Artificial intelligence

and big data:

Risks and benefits

to the HIV/AIDS response

KONG, Jolene Yiqiao[1]; BURZYNSKI, Richard[2]; and WEBER, Cynthia[3] 2019

---

[1] Masters student, Graduate Institute, Geneva, Switzerland
[2] Senior Advisor, UNAIDS, Geneva, Switzerland
[3] Professor of International Relations, University of Sussex, United Kingdom

Executive Summary

Over the past few years, digital technologies, big data and artificial intelligence (AI) have emerged as a significant force in the response to HIV. These tools will speed up clinical research and improve access and delivery of HIV services. However, these tools also present challenges to the people-centred approach that characterizes the HIV/AIDS response as the potential for human rights violations increase.

Through case studies and scenarios, this paper explores three forces that intersect on this issue: the role of stakeholders to reach the globally agreed upon final target of zero new HIV infections, zero discrimination and zero AIDS-related deaths,the technological advances and their availability, the political narratives framing AI and its uptake, and how the HIV/AIDS response needs to evolve considering the above.

It concludes by highlighting three key considerations for the future of the HIV/AIDS response to limit human rights violations as new forms of fear, stigma and discrimination evolve in the digital era.

Introduction

This paper highlights the emergence of new technologies and digital tools and how they challenge human rights in the context of HIV/AIDS. It also focuses on the challenges that HIV/AIDS response faces in this new digital era.

Today, the HIV/AIDS response incorporates the use of digital technologies, big data and artificial intelligence (AI) to accelerate ending the AIDS epidemic as a public health threat. These tools relate to HIV testing, prevention, care and treatment. Their use will increase ahead and is likely to be common in the near future – the next generation HIV/AIDS response.

On a positive note, digital technologies, especially AI, will affect the HIV/AIDS response in multiple ways. They can speed up clinical research; increase operational efficiencies of testing, diagnosis, care and treatment; reduce the need for human capital; improve access to health-care services in remote areas, and much more. However, such technologies also present challenges and risks that threaten the human-centric approach championed by UNAIDS and other stakeholders and threaten to increase human rights violations of people seeking HIV services.

Another challenge is how to interpret, mobilize and understand the use of digital technologies, including AI, in HIV/AIDS prevention, care and treatment services.

The main purpose of this paper is to examine the choices for the HIV/AIDS response that incorporates digital technologies, big data and AI to provide for the populations they serve, while confronting the human rights concerns that these tools raise.

The three forces

Three forces are intertwined in this issue: how stakeholders need to evolve the HIV/AIDS response, technological advances and their availability, and political narratives that frame AI and its uptake.

The first force focuses specifically on stakeholders – the United Nations system, governments, the private sector, global institutions and people living with and most affected by HIV/AIDS – and how they achieve universal access to HIV prevention, treatment, care and support while concomitantly ensuring zero discrimination, the third prong of the globally agreed upon strategy of zero new HIV infections, zero AIDS-related deaths and zero discrimination *(1)*. There are future decisions on how to catalyze the next generation HIV/AIDS response to remain rooted in a human rights framework.

The second force is the rise of the digital era. In conjunction with rapid technological progress—especially in the arena of big data and AI—the medical system has evolved in both appearance and content. Health-care services and the social process of health care have been reshaped by the digitalization of medical records; the use of connected health or technology-enabled care for health providers, patients and insurance companies; and the invention and implementation of devices such as activity trackers, multi-measure wellness tools and diet tools *(2)*. How stakeholders catalyze the HIV/AIDS response is inevitably influenced by this context. It provides both opportunities and risks to the strategic planning of the response.

The third force concerns the political narratives and framing of big data and AI, and their impact on the HIV response. The narratives of AI can be classified into three accounts: the dystopian account of AI driven by fear, the ethical account of AI driven by hope, and the entrepreneurial account of AI driven by the desire for freedom from both state regulation and individuals' full and sustained ownership and control of their personal data *(3)*. These three accounts compete and combine at different levels of strategic planning and policy making towards the next generation global HIV/AIDS response, affecting how stakeholders position themselves and pitch the idea of using AI to end the HIV/AIDS epidemic as a public health threat in its advice to governments.

A recent "AI for Health" workshop organized by the International Telecommunications Union and the World Health Organization was framed around an ethical narrative driven by the hope that AI would be made safe for the greater human good, and help international organizations, governments and civil society to achieve the Sustainable Development Goals and a better life for all *(3)*. Yet some participants were more aligned with the freedom narrative than the hope narrative, emphasizing the profit-making potential of selling medical data collected by the very same apps the ITU and WHO want to mobilize for the greater good. How these narratives combine, align, contradict, and potentially undermine one another is crucial in the crafting of public health policy, for HIV/AIDS and more widely.

These three forces react and intertwine with each another, requiring the next generation HIV/AIDS response be evaluated so that dignity, security, and human rights of people living with HIV can be assured. Current concerns about digital technologies and AI revolve around the privacy, confidentiality, and actual safety of people seeking HIV services. However, looking beyond the issue of privacy, the use of AI and other technologies could change the human-centric nature of the HIV/AIDS response and thus jeopardize reaching the goal to end the HIV/AIDS epidemic as a public health threat.

To provide some answers to this question, this research takes some preliminary steps to find out how new technologies, big data and AI are being implemented for HIV prevention, care and treatment services. It is then necessary to analyse the benefits, concerns, risks and possible implications of using such technologies, especially as it affects vulnerable groups, in the next generation of the global HIV/AIDS response.

