

A Viable Architecture for the Integration of a Recommender System and Mobile Counselling system for the Management of Chronic Illnesses and Stigma-Related Infections

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Background and Purpose: Mobile devices are a common sight everywhere in the world with attendant phenomenal growth in communication. As a result of their mobility, there has been an increase in telecommunication industry's penetration. Besides, the impact on socio-economic status of the global village is staggering. As a result of this impact, there have been changes in the ways businesses are done in commerce, economic and health sectors. One of the changes this has brought about is the use of mobile devices in the real-time monitoring of individuals who lack physical mobility due to illness. There have also been reports of their use in the management of certain ailments, drug administration among others. In this work, the mobility and a degree of privacy that mobile devices offer combined with the ability of recommender systems to make personalized medical assistance to individuals with chronic ailments and stigma-related infections is explored. Recommender systems in medical and healthcare context are emerging significantly with attendant positive impacts on the speed and accuracy of diagnosis. A few successful implementation of such recommender systems alongside few with good results have been highlighted in literature. This paper however proposes the integration of two architectures in order to achieve a better result. The fusion of a recommender system into HIV/AIDS mobile management system where personalized assistance can be given to individual who are afraid to seek medical care openly because of stigmatization is the desired goal of this work. While the overall goal of this project is to use the integrated architecture for providing personalised assistance to people living with stigma-related and chronic illnesses, the focus of this paper is on providing personalised assistance to people living with stigma-related infections such as the HIV/AIDS using the integrated architecture. On the potential of mobile devices for use in counselling and discussing health related issues including HIV/AIDS, the result of survey conducted shows that over 80% of the respondents are comfortable using this medium prior to face-to-face contact. This is an indication that mobile devices have the ability to act as the medium for the first contact for victims of stigma-related illnesses and to play a vital role in the disease management. In-depth analysis of the results of the survey revealed that synergies among some key components will produce a desirable architecture presented in this paper

Methods: Questionnaire was administered on potential users who are drawn from 250 youth and health workers from the ages of 18-50. Respondents were drawn from students in three universities in Osun State Nigeria and health workers in a nearby hospital. The analysis was performed using the SPSS.

Results: survey conducted on the potential of mobile phones for counselling those infected with HIV/AIDS shows over 80% of the respondents indicating that they are comfortable discussing health issues (including HIV status) via mobile devices before face-to-face contact. From the analysis of the result of the survey, the need to enhance the performance of the management system was also seen. Integration of a recommender system that would provide the desired personalised services became a desirable option. The architectures for the management system and the proposed integration are presented in this paper.

Conclusions: It can be seen from the analysis of the survey and the presented architectures that mobile devices have a role to play in the management of ailments for which people are stigmatized (such as HIV/AIDS), and is more effective when integrated with dynamic recommender systems.

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1 Introduction

HIV/AIDS-related stigma, which includes prejudice, discounting, discrediting and discrimination directed at people perceived to be living with HIV or AIDS is a major barrier toward better care for those infected [1,2,5,6,30]. Worse still, those who provide direct services to individuals affected also suffer stigma [32]. The rate of prevalence among the most vibrant population (15-49) is alarming and the effects of HIV/AIDS epidemic on economy can be very damaging. These are slow or reverse economic growth, reduction in savings and investment of families because of increase in expenditures of HIV/AIDS related issues, diversion of public spending from investment on human and capital to health, and increase in poverty rate [14, 18,19]. Globally 35.3 million people were living with HIV in 2012 with Sub-Saharan Africa home to 70% of all new infections [34]. Among the problems responsible for the prevalence is lack of access to medication and good counselling which is due largely to prejudice and stigmatization [34]. A report on how stigma affected women with HIV infection shows that the rejection caused by stigma affects access to health care, medication adherence, social interaction and social support [9]. Another report on HIV-infected individuals' ability to access care shows that more than half of the respondents reported difficulty accessing care at baseline and follow up due to stigma [17]. Even in Diaspora, stigma within the communities has been reported as a barrier to accessing HIV testing and HIV services among HIV-infected African migrants [8]. Research has shown that stigma and discrimination in the health care setting and elsewhere contributes to keeping people, including health workers, from accessing HIV prevention, care and treatment services and adopting key preventive behaviours [26]. Surprisingly though despite many positively directed efforts at reducing stigma encountered by infected people in Africa and elsewhere in the world, a recent report has confirmed an upward trend in internalized stigma in an African country [10]. While media and social networks have provided help in creating awareness and reducing stigma [15], exploring means of reaching out to individuals with infections in some personalized way can boost efforts to eradicate the infection. Modern technology has provided several means of reaching individuals on a more personal level without fear of stigmatization. One of such means is the use of mobile technology.

