Biometrics and public health surveillance in criminalised and key populations: policy, ethics, and human rights considerations

Matthew M Kavanagh, Stefan D Baral, Maureen Milanga, Jeremy Sugarman

Widespread public health surveillance efforts focused on key populations (men who have sex with men, sex workers, people who inject drugs, and others) gather data on population sizes, HIV prevalence, and other information for planning and resource allocation. Biometric identification might improve this data gathering. However, in the context of extensive criminalisation of these populations, the use of biometrics such as fingerprints raises concerns that are insufficiently addressed in current policies. These concerns include infringing privacy, exposing participants to risks of legal action or violence, biasing surveillance results, and undermining trust in the health system. We set out key ethics and human rights considerations regarding the use of biometrics in HIV surveillance among these populations, and outline a typology of jurisdictions wherein such methods might be considered, based on data about legal, political, and social environments. In this Review, we suggest that the biometrics approach is not currently likely to be appropriate in many jurisdictions.

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O'Neill Institute of National & Global Health Law, Georgetown University, Washington, DC, USA (M M Kavanagh PhD); **Department of Epidemiology, Johns Hopkins University, Baltimore, MD, USA** (S D Baral MD); **Health Global Access Project, Nairobi, Kenya** (M Milanga); **and Berman Institute of Bioethics and Department of Medicine, Johns Hopkins University, Baltimore, MD, USA** (Prof J Sugarman MD)

Correspondence to:
Dr Matthew M Kavanagh,
Georgetown University, O'Neill
Institute of National & Global
Health Law, Washington,
DC 20001, USA
matthew.kavanagh@georgetown.edu

Introduction

The global strategy to end the public health threat of the HIV pandemic is increasingly based on target setting for HIV testing, treatment, and prevention programming, with marked specificity of geography, population, and age to maximise effects on mortality, morbidity, and transmission.[1–3] The gathering of data to enable such targeting necessitates robust public health surveillance efforts, including among key populations: gay men and other men who have sex with men, sex workers, transgender people, prisoners, and people who inject drugs.[4,5] Availability of services for these groups can depend on estimates of population size and HIV prevalence. However, in many contexts, the populations, occupations, and practices among those at the highest risk of HIV infection are stigmatised or criminalised, making ascertainment of these estimates challenging. Use of biometric identifiers has been proposed as a means of enhancing the accuracy of HIV surveillance, but is associated with hazards related to stigmas and punitive legal frameworks in many jurisdictions. Current policies insufficiently address the use of biometrics in HIV surveillance; neither WHO nor the major global funders of surveillance activities, such as the US President's Emergency Plan for AIDS Relief (PEPFAR) and The Global Fund to Fight AIDS, Tuberculosis, and Malaria, have publicly issued policies on the use of biometrics for this purpose.[6] In this Review, we set out key ethics and human rights considerations regarding the use of biometric identifiers in HIV surveillance among criminalised and key populations, and delineate policy recommendations for their appropriate use.

HIV prevalence and incidence among key populations are substantial. Members of these populations and their sexual partners account for nearly half of all new HIV infections globally.[7] HIV prevalence among sex workers ranges from 50% to 70% in southern Africa.[7] Furthermore, high and sometimes rising rates of new HIV infections among men who have sex with men have been documented over the past several years in countries as diverse as China, Kenya, Senegal, Thailand, and the USA;[8] and almost a third of HIV infections worldwide, outside of sub-Saharan Africa, are associated with injection drug use.[9] These key populations commonly experience stigma, violence, and harassment.[10] Sex work and possession of illicit drugs are criminalised to varying degrees in most countries, as are same-sex practices in many, with penalties ranging from imprisonment to death.[11] These realities create substantial risks and challenges for effective public health programming, given the understandable reluctance among key populations to disclose stigmatised and criminalised practices. Additional priority or vulnerable populations of people who face higher risk in certain situations or contexts (eg, migrants and people with disabilities) have also been identified.[12] Although this Review mostly focuses on key populations who face structural HIV risk, in some contexts, other populations, particularly migrants, are subject to criminalisation alongside HIV susceptibility.[4] In each context, criminalisation and related social realities impose particular ethical and human rights challenges for HIV surveillance among these groups. Such challenges are crucial to consider in the context of deploying technologies such as biometric identifiers in these surveillance efforts.

