



“Everyone said no”

Biometrics, HIV and Human Rights

A Kenya Case Study

KELIN and the Kenya Key Populations Consortium



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About KELIN

KELIN is an independent Kenyan Civil Society Organization working to protect and promote health related human rights in Kenya. We do this by; Advocating for integration of human rights principles in laws, policies and administrative frameworks; facilitating access to justice in respect to violations of health related rights; training professionals and communities on rights based approaches and initiating and participating in strategic partnerships to realize the right to health nationally, regionally and globally.

While originally created to protect and promote HIV-related human rights, our scope has expanded to also include:

- Sexual and reproductive health and rights,
- Key populations, and
- Women, land and property rights.

Our goal is to advocate for a holistic and rights-based system of service delivery in health and for the full enjoyment of the right to health by **all**, including the vulnerable, marginalized, and excluded populations in these four thematic areas.

About the Key Populations Consortium

The key population consortium comprises networks of over 90 organizations and community representatives working with and around issues of Key Populations HIV programming namely Female and Male Sex workers (SW); People who Inject Drugs (PWIDs); and Men who have Sex with Men (MSM). The consortium was conceptualized to get: key populations to speak with one voice; enable them to directly take charge of their own health, human rights and socio-economic needs and concerns and to chart a way forward on how KPs would engage the Global Fund (GF) as stakeholders in its (then) new funding model, and as beneficiary populations/implementing organizations. Their vision is to ensure KPs are respected and their dignity upheld and affirmed in Kenya. While their mission is to directly address and promote the health, human rights and socio-economic wellbeing of KPs in a comprehensive, integrated, multi-disciplinary and sustainable manner.

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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immunodeficiency Syndrome
ART	Antiretroviral therapy
CCM	Country Coordinating Mechanism
CDC	Centre for Disease Control
DNA	Deoxyribonucleic Acid
FSW	Female Sex Worker
HIV	Human Immunodeficiency Virus
IBBS	Integrated Bio- Behavioral Surveillance
ICCPR	International Covenant on Civil and Political Rights
ID	Identification
IRB	Internal Review Board
KELIN	Kenya Legal and Ethical Issues Network
KP	Key Populations
LGBT	Lesbians, Gays, Bisexual, Transgender
MSM	Men Who Have Sex with Men
NACC	National AIDS Control Council
NASCOP	National AIDS and STI Control Program
OECD	The Organisation for Economic Co-operation and Development
PEPFAR	President's Emergency Plan for AIDS Relief
RFID	Radio Frequency Identification
TB	Tuberculosis
UDHR	Universal Declaration of Human Rights
UN	The United Nations
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNODC	United Nations Office on Drugs and Crime
WFP	World Food Program
WHO	World Health Organization

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Special appreciation goes to the research team; Dr Meg Davis, Mumbi Kyalo, Ted Wandera and Timothy Wafula. I also thank Grace Kamau (KP Consortium Coordinator) for reviewing and editing the report. Special thanks to Impact Africa Limited for editorial support, design and layout of this report.

A handwritten signature in black ink, appearing to read 'Allan Maleche'.

Allan Maleche
Executive Director (KELIN)

EXECUTIVE SUMMARY

The Sustainable Development Goals commit states to “leave no one behind” in the push to end HIV, tuberculosis and malaria by 2030. But in many countries, the key populations most affected by HIV -- sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prison or other closed settings -- lack access to health services, and criminalization and discrimination drive them underground. Kenya has a high burden of HIV among key populations, and relies on external donors to support national HIV programs.

In 2015-17, the Kenyan national health authorities developed a plan, funded by the Global Fund to Fight AIDS, TB and Malaria, to conduct a study of HIV and key populations. The planned study included a survey of the number of each key population group, information about their HIV incidence and prevalence, risk behavior and intervention exposure, and included plans to use biometric methods of identification: the measurement and analysis of biological data, using such attributes as fingerprints or iris scans.

Key populations advocates stated that they learned of the plan to use biometrics late in the planning process. Raising human rights concerns, and leveraging support from the Global Fund, UNAIDS, and other international agencies, they vocally mobilized to eliminate the proposed use of biometrics from the planned study before it began.

As a result, the researchers agreed to involve community researchers when the study takes place in the future.

This report analyzes human rights issues raised by use of biometrics in HIV research, and documents the Kenya case. Kenyan key populations highlighted the risk of **function creep** in use of biometrics (with data collected for health purposes potentially being used by police to target key populations for arrest); the risk of **data breaches** that could expose stigmatized populations publicly to their families and communities; the resulting risk of discrimination, including in access to government services; about the relationship between the state and private sector in biometrics data-gathering; and the need for meaningful informed consent and participation by communities in decisions that affect their health and rights.

This report provides an overview to the HIV epidemic in Kenya, an analysis of the legal and human rights issues in use of biometrics in HIV research, and documentation of the case study and advocacy in Kenya. As one key populations’ advocate said, the advocates were and remained strongly unified in their opposition to use of biometrics, which they saw as both high-risk and intrusive: “Everyone just said *no*, and we kept saying *no*.” They also successfully involved global health donors and UN agencies to support their engagement. The report makes recommendations to global health donors, Kenyan authorities, and civil society groups facing similar debates in other countries.

Recommendations

To global health finance agencies and UN agencies:

- a) Provide clear guidance to governments that receive aid for health on expectations of measures they should take to protect security of those studied in research financed by that aid.
- b) Do not fund projects that include biometrics and other intrusive forms of data-gathering if the legal environment lacks clear and sound data protection laws, and if the populations to be studied are criminalized.
- c) Clarify in UN technical guidance on size estimation that all planning and implementation of health research financed by those agencies should include community representatives as co-investigators, and not only as low-paid data enumerators and researchers.

To the government of Kenya:

- a) Review the Penal Code and County by-laws to decriminalize sex work, in line with international human rights obligations and best practices in the field.
- b) Review the Penal Code to decriminalize same-sex sexual behavior, in line with human international rights obligations and best practices in the field.
- c) Review the Narcotics and Psychotropic Substances (Control) Act to decriminalize drug use, in line with international human rights obligations and best practices in the field.
- d) Draft and adopt a comprehensive data protection framework with adequate and

coordinated levels of enforcement, with clear safeguards for sensitive information such as health data and biometric data.

- e) Develop and implement data privacy guidelines and policies for government agencies, including health and research services.

To civil society in other countries:

- a) Develop unified consortia and coalitions that bring together key populations-led networks and organizations.
- b) Learn about the methods used in health research, including ethical requirements and the technologies involved in the process.
- c) Insist on the meaningful inclusion of key populations representatives in the design and oversight of health research that studies key populations.

Background

The Sustainable Development Goals have committed states to “leave no one behind” in the push to end HIV, tuberculosis and malaria as global public health threats by 2030.¹ In many countries, however, the key populations most affected by HIV -- sex workers, men who have sex with men, transgender people, people who inject drugs, and people in prison or other closed settings -- lack access to health services.²

1 United Nations Statistics Division (UNSD), The Sustainable Development Goals Report *United Nations Organization* 2017; <https://unstats.un.org/sdgs/report/2016/leaving-no-one-behind> (accessed November 17, 2017).

2 World Health Organization (WHO). *Consolidated Guidelines on HIV Prevention, Diagnosis, Treatment, and Care for Key Populations: 2016 Update*. Geneva: WHO, 2016.

To reach the Sustainable Development Goal on health, national health planners need epidemiological data that can help them to target their limited funds and reach those most in need. Kenya, which has a high burden of HIV in the general population and an extremely high burden among key populations, relies on external donors to support this work.

In 2015-17, the Kenyan national health authorities developed a plan, funded by the Global Fund to Fight AIDS, TB and Malaria (“the Global Fund”) to conduct a study of HIV and key populations. The study, which was approved by Kenya’s national ethics review board, included both key population size estimation and use of biometrics, among other things.

Key populations advocates stated that they learned of the plan to use biometrics after the ethical approval, and late in the planning process. Raising human rights concerns, and leveraging support from the Global Fund, UNAIDS, and other international agencies, they mobilized to stop the plans to use biometrics before the study began, and to include community researchers in the study when it is conducted.

