

# **Advances from COVID-19: Innovative digital technologies to deliver HIV prevention and treatment**

Policy brief: June 2021

## Overview

The COVID-19 pandemic continues to have a huge impact on global health and well-being. This is not only because of the severity of the symptoms the infection can cause, but also because it is affecting the prevention, diagnosis, treatment and care of many other health conditions, including HIV.

The World Health Organization (WHO) declared the COVID-19 outbreak a Public Health Emergency of International Concern in January 2020 and a pandemic in March 2020. Since then, we have witnessed a surge in the already accelerating use of digital technologies in healthcare. Adaptations and innovations have occurred both within and beyond the HIV prevention and care continuum. From the human toll of COVID-19, opportunities have emerged to learn about and improve the prevention, treatment and care of people vulnerable to and living with HIV, as well as other infectious diseases. But with those opportunities come risks.

To this end, the Industry Liaison Forum (ILF) of IAS – the International AIDS Society – identified and prioritized a set of digital technological innovations, based on advances that have been made during the COVID-19 pandemic and that should be pursued vigorously now and/or in the future across the HIV prevention and care continuum. To mitigate risks and concerns, the ILF also agreed on a set of principles that all those involved in developing technologies and innovations should consider before proceeding with implementation.

## Context

In May 2020, WHO, the Joint United Nations Programme on HIV/AIDS (UNAIDS) and others warned that if efforts were not made to mitigate interruptions in health services and supplies during the COVID-19 pandemic, a six-month disruption of antiretroviral therapy (ART) could lead to more than 500,000 extra AIDS-related deaths and set back progress by up to 25 years [1,2,3]. At AIDS 2020: Virtual – the 23rd International AIDS Conference – in July 2020 [4], WHO presented data about the risk of treatment disruptions for people living with HIV: 73 countries reported being at risk of antiretroviral (ARV) stock-outs, of which 23 had less than three months of stock remaining. Reports from South Africa, Australia and the USA [5,6,7] also highlighted worrying impacts on people vulnerable to or living with HIV, including reductions in the number of people collecting medication, decreased attendance at sexual health clinics and delays in prevention programmes [2]. The most significant impact on incidence and mortality from HIV is ART interruption.

In December 2020, UNAIDS [8] said that although COVID-19 was likely to negatively affect the trajectory of the HIV response, its impact could be short lived if the necessary investments to mitigate risk were made. Worryingly, however, the report from the UNAIDS Secretary-General, published in March 2021 [9], stated that the COVID-19 pandemic was “overwhelming even the most sophisticated health systems, worsening gender inequalities and gender-based violence, threatening the education of a generation of young people, and disrupting HIV prevention, diagnosis and treatment initiation”. At the same time, it said that COVID-19 had highlighted how the agility of community-led service delivery pioneered by the response to HIV was helping overcome the obstacles created by this new pandemic.

Even in these extraordinarily challenging times, innovations in HIV policy and services delivery have increased, supported by community engagement [8], implementing organizations, healthcare workers and individuals who have worked tirelessly to ensure that care and support have been delivered to those who need it most.

The pandemic has also greatly accelerated the global trend toward increased use of digital technologies in the care continuum across disease areas. For example, these technologies have supported delivery of ARVs directly to people's homes, helped address misinformation about vaccines via social media, and provided mental health support online when face-to-face engagement has not been possible. A survey report from the Global Networks of People Living with HIV is just one of many that describe how the HIV community has adapted to the use of digital technologies during the COVID-19 pandemic [10].

Both private and public sector organizations support this use of digital technologies. Development agencies, including the United Nations and WHO, are actively encouraging guidance and technical cooperation to help governments of low- and middle-income countries assess their digital health

needs, develop strategies and scale up interventions [11]. Agencies such as the Global Fund to Fight AIDS, Tuberculosis and Malaria also support this financially. However, without safeguards to ensure trust, equity and respect for human rights, there is a risk that public support for these technologies will be eroded and beneficial technologies not adopted.

The IAS Industry Liaison Forum has prioritized a set of digital technological innovations arising from the COVID-19 pandemic that should be pursued across the HIV prevention and care continuum.

