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Leapfrogging Paper-Based Records Using Handheld Technology: Experience from Western Kenya

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Abstract

Problem: There is limited experience with broad-based use of handheld technologies for clinical care during home visits in sub-Saharan Africa. Objective: We describe the design, development, implementation, and evaluation of a PDA/GPS-based system currently used during home visits in Western Kenya. Results: The system, built on Pendragon Forms, was used to create electronic health records for over 40,000 individuals over a three-month period. Of these, 1900 represented cases where the individual had never received care for the identified condition in an established care facility. On a five-point scale, and compared to paper-and-pen systems, end-users felt that the handheld system was faster (4.4 ± 0.9), easier to use (4.5 ± 0.8), and produced higher quality data (4.7 ± 0.7). Projected over three years to cover two million people, use of the handheld technologies would cost about $0.15 per person – compared to $0.21 per individual encounter entered manually into a computer from a paper form. Conclusion: A PDA/GPS system has been successfully and broadly implemented to support clinical care during home-based visits in a resource-limited setting.

Keywords:

Handheld computers, Computerized medical records systems, Developing countries

Introduction

Many people in developing countries have little to no interaction with the healthcare system. The problem of accessing healthcare in these settings is usually two-fold: "*On the supply side, good quality, effective health care may not be offered. On the demand side, individuals may not utilize services from which they could benefit*." [1] As an example, in sub-Saharan nearly, 80% of HIV-infected adults are unaware of their HIV status [2] - this despite an interest by individuals in being tested [3]. Similar deficiencies are also seen in the diagnosis and management of diabetes, hypertension, chronic cardiovascular disease and tuberculosis, among others [4, 5]. Such poor access to healthcare leads to increased mortality and morbidity in these settings.

Approaches that take health services directly to individuals (as opposed to waiting for patients to come to the care facility) are being increasingly adopted to improve access to care. There is increasing adoption of home-based counseling and testing methods for HIV [6]. In addition, governments in developing countries are increasing the number of community health workers tasked with delivering care services directly into homes and communities.

By their very nature, home-based clinical encounters lead to care outside established health facilities. In the setting of sub-Saharan Africa, these visits often represent the first interaction of some individuals with the healthcare system. Such individuals typically have no established medical records, and data collected during home visits often represent the first medical records on them. As such, it becomes very important to collect this clinical information in a way that is useful not only during return visits to the home, but also for clinic-based follow up and for reporting purposes.

The USAID-Academic Model Providing Access to Healthcare (USAID-AMPATH) [7] in Western Kenya recently embarked on an effort to conduct home visits to the two million individuals in its catchment area. The goal was to collect basic health information and offer focused care services to individuals when needed. Typically, records collected for such visits would have been paper-based. We however hypothesized that it would be possible to completely leapfrog paper-based records, and create electronic health records (EHRs) for each individual for whom we conducted a home-based clinical visit.

The premise of our approach was based on the observation that resource-limited settings like ours had already made similar technological leaps [8]. The classic example was the leap from no telecommunication services to broad use of mobile telephony [9]. In addition, mobile devices had also been successfully used for limited research and clinical purposes in settings similar to ours [10, 11]. However, there was very little evidence to demonstrate the feasibility of broad-based implementation of mobile handheld technology for direct clinical care in these settings.

In this article, we describe the design, creation, and implementation of a customizable, modular-based handheld program to support Community Health Workers (CHW)s during home-based visits in a resource-limited setting. We also reports findings of a satisfaction survey of the end-users of the program and cost implications of using this system.

Materials and Methods

Setting

This work was conducted in Western Kenya, within a catchment area served by the USAID-AMPATH partnership. This program (made up of Moi University School of Medicine in Kenya and a consortium of universities in North America led by Indiana University School of Medicine) has provided comprehensive HIV care to individuals in western Kenya since 2001 [7]. In the last two years, the program has begun a transition into primary care.

Recognizing its responsibility to improve access to care for all individuals, the USAID-AMPATH program decided to conduct population-wide, clinically focused home visits to all households in its catchment area of two million people. The primary goal of this undertaking was to identify HIV-positive patients who were unaware of their status, and to offer care services as needed. In addition, this program aimed to identify pregnant women not receiving antenatal services; orphaned and vulnerable children; children who had not received all recommended immunizations for age; and individuals at higher risk of tuberculosis infection. During the home-visits, eligible individuals were offered rapid testing for HIV, sputum testing for Tuberculosis, deworming medication, and mosquito bednets. All clinical data gathered during these visits were captured on handheld devices.