Public health surveillance of key populations

Substantial expansion in surveillance activities has occurred in response to the push by activists, financing institutions, and governments in recent years for more and better data on key populations. These activities include efforts to establish baseline estimates of the size and geographical distribution of populations of sex workers, men who have sex with men, people who inject drugs, and other groups;[13–17] HIV prevalence and risk factors among these key populations;[14,18–20] and coverage of services, including access to antiretroviral therapy and prevention programmes and measures of treatment adherence and viral suppression.[21–25] Baseline estimates are often paired with behavioural surveys that assess characteristics such as HIV knowledge, number of sexual partners, sexual practices, condom use, drug use and equipment sharing, and frequency of selling sex, along with discrimination and other community-level determinants of risk.[6] These efforts provide reference points for service delivery and allocations of funding by microtargeting the gaps in coverage among different subpopulations.[3,26]

The gathering of accurate data on key populations is difficult because it requires counting people whose identities or activities are, in effect, hidden. HIV surveillance efforts therefore deploy a mixture of methods to address these challenges, including census methods (counting visible members of key populations), multiplier-based methods (such as capture–recapture, which identify key populations at multiple times or places and calculate estimates on the basis of the overlap), and survey-based estimations.[6]

Nevertheless, given the hidden nature of key populations, there are concerns about the internal and external validity of these surveillance studies.[27,28] Most efforts assume that key populations are networked and that identifying visible members can help to estimate the majority who are not. However, networking itself can result in the same person being counted multiple times, such as when they are associated with different survey sites (eg, a sex worker who works at more than one site).

By contrast, existing approaches might under-represent the true size of populations and undercut sufficient investment in programmes for key populations. Some governments downplay the size of populations connected to behaviours and identities they consider morally objectionable.[29] Even supportive HIV programme managers and donor agencies have downplayed the relevance of key populations in generalised epidemics.[30] Indeed, a data paradox exists, wherein data are most scarce for many of the groups and settings in which scale-up is most needed, with implausibly low or absent size estimates common for key populations in countries where these populations face criminalisation.[31,32] A 2018 study[33] using data from Facebook and other social media revealed population counts many times larger than other estimations.

See Online for appendix

Biometric identifiers

The use of biometric identifiers has been proposed, and implemented in some settings, as a strategy to address duplication and increase accuracy of public health surveillance. The term biometrics refers to the automatic identification of a person on the basis of their anatomy or physiology, including voice, face, fingerprint, or iris. Biometrics allow easy and repeated recognition of an individual and automated actions on that basis.[34] Fingerprint scanning is the most commonly used identifier because of its convenience and efficiency, and is used in various contexts including smartphones, immigration entry points, and access to social service benefits.[34] There is also substantial interest in the use of biometrics for patient identification to improve health service delivery and continuity.[35] In the context of public health surveillance efforts, research staff using biometric scanners can quickly initiate a respondent record, automatically connect a current response to past responses in a database, and check to ensure that a respondent has not already participated. Technology now permits survey administrators to simply scan a fingerprint with an inexpensive device linked to a laptop or tablet device and commence the survey with little effort.