Besides their common use in other sectors of the economy, Mobile devices have become a ready and effective tool in healthcare, especially for monitoring, service delivery and sometimes management. There have been efforts to provide effective solutions for mobile health in the broad context of cost reduction and just-in-time services (such as in [34]). The mobile phone has been found useful in patient care and monitoring. Specific example is the use of Smartphone's feature for monitoring patients with Alzheimer's disease. [28]. The effectiveness of mobile devices for medical counselling is yet to be fully explored especially in developing countries where individuals living with infections for which people are stigmatized are reluctant to freely seek medical care. Some informal charges such as transportation and other out-of-pocket expenditures can also present a significant barrier to people gaining full access to HIV/AIDS treatment and care services [38] and these become something not to worry about with the use of mobile devices. Listed as one of the areas on which interventions must focus in order to combat stigma in health facilities is the individual [26] and one of the most effective ways to reach people on a personal level without fear of being stigmatized is the use of mobile device. With HIV/AIDS becoming endemic in most developing countries and victims becoming afraid to openly to seek medical care because of stigmatization, mobile-technology-based health management system surely has a unique role to play. It is noteworthy however that use of mobile devices in assisting to care for HIV-infected individuals has been documented in literature. Such interventions are seen in their use to help infected individuals to adhere to treatment [35]. In a project tagged "Cellphones4HIV", conducted in South Africa, three pilot projects were examined to see how mobile technology can be used in the prevention, treatment and care of HIV and AIDS, and to support the HIV sector in general [30]. In this work the need for integrating an HIV/AIDS mobile management system with a recommender system is explored. This is necessary in order to provide a common platform that can be used to achieve the desirable objective of an interactive health management for persons living with HIV/AIDS. Broadly the common features of the proposed system from the viewpoint of users and experts are determined to make the entire system useful and transformative following integration with the existing Hospital Information systems. The resultant architecture is the fusion of architecture for a mobile management of HIV/AIDS infections and that of a recommender system.

The use of mobile devices in administering care will pose little or no problem because the general perception of mobile phone use among physicians has been shown to be very promising [28]. One typical manifestation of this is seen in a report on acceptance of e-prescription technology among South African Physicians. Data was collected from a sample of 72 physicians. Results indicated a general acceptance of e-prescribing amongst physicians who on average reported strong intentions to use e-prescribing technologies if given the opportunity [13]. Besides the favorable attitude towards electronics tools, accepting mobile technology specifically as an important tool in administering effective care does not pose any serious problem among care providers, even those dealing with HIV/AIDs infections, as different reports have indicated [36, 3, 16]. However, a better intervention can result with mobile technology integrated with other technology-related tools; in this case we are proposing a recommender system.

Recommender systems in medical and healthcare context are emerging significantly with attendant positive impacts on the speed and accuracy of diagnosis. A few successful implementation of such recommender systems with good results have been highlighted in literature [18, 37, 29]. A recommender system proactively suggests items of interest to users based on their objective behavior or their explicitly stated preferences [31]. Recommender Systems provide users with predictions and recommendations of items [5]. Recommender system has become an important tool in commerce and other sectors (such as health) of our social and economic life. The typical implementation of recommender system known to many people is the search engine such as the Google. The main characteristic of recommender systems is that they can personalize their interactions to each individual user. Personalization involves the design of systems that are able to infer the needs of each person and then to satisfy those needs [33]. Some researchers have cited the terms *individualized*, *interesting* and *useful* as differentiating criteria [7, 27]. Interestingly these are the desired characteristics of the integrated system this work aims to achieve. Recommender systems have been developed to meet the needs of users in different domains and using different methods and algorithms [33]. Some of the recommender systems highlighted in literature have some form of intelligence built in them but lack the ability to learn and make automatic, personalized recommendation dynamically. Moreover, some diseases change symptoms (e.g. cancer, HIV/AIDS) as they progress to maturity or get worse. Individuals living with such diseases will benefit from personalized recommendations based on the progression. Learning from the user's past activities or requests, useful personalised recommendations are possible.