This report analyzes some of the human rights issues raised by use of biometrics in HIV research, and documents the Kenya case. *Key population size estimates* are critical for planning and resourcing programs in the HIV epidemic. These numbers help epidemiologists to predict likely rates and locations of HIV infection, based on speed of transmission and frequency of

contact. Planners use them to prioritize and locate services to combat and treat HIV infections. WHO and UNAIDS recommend beginning a population size estimate by defining the population and geographic area; conducting formative research using qualitative research methods to learn more about visibility and practices of the population to be studied; and reviewing available data.

Research methods for the size estimation include census and enumeration methods (for example, using face-to-face interviews to count populations), the capture-recapture method (in which successive groups of people are counted in a given location), “snowball” sampling (in which respondents introduce other respondents), and others.³ Because of the challenges in measuring hidden populations, many key population size estimates use several methods and triangulate the results.

Biometrics is measurement and analysis of biological data, using such physiological attributes as DNA, face, fingerprints, eye retinas and irises, hand geometry, veins and/or behavioral data such as voice, handwriting, or gait for authentication purposes.⁴

3 WHO and Joint UN Programme on HIV and AIDS (UNAIDS), *Guidelines on Estimating the Size of Populations Most at Risk to HIV* (Geneva: WHO, 2010), 7.

4 Tzaphlidou, Margaret, and Fotini-Niovi Pavlidou. “Biometrics Applications: Technology, Ethics, and Health Hazards.” *The Scientific World Journal* 11 (2011): 529–31. doi:10.1100/tsw.2011.53. Thomas, Rebekah. “Biometrics, International Migrants and Human Rights.” *European Journal of Migration and Law* 7, no. 4 (2006): 377–411.

In recent times, biometrics has increasingly been used as a means to track migrants in response to security threats post-9/11, as well as in response to the increasing sophistication of transnational transaction fraud. Increasingly, biometrics is used for other purposes; in Kenya, they are used to identify voters at the polls. Kenya appears to be on the leading edge of governments using biometric identifiers in managing access to government-provided services.

However, the growing use of biometrics has been challenged. In India, the state requires photographs, iris scans and fingerprints for citizens to access legal benefits, including antiretroviral treatment for people living with HIV. This system has created the largest biometric database in the world, with 1.14 billion unique identifier codes (UIDs).

In August 2017, India's Supreme Court upheld the right to privacy, opening the door for petitions to oppose mandatory enrollment.⁵ Concerns raised in Kenya similarly highlighted the risk of function creep in use of biometrics (with data collected for health purposes potentially being used by police to target key populations for arrest); the risk of

⁵ Vidhi Doshi, "India's Supreme Court says privacy is a fundamental right in blow to government." *Washington Post*, August 24, 2017; https://www.washingtonpost.com/world/indias-supreme-court-says-privacy-is-an-intrinsic-right-in-blow-to-government/2017/08/24/2c-0b762c-8828-11e7-96a7-d178cf3524eb_story.html?utm_term=.b0fc12f90e54 (Accessed November 13, 2017); Jyoti Panday, "Aadhaar: Ushering in a commercialized era of surveillance in India". Electronic Frontier Foundation blog, 1 June 2017. Available from: <https://www.eff.org/deeplinks/2017/05/aadhaar-ushering-commercialized-era-surveillance-india> (accessed 14 August, 2017).

data breaches that could expose stigmatized populations publicly; the resulting risk of discrimination in access to government services; concerns about the relationship between the state and private sector; and the need for meaningful informed consent and participation by communities in decisions about public health research.

This report provides an overview to the HIV epidemic in Kenya, an analysis of the legal and human rights issues in use of biometrics in HIV research, and documentation of how key populations stopped the process before it began in Kenya. Kenya's uniquely strong civil society sector includes a Kenya Key Populations Consortium, a coalition of national networks representing sex workers, people who inject drugs, and men who have sex with men. The consortium was formed during an earlier round of Global Fund financing, and led the successful advocacy to prevent use of biometrics, as well as co-authoring this report.

The HIV epidemic in Kenya

Kenya's HIV prevalence is estimated at 6.0% with an estimated 1.6 million persons living with HIV.⁶ Over 80% of the total new HIV infections each year occur among adults, with 37% among men and 49% among women.

⁶ National AIDS and STI's Control Programme (NAS COP), *Kenya HIV Estimates Report*, 2015. (Ministry of Health 2016). Available from: <http://nacc.or.ke/wp-content/uploads/2016/12/Kenya-HIV-Estimates-2015.pdf> (accessed November 17, 2017).

Key populations bear a heavy burden of new infections (see Table One), due to socio-cultural and legal barriers that limit access to HIV prevention, care and treatment services; including criminalization of sex work, homosexuality, and Injection drug use, and lack of legal recognition of change of gender identity. Socio-cultural and religious factors have led to stigmatization of key populations among mainstream health service providers.

Together, these factors make key populations often hidden populations, with strong avoidance of the police, fear of public disclosure, and resulting social isolation.



These factors contribute to high HIV prevalence: among men who have sex with men in Kenya, it is over three times higher than that of the general population.⁷ Similarly, in 2011, it was estimated that 18.3% of people who inject drugs (PWID) were living with HIV, the majority in Nairobi and Mombasa, and that PWID accounted for about 5.8% of new infections.⁸

While UNAIDS does not currently publish an official estimate of HIV prevalence among sex workers, according to the *Kenya AIDS Response Progress Report* from 2016, an estimated 29.3% of female sex workers are living with HIV.⁹ A 2009 *Modes of Transmission* study attributed 14% of new HIV infections to female sex workers and their clients.¹⁰

7 International Organization for Migration (IOM) '[Integrated Biological and Behavioural Surveillance Survey among Migrant Female Sex Workers in Nairobi, Kenya](#)' Nairobi IOM (2010)

8 University of California, San Francisco, Institute Global Health Sciences '[Implementing Integrated Bio-Behavioral Surveys among Key Populations at Higher Risk of HIV Exposure with an Emphasis in Respondent Driven Sampling](#)'; Lessons Learnt from the field 2010 – 2012 San Francisco (2012)

9 National AIDS Control Council (NACC) '[Kenya AIDS Response Progress Report 2016](#)' Ministry of Health; Nairobi (2016); .

10 National AIDS Control Council (NACC) *Kenya HIV Prevention Response and Modes of Transmission Analysis* Ministry of Health, Nairobi (2009)

These estimates, however, are all based on percentages of past key populations size estimates that have often been questioned by both HIV experts and key populations advocates themselves. LGBT advocates believe the number reported for MSM is implausibly low; some sex workers argue the 2011 size estimate fails to capture the many women and men who engage in transactional sex; some suggest that female sex workers (FSW) have the highest HIV prevalence of any key population group.

Harm reduction advocates also believe the true numbers of people who inject drugs in Nairobi and along the coast to be significantly higher than the 2011 numbers reflect. The data also reflects significant gaps: currently reported size estimates, as shared on the UNAIDS website, include no numbers for transgender people or prisoners, and no official HIV prevalence for sex workers.

In 2014-15, global health donors such as the Global Fund and the US President’s Emergency Program for AIDS Response (“PEPFAR”) held stakeholder consultations in Kenya to review the data and past performance of their HIV funding. They found critical data gaps on HIV and key populations. Key populations advocates asserted that key population size estimates were implausibly small, said one participant:

Other interviewees noted that the absence of accurate size estimates makes it challenging to persuade donors to provide sufficient funding for health services to key populations.¹¹ In response, the Kenyan health authorities agreed to conduct a new size estimation study, with support from the Global Fund.

Table One: Official key population size estimates and HIV prevalence reported by Kenya to UNAIDS¹		
Key population	Size estimate reported to UNAIDS	HIV prevalence reported to UNAIDS
Sex workers	130,000	Not available
Men who have sex with men	13,000	18.2%
People who inject drugs	18,000	18.3%
Transgender people	Not available	Not available
Prisoners	Not available	Not available

¹¹ KELIN and KP Consortium interview with civil society representative, Nairobi, 20 September, 2017.

