Preferences for linkage to HIV care services following a reactive self-test: discrete choice experiments in Malawi and Zambia

Marc D’ELBÉE¹, Pitchaya P. INDRAVUDH², Lawrence MWENGE³, Moses M. KUMWENDA², Musonda SIMWINGA³, Augustine T. CHOKO², Bernadette HENSEN⁴, Melissa NEUMAN⁴, Jason J. ONG⁵, Euphemia L. SIBANDA⁶, Cheryl C. JOHNSON⁸, Karin HATZOLD¹⁰, Frances M. COWAN⁶, Helen AYLES³, Elizabeth L. CORBETT², Fern TERRIS-PRESTHOLT¹

Running head - Preferences for linkage to care after HIV self-testing

Word count: 1,795/1,800 max

¹ Department of Global Health and Development, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom
² Malawi-Liverpool Wellcome Trust Clinical Research Programme, Blantyre, Malawi
³ Zambart, Lusaka, Zambia
⁴ Department of Infectious Disease Epidemiology, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom
⁵ International Diagnostics Centre, Faculty of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, London, United Kingdom
⁶ Centre for Sexual Health HIV and AIDS Research, Harare, Zimbabwe
⁷ Department of International Public Health, Liverpool School of Tropical Medicine, Liverpool, United Kingdom
⁸ Department of Clinical Research, Faculty of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, London, United Kingdom
⁹ Department of HIV/AIDS, World Health Organization, Geneva, Switzerland
¹⁰ Population Services International, Harare, Zimbabwe
¹¹ London Centre for Neglected Tropical Disease Research, Faculty of Infectious and Tropical Diseases, London School of Hygiene and Tropical Medicine, London, United Kingdom
**Corresponding Author** - Marc d’Elbée, Pharm.D. MSc. London School of Hygiene and Tropical Medicine, 15-17 Tavistock Place, Kings Cross, London WC1H 9SH, United Kingdom. Email: marc.delbee@lshtm.ac.uk. Telephone: +44 (0)749 0405 594.

**Competing interests** - The authors declare that they have no conflict of interest. EC is funded by a Wellcome Trust Senior Research Fellowship in Clinical Science (WT200901/Z/16/Z).

**Compliance with Ethical Standards** - All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

The research project has been approved by the College of Medicine Research Ethics Committee in Malawi, the Biomedical Ethics Committee of the University of Zambia and the Research Ethics Committee of the London School of Hygiene and Tropical Medicine.

Informed consent was obtained from all individual participants included in the study. In cases where the participants were illiterate, they were asked to give verbal consent plus a witnessed thumb print. Finally, parental consent was required if participants were 16 or 17 years old. The surveyors answered any questions raised by the participant and allowed them sufficient time to respond during the questionnaire.
Abstract

Objectives: The current research identifies key drivers of demand for linkage into care following a reactive HIV self-test result in Malawi and Zambia. Preferences are explored among the general population and key groups such as HIV positive individuals and adolescents.

Design: We used discrete choice experiments (DCE) embedded in representative household surveys to quantify the relative strength of preferences for various HIV services characteristics.

Methods: The DCE was designed based on a literature review and qualitative studies. Data were collected within a survey (Malawi n=553, Zambia n=388), pooled across country and analysed using mixed logit models. Preference heterogeneity was explored by country, age, sex, wealth, HIV status and belief that HIV treatment is effective.

Results: DCE results were largely consistent across countries. Major barriers for linkage were fee-based testing and long wait for testing. Community-based confirmatory testing, i.e. at the participant’s or counsellor’s home, was preferred to facility-based confirmation. Providing separated waiting areas for HIV services at health facilities and mobile clinics was positively viewed in Malawi but not in Zambia. Active support for linkage was less important to respondents than other attributes. Preference heterogeneity was identified: overall, adolescents were more willing to seek care than adults whereas HIV positive participants were more likely to link at health facilities with separate HIV services.