2 Materials and methods

This work is divided into three different phases. The first phase involves conducting a sample survey. The sampling method used is the convenience sampling of non-probability sampling method. This method was adopted because the part of the population surveyed are easily accessible for follow up during subsequent phases of this work. The population studied consisted of youth between the ages of 18 and 45, and health workers. The sample survey was carried out in three higher institutions of learning in Osun state of Nigeria for two reasons: (i) the population is readily accessible for further research activities such as requirements refinements and testing of the mobile management system prototype, (ii) the assumption that the population represents the age range that is susceptible to the malaise and that easily use the proposed technology. The SPSS was used to do the analysis of the data. The survey was also used to gather features that respondents would like the proposed system to have. The suggested features were ranked in the order of preference by users. The questionnaire used has both open and closed ended features using direct personal interview. This was done in order to obtain correct and reliable information from respondents. Typical questions used are indicated below.

1. *If a mobile phone based system was to be developed for monitoring patients from your health centre, do you think it would be beneficial to you? Yes () No ()*
2. *How comfortable are you discussing personal issues on a mobile phone?
Very comfortable () Comfortable () Hardly Comfortable () Not Comfortable ()*

Following qualitative and quantitative analysis of the data and the development and integration of the architectures, verification was carried out on the architectural model with potential users and identified software developer who have some knowledge of quality assurance. Examples of questions used as a guide are indicated below. The questions were used as guide during the discussion.

3. *Suggest any areas that you feel require improvement to fully support effective counselling of HIV/AIDS patients:*
4. *What other feature(s) do you want such a system (mobile counseling system) to have?*

3 Results

The sample survey carried out to determine users' perception on the effectiveness of mobile phones in the management of HIV/AIDS patients shows that 70% of the respondents have no problem using mobile technology as a medium of counselling on HIV/AIDS and other stigma-prone infections. 80% of the respondents however show that they feel comfortable using mobile devices for consultation. The result indicates that portability and privacy, especially since encryption of discussions will be ensured, are among the features of mobile technology that respondents chose as the determining factors. Other features extracted are check-up reminders, health information updates, information about drugs and availability, prevention and support, and clinic attendance.

The survey also pointed to the non-functional attribute of viability, usability and usefulness of the entire integrated system.

3.1 What the Study Reveals

The following inferences are drawn from the analysis of the survey considering the aim of the research.

(a) Users are comfortable discussing confidential matters over phone as long as they are sure the person on the other side can be trusted

The result of the survey indicated that phone is a least known device for receiving personalised interactive counselling. Although a greater percentage (96.7%) of the respondents indicated that they had not received any formal counselling through phone but 53.7% of the same population agreed they would feel comfortable discussing some personal matters, including HIV/AIDS and other stigma-related infections, on the phone as long as they are sure that the other person can be trusted. This is especially important because of confidentiality of health information.

(b) Phone is useful for an initial contact to build confidence and learn

Since all the respondents have phones and have been using them for a while, some 62% agreed they were able to build confidence in their mobile friends after discussing together over the phone for a period of time even before they were able to meet face-to-face. This is a promising indication that confidence can be built even if the first the attempt to do this has been initiated through mobile devices.

(c) Updates are desirable (a recommender system has a role to play)

This is a key issue from the outcome of the analysis of the result of the survey. More than 80% of the respondents would like to have updates concerning their health issues. This ranges from check-up reminders to information about drug and recent breakthroughs in treatments and management of ailments and infections such as in HIV/AIDS and other chronic ailments.

(d) Organizations have key roles to play

Since survey respondents emphasized the need to have updates on treatment and drugs from credible and reliable sources, we feel that professionally recognized and internationally certified local and international organizations whose claims are verifiable have vital roles to play in order to achieve this. These supportive roles are relevant in counselling and management of chronic ailments and stigma-prone infections. Information and updates from such organizations must be easily accessible and location-independent. However, the roles of other stakeholders may become clearer during system appraisal in challenging contexts (such as in low resource bloc).

3.2 Architecture for Mobile Management of HIV/AIDS

Figure 1 shows the proposed architecture of the Management component of the integrated architecture. In this architecture there are hospital organization, the international organization, and the users as an entity. The user interacts with national and international organization through the consultant, an entity within the hospital organisation, via the mobile device. If the infected person has not built enough confidence in the

counsellor and has not revealed his identity to allow face-to-face consultations, then the identity is uniquely coded. He is then given a key that can be used during subsequent contacts for easy identification. The data along with the unique code and the key are kept in the temporary data storage virtually created and accessible to the consultant or counsellor only. The hospital information system is available to provide background medical history of identified individuals who are registered at the hospital.