Such studies of hidden populations are difficult to conduct in a context of criminalization and discrimination. Criminalization of same-sex sexuality is associated with implausibly small or absent size estimates of men who have sex with men.¹² Recent events in East Africa have amplified key populations' anxieties: an influx of lesbian, gay, bisexual and transgender (LGBT) refugees from Uganda; the Tanzanian government crackdown on HIV prevention programs that distribute lubricants to key populations; vigilante violence targeting key populations in Kenya's urban slums; heightened rhetoric by some political and religious leaders, and more.¹³ The trust between health providers and hidden key populations is fragile at the best of times. In a politically fraught environment, any suggestion of coercion or intrusion can undermine the state's ability to gather the information it needs to reach its health goals.

Methodology

To examine concerns about use of biometrics in HIV research, staff and consultants working with KELIN and the Kenya Key Populations Consortium conducted desk research, looking at news media, open letters, published statements,

law and policy, peer-reviewed journals, and grey literature. Member organizations of the Key Populations Consortium also contributed their analysis of these materials and shared the timeline of events published by NASCOP.

KELIN and the Key Populations Consortium spoke with representatives of sex worker, LGBT, and MSM member organizations of the Key Populations Consortium, as well as with other experts from civil society organizations in Nairobi (including organizations led by transgender people), and representatives of the UN and US government. KELIN requested interviews with representatives of people who inject drugs, who were not available; however, two harm reduction organizations did share their views.

All those who spoke to the researchers were informed of the purpose of the research, and all direct quotes are anonymized. Their discussions covered topics that are part of their daily work as public representatives of key populations or as technical experts on HIV and key populations, so no risk was created.

In addition, KELIN wrote to UNAIDS, NACC, the National AIDS and STI Control Program (NASCOP), World Food Program, PEPFAR, the Global Fund, UNODC and CDC requesting interviews and sharing a list of questions for the report. The letters, and any responses received, are included in the annex.

12 Davis, Sara LM, William C. Goedel, John Emerson, and Brooke Skartvedt Guven. "Punitive Laws, Key Population Size Estimates, and Global AIDS Response Progress Reports : An Ecological Study of 154 Countries." *Journal of the International AIDS Society* 20, no. 1 (March 17, 2017). <https://doi.org/10.7448/ias.20.1.21386>.

13 See Gitta Zomorodi *SOGI-Related Forced Migration in East Africa: Fleeing Uganda After the Passage of the Anti-Homosexuality Act* (The Global Philanthropy Project July 2015). See also Statement by the Minister for Health, Community Development, Gender, Elderly and Children, Hon. Ummu Mwalimu on key populations HIV services in Tanzania: 27th October, 2016. Available from: <https://www.facebook.com/afyatz/posts/1230922863594845> (accessed November 17, 2017).

In particular, KELIN repeatedly requested an interview with NASCOP, which led to the proposed study, but they did not respond. However, interviews were conducted with participants in meetings with NASCOP, who shared their recollections of the discussions and some of NASCOP's presentations. Before analyzing the Kenya case study, the report analyzes some issues raised by the use of biometrics.

Analysis: Human rights and biometrics

While governments gather and track individual data in order to identify people, biometrics bring another level of intimacy and a more intrusive degree of surveillance, extending to the individual body. This section outlines general human rights concerns with the use of biometrics, and then discusses how they apply to the case study in Kenya.

While biometric data in some sense are not qualitatively different from the use of photographs, addresses or identification cards in authentication of individuals, they can be used to rapidly and positively surveil, track and identify hidden populations who have successfully avoided other forms of official identification. For that reason, and because of the increasingly intrusive and commodified qualities of government surveillance, biometrics have become a flashpoint for a number of human rights

concerns about privacy. These include concerns about risk of function creep, the growing and under-regulated role of private companies, discrimination, and the risk of data breaches which could lead to worrying violations of privacy.

The biometrics process includes gathering raw data (or "enrolment") by taking biodata such as fingerprints, iris or retina scans, DNA or toe prints, storing the data in memory, and, in some cases, reading these through "a contactless integrated circuit chip also called RFID (Radio Frequency Identification).¹⁴

Newer forms of biometrics can identify individuals through gait, voice, heartbeat and silhouette.¹⁵ Government agencies may soon be able to recognize faces in crowds through surveillance video, or conduct iris scans in crowds.¹⁶ Biometrics are used at a growing number of border controls to monitor suspected terrorists and prevent illegal migration.¹⁷

Biometrics are also used in court cases, for identity cards, and in private business -- for instance, fingerprints and facial recognition are now used to access iPhones.

¹⁴ Thomas, Rebekah. "Biometrics, International Migrants and Human Rights." *European Journal of Migration and Law* 7, no. 4 (2006): 377-4

¹⁵ John Koetsier, "This biometric sensor knows if your finger is alive -- or dead". *VentureBeat* 15 October 2013. Available from: <https://venturebeat.com/2013/10/15/unlike-apples-touchid-this-biometric-sensor-knows-if-your-finger-is-alive-or-dead/> (accessed 14 August 2017).

¹⁶ "Biometric Security Poses Huge Privacy Risks," *Scientific American*, 1 January 2014. Available from: <https://www.scientificamerican.com/article/biometric-security-poses-huge-privacy-risks/> (accessed 14 August 2017).

¹⁷ Thomas, Rebekah. "Biometrics, International Migrants and Human Rights." *European Journal of Migration and Law* 7, no. 4 (2006): 377-411; p. 383.

The growing use of this technology raises questions about the state's role in tracking individuals, who owns the data, and how it is controlled. Any form of identity tracking can raise privacy concerns in a context of increasing mechanisms of state surveillance, and there are numerous international and regional standards on state gathering of individual data. The *Universal Declaration of Human Rights (UDHR)* and the *International Covenant of Civil and Political Rights (ICCPR)* uphold the right to privacy.¹⁸

The UN General Assembly, Council of Europe and OECD have guidelines of "minimum guarantees" for use of personal computerized data, and the European Union has a Data Protection Directive which is to be incorporated into the laws of member states, and which will be superseded by a General Data Protection Regulation in 2018.¹⁹ The African Union also has a *Convention on Cyber Security and Personal Data Protection*.²⁰

18 United Nations General Assembly, *Universal Declaration of Human Rights* (adopted 10 December 1948) 217 A (III), article 12; UN General Assembly, *International Covenant on Civil and Political Rights* (adopted 16 December 1966, entered into force 23 March 1976) 999 UNTS 171, article 17.

19 UN General Assembly Guidelines to Computerised Data Files 1990, Article 3; Council of Europe *Guidelines on the Protection of Individuals with Regard to the Processing of Personal Data in a World of Big Data* T-PD(2017)01, 23 January 2017; OECD *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data* (2013 revised), available from <http://www.oecd.org/internet/ieconomy/privacy-guidelines.htm> (accessed 14 August 2017); European Union, *Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data* (adopted 13 December 1995); European Union, *Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC* (General Data Protection Regulation); 20 African Union *Convention on Cyber Security and Personal Data Protection* (adopted 27 June 2014). Available from: <https://www.au.int/>

At the same time, the right to recognition of identity is also a fundamental human right recognized in the *International Convention on the Rights of the Child*.²¹

In some ways, biometrics do not pose substantively different problems than the use of passports and identity cards for tracking individuals. However, their physical intrusiveness does raise heightened questions about privacy, security and the relationship between states, the private sector and individuals. In addition to the physical risks posed by some forms of biometrics (for instance, eye damage due to use of infrared light in iris and retina scans), they create numerous risks of abuse.²²

The most urgent concern raised by key populations in Kenya was **function creep**, in which data stored for one purpose is later used for another purpose not originally consented to, for instance as an institution's mandate expands. The U.S., for instance, began gathering biometric data in order to track international migrants, but now uses it to track U.S. citizens as well.²³

www/sites/default/files/treaties/29560-treaty-0048_-_african_union_convention_on_cyber_security_and_personal_data_protection_e.pdf (accessed 14 August 2017).