## Recommendations

Recognizing the surge in the use of digital technologies resulting from the COVID-19 pandemic, the ILF identified more than 100 adaptations and innovations that have arisen during the pandemic, both within and beyond the HIV response. The ILF then reviewed and shortlisted the innovations that, in its opinion, should be considered for immediate implementation or scale up and/or future implementation within HIV services. These were placed into three categories in the HIV prevention and care continuum: testing and data management; research and delivery; and monitoring of adherence for treatment and prevention services.

The criteria for **immediate implementation or scale up as part of existing services** were:

- Is the innovation needed now?
- Is it acceptable, equitable and feasible?
- Can it be implemented within existing structures and/or settings or with only slight modifications to existing systems?
- Is there a readily addressable reason why it has not already been implemented?
- Is there evidence for the effectiveness of the digital intervention, and is it cost effective and a good use of funds?
- Does it respond to national and community leadership's expressed needs?

The criteria for **future implementation within HIV services\*** were:

- Is the innovation needed?
- Does it have the potential to make a significant difference but require more consideration, for example, better evidence, management of equity issues and/or training?
- Is there evidence for the efficacy of the digital intervention, and whether it is cost effective and a good use of funds?

\*The ILF has purposefully not stipulated a timeline for future services as this will vary by demand, need and country settings, among other factors.

# 1. Priorities for testing and data management

During the COVID-19 pandemic, apps have been used to both return SARS-CoV-2 testing results and track symptoms. In tandem, data management collaborations have helped track COVID-19 over time and, with varying success, supported the development of testing and contact tracing systems. This use of digital technology has helped overcome disruption caused by closure of clinics and reduction in face-to-face engagement due to transmission risks and symptom overlap,

and showed what could be possible for HIV and other sexually transmitted infections and infectious diseases.

The following table sets out priorities for HIV testing and data management alongside concerns, risks and their mitigations that should be considered before new healthcare technologies are piloted or scaled up.

## Testing and data management

### Priorities for immediate implementation

#### Testing

HIV testing services should consider the use of SMS or programmes that run on mobile devices (apps) to simplify the return of test results to service users.

### Priorities for future services

#### Testing

HIV testing services should consider the use of SMS or programmes that run on mobile devices (apps) to simplify the return of test results to service users.

### Concerns, challenges and considerations

#### Testing

- The need for broad and equitable access to smartphones and apps
- Confidentiality, security and the use of app technology that may become quickly outdated
- Meaningful communication of results, such as undetectable viral load, mindful of the limits of HIV testing
- Feasibility of appropriate linkage to care (depending on results) and likelihood that a user would seek care if receiving results in this format

### Data management

HIV and TB services should prioritize the establishment of public repositories of anonymized HIV, co-infection and co-morbidity clinical data to better enable data sharing and foster collaboration and innovation with the aim of improving access.

### Data management

HIV and TB screening should be introduced in emergency departments to support increased diagnosis, as per a model introduced successfully in Chicago during the COVID-19 pandemic [10].

With appropriate safeguards and following a risk-benefit analysis, encourage partner notification to support HIV and TB prevention, as well as an app that, with the client's permission, can support client and clinician care management through the monitoring of medicine intake and tracking of adherence.

Public data repositories and centralized data management were also considered high priorities.

### Data management

- Significant concerns when public repositories of clinical data relate to diseases (HIV and TB) with substantial associated stigma and discrimination
- Appropriateness and feasibility of implementing partner notification. While stakeholder engagement and discussions between governments and industry representatives may help mitigate user scepticism, significant investment is required to address legal barriers, stigma and discrimination before partner notification could be introduced in many countries
- Restrictive laws and policies during the COVID-19 pandemic may have reversed human rights gains, particularly among key and vulnerable populations
- Sustainability and public scepticism over the use of data and tools by government and industry
- Interoperability and standardization of data storage systems
- Confidentiality and security risks these tools represent to privacy and non-discrimination, given poor or absence regulation of data in many countries

## 2. Priorities for research and delivery

The COVID-19 pandemic has had a mixed impact on clinical research. While a number of trials have continued uninterrupted with community support, recruitment to some has been affected. For example, the Mosaico vaccine efficacy trial was paused in some countries [12]. In another trial, injected pre-exposure prophylaxis [13] was briefly replaced by a tablet to allow it to continue during a supply outage.

Online ordering of repeat prescriptions and multi-month dispensing have mitigated the impact, with their success largely attributed to involvement of the HIV community at a local level.

The following table sets out the priorities for HIV research and delivery alongside concerns, risks and their mitigations that should be considered before new health and care technologies are piloted or scaled up.