The hospital is recognized by the organization providing additional services via the mobile device. The provider or the consultant is registered with the hospital and therefore can use its resources and access patients' records that are kept in the hospital database when offering this service. The temporary data storage (database) is provided to keep the data of "unidentified" individuals seeking help. The unidentified individual is a person whose data is not on the hospital database or whose identity is yet to be known so as to determine where the health data is located. Keeping the data of this individual is necessary for two reasons: (1) to have the records of the individual for reference until he seeks medical attention face-to-face at the clinic, (2) to help the provider give adequate help during subsequent contacts, having reviewed the given information and made further research or consultations before such contact days. This data may be merged with his record in the hospital information system at a later date.

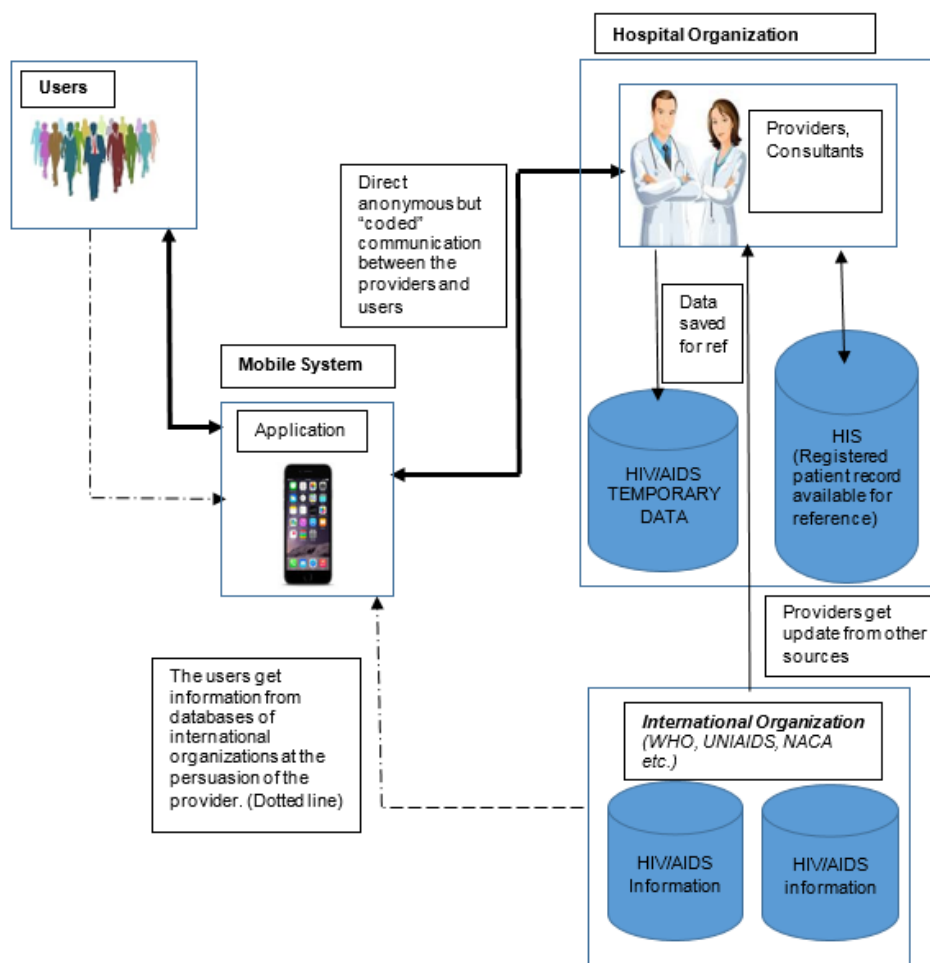


Figure 4. Proposed architecture for Mobile Management for HIV/AIDS

However, the result of the survey indicated the need for users to get update on new treatments, management methods and drugs. This sources should be very reliable and verifiable. Hence, the incorporation of databases from reliable National and International organizations such and the WHO, USAIDS, NACA among others. The hospital organization makes this available to the providers (consultants or counsellors) working within their organization, or as it may be, a provider access them directly as a registered professional in the field.

No doubt the update from national and international health and HIV/AIDS- related organizations can be very useful and helpful in assisting and counselling the infected individuals. Effective treatment and management procedure used by others may also prove very useful. This informs the integration of another architectural component with the architecture presented in Figure 1. The integrated architecture is shown and discussed in the following section.