In this paper, the research purpose is tackled using a case study analysis. Two scenarios are created based on current situations and trends, posing problems for the AIDS response to solve in the context of the research question. Both cases are based on existing technologies, but the scenarios are fictitious and inspired by current or emerging trends. The first case focuses on HIV testing, and the second on prevention and treatment. Both these components will need to be scaled up to achieve the overarching global strategy of the three zeros.

A quick overview of the HIV testing, prevention and treatment approach

What is the HIV testing, prevention and treatment approach, and where might digital technologies, big data and AI appear in the HIV/AIDS response?

In 2013, UNAIDS released the new targets for ending the AIDS epidemic as a public health threat: the 90–90–90 targets. The aim is that, by 2020, 90% of people living with HIV know their HIV status, 90% of people who know their HIV-positive status are accessing treatment and 90% of people on treatment have suppressed viral loads. In most parts of the world, large numbers of people who have HIV do not know their HIV status, attend medical services, receive effective treatment or have their HIV levels effectively suppressed. For instance, approximately 25% of people living with HIV globally were still unaware of their HIV status. Young people aged 15–24, adult males and people from key populations (gay men, other men who have sex with men, transgender people, sex workers, people who inject drugs, and people in prisons and other closed settings) often have significantly lower access to HIV testing services for a number of reasons, are less likely to be linked to treatment and care, and have lower levels of viral suppression *(4)*.

To end the HIV/AIDS epidemic as a public health threat, these gaps need to filled. While prevention takes many forms, making sure that people living with HIV know their status is an important step. In terms of HIV prevention and treatment services, testing and diagnosis is required. For the HIV response today, antiretroviral therapy (ART) is used for both treatment and prevention (pre-exposure prophylaxis—PrEP). Technology-based interventions can be employed at various stages in

treatment, prevention and care to achieve specific outcomes and globally or nationally-agreed upon targets.

Case studies

- **Scenario 1: New HIV diagnostic tool**

Researchers and corporations have released a new home testing device onto the market: a low-cost (around US$ 35) smartphone gadget that can detect HIV status in 10 minutes (see Figure 2). With a plug that connects to the audio jack of the smartphone, users simply need to download the software from app stores, prick a drop of blood from fingertips into the device cassette, and wait for the application to analyse the result. This case study is designed to help stakeholders analyse the benefits and risks of the new HIV diagnostic tool and provide guidelines to country offices and field workers before promoting use of the device.
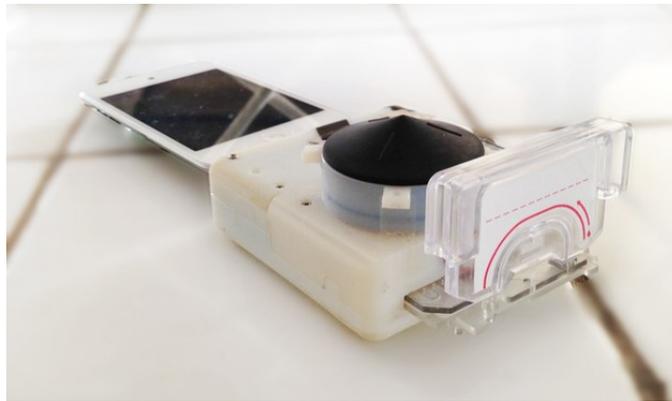
Figure 1   Example of the device

<u>Background</u>

Efforts have been made to scale up HIV testing, including expanding testing centres, and launching testing programmes and hospital screening initiatives. However, issues such as the feasibility of reaching all individuals (especially high-risk groups), associated stigma and fear, inconvenience, high costs and a lack of privacy have hindered the execution and progress of HIV testing and diagnosis. As a result, only people who have access to HIV health-care services have been reached. To reach a wider audience for HIV testing, home-based HIV testing was introduced and achieved promising results in resource-limited settings and among high-risk groups *(5)*.

There are two different kinds of home testing: home tests and home-collection tests. Home tests usually require an individual to purchase a self-test kit in pharmacies, collect specimens with the help of the self-test kit, and interpret the results without the aid of health professionals. These home tests are also called HIV rapid diagnostic tests (RDTs). Home-collection tests require individuals to collect specimens at home and mail them to a laboratory for professionals to conduct

tests; the individual receives the result of the test a few days later *(6)*.[4] With the introduction of home tests, people without access to testing centres because of the fear of stigma can take an HIV test at a low cost.

Scenario analysis

The smartphone gadget mentioned in the scenario is no futuristic fantasy. Similar self-testing devices have already been invented, and it might only be a matter of time until such devices would be mass-produced and distributed. Researchers and scientists have been trying to make self-test devices cheaper, smaller, more convenient and more accurate. These innovations are intended to greatly improve the lives of many, especially key populations who are more susceptible to the fear of stigma. Self-testing using the new HIV diagnostic tool is intended to be completely private and confidential. Purchasing the device is anonymous and testing and using the smartphone app do not require users to share any personal information. This new HIV diagnostic tool would bring HIV testing to resource-limited areas, where laboratories or professionals are difficult for people to reach. The only prerequisite is for users to own a smartphone, which might be a hindrance for many people. Although the rates of smartphone ownership in emerging and developing economies are climbing at an astounding rate, fewer than 50% report owning a smartphone in 12 of the 22 countries surveyed *(7)*.

