REACH Lab Project

Final Report
2010-10-20

ecGroup Inc.
eCommerce | eHealth | Consulting
www.ecgroupinc.com
+1 (905) 515-0045

Contents

Executive Summary

Project Deliverables

The purpose of the Research in Enterprise Architecture for Coordinated Healthcare (REACH) project was to establish an applied research lab focused on the elements of eHealth EA specific to the requirements in low-resource and developing country environments. This lab would be located in an academic setting in South Africa at the University of KwaZulu-Natal (UKZN) and would include a working electronic health records system (EHRS) reference implementation.

The project deliverables, as defined (verbatim) in the original proposal, were as follows:

- Attend the Greentree EA session in New York; share information and coordinate REACH activities with stakeholders and partners (end-July, 2010)

- Completion of EHRS reference implementation training, at the Mohawk Applied Research Centre for Health Informatics (MARC-HI) for 4 UKZN / Jembi team members (mid-August, 2010)

- Setup of working health information access layer (HIAL) reference implementation at UKZN lab (end-August, 2010)

- Project interim report (August 31, 2010)

- Completion of EHRS demonstration prototype, including rudimentary mHealth-based workflow (September 12, 2010)

- Establishment of new eHealth applied research centre at UKZN, including organizational structure, operating plan, governance and IP management policies (end-September, 2010)

- Project presentation and/or demonstration at the Medinfo conference in Cape Town, South Africa (mid-September, 2010)

- Project final report (October 31, 2010)

Every one of these targets was successfully met within the timelines and budgets established for the project.

Recommended Next Steps

UKZN Lab

A new Healthcare Enterprise Architecture Lab (HEAL) is in the process of being established at UKZN. A proposal has been prepared by Dr. Deshen Moodley and Dr.Chris Seebregts and is currently under review by Rockefeller Foundation and IDRC for sustained funding. The proposal recommends a set of research areas, a scope of operations and targeted activities to be pursued over a 3-year time horizon.

A fulsome discussion of recommendations is included in the report. In summary, the following are recommended as actions and/or activities that IDRC should undertake in support of the new healthcare enterprise architecture lab:

- In the immediate term, it is recommended that IDRC fund, and help lead, the development of a strategic plan for the new lab at UKZN.

- It is recommended that IDRC take a very active role in the new lab's Technical Advisory Committee (TAC) – even so far as to advise UKZN regarding potential TAC members and providing funding for attendance at face-to-face meetings, as may be required.

- IDRC should fund and facilitate attendance by representatives of the UKZN lab at the annual Canadian eHealth Conference (sponsored by COACH).

- IDRC should fund and facilitate academic exchange between UKZN and Mohawk College.

Medinfo Demo

The motivation for developing a working prototype of the EA, and demonstrating it at the Medinfo conference, was to inform the ongoing debates regarding appropriate IT and architecture for low-resource settings. This has been a significant step forward. The discussions on this important topic are now *fact-based* rather than simply theoretical. The need for the Healthcare Enterprise Architecture Lab has been clearly demonstrated and a number of research areas have been made obvious through lessons learned in developing the demonstration.

In order to leverage, and sustain, the success of the Medinfo demonstration, the following are recommended:

- It is recommended that IDRC fund the configuration and hosting of a cloud-based instance of an EA prototype, based initially on the Medinfo demo architecture, that may be used for demonstration and research purposes.

- It is recommended that IDRC develop a consumer-friendly presentation (a narrated PowerPoint show or video) that leverages the success of the Medinfo demo and the use case and storyboard that were developed for it.

Summary Remarks

The REACH project came together, in a very short timeframe, due to the collective efforts of a number of stakeholders: IDRC, Canada Health Infoway, COACH, Mohawk College, Jembi, Zilics and others. This has been, very much, a shared success. Even so, special recognition and thanks is given to Chaitali Sinha, Don Newsham, and Chris Seebregts for their leadership and vision.

ecGroup is proud to have participated in this important initiative.

UKZN Lab

Project Targets / Goals

A primary motivation for the REACH project was to develop, in Africa, an applied research capacity focused on eHealth enterprise architecture (EA). As an applied research centre, the lab would not only develop engineering and implementation artefacts, but would host a working test bed which may be employed to develop and test new innovations and to mitigate the project risk of future EHRS and eHealth implementations in low-resource settings.

