

RESEARCH PROTOCOL

Assessing a Human Rights-Based Approach to HIV in Kenya

NEILOY R. SIRCAR, TABITHA G. SAOYO, AND ALLAN A. MALECHE

Abstract

Kenya is actively encouraging HIV testing and notification services in order to identify persons living with HIV and link them to treatment. Recently, Kenya and international supporters of its HIV program have sought to scale up these services through increased capacity and training. However, little is known about how this strategy has been implemented and is being sustained, particularly regarding the human rights of persons living with or at risk for HIV. This exploratory qualitative study seeks perspectives from health providers and populations at risk for HIV, including young women, men who have sex with men, sex workers, and injection drug users. Our primary data collection methods will be focus group discussions and in-depth interviews. We will transcribe and analyze data under a grounded theory approach to compare outputs from populations at risk for HIV with outputs from health providers. We will also apply a rights analysis to the data's codes and themes to assess how effectively Kenya's HIV strategy, policies, and practices adhere to a human rights-based approach. The results will support both rights realization among at-risk populations and the public health objectives for HIV testing and treatment.

NEILOY R. SIRCAR is a 2018–2019 NIH/Fogarty-Northern Pacific Global Health Fellow and a 2018–2019 Afya Bora Fellow, University of Washington, USA.

TABITHA G. SAOYO is deputy director of the Kenya Legal and Ethical Issues Network, Nairobi, Kenya.

ALLAN A. MALECHE is executive director of the Kenya Legal and Ethical Issues Network, Nairobi, Kenya.

Please address correspondence to Neiloy R. Sircar. Email: nsircar@uw.edu.

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Introduction

HIV is a tragic health and human rights concern made all the more problematic where the human rights of those persons at risk for HIV or living with HIV are compromised in the pursuit of a public health strategy. Violations of individual consent, privacy, and confidentiality are rarely justifiable, even when the goal is to promote access to treatment and care.

Kenya has enacted policies and encouraged practices that support human rights for persons who are at risk for HIV or living with HIV. However, the communities at risk for HIV do not always experience the best practices for the protection of their rights or know that there are laws and policies that protect them. Further, historical discrimination against communities at risk for HIV—due to sexual orientation, gender, work, and habits and lifestyle—can color individual and community perceptions of health services even before any interactions.

To address these concerns, Kenya has adopted laws, practices, and statements affirming a human rights-based approach to HIV that rests on a public health strategy that protects, respects, promotes, and fulfills the human rights of all persons at risk for HIV or living with HIV.

Beyond affirmations alone, the implementation of a rights-based approach—as reflected in the perceptions, policies, and practices of health care professionals and validated in the perceptions and experiences of those individuals at risk for HIV who access the Kenyan health care system—provides an opportunity for research into how public health programs can be evaluated and analyzed utilizing a rights-oriented framework. Public health programming may better achieve its objectives through complementary, tangible rights-realizing interventions. Research that assesses the efficacy of public health policies and practices in respecting, protecting, promoting, and fulfilling human rights will support fidelity to a human rights-based approach.

Background

Kenya's HIV epidemic disproportionately affects

vulnerable communities, including young women and persons from key populations, such as sex workers, men who have sex with men, and people who inject drugs.¹ We refer to these groups collectively as “key and affected populations.” As a result, the Kenyan National AIDS and STI Control Programme (NAS COP), the Ministry of Health, and other Kenyan public health authorities (as well as international supporters such as the US President's Emergency Plan for AIDS Relief, or PEPFAR) have been scaling up their HIV testing strategies to increase testing rates and to widely implement notification services, chiefly assisted partner notification services, to connect at-risk persons to HIV testing services.

As outlined in NAS COP's 2015 National HIV Testing Services Guidelines, Kenya employs several approaches to HIV testing in order to facilitate access to HIV services, testing, and treatment in a variety of conditions.² These include facility-based and community-based settings that offer both client-initiated and provider-initiated testing and counseling. In addition, assisted partner notification services have been particularly effective in identifying persons for outreach and testing, utilizing an index case (a person living with HIV) to identify other parties—usually partners, though children as well—to simplify case finding.

