Innovations in Mobile-Based Public Health Information Systems in the Developing World: An example from Rwanda

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Overview

This paper will examine new applications of mobile and wireless technologies to the challenges of public health in the developing world, particularly the Least Developed Countries (LDCs). After a brief review of initiatives underway in Africa and India, the bulk of the paper will describe a national HIV/AIDS information system currently under development in Rwanda. This system relies on a combination of internet technology and traditional telephony (both fixed and wireless) to connect even the most remote rural health clinics. Potential merits of this system will be examined in light of Heeks' (2002) review of information systems projects in developing nations. This analysis will suggest that certain fundamental properties of wireless/mobile technologies are likely to increase the efficacy, scalability, and sustainability of public health information systems in low teledensity settings.

For the purposes of this workshop, the paper applies both to the "mobile technologies for disadvantaged persons" as well as to the "doctors communicating with doctors" tracks. However, given the severity of the HIV/AIDS pandemic, and given its particular impact on the LDCs, it is important to consider these applications as critical tools in what can only be described as one of the biggest and most protracted "health care emergencies" the world has ever confronted.

Background

Low-teledensity settings are those where connectivity, particularly voice connectivity, is scarce. We know there is a strong correlation between a country's per-capita wealth and its levels of teledensity (Grace, Kenny, & Qiang, 2001; Saunders, Warford, & Wellenieus, 1994) Whether increases in teledensity are a result of increases of GDP, or can actually cause increases in GDP remains a lively discussion between economists and technologists (Roller & Waverman, 2001). What is important for this paper is that the poorest nations tend to have the poorest information infrastructure. For organizations in these settings, information is comparatively more expensive to produce, gather, store, and share. Thus less information is available throughout the system, and overall organizational productivity tends to suffer. Yet due to resource constraints and a lack of connectivity options, in many cases it is precisely the settings where an incremental increase in investment in ICTs might have the most effect

where this investment is least likely to occur. How is a school to chose between a PC and school lunches (when the school meal is the only meal of the day?) How is a rural hospital to choose between sterile bandages or latex gloves and the cost of installing a landline telephone? Individual decision-makers, charged with addressing the daily challenges of running their offices, firms, and hospitals with very limited resources, are simply trapped, leaving the system to settle on an equilibrium of low-information generation and processing, and of low intra- and inter-organizational communication.

Public health information systems in LDCs have changed only gradually in the last 30 years. In the ministry offices and urban hospitals, there have phones on the desks of some staff for quite some time. Perhaps in the 1990s some PCs (that worked some of the time) appeared. and perhaps, in the last few years, the offices have acquired a slow internet connection or two. Photocopiers and printers are scarce, as are and paper and toner supplies. The general impression would be of an organization with plenty of paper, but not particularly extensive methods of information sharing and analysis. Meanwhile in the regional hospitals in major towns, perhaps there was likely to be a phone for the clinic as a whole. In the rural villages, the health clinics most likely did not have a phone at all. As in the headquarters, everywhere at the district and local levels there is paper, and lots of people trained to fill it out and move it around. On the connectivity side, the system had settled on this rural-urban split, as people waited for gradual improvements as the monopoly telecommunications providers gradually rolled new telephones out to more villages. On the information processing side, information moved slowly between the center and the periphery, and infrequently (if at all) between outlying parts of the public health system. As a result, stockouts (drug and supply shortages) were common, patient files were lost, there was little knowledge transfer between experts and local staff, and systems were slow to react to disease outbreaks; all these were parts of the accepted but-lamentable status-quo 'equilibrium' in public health.

In the past few years, however, there has been a flurry of innovative efforts to break out of this lamentable equilibrium and address many of the connectivity and information-processing challenges facing public health systems in LDCs. Consider, for example, these projects, each of which takes advantage of wireless and/or mobile information devices:

- In Uganda, <u>Satellife¹</u> is using PDAs to deliver local reference material and medial journal content to rural health clinics, using email-enabled Palm handhelds.
- In South Africa, On-Cue Compliance² offers a service to allow heath care providers to use mobile phones to send patients text-message reminders to take their medication, for example, for TB.
- In India, Jiva's Teledoc³ initiative and CoOptions Technology⁴ each use PDAs to collect information from villagers using a pre-designed consultation form. This information is then transferred to a doctor in the city, who diagnoses the problem and suggests appropriate treatment, precautions, and medication. The doctor's diagnosis and suggested treatment is then once again transferred to the PDA and carried back to the villager. Meanwhile, The Community Access to Sustainable Health (Ca:sh)⁵