Technologies for biometric data collection and storage have varying levels of security.[36] For example, although some scanners save a full image of a fingerprint, higher-end software retains only specific unique characteristics, converted into an encrypted key (a series of numbers) that cannot be reconverted to copy or steal the fingerprint. However, any person whose fingerprint is scanned can be linked directly to records in the database. The security of those data is a product of the methods used to encrypt, transfer, and restrict access to the database, as well as laws or policies on authorised use. Safety of the use of biometrics is therefore variable, with many examples of unauthorised access occurring through breakdown in technology, inadequate policy, or ineffective measures to restrict access to the data.[37]

Fingerprint scans and other biometrics have been used in epidemiological and behavioural surveys in HIV surveillance activities of key populations.[38–50] These activities have included surveillance among various different key populations and in multiple countries, including places where these populations face criminalisation (appendix). However, the use of biometrics has been contentious. For example, in Kenya, representatives of key populations and people living with HIV strongly opposed the use of fingerprinting technologies.[51]

Alternative methods to address the problem of duplicate participation have been used, including the use of anonymous and reproducible codes, ensuring consistent staff during study implementation, and noting identifying marks of participants (eg, tattoos). None of these alternatives is perfect, but each can help to minimise duplication.

Biometrics are attractive, in theory, because identifiers are not required to be linked to a name or other personal information.[34] However, important privacy concerns arise when the same biometric marker is used across multiple types of records or when information that could endanger the respondent can be accessed through a trait that cannot be discarded, such as a fingerprint. In addition, because data can be geocoded (even to a person's home) to identify hot spots, privacy concerns are especially serious. When data are used to create databases of criminalised people, these concerns present substantial ethical and human rights considerations.

Ethics and human rights considerations

Although there are various approaches to understanding the ethics of clinical practice and research, efforts to describe ethical obligations in public health are most relevant to the context of biometrics use in HIV surveillance. Kass[52] and Childress and colleagues,[53] for example, have described sets of considerations that balance whether infringing on individual autonomy is justified, and the UN Siracusa principles[54] provide a framework for considering limitations of civil and political rights. According to these approaches, justifications for activities that infringe on liberty and privacy must generally be based on considerations such as the effectiveness of an intervention in addressing a legitimate public health goal, whether the benefits proportionally outweigh the harms, whether infringement is necessary to achieve the public health goal, whether the activity represents the option with least infringement (with harms minimised to the extent possible), and whether these actions have been publicly explained and communities consulted. In regard to both surveillance efforts and public health research, Gostin observes that "the potential for violating privacy rights is formidable where there is wide-scale collection, transfer and use of information. Systematic gathering, reporting, and sharing of information about a group can be highly detrimental to the group and its members. The use of sophisticated computer technology to store and use personal data among countless sources only heightens the concern over privacy, stigmatisation, and discrimination."[55]

Ethics guidance has been suggested to safeguard surveillance efforts.[56] Core principles include collection of individual identifiers only when absolutely necessary to achieve public health goals; acquiring the minimal amount of information necessary; ensuring effective protection of collected data; and engaging affected communities in establishing collection and dissemination strategies. Lee and colleagues[57] noted that the fundamental matter is whether the risk of collecting and holding the data is worth the expected outcome. In addition, best practices suggest the need for community members to be engaged as full partners in the design, implementation, and dissemination of results.[58] Furthermore, when surveillance activities involve research rather than public health practice, standard research ethics principles and guidelines should be considered.[59]

Human rights frameworks delineate additional obligations and perspectives. First, many entities involved in surveillance activities are nation states and are subject to commitments and obligations under international law. Second, human rights emphasise the need to simultaneously address broad public health imperatives and the dignity of individuals. As argued by Jonathan Mann, setting individual freedoms above and apart from quality public health interventions is neither necessary nor effective in responding to AIDS and other major health issues.[60,61] Indeed, rights-based approaches can themselves be crucial for achieving public health goals: protection of privacy, for example, is necessary to bring people into the health system and build the trust necessary for reaching people with the highest HIV risk.