It is estimated that half of all people living with HIV in Kenya are unaware of their HIV status.³ Overall, testing for HIV is improving, yet testing rates among key populations and young women remain stubbornly low: while 80–90% of female sex workers in Kenya report having tested for HIV within the past 12 months, only 77% of men who have sex with men, 84% of people who inject drugs, and 53% of women aged 15–24 report having done so.⁴ These rates represent significant improvements since 2011 (for example, in 2011, a mere 29.2% of women aged 15–24 had tested for HIV within 12 months of being asked, as well as just 35.5% of men who have sex with men), which makes it all the more important to sustain this momentum in testing and to do so in a manner that is respectful of the rights and dignity of persons at risk for and living with HIV.⁵

HIV and risks to patients' rights

HIV testing strategies have been increasingly looking to high-yield methods for identifying persons at risk for HIV and facilitating their access to care. Partner notification services and similar approaches have been shown to be effective at identifying persons within the immediate orbit of an index case.⁶ Nevertheless, some communities at risk for HIV or living with HIV have concerns about disclosure, particularly its potential to increase stigma, discrimination, abandonment, and intimate partner violence and other forms of violence.⁷ These feelings inhibit positive perceptions of HIV testing services and assisted partner notification services, and they reflect people's conceptions concerning their human rights and how those rights are regarded when being tested for HIV or being asked to disclose a positive status to others.⁸

Coercive HIV testing, as well as coercive notification of a partner or other person about one's status, is a gross violation of human rights that nevertheless has been widely experienced within at-risk communities. In 2013, Eileen Moyer et al. noted that the non-consensual disclosure of a person's HIV status in Kenya was commonplace and that some people had been coerced into testing, which affected community perspectives on HIV testing and on health services generally.⁹ Even where coercion was not overt (such as a threat or an unlawful requirement to test for HIV before receiving other services), constructively coercive environments—such as clinical settings where patients could not enjoy privacy or confidentiality—were found to unduly affect individuals' autonomy.

HIV and a human rights-based approach to improving public health

A human rights-based approach to HIV testing and disclosure places the rights of people being tested at the center of all services. Kenyan health authorities and supporters such as PEPFAR concur that rights-based approaches need to form the basis of training for health service providers, especially for “[key population] friendly services.”¹⁰ The human rights of persons at risk of and living with HIV and AIDS include their rights to dignity,

respect, privacy, and confidentiality, as well as the right to provide informed consent and to refuse consent.¹¹ Training health service providers in the adoption of a rights-based approach necessitates sensitivity, recognition, and familiarity with the concerns of key populations. Further, accomplishing and cementing such training requires a strong legal and policy framework under which health care professionals can work. HIV testing must be voluntarily consented to, and the patient must be fully informed (for example, by receiving adequate pre-counseling) and their information kept private and confidential. Kenya's 2010 Constitution and its 2006 HIV and AIDS Prevention and Control Act afford the right to—and expectation of—privacy and confidentiality, in accordance to international law and norms including those adopted by the East African Community (of which Kenya is a member).¹² Kenyan health authorities and providers are thereby obligated to ensure that all Kenyans enjoy their rights consistently and uniformly whenever and wherever they interact with the health care system.¹³

Yet, at the time of writing, neither NASCOP's guidelines on assisted partner notification services nor the required privacy regulations under the 2006 HIV and AIDS Prevention and Control Act had been adopted by Kenyan authorities. The degree to which rights-related training has been integrated into health care worker education in Kenya is unclear, as is the extent to which policies and practices on patients' rights are upheld in a uniform and consistent manner.

Research rationale

We believe that an evaluation of how a rights-based approach is implemented is vital to identifying, and improving on, effective and rights-enabling components of Kenya's HIV strategy. In addition, we intend to demonstrate the utility of a human rights-oriented analysis for public health programming (in other words, we seek to evaluate the “approach” in “human rights-based approach” to HIV). Given concerns of abuse, stigma, discrimination, and other negative consequences among

the key populations and vulnerable groups at risk for HIV, Kenyan HIV policies and practices should reflect on and be informed by studies showing implementation gaps with respect to human rights.¹⁴ Our study and its results will aid public health policy planners and health providers in their engagement with at-risk communities and so contribute to building trust and confidence among key stakeholders in Kenya's HIV and human rights context.

Research objectives

General objective

This research asks how normative statements in law and policy documents become embedded (or not) in health care workers' practices and patients' experiences. The study collects opinions, feelings, and perspectives from both the HIV at-risk communities generally targeted by Kenyan and international public health actors and the Kenyan public health and health care workers who design and implement HIV testing and notification strategies. This data will help us understand how, and to what degree, Kenyan HIV testing and notification policies and practices are rights realizing with respect to key and affected populations, particularly concerning their rights to consent, privacy, and confidentiality.

Specific objectives

Our study contains three specific objectives, refined through peer review with our respective institutional review boards at Georgetown University and Kenya Medical Research Institute.

