delivery integration. In India, a few civil society organisations (CSOs) are making efforts towards the meaningful involvement of people with lived experiences as key stakeholders in the design of health programmes. I am actively associated with Healthy India Alliance, a coalition of 26 CSOs working for the prevention and control of NCDs.

Health programmes for NCDs and HIV/AIDS can work together holistically- strategies for integration must be tested and scaled up. **Collecting data on HIV and NCDs at public health facilities will help to make sure we have the right services for the right people, in the right places.** We must continue to work together to advance and strengthen the evidence base for equitable, impactful, cost-effective, gender-sensitive and age-responsive integration.



Keep dancing: facing HIV and cancer

Tara Chaudhary, 26 years old. Transgender woman from Nepal, living with HIV and a cancer survivor.

My name is Tara Chaudhary and I am a 26 year old Transgender woman living in Nepal. I have come to this point after fighting HIV and cancer for the past two years.

After I completed my schooling I worked as a teacher but it was difficult to manage on the monthly salary I received so I left and went in search of work. One day I saw a vacancy at a community-based organisation on Facebook and I went there with my curriculum vitae. I was very happy to be appointed as a Community-Based Supporter, where I reached out to gay men, men who have sex with men, and transgender people with HIV prevention information and referrals. I was also exploring my own gender identity, coming to terms with my identity as a transgender woman.

Around that time, I thought of checking my health and I tested for HIV. And so at the age of 23, I was diagnosed HIV positive. It felt like a dream and I was very scared. But I could not get away from reality. I felt a little relief when a staff member of the organization comforted me and gave me information about HIV. I was very afraid to tell my family about my HIV status, I had so many questions buzzing in my head that I felt weak.

I started taking my HIV treatment but after 3 or 4 months on treatment, I began to feel very unwell. I experienced nausea and heartburn and I could not sleep all night because of the pain. It seemed like the treatment was making me weaker. After a lot of pain and many tests I was told that I had a tumour in my stomach and I was referred to the cancer hospital. A doctor informed me that the tumour must be removed as soon as possible.

He also said that one member of my family must be there for the operation. I was afraid because no one in my family knew about my HIV status or my health challenges. I am thankful to my co-worker who told my elder brother about my situation. My brother finally said that he would support me. That time was nothing short of a battle for me.

The operation was a success but I had to wait 15 days for the results of the tests from the tumour. The doctor told my brother that it was stage three cancer and that I had to have chemotherapy. Hearing that I had to catch my breath! I felt so much sadness and confusion. I thought of suicide many times.

Our family finances were critical and the cost of the treatment stressed me. My brother calmed my heart when he said he would even take a loan to make sure I got treatment.

I underwent chemotherapy, with my brother's support and with money collected from my colleagues and fundraising. I am filled with gratitude for all these helping hands.

After eight rounds of chemotherapy scans show that I am okay, although I still have to attend follow-up appointments.

These bitter and sweet experiences of my life have taught me a lot. I experienced stigma because of my gender identity and my HIV status.

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I was not treated the same way that other patients were, the doctors and nurses were distant from me and were reluctant to touch me. My HIV status was disclosed to my family without my consent and when they found out they started acting differently – this was devastating, and I felt there was no point in living.”

Since this happened, I have been unable to work and I have relied on sex work to support myself. This has not been easy as it is unsafe and I could also face arrest. I also have costs for my follow-up treatment that I have to cover myself.

In all these problems and challenges support is needed, but the more positive and strong you can make your self-esteem, the more successful your journey will be. I continue to search for opportunities to share my experience and educate others about HIV and cancer as a role model and young leader.



From stigma to strength: navigating life with HIV and NCDs

Manoj Pardeshi, 54 years old, India, living with HIV and hypertension

My diagnosis with HIV came as a big shock to me. I remember feeling afraid, fearful of death and full of shame – like I was cursed. Despite numerous ups and downs, my journey from despair to hope is one I'm always eager to share. Hence, I'm leveraging this global platform to share about my lived experience with a hope of inspiring others to speak out about their own journeys.

Before my diagnosis with HIV, I had acquired high cholesterol at an early stage, and after my diagnosis, I developed antiretroviral-induced high blood pressure in my 40s. Managing both HIV and a noncommunicable disease has been quite challenging, but I remain hopeful. I enjoy trekking but unfortunately, I face limitations due to an increased risk of bone fractures and have had to reduce my hiking time. Often, I wish things could return to how they were before. As a person living with HIV and an NCD, I chose to actively involve myself in advocacy and become the health activist I am today. Since my diagnosis, my curiosity about developing scientific knowledge around HIV and its linkages with NCDs as well as its management, has grown significantly.