This innovative diagnostic tool seems to be in perfect alignment with the three forces mentioned earlier. First, it responds to the UNAIDS strategy to achieve the three zeros: zero new infections, zero HIV-related deaths and zero discrimination. The 90–90–90 targets are an important approach to achieve the three zeros. Second, the new HIV diagnostic tool uses digital technology and AI to speed up HIV diagnosis, reduce its cost and reach out to a massive population. Third, it coincides with the ethical narrative that digital technologies and AI will be a hope for mankind and provide solutions to existing problems. These three forces brought about the birth of such devices, and many more will be invented in the near future for the next generation response.

Before we are driven into this "hope" narrative, the issues around this device need to be scrutinized. Indeed, security for mobile apps is an issue across all sectors. The device and mobile app mentioned in the scenario have three major risks, as discussed below.

Risk 1: Is there informed consent by users?

The two biggest platforms for mobile apps, Apple iTunes and Android Play Store, compete with each other on the number of application programming interfaces (APIs) they expose to third-party developers. When more APIs are accessible, developers can add more functionality and develop

---

[4] Current home-collection tests require users to order a test kit online or from pharmacies at around $US 40–60. Using a lancet (sharp instrument) inside the kit, users prick their finger and drop a blood sample onto a piece of paper in the kit. The sample is put in an envelope and sent to a laboratory for HIV testing. Using a code given in the test kit, the user can call the toll-free number a few days later to obtain results anonymously.

more complex and appealing functions to attract more users. Many of the APIs include the ability to gain access to sensitive functionality and/or user data if permitted by users. In addition, many apps upload and store user data in their databases to allow better performances and more accurate analysis of results through AI algorithms.

However, the fact that Android, for instance, allows developers to choose from more than 130 possible permissions makes it unrealistic for users to exercise informed consent over their permissions and rights *(8)*. Most users of a mobile app will not read all terms and conditions. Even if a user does read carefully and give consent to the regulations, this does not constitute informed consent, for the following reasons. First, the scope of analytics is unclear at the time of data collection, because users have no knowledge about when their behaviours are tracked. Second, secondary data usage is unclear, because data could be sold or shared with third parties, so that users completely lose control of the data.

As a result, most users could not identify what they have agreed to and what they are giving up. Once the HIV test is completed and uploaded, how the information is stored, used, transferred or exchanged is out of the hands of the users. Misuses and exploitation of user data are highly possible, which could jeopardize the confidentiality of home-based test participants and lead to possible stigmatization of HIV-positive users.

Risk 2: Do people feel safe?

Ensuring the confidentiality of patient information is extremely important for HIV services. It concerns each individual who seeks HIV services, especially key populations and people living with HIV. Studies have shown that, when confidentiality settings are ambiguous to people living with HIV seeking help, they are often reluctant to engage with these services *(9)*. This is because of the longstanding discrimination and stigmatization faced by people living with HIV in many parts of the world. Despite years of public education, HIV/AIDS continues to be seen as contagious, severe, life-threatening, and presumably the result of a norm-violating behaviour such as commercial sex work, homosexuality or promiscuity *(10, 11)*.

The feeling of safety and security is the main reason people prefer home tests. As mentioned above, associated stigma and fear, inconvenience, high costs and a lack of privacy are the main reasons hindering the execution and progress of HIV testing and diagnosis.

Current home tests such as RDTs are mostly blood-based (finger prick/capillary) or oral fluid-based tests that produce results in less than 30 minutes. The cost of HIV self-test kits varies from $US 0.50 to $US 50. Because RDT kits can be purchased online or at pharmacies, the test result can be with totally anonymous.

The new HIV diagnostic tool mentioned in the scenario is a digital version of an RDT that requires less time for testing. It can also be reused multiple times. The main difference between current RDTs and this new HIV diagnostic tool is the involvement of data that change a home test from being totally anonymous to being partially anonymous; in the context of big data, no "personal"

data are personal, and anonymity cannot be assured. As personal data are routinely being anonymized, AI can be employed to de-anonymize data by linking personal data to public data. In this process, HIV-positive people could be misclassified, misidentified, discriminated against and judged negatively through the automated decision-making features of AI. People who are aware of this issue may refrain from using this device; others may be attracted by the convenience of the device and bear the risks of information leaks. The next section focuses on their information safety.

Risk 3: Are users' data really safe?

Again, in the big data era, no "personal" data are really personal. Indeed, data collected belong to app developers. They could be the entrepreneurs who invented this app or big corporates who own many apps.

In September 2018, an entrepreneur who invented a mobile app for scanning skin images and detecting skin diseases using machine learning spoke at a workshop organized by the International Telecommunications Union and the World Health Organization. He mentioned that his goal is to make money, and data collected (images of people's skin problems and AI analysis) by the mobile app are the most important asset of his company. He actively seeks to sell his data to people who might be interested, such as academic engineers or dermatologists who need data for research and publication. People who trusted this mobile app uploaded their personal images, which have now become a personal asset of the entrepreneur.

This incident illustrates a tiny edge of the enormous structure of the big data business model. In the profit-driven reality, companies track online activities and then sell these data or results of analytics to other parties as a major source of income. To most entrepreneurs, making money is the priority, rather than users. Their interests are profit-centred. Therefore, user data can be traded or exchanged for money among business enterprises for profit, with no consent needed from users. This illustrates how – even under the umbrella of a wider ITU and WHO hope narrative that seeks only to use 'AI for good' – an entrepreneurial freedom narrative may value profits over users, putting users at greater risk. Because an entrepreneurial freedom narrative is profit-centred by being data-centred, it also conflicts with the human-centred approach that has characterized the HIV/AIDS response by so many stakeholders, chief among them UNAIDS programme. The humans that the UN wishes to protect are people seeking HIV prevention, care and treatment services. In the current context, where new technologies and AI are prevalent, the UN mission to protect humans has to expand into the field of protecting "data about humans".