1. Document opinions, concerns, attitudes, and perspectives (both positive and negative) within at-risk communities related to testing for HIV and disclosing HIV status, and connect those concerns to recognized human rights in Kenya.
 - a. Sub-objective: Assess at-risk communities' level of awareness of their human rights under Kenyan and international law as they relate to HIV testing and notification services.
 - b. Sub-objective: Gauge key and affected pop-

ulations' level of trust and confidence in the health system with regard to their legal rights.

Approach: Focus group discussions and in-depth interviews with key and affected populations.

2. Document providers' and health professionals' perspectives on HIV testing and disclosure practices regarding at-risk communities, including opinions on training programs for health care workers that relate to key and affected populations' sensitization and patients' rights.

a. Sub-objective: Assess rights awareness and attitudes toward balancing human rights for persons at risk for or living with HIV with public health imperatives to identify and link at-risk persons to testing and treatment services.

Approach: Key informant in-depth interviews with HIV health care providers and professionals (nurses, counselors, doctors, and policy experts).

3. Explore whether and where human rights interventions—including reforms in policy, law, training, and practice—might contribute to rights realization and increased health care utilization among HIV at-risk communities.

Approach: Legal analysis relating Kenyan and international human rights law to the emergent codes and themes from our qualitative analysis (our "facts," if anecdotal), and concluding how well the human rights-based approach in Kenya is being implemented procedurally and substantively.

Design and methodology

Setting

Kenya's legal and policy framework is supportive of human rights in health, including for key and affected populations who bear the brunt of stigmatizing exclusion, and guidelines around privacy, confidentiality, and consent are extolled within HIV public health programs. As a result, Kenya presents a strong foundation to conduct a legal analysis for the implementation of an HIV public health strate-

gy that adheres to a human rights framework.

Taking into account prevailing key and affected population demographics and high HIV prevalence, we selected four study sites to conduct our discussions: Nairobi County (high concentration of men who have sex with men), Kisumu County (high concentration of sex workers), Homa Bay County (high population of young women), and Mombasa County (high concentration of people who inject drugs).

Sample size

Our total sample size is expected to be 50 persons: 36 focus group discussion participants and 14 in-depth interview participants.

Inclusion criteria

- Self-identification with one of our target populations (men who have sex with men, people who inject drugs, young women aged 18–24, sex workers, and health care providers or professionals).

Exclusion criteria

- Participant not independently capable of consenting to participate.
- Participant not willing to participate primarily in English or Swahili.
- Focus group: participant already taking part in an in-depth interview.
- In-depth interview: participant already taking part in a focus group.

Recruitment

Our study benefitted from established relationships between our organization, Kenya Legal and Ethical Issues Network, and members of Kenyan civil society. Community-based organizations and civil society organizations supported participant mobilization by circulating invitations to participate in our study to members and affiliates. We instructed these partners that all participation must be voluntary and unrelated to a participant's role in their respective organization (for example, the focus group discussions and in-depth interviews were

not official events for those organizations where attendance may be mandatory or perceived as such).

Health care providers and professionals were individually invited to participate, voluntarily and without consequence. We sought to recruit providers and professionals at both the point-of-care level and the policy level.

Risks

We identified minimal to no risks to participants but took measures to mitigate any potential risks that may stem from their participation, including ensuring anonymity in their participation, taking all reasonable measures to ensure privacy and confidentiality, and providing substantive consenting procedures. We informed participants of their rights—including their right to refuse to answer any question and to withdraw consent at any time, for any reason, and without consequence—prior to their participation.

Ethical review

Georgetown University's Institutional Review Board (2018-1148) and Kenya Medical Research Institute's Scientific and Ethics Review Unit (Non-KEMRI No. 654 (2019)) approved this study following substantial and helpful review.

Data collection

Data collection comprises (1) key informant and in-depth interviews (one to three persons per site, up to ten total) with health professionals (health care workers, policy experts, providers, and planners); (2) in-depth interviews with one to two self-identified members from each of the at-risk populations; and (3) focus groups with participants from at-risk populations (one focus group per population consisting of five to nine persons). Our study pre-tested the focus group and interview question guidelines before beginning data collection to ensure efficacy and sensitivity, utilizing individuals from key and affected populations and individuals with health professional backgrounds. All materials have been translated into Swahili and back-translated into English for fidelity. Data collectors utilize audio-re-

ording devices and note taking; transcriptions will be translated into English.

Data collection is ongoing at the time of this publication and is anticipated to conclude by July 2019, with analysis to follow.

We consulted with our community-based and civil society partners to identify and hire interviewers and moderators who are professionally capable and familiar with, if not members of, the respective at-risk communities.

Consent

All participants are required to sign written consent forms prior to any discussion or data collection, and they must have the independent capacity to do so. All participants are offered multiple opportunities to ask for and receive information or answers to any questions, including prior to their consenting to participate. We ensure that participants know their rights regarding their participation, including the right to refuse and the right to withdraw consent.