Despite several hardships, I am sincerely appreciative of the healthcare providers who have continued to stand by me and offer their support as I navigate my treatment and persevere to overcome many barriers.

While I might be fortunate, several others like me are often denied treatment, especially during surgeries, due to their co-morbid conditions.

Unfortunately, this results in unwanted deaths that remain unaddressed as even families avoid pursuing matters due to the longstanding stigma attached to people living with HIV. Before, I thought HIV was a death sentence. **As I received counselling at the National AIDS Research Institute in India and from other healthcare providers, I became more aware of my condition and felt encouraged to actively engage and participate in my personal health journey.** This has really helped me gain a sense of control in my life. I am filled with gratitude as I continue to receive abundant support and acceptance from family and friends.

Contrary to popular belief, HIV management is straightforward, and the medication requirement is minimal. At the same time, NCD management motivates me to continue learning about my health and maintain a healthy lifestyle. **My vision for myself and others living with HIV and NCDs, is equitable access to universal health coverage and high-quality treatment for all.** I believe that enhancing community sensitisation and participation can help people living with HIV and NCDs live a better quality of life and optimally manage their conditions without stigma and discrimination. I believe that by voicing our experiences, we can foster greater understanding and empathy. Equitable and high-quality treatment should be a fundamental right for all.



Analysis

Below you will find a more detailed summary of the three key challenges presented earlier in this publication, together with related quotes from those who have so generously shared their stories.

Increase awareness of the risks and burden of NCDs and eliminate stigma

People living with HIV who shared their experiences in this collection were unprepared for their diagnosis of NCDs such as cardiovascular disease (hypertension), diabetes, or cancer and were unaware that their HIV status increased their risk of developing some NCDs. Their NCD diagnosis placed additional strain on their mental health, in addition to managing their symptoms and continued adherence to another medication. This supports recommendations made in '15 Transformative Solutions', to develop contextually appropriate, person-centred information about NCDs and their risk factors for people living with HIV and update national HIV guidelines to include detailed guidance on prevention, testing and treatment of NCDs, based on simplified and streamlined algorithms.

Healthcare workers in HIV care must be trained to identify and treat NCDs and NCD risk factors among people living with HIV, which is a recommendation made in 'Long, Full Healthy Lives'. People living with HIV must be informed about their increased likelihood of developing an NCD, appropriate to their age, gender, and other factors, by healthcare providers who have received training on the relationship between NCDs and HIV.

HIV-related stigma within the healthcare system also emerged as a significant barrier to care for many people sharing their experiences and affected the quality of care provided. Building capacities among health workers in HIV care would go a long way to provide support for linkage and follow up, making sure that people living with HIV access stigma-free NCD treatment in other healthcare settings.



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My wish is that healthcare workers and even clinicians themselves at HIV clinics are trained to recognise diseases like hypertension and diabetes.”

Domitilah Anyango Okeymo,
Kenya, living with HIV and hypertension

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Each time I told my doctor [about my symptoms] I was just given laxative medication and sent home. The focus was on treating us for HIV and not on our overall health.”

Ashleigh Nikki Bezuidenhout,
South Africa, living with HIV, cancer survivor

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Every time I've sought treatment for health issues other than HIV, discrimination has been my constant companion.”

Mona Balani,
India, living with HIV and hypertension

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I believe that enhancing community sensitisation and participation can help people living with HIV and NCDs live a better quality of life and optimally manage their conditions without stigma and discrimination.”

Manoj Pardeshi,
India, living with HIV and hypertension

Integrate HIV and NCD services

All those sharing their experiences in this collection described difficulties in negotiating siloed and fragmented health systems. This was most starkly evident in experiences where people had to attend multiple facilities and appointments treating their NCD conditions and HIV separately. In other cases, adhering to multiple medications was a challenge without holistic advice on how and when to take them.

Integrating HIV and NCD care can eliminate the frustration and stress experienced by service users, and reduce their costs and time away from work for attending multiple facilities. Recommendations in 'Long, Full Healthy Lives,' '15 Transformative Solutions' and 'Spending Wisely' indicate a process that could be implemented to integrate HIV and NCD services. This includes exploring opportunities and conducting research into cost-effective and sensitive integration, increasing financial and technical support for integrated services, particularly in primary healthcare, and utilising existing HIV funding and programme platforms. Other recommendations highlight consulting healthcare professionals about integration, monitoring indicators and targets for service delivery, and strengthening supply chains.



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[it was] my worst nightmare. I now had three different clinicians, three clinics and three different appointments - and they weren't speaking to each other and didn't tell me about drug interactions or explain things to me holistically”

Serah Mbovi Makau, Kenya, living with HIV, hypertension and diabetes, and lived experience of TB.

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I would like NCDs to be integrated into HIV clinics, from labs for screening to just checking blood pressure. This will mean that everyone, including young people, can access screening and take care of their health.”