International agreements obligate state actors to address both health and privacy concurrently. The Universal Declaration of Human Rights recognises health as a core concern, and the International Covenant on Economic, Social and Cultural Rights (article 12.1) requires parties to recognise "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health".[62] In addition, the International Covenant on Civil and Political Rights identifies rights to privacy and bodily integrity.[63] The availability, accessibility, acceptability, and quality (AAAQ) framework, developed by the UN Committee on Economic, Social and Cultural Rights, incorporates guarantees against abuse by the state and third parties as well as obligations to provide for the public health (panel 1).[64]

Within these human-rights frameworks, it is, as a general matter, neither acceptable for governments to declare that data on key populations are impossible to ascertain (and, thus, that well informed, evidence-based public health strategies for key populations are impossible), nor for these data to be gathered in ways that violate individual rights and liberties, except under very

Panel 1: Sections of the availability, accessibility, acceptability, and quality framework on the UN International Covenant on Economic, Social and Cultural Rights (general comment 14)[65] applicable to public health surveillance

- The rights to human dignity, privacy, and access to information, and the freedoms of association, assembly, and movement, addressing integral components of the right to health (paragraph 3)
- The right to control one's body and to be free from interference, including non-consensual medical treatment and experimentation (paragraph 8)
- The right of participation of the affected population in health-related decision making (paragraph 11)
- Information accessibility, which "includes the right to seek, receive and impart information and ideas concerning health issues. However, accessibility of information should not impair the right to have personal health data treated with confidentiality" (paragraph 12)
- Acceptability, which includes services that are "respectful of the culture of individuals, minorities, peoples and communities [...] as well as being designed to respect confidentiality and improve the health status of those concerned" (paragraph 12)
- Access along with proactive protections "especially [for] the most vulnerable and marginalized", requiring particular attention to the needs of groups such as key populations (paragraph 12)
- The right to prevention, treatment, and control of diseases, which includes "states' individual and joint efforts [...] to make available relevant technologies, using and improving epidemiological surveillance and data collection on a disaggregated basis" (paragraph 16)
- The obligation to protect the right to health includes the duty of states "to ensure that medical practitioners and other health professionals meet appropriate [...] ethical codes of conduct" (paragraph 35)

	Ethical implications	Human rights implications*
Scarcity of accurate data undermines access to services and resource allocation for key populations, necessitating HIV surveillance efforts	Ethical imperative to address public health priorities justifies the conduct of surveillance, although the benefits and risks of methods used must be weighed	State duty to collect disaggregated data and help vulnerable groups access the highest attainable standard of health (paragraph 16)
Requiring biometrics denies ability to participate in surveillance without disclosure of identifying information	Raises concerns over infringement of the principle of acquiring the minimal amount of information necessary	Right to seek and impart information and ideas concerning health issues without impairing the right to have personal health data treated with confidentiality (paragraph 12); right to control one's body (paragraph 8)
Technology is not always secure and data privacy might be unregulated	Infringes on obligation to ensure any data collected are securely protected	Protecting confidentiality is repeatedly expressed as a core state obligation (paragraph 12)
Identifiable data expose participants to risk of legal action or violence	Imposes substantial risk without direct benefit to the individual; imposes particular risks on vulnerable groups, which violates the ethical principle of justice in the distribution of both benefit and burden	Obligation to respect includes avoiding actions, policies, or laws likely to result in bodily harm or de jure or de facto discrimination, or that interfere with enjoyment of the right to health (paragraph 50)
Use of biometrics could suppress participation, resulting in artificially low size estimates and biased samples	Undercutting accuracy reduces the justification for infringing on liberty	State obligation to assemble accurate data and craft strategies that "shall give particular attention to all vulnerable or marginalized groups" (paragraph 43[f])
Potential to instil fear in criminalised groups about safety of public health services	Potential harm to individual and group wellbeing	Right to a system of health protection that provides equality of opportunity for people to enjoy the highest attainable level of health (paragraph 8); infringes on accessibility element of the right to health, which states that "services must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact..." (paragraph 12[b])
Groups representing key populations, when consulted, have opposed the use of biometrics and called for alternatives	Ethical obligation to meaningfully engage affected communities requires responding to communities' issues and concerns	Right of individuals and groups to participate in decision-making processes that might affect their development (paragraph 54)

*Cited paragraphs of general comment 14 on the UN International Covenant on Economic, Social and Cultural Rights[65] are shown in brackets.