Analysis

Qualitative analysis

With the aid of appropriate software, we will analyze data under an exploratory grounded theory for qualitative research. With respect to HIV policies and practices, we will look for patterns and linkages in participants' experiences; code and evaluate commonalities and distinctions; and use that data to induce efficacy, opportunities, and challenges in Kenya's HIV testing and notification strategies. Identifying emergent themes in the data will inform our study's most salient outputs and, in particular, the breadth and depth of experiences and perspectives within key and affected populations' interactions with Kenyan health care workers and officials. Not every code or theme may have a direct human rights dimension, but in determining them, our work may identify actionable points for public health interventions.

Rights analysis

We are interested in whether the policies and practices employed by Kenyan health care workers and

professionals, and experienced by key and affected populations, are rights compliant. Predominantly, our study is focused on the human rights to free and fully informed consent, privacy, and confidentiality, which are codified under Kenyan law. Our rights analysis will broadly take a form reminiscent of the IRAC legal analytical tool:

- **Issue:** the code or theme under review emerging from the qualitative analysis.
- **Rule:** the pertinent human right(s) rule within the relevant domestic legal framework and under international human rights law.
- **Application/Analysis:** apply the rule to the issue and assess the risks or breaches to human rights—or the adequate protection and fulfillment of human rights—within the code or theme.
- **Conclusion:** determine how the specific human rights related to the code or theme are enjoyed by key and affected populations and upheld by health care providers.

We aspire to include analysts from the relevant at-risk communities, as we believe that implementation science in global health research should ensure that the communities in which such research occurs contribute to and benefit from such work.

Discussion and dissemination

Our "Discussion" and "Recommendations" sections will identify opportunities, possible interventions, and challenges for Kenya's human rights-based approach to HIV testing and notification. Evaluating health programs from the perspective of rights realization creates a new metric for measuring efficacy and outcomes in HIV public health programs, through (1) identifying successful and sustained practices and policies within HIV testing and notification strategies that promote, protect, respect, and fulfill human rights, and (2) identifying any gaps and opportunities wherein the rights-based concerns of at-risk communities are not appropriately addressed as matter of policy or practice. Our

analysis may address issues such as the adequacy and sufficiency of health care provider training on human rights; the reach of best practices that support a human rights-based approach; and the necessary reforms to policy or practice in order to achieve both greater rights realization and (relatedly) trust and confidence in the health care system when it comes to HIV-related care and services.

Our dissemination plan is as follows:

1. Disseminate the research analysis to pertinent government and public health institutions in Kenya.
2. Disseminate the research analysis to the community-based and civil society organizations in Kenya that participated in its creation.
 - a. In addition, organize workshops, seminars, and meetings with key stakeholders (community members and representatives).
3. Publish our research in peer-reviewed journals and present it in suitable forums at the local, regional, and global level.

Limitations

Certain limitations affect our study's scope and reach, and we hope that future projects will expand upon our research.

- Geographic limitations: our study focuses on Kenya, and primarily four counties within Kenya. Perspectives and human rights-related experiences may vary in other locations and contexts; perceptions on HIV-related stigma certainly do.¹⁵
- Representation limitations: our participants may not be able to comprehensively reflect the perspectives of every member of their self-identified group, especially those who may live in other contexts. While we hope to have sufficient sampling from each of the populations, future studies may go further by having a larger sample size or targeting additional demographics for inclusion (for example, refugees and the trans community).

- Language limitations: our participants will be required to speak comfortably in either English or Swahili.
- Other limitations: due to resource constraints, we excluded persons who could not independently consent to participate. Future studies may consider including adolescents and minors, persons living with certain disabilities, and persons for whom consenting may require extra processes (such as prisoners).

