

Interrupting stigma in the household using home HIV test offers in South Africa and Uganda

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Home-based HIV
Testing



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The Problem



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Preliminary Data
from Uganda



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Preliminary Data
from South
Africa



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Next Steps

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>20% of people living with HIV do not know their status.

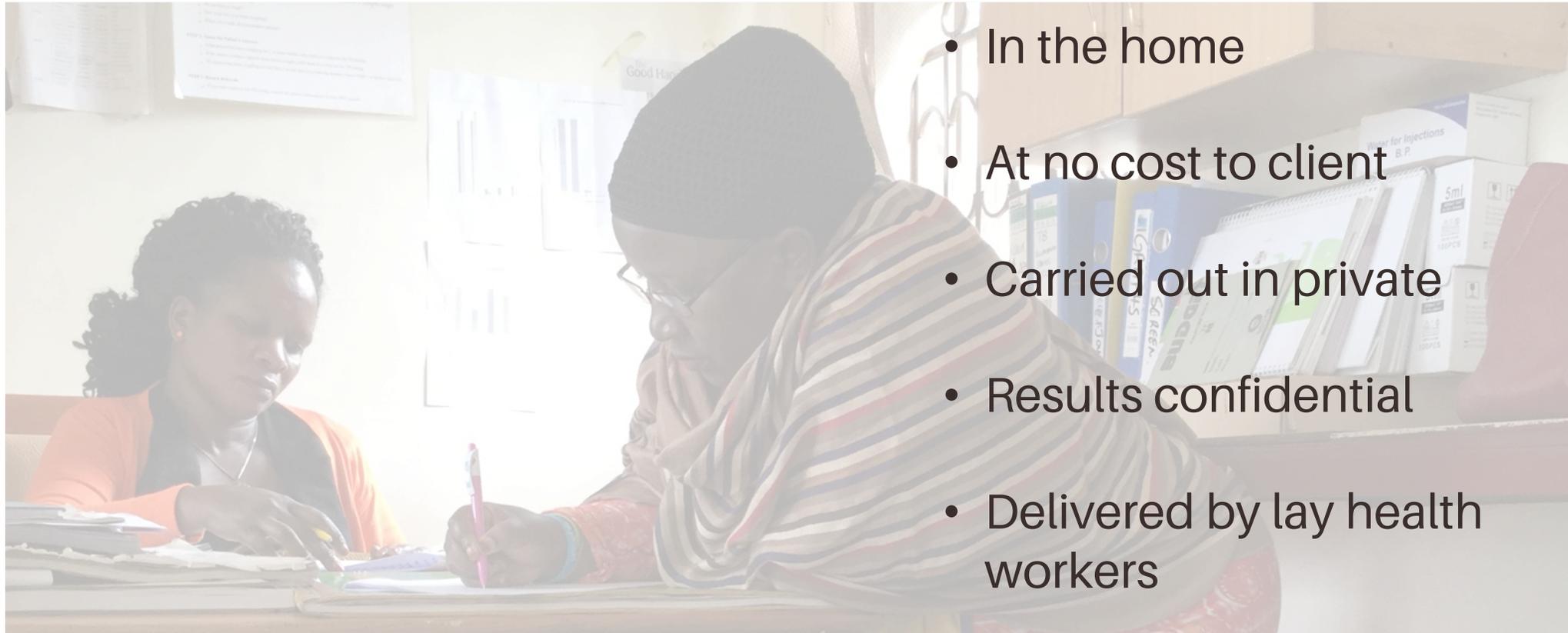
Achieving high status awareness is more challenging than high ART uptake or viral load suppression in some settings.

Justman et al. 2018, New England Journal of Medicine





Home-based HIV counseling and testing (HCT)



- In the home
- At no cost to client
- Carried out in private
- Results confidential
- Delivered by lay health workers

Home-based HIV counseling and testing (HCT)

- Home HIV testing can increase proportion of individuals who know their status (Shanaube et al. 2017, *AIDS*)
- People who learn of their status at home are more likely to remain engaged in HIV care than those diagnosed at a clinic.
(Genberg et al. 2018)
- Rates of home HCT uptake range from **58-99%**
(Sabapathy et al. 2012, *PLoS Medicine*)





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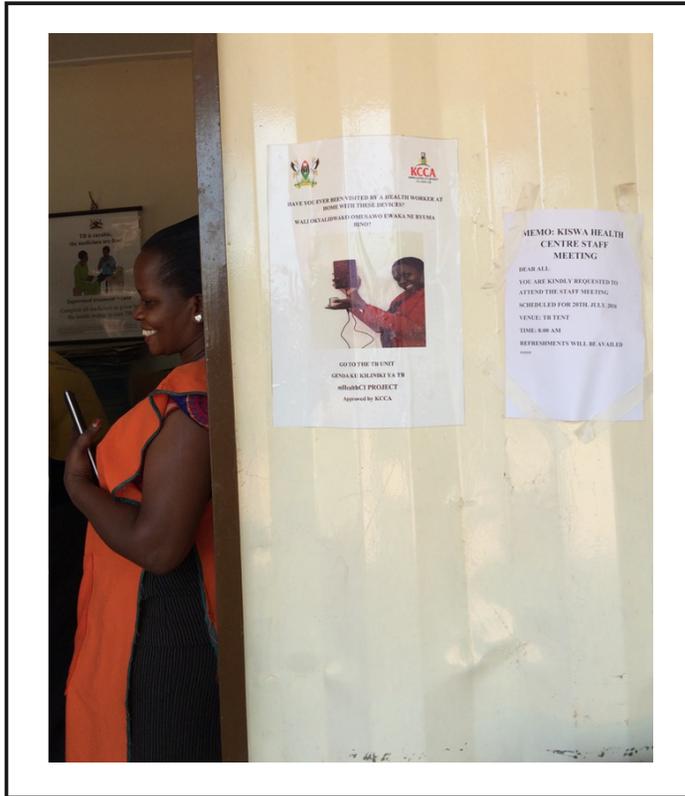


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Integrating HCT with TB screening could

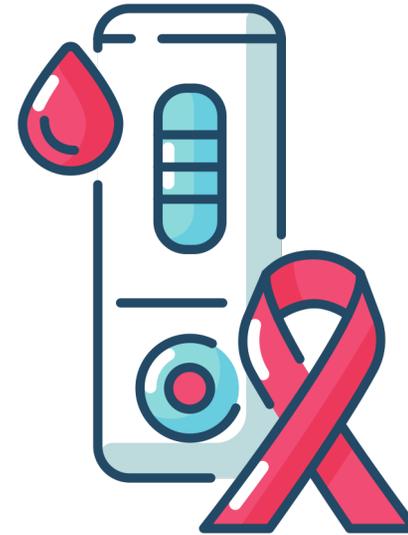
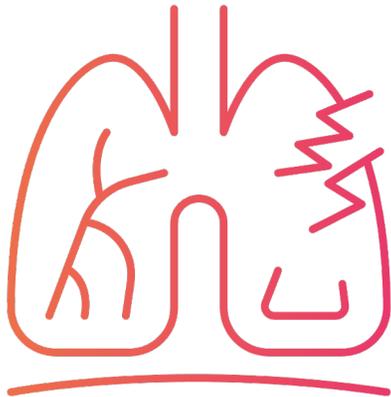
- improve status awareness for key, high-risk populations
- Add value to TB contact tracing

***But layered stigma may reduce uptake during TB home visits.**



Stigma is implicated in testing hesitance.

