Update II – August 2025

Advanced HIV Disease Community Innovations

April – July 2025

Human Centred Design
Immersions & Workshop Report

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Prepared by
Human Centered
Design Partner MBX

This report forms part of the Human Centered Design solutions process under IMPAACT4HIV for South Africa, Democratic Republic of Congo, Nigeria, Côte d'Ivoire, Sierra Leone and Mozambique.

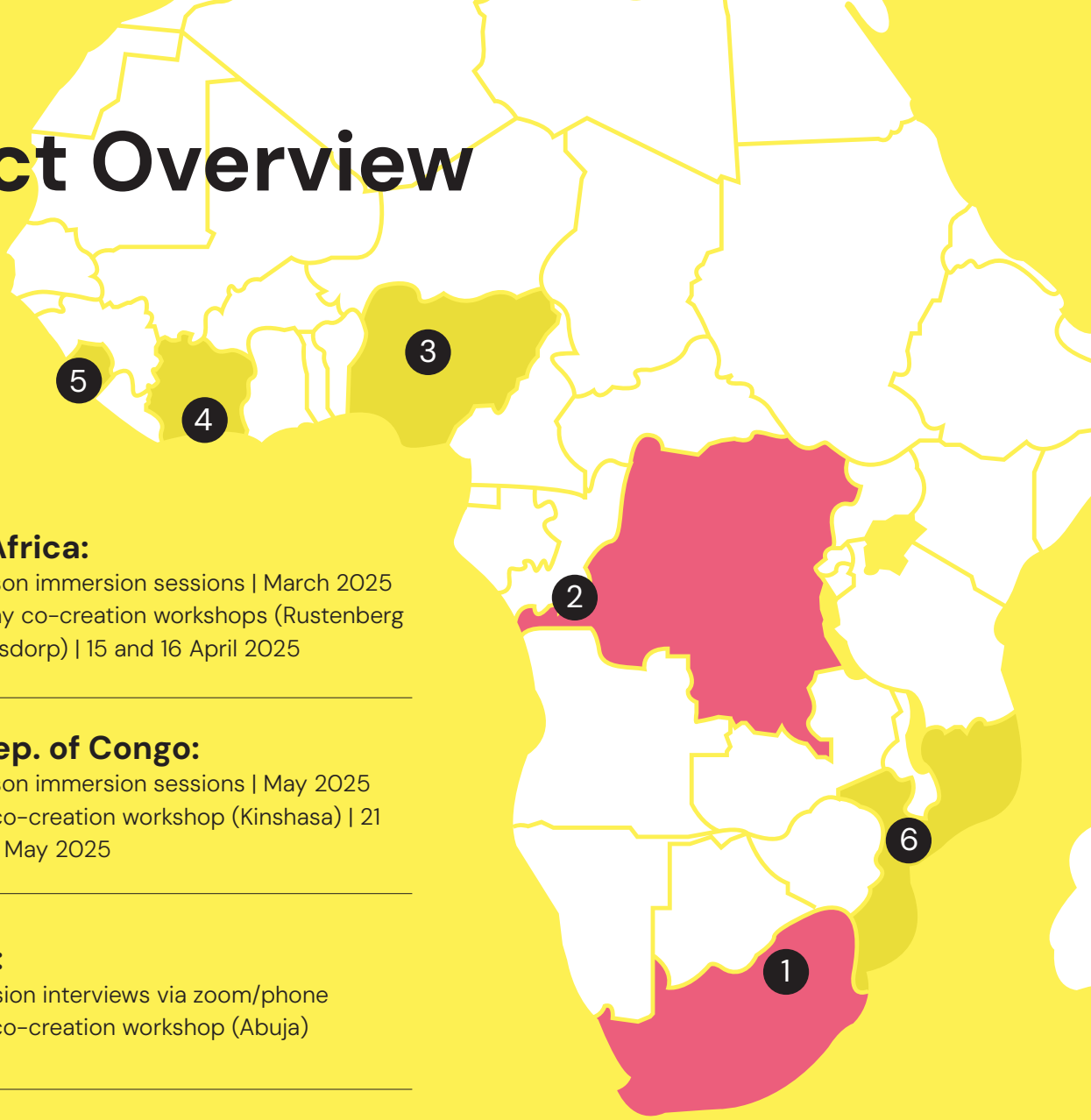
IMPAACT4HIV is using human centered design (HCD) to co-create viable, feasible and desirable country specific solutions to support effective and sustained adoption of the STOP AIDS toolkit, including community, systems actors and health care providers engagement mechanisms, and toolkit refinement.

HCD puts human beings at the center of all challenges and opportunities.

HCD emphasizes empathetic understanding, systems thinking, and collaborative problem-solving to engage with health system stakeholders from community to national level. Threading HCD methodology into solutions for advanced HIV disease, helps to:

1	Understand	mindsets, beliefs, perceptions and how existing national health system and local implementation variations influence health professionals and community members in decision making and behavior
2	Identify	facilitating factors, reward triggers and barriers to successful program implementation
3	Identify	facilitating factors, reward triggers and barriers to health seeking behavior change
4	Uncover	insights that lead to meaningful motivation to improve systems and/or health seeking behaviors
5	Generate	rich interactions that feed a collective creative force for pragmatic tailored and scalable solutions on national, regional, provincial and community specific levels

Project Overview



1 **South Africa:**
- In-person immersion sessions | March 2025
- 2 x 1 day co-creation workshops (Rustenberg & Klerksdorp) | 15 and 16 April 2025

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2 **Dem. Rep. of Congo:**
- In-person immersion sessions | May 2025
- 2 day co-creation workshop (Kinshasa) | 21 and 22 May 2025

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3 **Nigeria:**
- Immersion interviews via zoom/phone
- 2 day co-creation workshop (Abuja)

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4 **Côte d'Ivoire:**
- In-person immersion sessions
- 1 day co-creation workshop in Abidjan

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5 **Sierra Leone:**
- Immersion interviews via zoom/phone
- Workshop outcomes/prototypes HCD testing

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6 **Mozambique:**
- Immersion interviews via zoom/phone
- Workshop outcomes/prototypes HCD testing

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7 **All:**
- Consolidated HCD Report with Recommendations and Finalised Prototype Solutions

HCD process

Instead of developing a 'one-size-fits-all' approach, the Human Centered Design process recognizes that different contexts and users may and likely require different types of interventions that respond to unique challenges/barriers. HCD methodology can uncover perceptions, behaviors and motivators as well as barriers to successful program implementation and behavior change.

An HCD process is solution-oriented, with an emphasis placed on prototyping new tools, strategies or products with users, rather than for them. Before we can understand those elements as a group, the team undertake a robust immersion process to understand individual experiences.

Key Immersion Insights

1

Disclosure Is the Emotional Fault Line

- **Disclosure is a tipping point, not a milestone.**
  The timing, language, and method of disclosing to a child matters deeply. Poor disclosure leads to denial, anger, shame, and adherence issues later—especially in adolescence.
- **Parents fear emotional backlash and stigma more than the virus**
  Caregivers delay disclosure due to fear of judgment from the child and community. They lack the emotional tools, not the clinical information.
- **Children live with half-truths and confusion**
  Many children don't know how or why they contracted HIV, which creates emotional instability, mistrust, and deep identity issues in adolescence.

2

Caregivers Are the Hidden Leverage Point

- **If the caregiver is in denial, the child will not benefit**
  The child's experience is a direct mirror of the caregiver's own acceptance, understanding, and willingness to engage with the diagnosis.
- **Most caregivers are under-resourced, unsupported, and overwhelmed**
  Especially aunts and grandmothers, who often default to denial, misinformation, or silence. Their own trauma, shame, or religious beliefs interfere with adherence.
- **Empowered caregivers = empowered children**
  Where caregivers have been well-trained and emotionally supported, children show better viral suppression, adherence, and psychosocial wellbeing.

3

"Even when the system is technically comprehensive, it is emotionally inadequate"

- **The policy is thorough; the practice lacks humanity**
  Staff follow protocols but lack the emotional training and time to provide holistic support. Disclosure policy is a "book that doesn't work."
- **Clinical flow, stigma visibility, and poor environment worsen outcomes**
  Clinics often expose patient status unintentionally—via room labeling, queues, or lack of privacy—reinforcing stigma and dropout.
- **The emotional burden is falling through the cracks**
  Everyone—from CHWs to nurses—recognizes that clinical systems are not equipped to deal with the emotional, family, and social complexities of AHD care.

4

Peer and Group Support Changes Everything

- **Teen clubs and peer mentors are saving lives**
  Children disclosed to properly and placed in clubs or peer groups do better in every dimension—medication, mental health, and hope for the future.
- **"I need to talk to someone like me"**
  Children and caregivers express a clear desire for peer connection—hearing from "someone who's been through it" builds trust and motivation.
- **Age-based, language-sensitive metaphors build understanding**
  Concepts like "goodnight medicine" or "the virus is a sleeping germ" are resonant and effective. These communication tools are missing in many clinics.