3.3 Proposed Integrated Architecture of Recommender System and Counselling System

Figure 2 shows the proposed architecture for the integration of dynamic Recommender system and the HIV/AIDS management system shown in Figure 1. The HIV/AIDS management system architecture has been described in the earlier section. However, the integration is done in order to allow for more effective use of current updates. With the aid of a dynamic recommender system, the provider can search for and automatically receive updates that will help the professional counsellor (or consultant) on treatment and wellness procedures. With the integration, the user may also get updates directly and dynamically. This is done whenever there is an update to any of the connected databases. This feature is however, optional for users and other care-givers.

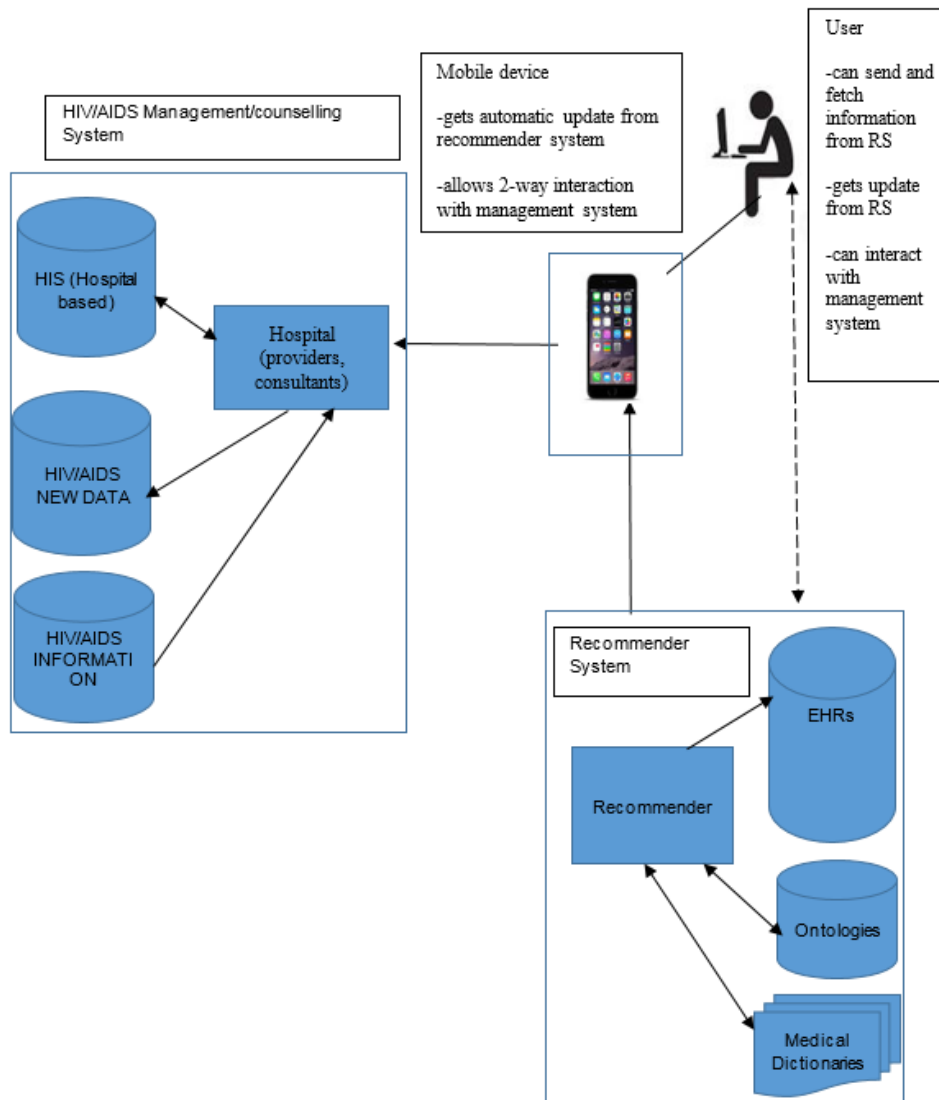


Figure 5. Integrated Recommender System and Management system Architecture

As a result of the sensitive nature of patient data and information, high level of anonymity will be ensured while transferring data across the mobile devices. This will be done by removing all references to patient's identity. Essential information needed are diagnosis, treatment procedures, and results. As indicated earlier, during interactions between infected persons and the consultants providing assistance the identity of the infected will be uniquely coded until confidence is built between the participating individuals while the data will be encrypted.

