From the Ground Up: User Involvement in the Development of an Information System for use in HIV Voluntary Counselling and Testing

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This research investigates end-user involvement in the development of a simple HIV Voluntary Counselling and Testing (VCT) data collection instrument and associated spreadsheet. The research involved end-user participation in developing a paper-based VCT data collection instrument, followed by the development of, and training in an associated electronic spreadsheet. The collection of data together with the electronic storage and retrieval of the data constitute, however simple, an information system. The findings show that involving the end-user in the development and use of something fundamental to their mission, not only gives them something tangible that can assist in developing strategies for identifying groups for VCT sessions, manage resources and data, and generate reports, but can also encourage the collection of useful and complete data, invoke a sense of achievement and positive prospects for the future. The study involved working with end users from six rural Ugandan NGOs who deliver VCT in rural communities in the Mukono district.

Categories and Subject Descriptors: H.4 Information Systems Applications
General Terms: Information systems development

1. Introduction

The killer disease of the 20 and 21 centuries is undoubtedly AIDS resulting from a HIV infection. The disease has spread rapidly across the globe; in 2006 sub-Saharan Africa was the most HIV infected region in the world with nearly 24.7 million people living with HIV – nearly two-thirds of the global burden [UNAIDSa n.d.]. In Africa as whole, the death rate in 2007 is reported to be 7 million [WikiAnswers n.d.]. These figures are more staggering when you look at the results alongside findings that only 12% of men and 10% of women in the general population had been tested for HIV and received their results [WHOa n.d.]. In addition, many of the men and women who seek HIV testing and counseling, are already in the advanced stages of the disease [Hogg, et al. 2006]. The WHO and UNAIDS proclaim that “early diagnosis presents an opportunity to provide people with HIV the information and tools to prevent HIV transmission to others” [WHOb n.d. p16]. A voluntary counselling and testing (VCT) program has been formulated by the WHO and UNAIDS to encourage people to be pre-HIV test counselled, tested and post-HIV test counselled in an endeavour to prevent infection and transmission of HIV.
In Uganda, the occurrence of new cases of HIV is on the decline (15% in the early 1990’s, 6.4% by 2004 [UNAID 2006]. Although the 6.4% figure is a great achievement over the 18 years, there is a significant difference between urban and rural prevalence; 10.1% and 5.7% respectively [UNAIDS a n.d]. It is also reported that HIV prevalence is also higher among women (7.5%) than men (5.0%) [UNAIDSb n.d]. These figures may however be misleading as data has been generated from only a small proportion relative to Uganda’s population size with the rural/up-country regions being under-represented.

HIV counselling and testing is one of the factors claimed to have brought about the decline in HIV prevalence. (Other factors are the Ugandan government’s advocacy of ABC – Abstinence, Be faithful, and Condom use). The acceptance of the delivery of HIV counselling and testing as a common and routine event in a community should increase an understanding of HIV and living with and preventing HIV transmission, as well as a probable increase in the uptake of HIV testing.

The Ugandan government in 1990 founded the AIDS Support Organisation (TASO). TASO is a critical link in HIV counselling and testing, and together with more than approximately 2000 of the non government organisations (NGOs) in Uganda are active in HIV work [Coutinho 2003] by informing, counselling and testing the population. The large-scale delivery of VCT however, is only one step towards addressing the HIV pandemic; scaling up best practice of VCT is another critical step [Coutinho 2003]. The findings presented in this paper hope to demonstrate one example of best practice in VCT data collection and management procedures.

This paper is organised as follows. Section 2 presents the context of the study - an overview of VCT – specifically in Uganda. Section 3 depicts the importance of the end-user in the design and development of information systems – even when they are primarily paper-based. Section 4 outlines the study design and results. The paper concludes with a discussion of the known benefits to-date of the information system, and its possible impact on surveillance of HIV in rural communities and deliverers of VCT.

2. HIV VCT

A greater knowledge of HIV status within a community (and/or nation) is critical to expanding access of HIV treatment, care and support in a timely manner as it offers people living with HIV an opportunity to receive information and tools to prevent HIV transmission to others [WHOa n.d]. The most successful method of gaining knowledge about HIV has been through Voluntary Counselling and Testing (VCT).