5

The Disclosure Gap Is a Design Opportunity

- **Children have a right to know, but systems are afraid to tell**
  The tension between protecting the child and being honest is unresolved—this is both a policy gap and a design challenge.
- **Half-disclosures harm more than they help**
  Children who are partially informed grow up confused and mistrustful, especially when physical changes or relationship questions arise during puberty.
- **Disclosure should be an ongoing, supported journey—not a one-time event**
  Designing disclosure as a multi-step emotional process (not a checklist item) is essential.

HCD process

Through co-creation workshop activities, participants work with each other to come up with innovative, pragmatic solutions that respond to the real-life experiences and understanding of their own barriers. Bringing together individuals with varied backgrounds and multiple perspectives in the process of collaborative problem solving can enable more effective and successful solutions that appeal to different user groups.

Co-creation Workshop Activities

1	Official Opening
2	Human Centred Design
3	Definition of Success
4	Testing Truths
5	Challenges
6	Tea Break
7	Practical Empathy
8	How Might We?
9	Lunch
10	Prototype Solutions
11	Sharing
12	Next Steps

Participants included:

Adolescents

Care-givers

Healthcare providers

Public health professionals

Stakeholders

Relevant community members

Definition of Success

– as ranked by groups from MOST important to LEAST

c

Caregivers, teens, and vulnerable groups have measurably improved AHD knowledge and health-seeking behavior

b

Confidence in AHD-related action among health system actors incl. CSOs and caregivers

e

(e)Ability to find/address AHD gaps using data and expertise

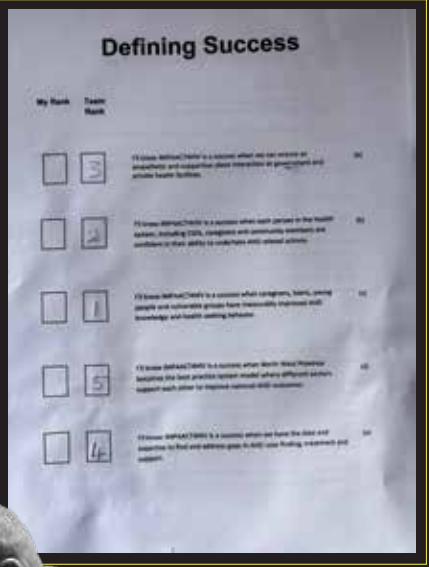
a

(a) Supportive client interaction in health facilities

(d) North West Province becomes a national best practice model

The top two definitions (c and b) reflect a strong emphasis on:

- Empowering caregivers and youth with real knowledge and agency
- Building confidence across the health ecosystem to engage meaningfully in AHD care



Participants Share

Rustenberg, South Africa

Refilwe wanted to speak out

Refilwe is 21 years old. She found out she was living with HIV at 10 years old when she was hospitalised with a serious case of TB. She had watched her mother pass away through denialism and refusing treatment.

Refilwe is a power house of ideas and potential, but tripped up by life's circumstances and her HIV diagnosis. She has faced incredible stigma and economic difficulties.

Refilwe was on her own since diagnosis with no social worker follow-up. She found solace in sharing her triumph with other kids, revealing her as a born leader who needs help to reach their potential.

Insight from Refilwe

> **Where is the safety net for kids in dysfunctional families and schools?**

She found the workshop felt like a part of what she has been looking for for so long - a chance to hear and be heard and contribute to something bigger than her.

Testing Truths

South Africa

Agreed Truths (Green Arrow)

These reflect widely accepted insights—confirmed lived realities or working assumptions.

CLEOs are key actors in decentralizing AHD support. It's better to repeat the same message about AHD over time so it is internalized.

There are good guidelines like KidzAlive, but HCWs/CSOs/CHWs aren't aware of them. Progressive disclosure of HIV can be confusing for both caregivers and children.

Caregivers and older teens must be given medical information in clear, digestible formats. Caregivers need to be incentivized to engage in proactive care.

Uncertainty / Need for Discussion

Statements that received mixed reactions or were placed in "don't know" areas.

Standardized messaging like WHO's STOP AIDS toolkit should replace audience-specific tailoring.

Disclosure happens only once, so it's important to do it right.

Case finding is not a problem for AHD in North West Province.

Accessing AHD care is a joint decision between couples.

Disagreed Truths (Red Arrow)

These challenge dominant assumptions and reveal strong counter-narratives or resistance.

Parental/caregiver involvement in adolescent AHD issues is counter-productive.

Raising awareness about AHD will further stigmatize those living with it.

HIV & AHD SBC campaigns need not include community context.

Traditional healers should not have a role in AHD support.

Testing Truths

South Africa

Agreed Truths (Green Arrow)

These represent beliefs that are validated by participants' experience:

- When children transition to adolescent care, they often fall through the cracks.
- Caregivers often say 'yes' to health workers even when confused or in disagreement.
- Psychosocial support is essential—not just 'nice to have'.
- Data doesn't drive empathy—stories do.
- Repeating the same message about AHD (rather than changing it) improves retention.
- Community members delay action until visible symptoms appear—often too late.

Uncertainty / Debate (Neutral)

These represent areas of tension, ambiguity, or mixed beliefs:

- Men have become responsive as caregivers.
- An AHD toolkit should encourage peer-to-peer disease communication.
- Children's attitudes and reactions fluctuate—need specific guidance.
- CLEOs are key actors in decentralizing AHD support.

Disagreed Truths (Red Arrow)

These statements were rejected or challenged by participants:

- Disclosure only happens once—so it must be done right.
- Traditional healers should not have a role in AHD support. Messaging on AHD should be standardized rather than tailored.
- Case finding is not a problem in North West Province.
- Raising AHD awareness will stigmatize those living with it.
- Caregiver involvement in adolescent AHD issues is counter-productive.
- SBC campaigns don't need community context.
- Accessing AHD care is a joint decision between couples.

Testing Truths

Democratic Republic of Congo

Agreed Truths (Green Arrow)

These represent beliefs that are validated by participants' experience:

- Disclosure as a delicate, singular moment: "Disclosure happens only once, so it's important to do it right."
- The importance of human connection and storytelling: Data capturers and managers need stories to humanise the numbers and care more about system improvement.
- The value of repetition and simplicity: Repeating the same message over time (rather than changing it) helps communities internalise AHD information.
- Community actors' central role: Community Health Workers are vital to decentralised AHD support.
- Standardised messaging: Some participants preferred WHO-style toolkits over audience-specific tailoring.
- Barriers to care: Financial strain, interpersonal gaps, and lack of awareness are significant barriers to adherence and early diagnosis.
- Communication and emotional burden: Discussing and initiating treatment is one of the most difficult emotional processes for families.

Uncertainty / Debate (Neutral)

These represent areas of tension, ambiguity, or mixed beliefs:

- The role of community-based messaging on Mpox and HIV.
- Talking about sex and stigma in Mpox communication.

Disagreed Truths (Red Arrow)

These statements were rejected or challenged by participants:

- Whether men are as responsible as women in clinic attendance.
- The need for segregated clinic spaces.
- The necessity of integrating broader community context into messaging.
- How stigma and perception impact provider-patient relationships.

Participants Share

Kinshasa, DRC

A Healing Relationship

In my work supporting people living with HIV, I once met a woman who was a devout Adventist. At first, she was reluctant to start treatment, possibly due to her religious beliefs or fear. But through compassionate care and building trust, I helped her understand the importance of treatment. Eventually, she agreed to start antiretroviral therapy.

A few months later, her health had greatly improved. She now feels well and is deeply grateful for the support I provided. Whenever she visits Kinshasa, she comes to see me—just to say thank you. Her appreciation reminds me why this work matters so much.

From: Dagobert N'Tangu

Insights

Trust and empathy can overcome initial resistance to treatment, even in faith-influenced contexts.

Supportive relationships between health workers and PLHIV are critical to long-term adherence.

Religious beliefs may delay treatment, but they can also coexist with medical care when approached with respect.

Gratitude and follow-up visits reflect the power of relational, human-centered care.

Testing Truths

Combined Analysis

System Gaps and Caregiver Burden are Widely Validated

Participants across both workshops consistently affirmed that:

- Caregivers—especially for adolescents—are overwhelmed, under-supported, and often confused.
- Adolescents "fall through the cracks" during transition phases.
- Psychosocial support is critical but undervalued.
- Caregivers frequently "perform compliance" by saying yes when unsure or disagreeing, indicating a need for clearer communication and better relationships with providers.

