Technology, e-health and HIV programming

KEY POINTS

- E-health can play an important role in making services more accessible and person-centred, as well as improving the operations and financial efficiency of health systems.
- Unequal access to technology means not everyone can benefit from e-health initiatives, so addressing its limitations is also important.
- E-health interventions can benefit clinicians, enabling them to reach key populations and improving the exchange of information between health service providers.
- User-involvement is key for successful implementation of technology and e-health-related HIV programmes

Explore this page to find out more about why e-health is important, how it is being used, the benefits for consumers and clinicians, barriers and limitations, and factors for successful project implementation.

What is e-health and why is it important in HIV programming?

E-health refers to the use of information and communication technologies (ICTs) to deliver or enhance health services and information.

E-health is becoming an integral part of delivering improvements in the health sector. It is increasingly being used in a wide range of areas including health education, health campaigns, healthcare delivery, training, data collection and research.1

Many see e-health as key to improving the operations and financial efficiency of health systems. However, in recent years a number of studies have found e-health to be beneficial for clinicians in ways that go beyond simple cost and efficiency savings. Evidence suggest e-health can be beneficial for those using health services (consumers) in a variety of ways.[2]

E-health interventions are already being used within the global HIV response, and are increasingly being viewed as an essential factor to ending AIDS as a public health threat. For example, mobile technology is helping people affected by HIV in remote areas access information about HIV prevention or adhere to treatment. Electronic health records are strengthening the HIV care cascade by providing accurate and timely patient information. Social media is bringing people most affected by HIV together to share information and campaign for their rights.

Addressing e-health's limitations within the HIV response is equally as important as celebrating the opportunities it provides.

The increasing spread and sophistication of technology worldwide means the landscape of e-health is constantly evolving, and with it the potential to dramatically improve HIV prevention, care and treatment services. However, access to technology is unequal, particularly internet access, which means that some parts of the world and some population groups are unable to benefit from the wide range of e-health initiatives on offer. As a result, addressing e-health's limitations within the HIV response is equally as important as celebrating the opportunities it provides, and the successes it is already delivering.

What technologies/platforms are being used for e-health and HIV programming?

M-health

One of the largest areas of technological innovation in health uses mobile technologies. This is known as m-health, which the World Health Organization (WHO) defines as the use of mobile devices – such as mobile phones, patient monitoring devices, personal digital assistants and wireless devices – for medical and public health practice.[3]

Examples of m-health interventions used within the HIV response cover a broad spectrum. For example, a number of m-health apps (computer programmes that are downloaded onto mobile devices) exist to help people living with HIV keep track of when they have taken antiretroviral medication or to help health workers record and evaluate patient data.

Increasingly, communications apps such as WhatsApp are playing an important role in helping people communicate with trained healthcare providers and counsellors at times and in places that suit them.

M-health also includes the use of short message services (SMS). For example, SMS reminders may be

sent to patients to remind them of care appointments.

Electronic health records

Electronic health records (EHR) enable clinicians to access complete patient information during someone's appointment (also known as 'point of care'). EHRs have been found to greatly improve the quality and timeliness of care, as well as providing useful data on the populations most affected by health conditions and epidemics as well as the effectiveness and coverage of interventions. However, implementing EHR programmes is complex and costly, resulting in less than half (47%) of countries using national EHR systems as of 2016.[4]

Big data

'Big data' refers to massive volumes of digital data being generated through the use of ICTs. Some data sources are more obvious than others. For example, online patient surveys clearly exist to generate data, however comments made on social media in response to a health campaign are also a data source.

Using new analytical tools on big stores of digital data is providing the HIV response with the means to evaluate changes in the epidemic at individual, community, population, local, national, regional and global level in a more accurate and valuable way than ever before.[5]

Telehealth

Telehealth or telemedicine refers to a practice whereby technology is used to enable a health worker to interact with an individual when they are separated by distance. This could be through a telephone or video call or through an instant messaging service.[6] For example, studies have suggested a high level of satisfaction with HIV-self testing when supported by video chats with an HIV testing counsellor.[7]

Telehealth can increase the speed at which someone can access care and can reduce the costs associated with accessing it, such as travel costs. It particularly holds promise for the delivery of healthcare in rural areas.

