Herstory: rewriting the narratives of women living with HIV.

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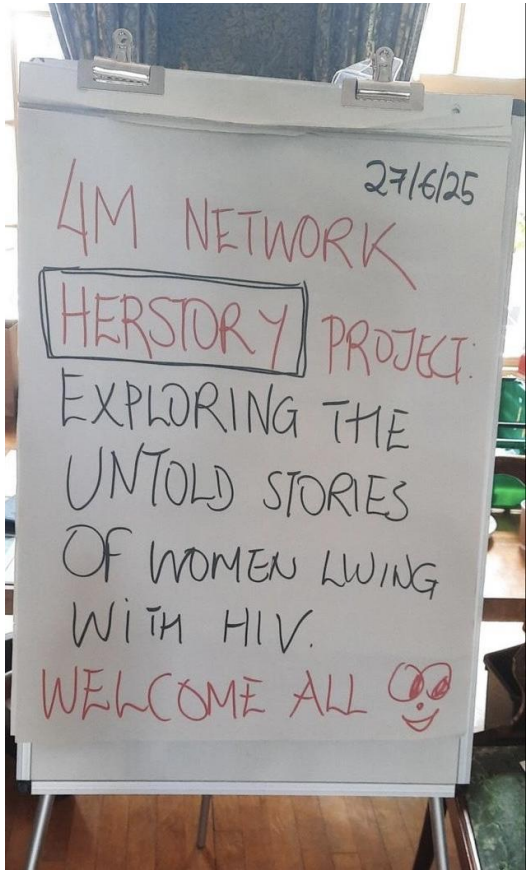
Overview of presentation.



Background and context of women living with HIV

Overview of what KIP 3: Herstories is

Brief summary of what we did and the project's philosophy

Therapeutic storytelling – my life in a book

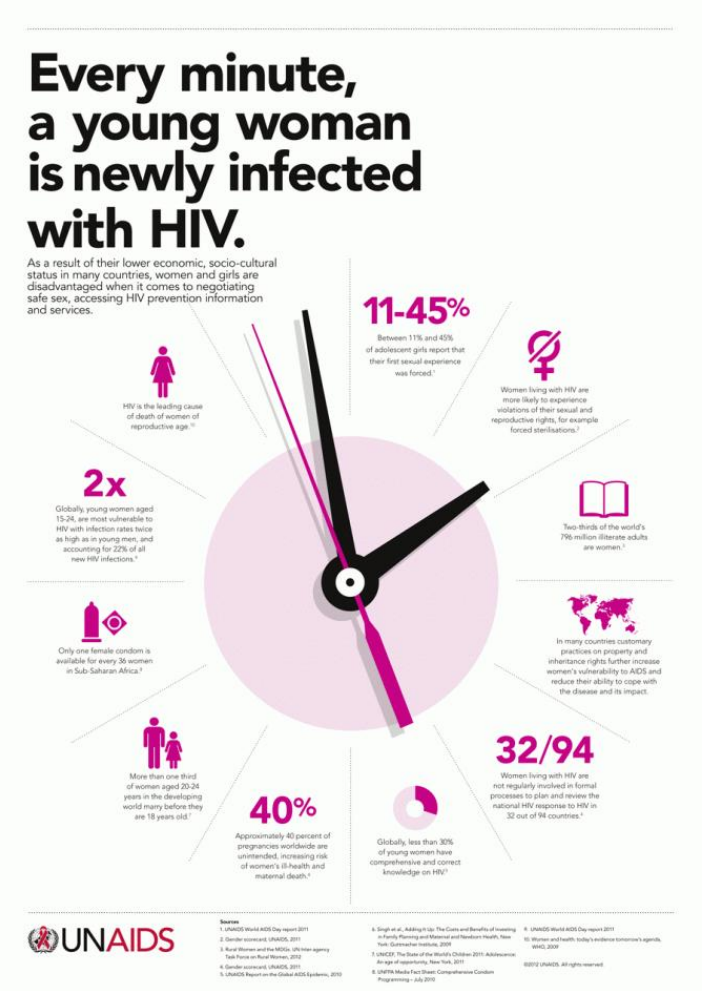
What the women told us

Trauma, Time, and the limits of storytelling

Implications of KIP3 and next steps

Concluding thoughts

Background and context within HIV care



Approximately 40.8 million people were living with HIV worldwide in 2024, and women and girls accounted for 53% of all people living with HIV globally (UNAIDS 2026).