Implication:

Interventions must focus on emotional support, plain-language communication, and transition-sensitive continuity of care.

Communication Must Be Clear, Consistent—But Also Contextual

There was widespread agreement on:

- The value of repetition in messaging for AHD to increase retention and understanding.
- Storytelling and peer-to-peer communication were favored, but with caution about misinformation risks.

However, participants rejected overly standardized approaches, such as:

- One-size-fits-all messaging (e.g., WHO toolkit without adaptation).
- The idea that disclosure is a once-off event.

Implication:

Communications should be layered, repeated, and tailored—rooted in local realities while retaining clarity.

Community Dynamics and Cultural Factors are Essential, Not Optional

Both groups strongly rejected the notion that:

- Traditional healers should be excluded.
- Social & community context is irrelevant to AHD & HIV communication.
- Raising awareness would lead to stigma.

Instead, participants emphasized:

- The importance of involving trusted local actors (like CLEOs and traditional healers).
- The need to equip communities with tools and confidence, not just health professionals.

Implication:

Sustainable AHD support requires community engagement as a foundation, not an add-on.

Testing Truths

Combined Analysis

Health Worker Empathy and Literacy Gaps Are Barriers

There was clear consensus that:

- Many health workers lack interpersonal skills.
- Data and statistics alone don't motivate health system change—narrative and emotional framing are essential.

Implication:

Programs must train and support HCWs to be emotionally intelligent communicators, not just clinical implementers.

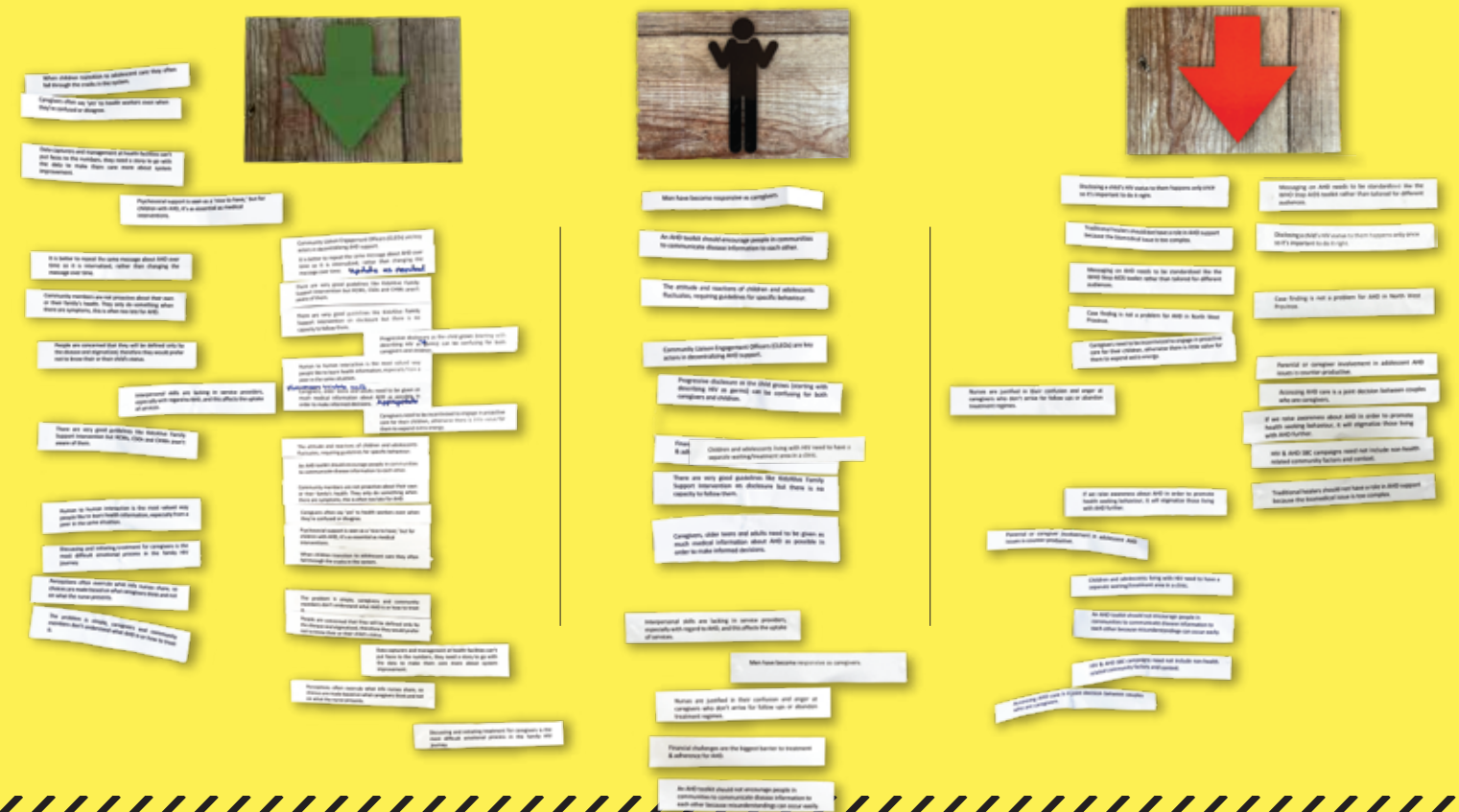
Gender and Decision-Making Realities Are Nuanced

While there is some optimism (e.g., "men are becoming responsive caregivers"), the rejection of statements like "AHD care is a joint decision between couples" shows:

- Gender norms and power asymmetries in health decisions remain prevalent.
- Messaging and support structures need to acknowledge and navigate these dynamics rather than assume equality.

Implication:

Gender-responsive design is essential; strategies should account for unequal caregiving and decision-making roles.



Participants Share

Rustenberg, South Africa

Precious & Lena — Straight-Up Honesty at Home

Lena and Precious (mom and daughter) approach HIV with openness and humour. Their relationship is built on Lena's decision early on to be honest—after losing her father, brother, and uncle to HIV-related illness, she vowed not to repeat the silence. When Precious's father became ill, he asked her to test with him. That shared moment of action likely saved her life.

In the immersion, they described how this foundation of honesty shaped how they manage treatment, disclosure, and everyday life. Even their 12-year-old son—who hasn't been formally disclosed to—reminds them to take their pills.

Insight

What practical steps and support can help other caregivers build this kind of openness with their children?

Final Takeaway

The workshops reveal that real success in AHD support will come from a fusion of:

Messaging and care models that oversimplify reality and overcomplicate biomedical explanations, or fail to include community voices—will be ineffective.

Participants Share

Kinshasa, DRC

The Cost of Refusal

Unfortunately, not all stories have a happy ending. Some people living with HIV refuse treatment altogether. By the time the disease progresses, it's often too late to intervene.

I experienced this personally with my brother-in-law. Despite my repeated efforts to convince him to start treatment, he firmly refused. His health deteriorated rapidly, and sadly, he passed away. His story is a painful reminder of the importance of early diagnosis and adherence to treatment.

From: Dagobert N'Tangu

Insights

> **Delayed treatment initiation due to denial or fear can lead to fatal outcomes.**

> **Family support alone may not be enough to overcome resistance—systematic, early interventions are needed.**

> **This story illustrates the consequences of untreated HIV and the emotional toll it takes on families.**

> **Emphasizes the need for stigma reduction and proactive, culturally sensitive engagement.**

Exploring challenges

archetypes

In health market research, an archetype refers to a representative model or character that embodies the shared traits, behaviors, motivations, and challenges of a broader group of people within a health system. Unlike individual case studies, archetypes are composite profiles distilled from patterns observed during qualitative and ethnographic research—such as interviews, observations, and immersion sessions. They help stakeholders humanize data, identify systemic barriers, and design more targeted, empathetic, and contextually relevant interventions.
Archetypes are especially useful for mapping emotional, social, and structural dynamics in care journeys. In this project, they serve as a storytelling and strategic design tool to illuminate the lived realities of key actors in advanced HIV disease (AHD) care—informing more effective communication, service design, and policy recommendations.

Key Personas Identified

South Africa

1

The Protective but Overwhelmed Mother

- The biggest problem is stress due to lack of support and guidance (feels isolated)
- Doesn't know where to go for help or how to navigate the system.

2

The Frustrated Health Care Worker

- Lack of adequate resources and persistent staff shortages (Insufficient support from the Department of Health)
- Overwhelmed, angry and frustrated due to system inefficiencies. (Delays in diagnosis due to lengthy AHD guideline processes.)
- Lack of debriefing, training, and emotional support mechanisms.
- Faces patient attitudes that are difficult to manage.

The Older Caregiver

- Feels responsible or guilty for not disclosing in time. (Doesn't know much about AHD)
- Confused about medication dosages. (Tends to forget key care steps or instructions.)
- May avoid care due to trauma, stigma, or prior loss.