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References

1. AVERT, *HIV and AIDS in Kenya* (2018). Available at <https://www.avert.org/professionals/hiv-around-world/sub-saharan-africa/kenya>.
2. National AIDS and STI Control Programme, *2015 national HTS guidelines* (Nairobi: Ministry of Health, 2015).
3. AVERT (see note 1).
4. G. Githuka, W. Hladik, S. Mwalili, et al., "Populations at increased risk for HIV infection in Kenya: Results from a national population-based household survey, 2012," *Journal of Acquired Immune Deficiency Syndrome* 55/Suppl 1 (2014), pp. S46–S56; National AIDS Control Council, *Kenya AIDS response progress report 2016* (Nairobi: Ministry of Health, 2016), p. 51.
5. UNAIDS, *Greater involvement of people living with HIV and AIDS* (Geneva: UNAIDS, 2007).
6. See, for example, S. Dalal, C. Johnson, V. Fonner et al., "Improving HIV test uptake and case finding with assisted partner notification services," *AIDS* 31/13 (2017), pp. 1867–1876.
7. *Preventing intimate partner violence in Uganda, Kenya, and Tanzania: Summary of a joint workshop by the Institute of Medicine, the National Research Council, and the Uganda National Academy of Sciences* (July 24, 2015). Available at <https://www.ncbi.nlm.nih.gov/books/NBK316382>.
8. S. Kalichman, C. Mathews, M. Kalichman, et al., "Perceived barriers to partner notification among sexually transmitted infection clinic patients, Cape Town, South Africa," *Journal of Public Health* 39/2 (2017), pp. 407–414.
9. E. Moyer, E. K. Igonya, R. Both, et al., "The duty to disclose in Kenyan health facilities: A qualitative investigation of HIV disclosure in everyday practice," *SAHARA-J: Journal of Social Aspects of HIV/AIDS* 10/Suppl 1 (2013), pp. S61, S64, S66–70.
10. U.S. President's Emergency Plan for AIDS Relief, *Kenya country operational plan 2018: Strategic direction summary* (Washington, DC: U.S. President's Emergency Plan for AIDS Relief, 2018), pp. 41–42.
11. UNAIDS, *Human rights* (2019). Available at <http://www.unaids.org/en/topic/rights>.
12. Constitution of Kenya (2010), art. 31; *HIV and AIDS Prevention and Control Act* (2006), art. 3(b), 6(3), 14, 17, 18, 20, 21, 22; East African Community HIV and AIDS Preventions and Management Act (2012), §§19–32; World Health Organization, *Consolidated guidelines on HIV testing services 2015* (Geneva: World Health Organization, 2015), pp. 9, 39, 147; World Health Organization, *Supplement guidelines on HIV self-testing and partner notification 2016* (Geneva: World Health Organization, 2016), p. 58.
13. Kenyan National AIDS and STI Control Programme, *Key population* (2019). Available at https://www.nascop.or.ke/?page_id=828; National AIDS Control Council, *2014/15–2018/19 Kenya HIV and AIDS research agenda* (Nairobi: Ministry of Health, 2015). Available at https://nacc.or.ke/wp-content/uploads/2015/10/HIV_2.pdf.
14. National AIDS Control Council (2016, see note 4), pp. 26–27.
15. *Ibid.*, p. 24.

APPENDIX A**Focus Group Discussion Guidelines****INTRODUCTION BY MODERATOR (10 minutes)**

Hello, my name is <Name> and I am part of a research team working with the Kenya Legal and Ethical Issues Network on HIV and human rights. We are working with the University of Washington and Georgetown University to explore people's thoughts and opinions about HIV testing and notification, or disclosure, and respect for legal rights. We are interested in your participation in this focus group so that we can hear about your experiences and perspectives regarding health care and HIV. This will help us understand what is working and what is not in terms of supporting your human rights and HIV treatment.

This discussion is free and open; we want to hear your feelings and concerns so we can suggest improvements. Your participation is helpful, but you do not need to talk to us if you do not want to. You may stop participating at any time and without any consequence. We are recording this conversation, but your personal information—name, address, or other identifying information—will not be published. This conversation is private and confidential, and we ask all participants to respect one another. This is a “safe space” for us to discuss HIV and human rights in your community.

You are not required to provide, and we will not use, any personal information, including HIV status. We will use codes to refer to any participants, and the study will use neutral terms in English (“they,” “them,” and “their”) when referring to persons.

Do you have any questions?

Do you agree to begin this conversation?

Obtain oral affirmation of focus group participants.

All participants will additionally consent in writing at the same time.

FOCUS GROUP DISCUSSION (60–90 minutes)Engagement/warm-up

1. Let's briefly introduce ourselves. This is for today's discussion only; your names will not be used in the study. Please say your name, your age, and something you like to do for fun.
 - a. *Moderator starts*
2. Survey question: Please raise your hand if you, your child, or a young relative has been to a health clinic or hospital in the past 12 months, for any reason.
 - a. Follow-up: How was your experience?
 - b. Follow-up: How were you received?
 - c. *To people who did not raise hands:* Do you have any reasons for not going to a health clinic or hospital?
 - i. *Follow-up probing based on responses*
 1. Example: Can you give an example from your own life or someone else's...?
 2. Example: This seems really important. Do you have anything more to say?
 3. *To others:* Do others have, or know people who have, experiences like this that they can share?
3. Generally speaking, do you feel you can trust health care workers with your information when you go to a clinic? (closed question)
 - a. *Follow-up probing:* Why or why not? Do you know any experiences that make it easier to have confidence in health care workers? Make it harder?