Conclusions: Populations in Malawi and in Zambia were responsive to low-cost, HIV care services with short waiting time provided either at the community or privately at health facilities. Hard-to-reach groups could be encouraged to link to care with targeted support.
Keywords: HIV self-testing; discrete choice experiments; Malawi; Zambia; linkage to care; preferences
**Introduction**

The HIV burden remains highly concentrated in southern Africa, with an estimated adult prevalence of 8.8% in Malawi and 13% in Zambia between 2014 and 2015 (1, 2). Despite substantial progress, there is a significant gap in HIV testing, with just 73% and 67% of HIV-positive individuals know their status in Malawi and Zambia, respectively (3). HIV self-testing (HIVST), now recommended by the World Health Organisation, is defined as the process by which a person collects his/her own specimen, performs a test for HIV and interprets the results (4). A reactive HIVST needs to be confirmed by a healthcare professional with referral to ART services if HIV positive. HIVST has demonstrated high acceptability, though rates of linkage to confirmatory HIV testing and treatment have remained sub-optimal among self-testers (5, 6).

Discrete choice experiments (DCE) are a valuable way of measuring and quantifying user preferences for goods and services, particularly when there is a dearth of data around observed behaviour (7-9) and only limited service configurations are available. DCE have been used in a myriad of health interventions in sub-Saharan Africa including the investigation of populations’ preferences for the design of sexual and reproductive health care services (10-12), including to inform the design of a voluntary medical circumcision program (13) and guide of HIVST kit distribution (14). This research uses a DCE to identify drivers of demand for linkage into confirmatory testing and care following a reactive HIVST in Malawi and Zambia.

**Methods**

*Sampling and data collection*
The DCEs were nested within household surveys to evaluate the impact of community-based delivery of oral-fluid HIVST kits in Malawi (NCT02718274) and Zambia (NCT02793804) under UNITAID/Population Services International HIVST Africa (STAR) (15). The DCE design is presented in the supplemental material. The DCEs were administered between June 2016 and December 2016 before community-based distribution of HIVST kits in rural Malawi (Blantyre, Machinga, Mwanza and Neno districts) and rural Zambia (Choma, Kapiri Mphoshi, Lusaka and Ndola districts). The questionnaires, programmed onto electronic tablets and administered by surveyors, captured data on socio-demographic background, HIVST history, previous HIV service utilisation and beliefs related to HIV. To administer the DCEs, interviewers explained each design attribute and level and provided a demonstration of the oral-fluid self-test. Each choice set included three alternatives: two for linking to care and one opt-out alternative described as “I would not link to confirm my HIV self-test results”. An example of a scenario exercise in Malawi and in Zambia is presented in the supplement Figure S1.

**Statistical analysis**

Given the similarities in cross-country DCE designs, the Malawi and Zambia datasets were pooled to test for differences in preferences across countries. Random parameter logit (RPL) models estimated the effect of the attributes on the choice made between the sets of alternatives (16). The outputs coefficients of these models represent relative Utility, i.e. the direction and relative magnitude of preferences for each attribute level. These quantitative utilities also allow for testing for heterogeneity, that is how the strength of preferences varied by observable respondent characteristics (23). The log likelihood ratio (LL) ratio test and Akaike’s Information Criterion (AIC) were used for assessing model fit (16, 17). We interacted the attribute on separation of HIV services with the health facility and mobile clinic attribute levels given the applicability of these services only to clinic settings. Price values were
converted using purchasing power parity metrics to equalize the value of Malawian and Zambian kwacha (18).

To explore observed heterogeneity in preferences, the model examined interaction effects between the attributes, the countries, and socio-demographic and HIV-related variables. Sex and age were included to understand the systematic failure to link and underutilization of HIV services among men, young and old groups (6, 19-21). We evaluated the effect of direct/indirect costs as a demand-side barrier (21-24) to linkage to care by including a proxy for household socioeconomic status (25). HIV status was examined to understand how the salience of the choice affects preferences. Given the policy relevance of treatment as prevention interventions, we assessed beliefs towards ART efficacy and included a five-item Likert scale response to the following statement: "I believe that HIV treatment makes people with HIV less infectious" (26). Data were analyzed in Nlogit 5 software (27).