The primary benefit of telehealth is that it can increase the speed at which someone can access care and can reduce the costs associated with accessing it, such as travel costs. For these reasons, it particularly holds promise for the delivery of healthcare in rural areas, although telehealth may also be of benefit to urban areas.

Gamification

The use of digital games that include elements of game playing (gamification) are rapidly becoming an important tool for improving health behaviours and supporting the delivery of care and education. As a result, gamification has been found to be an effective way to reach certain groups with information about HIV prevention, testing and treatment services, particularly young people.[8]

Websites

Since the 1990s, people have been using websites to learn about health-related issues, including HIV. Much of the information on the Internet is valuable and is being used by people to inform themselves about their own health. However, there are concerns that people may be at risk of being overwhelmed or misinformed when seeking health information in this way. As a result, a number of organisations such as America's National Institute of Health have issued guidelines on how to evaluate whether a website can be trusted as a source of health information.9

Social media

Social media, such as Facebook, Twitter and YouTube, provide interactive platforms for individuals, communities and organisations to share and discuss content, debate issues and promote new ideas. As a result, they are changing the dynamics and nature of interactions between healthcare consumers, health workers and health care organisations.10 Many organisations are also using social media – and dating apps, a particular subset of social networking – to target and interact with people living with, most affected by, or at risk of HIV who may feel isolated or less visible.11 Global positioning systems (GPS) and other data collection strategies used by the vast majority of social media are helping organisations to target people more precisely and effectively.

Crowdsourcing

Crowdsourcing, the process of shifting individual tasks to a large group, is being used to enhance various aspects of the HIV response – and in a similar way to some aspects of social media, on which crowdsourcing often relies. For example, crowdsourcing ideas and experiences from a certain community has been successfully used to shape information materials for an HIV testing campaign and inform decision makers of the views of groups most affected by HIV, such as young people.12

What are the benefits of technology and e-health in HIV programming?

Benefits to consumers

E-health interventions can be tailored to suit important factors in someone's life, which has the potential to bring about more person-centred health experiences. This can be of huge benefit for groups who have struggled to access HIV services and information due to where they live or other factors such as their age or whether they have a disability. This means people are more likely to engage with services or access information.

In Lesotho, for example, which has the world's second-highest prevalence of people living with HIV (25%), the country's Ministry of Health has collaborated with Vodafone on a smartphone app for health professionals, allowing anyone who is identified as HIV-positive in remote communities to receive transportation funds to treatment centres via Vodafone's M-Pesa money transfer scheme.13

Linked to this, is the way in which e-health can enable people to be more in control of their health service experiences. For example, e-health initiatives are enabling people living with HIV to monitor their own test results and share this information with people they trust in a secure and confidential way. This has the potential to be incredibly empowering as it can improve people's self-efficacy (a

belief in one's abilities) to manage their health.

CASE STUDY: Person-centered health apps - HIV iChart and the PrEP locator

Numerous m-health apps are now available for people living with, and most affected by, HIV.

These include the HIV PrEP (pre-exposure prophylaxi) Locator app, which has been developed to enable people in the USA to search for PrEP providers according to their zip code, state or full address, and filter out services that do not offer PrEP to the uninsured.14

Similarly, the HIV iChart app provides up-to-date information on potential reactions between antiretroviral drugs and other prescription drugs, as well as over-the-counter, recreational, and alternative medications.15

The privacy and anonymity provided by digital interventions can also be beneficial for people living with, and most affected by HIV, who experience high levels of stigma, discrimination and criminalisation.

For example, the privacy provided by online dating apps has made them popular among men who have sex with men, particularly in countries where same sex behaviour is criminalised or highly stigmatised.16 Seizing on this opportunity, a number of m-health dating apps such as MISTER have been designed that encourage users to respect each other's HIV status – for example, by selecting an option to state that they are open to relationships with users of any status. In return, they can receive an icon on the site, which is likely to make users who are unwilling to disclose their status feel more comfortable.

