Real-time monitoring through the use of technology to enhance performances throughout HIV cascades

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Purpose of review
Controlling the HIV epidemic requires strong linkages across a ‘cascade’ of prevention, testing, and treatment services. Information and communications technology (ICT) offers the potential to monitor and improve the performance of this HIV cascade in real time. We assessed recent (<18 months) peer-reviewed publications regarding uses of ICT to improve performance through expanded and targeted reach, improved clinical service delivery, and reduced loss to follow-up.

Recent findings
Research on ICT has tended to focus on a specific ‘silo’ of the HIV cascade rather than on tracking individuals or program performance across the cascade. Numerous innovations have been described, including use of social media to expand reach and improve programmatic targeting; technology in healthcare settings to strengthen coordination, guide clinical decision-making and improve clinical interactions; and telephone-based follow-up to improve treatment retention and adherence. With exceptions, publications have tended to be descriptive rather than evaluative, and the evidence-base for the effectiveness of ICT-driven interventions remains mixed.

Summary
There is widespread recognition of the potential for ICT to improve HIV cascade performance, but with significant challenges. Successful implementation of real-time cascade monitoring will depend upon stakeholder engagement, compatibility with existing workflows, appropriate resource allocation, and managing expectations.

Keywords
HIV cascade, information and communication technology, real-time monitoring

INTRODUCTION
Enormous strides have been made toward reversing the HIV epidemic; however, HIV incidence remains high among members of key populations who account for some 40–50% of all new infections worldwide [1]. UNAIDS estimates that, to control the epidemic, 90% of people living with HIV should know their HIV status, 90% of people living with HIV should be on treatment, and 90% of people on treatment should have suppressed viral loads [2]. Meeting these goals will require strong linkages across a continuum of HIV prevention, testing and antiretroviral treatment (ART) services. Managers and researchers in recent years have applied a cascade framework to characterize performance across this continuum; identify losses of client engagement; prioritize actions to improve performance; and apply resources strategically [3].

The HIV cascade is comprised of several stages, which are as follows:

1. Reaching high-risk clients with HIV-prevention education and referral to services
2. HIV testing and diagnosis of new positive cases to achieve the first ‘90’
3. Timely initiation of HIV treatment to achieve the second ‘90’
4. Treatment retention and adherence to achieve viral suppression, the third ‘90’
Effective cascade monitoring depends upon access to timely and accurate data imbedded in systems linked across the entire cascade. Recent information and communication technology (ICT) advancements offer potential solutions to this challenge [4]. Below, we summarize advancements relating to ICT across the HIV cascade published over the past 16 months, highlight the breadth of ICT applications improving HIV cascade performance, and identify gaps in the literature. We searched PubMed, Global Health, Academic Search Premier, Popline, and Google Scholar, from January 2016 to April 2017, using the following search terms: (‘real time data’ OR ‘real-time data’ OR ‘real-time’) AND monitoring AND (HIV OR AIDS OR ‘acquired immune deficiency syndrome’). The search was performed both with and without the additional terms AND (evidence OR evaluat* OR ‘lessons learned’). This search resulted in 133 papers identified; however, we identified no papers on the development or outcomes of ICT systems to track individual or program performance across the entire HIV cascade during the review period. We included in this review 29 papers that described applications of ICT to different cascade ‘silos’.

Information and communications technology to improve programmatic reach and targeting

Any successful HIV program must target the right populations in the right places at the right times. Buthelezi et al. [5] and Mesmar et al. [6] highlighted the use of ICT for data collection – particularly for georeferenced data to inform location-specific interventions – data aggregation and analysis. Mobile survey tools such as those described by Fisher et al. [7] were successfully applied to inform rural water and sanitation monitoring, and to inform the rapid response to a cholera outbreak [4]; faster and more granular data on HIV-risk practices and service needs can equally guide program targeting of HIV programming for key populations.

Recently published literature also points to social media platforms such as Twitter as new sources of information on HIV-related knowledge, attitudes, and practices. Young et al. [8*] reported on an automated process for filtering tweets related to HIV risk behaviors that reduced the time to analyze social media content from weeks to hours and did so with high accuracy; similarly, Kalyanam et al. [9] used unsupervised machine learning to analyze 11 million tweets and identified themes and trends in the nonmedical use of prescription drugs.