Design and Development of Handheld Program

We started by engaging an interdisciplinary team of providers (including public health providers, nurse CHWs, and physicians), overseen by an executive steering committee. This team identified the data elements to be collected during the home visits, provided information on criteria and algorithms to be used (e.g. algorithm for HIV testing), and informed the team about the workflow relevant to the home visit exercise.

Modules

Several modules were identified as necessary for the home-based visits, and were programmed into the handheld devices. (Figure 1) The modules included:

Individual registration

Each individual who was visited by a CHW received a unique identifier. Households were also assigned unique identification numbers. These identifiers were generated from one central location, and had a check-digit. For the household, we captured the Global Positioning System (GPS) location and other information about the household, including number of residents. The individual demographic information collected included: first, middle, and last name; gender; birthdate [with ability to record estimated dates]; address; and phone number (when available).

HIV Module

The HIV module collected information about each individual's HIV testing history. We documented whether the individual had previously been tested, the year of their last test and the results. If the individual was known to be HIV-positive, we captured details of the HIV-treatment program to which they were enrolled. During the home visits, eligible individuals were offered HIV testing, and details of the testing were also collected. These included information about pre- and post-test counseling during the home visit; consent or assent to testing; results of two parallel rapid tests and of a third tie-breaker test (when it was done); referrals; and information on whether the

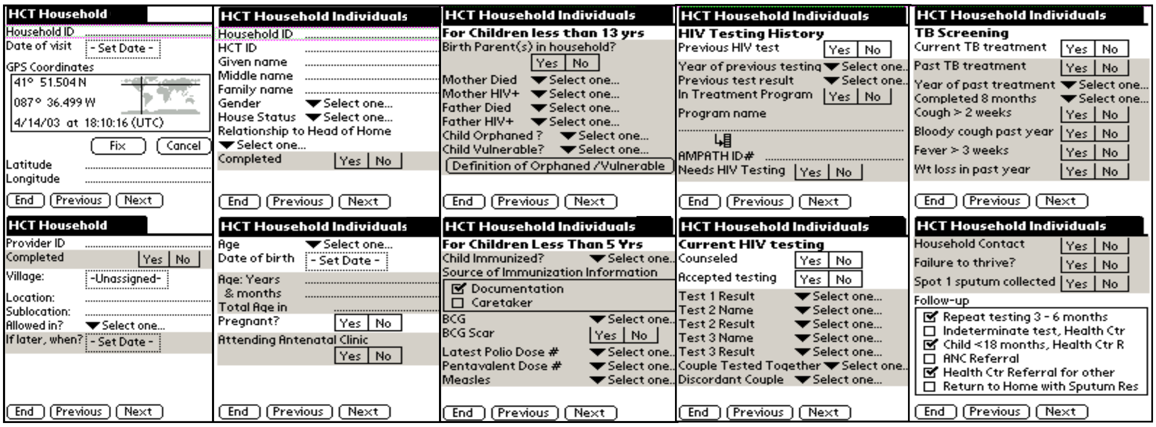

Figure 1-Screenshots outlining the various modules

HIV-statuses of a couple were discordant.

Pediatric Module

For children, we determined whether the child was orphaned or vulnerable (OVC) using a pre-defined set of conditions. A child was eligible for testing if their mother's HIV status was positive or unknown, or their mother had died or living status was unknown, and the relevant information was recorded. For children younger than five-years, we also recorded immunization history - including the source of the immunization information; details of measles, polio and pentavalent vaccination; and whether there was any visible BCG scar to signify immunization against TB.

Tuberculosis Module:

For all individuals visited, we documented history of current or previous TB treatment and responses to TB screening questions (e.g. bloody cough, fever, and weight loss). We also documented whether a sputum sample was collected for at-risk patients and the phone number to contact the individual with the results.

Antenatal Care Module:

For females of reproductive age, we documented pregnancy status. If pregnant, we documented whether they were enrolled into an antenatal clinic.

Software and Hardware

We developed the program to collect individual health data using Pendragon Forms software (Pendragon Software Corporation, Illinois, USA). Like most other Personal Digital Assistant (PDA)-based form-creation software, [10, 11] Pendragon Forms has a Windows application for designing customized data-collection forms. This program supports over 20 field types, and has scripting capability for data validation, calculations, and for form navigation control. Once developed, forms can be uploaded to Pendragon's PDA runtime application that runs on Palm-powered handhelds and on Windows Mobile Pocket PCs. Data collected on PDAs can be synchronized into a database (like Microsoft Access or SQL server) or exported to ASCII and Excel. Pendragon Forms support multiple users, and synchronization can be bidirectional.