Despite major scientific advances women remain deeply connected to broader issues of gender equity, human rights, and social justice. Addressing HIV in women therefore requires an integrated biopsychosocial and trauma-informed approach.

Women living with HIV, particularly black and minoritised women, continue to experience barriers to engagement, confidence in treatment decision-making, and inconsistent care outside specialist HIV services.

Peer-led approaches offer an opportunity to generate relevant insight grounded in lived experience that can help shape care.

About KIP 3 – Knowledge is Power : Herstories

- KIP 3 **(Knowledge Is Power 3**) is the third project in the KIP series which have been developed and delivered by 4M Mentor Mothers Network (4MNet).
- KIP 3 was created in direct response to women living with HIV consistently telling us that their voices, priorities, and lived experiences are not visible in healthcare education, policy and service design.
- KIP 3 was designed to drive policy and practice change, ensure the healthcare needs of black and minoritised women living with HIV are embedded in discussions at local, national and global levels.
- KIP3 combines education, advocacy, peer support and therapeutic storytelling to address health inequalities and to encourage women to advocate for themselves.
- The project centres women's relationship with treatment, wellbeing, and care , recognising that confidence, mental health, stigma and structural barriers all shape engagement in care.

KIP3 was underpinned by a women- centred , peer led and trauma informed philosophy

Project Philosophy and Values

Professional facilitation and Trauma- informed practice.

Writing for Wellbeing sessions were facilitated by a professional with specialist experience in supporting reflective and emotionally sensitive group work.

Working in partnership

KIP 3 was developed and delivered through collaboration between women living with HIV, peer leaders, clinicians, and specialist organisations, ensuring the project remained grounded in lived experience.

Workshops and activities were **co-designed** and **co-facilitated** with women living with HIV, with topics shaped by women's Priorities and questions.

Rational for hybrid delivery model

Hybrid models are critical to equitable access for women living with HIV. Online sessions reduced concerns around visibility, confidentiality, and travel, while in-person sessions supported trust-building, peer connection, and emotional safety.

Between March and October 2025

Two workshops

- Workshop 1 – face to face (27 women)
- Workshop 2 – online (18 women)

Writing for wellbeing sessions

- Follow-up session (27 women)
- Drop-in session (27 women)

Three sets of reflective email prompts

- Allowing women to share their experiences in their own time**.**

Personal story writing support

- Therapeutic storytelling through my life in a book as a private, optional wellbeing resource for women. It was not used as a source of evidence for this project.

Women-led educational video recording

- What good respectful care looks like in practice.
- Impact of stigma in healthcare settings.
- Barriers to engagement in care.
- Digital access and inclusion

What the women told us – Key themes

Theme 1 : Engagement in care is shaped by life realties, not motivation.

Women described missed or delayed appointments as being linked to:

- Work schedules
- Caring responsibilities
- Fear and trauma related to procedures
- Exhaustion and competing priorities

Theme 2:Confidence in treatment decisions depends on being heard

Women report high confidence when:

- They had time to ask questions.
- Explanations were clear and respectful
- Their lived experiences were valued

Theme 3: Non–specialist care remains a source of anxiety

Women raised concerns about:

- Sharing their status outside HIV clinics
- Stigma and outdated HIV Knowledge
- Confidentiality in Primary care and dentists

Therapeutic Storytelling and My life in a Book

- Women with HIV constantly tell us that their stories are fragmented across services, their experiences are rarely recorded on their own terms and that emotional safety and control often have low priority.
- A core element of KIP3 was therapeutic storytelling to support women's well-being and to ensure that learning from the project was in women's own words.
- My life in a book is a platform that enables individuals to document their life experiences in a structured and supported way, resulting in a printed keepsake book.
- Women were offered guided writing prompts, writing for wellbeing sessions, and optional one-to-one support
- Women retained full ownership and control over their stories. Participation in writing did not require public sharing and women could pause and stop at any point.

The flexibility recognized the realities of women's lives and the emotional labour in storytelling.

Trauma, Time, and the limits of storytelling.

Many women living with HIV faced multiple pressures, having very limited space, time and emotional capacity to write

Writing and reflection resurfaced experiences of unresolved trauma, including health-related stigma , loss, violence and long-term stress.

Engaging in therapeutic storytelling highlighted the need for sustained trauma-informed support rather than one-off interventions.