4

The Silenced Adolescent Leader

- Not included in decisions about their own care or treatment.
- Lacks a platform to lead or support peers.
- Experiences stigma, fear, or shame related to disclosure. (May feel invisible or discouraged from speaking out.)
- Wants to contribute but is not trusted, acknowledged, or empowered.

5

The Community Healer or Connector

- Not officially recognised or supported by government or stakeholders. (At risk of being exploited or marginalised.)
- Lacks resources and training opportunities. (Excluded from structured knowledge-sharing or capacity-building efforts.)
- Faces barriers in integrating with the biomedical system. (Tension between indigenous knowledge and Western systems.)

The Quietly Struggling Child

- Struggles silently with illness or emotional distress. (Carries internalised stigma or fear of judgment.)
- Lacks a safe space or trusted adult to open up to.
- Doesn't understand what's happening to their body or health. (May miss doses or appointments out of confusion or fear.)
- Not necessarily that they misunderstand, but rather that they are misunderstood.

Participants Share

Kinshasa, DRC

Living with HIV Since Birth

I was born with HIV—transmitted from my mother at birth. For years, my family hid the truth from me. Eventually, I found the strength to face the reality and began treatment. I started feeling much better and regained my energy.

I was in a relationship and became pregnant. Thankfully, with proper medical care, my baby was born HIV-negative. However, when I disclosed my HIV status to my partner, he left me. That experience taught me how important it is to prepare for and carefully manage disclosure. Fear can destroy relationships—but knowledge and communication can build understanding.

From: 28 year old Mother of two sons, Member of NGO "Jeunesse espoir" (Youth's Hope)

Insights

Delayed disclosure to children born with HIV can cause confusion and emotional harm.

With access to treatment, people born with HIV can live full, healthy lives and have HIV-negative children.

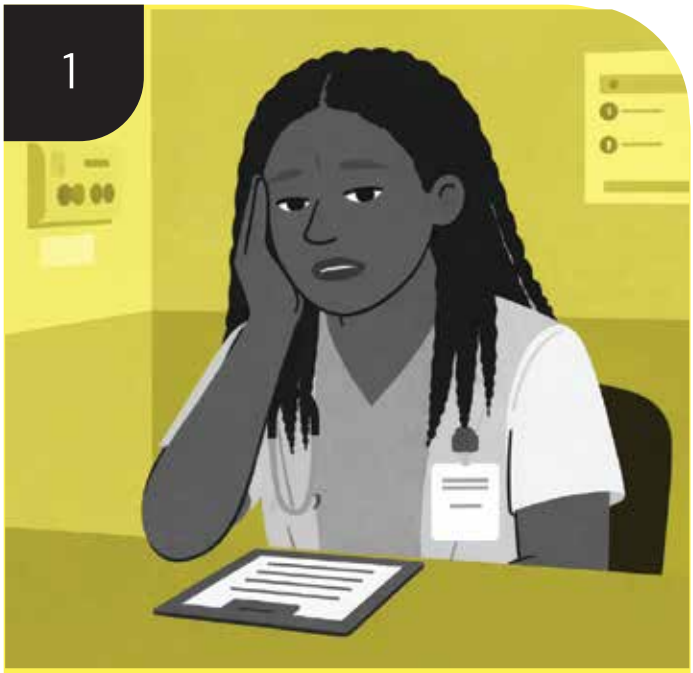
Disclosure must be managed carefully to avoid emotional trauma and relationship breakdowns.

Knowledge and self-awareness empower long-term health and parenthood.

Key Personas Identified

Democratic Republic of Congo

1



Lucie (Health Worker)

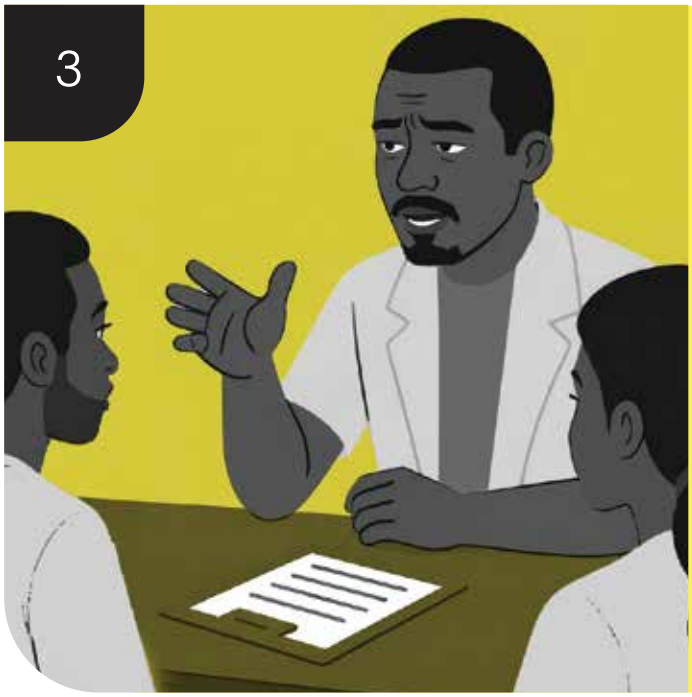
- Burnout.
- Overload.
- Unpaid tasks.
- Lack of time.
- Reduced service quality.

2

Mireille (Counsellor)

- Persistent stigma.
- Lack of recognition.
- Emotional fatigue.

3



Guy (Health Manager)

- Limited funding.
- Lack of equipment and staff.
- Legal pressures.
- Community mistrust.

Key Personas Identified

Democratic Republic of Congo

4

Aicha (PLHIV):

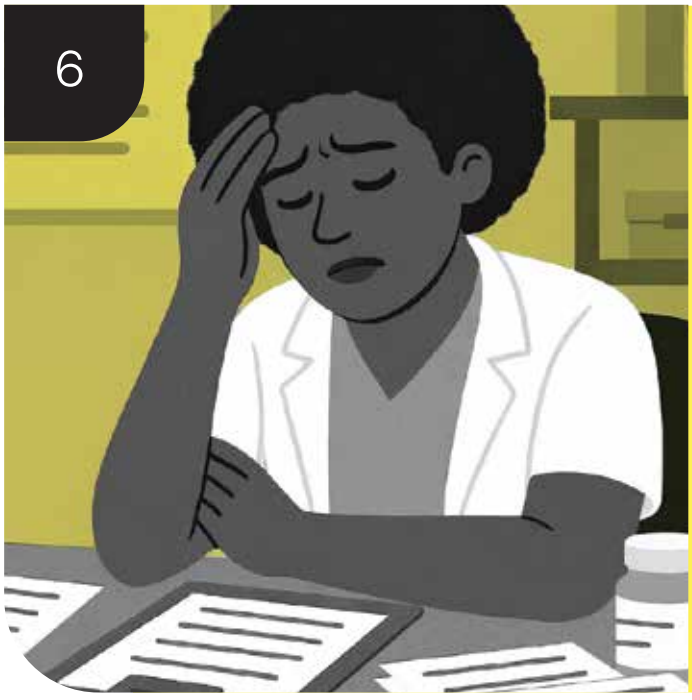
- Self-stigma.
- Fear.
- Secrecy.
- Poor adherence.

5

Mama Grace (Religious Leader)

- Moral guilt.
- Spiritual conflict.
- Misinformation.
- Lack of community support.

6



Jean-Baptiste (CHW)

- Lack of knowledge.
- Service disruptions.

Participants Share

Klerksdorp, South Africa

Mogale & Thabo — Half-Truths and the Need to Know

Mogale has known about his HIV status since age 12, after his mother passed away. But the story of how he got it was never shared. His aunt disclosed partially, leaving Mogale confused and dissatisfied.

"They didn't explain how I got it," he says—something that still weighs on him.

Thabo, his uncle, agrees the family should have told him more. He suspects the truth but finds it hard to say aloud. Instead, he reassures Mogale that it wasn't his fault. They've since developed a strong bond.

Mogale now sees his pills as *"my friend,"* and says the community's assumptions don't define him—thanks in part to a metaphor from a B-OK demo:

"People see you as the red bottle, but inside you're black—you're strong."

Insights

Incomplete disclosure can create long-term emotional gaps.

Youth need full, honest explanations of their diagnosis.

Trust and consistent support—like pill reminders—make a difference.

How Might We?

How Might We process

In Human Centred Design and Design Thinking processes, How Might We questions are a powerful tool for transforming identified challenges into opportunities for creative problem-solving. By reframing barriers through the lens of possibility, HMWs invite collaboration, curiosity, and ideation without prematurely jumping to solutions. Rooted in empathy, they help teams stay grounded in the lived experiences of real people. These statements bridge insight and action, turning complex human challenges into designable prompts that guide prototyping and co-creation.