¹ http://pda.healthnet.org/

² <u>http://www.on-cue.co.za/</u>

³ http://www.jiva.org/health/teledoc.asp

⁴ http://www.cooptionstech.com

⁵ http://kaash.sourceforge.net/

project puts patient records in the hands of local paramedic workers, enabling faster diagnosis as well as real-time surveillance.

Each project is an example of a relatively inexpensive, easy-to-use response to changes in the overall telecommunications environment. Specifically, each takes advantage of not only the very visible wireless and portable devices, but also of the less visible improvements to communication networks that carry data and the international data protocols that support them. These changes in device availability and network capacity and connectivity have enabled locally-developed innovations that promise to work where other such projects have failed, or never been attempted. Stepping back, it is apparent that the public health information systems are in a period of rapid innovation and experimentation. Thirty years ago, the paleontologists Eldridge and Gould (1972) proposed a theory of Punctuated Equilibria, suggesting that evolution and changes in speciation happened not just gradually (as had been previously thought), but both gradually and in occasional batched 'bursts' of interconnected, rapid change. This theory has been applied to explain changes in technological approaches (Loch & Huberman, 1999) and the metaphor seems appropriate here. Like elsewhere, the low-information equilibria of public health information systems in LDCs are undergoing 'punctuation' due to the introduction of applications based on wireless and mobile technologies. Many approaches are experiments or pilots, and not every new application will survive, but in general, what was previously impossible or impractical is now both possible and practical.

Example

For a closer look as to why the wireless and mobile and wireless technologies have created the conditions for this punctuation, we can look in-depth at an example of a new approach to an HIV/AIDS information system, currently under development in Rwanda.

Working with the Rwandan Treatment and Research AIDS Centre (TRAC), the US Centers for Disease Control is currently funding a pilot project to build an HIV/AIDS information System for Rwanda. This system is being built and deployed by Voxiva, Inc.⁶, in partnership with the Center for Global Health and Economic Development at Columbia University. The system will be a timely addition to the Rwandan government's overall health infrastructure. On the one hand, circumstances are dire – a true emergency. In Rwanda an estimated 8% to 14% of its 8 million people are living with HIV or AIDS. Yet there is also hope. Rwanda, like many of the LDCs, is beginning a process to rapidly increase the delivery of treatment (particularly Anti Retroviral Drugs) to its citizens living with HIV/AIDS. Rwanda, for example, has stated that it would like to move from roughly 1000 people on treatment to 50,000 within five years. With increased support from the Global Fund to Fight AIDS, TB and Malaria, USAID/CDC, and others, Rwanda has the resources and commitment to make strong steps towards this goal.

The anticipated increase in patients will put a strain on the health system and on the information system which supports it. The old equilibrium, with paper reporting moving between rural clinics and the center perhaps only once every month or so, was not going to be satisfactory. Nor was a system in which, when a rural clinic runs short of critical, life-sustaining drugs, the designated nurse or pharmacist takes a day-long bus ride to the capital and literally knocks on the front door of the national pharmacy warehouse. Nor was a system

⁶ http:///www.voxiva.net

where, if blood work was ordered at all, the sample had to be sent slowly to one central lab, and then the results sent back just as slowly (in paper form) to the rural clinic. Nor was a patient treatment regime where if a patient moved from one village to another, the doctors and caregivers in the new village would have no access to a patient's previous tests, prescribed drugs, or diagnoses.

A new level of information processing and communication was clearly required. Specifically, the government required: timely and accurate information about the number of patients enrolled at each treatment location, the current and projected supply of drugs and other critical consumables. Meanwhile, doctors and caregivers needed accurate and rapid testing of their patient's CD4 counts (a measure of the HIV infection's strength in the body) in order to manage treatment and modulate drugs effectively.