- **Perceived** or **anticipated** stigma: people seek to avoid negative labeling, status loss & discrimination
- **Structural** stigma: opportunities for testing with dignity are constrained



The influence of stigma is particularly complex during TB contact investigation.

- Household members grapple with stigma for both TB and HIV.
- Individual status has social implications for entire household.

“Give Me Some Time”: Facilitators of and Barriers to Uptake of Home-Based HIV Testing During Household Contact Investigation for Tuberculosis in Kampala, Uganda

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Background: Integrating home-based HIV counseling and testing (HCT) with tuberculosis (TB) evaluation could improve the uptake of HIV testing among household contacts of patients with active TB. We sought to identify the facilitators of and barriers to HCT during household contact investigation for TB in Kampala, Uganda.

Methods: We nested semi-structured interviews with 28 household contacts who were offered home-based HCT in a household-randomized trial of home-based strategies for TB contact investigation. Respondents reflected on their experiences of the home visit, the social context of the household, and their decision to accept or decline HIV testing. We used content analysis to identify and evaluate facilitators of and barriers to testing, then categorized the emergent themes using the Capability, Opportunity, Motivation, and Behavior (COM-B) model.

Results: Facilitators included a preexisting desire to confirm HIV status or to show support for the index TB patient; a perception that home-based services are convenient; and positive perceptions of lay

health workers. Key barriers included fear of results and feeling psychologically unprepared to receive results. The social influence of other household members operated as both a facilitator and a barrier.

Conclusions: Preexisting motivation, psychological readiness to test, and the social context of the household are major contributors to the decision to test for HIV at home. Uptake might be improved by providing normalizing information about HCT before the visit, by offering a second HCT opportunity, by offering self-tests with follow-up counseling, or by introducing HCT using “opt-out” language.

Key Words: home-based HIV counseling and testing, tuberculosis, household contact investigation, lay health workers, integrated HIV/TB evaluation, implementation science

(*J Acquir Immune Defic Syndr* 2018;77:400–404)

INTRODUCTION

In settings with high HIV prevalence, guidelines recom-

HIV test uptake is notably low during TB home visits.

Uptake during TB visits ranges from
35% (South Africa) to 61% (Uganda).



RESEARCH ARTICLE

Household HIV Testing Uptake among Contacts of TB Patients in South Africa

Kavindhran Velen^{1,2}, James J. Lewis³, Salome Charalambous^{1,2}, Llesli Page-Shipp¹, Flora Popane¹, Gavin J. Churchyard^{1,2,4}, Christopher J. Hoffman^{1,2,5*}

1 The Aurum Institute, Johannesburg, South Africa, **2** The School of Public Health, University of Witwatersrand, Johannesburg, South Africa, **3** London School of Hygiene and Tropical Medicine, London, United Kingdom, **4** Advancing Care and Treatment for TB and HIV, MRC Collaborating Centre of Excellence, Johannesburg, South Africa, **5** Johns Hopkins University School of Medicine, Baltimore, United States of America

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Abstract

Background

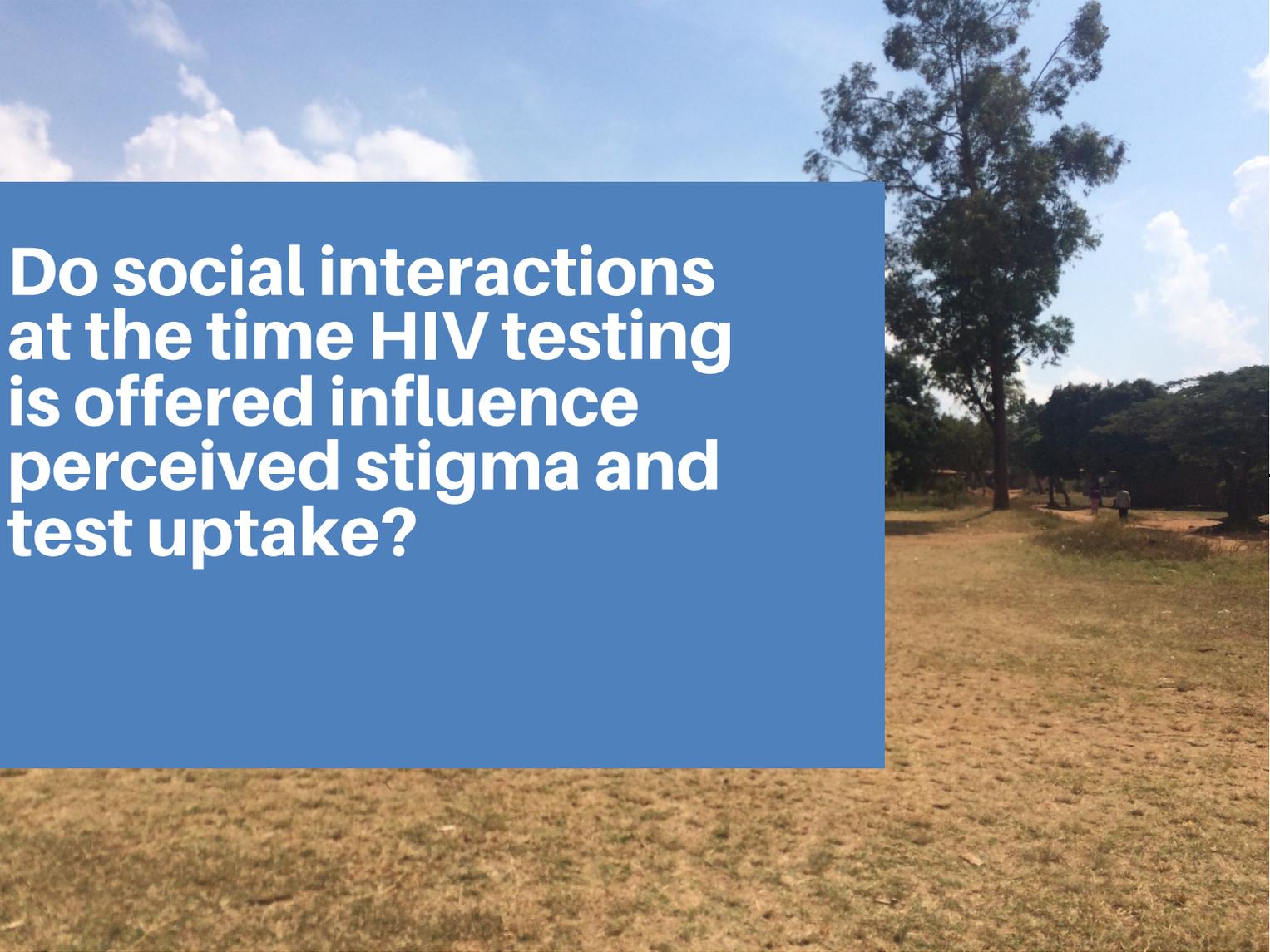
In high HIV prevalence settings, offering HIV testing may be a reasonable part of contact tracing of index tuberculosis (TB) patients. We evaluated the uptake of HIV counselling and testing (HCT) among household contacts of index TB patients and the proportion of newly diagnosed HIV-infected persons linked into care as part of a household TB contact tracing study.