HIV VCT voluntary pre-test counselling, testing, and post-test counseling, it is “the process of providing counseling to an individual to enable him or her to make an informed choice about being tested for HIV…… VCT is an entry point for prevention and care” [Family Health International 2004 p5]. It is an efficient and cost-effective strategy in expanding access to prevention, treatment and care services. It facilitates behaviour change [Family Health International, 2004], reduces the stigma attached to those who live with HIV/AIDS [Coutinho 2003], and early VCT can lead to a delay
in HIV deaths [Family Health International 2004]. Knowing your HIV status (that is whether positive/ reactive or negative) is important, as it assist in the way you behave and thus affecting the state of your life style and health. Undertaking VCT offers a personal and individual way to learn of one’s HIV status, and a way to maintain a negative status or if HIV positive, a way of maintaining a quality of life as well as access to treatment, care and knowledge on how to prevent transmission to others.

It is disheartening to know, that even with over 2000 Ugandan NGOs who are active in HIV work, including working in VCT programs, there are still many Ugandans who do not know their HIV status [UNAIDSb n.d.]. Table I presents the results of a 2003-2005 study showing the percentages of all men, all women, HIV-positive men and HIV-positive women (aged 15–49 years) in Uganda who were ever tested for HIV and received the results (the number of participants was not reported in the report).

**Table I. HIV status**

<table>
<thead>
<tr>
<th>Country</th>
<th>Uganda: Date of survey 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>percentage of all men who knew their status</td>
<td>12.7</td>
</tr>
<tr>
<td>percentage of HIV-positive men who knew their status</td>
<td>23.5</td>
</tr>
<tr>
<td>percentage of all women who knew their status</td>
<td>10.8</td>
</tr>
<tr>
<td>percentage of HIV-positive women who knew their status</td>
<td>15.0</td>
</tr>
</tbody>
</table>


The report also showed that in most countries of sub-Saharan Africa, knowledge of status was higher among people living in urban areas than among those living in rural areas; indicating that more needs to be done for those who live in rural regions. Furthermore, even in settings where VCT is routinely offered, for example, programmes for prevention of mother-to-child transmission, the number of people who avail themselves of these services remains low in many countries. Stigma and discrimination are the two main factors that continue to stop people from having a HIV test [WHOb n.d].

Health organizations worldwide are advising governments that the large-scale delivery of VCT is only one step towards addressing the HIV pandemic; scaling up best practice of VCT is another critical step [WHOa n.d. pg 48]. One way of doing this is in improving on the collection, reporting and dissemination of useful data regarding VCT. However, in practice, and in particular in rural areas where the majority of VCT is conducted by grass-root NGOs, formal - let alone valid and useful data, has rarely been collected with little analysis and dissemination. One of the issues in collecting the data is that many of the organisations conducting the VCT do not have an acceptable nor simple data collection instrument that they understand, nor a way to correlate the data into information that is useful to them. Often is the case ‘why and what to record in the note book?’ if there is no direct benefit. The study presented here, aimed to give
meaning to collecting data during VCT with the objective of benefiting those who collected it and their ‘clients’ through involving the end-user in the development of a simple data collection and analysis system.

3. End User Involvement In Information Systems Design

Information systems design is a complicated and time consuming process. It is considered to be the job of professionals. Regardless of how good the professional or practitioner is, many systems fail or are not used in the way that the system designer had in mind. Conversely, those information systems that are solely developed by the end-user are often missing technical and system features that would not only improve the robustness of this system, but also improve the technical efficiency of the system. It has long been argued that the participation of the end-user in the design of the information system tends to result in a more effective, efficient and accepted system. Collecting the user-requirements for a system is a challenging task in systems development [Pekkola et al 2006], “This includes information about the domain and context specific technical issues, and about multifaceted cultural, political, communicational, motivational, and personal issues” [ibid p21]. A development team that intricately involves both the end-user and system designers, though not a guarantee, has a greater chance of success of obtaining accurate information as stated by Pekkola et al [2006] than without the cooperation and collaboration between the two parties.

Systems development begins with an analysis of what is required of the system together with interaction with the end-user to obtain the data for the system. Though we are in the age of the ‘paperless office’ this is rarely the case, and many data items that are found in a system have initially be captured manually on a paper form. One of the disheartening trends in today’s information systems development is that often the development of any associated paper-based data capturing form is produced with no more than a token gesture to end-user input (if at all). A way of giving meaning to a data collection instrument is to give a tangible reason for its collection. Involving the end-user in the design of the system –even a paper system, can improve the systems usability and acceptance. Without the end-user being involved in the design of the system, it can become less relevant, under-utilised or abused. Tushabe et al [2008] found that the functional usage of customized software in Uganda by Ugandan companies is approximately 42% [ibid p27]. An interesting figure but not a surprising one as the study also reports that only 12% of customized software in Ugandan organizations is locally developed [ibid p25]. The respondents indicated that one of the reasons for under-utilisation was that the end-users are “not playing a sufficient role within the software development process” [ibid p27]. Their study supports the hypothesis that if VCT counsellors were involved in the design of a system to assist them in the collection of data obtained during VCT, then they would collect more reliable data, as well as use the system more efficiency and effectively.
4. The Study