4. Have you ever felt pressured to do something related to your health or the health of a family member or friend?
 - a. *Moderator seeks a few examples.*
 - i. *Follow-up:* Have you ever done anything that you did not feel entirely sure about, but someone else really wanted you to?
5. Are you familiar with your legal and human rights such as:
 - a. A right to privacy concerning your information (meaning that nobody else can join or hear what you say with a health care worker if you do not want them to)?
 - b. A right to confidentiality (meaning that your information may not be shared with anyone you do not want to share it with, including health information such as HIV status)?
 - c. A right to fully informed consent (meaning that you may request, and must receive, any information you want about a procedure, including risks and benefits, before agreeing in writing to participate)?
 - d. A right to safety (meaning that you have a right to be free from abuse, discrimination, stigma, and violence)?
 - e. A right to dignity and autonomy (meaning that you must be respected at all times as a person who can make independent decisions for yourself or can choose who makes those decisions for you)?
 - i. *Follow-up:* Has anyone experienced, or feels their community has experienced, any issues or problems about these rights when dealing with health care workers and counselors?
 1. *Probe*
6. *For people who use drugs, sex workers, and men who have sex with men:* Generally speaking, how do you feel about:
 - a. Police
 - b. Health care workers
 - c. *Probing questions based on responses*

Exploration/main questions

1. As we know, HIV is a major health concern in Kenya. Many people like you in this group are thought to be at risk for HIV. Health care providers and Kenya's public health agencies recommend that more people test for HIV, especially people in your community. How do you feel about HIV today, in your community?
 - a. *Follow-up probing based on responses*
 - i. Example: Many people in your group are not testing for HIV. Why do you feel that is?
 - ii. Example: Do you think it is important to test for HIV?
 1. Who should test?
 2. Should we encourage testing? (*closed question*)
 3. Should we require testing? (*closed question*)
 - a. Why or why not?
 - i. *Note the human right to refuse to consent to testing*
 - iii. Do you feel that people in your community would feel safer testing:
 1. At home (self-testing)?
 - a. Why or why not?
 - i. *Probe for stigma/discrimination concerns*
 2. In a clinic?
 - a. Why or why not? (*group discussion*)
 - i. *Probe for stigma/discrimination concerns*
 - b. Are there any advantages to testing in a clinic?
 - i. Disadvantages?

2. One important part of a health care system is to protect your safety and privacy and to respect you as an independent person (*for people who inject drugs/men who have sex with men/sex workers: "regardless of your activities"*). This is especially true for HIV testing: testing should be private (between you and your health care provider) and confidential (your information should not be shared with anyone else without your consent). Your consent must always be voluntary and come after you feel you have all the information you need in order to decide whether to test.
 - a. Please describe how you feel about or any experiences with:
 - i. Nurses
 - ii. Doctors
 - iii. Administrators
 - iv. Insurers
 - v. Others (community)
 - vi. *For people who inject drugs/men who have sex with men/sex workers:* Police
 - vii. *Probing questions:* Did you feel respected when they spoke with you about your health?
 - b. Some of you might have tested for HIV, or friends or family may have tested for HIV. Under Kenyan law and international law, health care workers and hospitals must fully inform you about why testing is important and what it means to test, provide you with information, answer any questions you might have, and tell you about the benefits and risks of testing. Then, you decide whether you want to test without pressure or influence.
 - i. How do you feel about the way in which health care workers engage with people at risk for HIV, like those in your community?
 1. *Follow-up:* What could be better?
3. In addition to testing for HIV, notification or disclosure (sharing) of one's status with others can be an important way to find others who might be at risk for HIV and get them on treatment. This might be important for children of HIV-positive parents, husbands and wives, HIV-positive children whose parents do not know of their status, or any partners. At the same time, disclosure can put someone at risk of stigma, discrimination, and even abuse.
 - a. Do you feel there are any risks with disclosing or sharing HIV status?
 - i. *Probing:* Like what?
 - b. How do you feel about disclosing HIV status to others?
 - i. *Follow-up:* Who should disclose status?
 1. *Probing:* Should someone refuse to disclose their status?
 - a. *Ask for responses from other speakers*
 - ii. *Follow-up:* How should someone's status be disclosed?
 1. To whom? (parents, children, partners)
 2. When?
 - iii. Would disclosing HIV status be easier if a health care counselor or worker assists (e.g., assisted partner notification services)?
 1. Why or why not?
 - iv. When should someone's HIV status be disclosed without their consent?
 1. How should they be protected from any risks?
 - c. What can health care workers do to make you, and people like you, feel safer before and after HIV testing and disclosure?