Current legislative measures allow and encourage freedom of such business activities. The European Union General Data Protection Regulation (GDPR) takes a stricter approach to privacy protection of individuals, but in most parts of the world regulations on personal data are loose. Governments also systematically collect data without user consent through the linking of unrelated government databases, monitoring of social media and online activities, and blanket collection of phone records without cause. These actions are opaque to individuals, with no clear standards for privacy and individual data protection.

<u>A potential role for stakeholders</u>

Many stakeholders might be involved when people are using this home-testing device: entrepreneurs, big enterprises, government authorities and so on. The aim of the entrepreneurs and big enterprises often is to make as much money as possible through the data they can obtain. Government authorities might want to increase surveillance over public health, or to criminalize certain groups of people through findings obtained using big data analysis. None of them have the same responsibility as the UN, which is to serve people who seek HIV prevention, care and treatment services, and defend their dignity and rights. People might be experiencing stigmatization, discrimination and other unfair treatment in the meantime, and their plight could be worsened with the widespread distribution of their personal data through this new HIV diagnostic tool. The next generation HIV/AIDS response needs to thoroughly account for these risks and benefits from the standpoint of individuals using the new HIV diagnostic tool before these devices are distributed on a massive scale.

Table 1 Comparison of current RDTs and the new device

	Current RDTs	**New HIV diagnostic tool**
Time	30 minutes or less	10 minutes or less
Cost	US$ 0.50–50.00	US$ 35 (smartphone as a prerequisite)
Validity	One time	Multiple usage
Data storage	No storage	Online storage
Test data ownership	User has complete control of test result, and can choose to divulge this information to whoever.	User has no control about who the information goes to. App developer could sell user data to other parties.
Anonymity	Anonymous	Anonymity in question

In a digital age, the hope narrative and the freedom narrative seem to be advantageous because people tend to think that digitalization is better than the old-fashioned ways. Digitalization has become a new symbol of modernization; it is believed to be "smarter" and thus "better". These political narratives about the use of digital technology are so techno-optimistic that policy-makers may not think thoroughly before promoting this technology further. This optimism about technology use could be quite risky.

The interests of people seeking HIV self-testing are not sufficiently prioritized in this scenario. The human-centric character of HIV testing risks being displaced by a technology that promotes efficiency, data generation, and likely profits at the expense of user privacy and the security of user data. Should this happen, users of this new HIV diagnostic tool could be worse off than if they used existing offline RDTs.

The next generation HIV/AIDS response needs to consider how to make sound judgements about these tools to protect key populations. Stakeholders will need to ensure that the next generation response to end the HIV epidemic as a public health threat be centred around the protection of human dignity and rights. In the digital age, this will need to include the protection of data about humans. Whenever new technologies are invented for HIV services, stakeholders need to consider the following questions: Is the new technology really better, and should it be cultivated to replace the old methods? Whose interests are satisfied, and whose might be harmed?

If this new device is to be used, a few changes and preliminary measures need to be implemented to ensure user safety. First, the test could be created as an offline app, and no test result could be saved, stored, leaked, or uploaded. Second, stakeholders will need to consider how to best ensure that users are informed about the possible risks. Third, stakeholders should make sure that RDTs are not completely replaced, so that people have an alternative choice that allows them to keep full control of their test results.