> The concept of 'gay' isn't the same as it was before. Mobile apps has increased reach. There are many men whose 'gay' lives are lived online through apps and whose first experience with the gay community, including safer sex messages, is through an app. Public health needs to learn how to reach these populations where they live, just like the brave people who went to bathhouses back in the 70s and 80s to do outreach.
> - *Carl Sandler, CEO, MISTER dating app*17

For people living with HIV, who need to engage with treatment and care throughout their lifetime, the benefits associated with e-health may significantly improve their journey through the HIV treatment cascade. These are the steps people living with HIV go through (testing, diagnosis, treatment initiation, treatment monitoring, adherence) in order to achieve and maintain viral suppression. As

someone with HIV who is virally suppressed will not suffer ill health from the virus and will be unable to transmit HIV to others, e-health interventions also have the potential to improve public health outcomes, which in turn reduces the demand on health sector resources.

CASE STUDY: SMS for treatment adherence in Kenya

The effective use of technology has an important role to play in improving rates of adherence to antiretroviral treatment. This has been particularly shown in low to middle-income countries.

In Kenya, for example, patients were sent a series of SMS messages once a week, with a follow-up telephone call if they did not respond within 48 hours or reported a problem.

While the adherence rate was less than 50% among patients who did not receive a message, 62% of patients who were given SMS reminders were reported taking at least 95% of their pills at six and 12-month follow-up, backed up by viral suppression results. 18

> Although patients may eventually tire of being reminded and told things they had not specifically asked about, they do not seem to tire of being asked how they are doing. Instead, they feel cared for. Patients also do not seem to tire of having access to their health care providers in times of need; this is the true power of having their health in their own hands through their mobile phones.
> - *Richard T Lester, University of British Columbia Centre for Disease Control*19

E-health has the potential to empower people, not only through producing more tailored healthcare experiences, but by challenging the stigma and discrimination people living with, and most affected by, HIV are likely to encounter.

For example, social media and online forums can enable people living with, or affected by HIV, to connect with others who are facing similar situations. Hashtags, often co-ordinated around events such as World Aids Day, can allow participants to instantly share their insights and interact with each other. In this way, technology provides a platform for peers to communicate, learn and take strength from one another, a massive asset for peer support and community-led programmes which are now seen as essential to the success of the HIV response.

Prominent social media accounts that openly discuss living with HIV can also be reassuring and empowering for others.

A lot of my followers on Twitter are alter egos of people living with HIV who use their accounts to discuss their lives with HIV but with their identities hidden. On Twitter, they can live openly about something they are frightened of sharing with the rest of the world; some of them to their own families. I'm public about my HIV status. I talk about HIV and living with it openly on my Twitter…like a statement, if you will: 'I'm living with HIV and I'm okay with it. I'm doing fine.'
- *Wanggo Gallaga, HIV advocate*[20]

CASE STUDY: Social media and sexual and reproductive rights in Thailand

The Sexperts! programme is a low-cost, community-led project offering accurate online sexual health information, social support and legal advice for men who have sex with men and people who are transgender in Thailand.

Compared to traditional peer support workshops and online peer education, this approach has been found to allow for greater tailoring of messages to meet the specific needs of particular groups.

For example, a transgender-specific strand of the programme (TLBz Sexpert!) ran an online peer-counselling service, which it promoted on its webpage and on open and closed Facebook groups for Thai transgender people. Regular advertisements enabled Facebook group members to know when a TLBz peer counsellor was online and available to chat via MSN messenger or Facebook's chat function on any issue they found relevant. These conversations were used as a way to provide information on HIV prevention, sexual health and legal rights.[21]

Benefits to clinicians

E-health interventions are benefitting clinicians in numerous ways, some of which overlap with the benefits experienced by patients.

A key area is the way in which technology is enabling people working within the HIV response to reach or re-engage with people most affected by, or living with HIV. Through m-health interventions, online forums and social media campaigns, health workers are able to target specific groups with tailored-services, as well as accurately tracking the levels of engagement a particular intervention is generating.

CASE STUDY: SMS campaign in Zambia - increasing HIV testing

Capitalising on the growing use of mobile phones, Zambia has targeted young people with a voluntary sign-up text service. As of 2016, it had more than 98,000 subscribers, most of whom are between 10 and 24-years-old.

Around 60% of subscribers have asked questions to counsellors, who offer quick replies. Every month the service receives between 8,000 and 10,000 messages.