21 UN General Assembly, *Convention on the Rights of the Child* (adopted 20 November 1989, entered into force 2 September 1990), UNTS 1577, article 7.

22 Tzaphlidou, Margaret, and Fotini-Niovi Pavlidou. "Biometrics Applications: Technology, Ethics, and Health Hazards." *The Scientific World Journal* 11 (2011): 529–31. doi:10.1100/tsw.2011.53.

23 Adam Schwartz, "End Biometrics Border Screening." *Electronic Frontier Foundation blog*, 9 August 2017. Available from: <https://www.eff.org/deeplinks/2017/08/end-biometric-border-screening> (accessed 14 August 2017).

In Kenya, key populations expressed a concern that data gathered for health purposes could be used by the police to target criminalized key populations for arrest. The storing of data beyond its immediate use is therefore sometimes restricted. For example, the European Parliament does not permit centralized storing of fingerprints and photographs.²⁴

Breaches of privacy and confidentiality may not only affect a person's dignity, but can also cause other harms. Article 31 of the Constitution protects the right to privacy.²⁵ Building on this, part IV of the HIV and AIDS Prevention and Control Act protects the right to confidentiality of persons living with HIV²⁶. However, there are currently no privacy guidelines on collection, use or management of biometric data.

Such privacy guidelines are necessary in order to establish the ethical and legal standards that the government wishes to achieve with regards to the protection and promotion of the privacy rights of all persons, including living with or vulnerable to HIV. Such standards should also inform the process of applying and/or interpreting any law that relate to data collection and protection, besides guiding any other relevant decision-making, especially in situations, such as in health surveillance, where

a decision-maker may face a wide array of options that entail the exercise of discretion.

However, some interviewees raised concerns that even a data protection policy might not work in Kenya, if a change in leadership put new leaders in place who chose to override it, or if a court ordered a health agency to share biometric data with the police. Some also raised a concern that biometric data such as fingerprints could be abused in election fraud, as Kenya's polls also use biometrics to identify voters.

This linked to a second concern, that gathering biometrics creates the **risk of security breaches, mass data leaks, identity theft, as well as forgery** ("spoofing") or data errors. The privacy of their identity is critical for key populations, whose families may not know that they are men who have sex with men, sex workers, or people who inject drugs.

Both the above risks also link to the risk of **discrimination** in access to health services. For migrants from developing countries, for example, the risk of harm, including discrimination, often outweighs the benefits to those individuals.²⁷ De Gruyter suggests that biometrics may increasingly reduce a human being to "an accumulation of data and cartographic criteria, paradoxically at a time when biology is moving away to some degree from the reductionist and analytic approach".²⁸

24 Thomas, Rebekah. "Biometrics, International Migrants and Human Rights." *European Journal of Migration and Law* 7, no. 4 (2006): 377–411; p. 384.

25 National Council for Law Reporting "Constitution of Kenya", 2010; *National Council for Law Reporting*, available at www.kenyalaw.org/lex/octview.xql?actid=Const2010 (accessed 5 December 2017).

26 National Council for Law Reporting, "HIV and AIDS Prevention and Control Act", Act No. 14 of 2006, Laws of Kenya; *National Council for Law Reporting*, available at http://www.kenyalaw.org/ki/fileadmin/pdf/downloads/Acts/HIVandAIDSPreventionandControlAct_No14of2006.pdf (accessed 5 December 2017).

27 Thomas, Rebekah. "Biometrics, International Migrants and Human Rights." *European Journal of Migration and Law* 7, no. 4 (2006): 377–411.

28 Gruyter, Walter de. "Biometrics, Identifying Data and Human Rights." *Jahrbuch Für Wissenschaft Und Ethik* 13 (2008): 403–18; p. 405.

Biometrics could lead to stigmatisation:

The constitution provides for Right to equality and freedom from discrimination (Article 27).²⁹ This should ensure that PLHIV are not treated differently and are not discriminated against in any way including in access to health care and security. The HIV and AIDS Prevention and Control Act also provides for the Right to non-discrimination (sections 31 - 38) to protect the rights of PLHIV in relation to accessing insurance services and health services.³⁰

Fourth, in various ways, many of those involved in the debate over biometrics in Kenya raised concerns about the **partnerships states form with the private sector** in the process of collection and storing of biometric data, considering the lack of transparency and accountability for private companies.³¹ For example, some noted with alarm that Microsoft is now engaged in a project to capture bio-identifiers of Kenyan schoolchildren, through a project called BioSIM that scans

29 National Council for Law Reporting, "HIV and AIDS Prevention and Control Act", Act No. 14 of 2006, Laws of Kenya; *National Council for Law Reporting*, available at http://www.kenyalaw.org/kl/fileadmin/pdf-downloads/Acts/HIVandAIDSPreventionandControlAct_No14of2006.pdf (accessed 5 December 2017).

30 National Council for Law Reporting "Constitution of Kenya", 2010; *National Council for Law Reporting*, available at www.kenyalaw.org/lex/actview.xql?actid=Const2010 (accessed 5 December 2017).

31 Gruyter, Walter de. "Biometrics, Identifying Data and Human Rights." *Jahrbuch Für Wissenschaft Und Ethik* 13 (2008): 403–18; p. 408; Mordini, Emilio, and Andrew P. Rebera. "No Identification Without Representation: Constraints on the Use of Biometric Identification Systems." *Review of Policy Research* 29, no. 1 (January 1, 2012): 5–20. doi:10.1111/j.1541-1338.2011.00535.x; p. 10.

the irises of children and sends text messages to their parents reporting on their location.³² Related to this, civil society advocates frequently mentioned a series of health sector fraud allegations recently exposed in Kenyan media. In May 2017, the U.S. government suspended \$21 million in aid to Kenya's Ministry of Health over fraud and corruption concerns.³³ Putting data protection policies and measures in place, while an important and needed step, may fail in practice to remove all these problems, because

In theory this delicate balance between an individual's fundamental right to privacy and a state's right [to fulfill its mandate] is safeguarded by principles of data protection. However, the question arises whether existing protection is appropriate and sufficient to cover all the uncharted territory that accompanies biometrics, not to mention whether [individuals] benefit in reality...³⁴

32 Microsoft Philanthropies MEA, "Kenyan NGO I Choose Life Africa", Facebook post, https://m.facebook.com/story.php?story_fbid=260805054327305&id=204244386650039&_tn=%2As%2As-R 18 June 2017 (accessed 12 November 2017).

33 Katharine Houreld, "U.S. suspends aid to Kenyan health ministry over corruption concerns." *Reuters*. May 9, 2017. Available from: <https://www.reuters.com/article/us-kenya-health-corruption/u-s-suspends-aid-to-kenyan-health-ministry-over-corruption-concerns-idUSKBN1851RY> (accessed November 8, 2017); Kizito Lubano, "The disease of corruption hits Kenya's health sector hardest." *The Standard*. December 28, 2016. Available from: <https://www.standardmedia.co.ke/lifestyle/article/2000228132/the-disease-of-corruption-hits-kenya-s-health-sector-hardest> (Accessed November 8, 2017);

34 Thomas, Rebekah. "Biometrics, International Migrants and Human Rights." *European Journal of Migration and Law* 7, no. 4 (2006): 377–411; p. 388.

For this reason, ethicists emphasize the importance of proportionality of means, as well as legitimacy principles:

The use of individual-level data must balance maximizing the benefits from their most effective and fullest use, and minimizing harm resulting from their malicious or inadvertent release.³⁵

Mordini and Rebera argue that use of biometrics should always

This then leads to the fifth problem raised in the Kenya case: the importance of meaningful participation and informed consent by those studied in gathering of biometric data. Informed consent cannot be provided freely in a case where people must provide that consent to receive life-saving services, such as testing and treatment for HIV.