Online platforms can also be useful in targeting high-risk populations. Prescott et al. [10*] reported on the development of a cost-effective national recruitment strategy for adolescent gay, bisexual, and queer men via Facebook and Google AdWords, whereas Sullivan et al. [11*] demonstrated the use of a mobile HIV-prevention application to promote condom use, at-home HIV testing, and HIV pre-exposure prophylaxis (PrEP). Three major structured reviews published in 2016 pointed to the potential for social media to reach large audiences quickly with sensitive information, though these interventions focused on men who have sex with men (MSM) to the exclusion of other audiences, and on prevention with little attention to HIV-positive populations [12*]. Although many social media-based intervention models have been proposed, research has been predominantly observational and descriptive, and what outcomes have been reported have been mixed [12*,13*]. As Tso et al. [14*] noted, there are methodological challenges to evaluating social media-based interventions. One study that did more rigorously assess the impact of a social media intervention on service uptake, by Lampkin et al. [15*], concluded that using social media application Grindr resulted in a more than 1500% increase in public health contacts with MSM over a 6-month period, and of the 816 individuals contacted, 35% received some combination of referral, testing, treatment and/or follow-up.

Information and communications technology to increase testing uptake and yield

Comparatively little attention has been paid to ICT improving delivery of HIV testing. Poon et al. [16**]
reported on real-time tracking of HIV genotypes in a drug treatment database, which generated monthly reports on infection clusters. The team identified an expanding cluster of infections among young MSM that resulted in follow-up, early identification of multiple new cases, and a reduction in onward transmission [16]. Additionally, Sutcliffe et al. [17] described implementation of an early infant diagnosis program of a combined text messaging and mobile phone system. Blood samples from infants were sent to a national laboratory for testing, and results were provided to a district referral hospital via short message service (SMS); staff then reached out to a rural health center or to the mother to collect the test results. As a result, almost all mothers received their child’s test results, with significantly earlier notification, and earlier ART among HIV-positive infants [17].

**Information and communications technology for treatment initiation and management in clinical settings**

Possibly the most widely researched use of ICT applications and tools across the HIV cascade has been within healthcare settings. This has included as a tool for managing electronic health records in a vertical system such as the CAREWare software developed to track ART patients in the United States [18]. Other literature has described the development, but not necessarily the outcomes, of systems to coordinate care across multiple providers, such as a monitor system for TB/HIV co-infected patients in Malawi [19], and a US-based mobile application allowing HIV and substance use treatment providers to identify, refer, and track patients in need of dual care [20].

Information and communications technology is also being used to guide clinical decision-making. A 2017 scoping review on mHealth in Sub-Saharan Africa highlighted the need to ensure evidence-based practices where clinical tasks are shifted to lower-cadre health workers. The review indicated positive attitudes among healthcare workers for using mobile clinical decision-making systems, which they viewed as making their work simpler and more accurate, improving trust between patients and providers, and simplifying reporting. The review also concluded there is insufficient evidence for the impact of such systems on the quality of care [21]. Although not directly related to HIV service delivery, a report on implementation of a electronic job aid for cervical cancer screening in Kenya showed increased confidence among nurses who used the job aid, improved patient–provider interactions, and allowed supervisory organizations to rapidly aggregate and review service delivery data, identify unusual patterns, and address problems in real time [22].

Finally, Fredericksen et al. [23] probed provider perceptions on ICT to facilitate same-day, patient-reported measures for use in HIV clinical care. That article concluded that a self-administered assessment could help clinicians identify problems that might be overlooked in a face-to-face clinical interaction and could prepare both parties to discuss sensitive issues [23]. Swendeman et al. [24] additionally reported a belief among healthcare providers that ICT for patient-reported outcomes could enhance patient engagement and satisfaction; providers in this study also felt that mobile self-monitoring tools could strengthen patient self-management and motivation. Notably, the available literature did not probe patients’ attitudes toward reporting or self-tracking tools.

**Information and communications technology to enhanced treatment adherence and retention**

There has been significant attention paid to ICT for HIV retention and treatment adherence via telephone communications using interactive voice response (IVR) or SMS. A Cochrane Review of 132 trials involving telephone systems for prevention and management of long-term conditions found mixed results regarding adherence, and insufficient evidence of effectiveness for HIV specifically [25]. However, a study among HIV/tuberculosis (TB) patients in Lesotho found that clients who received SMS treatment reminders reported higher levels of ART adherence compared with standard-of-care clients [26]. A similar study among Chinese ART patients also found higher self-reported adherence among patients receiving weekly supportive SMS messages [27]. Neither of these studies, however, measured medication levels in blood, and the Chinese study found no difference in CD4 levels between treatment groups.