It is estimated that the campaign has generated one additional HIV test out of every five young people who had not tested for HIV in the previous 12 months.22

Members of the WhatsApp group openly discuss HIV issues, provide peer-to-peer support, psychosocial and sometimes financial support through income generating activities.
*- Grace Muthoni, mentor and programme officer, Maxfacta Youth Group, Kenya*23

CASE STUDY: Adam's Love - Online to offline PrEP/testing promotion

In Thailand, finding ways to increase HIV testing and PrEP uptake among high-risk groups such as men who have sex with men and transgender women is a critical priority.

A novel online-to-offline (O2O) model was able to reach high-risk, 'closeted' men who have sex with men and transgender women. It did this by successfully reaching people online to increase uptake of HIV testing and PrEP services, offline, at clinics.

The O2O model was piloted by Adam's Love (www.adamslove.org), an HIV educational and counselling website. The organisation found it could reach more people online by using tailored, social media messages about PrEP and HIV testing than it could using traditional, face-to-face outreach.

Those interested in free PrEP and/or HIV testing services were able to contact Adam's Love staff online where they received real-time PrEP e-counselling. This helped to foster relationships with people in a non-judgemental setting. It also enabled counsellors to assess individuals at risk of HIV infection and provide basic education about PrEP and how to access it.

Those at risk of HIV infection were then given the opportunity to complete an online booking form to receive PrEP and HIV testing services at one of the four sites in Bangkok. Participants

were asked to give a preferred pseudonym and a valid email address when booking an appointment. The fact that no additional personal identifying information was needed helped overcome participant confidentiality and privacy concerns.

E-tickets and Quick Response (QR) codes were then sent to participants' mobile devices for their appointments, which enabled service uptake to be monitored.[24]

Technology has also been used to improve the exchange of information between health service providers, which can greatly reduce costs. For example, collecting and storing HIV testing results digitally eliminates the need to transport results and means they can be accessed at multiple sites. It also means clinicians can collect and analyse patient data more easily and efficiently.

WhatsApp is increasingly the communication and social network of choice in Southern Africa – both simple and low cost. In Zambia, where over 60% of health facilities are run by a single nurse or midwife, it is being used to change the way health workers practice and learn. It is being used both as a learning platform within continuing education courses, and increasingly as a way for isolated nurses to talk to other nurses about actual cases and clinical emergencies. WhatsApp has been used in similar ways in other countries such as Kenya and Brazil.[25]

CASE STUDY: Using Grindr to collect data on PrEP use

In Switzerland, PrEP is only available from private providers. As a result, data on its use is limited.