Participants in each workshop were asked to brainstorm How Might We statements, drawn from the Barriers exercise

HMW: How might we improve coordination between different roles (reception, nurse, CHW, CLEO) to streamline AHD care?

South Africa

- Extend health education outside the clinic
- APP for roles of each cadre on AHD
- Capacities – all stakeholders to meet once a month
- By creating teamwork, for example by doing workshops
- Regular staff group huddles
- By respecting each other's points
- Sharing new information on AHD during staff meetings
- By doing workshops for people that work as facilitators
- Complementary sessions according to scope of care
- Monitoring & patient folder system always maintained
- Morning information sessions
- Understanding each other's roles through training
- Each role to appreciate & respect the other and their value in AHD reduction
- Training to include all roles
- All must have common understanding of goal (i.e. AHD)
- Leadership to practice gender equality across cadres (all are important)
- Team building workshops with each role represented
- Cross-learning about each other's role
- By treating each cadre equally with no favouritism

South Africa

HMW: How might we learn from successful caregiver/parent & child relationships?

- Be in a good relationship with the child
- Effective communication with the child
- Naming the medication in a way the child understands (e.g. using slang or nicknames)
- Listening to the child as a caregiver
- Immersing myself into my children's situation/slang
- Giving out necessary information
- Narrative stories by caregivers to children
- Patience & open communication
- Observing how they treat each other
- Being natural, not comparing with other people or groups
- Ask other parents how they got it right
- Community campaigns on parenting & caregiving to share info & learn
- Caregivers clubs/support groups: share lessons learned
- Joining support groups for children and caregivers
- Knowing how your child is feeling
- By loving each other

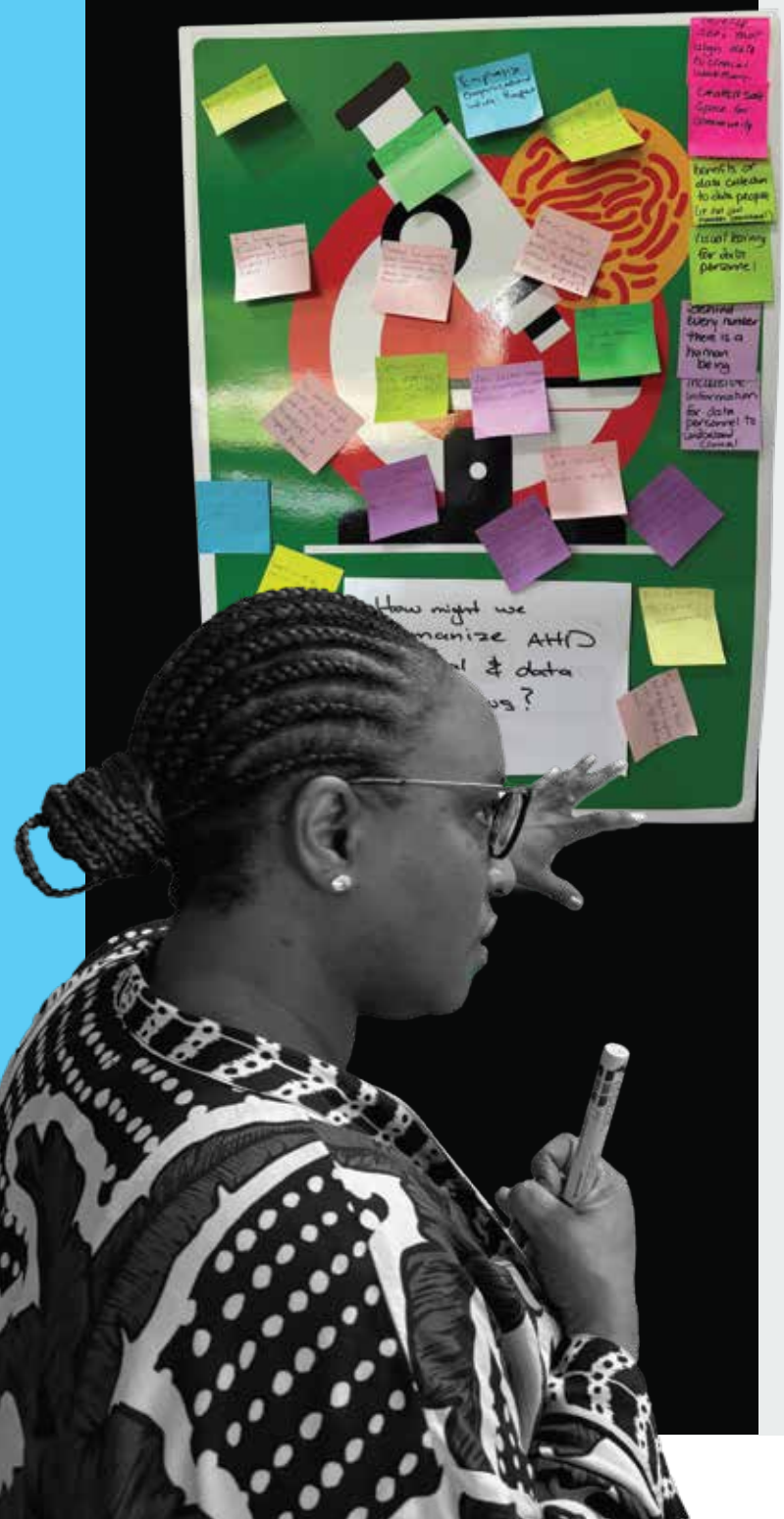
South Africa

HMW: How might we
make a toolkit useful to a grandmother, a teen, a health worker, and a traditional healer?

- Make it more easier to read
- Books, colourful pictures, drawings
- By using simple phrases and understanding
- WhatsApp QR code response tool
- Explain what the toolkit is & what its purpose is
- Use relatable visuals
- Define clinical terms for AHD
- Use simple basic language that they can all understand
- Include visual understanding and clear language
- Should include audio to explain the toolkit in a relevant language
- Simple illustrations for better understanding
- Culturally appropriate and sensitive visuals/info
- Patience
- By giving them information on how the toolkit works
- Verbalise – don't just give the toolkit
- Toolkit must be in different languages
- Using the toolkit in different languages not only English
- Simple terms for medication
- Include the dosage that is suitable for the patient (e.g. child)
- Adding pictures or diagrams in the toolkit
- It's important to educate people about the toolkit

South Africa

HMW: How might we humanize AHD clinical & data workflows?



- Emphasise compassion and values: respect
- Friendly, relatable health posters
- SOPs that align data to clinical workflows
- Create a safe space for community
- Benefits of data collection to data people (i.e. not just numbers)
- Visual learning for data personnel
- Focus must shift from just numbers to real human beings – PEOPLE FIRST!
- Behind every number there is a human being
- Inclusive information that helps community understand clinical
- Door-to-door socializing with people
- Implementing support groups
- Always cooperate & communicate together as one
- Conducting sensitisation & training sessions in clinics
- It's better when we communicate to each other
- Capturing the correct and truthful data at the end
- By creating community workshops to capacitate and inform
- Create a box or place where people drop their feedback for clinic services

South Africa

HMW: How might we
prepare the child's HIV understanding & emotions prior to sexual activity?

- A HIV does not stop you from having a normal life (emotional validation)
- Condom use to prevent unplanned pregnancies
- Consent is very important: NO MEANS NO!!
- Slogan: Sexual intercourse leads to babies
- Pictures of colourful common STIs
- Videos for education
- Use a condom before sex to avoid consequences of unprotected sex
- Tell them about the dangers of HIV
- Tell them they will remain emotionally challenged (expressive approach)
- Encourage them to learn more about HIV & other STIs
- Emotional consequences of HIV are heavier for young persons incl. teen pregnancy
- The partner increases your risk of HIV and other STIs
- Allow them to know about their rights and practice self-protection
- Teaching them about HIV and the impact of such a virus if not well managed
- Promoting an open relationship with the child and caregiver (sexual health topics)
- By educating the child about sexual intercourse
- By educating the child about the danger/circumstances of not using condoms
- Allow all the sisters to watch over each other
- By communicating with the child and educating the child about sexual activity
- Teach them about other STIs
- By involving child-led education at an early stage

HMW: How might we prepare the child's HIV understanding & emotions prior to sexual activity?

- Allow the child to ask questions without being judged.
- Create safe spaces to educate children.
- Use cartoons and videos.
- Teach children to express how they feel.
- Talk to children about sexual activity at a young age.
- Use accessible language and illustrations.
- Teach them the importance of condom use.
- Use storytelling to explain emotional issues.
- Use teen-friendly materials.
- Teach them about both HIV and puberty.
- Include emotions – teach the children to express themselves freely.
- Use roleplays to teach about emotions and sex.
- Explain to a child what HIV is before sexual activity.
- Use pictures to explain and build understanding.
- Create safe space where the child is free to talk.
- Create community support groups for children.
- Teach children the emotional and physical changes they go through.
- Support groups for children.