The system under development addresses each of these key needs by tying together the labs, pharmacies, ministries, and most importantly, the local and rural health clinics providing HIV treatment. This interconnection is achieved via Voxiva's multi-channel approach to the overall database. Users with a PC and Internet can interact with the system and its database though a secure website. In the meantime, users (generally in the rural areas) without a PC can add information to the system as well as request information through the use of any telephone, since the system uses menu trees and voice prompts to routinize standard data entry and queries. This unique combination of an internet and voice-based maximizes the amount of connectivity and information transfer possible given the levels of connectivity in Rwanda right now⁷. (See Figure) While the data captured and maintained by users of the system will be primarily used by the government itself, donors, international agencies, and researchers will also benefit from the new data sources.

⁷ The information infrastructure in Rwanda is changing quickly; The monopoly telecom provider has been joined, first by MTN, which has added over 100,000 mobile lines in 5 short years, and now covers 60% of the nation with GSM, and recently by TerraCom, a satellite/broadband internet provider which in the last year has been dramatically improving internet access in Kigali for major government offices and businesses.

Institutions Supporting ARV Treatment in Rwanda Current ICT Infrastructure

		N	Broad-band	Dial- up	Has PC	Landline /fax	Mobile
Kigali	Ministries	10	Possible	Yes	Yes	Yes	Yes
	Labs	1	Possible	Yes	Yes	Yes	Yes
	Pharmacies	1	Possible	Yes	Yes	Yes	Yes
	Research Hospitals	1	Possible	Yes	Yes	Yes	Yes
Regional Centers	Administrative offices	13		Yes	Yes	Yes	Yes
	Labs	2		Yes	Yes	Yes	Yes
	Pharmacies	2		Yes	Yes	Yes	Yes
	Reference hospitals	3		Yes	Some	Some	Yes
District	District hospitals	39		Some	Some	Some	Yes
	Local health centers	117				Some	Most

Shaded boxes represent the optimal channel for each organization

A telecommunications center for a rural hospital. Note: the voltage regulator is attached to a solar panel, the only source of electricity for the hospital.



As the figure above shows, the majority of the health clinics, who will interact with the system via telephone-based voice prompts, will do so via a mobile phone. The photo illustrates what the "communications center" of a typical hospital might look like. The rapid expansion of mobiles across the countryside in Rwanda (forecast to be 100% coverage within 5 years) is a key enabling feature of this particular information system; without it, the rural clinics, most of whom have never and (and may never) receive a land-line, would not be able to easily interact with the information system.

When a caregiver or administrator in a rural hospital wants to use the system, he or she calls a special toll-free number on her mobile, and enters her clinic number, her ID number, and a PIN number. Then, the user can follow voice prompts to a) add weekly information on drug supplies b) add monthly information on patient enrollment c) check on the current or historical test results for her patients or d) send special alerts, either as text options "do you have any drug shortages? If so, press 1..." or as a voicemail, which can then be sent to her supervisors and/or her peers. Finally, the user can pick up or send voicemail messages. The simplicity and ease-of-use of these voicemail and voice prompt systems is critical to the overall usability of the system for caregivers without a lot of training in information technologies.

When administrators and analysts in the district and national offices use the system, they will have a flexible web-based database, with drill-down and reporting features, as well as

geographic information systems (GIS) capabilities. They can also arrange to send (or receive) voice or text-based alerts, and to export data or tables or figures to other software functions.

The custom applications currently under development for the Rwandan Treatment and Research AIDS Centre are:

- A national "data dashboard" that will integrate data from multiple sources standalone applications, AIDSNet and paper reports to provide an integrated national view of the HIV/AIDS program
- A tool for the national pharmacy (CAMERWA) to use to monitor critical drugs and supplies in all sites supplying anti-retroviral treatment
- A tool to provide rapid access to the results of CD4 and viral load tests for caregivers in remote health facilities
- A tool for regular collection of critical indicators for the monitoring and management of the HIV/AIDS clinical care and treatment programs

The system is currently in the development and testing phase, and should be ready for initial field testing in the near future. Though this is Voxiva's first implementation of an HIV/AIDS-specific system, Voxiva has deployed similar systems for disease surveillance in Latin America, the US, and the Middle East. If testing goes well and the system is useful to participants, we are hopeful that, with some adjustments, it can be deployed in a more extensively throughout the nation. Of course, such a rollout would only occur after careful evaluation, both by CDC and the Government of Rwanda, as well as by an independent group of health informatics researchers at Tulane University.

