

# ► A review of ICT systems for HIV/AIDS and anti-retroviral treatment management in South Africa

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## Summary

Telemedicine and e-health systems have been proposed as a support tool, to monitor and evaluate HIV/AIDS management strategies. The aim of the present study was to provide an overview of telemedicine and e-health systems for HIV/AIDS in South Africa as a basis for developing an e-health toolkit for anti-retroviral treatment (ART). An initial literature review and a subsequent interactive networking approach were chosen to identify telemedicine and e-health systems, projects and services for HIV/AIDS and ART facilities in low-resource settings and under-served areas. The literature review produced little useful information. In contrast, the face-to-face interviews and the focus group discussions provided useful information about projects and systems which had not been published. The meetings involved 1–5 people per session, about 30 people in total. The review showed that there were some plans for telemedicine and e-health implementation in South Africa. However, there was no all-inclusive ICT-based system in place for AIDS treatment there. With the exception of the major health information systems and electronic patient record systems, none of the telemedicine and e-health systems identified in the review were ready to be deployed across the country as a whole.

## Introduction

HIV/AIDS is a major global health problem. In South Africa, it is estimated that 5.4 million people are infected by HIV, out of a population of nearly 48 million, giving a prevalence rate of about 11%. About 600,000 individuals are infected with AIDS. Furthermore, the estimates show that, by mid-2006, some 711,000 people were in need of anti-retroviral treatment (ART), while 225,000 were actually receiving it.<sup>1</sup>

HIV/AIDS treatment and management strategies require ongoing monitoring and evaluation, and telemedicine and e-health systems have been recommended as a supporting tool.<sup>2,3</sup> One of the challenges for access to treatment through anti-retroviral medication is the difficulty of receiving accurate and up-to-date information at the planning level.<sup>1</sup> Information and communication technology (ICT) has been used in a number of pilot studies to address this bottleneck, by providing an infrastructure for telemedicine and e-health applications.<sup>4,5</sup> These projects suggest that the ART delivery to poor communities can be significantly improved by integrating local primary

health-care information with centralized databases to allow national monitoring.

So far, little evidence has been documented on the use of ICT for mitigating HIV/AIDS<sup>6</sup> in South Africa and elsewhere, with a few exceptions.<sup>3,7–9</sup> To our knowledge, there is no baseline study on telemedicine, e-health or e-readiness for South Africa. There is no agency, private nor public, which offers an overview of e-health and telemedicine projects and systems in South Africa. The WHO 'Global e-health observatory' has so far no information on South Africa.<sup>10</sup> However, a Presidential National Commission on Information Society and Development has been established, with a section on e-health. The mandate states that it will investigate the use of e-health in the country.<sup>11</sup>

The aim of the present study was to provide an overview of telemedicine and e-health systems for HIV/AIDS in South Africa as a basis for developing an 'e-health toolkit' for ART.

## Methods

The study was conducted from September to December of 2006. An initial literature review and a subsequent interactive networking approach were chosen to identify telemedicine and e-health systems, projects and services for

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HIV/AIDS and ART-facilities in low-resource settings and under-served areas.

A total of three scientific databases were searched, namely Pubmed/Medline, Science Direct and Biblioline. The searches were limited to articles published between 2002 and 2005, inclusive. Queries were made for telemedicine and e-health studies conducted in South Africa. Additional criteria were that studies were reported in the English language and that they were studies on human subjects.

We used the following search words: 'ART', 'ARV', ('Anti-Retroviral' and 'HAART'), 'HIV', 'AIDS' and 'ICT', 'e-health' (eHealth), 'tele-health', 'telemedicine', 'cell-phone' (cell phone), 'mobile' (application), 'Internet', 'web'. Searches were also made for 'needs-assessment' and 'review' in order to check for similar studies.

A systematic web search was conducted in a similar manner. This entailed searching specific websites that were likely to have the desired information, e.g. funding agencies, government and research,<sup>12</sup> as well as general web searches using Google and the search words as listed above. A database with 1615 papers collected for a review study on methods of telemedicine and e-health literature (1990–2005) was searched.<sup>13</sup> The last search was performed in November 2006.

Since very little information was found with these search strategies, each province was contacted via email and asked if they could assist with information on ICT-related systems or projects in their province. Project managers, health-care professionals, and telemedicine and e-health stakeholders were contacted by telephone and in face-to-face meetings. The preliminary findings of the review and interviews were presented and revised after discussions with a group of researchers and other stakeholders.