HMW: How might we make a toolkit useful to a grandmother, a teen, a health worker, and a traditional healer?

- To make a grandma use the toolkit it must be simple to understand and easy to read.
- Use the language that is commonly used not complicated words.
- For teenagers, use content that is relevant to them.
- Explain better with visuals & simple language.
- Grandmothers no big terms – simple large pictures.
- Use more visuals and fewer words.
- Traditional healer posters for rules.
- Toolkit – emojis – roleplays – music – appropriate.
- Use posters for interactive learning with children.
- Use either audio or visual and beads for traditional healers.
- Create a child-friendly environment and child-friendly tools.
- It must be written in understandable language – e.g. vernacular.

HMW: How might we improve coordination between different roles (reception, nurse, CHW, CLEO) to streamline AHD care?

- Increase appreciation of others' roles – team building – AHD strategy training.
- Share all content with everyone.
- Training with diverse groups.
- MERL – Mentoring, Evaluation, Research, Learning – clinical satisfaction.
- Filing + document capture.
- Debrief.
- Teamwork + teambuilding.
- Create a methodology – shared training, simplified supervision structure.
- Capacity building and consistent workshops.
- Understand scope and delineation of responsibilities.
- Training.
- Role clarification + location.
- Role clarification – know what to both use.
- Co-organizing team meetings of those managing children – discussion about the team.
- Management coordination protocols.

Participants Share

Kinshasa, DRC

Faith, Treatment, and Transformation

My journey began with frequent illnesses. After many hospital visits, I was finally tested for HIV—and the result shattered me. At first, I refused treatment, convinced I was going to die anyway.

As my condition worsened, I finally agreed to start medication, and soon my health improved significantly. Feeling "cured," I stopped taking my medicine. But a few months later, I relapsed. I turned to my church, where the pastor told me to rely solely on faith— that I didn't need medication if I truly believed. I followed his advice, but my condition worsened.

Eventually, I changed churches. My new pastor told me something that changed everything: *"God helps us through medicine and science. Prayer and treatment go hand in hand."* With renewed faith, I resumed treatment, and this time, I stayed on it. Soon, my viral load became nearly undetectable. I joined the Kimia Club, a support group for people living with HIV. There, I found community, encouragement, and purpose. I even became a coach, helping others overcome the same challenges I once faced. Despite the stigma—even from my own family—I now live with confidence, strength, and pride.

From: 25 year old Girl coach and Member of NGO "Jeunesse espoir" (Youth's Hope)

Insights

- **Initial rejection of ART may stem from fatalism or spiritual beliefs; relapse can be a turning point.**
- **Faith leaders have the power to either support or undermine HIV treatment adherence.**
- **Combining spiritual and biomedical narratives ('God helps through medicine') can increase adherence.**
- **Peer support groups (like Kimia Club) play a vital role in building confidence and community for PLHIV.**

Democratic Republic of Congo (DRC) **How Might We Co-Design Themes**

1 Storytelling for Behaviour Change

- Testimonial conferences with PLHIV
- Theatre, cartoons, oral tradition
- Tools in local languages and tones of hope

2 Inclusive, Multi-Audience Toolkits

- Colourful visuals and simple messages
- Short films and songs in local languages
- Tools accessible to elders, teens, healers, and HCWs

3 Empowering Community Gatekeepers

- Conferences and training for religious and traditional leaders
- Integration into health outreach
- Formal recognition of their roles as health allies

4 Symptom Recognition and Rapid Response

- Focus groups and training for caregivers and peer educators
- Provision of easy symptom ID tools and self-tests
- Support for proactive, early-stage care

Participants Share

Klerksdorp, South Africa

System Failures from Clinic to Community

Tsego's role sits at the intersection of clinic and community—and she sees challenges at every level. Parents often don't understand how HIV treatment works. They miss appointments, avoid disclosure, and don't follow the national guidelines. Some children aren't told the truth until well after age 10, if at all.

At clinic level, poor systems compound the issue. Patient contact info isn't updated. Reception staff fail to direct patients to CLEOs. Nurses sometimes respond to distress with verbal abuse, pushing patients away. AHD meds are occasionally out of stock, and clinic design still enables stigma—patients are visibly marked by where they queue or which door they enter.

Despite this, youth care clubs and initiatives like "Adopt an AHD Child" are starting to fill gaps. Off-site parent support groups could offer another path forward.

Insights

Caregivers can't support treatment they don't understand.

Disclosure guidelines need updating—and implementation support.

Clinic admin systems (like reception, data entry, and flow) need redesign and accountability.

Better coordination between CLEOs and clinic staff could improve retention and dignity.

From the How might We brainstorm, a number of prototype solution ideas grew. Groups fleshed out these design insights and the results are included here:

South Africa

Prototype 1:

AHD Visual Roadmap and Role Clarification

Create a visual roadmap of AHD care steps

(e.g., Registration → Data Room → Clinical Consult).
Clarify roles and responsibilities for each step.

Why

- Improve coordination & understanding among staff
- Ensure consistent messaging and quality of care.

Who

- Operation Manager (HR) for role clarification.
- Trainers/mentors/facilitators for capacity building.

- Within the healthcare facility.

- Monthly sessions.
- As needed, especially when new staff join.

South Africa

Prototype 2:

Emotional Intelligence Training for Health Providers

Train health providers and clients on Emotional Intelligence (EI).

Practice effective communication and address myths about emotional expression.

Provide education on managing emotions in healthcare settings.

Why

- Enhance understanding of communication dynamics.
- Save time for patients and improve client satisfaction.
- Help clients identify their “champion” within the healthcare system.

Who

- Trainers.
- Healthcare providers.
- Facility management.

Where

- During service hours at healthcare facilities.

When

- At appointments.
- During attendance.
- Debriefing moments.

South Africa

Prototype 3:

Child-Friendly HIV Disclosure Toolkit

Develop a toolkit to aid caregivers in disclosing HIV status to children.

Include age-appropriate materials and activities.

Why

- Support caregivers in managing the emotional aspects of disclosure.
- Provide children with a better understanding of their health.

Who

- Caregivers.
- Healthcare providers.
- Support staff.

Where

- In clinics.
- Homes.
- Community centers.

When

- At appropriate stages of the child's development and understanding.

South Africa

Prototype 4:

Peer Support Model for Adolescents

Establish a Peer Buddy Program matching adolescents with trained AHD mentors.

Offer one-on-one or group support formats.

Why

- Provide adolescents with relatable support.
- Address feelings of isolation and fear associated with HIV treatment.

Who

- Slightly older peers trained as mentors.
- Adolescents living with HIV.

Where

- Clinics.
- Schools,.
- Community spaces.

When

- Regular check-ins via WhatsApp or in-person meetings.

South Africa

Prototype 5:

Humanizing Clinic Experience

Introduce a Welcome Station at clinics to orient children and caregivers.

Use visual aids and friendly illustrations to explain clinic flow.

Why

- Create a respectful and predictable clinic experience.
- Reduce feelings of judgment and confusion.

Who

- Clinic staff trained in welcoming language and emotional cues.

Where

- At the entrance or reception area of clinics.

When

- Upon arrival for appointments or services.

South Africa

Prototype 6:

Community Connector Toolkit

Equip community influencers with tools to identify AHD signs and offer support.

Include visual guides, flipbooks, and referral materials.

Why

- Leverage trusted community figures to bridge gaps in healthcare access.
- Reduce stigma and mistrust in formal health systems.

Who

- Traditional healers.
- Church leaders.
- Teachers.
- Respected community members.

Where

- In community settings.
- During outreach activities.

When

- As part of ongoing community engagement efforts.

South Africa

Prototype 7:

Emotional Readiness Journey Map

Create an age-appropriate toolkit guiding children through understanding their HIV status.

Include illustrated maps, caregiver guidance, and interactive activities.

Why

- Support phased understanding rather than one-time disclosure.
- Help children process their diagnosis emotionally over time.

Who

- Caregivers.
- Healthcare providers.
- Children living with HIV.

Where

- In clinics.
- Homes.
- Educational settings.

When

- At various developmental stages of the child.

Participants Share

Klerksdorp, South Africa

“Treatment is a Human Problem, Not a Medical One

Dinah works closely with children and adolescents living with HIV, and she’s frustrated. Most caregivers—often aunts—are in deep denial. Children are told they have TB or diabetes. Even when medication is delivered to their homes, it often goes unused. Some caregivers skip doses or refuse to disclose entirely.