Tanner et al. [28] reported on the development of a social media-based intervention to provide theory-based information and messages, build social support, and deliver treatment reminders for young, HIV-positive MSM across multiple platforms tailored to an individual client’s social media preferences. There are as yet no reported outcomes from this intervention [28].

**Information and communications technology across the HIV cascade**

There is significant interest in the use of ICT to improve HIV cascade performance, with various innovations proposed, developed, and (to a lesser extent) evaluated to improve reach, enhance testing...
uptake, increase treatment initiation, and ensure retention in care. However, these approaches tend to focus on improving performance at a single step along the cascade without considering the impact on overall progress toward 90-90-90 goals. What is missing is consideration of ICT to track and improve performance across the cascade as a whole. There are tools available in the market, including CommCare (Dimagi, Cambridge Massachusetts, USA); Magpi (Magpi, Washington, District of Columbia, USA); and Open Data Kit (ODK, University of Washington, Seattle, Wisconsin, USA) that help organizations to design and manage real-time data systems. Implementing such a system would entail monitoring an open cohort from reach to testing to treatment and retention. This would allow programs to characterize populations served and identify coverage gaps; to map HIV seroprevalence to outreach and identify highest-risk geographic hot spots or subpopulations; to identify cascade ‘leaks’ and respond to losses to follow-up in real time; and to facilitate instant connection and follow-up between program managers, implementers, and clients. There are examples of similar systems for other health areas, such as the Mobile Technology for Community Health Suite applied to coordinate continuum of care services for maternal and child health in India [29], and the use of ODK for case identification and management, investigation and contact follow-up, and strategic planning during the recent Ebola outbreak in Nigeria [30]. There is at least one example of a full, real-time cascade monitoring program currently being piloted for the HIV cascade and which was presented at the 2016 International AIDS Society Conference in Durban, South Africa [31]; however, there are as yet no publications formally documenting this model.

**DISCUSSION**

The benefits of real-time data collection and program monitoring are clearly documented in the literature. By aggregating real-time service delivery data, program staff could access information quickly and efficiently, allowing time and resources to be focused on other activities and enhancing implementation challenges have meant the realization of that potential has been slower than anticipated. The literature on developing ICT systems for different ‘silos’ of the cascade also describes numerous of these implementation challenges, perhaps the most serious of which regard partner agency ownership and motivation. To be successful, any system needs to tie into national databases while remaining useful to local service providers. Numerous researchers reported difficulty convincing implementing partners to adopt a new monitoring system that was viewed as serving the needs of the donor agency [6,21,32**], particularly if that system did not fit within their existing workflows [33**] or duplicated existing data collection systems [21,24,32**]. Medford-Davis et al. [34*] showed what happens when ICT solutions are not well planned—they investigated the introduction of electronic health records in a US hospital, which, because it did not account for existing, paper-based practices in HIV screening, resulted in a 46% reduction in testing over a 6-month period and an estimated 167 missed diagnoses.

In their study on healthcare providers’ attitudes toward ICT-enabled patient management, Swendeman et al. [24] noted that doctors felt overwhelmed by multiple electronic medical record systems. Similarly, Adepoju et al. [21] found that the use of a mobile clinical decision-making system doubled the time needed to complete some tasks. This tension can be exacerbated if newly introduced systems are viewed as producing low-quality data [17*] or data that do not meet the needs of other stakeholders [32**], which can result in the development of parallel data collection platforms.

Privacy is also a major concern [5,6,8*,16**]. Mobile data collection systems collect a great deal of information about clients, and at present, guidelines around access to, use, and sharing of these data are relatively limited [35]. Conversely, full cascade tracking depends upon a free flow of information across potentially multiple service delivery agencies, but existing regulatory or organizational regimes may hamper the full realization of benefits from real-time cascade monitoring systems [24,33**].

Finally, implementation of an ICT-based cascade monitoring system requires sufficient infrastructure [4], start-up and operating costs [4,33**], staff time and training needs, and so on [17*,21,23,32**], and it is easy to underestimate these needs during initial planning. These resource commitments can contribute to questions regarding the long-term sustainability of ICT-focused solutions, as Moucheraud et al. [32**] noted: ‘each of the systems relies . . . on contributions from external sources, and there was a near-universal perception that the systems would not exist without substantial external financing’. It is questionable
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whether such an investment would be practical or beneficial for all programs, though the costs might be well worth it in settings with a need to better characterize their HIV cascade or understand where to invest resources.