The study is situated in rural Uganda - one of the poorest countries in the world (GPD – per capita in 2007 was US$1000, [CIA n.d.]), with little national infrastructure - however, it has made vast improvements within the last 10 years to alleviate the burden of poverty, disease, poor sanitation and limited utilities. HIV VCT has been regarded as a means to reduce the transmission of HIV. To be informed as to the state of HIV in Uganda (or any country for that matter), useful data needs to be collected, reported and used by those who are at the front line delivery of VCT.

This study hypothesised
1. VCT counsellors will collect more reliable and usable data if they are involved in the design of the data collection instrument.
2. The data generated could be used to inform planning.

Building on the hypotheses, the aim of the study is to develop a useful information system that could be used in rural Uganda for collecting VCT data.

Data obtained could then be used to:
1. Obtain accurate and informative data on HIV prevalence within villagers by gender, age, occupation and sexual behaviour.
2. Develop strategies to enable a more efficient and effective use of limited resources in the fight against the spread of HIV.

4.1 Study Design

The study is longitudinal in nature, using an ethnographic action research approach with its beginnings in investigating then discussing the user requirements for an information system to improve the efficiency and effectiveness of data collection during VCT.

The study was conducted in two stages:

*Stage One* consisted of end-user involvement in the design of a simple paper-based data collection form for use in the VCT process. From this form an electronic spreadsheet was developed, the NGO workers were trained in using the spreadsheet and in the importance of completed forms and participant’s consent. The NGO involved in this stage was Voluntary Services Trust Team (VOLSET). VOLSET concentrates its VCT in rural villages in and around Lake Victoria, and in the Mukono sub-county. (A detailed description of the design of this stage can be found in Lynch, Lynch and Bazira, 2008.)

The VCT data collection form was printed on a single page, the questions were written in plain English, and there was adequate space to write the responses (see Figure 1).
Figure 1. VCT data collection form (version 1)

The questions included—place of residence, demographic data (age, gender, occupation, fertility history), sexual behaviour data (marital status, number of partners, condom use), and date of last HIV test. Each of these variables were deemed necessary by the VCT counsellors as important in understanding their clientele, and therefore enabling them to assist them further if necessary. It is interesting to note that even though the participants were not aware of all (if any) of the detail contained in WHO or UNAIDS publications on guidelines for collecting VCT data, (such as WHOc n.d. p20-22), there were similarities between many of the variables identified and that recommended by WHO or UNAIDS. An Excel spreadsheet was constructed to accompany the data collection form. To reduce data entry errors caused by spelling or typing mistakes, the spreadsheet included drop-down lists from which to selected repeated data (such as gender, marital status, occupation, village). This technique also streamlined responses into categories for easy analysis.

Stage Two related to the refinement of the initial system (paper and electronic) by seventeen VCT counsellors from six different VCT providers who deliver VCT in rural parts Mukono sub-county (Uganda). In order to obtain feedback and improvements on the paper-based system, a focus group discussion was held during August 2008. At
the session, the participants were given a copy of the instrument. The conduct of the focus group was facilitated by a native English speaker with little Luganda, however a bi-lingual Ugandan research assistant was employed to take extensive notes of the discussion, and to translate if there was a need. After the session, the notes recorded were reviewed to extract repeating ideas, which were then coded. Analysis of the coded data was undertaken to highlight emerging themes. Ethics for the study was granted by the University of the Sunshine Coast (Australia) and the study was approved (and ethics approval sighted) by the Uganda National Council for Science and Technology.

4.2 Results

*Stage One* is reported in Lynch, Lynch and Bazira (2008), however, a summary is repeated here to present a full picture of the study. VOLSET started collecting data during VCT in August 2004. Exercise books were used to record participants details such as name, village, HIV result, and the data owner’s signature. Between August 2004 and February 2006, 218 responses were collected, however less than 30% of responses were usable for analysis due to incomplete data. Between March 2006 and December 2007 over 1000 people had their data recorded using this refined collection method, as a result of participating in VOLSET’s VCT program. Approximately 95% of the responses were usable; that is, the completion rate of the forms in regard to basic demographic data was high. Through discussion with VOLSET VCT counsellors it was discovered that this increase was due to the simplicity of the form, knowing what data to collect, the importance of complete data sets, and the usefulness of the information derived from the data.