The project, in addition to its technical deliverables, would also develop a set of reusable governance, legal and operating templates and artefacts which may be employed to establish similar EA initiatives in other regions where IDRC is active.

The specific REACH project goals related to the UKZN lab, as were described in the project proposal, are listed below:

- Completion of EHRS reference implementation training, at the Mohawk Applied Research Centre for Health Informatics (MARC-HI) for 4 UKZN / Jembi team members (mid-August, 2010)

- Setup of working health information access layer (HIAL) reference implementation at UKZN lab (end-August, 2010)

- Establishment of new eHealth applied research centre at UKZN, including organizational structure, operating plan, governance and IP management policies (end-September, 2010)

Project Outcomes

Training and Knowledge Transfer

In late July, four developers from South Africa arrived in Hamilton at Mohawk College's MARC-HI lab for two weeks of training and knowledge transfer (see Figure 1). During this intensive and busy time, Ryan Crichton, Wayne Naidoo, Pascal Brandt and Daniel Futerman (all of Jembi) had an opportunity to work with members of the MARC-HI team who have developed Canada's reference implementation of the Infoway-designed enterprise architecture for electronic health records (EHR).

Figure 1

Regarding technology and knowledge transfer from Infoway and MARC-HI to the new UKZN lab, the following accomplishments were achieved:

- A server-class computer was purchased and loaded with a working version of the MARC-HI enterprise architecture (EA) software platform plus current copies of the entire suite of Canada's healthcare messaging standards and engineering documentation (including implementation guides and message design documents).

- Members of the Jembi team were instructed in the configuration and maintenance of the reference implementation.

- The Jembi teammates learned about the internal workings of the EA and the design choices that were made by MARC-HI as this version of the reference EA (version 3) was developed. The SOA-based theories that underlie the software design were explained. Likewise, the standards-based health information messaging model (HL7v3) was described and its relation to the software design was explained.

- In order to aid in the learning process, every Jembi teammate was provided with a computer workstation at the MARC-HI lab. During the 2-week training period, they all had hands-on opportunities to work with the EA and to begin extending and altering it to suit the "low-resource" requirements of the Medinfo demo.

- Importantly, the Jembi teammates were able to establish close working relationships (and friendships!) with their counterparts and now new colleagues at MARC-HI lab. Although no formal relationship is in place yet, Chris Seebregts was able to meet with senior executives at Mohawk to discuss and plan for how a permanent relationship between Mohawk and UKZN/Jembi might be established. This process is now launched at both organizations.

Working EHRS Prototype at UKZN

Two of the teammates that attended the training in Canada work out of the Jembi lab located in the computer science department at the University of KwaZulu-Natal

(UKZN). The hardware purchased and configured during the training session at MARC-HI was installed and is presently operating at this lab (shown in Figure 2).

Figure 2

Over the course of the ensuing weeks leading up to the Medinfo conference (and demo), Ryan Crichton and Wayne Naidoo worked in concert with Jembi teammates in Cape Town to develop services and interfaces to companion products that would leverage the Canadian software and extend it to operate in an African context. This development work, which was finalized in Cape Town in mid-September, is now reflected in the operating prototype located at the UKZN lab. The architecture of this working prototype, as demonstrated during the Medinfo conference, is shown in Figure 3.

New EA Research Lab at UKZN

One of the goals of the REACH project was to have UKZN embrace the EA lab initiative and provide a "home" for it on an ongoing basis. To that end, a draft set of documents was prepared that describe a proposed governance structure, IP policy framework and partner contribution contract that may be used by UKZN. These documents were based on those developed and employed – with success – at Mohawk College when they were setting up MARC-HI. The proposed draft documents were communicated to Chris Seebregts, who passed them along to the Head of the Computing Science School at UKZN, Dr. Deshen Moodley.

During the development of the Medinfo demo project, personal relationships were leveraged to secure a working version of the Apelon terminology service application and ICD-10 code translation database. The Apelon service was configured as a core component of the demo infrastructure. Apelon has agreed to become the first private sector partner of the new lab and will contribute the software (valued at $30,000 USD per year) to be used to support ongoing research in applied health informatics.