***Table:* Issues associated with use of biometrics in HIV surveillance among key populations and the ethical and human rights implications**

rare circumstances.[66] Instead, key populations must be supported to realise these rights to access appropriate services and simultaneously to participate in efforts that impart information about themselves and their communities in ways that respect privacy and give attention to the special needs of vulnerable groups.[65] Governments of countries where surveillance activities take place and donor governments responsible for funding these activities through bilateral (eg, PEPFAR) and multilateral (eg, The Global Fund) mechanisms share these obligations as state duty bearers. HIV surveillance activities, however, often involve or are carried out by non-governmental organisations, universities, or other non-state actors. In such contexts, governments have regulatory power and a duty to ensure that their own agents and those they fund act appropriately when conducting surveillance activities, that the funding they provide is used in appropriate ways, and that policies are in place to ensure that activities of non-state actors meet rights-based standards.

Concerns about use of biometrics in contexts of criminalisation

Use of biometrics in public health surveillance among key populations raises several ethical and human rights concerns that must be considered by public health personnel, researchers, research ethics committees, and governments when determining whether it is appropriate to implement this approach (table).

Size estimations and HIV surveillance activities focused on key populations help meet a legitimate public health need: recognising and making visible a population of people at elevated risk for HIV, for whom health-related resources can be made available in the form of testing, prevention, and treatment programmes. Such activities are crucial in fulfilling states' obligations under the right to health to ensure fair distribution of health resources. However, these surveillance efforts mostly do not themselves provide a direct benefit to participants, and the balancing considerations therefore differ from those relating to the use of technologies directly in programmes to support treatment and care. The use of biometric identifiers can also infringe on the right to privacy, because individuals must connect sensitive personal health and life issues to a marker of identity that is not possible to discard. In an environment of criminalisation, this concern is acute.

Of 195 countries in the world, at least 72 criminalise same-sex practices, including several countries that apply the death penalty.[67] Selling sex is also directly criminalised in at least 50 countries, and a range of criminal and administrative laws are used to prosecute sex workers, including loitering laws that criminalise sex workers in nearly all countries.[68] Possession of commonly injected drugs for personal use is illegal in almost all countries, with over 20% of people incarcerated worldwide imprisoned for drug crimes.[69] In addition, migration status can exacerbate criminalisation dynamics because undocumented migrants, as a whole, face risk of arrest and deportation, and a lack of legal status can push people into criminalised work and deny access to basic protections and services that might otherwise be available, even to key populations.[70] Criminalised populations face state-sponsored threats that go beyond arrest. In many locations, key populations are often subject to harassment, violence, and, in the extreme, extrajudicial killings at the hands of police and other state actors.[71–74] In such contexts, the collection of identifiers requires disclosure of a status that, if known by the state, would open people to an elevated risk of harm.

The creation of an identity-linked database of criminalised people itself opens up possibilities for misuse that would not otherwise be available. For criminalised people, self-identifying in health programmes often presents risks. For example, clinics for sex workers, people who inject drugs, and men who have sex with men have been raided by police to gather information about the identities of people labelled as criminals.[75,76] Numerous cases of data about key populations being obtained forcibly by state and non-state actors have also been reported, with patient records made public, including names and photographs.[77–80] However, as individuals receive services through clinics and other programmes for key populations, the specific benefits of accessing these services might outweigh the risks. By contrast, in surveillance, an aggregated database creates a centralised risk that small key population-specific clinics do not, and the benefits are non-specific.

