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Project factsheet information

Project title	Real-time Hepatitis Reporting and Surveillance System in low- resource settings using ICT and mobile phones
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Dates covered by this report	16 – 07 – 2013 / 15 – 09 – 2014
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Country where project was implemented	Pakistan
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Partner organizations	N/A
Total budget approved	30,107.82 AUD
Project summary	Hepatitis is tremendous health problem not only in Pakistan but worldwide. It is prevalent in five different forms namely hepatitis A, B, C, D, E and is communicable. Pakistan is a developing nation of more than 180 million people, and many regions of the country have alarmingly high rates of uncontrolled outbreaks of hepatitis. Regardless of these alarmingly statistics, little efforts in form of awareness seminars mostly are being conducted in Urban Areas only. Around 75% of the Pakistani population resides in the rural areas where there is lack of access to clean water and proper sanitation conduction due to which Hepatitis (A & E) spread rapidly. Till date out of 200,000 patients treated at UM-Healthcare Trust in Mardan, 20% are carrier of hepatitis and are completely unaware of their critical situation. These statistics motivates us to develop a solution based on cell phones that will track and monitor its spread in rural communities. This model has been successfully implemented at UM Trust and shall be replicated for other diseases with our partners NRDP and CDRS, Pakistan. Additionally, this solution shall be provided to the health ministry for further research.

Table of Contents

Project Summary

Pakistan carries one of the world's highest burdens of chronic hepatitis and mortality due to liver failure and hepatocellular carcinomas[1]. A total of 7.4 per cent of population is infected with hepatitis of which 2.6 per cent are infected with hepatitis B while 4.7 per cent with hepatitis C [2]. The virus causes a deadly liver disease having same mode of transmission as AIDS. Due to this the mortality rate and the financial burden on government are also enormously increasing. Unfortunately there is not even a single disease tracking system that can highlight the root cause of this problem. So far the provided statistics have been either collected via survey questionnaires or simple screen tests which of course are not reliable source of information. An accurate Hepatitis surveillance continues to remain a challenge in Pakistan hence making it tough for health professionals, policy makers as well as relevant healthcare stakeholders to comprehend Hepatitis spread and its burden in rural communities.

With the generous support of ISIF we have successfully developed a Hepatitis Surveillance System to track Hepatitis patients in rural Mardan using cell phones and internet based devices (Laptops and PCs) to create an accurate picture of how the disease is spreading. We have also provide our tools to Rural Health Workers (RHWs) (including Rural Health Workers) and rural clinics access to mobile phones through which they can report infected patients to our central servers. This data is collated and plotted on GIS maps of the area so that proper surveillance of the disease can be performed. Furthermore, 'Contact Tracing' procedure was applied to track down the origin of the disease as well as Hepatitis exposed personals. A detailed report on the results is provided in later sections.

We also faced myriad challenges during the implementation of the project. Due to the sensitive security situation in Mardan and its neighboring districts as well as the deadly attacks on Polio Workers during their field visits made it difficult for data collection form target communities. In order to collect data related to hepatitis from the field, it was vital to first meet, orient and take permission from the concerned authorities and key stakeholders of the areas. After winning their confidence and approval, we initiated the data collection process through volunteers and RHWs. To complete this task efficiently, we were granted no-cost project extension by ISIF till September 2014. During this time period, we not only successfully collected data but also performed data analysis.

Our biggest achievement is partnership with NRSP (National Rural Support Program, http://nrsp.org.pk/) and CDRS (comprehensive Disaster Response Services, http://cdrspakistan.org for replication of Jaroka Tele-Healthcare. This partnership will long way in sustainability of this initiative. Furthermore, 1 research paper is High Capacity Optical Network (HONET 2014) to be held in Charlotte, USA and 1 chapter in CRC Press/Taylor & Francis Group, LLC is accepted for publication. We were also invited to various prestigious national platforms, conferences and institute to present our work and find the mutual grounds for cooperation in the domain of electronic and mobile health.