A meeting was held in Durban, South Africa on September 1, 2010 between Dr. Seebregts, Dr. Moodley and Mr. Ritz. As an outcome of that meeting, Dr. Moodley committed to having the new EA lab hosted within the computer science department at UKZN. Agreement was also reached regarding how Jembi and UKZN would partner on the lab and how it could be initially staffed.

This draft structure was written into a proposal document prepared by Dr. Seebregts and submitted to the Rockefeller Foundation (and to IDRC) for funding. A meeting

was held at Monkey Valley Resort (outside Cape Town, South Africa) on September 16, 2010 to discuss this draft proposal. After subsequent edits to reflect the results of the discussions at Monkey Valley, a revised proposal was developed and submitted for funding. This new proposal is under review.

Recommendations – UKZN Lab

A new Healthcare Enterprise Architecture Lab (HEAL) has been established at UKZN. A proposal for sustained funding has been prepared by Dr. Seebregts and is currently under review by Rockefeller Foundation for sustained funding; it is included as an appendix to this report. The proposal recommends a set of research areas and a scope of operations to be pursued over a 3-year time horizon.

The following are recommended as actions and/or activities that IDRC should undertake in support of the new healthcare enterprise architecture lab.

Immediate: Strategy Development

IDRC's investment in the REACH project has yielded success; there now is a healthcare enterprise architecture lab at UKZN. Exactly how that lab will launch, who will staff it, how it will collaborate with other labs, and what will be its research agenda are questions not yet answered. Support for this initiative has been expressed by the Rockefeller Foundation; however, this support is contingent on how some of these unanswered issues will be addressed by UKZN.

It is recommended that IDRC fund, and help lead, the development of a strategic plan for the new lab at UKZN. The rationale behind this recommendation is:

- There will be costs which must be bourne to undertake development of a strategy for the lab; UKZN does not have a funding envelope which it can dedicate towards this effort.

- The main proponents of the lab (Drs. Seebregts and Moodley) are time-constrained and would be helped by having external resources made available to them to assist with strategy development.

- IDRC, and other donor partners, have strategic goals for the lab related to the ways its work can support ongoing development and investment projects. As primary funders of the initiative, it is important that the lab's strategic plan is consistent with these goals and will yield the outcomes and benefits that warrant the donor's investment.

- A partnership approach regarding funding would allow the lab to launch, and operate on a contingent basis, during the period in which the strategy is being finalized. This would enable the lab to make good use of the positive momentum which has been generated by the success of the Medinfo demonstration.

Immediate: Advice, Governance and Oversight

The HEAL proposal contemplates a Technical Advisory Committee (TAC) which would "assist with the task of setting an appropriate research agenda for the lab and advising on strategic direction and technical implementation". As this lab will rely heavily on sustained donor support, it is recommended that IDRC take a very active role in the TAC – even so far as to advise UKZN regarding potential TAC members and providing funding for attendance at face-to-face meetings, as may be required.

The rationale behind this recommendation is:

- IDRC's interests (and those of the donors, generally) will be best served by fostering collaborations with international academic institutions in regions where there are active development investments and projects. The current proposal lists one local (South African) and two North American institutions as potential partners. Notably missing are collaborations with sub-Saharan African or south Asian institutions – even though many opportunities have presented themselves during and post Medinfo. The donors on the TAC should strongly influence the lab's collaborative ambitions.

- There are important areas of *applied research* which should be pursued by the new lab. IDRC, and other donors, should insure that the research agenda encompasses both academic (theoretical) and applied research. UKZN may favour the former, but it is the latter which will be most impactful in supporting ongoing development activities and country eHealth implementations. IDRC, and other donors, may wish to explicitly fund specific applied research areas of interest – including prototyping and/or piloting, as necessary.

- It is anticipated that IDRC will be a supporting donor for the new lab. As a matter of oversight, it is important that IDRC be able to regularly review the lab's budgets and expenditures.