### Research and delivery

#### Priorities for immediate implementation

##### Research

Use of telemedicine and cross-platform messaging applications, such as WhatsApp, are viable tools for retaining people in clinical research.

#### Priorities for future services

##### Research

Virtual training can educate study staff for ongoing or upcoming research trials and to build capacity to enable faster roll out of new treatments. Telemedicine and electronic informed consent (eConsent) are also high priorities.

#### Concerns, challenges and considerations

##### Research - telemedicine

- The use of telemedicine and messaging apps will need broad and equitable access to smartphones and apps
- Managing potential misdiagnosis, exacerbating gender-based violence, and issues of confidentiality and privacy
- Managing multiple messaging application (WhatsApp) groups. However, chatbots could help triage those who need direct communication
- Telemedicine and messaging apps could also be used to support retention in care and improving quality of care (e.g., by delivering training and supportive supervision to clinic staff)

##### Research - virtual training

- Ability to demonstrate the effectiveness of online training, growing virtual training fatigue and equitable access to training

## Research and delivery (cont.)

### Priorities for immediate implementation

#### Delivery

Medication and healthcare-related products, such as condoms and self-test kits, can be ordered online and delivered directly to homes.

### Priorities for future services

#### Delivery

Use of technology for demand planning and real-time tracking to support product supply and waste-avoidance.

### Concerns, challenges and considerations

#### Delivery

- Confidentiality concerning packaging of medicines delivered to homes
- Potential reluctance of older people to engage with telemedicine
- The need for broad and equitable access to smartphones and apps
- Lack of privacy and confidentiality (e.g., phone-sharing) could increase risk of stigma and gender-based violence
- Complexity of systems needed to manage these innovations
- Need for data-sharing agreements and standardization of data to support interoperability
- Ability to be aware of stock availability both centrally and locally
- Cost associated with establishing systems and data requirements

The first two concerns emphasize the importance of community and healthcare worker engagement with service users to influence packaging of products and service delivery, as well as support the use of mobile phone apps to increase uptake.

The Neglected Tropical Diseases Supply Chain Forum [14] was cited as a model public-private partnership that provides tools for demand planning and tracking in more than 100 countries.

### 3. Priorities for monitoring of adherence for treatment and prevention services

There were reports of reduced service delivery and drug access for both HIV and TB during the COVID-19 pandemic. For example, the displacement of young people away from cities has had an impact on continuity of HIV care in Kenya [15].

The acceleration in the use of telemedicine, including phone and online consultations, highlights opportunities to improve adherence to HIV treatment and reduce loss to follow up.

The following table sets out priorities for monitoring and adherence alongside concerns, risks and their mitigations that should be considered before new health and care technologies are piloted or scaled up.

#### Monitoring of adherence for treatment and prevention services

##### Priorities for immediate implementation

Apps can be used to motivate users to engage in both prevention and treatment services.

##### Priorities for future services

Digital tools can be used to support medication adherence and clinical follow up in order to support monitoring by service providers and adherence.

##### Concerns, challenges and considerations

- Complexity of the systems
- Privacy and stigma associated with app downloads
- Equity of access
- Potential adverse mental health implications of telemedicine

As well as using digital technologies in monitoring adherence, mobile apps can be successfully used in adverse event reporting. To this end, the South African Health Products Agency (SAHPRA) [16] has rolled out a mobile app for the public and practitioners based on the UK Medicines and Healthcare products Regulatory Agency's Yellow Card system.

## Summary of priorities

The following table highlights the priority innovations for existing and future services in the HIV care continuum. The concerns and challenges highlighted within this policy brief must be addressed if these innovations are to be successfully implemented.

	Testing & Data Management	Research & Delivery	Monitoring of Adherence
<b>For existing services</b>	<p>Apps or SMS to simplify return of results</p> <p>Public data repositories for HIV data</p>	<p>Telemedicine &amp; cross-platform messaging applications for retention</p> <p>Online ordering of medication and direct home delivery/via drop-off points</p>	<p>Apps to engage and motivate</p>
<b>For future services</b>	<p>HIV and TB screening in emergency departments</p> <p>Partner notification</p>	<p>Virtual training</p> <p>"Centralized" demand planning and real-time tracking tools</p>	<p>Digital tracking of/by service users</p>

## Principles for implementation

Many sets of principles for digital governance have been proposed by diverse actors in the UN, civil society and private sector. One that is widely endorsed is the [Principles for Digital Cooperation](#), which came out of the UNSG High Level Panel on Digital Cooperation. The ILF developed 10 principles to help implement the recommended priority actions, as well as future innovations in healthcare. Partners are encouraged to consider the adoption of these principles, and relevant international human rights standards, to mitigate associated risks and concerns.