OPEN ACCESS

Citation: Velen K, Lewis JJ, Charalambous S, Page-Shipp L, Popane F, Churchyard GJ, et al. (2016) Household HIV Testing Uptake among Contacts of TB Patients in South Africa. *PLoS ONE* 11(5): e0155688. doi:10.1371/journal.pone.0155688



There is a need for strategies to reduce stigma and increase HIV test uptake during TB contact investigation.



**Do social interactions
at the time HIV testing
is offered influence
perceived stigma and
test uptake?**

THE QUESTION



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Observational data

Sequential decisions of household contacts offered HIV testing in the intervention arm of a randomized, controlled trial



In-depth interviews

Interviews from a stratified random sample of household contacts offered HIV testing



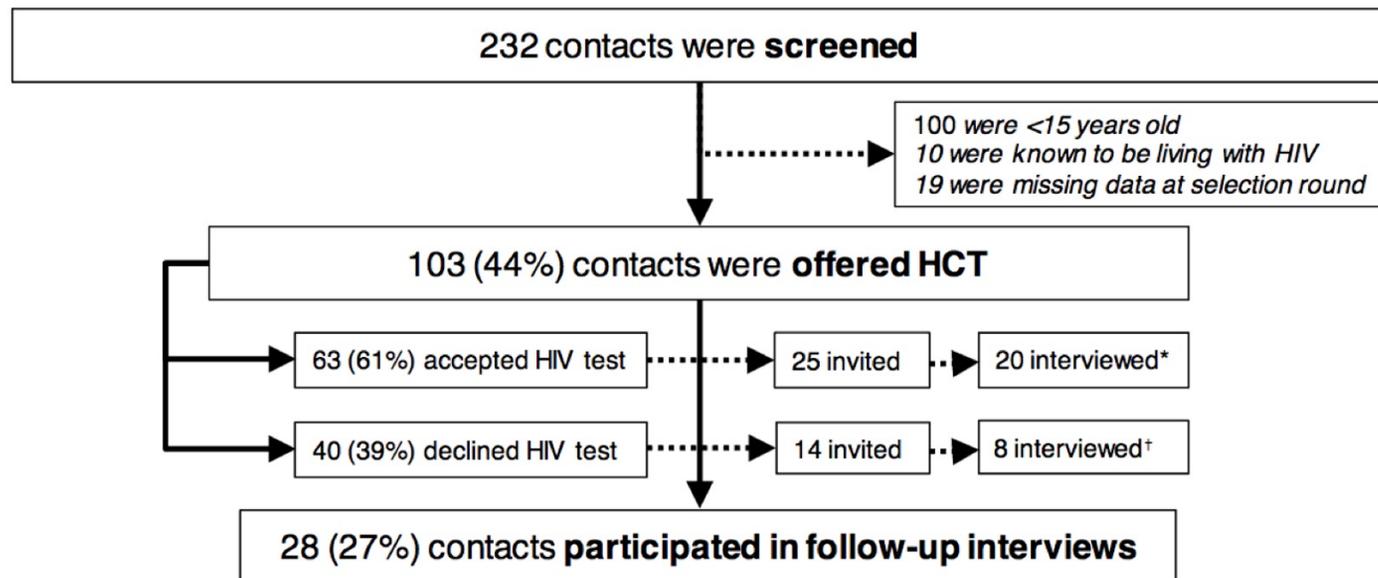
Focus group discussions

Focus group discussions with lay health workers who delivered the HIV test offers.

Formative Research Methods

We analyzed mixed quantitative and qualitative data from HIV test offers in Uganda to identify barriers and facilitators to uptake.

Interviews with contacts offered HCT





Contacts looked to family members for guidance.

"I had actually refused to be tested. I had feared to be tested... My husband was around and he immediately accepted and [then] I felt there was no need for me to refuse."

(Woman, 30, accepted)



Men tested because women asked.

“It was my wife who went first. I think it is because she was not trusting me because most of the times I am away on duty... She first showed me the [consent form] she had been given and then she told me to also have the test done before health workers leave the home. I was also tested.”

(Man, 24, accepted)



Observing another decline testing decreased willingness to test.

“You cannot accept to test when the rest have refused to do so.”

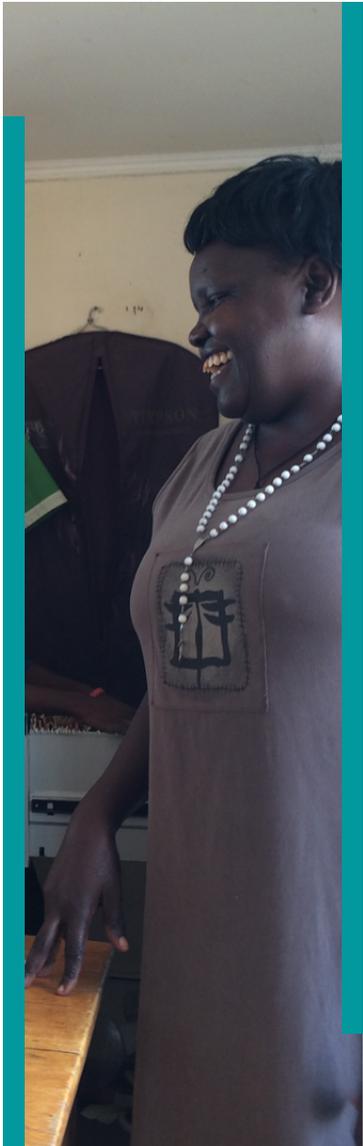
(Woman, 20, declined)

Sequential decisions of contacts offered HCT

Parameter	RR estimate (95%CI)	p-value
First tester declined	3.86 (1.30-11.46)	0.015
Age in years	1.01 (1.00-1.02)	0.09
Male	1.16 (0.81-1.67)	0.42
Baseline incidence rate	0.13 (0.05-0.39)	0.001

Legend: Multivariable GEE population-averaged model using a bootstrapped covariance estimator to adjust standard errors for clustering by household, with a log link and Poisson distribution in order to estimate risk ratios. Constant estimates baseline incidence rate (conditional on zero random effects).

Abbreviation: GEE, generalized estimating equations. RR, risk ratio.



TESTING WITH ONE'S HOME

The first person offered the test may help to establish testing as normative in the household.



PERCEIVED NORMS

Underestimating HIV test uptake in one's community is associated with not testing for HIV.