Of most concern is that these databases could be accessed to reverse-engineer a list of people designated as criminals. Identification becomes increasingly feasible because more jurisdictions are turning to biometrics for basic public data and identification purposes, from voter registration to money transfers.[81] Rothstein[82] expressed concern that substantial evidence exists that deidentified data can be reidentified by triangulating basic elements of a person's identity. This possibility presents the very real potential for data anonymised at the point of collection to be cross-matched with other databases, thereby permitting the identities of participants to be revealed.[34]

In addition, databases might be exploited on a one-on-one basis, in which someone with access could compel a person in their presence to scan their fingerprint or other biometric to check if they are in the database. This threat is not just theoretical. For example, in 2017, there were reports of police targeting of sex workers in China through biometric identification.[83]

When HIV surveillance among key populations is done by state actors, there are real and perceived risks that governments might not distinguish effectively between law enforcement, national security, and public health activities. Breach of confidential health data is common around the world, even from well designed and protected systems.[84] Regardless, in some settings, health workers are obliged to make data on key populations available to the police, as in the case of drug-user registries in some eastern European and central Asian countries.[69]

Use of biometrics could also distort surveillance efforts and lead to undercounting because of biased samples: if potential respondents know that biometric data are required, some might choose to avoid participating, especially those most concerned with the risk of exposure. After all, fingerprinting is often associated with law enforcement.[85]

Finally, where HIV surveillance activities are done at health clinics and through service programmes, fingerprinting at these facilities might cause people to avoid using them. As the Kenya Key Population Consortium

Panel 2: Appropriateness of using biometrics in HIV surveillance of key populations by type of jurisdiction, along with sources of data to supplement local legal analyses

Group 1*

Jurisdictions in which a given population is criminalised either by statute or in practice (for example, where indecency or loitering laws are used against men who have sex with men or sex workers, criminalisation occurs even where statute is not explicit).

Sources of data

- International Lesbian, Gay, Bisexual, Trans and Intersex Association (https://ilga.org/maps-sexual-orientation-laws; for men who have sex with men)
- Sexual Rights Database (http://sexualrightsdatabase.org/; for sex workers)
- Institute of Development Studies Sex Work Law (http://spl.ids.ac.uk/sexworklaw; for sex workers)
- The Global State of Harm Reduction (https://www.hri.global/the-death-penalty-for-drug-offences; for people who inject drugs)
- The Death Penalty for Drug Offences (https://www.hri.global/statplanet/global-hr-response; for people who inject drugs)

Appropriateness of biometrics

Use of biometrics cannot be justified. Alternatives should be used.

Group 2*

Jurisdictions in which a given population faces high levels of social stigma and marginalisation.

Sources of data

- People Living with HIV Stigma Index (http://www.stigmaindex.org/)
- Surveys of key populations to establish levels of stigma and marginalisation

Appropriateness of biometrics

Use of biometric identifiers cannot be justified. Alternatives should be used.

Group 3

Jurisdictions in which a given population is not criminalised but has no explicit protections and where stigma against a given population is relatively low.

Sources of data

- Sources listed for groups 1 and 2

Appropriateness of biometrics

Use of biometrics can be considered, with safeguards in place. Where no legal protections for the key population exist, these safeguards must include strong and explicit prohibitions on the disclosure of data, including liability and criminal penalties for such disclosure. Strong justification is needed for why these data are necessary to merit the risk. Alternatives should be carefully considered.

Group 4

Jurisdictions in which a given population is overtly protected by laws and policies prohibiting discrimination, and in which stigma against a given population is relatively low.

Sources of data

- Sources listed for groups 1 and 2
- Local knowledge covering legal protection of key population groups

Appropriateness of biometrics

Use of biometrics can be considered, with safeguards in place, which must include strong and explicit prohibitions on the disclosure of data, including liability and criminal penalties for such disclosure.

*Groups 1 and 2 can overlap

Search strategy and selection criteria

To identify reports of HIV surveillance studies among key populations, we searched PubMed and the Georgetown University One Search database through April, 2018, using the terms "size estimate", "surveillance", and "HIV prevalence", along with variations of terms for "men who have sex with men", "sex workers", and "people who use drugs". We then added terms associated with biometrics, including "biometrics", "fingerprint", "finger scan", "iris scan", and variations including truncated terms and abbreviations. We reviewed articles resulting from these searches, citing those of direct relevance in this Review. In our analyses, we adopted broadly accepted approaches to ethics and human rights frameworks.