Writing brought up complex and ongoing emotional experiences, reinforcing that meaningful storytelling requires time, safety and sustained trauma-informed support.

The learning from KIP3 reinforces that meaningful engagement with women's stories is a long-term process, requiring investment, trust and continuity, not short -term extractions of experience.

Women led educational videos

Four short videos were co-produced as an alternative and accessible way of sharing learning and educating women and healthcare professionals.

- Many of the women expressed a desire to be involved in the videos; only a small number felt safe enough to be recorded.
- The limited number of women able to appear on camera should not be viewed as a lack of engagement, but as evidence of the persistent stigma that continues to shape women's participation and visibility.

Videos themes:

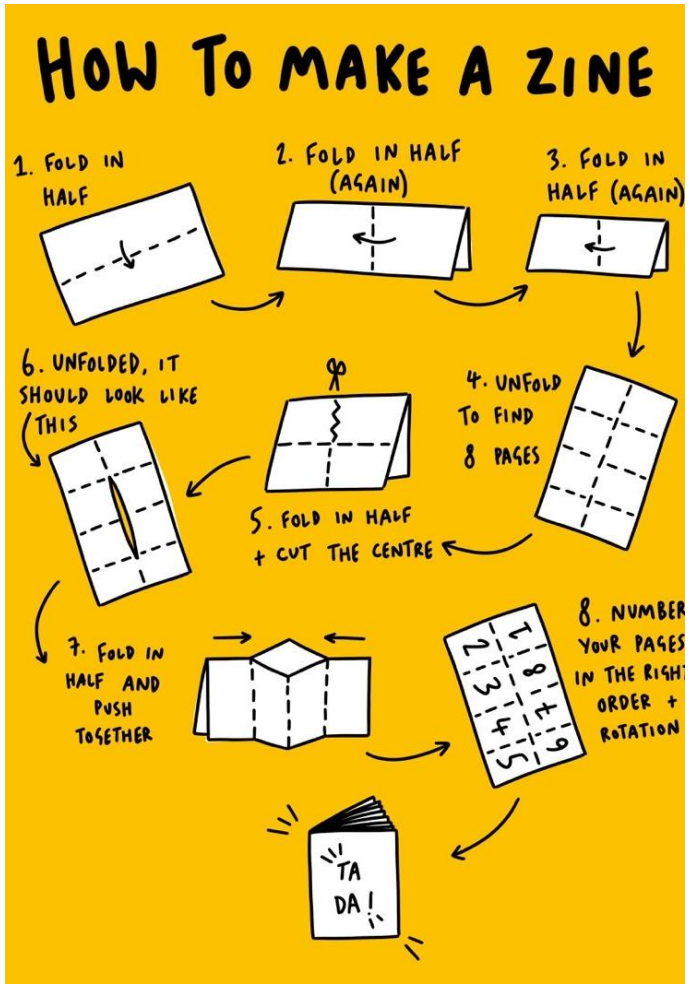
- What good, respectful care looks like in practice.
- Impact of stigma in healthcare settings.
- Barriers to engagement in care.
- Digital access and inclusion

HerStories
What Women Living with HIV Tell Us Must Change

Policy & Practice Learning from KIP 3
4M Mentor Mothers Network CIC
Reporting period: March–October 2025

Funder: ViiV Healthcare

Implications of KIP 3 and next steps



What women need …..

To be listened to without judgement, time to ask questions and express concerns, care that recognises cultural context, trauma and lived experiences.

Primary care is often the first and most frequent point of contact. Culturally competent, trauma-informed interactions can be decisive in whether care is trusted or avoided.

- Specialist services play a critical role in buffering the impact of wider inequalities faced by Black and minoritised ethnic women across the health.
- Women described anxiety and avoidance in non-specialist settings. For Black and minoriised ethnic women, these experiences intersect with wider experiences of racism and discrimination in healthcare.
- Reducing inequalities for women living with HIV requires sustained investment in approaches that address both clinical and social determinants of health

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Concluding thoughts.

Peer-led, trauma-informed spaces enabled women to articulate clear, practical insight into what supports engagement and confidence in care.

KIP3 highlights the importance of protected time for shared decision-making, integration of peer support, and consistent HIV knowledge across primary and non-specialist services.

Women's lived experience provides actionable learning to inform clinical practice and service design.

4M Network Members

Women Living with HIV in all our diversity & our allies

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