(Perkins et al. 2018)



TESTING FOR ONE'S HOME

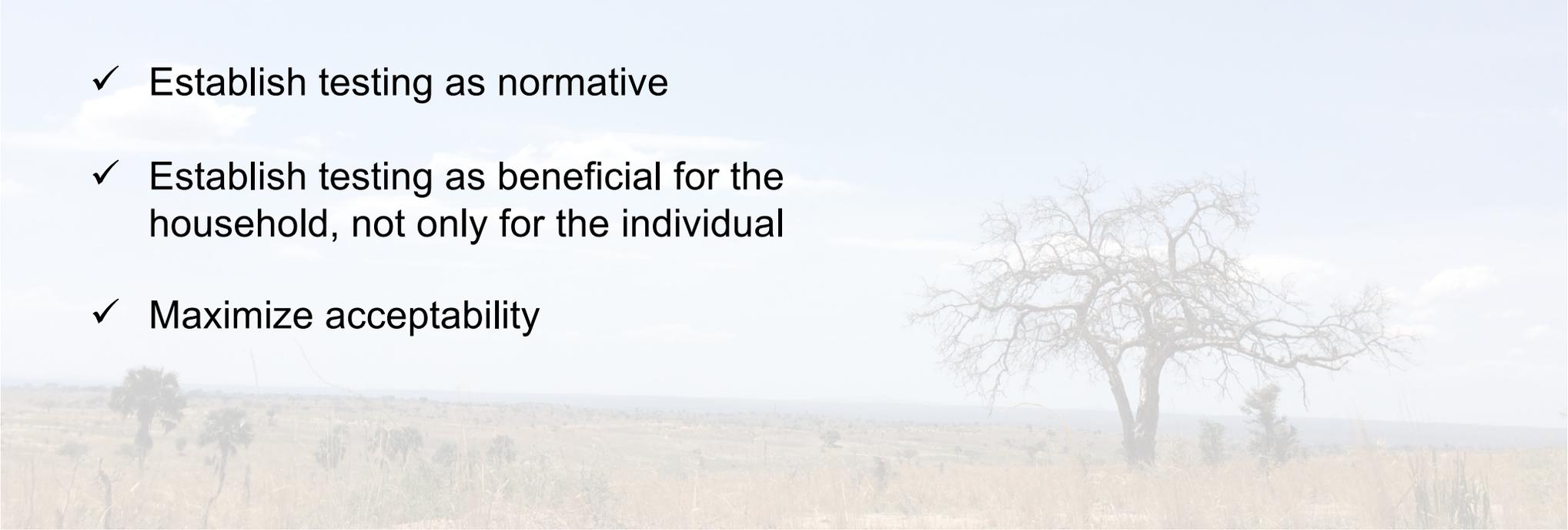
Some contacts test to motivate, appease, or communicate care for others—not for themselves.



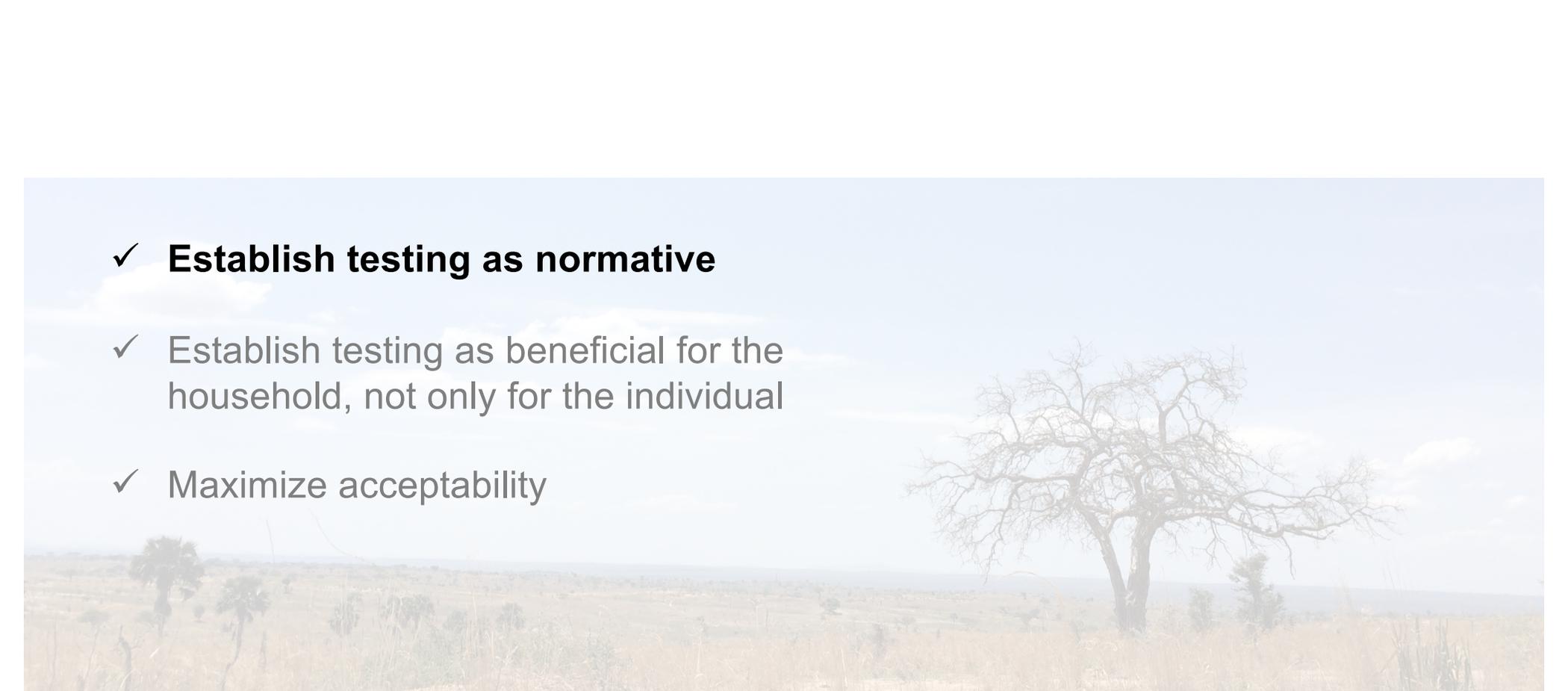
HOUSEHOLD DYNAMICS

Observing others' behavior shapes perceptions, judgments, and subsequent behaviors.