suggested, "use of biomarkers—finger printing, iris scanning, toe scanning—will introduce fear and uncertainty among communities facing criminalization about the safety of healthcare clinics. This will serve only to drive people away from healthcare and reduce participation in the [study]."[85]

The use of biometrics is not the only area in which new tools for data gathering in the context of HIV are triggering similar concerns. The use of phylogenetic analysis, for example, which uses viral genetic sequence data to infer transmission patterns, raises similar concerns about privacy and misuse in contexts in which HIV transmission is criminalised.[86]

Typology for use of biometrics and alternatives

The use of biometrics in HIV surveillance of criminalised populations cannot be ethically justified when the risks outweigh the benefits and core human rights are infringed upon. On this basis, we propose four broad typologies of settings with regard to the acceptability of using biometrics in surveillance (panel 2). Group 1 includes contexts characterised by criminalisation of a given population in law or in practice, group 2 where a population faces high levels of social stigma and marginalisation, group 3 where a population is not criminalised and faces low stigma, and group 4 where stigma is low and laws overtly protect a population from discrimination. Each subpopulation must be considered differently because the risks are not universal between groups in a given country. On the basis of the data sources listed, most jurisdictions will fall into group 1 or 2 for most key populations.

Our proposed typology should be helpful for identifying where biometrics might be considered, but actual decision making must take into account the local context and lived reality of the groups for whom surveillance with biometrics is being considered. In particular, the word "criminalised" is used here to reflect de facto law (ie, the complex interplay of written law, police enforcement, and judicial interpretation which requires looking beyond simply what is found in written laws and regulations [de jure law]). For example, a jurisdiction might seem to fall into group 3 (ie, populations are not criminalised but not legally protected, stigma is low) if it has no ban on sodomy, but, in practice, men who have sex with men might still face arrest and police harassment on the basis of broader indecency laws. In addition, in some contexts, people who inject drugs might have de jure protections against criminal penalties that are not actually exercised de facto and, thus, such jurisdictions could not be said to fall into group 4 (ie, populations have legal protection and stigma is low). Where other criminalised groups are the subject of similar surveillance activities because of locally elevated HIV risk, a similar analysis is needed. For instance, undocumented migrants are subject to criminal and immigration penalties that are likely to make biometric HIV surveillance inappropriate.

Conclusion

The rise in the use of biometric technologies has paralleled increasing recognition of the need to overcome barriers to gathering data on populations that are both at increased risk of HIV and whose identities and activities are often criminalised. Biometrics have been proposed, and in some cases implemented, in health surveillance and population size estimation of key populations to simplify the gathering of data and address duplicate participation. In many contexts, concerns have been raised that the very factors of criminalisation and stigma that drive increased risk of HIV and necessitate well done surveillance also mean that use of biometrics could contribute to artificially low estimates, while increasing safety risks and undermining access to services for individuals. We have examined these concerns in light of public health ethics and human rights doctrine. Exploring issues of privacy, data security, and perceptions of the health-care system reveals that collection of biometric data from criminalised populations can introduce substantial risk, while alternatives are available that allow for the least infringement on rights and safety. Without a clear link to an HIV prevention or treatment programme associated with individual health benefits, a well grounded justification is needed before additional risk is introduced. We propose a typology for assessing the appropriateness of biometrics in HIV surveillance among key populations on the basis of local legal and social environments. In many countries, the use of biometrics in criminalised populations is not likely to be appropriate given the current state of affairs. Technology is evolving rapidly and, with it, the ease with which personal data can be collected, stored, and retrieved, including data that could associate individuals with criminalised work, activities, and identities. Failing to address the real and perceived implications of doing so could undermine the effectiveness of HIV surveillance efforts and trust in the AIDS response as a whole. Clearer policies that address the use of biometrics in HIV surveillance activities and are responsive to ethics and human rights concerns are needed for governments, research ethics boards, and funding agencies.

Contributors

All authors conceptualised the article. MMK drafted the initial manuscript for which SDB, MM, and JS each drafted specific sections. All authors edited drafts, made critical revisions, and approved the submission of the final version.

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