In their analysis of the debates in Kenya, UNAIDS issued a statement which re-affirmed the right of key populations to be meaningfully consulted about the research methods.³⁶ A harm reduction advocate noted that a core principle of harm reduction is respect for the wishes of clients who use drugs:

35 Beck, Eduard J., Wayne Gill, and Paul R. De Lay. "Protecting the Confidentiality and Security of Personal Health Information in Low- and Middle-Income Countries in the Era of SDGs and Big Data." *Global Health Action* 9, no. 1 (January 2016): 32089. doi:10.3402/gha.v9.32089.
36 Joint UN Programme on HIV and AIDS (UNAIDS), "UNAIDS Advisory Note on the Use of Biometrics in the Kenya Integrated Bio-behavioral Survey Among Key Populations." 29 November 2016, on file with KELIN and Kenya Key Populations Consortium.

"We would have said, not in our program. [You have to] let the clients decide."³⁷

These issues are increasingly pressing, as Kenya is moving quickly to expand the use of biometrics. In 2014, the Kenya government announced the rolling-out of a new national ID initiative that aims to register all citizens in the country via their biographical details and biometric measurements.³⁸

The government opined that consolidation of all current registers of persons into a single national register with accurate and relevant information would address the prevailing security challenges.

There have also been talks around the use of biometrics to identify all patients and link them to their health records as a routine measure; thus, the NASCOP-supported IBBS study, incorporating biometrics, may have been a trial measure for this mooted national policy. The government is responsible for safeguarding patients' rights to privacy and confidentiality, and international clinical practice guidelines require the protection and confidentiality of medical records, in order to ensure individuals are willing to access services and to provide information necessary for quality care.³⁹

37 KELIN and KP Consortium interview with harm reduction advocates, Nairobi, 21 September 2017.

38 "The Kenya Government Biometrically Registering all Citizens" Available from <https://findbiometrics.com/kenyan-government-biometrically-registering-all-citizens/> (Accessed 29th August 2017)

39 David Kuria Mbote, Kip Beardsley et.al. "Policy Analysis and Advocacy Decision Model for Services for Key Populations in Kenya." Ministry of Health November 2014 P 8

When data collection and management systems are suspected of insufficiently protecting records, those with criminalized identities or behaviours will avoid health services collecting these data.⁴⁰

Kenya's HIV and AIDS Prevention and Control Act addresses human rights in the context of HIV research. Section 40 of the Act requires for written informed consent for any HIV and AIDS related human biomedical research. Further, the persons whose consent is sought should be adequately informed of the aims, methods, and anticipated benefits and potential hazards of the research.⁴¹

How Key Populations Stopped the Process in Kenya

In response to demands for better data by donors and key populations advocates in health finance consultations during 2014-15, Kenya's health officials, in particular NASCOP, committed to conducting an Integrated HIV Bio-Behavioral Surveillance study ("IBBS") financed by the Global Fund.

An IBBS study gathers information about HIV incidence and prevalence, risk behaviors, intervention exposure, and more information useful in planning and evaluating the progress of HIV programs.⁴² It also often includes an estimation of the size of each of the key population groups.

⁴⁰ *ibid*

⁴¹ *Supra* note 31.

⁴² *Protocol for an Integrated Bio-Behavioral Surveillance Study Among Most At-Risk Populations*

Plans were apparently developed by NASCOP and technical partners during 2015-16 and were approved by the appropriate national authorities, but without broader consultation with the communities to be studied.

When key populations and other civil society groups were informed of the plans in July 2016, they mobilized quickly through the Key Populations Consortium, a national collaborative platform for national networks and organizations led by key populations, using a combination of public statements and behind-the-scenes advocacy to voice their concerns. By mid-2017, NASCOP had agreed to put the planned study on hold and to remove use of biometrics from the protocol.

The following section outlines the sequence of events and advocacy tactics used. During 2015-16, NASCOP developed the Kenyan study protocol in collaboration with National HIV Reference Laboratory (NHRL) and National Microbiology reference laboratory (NMRL), University of Manitoba, University of California in San Francisco, U.S.

Center for Disease Control and Prevention (CDC), UN Office on Drugs and Crime (UNODC), and other local institutions.⁴³ Because the survey included providing health services such as HIV testing, and reportedly to avoid participants acquiring medicines for resale on the black market, biometric methods of identification were included.

⁴³ NASCOP, "Integrated Biological and Behavioral Survey 2015/16," Undated slide presentation on file with KELIN and KP Consortium.

A NASCOP slide presentation shared by key populations advocates who participated in relevant meetings outlines the process NASCOP and partners followed: a series of technical meetings during 2015 to develop the study protocol, submission of the protocol to the national Internal Review Board (IRB) for ethics review in 2015, and more.⁴⁴

Ethics review and approval by an IRB is normally required in all countries for any research that involves human subjects. This is the case because of the many cases that have occurred in the past, in many countries, where scientific research conducted without sufficient ethical protections has caused harm to human subjects. The review process must identify risks and benefits to any human subjects studied, and explain why the benefits outweigh the risks, as well as any protections researchers plan to put in place. NASCOP's presentation includes a slide titled "Ethical consideration", which outlines the methods that were proposed and approved in the protocol submitted to Kenya's IRB, namely:

- "Names or other identifying information will not be written on survey forms or lab specimens
- Staff will not ask for any identification eg government id from any participant
- Sex work, cruise or drug use sites and HIV test results will no be reported to the police

- All study staff will receive ethical training and sign confidentiality agreement
- Any adverse event will have to be reported to NASCOP within 24 hours
- Data collected will be made anonymous and unlinked to individual participants"⁴⁵

The slides also describe a process for obtaining informed consent from participants. These measures were reportedly approved by the Kenyan IRB in February 2016. In May 2016, NASCOP's presentation states that pre-assessments took place, and in July 2016 the results of the pre-assessment findings were reportedly presented to the Key Populations Technical Working Group.

The version of events in NASCOP's presentation describes early and frequent consultation with key populations. However, key populations representatives state that in fact, they only saw the slide presentation, and learned of the proposed use of biometrics in the IBBS, in a meeting of the Technical Working Group in November 2016.

By November 2016, NASCOP had apparently finalized the protocol, received IRB approval for it, procured equipment, hired staff, conducted pre-assessments, and were ready to fully launch into the research process.

44 NASCOP, "integrated Biological and Behavioral Survey 2015/16: Development process and updates." Slide presentation, on file at KELIN and KP Consortium.

45 NASCOP, "Integrated Biological and Behavioral Survey 2015/16."

This relatively late consultation with key populations created major problems, as key populations in the November 2016 Technical Working Group say that they immediately and vocally objected to the planned use of biometrics in the study, which was now about to begin imminently. This clearly caused anxiety for national authorities as, according to several interviewees and as clearly indicated by NASCOP's timeline in its November 2016 presentation, funds from the Global Fund grant had already been spent on equipment and staff, and could not be returned.

Civil society representatives at the November 2016 meeting reported that on learning of the proposed use of biometrics, they immediately raised serious concerns about risk to key populations, given the criminal laws.⁴⁶ Same-sex sexuality, sex work, and drug use are all criminalized in Kenya, and those convicted can be subject to harsh penalties. Similarly, harm reduction organizations distribute needles and syringes⁴⁷, but this is also potentially a criminal activity as provided for under Section 5 of the Narcotic Drugs and Psychotropic Substances (Control) Act.⁴⁸

46 http://www.healthgap.org/fighting_to_protect_human_rights_in_kenya_s_new_global_fund_and_pepfar_supported_key_population_size_estimate_study

47 KELIN and KP Consortium interview with harm reduction advocate, Nairobi, 18 September, 2017

48 National Council for Law Reporting, "Narcotic Drugs and Psychotropic Substances (Control) Act", Act No. 4 of 1994, Laws of Kenya; *National Council for Law Reporting*, available at <http://www.kenyalaw.org/lex//actview.xql?actid=No.%204%20of%201994> (accessed 5 December 2017).

According to several participants in the meeting, NASCOP representatives directly warned key populations representatives of potential negative repercussions for their organizations if the research did not proceed as planned with the use of biometrics.⁴⁹ Rather than backing down, however, this only entrenched the opposition by Kenyan key populations groups.