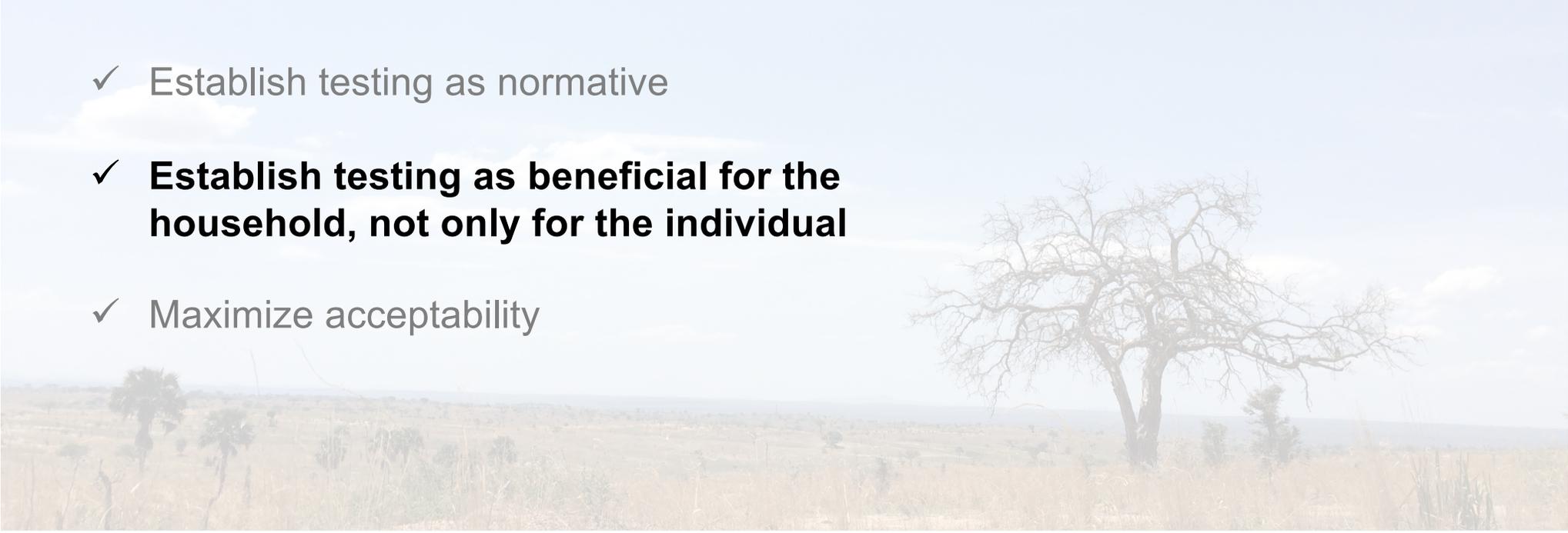
(Asch 1951, Campbell & Fairey 1989, Cialdini 2004)

- 
- ✓ Establish testing as normative
 - ✓ Establish testing as beneficial for the household, not only for the individual
 - ✓ Maximize acceptability

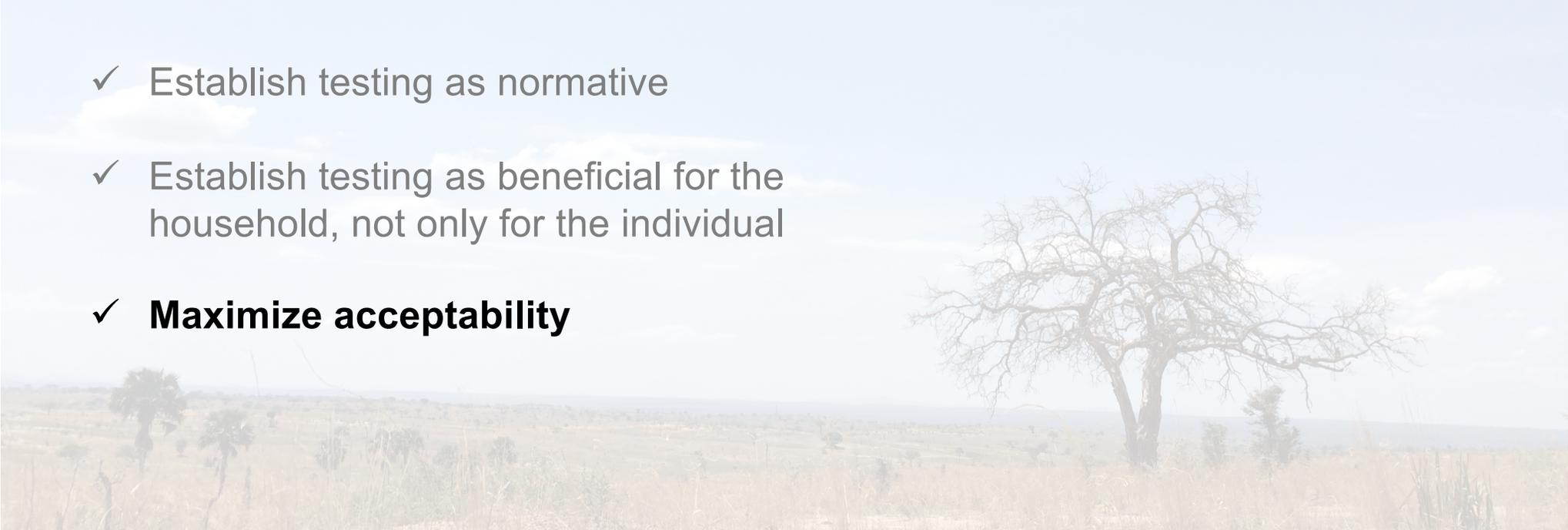
Delivery Strategy Components

- 
- ✓ **Establish testing as normative**
 - ✓ Establish testing as beneficial for the household, not only for the individual
 - ✓ Maximize acceptability

- Sequence offers to optimize likelihood that first candidate tests
- Maximize opportunities to share affirmative decisions
- Minimize risk that negative decisions can be deduced