Counsellors give advice but rarely sit with families during actual disclosure moments. One case stands out: a grandmother blamed her grandchild for being promiscuous, refusing to acknowledge the child’s mother died of HIV. These situations lead to anger, mistrust, and treatment interruption—some children even stop taking medication as a way to give up.

Despite this, Dinah helped start a teen club where participants have shown improved adherence and better viral suppression. She says peer support often does what caregivers can’t.

Insights

> **Caregivers are overwhelmed, afraid, and need practical help—not blame.**

> **Disclosure support must go beyond advice to active accompaniment.**

> **Peer groups like teen clubs can play a vital role in adherence and mental health.**

Democratic Republic of Congo

Prototype 1:

Treatment Reminder Cards – "Why Am I Doing This?"

A pocket-sized visual reminder designed to help people living with HIV (PLHIV) maintain adherence by reinforcing personal motivation and preventing internalised stigma.

Key Features

- Wallet-size printed cards with affirming messages and metaphors.
- Digital version (JPEG) formatted for WhatsApp sharing or saving in the phone photo album.
- Messages can be personalised with patient goals or names.

Target Users

- PLHIV (adults and adolescents)
- Caregivers
- Peer supporters

Why It Matters

- Many PLHIV struggle with treatment fatigue and stigma.
- Small, private tools that reinforce emotional resilience can improve adherence.
- A message in your pocket—or on your phone—becomes a daily motivator.

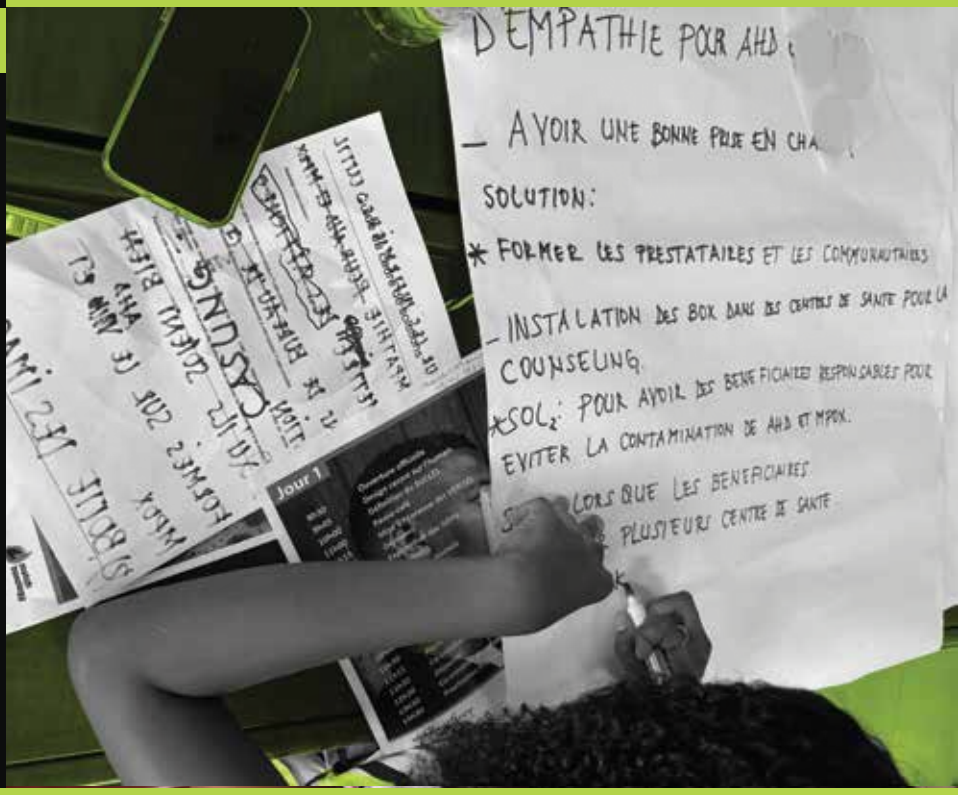
Where/When

- Distributed during clinic visits, home visits by CHWs, and support groups.
- Shared digitally via WhatsApp peer groups and clinic outreach.

Democratic Republic of Congo

Prototype 2:

AHD and MPOX Symptom Prompt Cards



A quick-glance guide to help patients and caregivers identify and report AHD and MPOX symptoms early, using simple language and visual cues.

Key Features

- Wallet-size cards with common symptoms illustrated.
- Clear icons and multilingual text.
- JPEG versions for WhatsApp/phone album access.
- Back of card includes 'What to do next' instructions.

Target Users

- PLHIV
- Caregivers
- CHWs
- CLEOs

Why It Matters

- Early symptom recognition can reduce morbidity and mortality.
- Many people miss symptoms or delay reporting due to low awareness.
- Empowers action and reduces anxiety.

Where/When

- Shared during disclosure counselling, clinic visits, community health days, and CHW outreach.

Democratic Republic of Congo

Prototype 3:

AHD Messaging Library

A collection of stigma-free, contextually grounded messages tailored for specific audiences to support awareness, adherence, and emotional resilience.

Key Features

- Sample talking points and metaphors per audience.
- Available in booklet and WhatsApp-friendly formats.

Target Users

- Religious leaders
- CHWs
- Caregivers
- Healthcare workers
- Teachers

Why It Matters

- Communication breakdowns perpetuate fear and misinformation.
- Tailored language builds trust and supports behaviour change.
- Enables trusted community actors to speak with confidence.

Where/When

- Introduced during HCD training, integrated into existing AHD materials, and used during community sessions.

Democratic Republic of Congo

Prototype 4:

Story-Based AHD Tools for PLHIV Groups

A discussion and roleplay toolkit for use in PLHIV support groups, built around fictionalised but relatable scenarios.

Key Features

- Scenario cards for small group discussion.
- Roleplay prompts to rehearse decisions.
- Facilitator guide with background and suggestions.

Target Users

- PLHIV group facilitators
- Peer educators
- Community-based organisations

Why It Matters

- Stories spark empathy and retention better than lectures.
- Roleplay helps people rehearse decisions safely.
- Encourages peer learning and emotional safety.

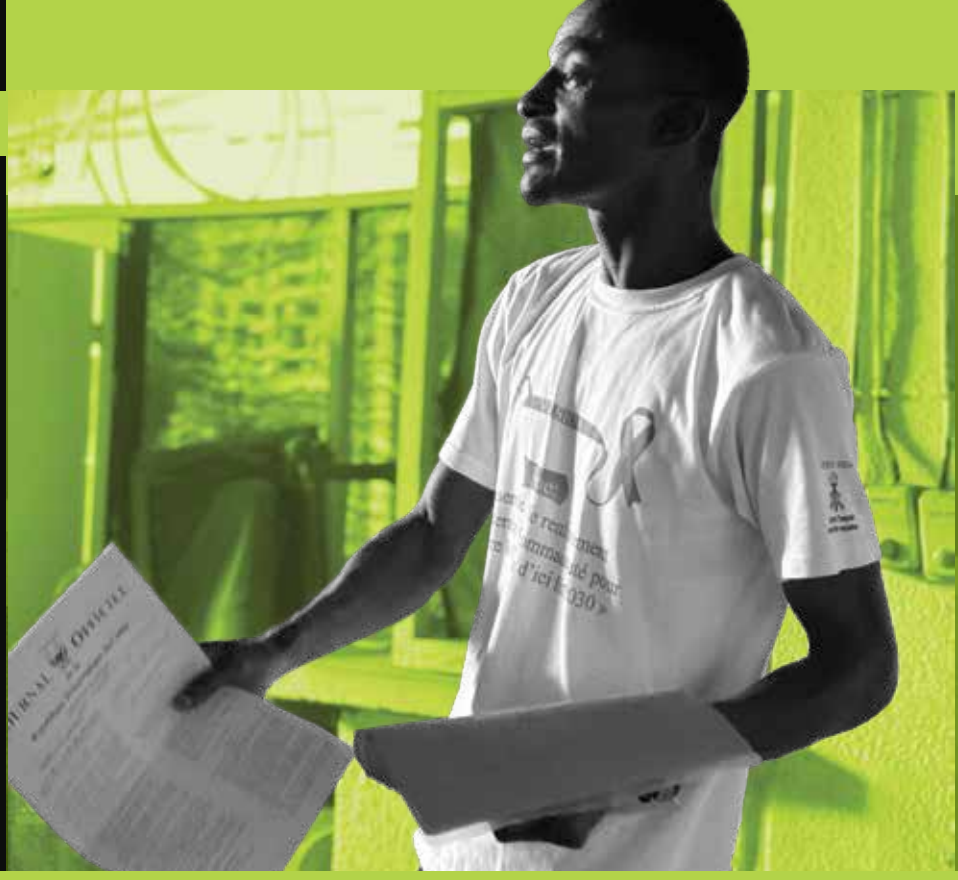
Where/When

- Support groups, teen clubs, community gatherings, or health facility waiting areas.