*Stage Two* began in August 2008 with the refinement of the VCT data collection instrument by seventeen VCT counsellors from six organisations that deliver VCT to rural Ugandans in the Mukono sub-county. The Director of VOLSET informed the other participants the value of the summary information obtained from data collected using the VCT forms, and how this analysis has assisted his organisation

> “we send it [the summary information] to organisations which have funded us for that programme or we also give it to the Government like the health centre in Ntenjeru and then Mukono District, Ministry of Health. And by doing so, our report works as an eye opener to the Government or to the local authority so that they can think about those isolated areas where we go HIV testing.” [Festus Bazira]

Further comment from those who are VCT counsellors with VOLSET added that the reports assisted them in who to target for their VCT sessions, “men or women, or villages that are not coming for HIV testing at all or VCT counselling.” Another counsellor indicated that it helped manage what they needed to bring to a VCT session, some sessions are conducted on an island that is over a 5 hour canoe ride “It gives you an indication of the time required, how many testing kits you need to bring next time or how much ARVs are needed - things to bringalong”

Two new variables were highlighted as important information to collect and generated much debate and were discussed at great lengths during the focus group session. These were the inclusion of the participant’s CD4 count, and their consent to their data being recorded.
CD4 count. The immune system contains different types of cells that help protect the body from infection. One of these specialized cells are called the CD4+ T-cells. HIV attacks these T-cells and uses them to make more copies of HIV, weakening the immune system, and making them unable to protect the body from illness and infection. The higher the CD4 count, the stronger the immune system. A CD4 count of 700 to 1000 in a regulated sample size is considered to be ‘normal’. HIV infected people are considered to have a ‘normal’ CD4 count if their CD4 count is above 500, however, when a count is below 200 the patient is considered to have AIDS [AIDS n.d.]. Counsellors use the CD4 count to assist in educating HIV positive people in how to stay healthy in a hope of keeping their CD4 level above 200.

Some participants thought that including the CD4 count was important for everyone, others said it was only important if their HIV results returned a positive reaction. The discussion continued, with comments such as

“CD4 is necessary for one to know whether they are ready for ARVs or not. Therefore let this variable be on the form.”

“These are people who are just being tested. They can’t know their CD4 count. But if they have ever been tested and now they are coming for a second test or counselling, then it can be possible”

“CD4 is used by health workers. I don’t think it is useful on this form. First time testing wouldn’t know their CD4.”

“Whoever tests [HIV] positive must be tested for CD4 count as well. Having a CD4 test is important. Therefore referral is important to tell them where to go for the CD4 count.”

The decision from the discussion was that there should be a place for the CD4 count to be record. The decision was based on that once a HIV result returns a positive reaction, the person should be advised to have a CD4 test done. A CD4 test can be conducted at the same time as VCT, with a result imminent in approximately an hour (depending on the type of rapid test used). Providing the CD4 count on the form would be useful for future reference, as well as assisting in record keeping.

Consent. The WHO suggests that specific consent for HIV testing is required and is actually implied if general consent for medical care has been given (WHOd n.d. p20-22). The focus group participants debated over the need to record that consent was given.

“there is need to improve on the form to provide for an area of consent from the client. The form does not show that the client consented to the testing or counselling.”

“When we goes to the Island, people come willingly. People come asking for VCT. However, though they come willingly we have to ask them to consent.”

There was an extended discussion in regard to consent from a minor

“How do you get consent from a minor?”

“There were many implications when many adults never wanted their children to be tested. The practice however has changed. For the minors who can not
consent on their own, … the caretakers can consent on their behalf. For children
of 12 and above years, these can consent by themselves.”

Even though, implied consent is given through allowing the counsellor to complete the form, it was decided to include a space to indicate that consent was obtained. The researcher questioned the need for a signature as this identified the participant. It was determined to make the recording of consent optional, and that a ‘tick’ indicating consent was sufficient.

Through active discussion and analysis of the notes taken during the discussion, the instrument was refined to include several new variables, these are listed in Table II together with the new form. These variables are consistent with the WHO guidelines for measuring national HIV prevalence [WHOd n.d. p20-22].