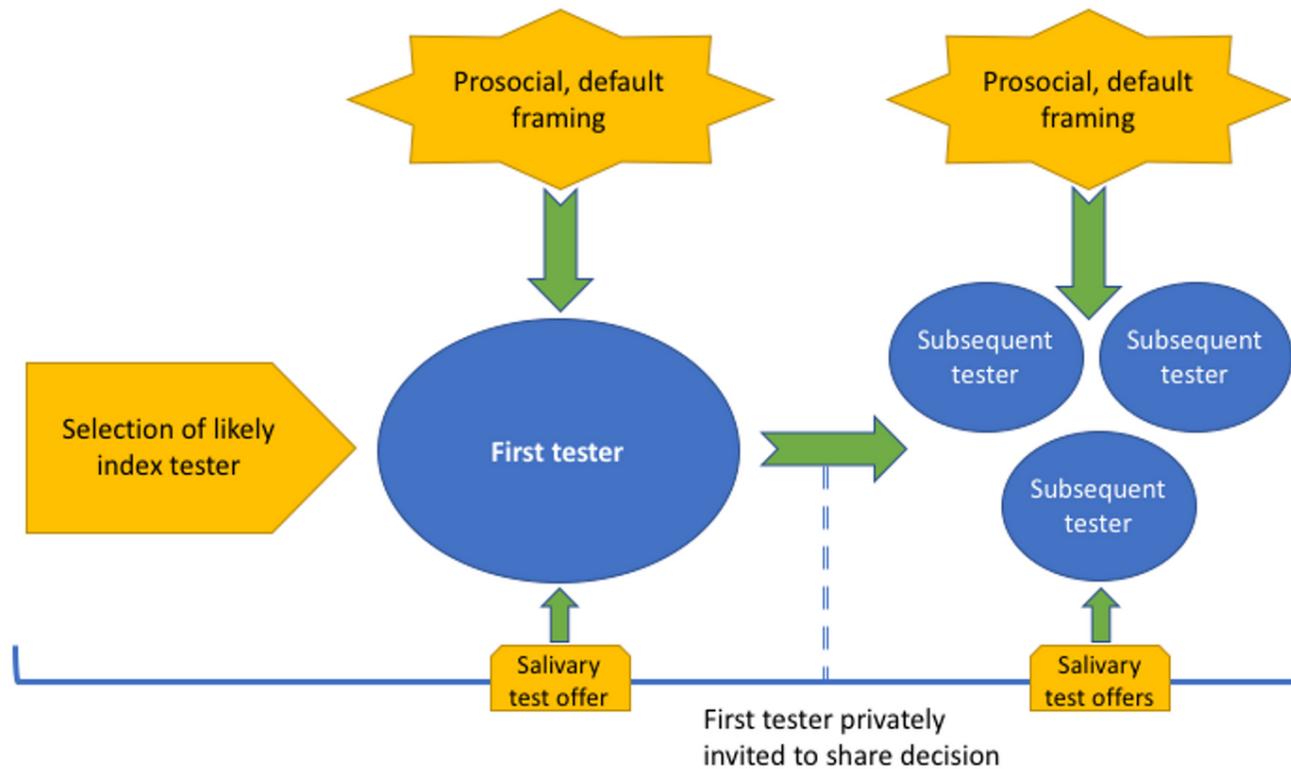
- 
- ✓ Establish testing as normative
 - ✓ **Establish testing as beneficial for the household, not only for the individual**
 - ✓ Maximize acceptability

- Frame testing as prosocial

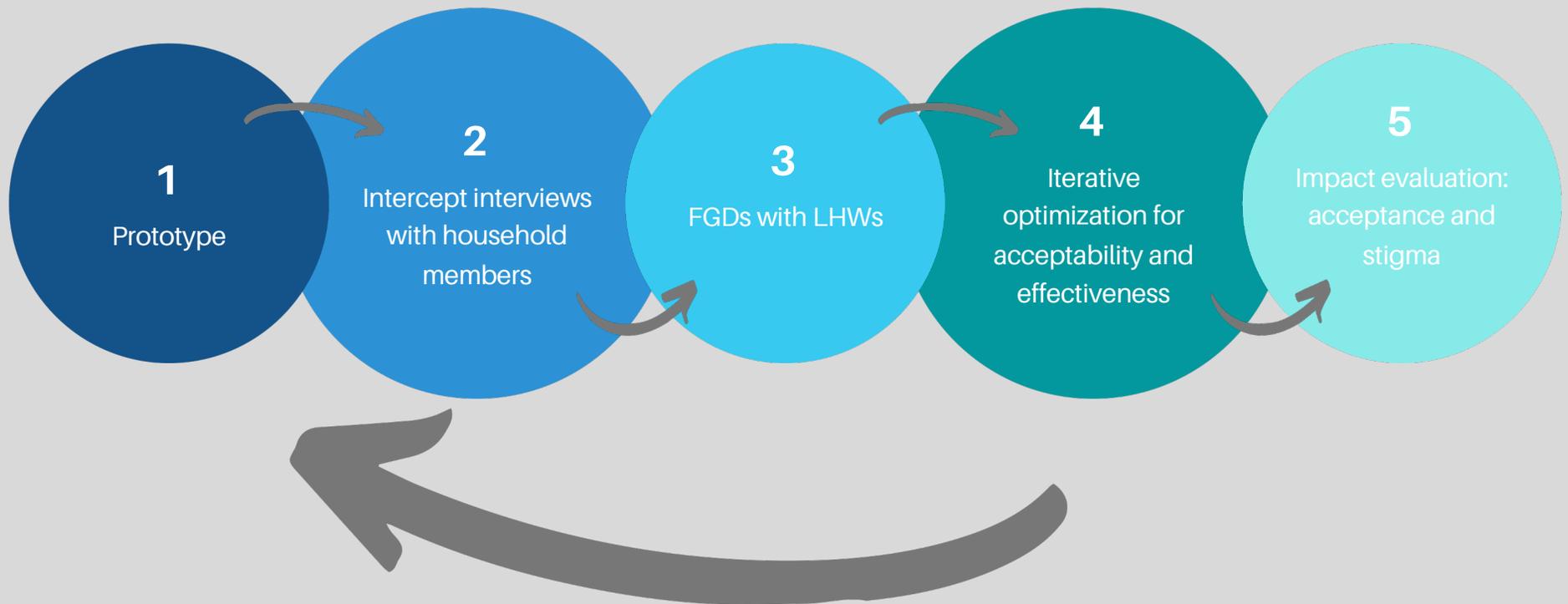
- 
- ✓ Establish testing as normative
 - ✓ Establish testing as beneficial for the household, not only for the individual
 - ✓ **Maximize acceptability**

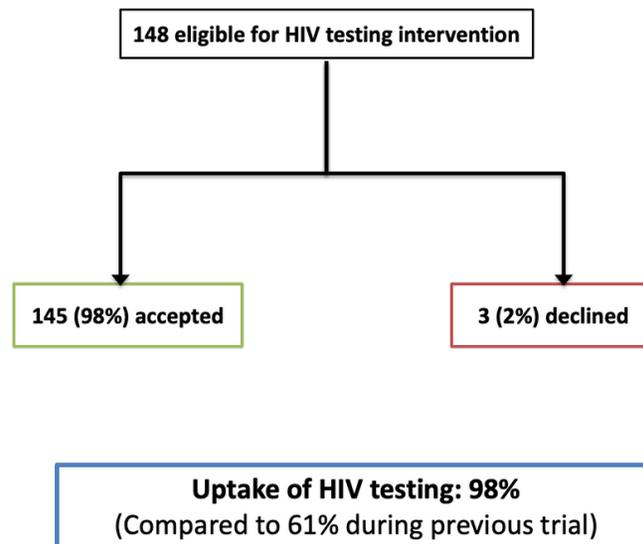
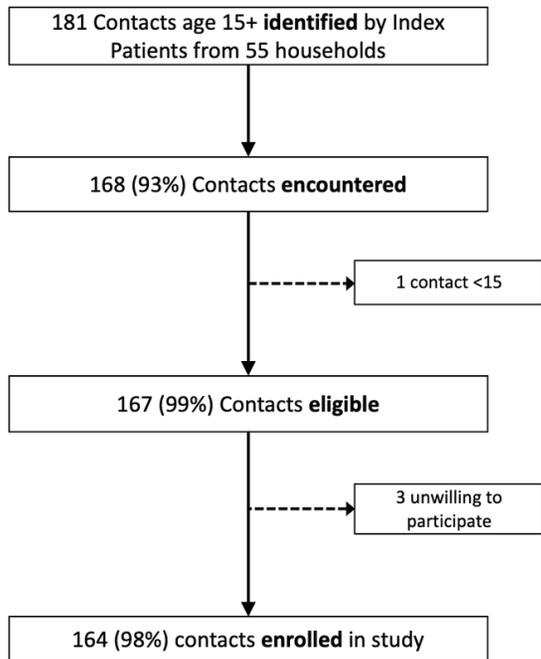
- Offer less invasive oral HIV testing
- Iterative, participatory research to adapt invitation script to households that have recently received a TB diagnosis

Delivery Strategy Components



OPTIMIZATION PROCEDURES





Optimization Results

In prototyping, acceptance of HIV testing during TB home visits rose to 98%.