Medium Term: Ongoing Relationships

The REACH project has been greatly assisted by and has benefited from a donation by Canada Health Infoway of its EHRS engineering and intellectual property and by a companion donation by Mohawk College of its EHRS reference implementation software. There were and are "no strings attached" to these donations. The impact, however, has been to establish professional (and personal) ties between the UKZN lab and its Canadian counterpart: Mohawk College. Likewise, professional (and personal) relationships have been established between the principals at Jembi/UKZN and various senior executives at Canada Health Infoway and at COACH, Canada's professional health informatics association.

These relationships are mutually beneficial, and important to the success of the UKZN lab. It is therefore recommended that IDRC provide explicit support for these relationships, including the following:

- IDRC should fund and facilitate attendance by representatives of the UKZN lab at the annual Canadian eHealth Conference (sponsored by COACH). The attendance funded by IDRC at the Vancouver conference in the Spring of 2010 was significant and impactful. It should be expected that presentations of the work and progress of the UKZN lab would be well received at the Canadian conference. Indeed, the international participation was so well received by the conference attendees that it is now actively sought by the COACH executive team for the 2011 conference.

- IDRC should fund and facilitate academic exchange between UKZN and Mohawk College. This could include faculty and/or student exchanges and IDRC should expect to leverage existing Government of Canada programs which are designed to support such initiatives. For their part, Mohawk College is very interested in participating in such initiatives. Over time, collaborations with other Canadian institutions can and should be similarly nurtured.

The rationale behind this recommendation is simple: "you go to the same well until you stop getting water there." There are a number of areas of health informatics where Canada is a recognized world leader; one of these areas is eHealth enterprise architecture. Important and mutually beneficial relationships, which have already been established by IDRC's investments so far, should be supported on an ongoing basis.

Medinfo Demo

Project Targets / Goals

One of the documented objectives of the REACH project was to show a prototype demonstration at the MedInfo 2010 conference in Cape Town, South Africa. This would provide the new EA project with visibility among national health information system initiatives in developing countries, as well as among donors and researchers working in this field. It was also expected, following the meeting at Greentree, that providing a live demo would inform the ongoing and active discussions within this stakeholder community regarding eHealth EA.

The specific REACH project goals related to the Medinfo demo, as were described in the project proposal, are listed below:

- Attend the Greentree EA session in New York; share information and coordinate REACH activities with stakeholders and partners (end-July, 2010)

- Completion of EHRS demonstration prototype, including rudimentary mHealth-based workflow (September 12, 2010)

- Project presentation and/or demonstration at the Medinfo conference in Cape Town, South Africa (mid-September, 2010)

Project Outcomes

Use Case Development

Initial use-case development was started, in collaboration with other attendees, at the Greentree meeting in New York. It was determined that 3 important elements should be characterized within the demonstration use case:

1. The use case should be reflective of the healthcare needs and technology environment typical of sub-Saharan Africa.

2. Where possible, the use case should address Millennium Development Goals.

3. The use case should illustrate how mobile phone technologies might be leveraged to good effect to support care delivery in low resource settings.

Mindful of these guidelines, a use case for the Medinfo demo was developed and reviewed by stakeholders. This use case went through 3 iterations and was eventually finalized as described in the *Medinfo Demo* overview document which is included as an appendix to this report.

The use case is summarized as follows:

> *Mosa Hakizimana is a 19 year old female living in RuralVillage. RuralVillage has no electricity and there is no land-line based telephone, although there is mobile phone coverage in the area. RuralVillage is 5km from a larger town, NearTown, where there is a regional clinic which provides basic care. The clinic in NearTown is operated as part of the Millennium Villages Project (MVP). Another town 15km away, called FarTown, has an HIV Voluntary Counseling and Testing (VCT) centre supported by the aid agency Partners in Health (PIH).*

> *Mosa is sexually active. She learns that her boyfriend has been with other partners and may have contracted HIV. Worried about her own health, Mosa makes her way to FarTown to the VCT clinic there. She is diagnosed with asymptomatic HIV and enters a care program which sees her visiting the clinic every 6 months for CD4 testing. Fearing the social stigma around HIV, Mosa does not divulge to her neighbours in RuralVillage that she is HIV positive.*