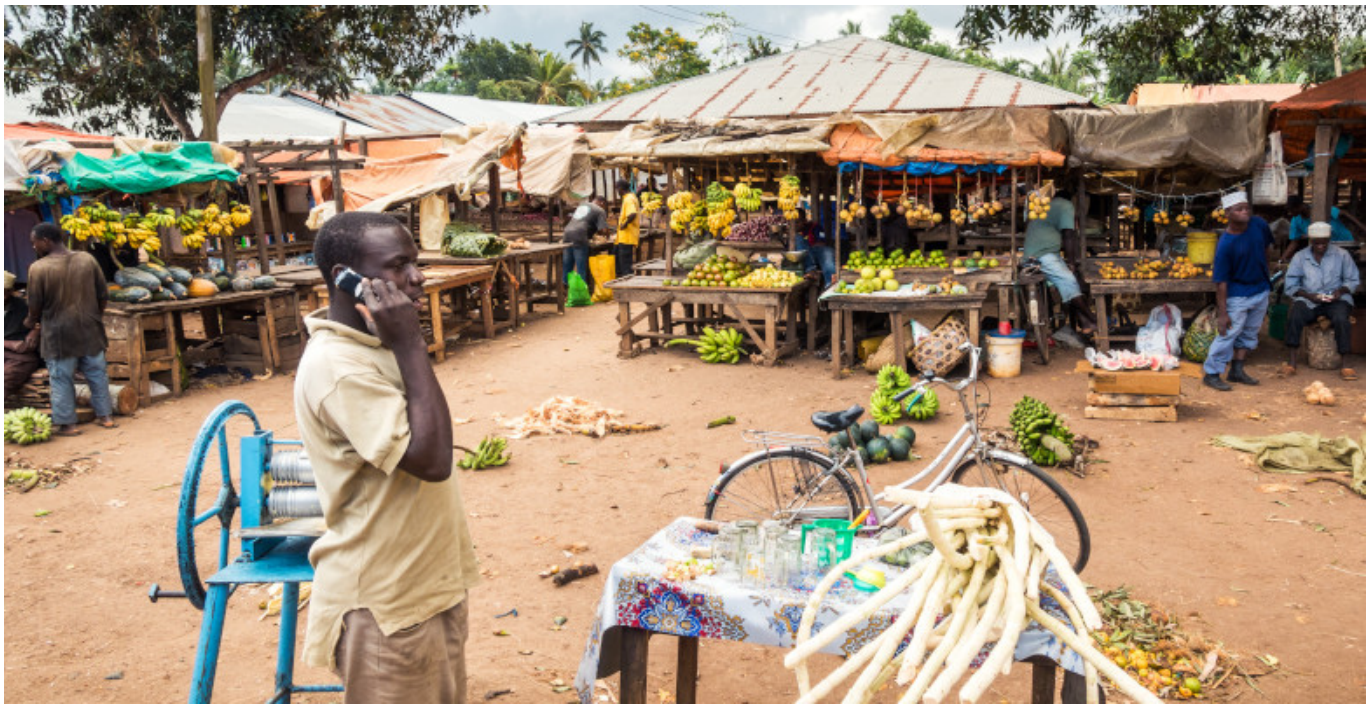
To address this issue, in January 2017, Swiss users of Grindr, a social networking/dating app for men who have sex with men, were asked to participate in a ten-question survey to find out whether they were already taking PrEP, or were considering using it, and whether they were taking it under medical supervision or not.

By conducting data collection through the popular social app, and by keeping the effort required to engage with the research to a minimum, the study was able to obtain more representative data for sexually active men who have sex with men in Switzerland than recent similar offline surveys. For example, the Swiss PrEP Acceptance Study, conducted between 2014 and 2016, had 556 participants. The Grindr study, conducted over a two-week period, had 2,500 respondents of which 1,900 responses were analysed.[26]

The digital divide: barriers and limitations to technology and e-health in HIV programming

Communications and technology infrastructure

Much progress has been made on the reach of mobile, broadband and wireless networks. However, regions most affected by HIV, where the need for HIV-related e-health interventions is greatest, often have the weakest technological infrastructure to deliver these interventions.



As of 2016, 95% of the global population lived in an area covered by a mobile-cellular network.[27] It is estimated that, as of 2015, there were more than 7 billion mobile phone subscriptions worldwide. Around 5.5 billion of these subscriptions, or nearly 92 per 100 people, were held in the developing countries.[28]

However, one-third of the global population does not have access to a mobile broadband network.29 The result of this, coupled with a serious lack of non-mobile (sometimes referred to as 'fixed') broadband access in developing countries, means that, as of 2016, 3.9 billion people - 53% of the world's population – were not accessing the Internet.30

There are huge variations between regions. For example, 75% of people in Africa are offline, compared to 21% of Europeans.31 For those who are online, experiences differ hugely due to broadband speeds.32 For example, only 29% of the world's 3.4 billion people living in rural areas benefit from the 3G-coverage that is needed to enable a rich online experience.33

Cost of Internet access

In the majority of the world's poorest countries broadband remains unaffordable, although mobile-broadband services are more affordable than fixed-broadband services. In 2011, the Broadband Commission for Digital Development set a target of making 'entry-level' broadband services affordable (amounting to less than 5% of average monthly income) in developing countries by 2015. In 2016, International Telecommunication Union reported that just five low income countries had achieved this target.34

Gender inequality

Internet penetration rates are higher for men than for women in all regions of the world.35 In fact, the global Internet-user gender gap grew from 11% in 2013 to 12% in 2016. In 2016, the regional gender gap was largest in Africa (23%) and smallest in the Americas (2%).36

Compared to the frequency of interventions designed for groups such as adolescents and men who have sex with men, the number of HIV-related digital interventions tailored for women has not yet matched the promise the technology holds to help women living with, or most affected by, HIV 37

Data privacy/confidentiality

People may be reluctant to use technology, as they fear it will leave them open to breaches of data or confidentiality.