Background and Justification

Viral Hepatitis is a serious global concern which is one of the major challenges towards achieving the health related United Nations Millennium Development Goals (UN-MDGs). It is leading to a significant increase in mortality rate worldwide, in general, and in the developing countries, in particular. Every 12th person in the world and 10th person in Pakistan is a hepatitis patient. A conservative estimate by World Health Organization (WHO) places over 12 million carriers of the virus in Pakistan. Unfortunately there is not even a single hepatitis reporting and tracking system that can highlight the root cause of this problem. So far the provided statistics have been either collected via survey questionnaires or simple screen tests which are not reliable source of information. Existing measures to address the prevalence of hepatitis infections have not eliminated the need for more vigorous efforts and greater resource allocation.

Hepatitis is third major disease in Pakistan. It is extremely potent and has the ability to spread really fast. It is defined as an inflammation of the liver, most commonly caused by a viral infection. There are five main hepatitis viruses, referred to as types A, B, C, D and E. Hepatitis A and E are caused by oral infection, contaminated water and unhygienic food. It is specifically occurs in developing countries especially rural communities due to the poor hygienic conditions. Hepatitis B, C and D are considered as global health problem and are caused by many factors including, unsterilized syringes, sexual transmission, blood transfusion, and from mother to infant (pregnancy). The main reason for its spread is the lack of awareness among the infected and what preventive

measure to take against its spread.

In Pakistan, about 80% of the population lives in villages, dependent on wells for drinking water. They lack awareness that well water is one of the reasons for spread of Viral Hepatitis and other water borne diseases in rural area because they are not clean. The monsoon floods (July 2010) in Pakistan, has not only destroyed the infrastructure of almost one-fourth of Pakistan but also exponentially enhanced the spread of communicable and infectious diseases. Millions of people including children are at risk of being hepatitis transmission.

It has been taken into consideration that out of 50,000 patients treated annually at UM Healthcare Trust (Jaroka Tele-healthcare Project http://www.tele-healthcare.org) facility 20% were carrier of hepatitis, completely unaware about their conditions and preventive methods. The lack of proper health facilities, poor economic status, and unawareness about the disease and its prevention may lead to a chronic stage of hepatitis, almost untreatable and so expensive that a poor person pocket could not afford such expense. Although vaccines are there but still no known cure for hepatitis could be found

We are doing capacity building of Rural Healthcare Workers because they mostly work in isolation and lack essential information about various variants of Hepatitis (HCV, HAV, HEC etc) which should be reported and controlled, so Healthcare Workers need to have updated knowledge. In case various variants of hepatitis are not reported and controlled on time it may lead to one of the major virally spread diseases in Pakistan. It is vital that awareness about preventive measures and treatment options be disseminated among the masses because early detection of the disease increases the probability of complete recovery.

We propose to build an innovative real-time hepatitis reporting and surveillance system, which will exploit the power of Information and Communication Technology and mobile phones to report and track hepatitis back to its source. Health Workers will be able to report the hepatitis cases in real-time to our central server from the field using Short Messaging Service (SMS/MMS) and can also strengthen their knowledge by querying the medical doctors at UM Healthcare about different type of hepatitis. We plan to send 20 Rural Health Workers to the 25 villages. This system will be first-ever geographic map of hepatitis transmission in the country and an accurate picture of the way the disease is spreading.

We are strongly encouraged to bring value to ICT and mobile phones by harassing their power for social challenges. The simple low cost mobile phone has reached as a promising solution for the resource constraints areas. if used intelligently, it can be a very powerful platform for data collection and dissemination as well as surveillance and feedback. This motivates us to build a surveillance system that can not only keep track of hepatitis cases but will also track back the cases to original sources. Once the root cause of the problem is known, strategies for preventive care will be easier and effective.

Our proposed model is scalable and low cost and will be replicated for other diseases in future. This data collected through the system will be shared with stakeholders so that extended research, preventive care and health policies can be carried out.