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Observational data

Decisions of household contacts offered HIV testing in a pilot study.



In-depth interviews

Intercept interviews from household contacts offered HIV testing during TB home visits.



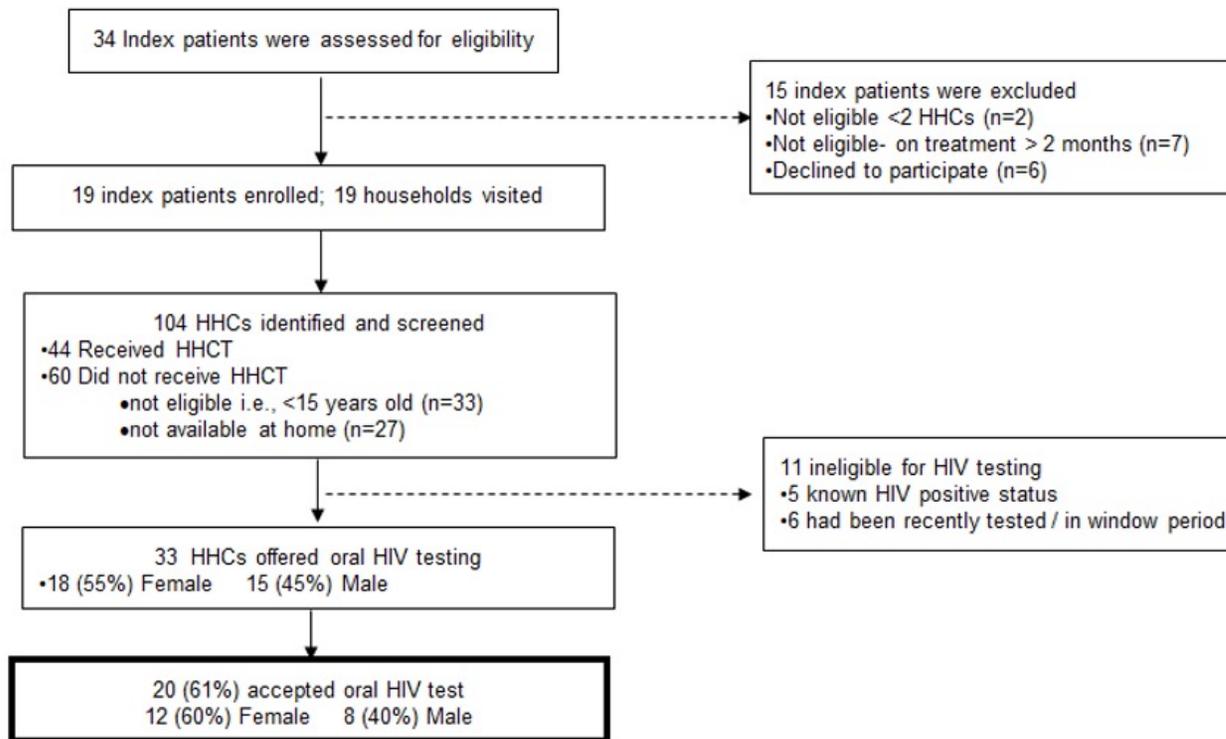
Focus group discussion

Focus group discussion with lay health workers who delivered the HIV test offers.

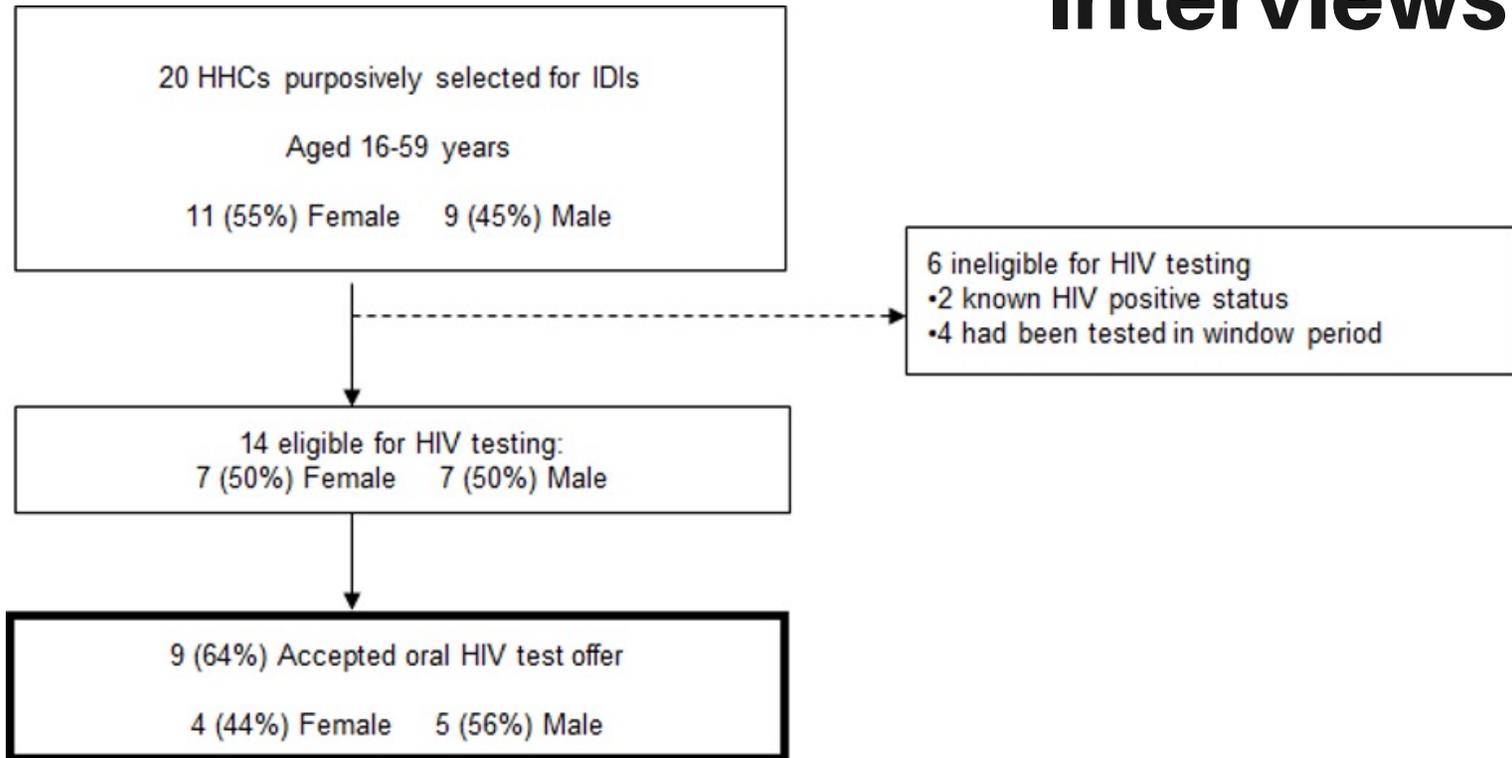
Formative Research Methods

We analyzed mixed quantitative and qualitative data from HIV test offers in South Africa to identify barriers and facilitators.