> *Mosa becomes pregnant.*

> *Mosa is visited by the Community Health Worker (CHW) who is doing regular follow-up visits in RuralVillage. The CHW notes that Mosa is pregnant and provides her with information about the Antenatal Care (ANC) appointments she should attend at the clinic in NearTown.*

> *Mosa attends her ANC appointment at the MVP clinic in NearTown. A care plan is developed for her that will help her have a safe pregnancy and will help her unborn baby be born without HIV.*

Project Execution

Preliminary software development work regarding the Medinfo demo was begun while the Jembi team was still at MARC-HI. In fact, this helped the learning process by giving the Jembi team hands-on opportunities and also helped refine the design by being able to engage directly with MARC-HI developers and benefit from their experience and expertise. A Medinfo Demo software architecture design diagram is shown in Figure 3.
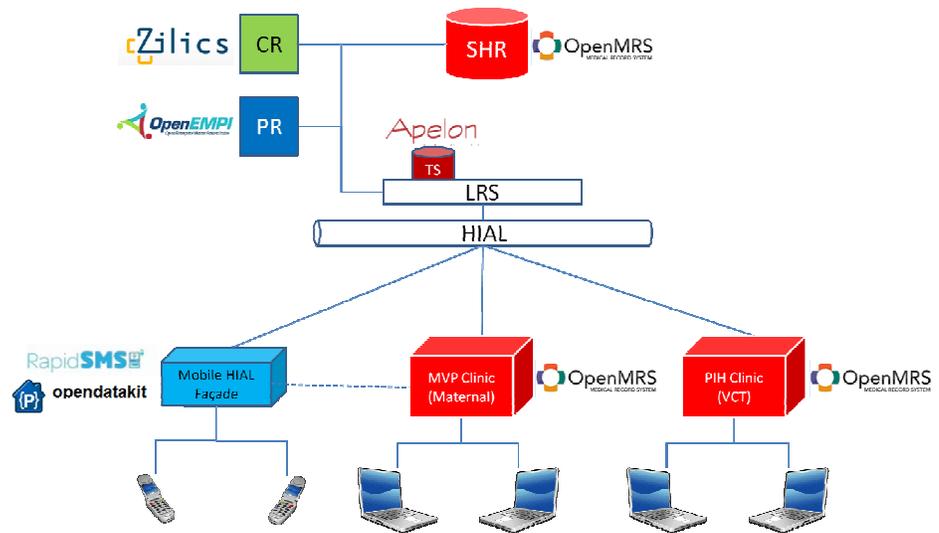
Figure 3

Regarding the Medinfo prototype development, the following project outcomes were accomplished:

- A design specification was developed that would allow the use case to be demonstrated with working software at the Medinfo conference. This design specification was reviewed by stakeholders, including by REACH lab demo partners (and/or "connectathon" participants at the Medinfo conference) and by members of the Rwandan EHR implementation design team. The design underwent 3 major revisions. The most recent version of this *Medinfo Technical Specification* document is included as an appendix to this report.

- A project plan was developed to realize the technical design of the Medinfo prototype. This project plan was revised and was managed based on input from the Jembi development team regarding resource allocations, effort estimates and scheduling. Effort expenditures against the plan were tracked and reported; during the software development process, daily team updates were conducted.

- During the course of the development effort, a software version control website was established based on the JIRA software platform. Source code for the Medinfo prototype was versioned, tracked and posted to this site. Issues (or bugs) were logged.

- Two operating versions of the HIAL (the system's health information access layer) were established; one at the UKZN lab in Durban, South Africa – the other at Jembi's offices in Cape Town, South Africa. The Cape Town HIAL was exposed to the internet so that it could be accessed by remote partners including Zilics Systems in Sao Paulo, Brazil.

- Due to a number of challenges, integration testing of the two Jembi "puzzle pieces" was not begun until September 8th and final integration testing with a local version of the Zilics client registry product was not possible until September 11th.

- Even in the face of many challenges, thanks to the outstanding efforts of project team members, the full solution was successfully demonstrated at

the IDRC/Rockefeller booth at the Medinfo 2010 conference during the course of the exposition (from September 13th -15th).