Using the Pendragon Forms software, we programmed data-collection forms containing information for our various modules. In addition, we programmed basic data validation, branch logic, and reminders/alerts into the forms. The forms were uploaded into Palm T|X PDA devices (Palm Inc®, California, USA). We also loaded valid identifiers, a check-digit verification algorithm, detailed information about the administrative locations in the region, and provider identifiers. Global Positioning System (GPS) coordinates were captured with an external e-Trex GPS device (Garmin®, Kansas, USA) linked via a cable connection to the PDA.

Data Collection

The handheld tools were iteratively tested and improvements made. We then conducted two days of formal training for the CHWs who would be the end-users of the PDA/GPS devices and software. Each CHW was assigned a specific device, and had primary responsibility to ensure that the device was always in good working condition. The CHWs carried the handheld devices during home visits, and recorded all needed data during the encounter in the Pendragon forms after seeking consent of individuals in the household – these individuals had already been sensitized about the home visits and the use of these gadgets through a concerted community-wide mobilization effort. Data managers would, on a weekly basis, transfer the data from PDAs to a central Microsoft Access database (Microsoft Corp®, Redmond, WA, USA).

User Survey

To assess end-user attitudes toward the PDA/GPS handheld tools implemented, we gave an anonymous self-administered survey to CHWs who were present at a full-group meeting. Respondents were asked to rate the reliability of the PDA program and the GPS device. They were also asked to compare the utility of these handheld tools relative to paper-and-pen based systems. Respondents also gave information about their PDA and computer experience.

Data Quality and Cost Calculations

We used data collected during home visits in the Turbo Division in Western Kenya to evaluate completion and quality of data collected using the handheld devices. Findings are reported using descriptive statistics. Our cost calculations were based on the expected resources needed to reach the two million people in our catchment area within three years (780 workdays). From home visit data from Turbo Division, we knew the average number of individuals a CHW could see per day. Using this number, we determined number of providers (and hence handheld devices) needed to complete the visits with the three-year timeframe. Our calculations accommodate a device breakdown rate of 25% per year. We also include the cost of developing the system, training, and maintaining the PDA/GPS devices, and compare this cost with one using paper-and-pen based system.

Results

EHRs during Home Visits in Turbo

Between July and October of 2008, 93 CHWs visited 14,648 households in the Turbo Division in Western Kenya. During these visits, they interacted with and created electronic health records for 40,111 individuals. Of these individuals, 55% (22,182) were female and 26% (9,509) were below 13 years of age. On average, each CHW saw and created records for 12 ± 6 individuals per day. In the first year of use, only one device was lost, and four failed (out of 93 devices).

The visits in Turbo Division uncovered cases for which the individual had never presented for formal care in an established facility – and where no records (paper or electronic) existed. Four hundred and three of 899 (45%) pregnant women identified were not receiving antenatal care. Of the 1,131 individuals with positive HIV test results at the time of the home visits, 693 (61.3%) had never had a previous HIV test. 376 individuals had been exposed to or had symptoms suggestive of tuberculosis. In all these cases, the electronic records created on the handheld devices were the first documented health records for these individuals or for their condition.

User Satisfaction

We administered our survey to a convenience sample of 70 CHW. At the time, there were 78 active CHW who had been using the PDA/GPS devices. All CHWs surveyed responded, for a response rate of 90% of all CHWs at the time. Sixty-five (94%) of the respondents had never used a computer, and 65 (94%) had never used a PDA prior to our implementation.

Compared to paper & pen-based systems and on a five-point scale, CHWs felt that using the PDA/GPS devices was faster (4.4 ± 0.9), easier (4.5 ± 0.8), and resulted in higher quality data (4.7 ± 0.7). Surprisingly, CHWs also felt that using the handheld devices made their interaction with the patient easier (4.0 ± 0.9). There was a sense that the devices made them look more professional. One CHW captured this sentiment in their written comments about the PDA: "*It boosts someone[s] moral[e] on duty, and puts [them] in a high class.*" In addition, CHWs reported being highly satisfied with the training received on the handheld tools (4.8 ± 0.5), and all wanted to continue using the devices during home visits (4.8 ± 0.5).

Data Quality

Analysis of uploaded data revealed that all individuals and households were assigned unique identifiers, with no duplicates. GPS information was captured for all households, but in 4,695 **(**32%) of the cases, the CHW had to enter this information manually into the PDA. Manual entry had to be done when the cable connection between the PDA and GPS device was not working properly. Despite programming the PDA to allow for easy manual-entry and verification of coordinates, there was always a chance of errors being made. Other quality checks confirmed that no males were assigned a pregnancy status, and that each record was completed. Queries of the number of daily visits recorded per provider revealed some outliers – as an example, four of the 93 CHWs had days with more than forty individual encounters entered. This seemed unrealistically high and demanded further investigation.