Analysis

Given that the HIV/AIDS Information System project is still very much in the development stages, we can not yet say whether it will be successful. Nevertheless, even at the current conceptual level, it is a very good example of the 'punctuation' discussed above. Thus, we can look a little more closely at the properties of the solution (particularly those leveraging the mobile phone) as part of an inquiry into why mobile and wireless applications are creating this punctuation right now. To do so, it is helpful to look at the proposal against the background of an assessment of the success factors necessary for information systems in the developing world, as proposed by Heeks (2002).

Heeks and his colleagues (Heeks, 2002, 2003; Heeks, Mundy, & Salazar, 1999) explain that many information systems projects in the developing world have failed, either partially or completely, to live up to expectations and to deliver the results promised at the time of investment. There are a myriad of factors at play, which Heeks summarizes as the result of a set of "design gaps" between the idealized design of the device/system and the challenging realities in which the systems must function. Heeks uses the "ITPOSMO" acronym to review gaps and issues in: Information, Technology, Processes, Objectives and values, Staffing and skills, Management systems and structures, and Other resources. These gaps occur when systems designed originally for the private sector are placed in the public sector (with its different set of skills, incentives, and regulations); when systems designed for the developed world are placed in the developing world (where there are different approaches to information, different levels of infrastructure, different skills, and lower resources), and when systems designed to work in a hard, rigid, rational way are placed into contexts where shifting

political and personal objectives add complexity and nuance to the tasks at hand. In a series of case studies and examples⁸, Heeks details varying degrees of success in closing these gaps.



Designing Successful Information Technology Projects in LDCs Adapted from Heeks (2002)

Adapted from: Heeks, R. (2002). *Failure, Success, and Improvisation of Information Systems Projects in Developing Countries*. Institute for Development Policy and Management.

As Heeks (2002) explains, two overall kinds of local improvisations (actions) can be taken which can which overcome these design gaps: properties of the information system can be changed to better match local realities and/or properties of the local organizations/realities can be changed to name them more receptive to information-systems interventions. Both of these actions are being taken in the case of the proposed Rwandan HIV/AIDS information system. The next few paragraphs will assess some of these actions, with the common thread being how the availability of the MOBILE/WIRELESS technologies have made such actions possible, therefore reducing the design-realty gaps identified by Heeks, and therefore, increasing the likelihood of success of the project.

The use of mobile technologies has helped *adapt the information system's design to local realities*⁹ in a number of ways:

⁸ http://www.egov4dev.org/causegap.htm#examples

⁹ Not all the actions taken to adapt the design to local realities are related to mobile/wireless functions. For example: The system is flexible and iterative (the custom database sits on top of general software platform which allows for relatively easy and rapid adjustment and customization). In addition, Voxiva has designed for public and developing world settings right from its inception: its founders have decades of experience in public health and in emergency/relief settings, and have integrated that learning into their approach to systems development.

- a. It is a mixed-channel system, allowing broadband-enabled, dial-up-enabled, and only telephone (mobile) enabled users to interact with the database. However, it is not a lowest-common-denominator solution; internet-enabled users still get to use tables, data export, GIS, and all the sorts of powerful tools we'd expect.
- b. It takes advantage of the existing infrastructure, rather than requiring the installation of dedicated hardware. Specifically, as long as any of the nurses or administrators in the health clinic has access to a clinic-owned or a personal mobile they can interact with the database. They do not need to wait for a PC or a landline to be installed.
- c. The system is relatively resilient in the face of developing-world conditions. While the system does require a traditional server in a controlled environment – it only requires one such room in the capital, which is relatively easy to provide with the proper backup generators and skilled technicians, even in the poorest capitals on earth. For the rest of the users, out in the countryside, they can trust a simple mobile-phone handset to draw small power and survive drops, dust and moisture better than an average desktop PC. The mobile signals are there regardless of rain or wind, and the calls can be made even when the power goes out (which it often does). If a handset fails, it can be repaired or replaced for comparatively little money.