Observational data



Interviews





Better to get bad news at home.

“Because *eh* if you arrive there (clinic) and then you are, your status says you are not negative *yoh* you become angry angry. And if you’re here at home you can just sleep and prepare yourself for the road, what you are going to face.”

(Man, 21, accepted)



Some contacts tested to motivate others.

That's why I told [LHW] to leave my result on the car so that I can motivate them to take the test. Because I know they are not comfortable when you're talking about this thing. So I told them that there is nothing wrong about testing. They need to know their status because I know now they are not comfortable, believe me.

(Woman, 38, accepted)



Even with family support, stigma in the community is a threat.

“My friends, they don’t treat people with HIV nicely. Because they think they will also be infected, things like that. Like they distance themselves, don’t go near them and they just want to play alone.”

(Woman, 18, declined)

Emergent themes in interviews and FGDs in Uganda and South Africa

Clients		Themes	Lay Health Workers	
Uganda (n=28)	South Africa (n=20)		Uganda (n=4)	South Africa (n=3)
"Give me some time"	"Beyond the word scary"	 Fear	Prioritize support	Prioritize services
"[Home] is convenient"	"I prefer the visitations"	 Home	Pride in offering test services	"Clients feel special"
Strong evidence of prosocial reasoning	Weaker evidence: Some tested to set example	 Family	Navigating intra-household influences	Generational differences, disclosure worries

In contrast to Ugandan participants, most South African participants said they do not discuss health matters at home.



Fear status awareness



Preference for home test



Household social dynamic



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Prosocial reasoning

Emphasize household rather than individual benefits of testing.



Re-norming

Frame testing as a family as normal and routine.

Because household dynamics differ in South Africa, these components may not be sufficient to shift perceptions or test decisions.

Discussion

How might we reimagine this delivery strategy for South African households given what we have learned?



Bring health home

Create opportunities to discuss health matters in the home.

— Next Steps

1

Implementation trial in Uganda

Multi-center, household-randomized trial enrolling 152 TB patient households with 304 household contacts to evaluate usual care versus norming intervention.

Outcomes: (1) Oral HIV test acceptance, (2) HIV diagnoses, (3) Linkage to care, (4) Change in perceived household stigma for HIV and TB

2

Optimization research in South Africa

Participatory prototyping pilot enrolling ~30 households participating in household contact investigation to adapt delivery strategy.

Measures: acceptability, feasibility, effectiveness at increasing test uptake



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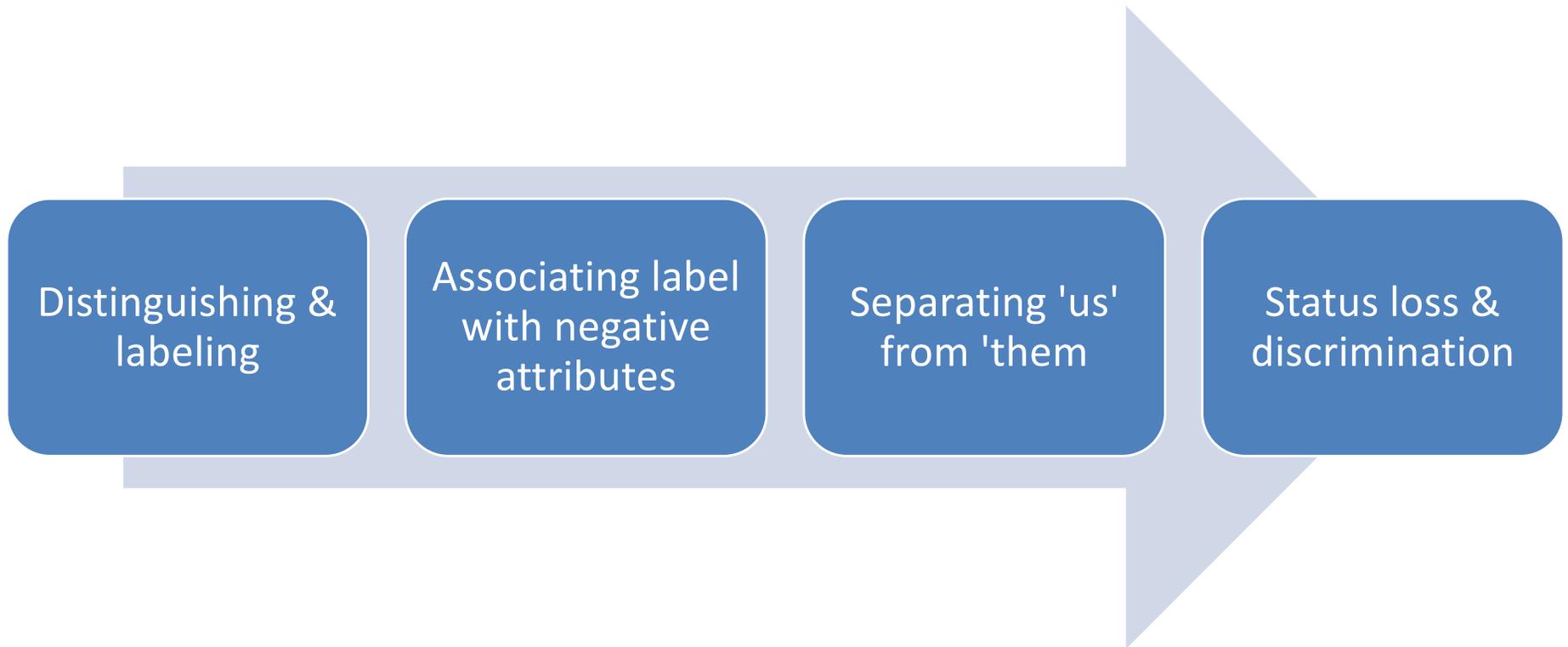
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Theory: Stigma process



Link & Phelan 2001, *Annual Review of Sociology*



First iteration

- 6 households
- 16 contacts interviewed

September 20



Second iteration

- 8 households
- 17 contacts interviewed

November 11



Third iteration

- 9 households
- 23 contacts interviewed

December 9