- **Scenario 2: Using ART to achieve zero new infections**

ART can be used for both treatment and prevention. Because of the high prevalence of HIV among key populations, a few governments have decided to identify key populations and people living with HIV by using big data analysis and AI to monitor and track social media accounts, dating apps and other online activities. Individuals identified by the government would be tested and automatically listed as ART treatment recipients, for either prevention (PrEP for HIV-negative people) or treatment. Public opinions on such measures are extremely mixed. Stakeholders need to consider the benefits and risks associated with the measures.
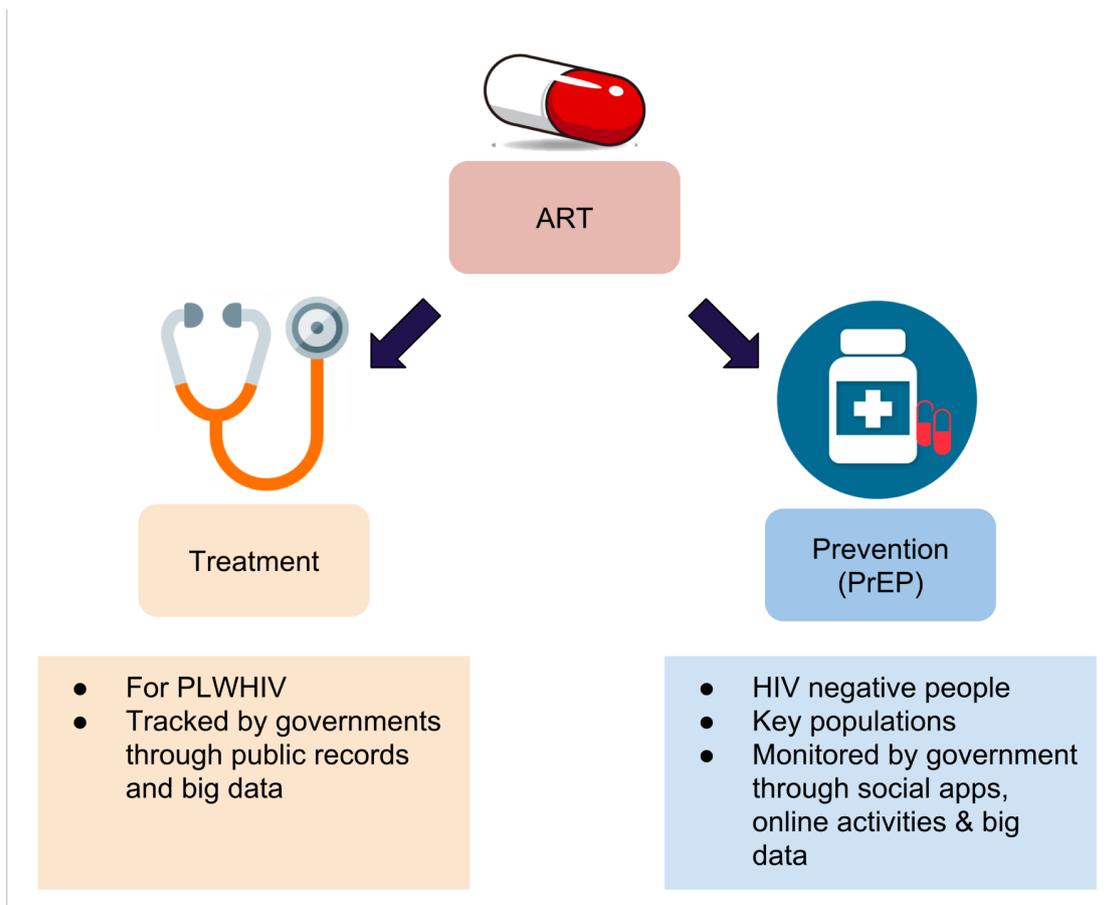
Figure 2   Visual illustration of the scenario

<u>Background</u>

ART can be used for both treatment and prevention, which are the two prongs for achieving zero new infections, zero discrimination and zero HIV-related deaths. In recent years, the number of adults acquiring HIV is decreasing too slowly, and in some key populations it is still rising *(12)*. In 2018, key populations and their sexual partners accounted for 53% of all new HIV infections globally. In some countries and regions, infection rates among key populations are extremely high—for example, HIV prevalence among sex workers varies between 50% and 70% in several countries in southern Africa.

Key populations at risk of HIV/AIDS include sex workers, people who inject drugs, transgender people, gay men and other men who have sex with men, and their sexual partners. In many regions, they commonly experience stigma, violence, discrimination, criminalization and harassment. Many governments criminalize same-sex practices through imprisonment or the death penalty, while many more governments criminalize sex workers and people who inject drugs *(13)*. The fear of stigma and criminalization hinders key populations in accessing health-care services and makes it difficult for health workers to reach out to them.

Gathering accurate data on key populations is difficult in almost all regions *(13)*. Current challenges faced by health workers are mainly about how to estimate the size and geographical distribution of

key populations; how to reach out to them in society; how to include them in testing, prevention and treatment programmes; and how to make sure they take their medications regularly. These challenges are also faced by health management efforts at country and global levels. Countering these challenges is the main approach for the next generation HIV/AIDS response to catalyse the response effectively in order to reach zero new infections.

Currently, of the new technologies for prevention programmes targeting key populations is PrEP. PrEP uses ART to prevent people from acquiring HIV. It is targeted at HIV-negative people who are at substantial risk of acquiring HIV (i.e. the key populations). Prevention using ART has been tested and proven effective, and when taken correctly and adherently PrEP reduces HIV infection rates by up to 90% compared with placebo *(14)*.

Increasing numbers of countries have decided to implement PrEP programmes as one component of their national prevention strategy against HIV/AIDS. Currently, such efforts happen in a bottom-up manner with substantial advocacy and community work at local levels. PrEP delivery is starting in a few places where locally trusted providers are working with communities to respond to early demand for PrEP. Service providers are trained to provide high-quality HIV testing to identify people who are HIV-negative, at substantial risk of HIV, and ready to have ongoing follow-up and regular HIV testing. The programme is voluntary and inclusive; participation in, and withdrawal from, the programme depends on each individual *(14)*.

PrEP is a key prevention measure increasing promoted today by various stakeholders, particularly for gay men and other men who have sex with men. It might be the main programme to be adopted to end the HIV/AIDS epidemic within this group in the future. Its importance is gradually being recognized by governments, and it may be further developed or implemented as part of national health-care programmes.

Scenario analysis

There are two main controversial issues in the scenario. First, governments are using AI and big data surveillance to "identify" HIV key populations and people living with HIV. Second, governments are making prevention and treatment using ART a compulsory programme for the identified key populations and people living with HIV.

Although this scenario is fictitious and no governments are practising these measures at the moment, technologies for identifying certain groups of people are readily available, and it might only be a matter of time and choice for some countries to make this scenario a reality. This would require governments to be able to identify and track those people they would require to take ARTs. AI and big data traces promise to make both identification and tracking of some key populations possible. For example, some scientists and researchers are working on AI algorithms that they claim identify LGBTQ+ people through facial recognition and language habits *(15)*. This research – which GLAAD - an American non-governmental media monitoring organization founded by LGBT people in the media - and the Human Rights Campaign have labelled 'junk science' *(16)* – is extremely dubious for several reasons. First, using AI to read public faces or public utterances is a

social (if not always legal) invasion of an individual's privacy. Second, using AI to accurately predict an individual's sexual orientation is highly contested, as is the very existence of a stable 'sexual orientation' that naturally corresponds to an individual. Third, an AI-generated sexual orientation may bear no relation to that individual's conduct or self-perception *(17)*.