Cost

We plan to visit two million unique individuals in our catchment area within three years (780 workdays). To meet this goal, an average of 2,565 individuals have to be visited each workday. From our Turbo Division data, we know that a CHW visits, on average, 12 individuals each day. This would mean having about 214 CHWs with PDA/GPS systems working on any particular day. Assuming that we have a breakdown rate of 25% for the PDA or GPS devices per year, we will need about 320 total PDA/GPS units over the period of the evaluation – i.e. an additional 53 devices at the beginning of the second year, and another 53 at the beginning of the third.

At a rate of $299 per PDA, $55 per Pendragon Forms license, $189 per eTrex GPS device, and $30 for the cable to connect the GPS and PDA devices, the cost of setting up PDA/GPS units per CHW would be $573 – bringing the total to $183,360 for 320 units. The data collected on handhelds will be synchronized into computers located at one of the 18 USAID-AMPATH clinics. At $1,500 per desktop computer, the cost of 18 computers will come to $27,000. Personnel costs include one-month programming time by a dedicated mid-level programmer based in Kenya for a cost of $1,600, 50% of an IT person's time ($22,000 for three years), 50% of a data manager's time ($22,000 for three years), and two dedicated data assistants ($45,000 for the three years). Training costs will come to about $1000, assuming two day training sessions for CHWs in groups of 70 to 80.

Adding all expenses, the total implementation costs for the handheld technology comes to $301,960. For each of the 2 million individuals visited, the cost of using the PDA/GPS technology per individual will be about $0.15. This estimate does not take into account the fact that the PDA/GPS devices can still be resold, or used for other purposes in the future. For comparison, if paper-and-pen based systems were used during home visits and the data entered by data-entry clerks, it would cost about $0.21 per record to simply enter this data – a typical data entry clerk is paid $17 per day and is expected to enter 80 encounters. In fact, the pen-and-paper based system would have other costs, including the supplies, the cost of computers, data management, and data cleaning.

Discussion

Our implementation in Western Kenya represents one of the largest applications of a PDA/GPS system for clinical care during home-based visits in a resource-limited setting. Most of the previously described, PDA-based eHealth applications have been largely used for research purposes or in limited clinical settings [10]. As our home visits focus on improving access to care, we found many cases where individuals had never received care in an established clinical facility. In such cases, no medical records existed, and our system (which created electronic health records) simply leapfrogged the typical paper-based charts found in this region.

Our approach, which is well-liked by the end-users, is scalable. The software created can be easily installed to more devices, and new clinical modules can easily be added into the existing software. We demonstrate that end-users with little experience with PDAs and computers can learn to use handheld devices. The typical concerns about reliability of the handheld system and theft of devices in settings like ours proved unfounded in our case. We find that CHWs who are given primary responsibility for a PDA device take as good care of it, as they do for their own personal mobile phones.

There is mounting evidence that collecting data via handhelds has multiple advantages over pen-and-paper systems. The data collected via PDAs frequently contain less errors, are often more complete, require less cleaning, and might not be any more expensive [12]. End-users also generally prefer handheld systems over pen-and-paper methods [13] – an observation reinforced in our survey. As Dwolatzky et al. point out, data collected electronically via handheld devices are also available for re-use in queries to generate reports, for case-management, and for follow-up within established clinics. The

GPS information can also help find patients lost to follow-up and signal disease outbreaks.

The handheld system we created is being linked to the electronic medical record system currently in use at USAID-AMPATH. Since 2004, USAID-AMPATH has been using the AMRS EHRs to support care of its patients [14]. AMRS was the first implementation of the open-source OpenMRS software [15] which already interacts with several mobile applications including EpiSurveyor,[16] the Android-based Open Data Kit,[17] JavaRosa-OpenRosa,[18] and Moca Mobile [19]. We chose Pendragon Forms because of its flexibility, but were fully aware that we would eventually integrate the data collected into our functioning, clinic-based EHRs.

Despite the success of the handheld technology in our setting, several key limitations of this technology need to be highlighted. Handheld devices generally have limited storage capacity and battery life. We also noticed that the connection between the cable PDA and GPS devices was not always reliable – we will be switching to PDAs that have inbuilt GPS capability. Handheld technologies also carry the risk of security breaches - either when devices are lost, or during transmission of data. As such, it is important to authenticate all users, and to encrypt data whenever possible [20]. Collecting precise locations using GPS also increases the risk of confidentiality loss, and appropriate measures must be taken to protect individual privacy [21]. We also have to remember that the success of handheld technologies will depend heavily on the use-case and the organization within which the technology is implemented. For example, clinical encounters that required extensive free-text might not be amenable to use of handheld technology. Consideration also needs to be given to workflow issues, user-input, and training.