CONCLUSION

Real-time tracking using ICT can characterize the performance of an HIV cascade from prevention to testing to treatment, to identify gaps or leaks in service delivery, and to allow implementers to intervene in a timely manner. However, most research has focused on ICT applications at specific stages of the cascade, rather than across it.

Implementing real-time cascade tracking requires extensive preplanning that should involve early and frequent engagement with stakeholders to understand their needs, map their work patterns and existing practices, and ensure the relevance and usefulness of the proposed platform for the end users [19,23,32\textsuperscript{a}]. Incremental implementation strategies are more likely to be successful than a ‘big bang’ approach [33\textsuperscript{a}].

Finally, despite high expectations for the impact of ICT, there is at present a lack of rigorous evaluation of ICT-based platforms and projects. Program planners seeking to implement ICT solutions should manage inaccurate perceptions of the capabilities of these systems. ICT is not a panacea to solve all implementation problems [7,21].

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Conflicts of interest

The authors declare no conflicts of interest.

REFERENCES AND RECOMMENDED READING

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest


First description of an effort to integrate HIV epidemiological expertise with a machine learning model to accurately and quickly identify HIV-related trends in large social media data sets. Implementation case study of ‘digital epidemiology’ to monitor, predict, and prevent the spread of HIV particularly among high-risk, Internet-savvy populations.


Description of a relatively fast and cost-effective social media-based recruitment strategy that demonstrates the value of targeted versus diffuse coverage but with the caveat that overly specific targeting criteria may hinder reach.


This pilot study demonstrated uptake of HIV prevention and testing services driven by a theory-based, health-specific mobile phone ‘app’, and is valuable in its demonstration of an mHealth intervention that extended beyond ‘reach’ to motivate service uptake.


Systematic review of 44 studies on social media-based interventions that showed support for online, peer-leader interventions in comparison to interventions based on informational posts only, but identified important gaps in terms of efficacy and effectiveness studies, and also applications of social media across the HIV cascade and for varied target populations.


Structured review of 16 articles describing 12 interventions which concluded that social network sites can reach large and hard-to-reach audiences rapidly and deliver messages widely and via 2-way interaction. The authors recommend incorporating probabilistic sampling approaches to reduce selection bias of at risk populations, and call for meta-analysis to ascertain overall effect estimates.


Inventories social media-based interventions to reach and engage high-risk populations in promoting safer sex, discouraging use of illicit drugs and generating demand for HIV testing. Describes methodological barriers to rigorous evaluation of social media-based interventions.


Showed acceptability and high levels of coverage and continued engagement with a social media-based HIV intervention for gay men. Additionally demonstrated measurable outcomes in terms of referral and uptake of HIV clinical services among participants.


Implementation case study that demonstrated real-time, automated monitoring of a drug treatment database to identify new infection clusters and guide field-based public health responses. This study highlights an important model for using real-time data to target intervention activities, potentially increasing HIV testing uptake and yield and reducing onward transmission and/or treatment resistance.

This observational study demonstrated a relatively low-tech approach (SMS) to improve ART initiation by linking national reference laboratories to rural health clinics to HIV-positive mothers in a low resource setting.


Describes key considerations for successful rollout of an electronic health system for medical care providers, including an extensive and participatory planning process and a well functioning paper-based back-up, particularly in the early stages of adoption.


Mixed methods implementation science study demonstrating the importance of flexibility for SMS/call-based interventions, including message frequency and timing. Suggests airtime may enhance acceptability but adds costs. In resource-limited settings, SMS may be reserved for those who lack other means of support.


This randomized controlled trial of an interactive, SMS-based treatment adherence program demonstrated high satisfaction with the ability to message healthcare providers back, resulting in higher levels of self-reported ART adherence though no discernable impact on CD4 count possibly relating to the short study period.


This qualitative study presents a multicountry comparison of factors influencing sustainability of eHealth systems and highlights the importance of clearly defined and broadly shared goals to ensure local ownership of a system. Findings are of importance to anyone planning to implement electronic systems for HIV cascade monitoring.


Synthesis of 44 structured reviews on e-health implementation, which identifies characteristics of the ICT innovations, the implementation context, the end-user characteristics, and the intervention process that impact successful adoption of an e-health intervention. Key highlighted barriers included adapting ICT to existing workflows, the need for recognized standards and supportive legislation, and the importance of evaluation to ensure potential benefits of new technology are highlighted.


This study described the negative impact on HIV testing uptake and case identification of implementing an electronic health records system that did not account for existing, paper-based clinical procedures.