Results

Participant characteristics

Participants’ characteristics are presented in Table 1. In total, 941 participants completed the survey (59% in Malawi). Malawians had a higher percentage of respondents without formal education (p <= 0.001), higher household food insecurity (p<0.001) and higher unemployment (p<0.001) than Zambians. Malawi respondents had lower testing rates (p <= 0.001) and HIV positivity rate (p = 0.020), but fewer misconceptions around ART effectiveness (p =< 0.001) compared to Zambian participants.

Average preferences and differences between Malawi and Zambia
The results from the RPL model are presented in Figure 1 where the bars represent the sample average preferences and the error bars indicate variation between countries. The full model outputs are presented in the supplement table S1. With high coefficient values and significant variation across countries, waiting time to access health care (Malawi: $\beta = -0.50$; Zambia: $\beta = -0.34$, $p<0.010$) and payment of a testing fee (Malawi: $\beta = -1.01$; Zambia: $\beta = -0.39$, $p<0.010$) were the most important factors for uptake of HIV care services. Preferences for separation of HIV services varied considerably by country suggesting the importance of the setting configuration on determining location-related preferences. In Malawi, participants had a stronger preference for separate HIV services at health facilities ($\beta = 0.74$, $p<0.050$) whereas participants in Zambia preferred inclusive services ($\beta = 0.38$, $p<0.050$). A similar effect was observed for mobile clinics. Participants also preferred confirming their test results at the counsellor’s home ($\beta = 0.15$, $p<0.05$), no significant result was found for linkage at the participant’s home. The preferred method of support for linkage to care was receiving a phone call reminder ($\beta = 0.162$, $p<0.010$) but, compared to other attributes, linkage support was relatively less important to respondents in both countries. Generally, there was a strong preference in favour of linking to care, estimated as $-1^*\text{utility of the opt-out: } \beta = -3.58$ ($p<0.010$) in Zambia and $\beta = -5.57$ ($p<0.010$) in Malawi (supplement table S1).

Preferences by socio-demographic characteristics and HIV-related indicators

Preferences by sub-groups were analysed on the pooled data. The pooled data set allows for testing for differences in preferences between countries. We report here the main effects of interest, the full model outputs can be found in supplement table S2.

There were no significant differences in preferences by sex. Older participants were less likely to link to care after a reactive self-test result (one year age increment: $\beta = 0.04$, $p<0.010$). Compared to HIV-negative respondents, self-reported HIV-positive respondents were more likely to link at health facilities with separate HIV services ($\beta = 0.21$, $p<0.100$). Finally,
participants reporting doubts about the effectiveness of ART were more likely to not link to HIV care services ($\beta = 0.64$, $p<0.010$).

**Discussion**

Findings showed high testing fees and long waiting times for services were the most significant barriers to linkage to care in both countries. These two attributes were closely related and represent economic costs to the self-tester, as the time associated with utilising services often represented an opportunity costs. The adverse effect of direct and indirect costs on the utilization of HIV services were widely acknowledged (19, 28, 29).

Location of HIV care services and how they were provided also mattered. Overall, separated HIV services at health facilities had strong effects on choice of location, albeit in opposite directions in Malawi and Zambia. This suggests that fear of stigma and the need for privacy, which are known barriers to HIV service utilization (19, 30, 31), could manifest in different ways, through desire for discreetness with either physical separation or integration with other services. A study in Malawi showed an increase in ART initiations following provision of home-based confirmatory testing and ART assessment compared to use of referrals following self-testing (32). Participants preferred to be followed-up after self-testing by the distributor through phone calls, similar to other HIVST studies (33-35). Although, previous literature demonstrated high rates of linkage and retention into care through an active referral, we found that support for linkage was the least important attribute and would have the smallest effect on encouraging self-testers to link (36-38). We found a strong willingness to link into HIV care given the proposed service configurations. A community-based implementation study in Malawi reported that 77% of 16,660 participants shared their self-test results with distributors.
This underpins the need for HIVST services to provide support for linkage to onward services to facilitate the potentially high demand.