**Table II Stage Two variables and form**

<table>
<thead>
<tr>
<th>Stage Two added variables</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Number of children given birth to; number alive, pregnant?</td>
</tr>
<tr>
<td>• Last testing organisation</td>
</tr>
<tr>
<td>• VCT record card given to client?</td>
</tr>
<tr>
<td>• Comments/recommendations (eg CD4)</td>
</tr>
<tr>
<td>• Consent obtained for use of de-identified and aggregated data.</td>
</tr>
</tbody>
</table>

It is important to note that the version two of the form included a ‘Private and Confidential’ box at the top right of the form. This was as a result of discussion at the focus group; and is a reminder of the ethical conduct to be followed during HIV testing and VCT.

The spreadsheet was modified to suit the new VCT data collection form, both of which are in use across the organisations represented at the Stage two focus group session.

5. Conclusion and Future Work

Although this study was limited to one then six VCT organisations in the Mukono sub-county of Uganda, the results suggest that the involvement of the end user in the design of an information system – even if primarily paper-based, together with input
from information systems design professionals (who have an understanding of local needs), and a purpose for the data collection, are instrumental in the acceptance and use of information systems.

The one organisation that has been using the VCT data collection instrument and associated electronic spreadsheet since March 2006, has noticed a significant increase in the number of people attending VCT, repeat visits, and recognition that they advancing in the fight against HIV, as stated by Bazira during the August 2008 focus group session in Mukono, “our report works as an eye opener to the Government or to the local authority so that they can think about those isolated areas where we go HIV testing.” Furthermore, those that record and analyse the data, are able to report on genuine statistics that they have an affinity with and understanding of, for example, Bazira continued, “whenever we do the testing, the percentage is higher than expected; sometimes 15% people who are positive. And still many [more people] needs to be done [tested].”

Once data are available and in a format that can be used and manipulate, information from the VCT data collection activities, can aid in developing strategies and plans for the best time and place to conduct VCT; comparison between sites (villages) in terms of when/who to visit, the number of counsellors and other resources required (eg brochures, VCT forms/cards, HIV rapid test kits).

Although the aim of the study was to develop a useful, simple and effective data collection instrument to assist VCT counsellors in understanding their client needs, develop strategies to assist them after VCT, and resource planning, the data gathered also shows information that can be used for inclusion into grant applications to up-scale and expand VCT coverage, and communicate the successes and challenges to the community (local, national and global).

Most of the 2000 NGOs that conduct VCT in Uganda need to report their work to health authorities within the country and to many organizations that financially support these NGO, such as the Global Fund. The Global Fund and other large funding bodies to Uganda, have (and could do so again) suspended funding if monitoring and reporting is not done rigorously and based on empirical work.

“One of the major bottlenecks in the implementation of large country grants, such as Global Fund grants, is a weak monitoring and evaluation system, with inappropriate indicators, inadequate data collection systems, a lack of capacity to collect data at the local level, and an inadequate capacity for data analysis. As HIV services evolve, countries need support in revising and strengthening monitoring alongside the implementation of programmes.” [WHOa n.d. p49].

The development and acceptance of a user directed VCT data collection system such as the one presented in this paper can enabled an empirical base for HIV VCT coordination, planning, training and procurement in a resource-limited regions such as Uganda. Each of these can directly lead to the up-scaling of VCT in an attempt to reduce the transmission and increase the prevention of HIV.
Furthermore, what we found interesting, is that even though the WHO has developed guidelines for the collection of VCT data, the participants in this study had little knowledge of these guidelines, let alone implemented by many of the NGOs that operate in rural, deep village or up-country villages in Uganda. The VCT data collection form developed during this study is inadvertently very similar to the WHO guidelines for addressing, up-scaling and expanding VCT into rural regions. The WHO guidelines were designed not only to collect information in regard to HIV prevalence, but at the same time suggest that data are collected on social, behavioural and biomedical factors. Data on some of these factors can be extracted from the form refined by the VCT counsellors who participated in the study presented in this paper.

This study has shown that involving those who use and need a system in the development of the system, results not only in a system that is used, but one that gathers acceptance further a field amongst peers and colleagues. This is due to an affinity with the wider-user group, an appreciation of the users, listening to their concerns and needs, as well as given them ownership of the system. End-user involvement in systems design and development is a recommended and accepted practice in systems development [Pekkola et al 2006]- however, it is not undertaken as often as required. This view is supported by Tushabe et al [Tushabe et al 2008], where they report that software applications (in the case of this study, an information system) need to be developed for Ugandans by Ugandans for the application to be successful.

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References