Exit questions/wrap-up

1. Health care workers, before testing, must provide people with adequate pre-counseling. After testing, and before any disclosure or notification, they must also provide post-counseling. These are human rights in Kenya, and no testing should occur without fully informed consent.
 - a. What should be covered in pre-counseling before HIV testing (or, what would you

want to know first)?

- i. Round robin:* Think back to earlier when we discussed why some people are not testing for HIV. What could help these people feel more confident about testing?
- b. What should be covered in post-counseling before HIV status disclosure?
 - i. Round robin:* What should health care workers do to ensure that people living with HIV feel respected?
 - ii. How should health care workers protect privacy around HIV status in general?
 - I. Follow-up:* What about when disclosing HIV status?
 - iii. Is there anything else anyone would like to share about their experiences with health care, their living experiences, or HIV testing?

APPENDIX B

Key Informant In-Depth Interview Guidelines

INTRODUCTION BY PRINCIPAL INTERVIEWER

Hello, my name is <Name> and I am part of a research team working with the Kenya Legal and Ethical Issues Network on HIV and human rights. We are working with the University of Washington and Georgetown University to explore people's thoughts and opinions about HIV testing and notification, or disclosure, and respect for legal rights. We are interested in your experiences and perspectives with health care and HIV, particularly about (1) HIV testing for key populations in Kenya and (2) HIV status disclosure with respect to the rights of the person living with HIV. This will help us understand what is working and what could work better to engage these communities, respect their concerns, protect their rights, and increase HIV testing and notification rates. This study, we hope, will lead to better rights realization, as well as better HIV testing and treatment.

This discussion is free and open; we want to hear your honest thoughts and opinions about your work, your organization, and the overall strategy to increase HIV testing rates in Kenya. Your participation is helpful, but you do not need to talk to us if you do not want to. You may stop participating at any time and without any consequence. We are recording this conversation, but your personal information—name, address, workplace, or other identifying information—will not be published. This conversation is private and confidential. We will use codes to refer to you, and the study will use neutral terms in English (“they” “them” “their”) when referring to other persons.

Do you have any questions?

Do you agree to begin this conversation?

Obtain oral affirmation of focus group participants.

All participants will additionally consent in writing at the same time.

INTERVIEW DISCUSSION (30–60 minutes)

Engagement/Warm-Up

1. Let's briefly introduce ourselves. This is for the discussion only; your name will not be used in the study. Please say your name, your age, and something you like to do for fun.
2. What is your job title?

- a. Follow-up:* What are your primary responsibilities?
3. How would you describe a typical day at your work?

Interviewee: Public Health Policy Maker or Similar Professional

1. One of the reasons we wanted to chat with you is because of your experience working in HIV. Kenya and international authorities like PEPFAR want to meet the 90-90-90 goals, and that means increasing HIV testing. According to surveys, though, several key populations at risk for HIV are not testing enough.
 - a. Could you describe some of your experiences working with people at risk for HIV?
 - i. How have you engaged with people at risk for HIV?
 1. *Probing:* Which communities are you most familiar with? Least?
 - a. Probe for teenage mothers and pregnant teens, young and adult men, men who have sex with men, people who use intravenous drugs, sex workers.*
 2. *Follow-up:* What do you think, or know, are the major concerns or barriers for <key population> ? *Note: this question relates to the 1–2 key populations identified in the preceding question.*
 - i. Probing:* Have you seen any efforts to address those specific concerns?
 - ii. Follow-up:* Has that worked?
 - b. Do you feel the <key population> understands the importance of HIV testing? *Note: this question relates to the 1–2 key populations identified in preceding questions.*
 - i. If yes:* What strategies do you think work, or what could work better that is not being done now?
 - ii. If no:* What strategies for outreach and inclusion might benefit these groups?
 1. *Listen and probe for health care provider engagement with or concerns about police (regarding people who inject drugs, men who have sex with men, sex workers).*
 - c. Do you feel all key populations are being addressed equitably?
 - i. Follow-up:* At this stage, our study is focused primarily on young women and men, two of the cohorts that undertest for HIV. Why do you feel they, specifically, are not testing?
 - ii. Probing:* What outreach is ongoing to other groups at risk for HIV, such as sex workers or men who have sex with men?
 1. *Probing:* Since these groups are often stigmatized, how well do you feel health care workers are mitigating that stigma?
 - iii. Follow-up:* What sort of training do health care workers receive when it comes to these groups (sensitivity, etc.)?
 1. Have training programs changed in the past 24 months?
 - a. Probing:* In light of the push for more testing, what sort of training do you think health care workers need or will need to increase rates in the key populations?
 2. With respect to health officials' goals, what sort of challenges do you feel must be overcome to increase HIV testing?
 - a. Listen for, or ask about human resources, effective outreach, stigma and discrimination.*
 - i. Probe based on responses.*
 3. Are health care workers receiving training on the legal and human rights of persons living with or at risk for HIV, including the following rights?
 - a. Right to provide fully-informed consent*
 - b. Right to privacy*