Domitilah Anyango Okeymo, Kenya, living with HIV and hypertension.

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“I want communities living with HIV to receive additional services beyond ARVs. These additional services mean that when a patient comes in, they receive their ARVs and can also be diagnosed with NCDs like high blood pressure and they can be given medication for it as well.”

Sara, Cambodia, living with HIV and hypertension.

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Looking at our local clinics here in Zambia, people take their treatment and go. They might not know that there are these mental health services. I would like to see all clinics give information to patients, in their languages, about mental health support.”

Luthando, Zambia, living with HIV and depression.

Improve affordability and access to comprehensive care and treatment

The experiences in this collection demonstrate the value of free and accessible HIV testing, treatment, and care. The collection highlights the need to address essential NCD prevention, diagnosis, and treatment services across the continuum of care for people living with HIV. The availability and affordability of NCD services needs to be improved to ensure more equitable access to care for people living with NCDs and HIV. In 'Long, Full Healthy Lives' and 'Spending Wisely,' recommendations have been made to enable access and affordability of NCD services within HIV services, such as subsidising NCD treatment and enhancing existing HIV supply chains, designing and implementing UHC benefit packages to include NCD essential medicines, and implementing flexible delivery models (e.g., delivery of services via the home, community, or remotely).

Integrating HIV and NCD care into primary healthcare programmes not only reduces out-of-pocket costs for those seeking care, but has been shown to lower the costs of essential HIV and non-HIV services²⁰. Since many NCDs share similarities in their screening, diagnosis, treatment, and management, including routine follow-up, treatment adherence, self-care and healthy behaviours, sharing resources across multiple diseases leads to more efficient use of healthcare workers and capital investments, such as facilities and equipment²¹.



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Our family finances were critical and the cost of the treatment stressed me. My brother calmed my heart when he said he would even take a loan to make sure I got treatment. I underwent chemotherapy, with my brother's support and with money collected from my colleagues and fundraising.”

Tara Chaudhary,

Nepal, transgender woman living with HIV and cancer survivor.

“

I receive a 6-month supply of HIV medications, but for my blood pressure medication, I must buy these myself from the chemist. You see, for those who are ageing with HIV, many of us are getting hypertension, diabetes, and cancers, and these NCDs are not treated for free in our country. This is a problem, especially for older people without support – HIV and NCDs don't know if you have no money”.

Isaac Lonzi,

Kenya. Living with HIV, hypertension and a disability.

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I support advocacy to ensure that we always have access to our medication – for private pharmacies to provide drugs on the community health insurance so we can go there for medication.”

Claude Karangwa,

Rwanda. Living with HIV, hypertension and diabetes

20 Deborah Goldstein, MD, Michael Salvatore, BA, Robert Ferris, DO, Benjamin Ryan Phelps, MD, Thomas Minor, MD. The Lancet July, 2023 Integrating global HIV services with primary health care: a key step in sustainable HIV epidemic control. DOI:[https://doi.org/10.1016/S2214-109X\(23\)00156-0](https://doi.org/10.1016/S2214-109X(23)00156-0)

21 NCD Alliance Integrating NCDs in the HIV response to protect decades of progress, <https://ncdalliance.org/why-ncds/universal-health-coverage-uhc/integrating-ncds-in-the-hiv-response-to-protect-decades-of-progress>

Conclusion

The experiences shared above provide powerful examples of the urgent need for effective integrated approaches and policy solutions. More than this, meaningfully involving people with lived experience of NCDs and HIV in strategic decision-making and accountability processes at global and national levels is essential to understand their priorities and meet their full health care needs²².

The experiences also provide further evidence for NCDAs recommendations on integrated and person-centred care and for actions to achieve the United Nations General Assembly (UNGA) commitment to ensure full coverage of NCD services for 90% of people living with, at risk of, and affected by HIV by 2025. This target is not only in line with the principles of UHC but offers better health outcomes for people living with NCDs and HIV. Treating people, not specific diseases, should be the cornerstone of NCD-HIV integration, as well as the driving principle to achieve health for all.

Advocates are encouraged to use these stories together with NCDAs other resources on integration, including in their advocacy leading up to the UN HLM on NCDs in 2025. Improved awareness of the risks of NCDs for people living with HIV, greater integration of NCD/HIV services and the availability and affordability of these services is critical for more equitable, person-centred care for people living with HIV and NCDs and will ultimately drive progress on UHC.



²² For further information, refer to the Greater Involvement of People Living with HIV/AIDS principle https://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf and the WHO for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions <https://www.who.int/publications/i/item/9789240073074>



OUR VIEWS, OUR VOICES

An initiative by the NCD Alliance and people living with NCDs