Even if AI identification techniques are discounted, big data traces can reveal a great deal of personal information about individuals. For example, dating apps, social media accounts, query data for on-line searches and other online apps all leave traces of personal information. After running these data through big data analysis and AI, hidden patterns and connections could be unravelled, exposing more information than people realize. These data can and have been used in the HIV response. For example, a 2018 longitudinal study in China used search query data relating to HIV and combined it with national statistics to estimate the number of new HIV diagnoses in China's Guangdong province *(18)*. Because search data query was positively associated with new HIV diagnoses and was location specific, researchers claimed it could improve nowcasting and forecasting new HIV diagnoses in China 'up to the province level'. This enables the allocation of testing kits, funds for information campaigns, and supplies of antiretroviral therapies to be targeted. In this and other studies, data was anonymized. However, these technologies can be used to identify specific individuals

These two controversies are analysed separately below.

1. Using AI and big data surveillance to identify key populations and people living with HIV
The word "identify" is ironic in this case, because new categories of people are created rather than identified by AI. Big data algorithms that are written by people often classify other people into inaccurate binaries: gay and straight, male and female, and so on. They incorrectly equate sexual activity with sexual orientation, as men who have sex with men are not necessarily gay. In addition, the way people portray themselves on dating sites may not necessarily reflect their behaviour in offline contexts. People are being "identified" as "homosexuals" or "transgender"—terms that are historical, cultural inventions and are not natural facts, but are based on sexualized stereotypes *(17)*. AI algorithms create falsifiable categories of people and sort people into these categories. People are at risk of being "identified" into categories that do not necessarily resonate with them.

Technological advances and AI seem to have supplied some easier, more convenient and more cost-effective ways of "identifying" key populations and people living with HIV among millions of people. Instead, they are displacing the human-centric nature of self-identification with AI-centric machine-made decisions. Governments and the general public are also getting used to the techno-optimistic narrative of the use of AI, because it makes faster decisions. However, the technology could be a Pandora's box for government authorities, because opening it might threaten individual human rights and curtain individual civil rights.

Risk 1: De-centring of humans

As mentioned above, AI algorithms displace the human-centric nature of self-identification and self-consciousness. As a person's profile is being analysed by AI, what the machine sees is not a person

but a data double that is created by a machine as a substitute for the person themselves. Algorithmic conclusions about this data double are further biased because they often reply upon pre-set prejudices and stereotypes (e.g., about gender and sexuality). As a result, many people will be wrongly categorized by AI algorithms. Wrongly identified people may be discriminated against and criminalized (for example, for not taking ARTs).

This scenario demonstrates how the replacement of people with data doubles threatens to displace or even replace the human-centred approach that promoted by many stakeholders with technology-centred AI. Should ART programmes and AI be combined in these ways, this could lead to a loss of human dignity for key populations and a curtailment of human and civil rights for these populations. This may well amplify the fear key populations have in participating in ART programmes, which could jeopardize individual health as well as the UNAIDS strategy of achieving zero discrimination.

Risk 2: Uncurbed access to personal information by other stakeholders

A boundary needs to be established regarding other stakeholders' access to private information, even when it is for a "beneficial" purpose. In this scenario, individual citizens have no control over their personal information, as their data stored on social networking apps and dating apps are owned by private companies. These data might be traded, sold or shared without user consent.

Also, in many countries, governments could gain access to these data with little or no barriers. In this scenario, government surveillance was conducted with an ethical purpose of ending the HIV epidemic and protecting civil citizens from illness. It seems to be in line with the global HIV/AIDS response. However, the method adopted is associated with major risks that would outweigh the benefits, as it seriously violates the principle and target of zero discrimination.

The phenomenon of multi-stakeholder involvement could be analysed through the three narratives of AI. The fear narrative illustrates government behaviours of using AI for power and control, which in this case means rolling out a public health agenda that would surveil key populations and potentially criminalize individuals who do not comply with ART government protocols. The freedom narrative supports this government fear narrative, by aligning entrepreneurial interests in data collection and profit making to government agendas. Should these alignments take place, then the ethically-driven hope narrative that seeks to use 'AI for good' would be undermined, against the intensions of well-meaning global health organizations like UNAIDS *(3)*.

Vigilance against such alignments and applications of AI apply equally beyond the realm of global health work. For the risks to key populations in ART programmes apply equally to how certain government authorities might target people with different political beliefs, religions, or ethnicities.

Risk 3: Promotion of HIV stigmatization and criminalization

The main targets of the technology are key populations and people living with HIV, who could be some groups of gay men; sex workers in higher-incidence locations; young women, girls and men in

settings with very high incidence of HIV; and the sex partners of people living with HIV. Among the target groups, people often face stigma, discrimination and social rejection from a young age. Even today, sexual behaviour between people of the same sex is criminalized in many countries. Furthermore, an important barrier exists in 57 countries that criminalize or prosecute transgender people. Such discrimination, violence and criminalization prevent these groups from getting the HIV services they need to stay healthy.