Democratic Republic of Congo

Prototype 5:

TikTok Testimonies/ “Radio Hero”



Short-form, emotionally engaging video or audio content featuring stories of PLHIV overcoming AHD or stigma.

Key Features

- 60-second TikTok-style videos or WhatsApp-optimized clips.
- Radio segments for local stations featuring lived experience.
- Scripted with real voices, optional animation or captions.

Target Users

- Youth
- Caregivers
- General community audiences

Why It Matters

- Testimonies shift perceptions and reduce stigma.
- Youth engage with video and audio content online.
- Builds motivation and symptom recognition.

Where/When

- Shared via TikTok, WhatsApp, Facebook, and community radio.

Democratic Republic of Congo

Prototype 6:

Empathy-Based Screening Tool for Nurses & HCWs

A practical screening tool that blends clinical indicators with empathetic questions to support early identification of AHD and MPOX.

Key Features

- Checklist includes physical and emotional/ social cues.
- Open-ended prompts alongside clinical screening.
- Includes guide on tone, body language, and listening.

Target Users

- Nurses
- Counsellors
- HCWs
- CHWs

Why It Matters

- Stigma and silence are stronger than symptoms.
- Empathetic engagement builds trust.
- Supports integrated, human-centred screening.

Where/When

- During triage, home visits, community screenings, and chronic care check-ins.

Democratic Republic of Congo

Prototype 7:

WhatsApp Voice Note Campaign

A series of pre-recorded, scripted voice notes that share motivational and factual messages about AHD and HIV care.

Key Features

- 30–60 second audio messages sent via WhatsApp.
- Includes reminders, affirmations, symptom education.
- Optional local celebrity or 'voice of community' involvement.

Target Users

- PLHIV
- Caregivers
- CHWs
- Teen clubs

Why It Matters

- Voice is powerful for low-literacy audiences.
- People can listen privately and share.
- Brings consistency to messaging outside clinics.

Where/When

- Weekly or bi-weekly via CHW groups, peer networks, or clinic WhatsApp lists.

Participants Share

Kinshasa, DRC

A Second Chance at Life

Eight years ago, I was diagnosed with advanced-stage HIV. My condition was so severe that doctors told my parents to begin preparing for my funeral. There seemed to be no hope.

But one of my aunts insisted we seek help at a specialized HIV care center. It was a turning point. Thanks to proper care and treatment, I slowly regained strength. Within months, I was stable again. To those around me, it was as if I had come back from the dead. My entire neighborhood celebrated my recovery—it felt like a miracle.

Since then, I've joined organizations that support people living with HIV. I use my experience to give others hope, show them that life goes on, and help them realize that they, too, can live fully and proudly.

From: Toussaint, President of NGO "Jeunesse espoir" (Youth's Hope)

Insights

- **Timely referral to specialised care can reverse even late-stage HIV, reinforcing the importance of early intervention.**
- **Visible recovery from advanced illness can transform community attitudes and reduce stigma.**
- **Survivor stories can become powerful tools for advocacy, motivation, and peer support.**
- **Lived experience positions survivors as key agents in HIV education and outreach.**

Participants Share

Rustenberg, South Africa

Practical Support That Sticks

Mamphiri runs Kids Alive—age-based support groups for children living with HIV (ages 10–14). Recruited through clinics and parents, the groups focus on adherence, basic HIV knowledge, and building comfort through routine and peer connection. Sessions run monthly for five cycles, ending when participants are stable on treatment.

She supports caregivers with disclosure guidance and uses simple metaphors—like **"goodnight medicine"** that keeps the germ asleep. Kids return to the group willingly, and many see her as a lifeline.

Her biggest challenge? Non-disclosing parents.

"They make me sick, I wish I knew what they're afraid of."

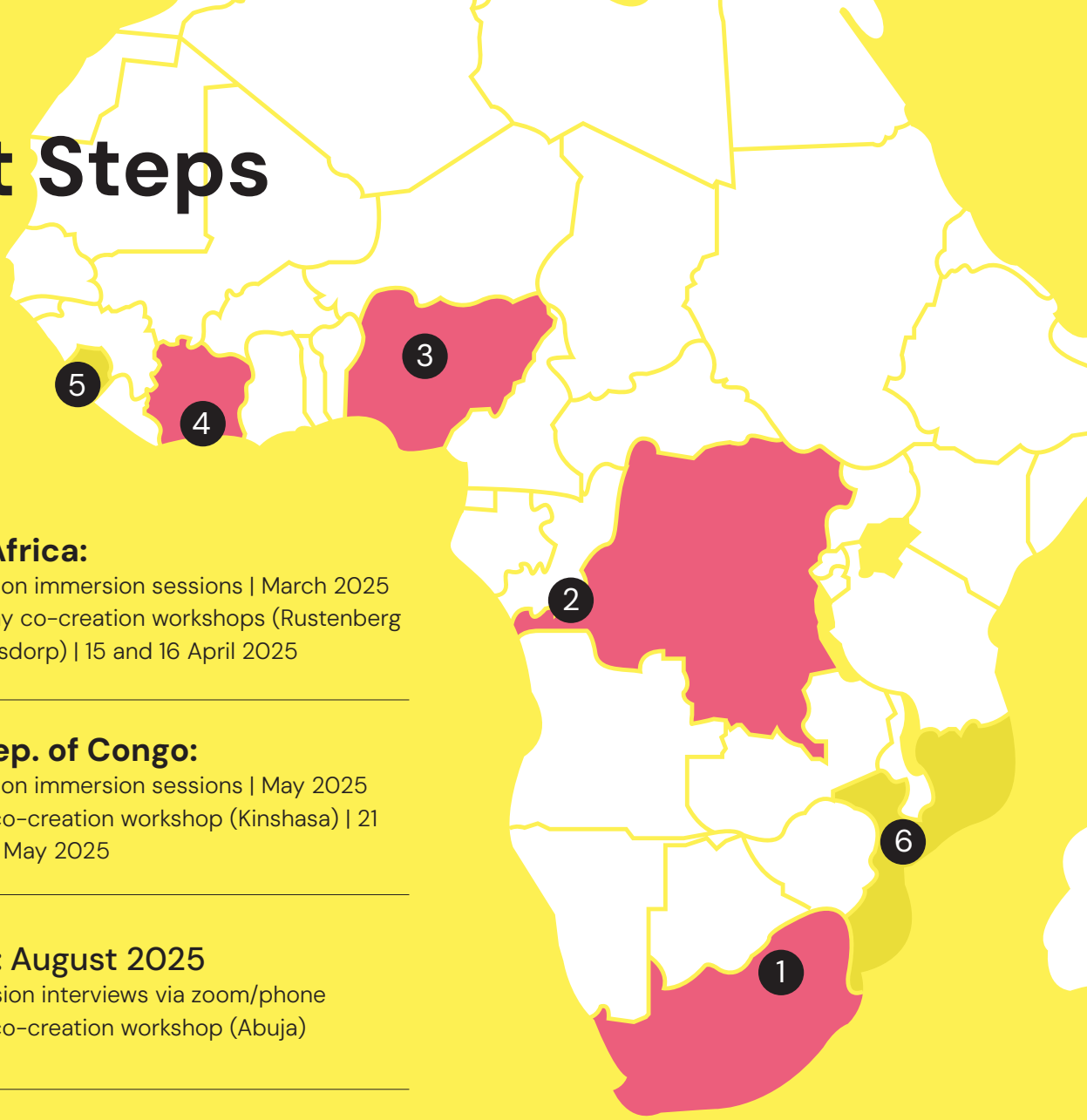
Insights

Age-based peer groups improve adherence and reduce isolation.

Simple, metaphorical language helps children understand treatment.

Caregivers need training and tools to handle complex emotional dynamics.

Next Steps



1 **South Africa:**
- In-person immersion sessions | March 2025
- 2 x 1 day co-creation workshops (Rustenberg & Klerksdorp) | 15 and 16 April 2025

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2 **Dem. Rep. of Congo:**
- In-person immersion sessions | May 2025
- 2 day co-creation workshop (Kinshasa) | 21 and 22 May 2025

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3 **Nigeria:** August 2025
- Immersion interviews via zoom/phone
- 2 day co-creation workshop (Abuja)

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4 **Côte d'Ivoire:** September 2025
- In-person immersion sessions
- 1 day co-creation workshop in Abidjan

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5 **Sierra Leone:**
- Immersion interviews via zoom/phone
- Workshop outcomes/prototypes HCD testing

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6 **Mozambique:**
- Immersion interviews via zoom/phone
- Workshop outcomes/prototypes HCD testing

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7 **All:**
- Consolidated HCD Report with Recommendations and Finalised Prototype Solutions