## Results

The literature review returned few publications on the topic. The majority of articles described projects about information on HIV/AIDS.<sup>14–16</sup> Only a few papers described clinical systems and direct patient communication,<sup>17,18</sup> such as Health Electronic Records in Haiti.<sup>19,20</sup> One of the few papers from Africa concerned electronic health records focusing on HIV/AIDS in Kenya.<sup>21</sup> The study 'Health toolkit' was the only study found which assessed ICT systems for health.<sup>22</sup> It focused on NGOs working with HIV/AIDS in various countries. Of the 17 products assessed, none was considered immediately deployable in the target settings.<sup>22</sup> No published scientific papers from South Africa were found, nor were technical reports or relevant information readily available.

The web searches returned several hits from South Africa, which were mainly conference abstracts and presentations.<sup>23–29</sup> Most of the information was collected through meetings and conferences with stakeholders. No reports of needs assessment and technology readiness were published within this specific field, but a few in-house

papers were uncovered through communication with project managers, telemedicine and e-health stakeholders. Table 1 gives an overview of the results grouped into the following categories: Health information systems (HIS), Electronic health records (EHR), Pharmacy management systems, Laboratory systems, Remote diagnostics (telemedicine consultations), Home-based care and direct patient communication, and Blended learning. There were far more ICT systems on information handling (HIS and EHR) than on direct patient consultations (Table 1).

**Table 1** Telemedicine and e-health for administering HIV/AIDS in South Africa

Type of ICT system	Examples	Comments
1 Health information (management) system	Paper-based national reporting system (for ART): Medicom and Paab modules are based on these requirements <sup>33</sup> PEPFAR-reporting system and other NGO systems <sup>31</sup> Home affairs national identification system (smart card, reduced EHR) <sup>34</sup>	There are health information systems at provincial and national level The private health, mining and military sectors each have their own systems
2 Electronic health records	Open MRS <sup>32</sup> Electronic medical records <sup>35</sup> Electronic health record, South Africa <sup>36</sup> Smart-card <sup>37</sup>	Two main types: with clinical data (identifiable) and for research only (non-identifiable) Various storage devices, (smart-card, database, web)
3 Pharmacy management system	Medicom HIS – HIV/AIDS component <sup>33</sup> ComputerKit Systems – Unisol <sup>38</sup> Mediware – JAC Stock Control and Drug Accounting System <sup>39</sup> iDART <sup>40</sup> PharmASSIST <sup>41</sup>	Some of the systems are commercial and some are NGO-based like iDART
4 Laboratory system	TOGA Laboratory System (Microsoft based) <sup>25</sup> NHLS information system <sup>42</sup>	Toga systems are deployed in rural and peri-urban settings in containers. NHLS provides diagnostic laboratory services to a national network of 250 pathology laboratories
5 Remote diagnosis (telemedicine consultations)	Teledermatology <sup>26</sup> Tele-ophthalmology <sup>27</sup>	Store-and-forward communication is used to assist rural under-served clinics where there are no specialists available
6 Home-based care and direct patient communication	After-care: Home-based carriers collect medical and socioeconomic data from AIDS-patients through applications on their mobile phones <sup>43</sup>	SMS reminders have been used for TB AIDS-patients use the alarm clock function in their mobile phones as private reminders to take medication <sup>43</sup>
7 Blended learning	Mindset Health Channel <sup>44</sup> Broadcasting health content through radio and TV, e.g. Soul City, Khomanani <sup>45</sup> NEPAD e-Schools health point <sup>46</sup>	The systems target various groups: for the general public, patients and health-care workers
8 Other	Simpill <sup>47</sup>	'Intelligent' pill-case with reminders for medication

No responses were received from the email messages sent to the provinces' health authorities. A strategic plan for the Department of Communication (2005–2008) has been developed which states that it will provide ICT-related support for health.<sup>30</sup> A departmental task team is finalizing an e-strategy, which should have been ready for adoption in 2005.

