Treatment journey of black African women in London: A qualitative exploration of factors that influence initial uptake and adherence to antiretroviral therapy

**Dr Renee M. West** 

**Development Manager, GMI Partnership/Positive East** 







## What was this study about?

### Background

- Continuous adherence to antiretroviral therapy (ART) is essential for effective HIV management.
- Understanding the reasons behind the initial uptake and adherence can help tailor support for black African women living with HIV in London.

#### Aim

 The aim of this study is to explore the factors that influence the initial uptake and adherence among black African women living with HIV in London.









### **Methods**

- Sampling frame: Positive East/GMI Partnership networks
- Data collection methods: semistructured interviews
- Analysis: thematic analysis
- Ethics: pre-interview information and consent forms







## Results: participant demographics

Participant	Age-range	Years LHIV	Country of diagnosis
P1	46-55	13	UK (not born in the UK)
P 2	46-55	16	UK (not born in the UK)
P 3	46-55	12	Ethiopia (not born in the UK)
P4	56-65	16	UK (not born in the UK)
P 5	36-45	Over 14	Nigeria (born in UK but moved to Nigeria as a child; returned to the UK as an adult)
P 6	56-65	27	UK (not born in the UK)
P7	36-45	20	Germany (not born in Germany)
P 8	56-65	24	UK (not born in the UK)
P 9	26-35	4	UK
P 10	56-65	14	UK (not born in the UK)
P 11	56-65	21	UK (not born in the UK)
P 12	56-65	20	UK (not born in the UK)







# **Key findings: reasons for HIV testing & reactions to diagnosis**

#### **REASONS FOR HIV TESTING**

- Severity of symptoms
- No improvement in symptoms with other treatments
- Pre-natal testing
- A&E testing
- Partner/family diagnoses with HIV/STI

#### **REACTIONS TO DIAGNOSIS**

- Shock
- Shame/embarrassment
- Denial
- Anger
- Depression and suicidal ideation
- Inability to perform daily tasks
- Non-disclosure of diagnosis





# **Key findings: factors influencing initial ART uptake and re-start**

- Severity of illness
- Pregnancy and baby's safety
- Family responsibilities
- Cultural beliefs and stigma
- Immigration status
- Housing insecurity
- Support from friends, family and healthcare providers

I started my medication because I just wanted to be well to look after my daughter who was sick. I didn't want to be sick because I'm the mother. (P8)

Because even when my sister passed away, even I wanted to die, but when I saw her children, her kids, they needed someone. Yes. So, I called them because when the funeral time, when I was there, and they say, 'Auntie, Auntie, please stay with us. Don't go, don't leave us.' So yes, because of the children. (P3)





**Key findings: factors leading to stopping ART** 

- Side effects of ART
- Difficulty taking medication
- Mental health issues
- Stigma and discrimination
- Stressful living conditions
- Gender dynamics and inequalities
- Misinformation
- Travel to visit family and friends
- Immigration status
- Lack of support network

...the side effects of the medication were so powerful, my body couldn't cope with the side effects. (P2)

[My husband] said, 'It's okay, but don't take the medication.' And he told me, 'These people, they aren't giving for black people this and that.' ... 'Don't take it, because they aren't giving you medication,' and 'No, you don't have HIV.' So, I just stopped. (P11)

I stopped my medication when I was going back home to see my mum. Because there was a lot of medication, and I didn't want people to know that I have HIV because they would just abandon me. (P8)





# **Key findings: supportive factors for ART uptake and adherence**

- Support from family and friends
- Support from community organisations
- Advice and support from social and healthcare systems

My son, daughters, and mum knew, and they were all very supportive. I thought 'I'm wanted again. I'm loved again.' Because [before I told them] I thought they'll just disown me, this is it. I've no family, so what am I doing here on earth? They always remind me, 'Mummy, have you taken your tablets? Can I see your box?' (P10)

...some women [at the charity] were looking good and I was very envious, you know, very confused that they were also HIV positive, and then they talked to me, 'Oh, we are positive as well. As long as you can take your medication properly and you eat well, don't worry, you'll be okay. We've been there like you.' I've always said, that the peer support I think helped me a lot. (P6)





### **Conclusion and recommendations**

- Interplay of emotional, social and structural factors
- Support networks
- Tailored, person-centred, interventions
- Research on the impact of social determinants on ART adherence