In a series of meetings, representatives of female sex workers and men who have sex with men led the opposition to use of biometrics. The representatives requested a meeting with the director of NASCOP, which took place two months later. At that meeting, according to people who participated in it, the director asked key populations to trust him with their biometric data, and that he would personally protect them, but trust had eroded significantly by this stage.⁵⁰

KELIN repeatedly requested meetings with NASCOP for this report, which did not respond. Other participants in the meetings and the process shared their understanding of the debate and their understanding of NASCOP's position, which hinged on four points. First, NASCOP's main argument for use of biometrics was reportedly in order to avoid double-counting of key populations in the size estimate, specifically in order to avoid acquisition of ARTs for sale on the black market, and to avoid the risk of fraud in collection of small incentives (normally, about Ksh. 500) that would be paid to study participants.

49 KELIN and KP Consortium interview with civil society representatives, Nairobi, 18-21 September, 2017.

50 KELIN and KP Consortium interview with Kenyan MSM representative, Nairobi, 20 September, 2017.

The reality of these risks were questioned by key populations advocates, who asserted lack of evidence of black-market sales of ARTs by key populations who were double-counted, demanding: “Why don’t you look at people who are not getting treated [instead]?”⁵¹

Second, technical partners in the meeting reportedly argued the study would not take thumb prints, which are used by law enforcement, but would use index finger prints instead, thus eliminating risk of arrest of criminalized individuals. Again, lack of trust by key populations of either government or partners made them reluctant to accept this solution. One interviewee noted that technical partners were hampered in making their case for this approach by the frequent changes in representation from the KP groups, meaning that ground covered in previous meetings had to be covered again. Key populations representatives rejected any form of biometrics for tracking individual study participants as being too intrusive.

Third, NASCOP and their technical partners reportedly argued that the study data would be protected, since it could not be shared with other agencies without a legal order.⁵²

They argued that other identifying information, such as names and addresses, could be just as unsafe as biometric data. They proposed a data-sharing agreement that would protect security of the data by limiting access.⁵³

51 KELIN and KP Consortium interview with sex worker representatives, Nairobi, 21 September, 2017

52 KELIN and KP Consortium interview with UN representative, Nairobi, 18 September, 2017.

53 KELIN and KP Consortium interview with US government representative, telephone interview, 20 September 2017.

However, key populations advocates rejected these proposals as unreliable, given that they had heard reports that in Tanzania, biometrics had recently been used to target LGBT participants in HIV meetings. It is not known whether biometrics actually played a role in the Tanzania arrests, which are part of a growing crackdown against LGBT groups in the country, but it is significant that key populations believed this had been the case and saw it as a legitimate threat.⁵⁴

Lastly, participants in the study design also reportedly argued that biometrics had been used in previous studies of key populations,⁵⁵ without any negative repercussions or harm coming to participants. This was also rejected by key populations advocates: in the words of one interviewee,

54 van der Zee, Bibi. “Tanzania illegally detains human rights lawyers for promoting homosexuality.” *The Guardian* 26 October 2017. Available from: <https://www.theguardian.com/global-development/2017/oct/26/tanzania-illegally-detains-human-rights-lawyers-for-promoting-homosexuality> (Accessed 8 January 2017).

55 National AIDS and STI Control and Programme (NASCOP) Ministry of Health, Kenya “2010-2011 Integrated Biological and Behavioural Surveillance Survey among Key Populations in Nairobi and Kisumu, Kenya” (NASCOP: Nairobi, 2014), available from <http://www.nascop.or.ke/?wpdmpromo=ibbs-survey-report-among-kp-in-nairobi-and-kisumu-kenya#> (accessed 22nd December, 2017).

56 KELIN and KP Consortium interview with Kenyan MSM representative, Nairobi, September 20, 2017.

Biometrics are used by a civil society organization in Kenya, Sex Workers Outreach Programme (SWOP), which serves sex workers, and technical partners and NASCOP pointed to this as evidence that biometrics data could be used securely for key populations health service provision.

SWOP takes thumb prints, not the index finger, and takes precautions to encrypt the data and delink it from other services or databases. However, other key populations representatives interviewed for this report stated that their own surveys show that some key populations they serve will go to great lengths to visit distant facilities in order to avoid using health services that require biometrics.⁵⁷ Thus, they did not find the SWOP example persuasive either.

Having failed to persuade the key populations advocates at the national level of the merits of using biometrics, key populations representatives reported that NASCOP also met with key populations groups outside of Nairobi. When this happened, the key populations networks reportedly discussed this among themselves, and agreed that all members of the consortium would report back to the consortium on any meetings with government representatives.

When offers were allegedly made to win some members of the consortium over to the use of biometrics, those individuals came under direct

peer pressure, and were publicly challenged in meetings by their peers.⁵⁸ During this process of advocacy and debate, the Kenya Key Populations Consortium worked largely behind the scenes; but they did issue an open letter to the agencies involved in the study summarizing their position, which asserted:

1. The Kenya Key Population Consortium is in support of the IBBS study and its component of collection of size estimate for key populations but does not support the use of biometrics as a method of data collection as it will only serve to introduce fear and uncertainty among criminalized communities and lead to under counting of key populations in the IBBS.
2. The consortium would like to suggest the use of a unique Identifier code that uses no biomarkers of any form as an option for collection of data for the IBBS study.
3. We recommend that the data collected from the IBBS is collected and stored by a third and neutral party identified by the communities
4. We recommend the development of data, safety and security guidelines for the collection of data to safe guard data that the government currently possesses and any future data collected for studies.

⁵⁷ KELIN and KP Consortium interview with Kenyan MSM representative, Nairobi, September 20, 2017.

⁵⁸ KELIN and KP Consortium interview with Kenyan LGBT representatives and sex worker representative, Nairobi, 19-20 September, 2017.

We recommend under the new Global Fund grant application that the government:

- (a) develops the new data and security guidelines that safeguard key populations health-related data;
- (b) conducts an IBBS study that does not use biometrics with support from partners so that the country is equipped with data to ensure better planning and continuation of the program.⁵⁹

As part of their behind-the-scenes advocacy, the Key Populations Consortium also reached out to UNAIDS to ask for support (both to the country office in Kenya, and to the human rights team in the UNAIDS Secretariat in Geneva), as well as to the Community, Rights and Gender team of the Global Fund and to PEPFAR.

In response to this request for support by the Key Populations Consortium, in November 2016, UNAIDS issued an advisory note to the Kenya Ministry of Health on the use of Biometrics in the Kenya Intergrated Bio-Behavioural Survey (IBBS) among key populations, co-signed by the Kenya country director, Jantine Jacobi, and the director of Rights, Gender, Prevention, and Community Mobilization, Mariangela Simao.⁶⁰

⁵⁹ Kenya Key Population Consortium, "Kenya Key Population Consortium response on the use of Biometrics for the IBBS in Kenya." Undated letter on file with KELIN and the KP Consortium.

⁶⁰ Dr. Jantine Jacobi and Dr. Mariangela Simao, "UNAIDS Advisory Note on the Use of Biometrics in the Kenya Integrated Bio-Behavioural Survey Among Key Populations." Unpublished statement on file with KELIN. 2 pp. 29 November 2016.

In their advisory, UNAIDS noted that the use of biometrics in the context of the IBBS poses two key issues for general consideration: first, the question of whether the use of biometric data is necessary and has specific benefits in the context of a HIV biological and behavioural survey.

Second, dedicated safeguards required, in relation to personal autonomy, safety and security and perceived risk of potential misuse, for the use of biometric data. They recommended:

1. A review of the current Draft 2016 IBBS Protocol by human rights and ethical experts together with the representatives of the key populations, to build consensus on critical aspects to be strengthened, in line with the international recommendations provided in the present document;
2. The final Protocol should fully reflect the elements described above, and as per consensus reached, including by providing clear information about the benefits of the biometric technique; the protection of data, informed consent and confidentiality; the fair balancing of the risks and benefits of the survey methods; and the process for ensuring effective participation of the representatives of key populations in the design and monitoring of the survey.