## The 10 suggested principles

### 1. Client-centred and co-created solutions

Innovations will be implemented more effectively if they are responsive to the needs of communities, healthcare providers and service users and if these parties are involved from the outset in the development, implementation and communication of innovations that may affect the provision, access and/or delivery of treatment and services.

### 2. Transparent and ethical leadership

Public and private organizations will help build trust if they are open and transparent about the innovations they are implementing and what they are enabling, how they are doing so and with whom. Established transparent monitoring and evaluation mechanisms and clear processes for continuous feedback will support this.

### 3. Collaboration, support and training

Effective implementation brings the necessary partners together to resource, build capacity and deliver sustainable, functional and user-friendly innovations. These partners include users and communities, global health organizations, governments, health service providers, industry and technology, data management and administrative bodies.

### 4. Equity of access

Innovations will have greater impact if they are adapted to settings where there is demonstrable need and distributed to those who could benefit most. Seeking to influence societal and human rights concerns that may adversely impact equity of access – such as other determinants of health, discrimination on the basis of gender, sexual preference- or gender-based violence, and stigma – will enhance that impact.

### 5. Confidentiality and privacy

Innovations designed and implemented to protect client confidentiality and privacy will help engender trust. Any or all consent must be informed, voluntary and obtained from all users in accordance with standard practice. Good practice dictates that users have the right to know how their information will be used and be able to withdraw consent at any time and for any reason and have any/all personal identifiable data permanently deleted.

### 6. Potential harms

Innovations are most likely to support the health and well-being of end-users if they are designed and implemented in a way that considers and mitigates potential harms, such as stigma, gender-based violence, legal barriers, discrimination and adverse mental health implications.

### 7. Provision of meaningful feedback and linkage to care

The greatest benefits to individual client care are realized when all health information or feedback relevant to their health is communicated to them in a timely, understandable, tailored and culturally competent way and, where appropriate, there are clear responsibilities for ensuring their linkage to care.

### 8. Interoperability

Innovations and their related systems, such as data management systems, will be more effective if they are designed and implemented in a way that avoids and/or reduces the occurrence of multiple, disconnected systems and parallel efforts.

### 9. Data sharing and information governance

Population health stands to benefit most when non-identifiable data is reported publicly and shared with relevant health ministries and organizations, or, where that is not possible, reported to organizations or intermediaries with legitimate public health goals.

### 10. Longevity and scalability

Innovations are more likely to be successful if they are affordable, are adaptable to settings with different technological capacities, are durable and offer long-term value, have potential for scale, and come with appropriate and sustainable investment.

## Additional considerations to ensure appropriate adoption of these principles are as follows:

In terms of equity, addressing the digital divide through provision of broad and equitable access to smartphones and apps is a key element in ensuring that digital innovations in healthcare reach their potential. For example, what is often missed in discussions about Africa's high level of mobile connectivity is that, in relation to median income, the continent has the world's most expensive prepaid mobile data plans, representing an average of 8.76% of income [17], according to a 2019 report. Although smartphone penetration is exceedingly high and growing steadily, even since this report [18], many users do not have mobile data or phone contracts and have basic phones rather than smartphones. Key to any adoption or scale up of digital health technologies, therefore, is strengthening infrastructure and ensuring access to internet and mobile data, as well as digital literacy in order to help address the digital divide.

In adopting the principles, implementing organizations should follow the [UN Guiding Principles on Business and Human Rights](#) [19], which require states to uphold human rights and require private companies to respect them, including by ensuring due diligence to assess potential risks of harm and taking steps to mitigate such harms.

In terms of patient confidentiality and data interoperability, General Data Protection Regulation (GDPR) [20] compliance for data privacy would set clear practices and procedures that must be in place for systems to process these kinds of data. While not legally enforceable outside the European Union, it is widely accepted as the current gold standard and most up-to-date framework that appropriately weighs the right to privacy against the need for access to information.

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