The development of data privacy legislation to address these fears has been slow but is steadily improving. In 2015, a global survey on e-health conducted by WHO found 78% of countries had some form of legislation to protect the privacy of personal information, but only 54% reported legislation to protect the privacy of electronically held patient data. 38

Skills and education

A lack of education and skills on how to use technology can act as a serious barrier to its use.

A technology that is not designed correctly or does not integrate well with existing technologies and workflows can also be a barrier.

This is why the most successful e-health interventions use technologies that are already in use, rather than asking people to learn new systems.

WHO's 2015 global e-health survey found that 75% of countries have institutions that offer pre-

service training or continuing education training on ICT for health for health care workers and 25% of countries offer in-service training on social media for health.39 However, training and support for consumers must also be addressed.

Loss of human contact

The fear that the quality of care decreases because of a lack of contact or due to a different kind of contact can also be an important barrier to adopting e-health initiatives – for both clinicians and health workers.

Factors for successful implementation of technology and e-health-related HIV programmes

In 2016, USAID released a set of guidelines to help development practitioners integrate established best practices in the use of information and communication technologies.40 Some of these areas are discussed below.

User involvement (healthcare workers and end users)

As far as possible, people living with and most affected by HIV, and those involved in delivering HIV information and services, should be involved in the development and implementation of e-health initiatives. For example, an m-health app designed to improve treatment adherence among teenagers living with HIV in rural Viet Nam should be developed in response to the specific needs and lifestyle of that group as well as the schedules and capacity of the healthcare workers that provide treatment support for them. Initiatives should be tested by the people they are intended for before they are rolled out.

In addition, all users should receive adequate training and instructions on how to use an e-health initiative when they are first introduced to it, and on-going support made available if needed.

Language and literacy

It is becoming widely recognised that information about health and health services needs to be provided to people in the language they speak. As a result, the most successful e-health initiatives provide multi-language options appropriate to the settings they are being deployed within.41. In addition, e-health interventions should provide content and information that is appropriate to the user – for example, advice on antiretroviral treatment might contain too many complex medical terms for someone simply wanting to know when to take their medication.

Cross platform

Users are more likely to make the most of e-health interventions if it is easy for them to integrate them into technology they are already comfortable using. For example, an initiative that enables testing appointment reminders to be pushed to the calendar on someone’s mobile device, with the information accompanied and supported by linked websites, is more likely to succeed than one that creates an online calendar specifically for this intervention and asks users to log-on on to a website to access it.42

Addressing potential legal issues

Legal issues relating to e-health initiatives need to be clearly thought through while they are being developed. Legal issues to consider include who is responsible for online systems, who owns the intellectual property to them, and how secure they are in protecting patient privacy.

The health sector may be particularly concerned with regulating the use of big data, not least because of the many perceived threats from the inappropriate use of personal data, together with concerns of use of cloud-based solutions (particularly when hosted outside the country).43

The future of e-health

New technologies and new applications of technologies open up a whole range of possibilities for the HIV response with the potential to be extremely effective if they are designed, used and targeted properly.44

Although access to basic mobile technology has reached near universal levels, major barriers to Internet access still exist. Until the cost of broadband access and the lack of network infrastructure is addressed, the potential for e-health to accelerate access to HIV information and services will not be met. Even if these logistical barriers are removed, social and economic barriers that prevent certain groups such as women and others who lack digital literacy must also be tackled or many groups living with, and most affected by, HIV will miss out on the huge promise e-health holds.

One of the most promising aspects of e-health is its potential for enhancing the integration of HIV services and HIV treatment cascade across provider, place, and time. However, this will only be achieved if e-health and health information system platforms have sufficient common ground to communicate and work together. This requires the establishment of and adherence to global standards for how data is structured and exchanged.45 Without close cooperation between governments, donors, and private healthcare providers to achieve this, the power e-health has for vastly improving the global HIV response will remain underused.46

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