3. Establish an advisory committee with the meaningful participation of key populationstomonitortheimplementationof the IBBS, and to help prevent and address any emerging operational, ethical and human rights challenge.⁶¹

In response to the request for support from the Key Populations Consortium, the Global Fund Community, Rights and Gender team in Geneva led a series of calls to better understand the situation, as did UNAIDS in Geneva.

According to key populations representatives who participated in the calls, the Global Fund and UNAIDS then involved the Country Coordinating Mechanism (CCM) in Kenya, which is responsible for oversight and governance of Global Fund grants, urging the CCM to find a solution that would satisfy the civil society stakeholders.

After these discussions, the Key Populations Consortium issued a second open statement, which displayed their now sophisticated understanding of social science research methods and health finance policy.

The letter outlined a number of methodological alternatives to biometrics, noted the risk of data breaches, and called for the Global Fund grant to not be “re-programmed” or re-allocated to other programs by the donor, but instead, “We call for the funds for size estimation to be

retained, and safer method of collection of size estimate to be used, to ensure that all key populations who require services are not left behind.”⁶²

As a result of the meetings, statements and donor interventions, by mid-2017, NASCOP agreed to remove the use of biometrics from the IBBS study protocol, and to include civil society representatives in design and implementation of the IBBS when it is conducted in 2018.

Conclusions

What worked to achieve this goal? Civil society interviewees said the clearly unified position of all civil society representatives engaged in the process was essential: “The major thing was the community coming together and speaking with one voice.”⁶³ As another put it, “We are organically obstinate and stubborn...Everyone just said no, and kept saying no.”⁶⁴

Several interviewees also noted that the Global Fund Community Rights and Gender team, and the CCM, were critical in putting the brakes on the process. The KP Consortium was founded in a previous Global Fund financing allocation in order to negotiate collectively for access to Global Fund financing.⁶⁵

62 Kenya Key Population Consortium, “Kenya Key Population Consortium analysis and conclusion of the use of Biometrics for the IBBS in Kenya.” Undated letter on file with KELIN and the KP Consortium.

63 KELIN and KP Consortium interview with Kenyan MSM representative, Nairobi, 20 September, 2017.

64 KELIN and KP Consortium interview with Kenyan LGBT representatives, Nairobi, 20 September, 2017.

65 KELIN and KP Consortium interview with Kenyan LGBT representative, Nairobi, 20 September, 2017.

61 Dr. Jantine Jacobi and Dr. Mariangela Simao, “UNAIDS Advisory Note.” 29 November 2016, p. 2.

The donor's engagement, along with the statement by UNAIDS, reinforced a donor requirement that key populations be engaged in and approve the outcome of the process. Clearly, also, study of the open letters shows that the rapidly-acquired expertise of key populations advocates in what methods can and cannot be used in health research, and in what funding policies allow, likely supported their case both in Geneva and at home.

Interviewees now say that they see a clear role for key populations representatives in the process, relying especially on peer educators for outreach through their existing networks: "Key populations understand themselves. If someone wants to intervene, that person must be from amongst the key populations."⁶⁶ Said another, "Communities are engaged from the word go.

We are moving in the right direction now."⁶⁷

At the same time, others noted that while the data may be used in making the case in external funding requests, it is not always used in making actual funding allocations.⁶⁸ The national health bill, for example, does not identify harm reduction as a government-funded health service, raising again the question of how biometrics would be used.

⁶⁶ KELIN and KP Consortium interview with Kenyan PWID representative, Nairobi, 18 September 2017.

⁶⁷ KELIN and KP Consortium interview with Kenyan MSM representative, Nairobi, 20 September, 2017.

⁶⁸ KELIN and KP Consortium interview with sex worker representative, Nairobi, 18 September 2017.

Once the IBBS is completed and Kenya has new size estimates, continued engagement will be needed to ensure programs are allocated to target the epidemic among those most vulnerable.

As the Kenya case study shows, the researcher-researched relationship is changing in global health studies, even as forms of information-gathering become potentially more intrusive. Those who are studied by authorities, even for purposes that advance the public good, increasingly expect more control over what information is gathered about them, how and why.

New and emerging technologies, such as biometrics, bring another level of intimacy and a more intrusive element into public health research. While biometric data in some sense are not qualitatively different from traditional forms of data, they can be used to rapidly and positively identify hidden populations, and thus are a flashpoint for a number of human rights concerns about privacy in the context of the HIV response.

The urgent priority for Kenya and donors is now finding ways to identify people vulnerable to HIV and to encourage those people to be tested and initiate treatment. Coercive measures clearly backfire, and anything that can jeopardize progress should be avoided. Finding and treating key populations who may be living with HIV relies on a fragile and delicate relationship of trust between government and

its citizens -- one that can only be protected and developed in a context of consistent respect for dignity, ethics and human rights.

Recommendations

To global health finance agencies and UN agencies:

- a) Provide clear guidance to governments that receive aid for health on expectations of measures they should take to protect the security of those studied in research financed by that aid, including the security of their information.
- b) Restrict or deny funding projects that include biometrics and other intrusive forms of data-gathering unless clear and sound data protection laws and policies are in place, and if the populations to be studied are criminalized. These decisions should be made after conducting independent human rights, privacy and personal data protection assessments of projects being proposed.
- c) Clarify in UN technical guidance on size estimation that all planning and implementation of health research financed by those agencies should include community representatives as co-investigators, and not only as low-paid data enumerators and researchers.

To the government of Kenya:

- a) Review the Penal Code and County by-laws to decriminalize sex work, in line with international human rights obligations and best practices in the field
- b) Review the Penal Code to decriminalize same-sex sexual behavior, in line with human international rights obligations and best practices in the field
- c) Review the Narcotics and Psychotropic Substances (Control) Act to decriminalize drug use, in line with international human rights obligations and best practices in the field.
- d) Draft and adopt a comprehensive data protection framework with adequate and coordinated levels of enforcement, with clear safeguards for sensitive information such as health data and biometric data.
- e) Develop and implement data privacy guidelines and policies for government agencies, including health and research services.

To civil society in other countries:

- a) Develop unified consortia and coalitions that bring together key populations-led networks and organizations.
- b) Learn about the methods used in health research, including ethical requirements and the technologies involved in the process.
- c) Insist on the meaningful inclusion of key populations representatives in the design and oversight of health research that studies key populations.



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 30 August, 2017

Dr. Martin Sirengo
Head National AIDS and STI Control Program
Nairobi
Email: head@nascop.or.ke

Dear Dr. Sirengo

RE: INTRODUCTION TO KELIN/PRIVACY INTERNATIONAL RESEARCH PROJECT

*IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA
HEALTH DATA COLLECTION*

KELIN is an independent Kenyan civil society organization working to protect and promote health-related human rights in Kenya. We do this by: advocating for integration of human rights principles in laws, policies and administrative frameworks; facilitating access to justice in respect to violation of health related rights; training professionals & communities on rights-based approaches and initiating and participating in strategic partnerships to realize the right to health, nationally, regionally and globally.

As you know, biometrics are on the rise in border control, in courts and in business contexts, including iris scans, fingerprints, toe prints, with new methods of identification constantly under development. This trend has raised numerous concerns for rights advocates globally. In 2015-16, stakeholder consultations held by global health donors (the Global Fund to Fight AIDS, TB and Malaria and the US President's Emergency Program for AIDS Response [PEPFAR]) in Kenya highlighted the absence of adequate data on key populations vulnerable to HIV, including the lack of plausible size estimates, testing and prevalence data for marginalized groups such as men who have sex with men, sex workers, transgender people, and people who inject drugs. In response to pressure from domestic key populations groups and global health donors, Kenya's health officials committed to developing improved data with donor support.

In November, 2016, the Government of Kenya announced plans to roll out the use of biometrics to determine key population size estimates as part of an Integrated Bio-Behavioral Surveillance

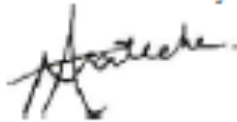
study (IBBS). Kenyan key populations groups immediately identified serious privacy and ethical concerns, given that laws criminalize same-sex sexuality, sex work and drug use in Kenya.