The legal framework in South Africa provides good procedures for retrieving aggregated health and patient information throughout all government levels. Most of the data reporting thus far has been in paper-based format (particularly from rural clinics to the provincial authorities). The paper-based system (in the form of data points collected at clinic level) is standardized throughout South Africa. The highest aggregated data-set from provincial to the national Department of Health has been delivered in digital format for some time. A number of health information and electronic health record systems have been used at provincial level to standardize reporting. Some of these systems have integrated HIV/AIDS and ART modules to support the primary health-care facilities of the public sector like Medicom, PEPFAR and Open-MRS.<sup>31–33</sup>

Since the findings were limited, we were not able to follow up with the subset of questions we had defined as the aim of the study. None of the systems were ready to deploy on a large scale.

## Discussion

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To obtain an overview of the field was challenging for a number of reasons: some studies were not reported in indexed journals and were therefore not found when searching scientific databases. Several studies were only published by research institutions as reports, books, conference presentations, abstracts or papers. These in particular are difficult to identify in a literature review, since searches must be conducted on specific websites and within universities' report summaries. Therefore, to find these reports, one must first be aware that they exist. The search strategy reviewing scientific papers was expanded to a networking approach: for every positive finding, the author or person in charge of the project (or person referring to a project) was asked whether or not they knew of any telemedicine or e-health projects or services in the area of interest. This strategy is not foolproof.

In South Africa as in many other countries, implementation and support of health systems is managed at provincial level. This has resulted in different provinces implementing different systems depending on their specific requirements. In addition, a number of systems are based on the requirements of international funding agencies (e.g. PEPFAR) or NGOs. Some of the systems are pilot implementations as part of research studies, e.g. OpenMRS, with the support of the Medical Research Council, or based on private health-care systems such as Medicom. The NEPAD report highlighted the issue of 'turf protection' in

their report, and it concludes that this is especially prominent in the public sector, impeding future collaboration and integration of services.<sup>3</sup>

As in other countries, the most common type of ICT system is for health information. Otherwise, various designs of electronic health records are in place. All clinics have some form of patient data-capturing system, be it paper-based or digital. Since clinics and health-care workers find different means of managing the data acquisition, paper-based and electronic systems can, in this environment, exist side by side. Most electronic health records are designed to suit the requirements of the local context. Due to the varying needs throughout South Africa's health services each province has a dominant EHR. However, none of these systems are implemented throughout any of the provinces. A number of the existing EHR systems have been developed and supported by NGOs as pilot projects which is an unsustainable situation. At the time of our study, a national initiative had been developed, calling for a tender to establish a national EHR system.

With the exception of the major HIS and EHR, none of the ICT systems found in the review were ready to be deployed in the country as a whole. The main reason for this was that the telemedicine and e-health activities identified were pilot projects and therefore not evaluated as a service in use. This means that there is consequently no telemedicine and e-health application which addresses various disciplines in health care. The study showed that there is no systematic review- or evidence-based telemedicine and e-health repository in South Africa. Such a system, for South Africa or for other developing countries, would assist stakeholders in their decision-making with regards to sustainable telemedicine and e-health solutions.

The study started out focusing on telemedicine and e-health for ART-management and HIV/AIDS. In the process of discussing the investigation with people working in the field, it became clear that the focus needed to be reviewed. Since nearly all primary health-care issues are related to HIV/AIDS issues, it is hard to draw a clear line between the telemedicine and e-health systems that should be included in the study, and the others. One example is teledermatology, which is a specific area within telemedicine and e-health. Patients are selected because they have a skin problem which may be linked to HIV, but they are not necessarily diagnosed with HIV/AIDS. The distinction between telemedicine and e-health for ART, and in general, was not very fruitful when it came to reviewing the status of telemedicine and e-health in South Africa. However, when discussing the target area and users' needs for telemedicine and e-health applications and systems, it was useful to narrow the scope.

## Limitations of the study

In view of the above complication, it is possible that some papers were omitted from the study due to their general approach to primary health care. If these had been reported and indexed as research reports, they would have appeared

in the searches. Some studies could also have been missed because 'smart-card' was not included as a search term. Nevertheless, these studies should have been identified with the telemedicine and e-health and HIV-related search terms.

Health-care authorities at provincial and national level were only contacted via email and information sought from their websites. With follow-up telephone calls, the outcome could be expected to improve somewhat.

## Conclusions

There is no all-inclusive ICT-based system in place for AIDS treatment in South Africa, but a range of pilot systems and projects are in use. Paper-based and ICT systems will clearly co-exist for some time to come. There is a need for sharing information on lessons learnt, in order to improve the development and research. With the exception of the major HIS and EHR, none of the ICT systems found in the review were ready to be deployed in the country as a whole.

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