REACH Project Demonstration

REACH project demonstrations were done every break-time (morning and afternoon tea, and lunchtime) during the Medinfo 2010 conference. The demonstration was set up at the IDRC/Rockefeller booth. A small computer network illustrated the various IT puzzle pieces indicated in Figure 3. Posters on the booth walls showed the "storyboard" of Mosa's healthcare journey and a host (Liz Peloso of Jembi) led the demo attendees through the story (see Figure 4).
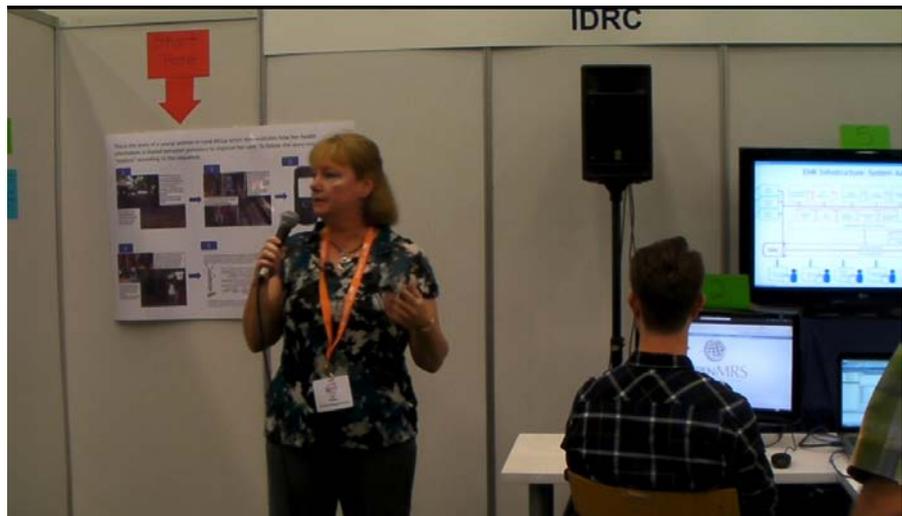

Figure 4

The REACH demonstration story followed a series of steps:

1. Mosa is introduced and her community is described.

2. The story begins when Mosa learns that her boyfriend has been with another woman and fears that she may have been exposed to HIV. She decides to attend at a Voluntary Counseling and Testing (VCT) clinic at a town far from her village to be tested.

3. Mosa arrives at the VCT clinic operated by Partners in Health (PIH). The clinic uses an OpenMRS electronic medical records system configured to support their HIV-related care delivery. Mosa's details are logged in the system and the appropriate tests are performed. Mosa's condition (HIV positive) is recorded in the OpenMRS system and she joins the care program for asymptomatic HIV patients.

4. The OpenMRS system creates a standard clinical message indicating Mosa's demographics and the diagnosis code for asymptomatic HIV. This message is transmitted to the shared health repository in the eHealth enterprise architecture using a standard format (HL7v3 XML). This information, including a coded diagnosis (using the WHO standard ICD-10 coding system), becomes part of Mosa's longitudinal health record.

5. Mosa returns to her village but does not divulge to her neighbours that she is HIV positive. Time passes. Mosa becomes pregnant.

6. Mosa is visited in her village by a community health worker (CHW) who has a mobile phone. Using a mobile phone based application, ChildCount+ (developed and implemented by the Millennium Villages Project), the CHW logs an SMS message on the cellular network indicating that Mosa is now pregnant.

7. An interface converts the SMS message to a standards-based HL7v3 message and communicates it to the shared health repository. An algorithm retrieves Mosa's existing health information and determines that she is now pregnant *and* HIV positive. An alert is created and sent back as an SMS reply.

8. The CHW receives the reply SMS indicating that Mosa is a *high risk pregnancy*. The CHW recommends Mosa immediately attend an antenatal care (ANC) visit at the local clinic. (NOTE: Mosa's privacy is not breached; the CHW is not told why hers is a high risk pregnancy).

9. Mosa arrives for her ANC appointment at the clinic operated by Millennium Villages Project (MVP). The MVP clinic uses a version of the OpenMRS electronic medical records system configured to support their community care delivery. Mosa's demographic information is logged in the system and her health records are retrieved from the enterprise architecture's shared health repository. Because they see that she is HIV positive, appropriate PMTCT (prevention of mother-to-child transmission) protocols are put in place and Mosa's care plan as a high risk pregnancy is established.