KELIN, with support from Privacy International, intends to conduct research to analyse international and domestic standards on privacy and biometrics, related ethical and human rights risks, and to document the advocacy tactics and arguments used by Kenyan civil society to successfully challenge biometrics use for key populations. It is anticipated that the research will result in a report and an academic article that can inform a broader discussion on the use of biometric data and human rights of key populations, as well as documenting Kenya's experience and lessons learned to share with civil society and advocates in other countries where biometrics are being proposed for size estimates.

The research team intends to interview stakeholders in the month of September to understand the sequence of events in 2016-17, the problem, arguments and advocacy approaches used, and outcomes of the advocacy.

Given your expertise and experience, we would be most grateful for a one-hour interview between the dates of 16-21 September 2017. Kindly indicate your availability for planning purposes.

Yours Faithfully,



Allan Maleche,
Executive Director.

MINISTRY OF HEALTH
OFFICE OF THE CABINET SECRETARY
RECEIVED INTERNAL
01 SEP 2017
RECEIVED: P.M.
TIME: 9:30 AM
ACTION BY: G.C.



Your Ref: TB/...

Date: 30 August, 2017

Dr. Cleopas Mailu
Cabinet Secretary
Ministry of Health
Afya House
Nairobi

MINISTRY OF HEALTH
OFFICE OF THE CABINET SECRETARY
RECEIVED INTERNAL
01 SEP 2017
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ACTION BY: G.C.

*Nothing
11/9/17
Kellin
Kindly
Provide
Ethical
approval
for the
Survey*

Dear Dr. Mailu

RE: INTRODUCTION OF BIOMETRICS IN AN INTERNATIONAL RESEARCH PROJECT

**IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA
HEALTH DATA COLLECTION**

KELIN is an independent Kenyan civil society organization working to protect and promote health-related human rights in Kenya. We do this by: advocating for integration of human rights principles in laws, policies and administrative frameworks; facilitating access to justice in respect to violation of health related rights; training professionals & communities on rights-based approaches and initiating and participating in strategic partnerships to realize the right to health, nationally, regionally and globally.

As you know, biometrics are on the rise in border control, in courts and in business contexts, including iris scans, fingerprints, toe prints, with new methods of identification constantly under development. This trend has raised numerous concerns for rights advocates globally. In 2015-16, stakeholder consultations held by global health donors (the Global Fund to Fight AIDS, TB and Malaria and the US President's Emergency Program for AIDS Response [PEPFAR]) in Kenya highlighted the absence of adequate data on key populations vulnerable to HIV, including the lack of plausible size estimates, testing and prevalence data for marginalized groups such as men who have sex with men, sex workers, transgender people, and people who inject drugs. In response to pressure from domestic key populations groups and global health donors, Kenya's health officials committed to developing improved data with donor support.

MINISTRY OF HEALTH
OFFICE OF THE DIRECTOR OF
MEDICAL SERVICES
01 SEP 2017
P. O. Box 30016 - 00100,
NAIROBI



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 7 November, 2017
"Advanced email copy"

Dr Kigen Bartilol
Head National AIDS and STI Control Program
Nairobi
Email: head@nascop.or.ke

Dear Dr Kigen

RE: INTRODUCTION TO KELIN/PRIVACY INTERNATIONAL RESEARCH PROJECT
IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA HEALTH DATA COLLECTION

We write in reference to our letter dated 30 August 2017, where you raised concern on whether or not KELIN had IRB approval to conduct the above-mentioned research project.

The "*Impact of Community Advocacy on the Use of Biometrics in Kenya Health Data Collection research*" is a desk review that aims to analyse international and domestic standards on privacy and biometrics, to analyse related ethical and human rights issues, as well as grey literature and correspondence on the issue by UN agencies and Kenyan civil society.

We interviewed key stakeholders and experts to better understand the results of the desk research, but this did not constitute human subjects research: any quotes will be used anonymously, and solely to help us to gain insight into the materials reviewed. Everyone we spoke with was fully informed of the purpose of the study, and discussed topics on which they engage in regular discussions as part of their daily work; thus there was no risk to those we interviewed.

As we finalize the report in the coming weeks, we would welcome input from NASCOP in regards to the reasoning behind the original plans to incorporate biometrics in the IBBS study, the budget allocation originally received for this purpose, expenditures made, and the current plans to conduct the IBBS in the future. To include your responses in the report, we would be grateful to receive your response by no later than 17 November 2017. Your letter and this letter will be included as annexes in the report, in full.

Hope this addresses all your concerns and we look forward to your kind reply.

Yours Faithfully,

Allan Maleche,
Executive Director



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 9 October, 2017

Sylvie Bertrand
Regional Advisor for HIV and AIDS
UNODC
Nairobi
Email: sylvie.bertrand@unodc.org

Dear Sylvie

**RE: REQUEST FOR INFORMATION KELIN/PRIVACY INTERNATIONAL RESEARCH
PROJECT**

***IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA
HEALTH DATA COLLECTION***

Greetings from KELIN,

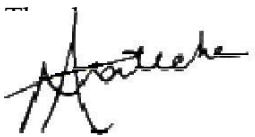
Hope this correspondence finds you well.

Thank you for considering our request for information on the planned studies regarding the health of key populations.

As part of KELIN's work on health and human rights, we are studying the growing use of biometrics in health research. In particular, the study focuses on concerns raised by criminalized and stigmatized key populations in relation to the IBBS which did not materialize as planned. We are studying Our study involves a review of relevant laws and policies, as well as key informant interviews among selected stakeholders from government, international organizations, health aid agencies, and civil society to enrich the analysis with their expertise.

We would like to ensure that your institution's views are fairly reflected in the report, and would thus be grateful to receive your responses to the following questions by Friday, 20 October 2017. This will enable the timely inclusion of your responses in contributing to this analysis. This letter, and your replies, will be published in full as annexes to the report.

- What were the objectives of the proposed IBBS?
- Why were biometrics proposed as part of the study?
- What steps were proposed in the study protocol to protect participants from the risk that biometric data could have led to violations of confidentiality, data leaks, or use of the data for other purposes than those for which the participants gave consent (e.g., by private sector or by law enforcement)?
- Where would the data have been stored?
- How much funding was allocated for this study?
- How much of the original funding allocated has been spent, as of September 2017?
- What are the future plans in regards to conducting the study?
- Is there anything else you would like to share for inclusion in the report?

 ch for your responses.

Allan Maleche,
Executive Director.



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 9 October, 2017

Dr Nduku Kilonzo

Director National AIDS Control Council

Nairobi

Email: ceo@nacc.or.ke

Dear Dr Nduku

RE: REQUEST FOR INFORMATION KELIN/PRIVACY INTERNATIONAL RESEARCH PROJECT

IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA HEALTH DATA COLLECTION

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Executive Director.



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 9 October, 2017

Jantine Jacobi

Country Director

Joint United Nations Program on HIV and AIDS

Nairobi

Email: jacobij@unaids.org

Dear Jantine

RE: REQUEST FOR INFORMATION KELIN/PRIVACY INTERNATIONAL RESEARCH PROJECT

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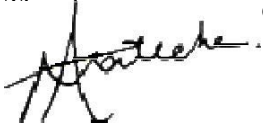
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Allan Maleche,
Executive Director.



Your Ref: TBA

Our Ref: C/KELIN/17

Date: 9 October, 2017

David Maina
Team Leader Governance and Devolution Unit
United Nations Development Program
Nairobi
Email: david.maina@undp.org

Dear David

RE: REQUEST FOR INFORMATION KELIN/PRIVACY INTERNATIONAL RESEARCH PROJECT

IMPACT OF COMMUNITY ADVOCACY ON THE USE OF BIOMETRICS IN KENYA HEALTH DATA COLLECTION

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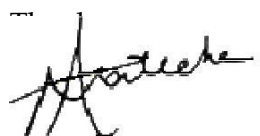
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Allan Maleche,
Executive Director.

(Footnotes)

1 UNAIDS, AIDSInfo. <http://aidsinfo.unaids.org>. Accessed 12 November 2017.

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