In the scenario, key populations and people living with HIV are to be "identified" and profiled using AI, by drawing information from public and personal data. People identified may be banned from travelling or working in certain sectors. The amplified stigmatization and discrimination may stop people from getting tested and accessing HIV services. This puts individuals as well as the HIV/AIDS response at risk. Thus, stakeholders need to step in and consider the decisions in this scenario including how to influence others who may be contemplating such a response.

2. Making ART compulsory for key populations and people living with HIV
In this scenario, governments automatically require key populations and people living with HIV to enter PrEP and ART treatment programmes. This could reduce the risk of further spread of HIV, but it leads to serious human rights issues.

Risk 4: Possible criminalization for people not taking medications on time

In the scenario, there was no mention of what would happen if identified people do not adhere to the preventive measures. Would they be warned, educated or charged?

In mid-2018, a Canadian man was charged under his province's Public Health Act for allegedly refusing to comply with a medical health officer's orders for HIV treatment. His criminal prosecution was because the medical health officer "reasonably believes that the person continues to pose a risk of harm to others, and voluntary and other measures have been exhausted" *(18).* In this example, the action of an HIV-positive patient failing to comply with the government's treatment service was criminalized. This might be the case for people in the scenario too.

As mentioned in the scenario, public opinion on this government measure is extremely mixed. Indeed, different countries have vastly different attitudes towards government surveillance and control. Many people think that it is good for public security and support the argument "you have nothing to fear if you have nothing to hide". In this case, because people living with HIV are feared and stigmatized heavily, people might think having more control over key populations and people living with HIV would be protecting public wellness, and thus the privacy and dignity of a small group of people could be temporarily sacrificed. This mindset that is nurtured in the scenario discriminates against, and is detrimental to, the people left behind.

A potential role for stakeholders

The core debate in this scenario is how far government power should intervene in people's lives. On the one hand, governments may want to better control and monitor disease outbreaks,

terrorism or other potential crises, and the birth of AI has fuelled some government authorities' desire to know it all and control it all. On the other hand, each individual citizen has the right to privacy, and to reveal and divulge only the personal information they wish to share. Each individual also needs to be respected with dignity and should not be targeted by the government as possible victims of prosecution, discrimination and criminalization.

Regarding the force of the UNAIDS strategy, the three zeros targets should complement rather than contradict one another. While pursuing zero new infections and HIV-related deaths, the target of zero discrimination should not be forfeited along the way. Like-minded stakeholders would need to publicly condemn such actions by governments. Although they are working towards a positive goal—to lower the rates of HIV—the method adopted is unethical and potentially undermines the global HIV/AIDS response.

In addition, stakeholders can consider a call for discussion and debate on implementing an international standard for governments' access to private information. International civil society needs to institutionalize this issue so that governments that violate the basic rights of their citizens can be penalized.

Conclusion

These two case studies illustrate the possible risks to human rights arising from the use of digital technology and AI for HIV testing, prevention and treatment. What do we learn from these cases? What are the implications for stakeholders to navigate the next generation HIV/AIDS response and address the problems?

There are three important considerations for stakeholders:

1. Continue focusing on a rights-based approach of "leaving no one behind" by defending people living with HIV, key populations and everyone seeking HIV services. The human rights response around HIV-related issues in the next generation response in the context of fast development of digital technologies and AI is bringing new challenges and new problems.

   AI could be used to categorize people into inaccurate binaries that may be used by governments to criminalize and control its citizens in unprecedented arenas. Human rights and civil liberty, as well as the HIV/AIDS response could be seriously harmed by the use of big data and AI.

   First, informed consent by users is almost impossible to obtain. Second, AI algorithms could lead to biased results and misclassification. The opaque process of AI-driven identification, profiling and automated decision-making may cause unfair, biased and discriminative outcomes. People living with HIV and key populations could be misclassified, misidentified, discriminated against and judged negatively through the automated decision-making features of AI. This would further stigmatize and harm people who are already vulnerable to violence, discrimination and fear of stigma. Third, such surveillance creates fear and stigma among

people living with HIV and key populations that may hinder their access to HIV services, thus jeopardizing individual health as well as the global HIV/AIDS response.

Therefore, the next generation HIV/AIDS response should remain human-centric and not compromised by machine-made decisions. Many stakeholders will continue to find themselves with the responsibility of speaking up for people living with HIV, and to defend their dignity and rights. Along the path to achieving zero new infections and zero HIV-related deaths, it is crucial that zero discrimination is also safeguarded.

2. Stakeholders should encourage more dialogue and discussion around these issues immediately as the push for new policies and regulatory measures continues to grow.

   In October 2018, Apple CEO Tim Cook spoke at a privacy conference in Brussels and called for comprehensive legislation on privacy issues internationally. He commented that modern technology has led to the emergence of a "data-industrial complex" in which private information has been "weaponised against us with military efficiency" *(19)*. In his interview with the BBC, he stated that the biggest crisis in the 21st century is about privacy. With the push for more regulations on data collection grow, how will the United Nations system and other stakeholders respond? Apart from greater legislative and regulatory protections, how do stakeholders make decisions and use sound judgement without regulations yet in place. How do they understand the implications and opportunities that should be the focus and therefore formulate positions around such human rights violations and privacy issues, navigate its future direction, and frame policy around digital technologies and AI? What is obvious is that stakeholders committed to a human-centric response need to establish their own set of policies and promote policies and protections with others to ensure that all decision-making remains centred on human rights in this new era.