Conclusion

We have developed and widely implemented handheld-based systems for use during home-based clinical encounters in the resource-limited setting of Western Kenya. This undertaking has enabled us to create electronic records for numerous cases where paper records did not even exist. Users prefer these handheld systems over pen-and-paper based systems.

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References

[1] O'Donnell O. Access to health care in developing countries: breaking down demand side barriers. Cad Saude Publica. 2007 Dec;23(12):2820-34.

[2] Towards Universal Access: Scaling up Priority HIV / AIDS Interventions in the Health Sector. Geneva: WHO. 2008.

[3] Kamya MR, Wanyenze R, Namale A. Routine HIV testing: the right not to know versus the rights to care, treatment and prevention. Bulletin of the World Health Organization. 2007;85(5).

[4] The millennium development goals for health: rising to the challenges. Washington, DC: World Bank2004.

[5] Jones G, Steketee RW, Black RE, Bhutta ZA, Morris SS, Bellagio Child Survival Study G. How many child deaths can we prevent this year? Lancet. 2003 Jul 5;362(9377):65-71.

[6] Bateganya MH, Abdulwadud OA, Kiene SM. Home-based HIV voluntary counseling and testing in developing countries. Cochrane Database Syst Rev. 2007;17(4).

[7] Inui TS, Nyandiko WM, Kimaiyo SN, Frankel RM, Muriuki T, Mamlin JJ, et al. AMPATH: living proof that no one has to die from HIV. J Gen Intern Med. 2007;22(12):1745-50.

[8] Technology Leapfrogs: Behind the bleeding edge. The Economist. Sep-21-2004.

[9] Ashurst M. Africa: Now, A 'Quiet Revolution' - Mobile Phones Leapfrog An Obstacle To Development. NEWSWEEK. 2001 Aug 27.

[10] Seebregts CJ, Zwarenstein M, Mathews C, Fairall L, Flisher AJ, Seebregts C, et al. Handheld computers for survey and trial data collection in resource-poor settings: Development and evaluation of PDACT, a Palmtrade mark Pilot interviewing system. Int J Med Inform. 2009;19:19.

[11] Yu P, de Courten M, Pan E, Galea G, Pryor J. The development and evaluation of a PDA-based method for public health surveillance data collection in developing countries. Int J Med Inform. 2009;78(8):532-42.

[12] Galliher JM, Stewart TV, Pathak PK, Werner JJ, Dickinson LM, Hickner JM. Data collection outcomes comparing paper forms with PDA forms in an office-based patient survey. Ann Fam Med. 2008;6(2):154-60.

[13] Lane SJ, Heddle NM, Arnold E, Walker I. A review of randomized controlled trials comparing the effectiveness of hand held computers with paper methods for data collection. BMC Med Inform Decis Mak. 2006;6:23.

[14] Tierney WM, Rotich JK, Hannan TJ, Siika AM, Biondich PG, Mamlin BW, et al. The AMPATH medical record system: creating, implementing, and sustaining an electronic medical record system to support HIV/AIDS care in western Kenya. Stud Health Technol Inform. 2007;129(Pt 1):372-6.

[15] Mamlin BW, Biondich PG, Wolfe BA, Fraser H, Jazayeri D, Allen C, et al. Cooking up an open source EMR for developing countries: OpenMRS - a recipe for successful collaboration. AMIA Annu Symp Proc. 2006:529-33.

[16] EpiSurveyor. http://www.datadyne.org/episurveyor Accessed on 10/12/2009.

[17] Open Data Kit. http://code.google.com/p/open-data-kit/ Accessed on 10/12/2009.

[18] JavaRosa. http://code.javarosa.org/ Accessed on 10/12/2009.

[19] Moca. http://www.mocamobile.org/ Accessed on 10/12/2009.

[20] Michel G, Marcy T, Shiffman RN. A wireless, handheld decision support system to promote smoking cessation in primary care. AMIA Annu Symp Proc. 2005:530-4.

[21] Dwolatzky B, Trengove E, Struthers H, McIntyre JA, Martinson NA. Linking the global positioning system (GPS) to a personal digital assistant (PDA) to support tuberculosis control in South Africa: a pilot study. Int J Health Geogr. 2006;5:34.