

# HIV testing models and their implications for patient engagement with HIV care and treatment on the eve of “test and treat”: findings from the Bottlenecks Study

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## Introduction

- With moves towards “test and treat” there are growing opportunities for HIV testing including: home-based testing, client-initiated voluntary counselling and testing, and provider-initiated testing and counselling through outpatient and antenatal clinics
- The principles of the 3 Cs should underpin all forms of HIV testing: Testing must be **confidential**, be accompanied by **counselling** and only be conducted with informed **consent**.
- The way that the three 3 Cs are applied in different HIV testing contexts may influence subsequent engagement in HIV care for those testing positive
- The ALPHA Network is conducting a study to understand how HIV policies and service delivery influences care-seeking and mortality in 10 health and demographic surveillance sites (HDSS) in Eastern and Southern Africa [1]. Drawing on data from the qualitative component of this study, the “Bottlenecks Study” we asked:

**How does PLHIVs’ experiences of undergoing HIV testing influence their subsequent engagement in HIV care ?**

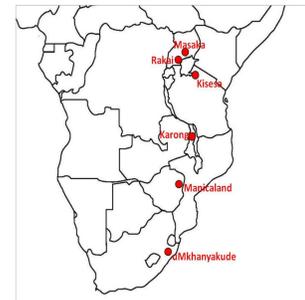
## Methods

- We drew on qualitative data collected in Uganda, Malawi, South Africa, Tanzania, Kenya and Zimbabwe
- In each site, in-depth interviews conducted with 4-18 health workers (HCW) and with 28-59 people living with HIV and aware of their HIV status sampled from HIV clinics and HDSS (table 1)
- Topic guides explored patient and HCW experiences of HIV testing and treatment.
- Themes were derived through inductive and deductive coding aided by NVivo10.
- Ethical approval was gained in all countries

Study sites	HCW	Diagnosed no ART	On ART	No longer in care	total
Kisesa (Tanzania)	8	6	18	5	37
Karonga (Malawi)	5	9	27	4	45
Rakai (Uganda)	6	16	14	6	42
Kyambaliwa (Uganda)	5	8	16	4	33
Kisumu (Kenya)	8	10	15	6	39
Manicaland (Zimbabwe)	4	13	35	11	63
uMkhanyakude (S Africa)	18	10	17	6	51
<b>TOTAL</b>	<b>54</b>	<b>75</b>	<b>142</b>	<b>42</b>	<b>313</b>

Table 1: Participants in each study setting

Fig. 1 Location of study sites



Clinic, Kisumu, Kenya



Manicaland, Zimbabwe



## Results

### CONSENT

- HIV testing through provider-initiated models was generally appreciated by PLHIV, but was rarely perceived as a choice.

*“...It is a Government policy that every pregnant woman has to be tested for HIV (HCW, Uganda)”*  
*“...HIV testing was compulsory for pregnant women” (HCW, East Africa)*

- There were instances of coercion in most settings including excessive insistence on “counselling until acceptance”, testing without consent or withholding further medical attention.

*I: What happens when mothers refuse to test for HIV?*  
*HW: If they decline HIV testing, we tell them that they cannot get treatment from our facility. For example, pregnant mothers receive pills for prevention of anaemia. ...she may not use them appropriately if she declines HIV testing. Therefore, we tell them that if they refuse HIV testing, we cannot give them any health services until they have tested for HIV. [HCW, East Africa]*

- Responses to “submission” during the testing process included subsequent disengagement from the HIV care process such as throwing away ART, or not returning to the clinic.

### CONFIDENTIALITY

- There were instances in some settings of family members or partners being informed about a patient’s HIV status without permission having been given

*Oho the testing process was in this way;...after testing, I was told my results. Thereafter it's when he called my wife at a separate place ...she was told that she tested negative, then she was told that your husband is positive. But I didn't know that she has already been told that I tested positive (Southern Africa, man, on ART)*

- Breaches in confidentiality were fairly uncommon, but were reported by participants from all models of HIV testing
- Concerns around confidentiality could lead to feelings of mistrust in health workers which could undermine subsequent engagement in care.

### COUNSELLING

- HCW viewed testing as an opportunity for delivering moral messages regarding sexual behaviours and expectations of clinic use.
- PLHIV were rarely motivated by the opportunity to gain HCWs advice, but rather wanted to “check” or “know” their status, particularly if ill, or perceived a risk from a partners’ known or unknown status and sexual behaviours

*What motivated you to get tested? I was ill. I had stomach pains. I had a headache and I had sores on the lips of my mouth.” (Southern Africa, man, on ART)*

- Repeat testing and counselling was common, even once diagnosed, and represented an opportunity to develop familiarity with clinics and build mutual trust with health workers which could support engagement in care

*Int: Did you believe the test results which indicated that you have HIV?*  
*Part: I did not first accept them because I was feeling healthy. After... two years, then my counsellor convinced me to accept them. He told me that “Sunday, let us test again”. I had many counsellors; Mrs. X, Mr. Y ..and others but those two played a big role [Man, on ART, East Africa].*

## Conclusions

- Opt-out clauses and procedures for obtaining consent during provider-initiated testing must be respected. Coercive practices may result in increased HIV testing and diagnosis rates, but are likely to be counter-productive in the long-term if they erode trust in HIV services and undermine therapeutic alliances with health workers that could enhance subsequent adherence to treatment.
- Conversely, patient-initiated testing and re-testing often represents an enactment of agency in the context of uncertain HIV exposures and risks, and this is often more important in promoting acceptance of a subsequent HIV diagnosis and facilitating engagement with long-term care than moralistic messages that focus on (sexual) behavioural change delivered by counsellors
- Information and messages provided during counselling sessions should be better aligned with clients’ motivations to undergo a HIV test. Repeat counselling should be encouraged for PLHIV who initially struggle to accept an HIV diagnosis to build up trust with health providers and services, address their concerns about HIV, and facilitate their subsequent engagement with HIV care services.