3. As key stakeholders advocate and develop policies and protections, there are 3 forces that need to be kept in mind – the need for the next generation HIV/AIDS response to keep human rights at the centre, the rapid technological progress in AI and big data, and the political narratives that frame AI and big data. Stakeholders can consider analyses and negotiate how these 3 forces combine, align, contradict and potentially undermine one another. They must also keep sight and develop strategies to address the internal contradictions in these narratives. These contradictions are most acquit in the political narratives that frame these discussions. In a UN context of hope that often emphasizes the benefits of 'AI for Good' to achieve SDGs, stakeholders have the opportunity to acknowledge and address the risks of AI and big data for their respective missions that follow from often-overlooked or de-emphasized fear and freedom narratives, which may endanger the human rights and civil liberties of the key populations the HIV/AIDS response is meant to serve.

In conclusion, there are choices to be made regarding new technologies, their role in the HIV response and potentially other public health emergencies. and what needs to happen to limit violations to civil liberties and human rights. Focusing on the HIV response, everyone implementing a response to HIV needs to realize that risks to individuals could become risks to the HIV/AIDS response, putting at risk the global HIV/AIDS response as new forms of fear, stigma and discrimination evolve.

Bibliography

1. UNAIDS 2011–2015 Strategy: Getting to Zero; 2010.
    https://www.unaids.org/sites/default/files/sub_landing/files/JC2034_UNAIDS_Strategy_en_4.pdf

2. Klimpel K. How digital technology is transforming healthcare. RN.com; 2015
    (https://www.rn.com/nursing-news/how-digital-technology-is-transforming-healthcare)

3. Weber C. How 3 key narratives shape popular views on artificial intelligence:
    opinion. ITU News. 8 January 2018 (https://news.itu.int/artificial-intelligence-politics-fear-hope-freedom)

4. WHO, UNAIDS statement on HIV testing services: new opportunities and ongoing
    challenges. Geneva: World Health Organization, Joint United Nations Programme on
    HIV/AIDS; 2017.

5. Ganguli I, Bassett IV, Dong KL, Walensky RP. Home testing for HIV infection in
    resource-limited settings. Current HIV/AIDS Reports. 2009;6(4):217–23.

6. Ibitoye M, Frasca T, Giguere R, Carballo-Diéguez A. Home testing past, present and
    future: lessons learned and implications for HIV home tests. AIDS and Behavior.
    2014;18(5):933–49.

7. Pew Research Centre. Social media use continues to rise in developing countries but
    plateaus across developed ones. Pew Research Centre; 2018.

8. Liu B, Lin J, Sadeh N. Reconciling mobile app privacy and usability on smartphones:
    could user privacy profiles help? In: Proceedings. 23rd International Conference on
    World Wide Web, Seoul, Republic of Korea, 7–11 April 2014. New York: Association
    for Computing Machinery; 2014:201–12.

9. Hai NK, Lawpoolsri S, Jittamala P, Huong PTT, Jaranit Kaewkungwal J. Practices in
    security and confidentiality of HIV/AIDS patients' information: a national survey
    among staff at HIV outpatient clinics in Vietnam. PloS One. 2017;12(11):e0188160.

10. Lyimo RA, Stutterheim SE, Hospers HJ, de Glee T, van der Ven A, de Bruin M. Stigma,
    disclosure, coping, and medication adherence among people Living with HIV/AIDS in
    Northern Tanzania. AIDS Patient Care and STDs. 2014;28(2):98–105.

11. Dapaah JM, Senah KA. HIV/AIDS clients, privacy and confidentiality: the case of two
    health centres in the Ashanti region of Ghana. BMC Medical Ethics. 2016;17(1):41.

12. *Global Aids Update. UNAIDS; 16 July 2019*

13. Kavanagh MM, Baral SD, Milanga M, Sugarman J. Biometrics and public health
    surveillance in criminalised and key populations: policy, ethics, and human rights
    considerations. Lancet HIV. DOI:https://doi.org/10.1016/S2352-3018(18)30243-1.

14. Oral pre-exposure prophylaxis questions and answers. Geneva: Joint United Nations
    Programme on HIV/AIDS; 2016.

15. Lewis P. "I was shocked it was so easy": meet the professor who says facial
    recognition can tell if you're gay. The Guardian. 7 July 2018
    (https://www.theguardian.com/technology/2018/jul/07/artificial-intelligence-can-tell-your-sexuality-politics-surveillance-paul-lewis)

16. Anderson, D. GLAAD and HRC call on Stanford University & responsible media to
    debunk dangerous & flawed report claiming to identify LGBTQ people through facial

recognition technology, https://www.glaad.org/blog/glaad-and-hrc-call-stanford-university-responsible-media-debunk-dangerous-flawed-report, September 8, 2017.

17. Weber C. The face of sexuality: why do AI-generated sexual orientations matter? The Disorder Of Things. 25 September 2017 (https://thedisorderofthings.com/2017/09/25/the-face-of-sexuality-why-do-ai-generated-sexual-orientations-matter)

18. Zhand, Qingpeng et al, Using internet search data to predict new HIV diagnoses in China: a modelling study, https://bmjopen.bmj.com/content/8/10/e018335

19. Proctor, J. Vancouver man charged with ignoring medical officer's orders for HIV treatment (https://www.cbc.ca/news/canada/british-columbia/hiv-medical-public-health-risk-1.4795491)

19. Vincent J. Tim Cook warns of "data-industrial complex" in call for comprehensive US privacy laws." The Verge. 24 October 2018 (https://www.theverge.com/2018/10/24/18017842/tim-cook-data-privacy-laws-us-speech-brussels).