The analysis did not identify variation in preferences by sex, however, our findings show that a long waiting time is a major barrier to linkage; which represents high opportunity costs especially for adult men (29). Although studies showed adolescents (16-19 years) have lower coverage of ART (19, 21), we found higher willingness to link for younger individuals, and this is suggestive of unmet demand within existing services and the need for tailoring services. HIV-positive participants preferred to have separate waiting areas for HIV services at health facilities, issues of HIV-related stigma might resonate more with these participants who expressed a stronger desire for private services. Those sceptical of the health benefits of ART were less willing to link to care. Consistent with studies in Ethiopia, South Africa and Zambia, misbeliefs around ART benefits had a deleterious effect on adherence and led patients to access traditional medicine (39-41). Future work should explore how to develop effective messages to ensure that patients have a clear understanding of ART benefits, which may enhance their willingness to seek care (42).

The current study has a number of limitations. While HIVST has potential to reach populations who are not covered by existing HTS services, the sampling method included the general population and a bigger sample of hard-to-reach groups such as HIV-positive individuals not linked into care could identify specific preferences to inform how to encourage their service uptake. The DCEs were administered to individuals who had not been exposed to HIVST; many had never received a positive HIV result. DCE is a method of stated choices, we acknowledge that willingness to choose one of the linkage services rather than opt-out may be inherently overestimated. Lastly, the variable on the belief of treatment efficacy had not previously been locally-validated neither in Malawi nor Zambia (43-45).
To our knowledge, this multi-country study is the first to explore preferences for linkage into care services following a reactive HIV self-test. Results may be generalised to consider more broadly how HIV service characteristics are likely to affect uptake of ART after a reactive self-test. The findings of this study will be used to inform the design of linkage programmes as part of an HIVST delivery strategy in southern Africa.
Acknowledgements - The study was undertaken in collaboration with UNITAID, PSI, WHO and the HIV Self-Testing Africa Research Consortium institutions. The authors would like to thank all their partners and study participants of Malawi and Zambia. This work was supported by the UNITAID/PSI HIV Self-Testing Africa (STAR) Project; grant number PO # 8477-0-600.

FTP and MD were responsible for the conceptual design of the study. MD, PI, LM, AC, MK and MS contributed to the initial design of the DCE. MD, PI, LM, EC and FTP were involved with the experimental design of the DCE. PI, MN and HA oversaw data collection. MD drafted the paper; all authors revised and approved the final manuscript.
Reference list


27. Greene W. Nlogit 5 Econometric Software.


37. Knight LC, Van Rooyen H, Humphries H, Barnabas RV, Celum C. Empowering patients to link to care and treatment: qualitative findings about the role of a home-based HIV counselling, testing and linkage intervention in South Africa. AIDS Care. 2015;27(9):1162-7.


Figures and Tables

Table 1. Study population characteristics in Malawi and Zambia

Figure 1. Random parameter logit - Main effects with differences by country (Model 2). The utility coefficients are averages per country and variation between the countries is in brackets. Instruction leaflet and mobile clinic (separate HIV services) are the omitted categories, therefore variation by country could not be explored. Health facility and mobile clinic locations have either inclusive (all) or separated (sep) HIV services. *10%, ** 5%, ***1% level of significance.

Figures and Tables - Supplement

Table S1. Random parameter logit with main effects (Model 1), country effects (Model 2) and interaction effects with sex, age, wealth, HIV status and belief in ART effectiveness (Model 3)

Tables S2a/S2b. Random parameter logit (Model 3) with interaction effects: sex, age, wealth, HIV status and belief in ART effectiveness

Figure S1. Sample choice task in Malawi (left) and Zambia (right). Choice scenario administered by the interviewers to the participants during the electronic tablet based household survey. English versions of the DCE presented here, administered in local languages (Chichewa) in Malawi and (Nyanja, Bemba and Tonga) in Zambia.