Similarly, the spread of mobile technologies in Rwanda has helped *improve local receptivity* to the proposed information system in a number of ways.¹⁰

- d. Most importantly, the voice and numeric data entry styles are in alignment with the developing skills and data-use conventions of the most numerous of the system's users the rural health care providers. As mobiles have spread thorough Rwanda, many people have become comfortable a) making phone calls and b) managing text messages, such as those required to refill airtime on pre-pay cards. Though overall phone penetration and ownership is still quite low, key elements of the population are becoming more comfortable and literate with their phones. Using the mobile to update HQ on the status of their health clinic will not seem so far-fetched to the users.
- e. On a deeper level, the use of the mobile may be seen as signifying importance, individuality, and agency, and should be a draw rather than a hindrance. The mobile phone is a powerful symbol of such elements worldwide (Donner, 2003; Varbanov, 2002). In Rwanda, in particular, the local mobile provider is probably the most widely-advertised brand in the nation.
- f. Public health is a 24-hour task; alerts come in at all hours. Thus, the mobile's unique ability to be carried between the domestic sphere and the work sphere make it well-suited to this system. "Paging" is a fact of life for doctors in the developed world. Now, for the first time, thanks to the installation of a mobile network in Rwanda, the caregivers, managers, and administrators of the system will also be accessible at all times and at all locations in the country. They have, for other reasons, begun to carry their mobiles everywhere so they will be more receptive to the requirements of this information system.

¹⁰ Again, some other efforts (unrelated to mobiles) are underway to improve organizational receptivity to the proposed information system For example, through the investments in detailed training curricula and extensive training time for new users

g. The system will both benefit from and contribute to a general trend towards the development of a culture of information sharing (vs. guarding), and towards decentralization (vs. centralization). As telecommunications costs are dropping, more information can be exchanges at lower cost, and more quickly. This is occurring in parallel with a government effort to decentralize decision-making (in matters such as health care) towards the districts, regions, and villages. Such information-sharing can occur both at the level of data/information, and of knowledge and skills transfer, some of which can be done via voicemail over the Voxiva system.

In summary, placing mobile technologies at the heart of this information system has helped make it relatively inexpensive on an ongoing basis (the single most salient local reality is resource constraints), and remarkably easy to use (the single most salient organizational constraint is one of skills). These twin attributes, both virtually fundamental to mobile technologies as we tend to think of them, should increase the eventual efficacy and sustainability of the system. Looking back to other experiments, such as the ones described earlier in this paper, it is easy to see the twins of affordability and ease-of-use in evidence again.

Concluding Remarks

Of course, the system is still a pilot, and there is much to be learned. Some of this analysis presented in this paper should be re-visited when more data is available and there is more experience with the system. One thing, in particular, to watch for is the ways the system is adapted by its users over time (and how the user's organizations are changed by the system). This process can be viewed through the lens of structuration (Braa & Hedberg, 2002; Giddens, 1984; Poole & DeSanctis, 1990).

Another important issue is to not confuse the impacts and benefits of voice telephony and mobility. In the developing world, where mobiles have outpaced landlines, it can sometimes be difficult to tell just what people are buying and valuing – the dial tone or the fact they can take that dial-tone with them. On the other hand, watching users adapt to having connectivity where before there was none is a good reminder of just how valuable connectivity of any kind actually is. The potential exists for some rapid and profound transformations in the ways these clinics interact with each other and with headquarters.

It is also essential to keep in mind that no information systems application will succeed without the commitment of government and the users of the system. The government must be not only a client for the technology vendor but an active participant and champion n the significant organizational change" initiatives that accompany the introduction of any new information system, whether wired or wireless.

Finally, while the punctuated equilibrium metaphor proposed earlier is a good way to explain the rapid pace of change in public health information systems in LDCs, this is not to say that we should be comfortable with experimentation. Coming back to the point made in the introduction, HIV (and malaria, and TB, and malnutrition, and heart disease) are all heath care emergencies that have been around for so long that we often forget to think of them in such terms. Just as nations like Rwanda require massive scaling-up in the resources they have available to respond to these emergencies, they require comprehensive and nationwide information systems to support these efforts. The wireless and mobile boom is enabling public health informatics to experience a 'punctuation' in the tools it brings to bear, but we need to arrive -- soon – at a new equilibrium where there is more timely, actionable, valuable information available to the people engaged in these fights in every village and every capital, not just in experimental sites. Only then will the information systems really contribute to national and global level changes in health outcomes.

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