- c. Right to confidentiality
- d. Right to refuse
- e. Right to dignity and autonomy
- f. Right to safety (freedom from stigma, discrimination, abuse, violence)

Interviewee: Care Providers and Counselors

1. Health authorities (such as the Ministry of Health, NASCOP, and National AIDS Control Council) and foreign donors (such as PEPFAR) want to increase HIV testing and notification services in Kenya, through both increased resources and increased training.
 - a. Have you or colleagues undertaken training, such as sensitivity training, in the past 24 months related to HIV testing?
 - i. *If yes:* How would you assess that training? Did it help improve your practice? Did it help improve outreach to these communities?
 1. *Follow-up:* Following this training, do you feel you better understand and respect the concerns in these key populations?
 - ii. What could be improved?
 1. What would you like to know to better engage with these persons?
 - b. Have you or your colleagues undertaken rights-based training? In other words, have you or other health care workers been trained in patients' legal rights?
 - i. Did your training help you talk with patients about their legal rights, whether before or after HIV testing?
 - ii. Are health care workers trained to respect a patient's decisions, even if they disagree?
 1. *If yes:* How are they being trained?
 2. *If yes:* How would you assess that training?
 3. *If yes:* How could that training be improved to respect the patient and their concerns and to encourage more HIV testing?
2. Informed consent
 - a. What does informed consent mean to you or your organization?
 - b. Are there measures in place to ensure persons testing for HIV fully understand what the test is about before testing?
 - i. *Follow-up:* What measures are in place to ensure nobody is coerced or pressured into testing for HIV?
3. Privacy and confidentiality
 - a. What measures are in place to ensure a patient's information is private?
 - b. What measures are in place to ensure confidentiality with that information?
 - i. *Follow-up:* Does this include keeping information from other authorities, such as if a patient is a drug user or a sex worker?
 1. *If yes:* How is this ensured?
 2. *If yes:* How is this communicated to the patient?
 - c. Have you received particular training in privacy and confidentiality for HIV data?
4. Are health care workers communicating with people about privacy and confidentiality in pre- and post-counseling?
 - a. Thinking back to earlier questions, how do you feel trust for health services in these under-performing communities could improve?
5. Disclosure
 - a. Health authorities and donors want to identify more cases for HIV testing, particularly at-risk cases. As you know, index testing is an effective way to identify cases and get people on treatment.
 - i. Disclosing HIV status to third parties can be very risky to the index case. How do you and your colleagues initiate that discussion?

1. *Follow-up*: What are the concerns you hear from patients about disclosing their status?
 - a. *Probing*: How are those concerns addressed?
 - b. *Probing*: How can those concerns be better addressed?
- ii. What measures do you follow or know of to ensure a patient is fully informed about the benefits and risks for disclosure before they consent to it?
- iii. Are you and other health care workers trained to discuss disclosure?
 1. How would you assess the training?
 - a. *Probing*: Is it effective? Are there things you would like to know more?
 - b. *Follow-up*: What might improve training or improve health care workers' abilities to connect with patients and discuss disclosure?
 2. Do health care workers receive training to spot potential risks to the index case from disclosure?
 - a. *Probing*: A major concern in Kenya is violence and abuse, especially against women. This is especially true for HIV-positive women and children who might face stigma, discrimination, or abuse from family, partners, and their communities. How have you been trained to identify risks for harm when disclosing an index case's HIV status?
 - i. What methods do you and your organization follow when disclosing? (assisted partner notification services, for instance)
 1. *Probing*: How would you assess your training in those methods?
- b. As before, the legal rights of patients are important parts of disclosure. Consent is typically required, and respect for their issues and even refusal to consent.
 - i. Are health care workers trained in the legal rights around disclosing status to third parties?
 - ii. Do health care workers inform patients of their legal rights prior to disclosing status to third parties?

Conclusion

We appreciate you taking this time to share your views and opinions. As a reminder, we have recorded this conversation and will maintain your privacy and confidentiality. Your name and any identifying details will not be published.

Are there any details you would like to share with us that we have not asked?

Are there any final suggestions or comments you would like to make?