10. The OpenMRS system creates a standard clinical message indicating Mosa's demographics and the diagnosis code for high-risk pregnancy with PMTCT, plus any other clinically relevant findings arising from her assessment. This message is transmitted to the shared repository and also becomes part of her longitudinal health record.

11. At the conclusion of the demonstration, the host reviews Mosa's storyboard with the attendees. Mosa's coordination of care is supported by the eHealth enterprise architecture in a way that would be impossible without it. By providing the shared health information, Mosa's health, and the health of her baby, is fundamentally improved.

The REACH demonstrations were very well attended and very well received. Importantly, the demonstration sparked discussion regarding how eHealth EA could be leveraged in actual country-specific settings – in many of which there are initiatives and projects presently underway. The Jembi team received numerous requests for information and invitations to explore how they could participate in these projects.

Recommendations

The motivation for developing a working prototype of the EA, and demonstrating it at the Medinfo conference, was to inform the ongoing debates regarding appropriate IT and architecture for low-resource settings. This has been a significant step forward. The discussions on this important topic are now *fact-based* rather than simply theoretical. The need for the Healthcare Enterprise Architecture Lab has been clearly demonstrated and a number of research areas have been made obvious through lessons learned in developing the demonstration.

In order to leverage, and sustain, the success of the Medinfo demonstration, the following are recommended.

Immediate: Cloud-based Demo Service

The Medinfo demonstration architecture relied on multiple servers connected in a local area network at the IDRC/Rockefeller booth. Using virtualization and IP addressing, a version of the eHealth enterprise architecture could very readily be set up to operate "in the cloud" (hosted as an internet-available service). Such a configuration would be accessible from anywhere in the world where there is an internet connection. This would significantly reduce the "footprint" and, therefore, the cost of demonstrating the Medinfo storyboard.

Sufficient connectivity was not available from the Jembi office nor from the UKZN lab to successfully host such a configuration. Based on a discussion with Mohawk, however, a cloud-based version of the Medinfo configuration could readily be hosted using the College's datacenter. This provides a cost-effective option; other options using 3rd party hosting facilities could also be considered.

It is recommended that IDRC fund the configuration and hosting of a cloud-based instance of an EA prototype, based initially on the Medinfo demo architecture, that may be used for demonstration and research purposes. The rationale behind this recommendation is:

- Having a cloud-based demonstration EA will enable presentations to be readily and inexpensively made to stakeholders and interested audiences, wherever they might be, using only a client PC and a cellular phone. This will help, from a "marketing" point of view, to build collaborative partnerships and inform discussions regarding the importance, impact, and *viability* of healthcare EA for low-resource settings.

- If the hosting is done by Mohawk, or by any other academic partner, it will operationalize the collaboration between UKZN and the hoster. The collaborating institutions, out of practical necessity, will have to stay "in sync" with each other.

Immediate: Consumer-friendly Presentation

The reactions from attendees at the Medinfo demo were very positive. Mosa's is a compelling story. It vividly illustrates the way healthcare enterprise architecture can impact the health of a young woman; it shows how pervasive health IT can support progress on multiple Millennium Development Goals (4, 5 and 6). These are important messages for IDRC; they represent the heart of IDRC's motivation for making investments in this area.

It is recommended that IDRC develop a consumer-friendly presentation (a narrated PowerPoint show or video) that leverages the success of the Medinfo demo and the use case and storyboard that were developed for it. The rationale for this recommendation is that Mosa's story is one which will help IDRC clearly and compellingly communicate to non-technical audiences (funding partners and interested stakeholders, including the Government of Canada) the motivations for investment in healthcare enterprise architecture.

Appendices

Medinfo Demo (final draft)

Medinfo Demo Technical Specification (final draft)

UKZN Lab Operating Documents (Draft)

Sample MNDA

Sample Contribution Agreement

Schedule A – Sample Advisory Council Terms of Reference

Schedule B – Sample Project Charter

Open Health Tools IP Policy