4 Discussion

This paper has focused on three important stages. First, what the study reveals. Second the need for a mobile management system of chronic illnesses and stigma prone infections. Finally, the synergy between the mobile management system and recommender system. Two important issues have been raised concerning the drastic reduction of stigma against those suffering HIV/AIDS infection. One major issue is that of providing care tailored to the personal needs of individual. The other is the reduction in cost and time associated with meeting up with counselling schedules [38]. Although the cost may appear to be initially insignificant but the cumulative cost and time spent over time when repeated calls have to be made to clinic can be well beyond what is affordable to infected ones who are generally poor and already weighed down by the burden of the infection. In a report regarding the use of mobile device as a tool, health workers were able to save some hours, transportation costs, and double the capacity for treatment in less than a year [22]. In a similar vein, the care and counseling seekers can also benefit from reduction in cost, time, and efficient care services.

In addition to this is the problem of bureaucracy at the point of care. In some cases, the infected individuals spend so much time because of poor organisation and the long list of others waiting to access the same care. Indeed in the African context, most of what is currently referred to as HIV counseling still means just information giving and supportive counseling and advisement, targeted not to any particular needs of the clients being served [25]. However, from the study conducted more than half of the population surveyed agreed that discussing some confidential matters, which include their HIV/AIDS status, via mobile devices would not be a problem. This is possible even if the other individual has not been familiar with the counselor. This however depends on the assurance that, by virtue of the counselor's profession, some level of trust can be established. The implication of this is that many of these respondents would be willing to volunteer some personal information if it is obvious that they are discussing with care providers and other health workers who have been trained to help them.

Achieving this will pose little or no problem to individual counseling seekers. This is confirmed from the result of the survey. Besides the significant level of confidence they have built using mobile devices in discussing personal issues, all the respondents have one kind of mobile devices or the other and are conversant with their use. They were also able to affirm that they can use mobile devices as a means of first contact before face-to-face meeting. On how long this can go before they can be confident enough to submit to physical contact may depend on the person seeking help, the skills and experiences of the counsellor, and how serious the seeker considers the need. Notwithstanding the highlighted factors good result is achievable if the counsellor has a good knowledge of the infection and a considerable level of trust can be built within some reasonable period. Another important issue is the possibility of having many able to explore this option. There is an undisputed indication that mobile telephony is rapidly developing as the major communications platform in the developing world with mobile penetration in Africa having a growth rate of more than 60 percent from 2006-2011 [23]. Future growth is expected to be very promising. A report has indicated that Africa will witness the fastest subscriber growth and annual Growth Rate of 7.3 percent to reach nearly 8.5 billion by end of 2016. Smartphone shipments in Africa are expected to grow at the fastest rate, and it is anticipated that the African market will grow at a CAGR of 38.6 percent all over the 2011-2016 period[24]. This report has added weight to the availability and the potential of mobile devices to play crucial roles in care giving.

Besides providing counselling and care at an individual level, it is clear from the result of the survey that something more is needed. Such things as check-up reminders, information about drugs, recent treatment breakthroughs and management of ailments and infections are necessary. To show the importance attached to this kind of updates concerning health issues more than eighty percent of respondents would like to see this feature in the proposed system. Reports have indicated that mobile health tools have played a significant

role in improving medication adherence, health, and appointment follow-up [20, 12, 21]. To achieve the credibility of the updates that will be provided these must come from reliable sources, in this instance professionally recognized and internationally certified local and international organizations whose claims are verifiable have vital roles to play. This informs our proposal to have databases of international and national organisations such as the USAIDS, WHO, NACA among others integrated with the system. These databases contain standard procedure for treatments as well as recent breakthroughs on chronic illness and stigma-prone infections as well as other important information that might be relevant to the infection and useful for the infected. Integrating recommender system into the counselling and management system provides a powerful tool for achieving a well-rounded care for individuals infected with HIV/AIDS.

5 Conclusion

Prevalent stigma toward individuals living with HIV/AIDS infection and other ailments for which people can be stigmatized is a major roadblock toward achieving the desired care for those facing the challenge. Hence many of them are reluctant to come to the open to seek the necessary care despite the attendant effects of this on human survival and economic growth. However, with increasing penetration and mobility of mobile technology, it is possible to provide care for the teeming population of people living with HIV/AIDS and other stigma prone infections. The dynamic recommender component integrated with the mobile counselling architecture will make it possible for users to receive useful updates on treatments and drugs. This component of the integrated architecture is also intended to be adapted in the management of chronic ailments. Cost of implementation and security are two important issues toward an effective implementation of this architecture. These will be addressed in our future work.

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