Project objectives

We aim to build “Real-time Hepatitis reporting and surveillance system via ICT and mobile based Technology”. This model will not only serve as a solution to track the disease but to track the origin of the disease itself (the source), so that necessary measures are taken to prevent it from further spreading. The model shall be easily replicated for other communicable diseases in future. The specific objectives as per ISIF proposal are as follows:

- Devise and implement a replicable hepatitis surveillance system using ICT and mobile technology. This system will be first-ever geographic map of hepatitis transmission in the country and an accurate picture of the way the disease is spreading.

- Develop an innovative solution for tracking and tracing Hepatitis back to its source.
    - Collection of this data will take place by using cell phones.
    - Mapping of the collected data on Google maps in real time to see its spread from village to village. This will provide a visual representation of data to different stakeholders.

- Bringing awareness to general public on the preventive methods of the spread of virus.

- Share the data with Ministry of Health, Policy makers and relevant stakeholders to develop and implement strategies, where the impact of disease has the potential to be momentous.

- Foster collaboration with national and international stakeholder to strengthen hepatitis prevention, control and mitigation on the large-scale health and economic impact following the disease.

Users and Uses :

Listed below are the present and future users of this project and the benefits they will provide with the help of this grant

1) Under-served communities from rural areas:

Communities will become more aware of Hepatitis and as a result they will play a major role in preventive methods e.g. When the Doctor or rural health workers would check the infected patient, they would inform them and tell them about preventive measures, which will increase awareness in the patients and as a result they would take preventive measures more seriously. Also, once awareness about preventive measure is known, reduction in mortality rates due to hepatitis would take place and as a result their cases will be reported to the health ministries and other NGOs would be able to place prevention strategies well in time.

2) Health Ministry and Health related NGOs:

With the help of UM Healthcare Trust- data sharing, the relevant health related organizations will get authentic and real-time data and information on hepatitis so that better monitoring and tracking of communicable diseases can be done in Pakistan This data will play a vital role in strategies healthcare policies and projects and the solution can be replicated by the organization for other diseases as well. The solution will help organization to optimize the resources allocation in case of disease outbreak or natural disaster. As a result wastage of resources, effort and time would be avoided in that crucial time, when we already have a system that easily and correctly tracks and traces the disease-map in the right time, on the right people. It will also help Health ministry and other health related NGOs to facilitate research on Hepatitis.

3) Rural Health Workers (RHWs):

Rural health workers would be able to collect the data instantly through a low cost mobile phone instead of carrying heavy registers and paperwork to the field. This will save the resources and time as well as reduce the chances of errors and data duplication. The solution will empower RHWs by strengthening their knowledge on the nature and types of Hepatitis as well

4) Medical Doctors:

Medical doctors would be able to track back the origin of the Hepatitis. They will provide Timely advice and consultancy to patients and RHWs. The medical doctors at our Mardan facility will perform the most critical function in the project. Not only will they assist rural health workers and medical specialists in better tracking the disease, but will also play the vital role of actually performing Contact Tracing.

5) Students/Researchers:

It will help students in their Research projects, since the data would be available to the universities as well for better understanding and increased awareness

6) Telecommunication Industry:

Telecommunication industry will give this devise a multi-purpose usage by adding value to the mobile services e.g.

- Cell phones used for tracking the disease
- Cellphones used to create awareness about taking preventive measures against hepatitis
- Cell phones used for health related purposes

7) Medicine Companies / Distributors:
This System can also be used by the pharmaceutical companies and distributers to get not only Hepatitis related data but also trends and density of different diseases in far located rural areas in order to plan and distribute medicine according to the need and before time.

Indicators

Baseline	Indicators	Progress	Assessment	Course of action
A total of 2,000 (mother, children and men) were hepatitis patients in the disease trend for the year 2010 to2013	-20% are HIV patients visiting our facility -Identification of 75-80% patients at our facility -Identify hepatitis patients in 25 villages -Collect data from 25 villages	- Shortlisted the software - Purchased the equipment's like laptops and SMS GW - Hired the team(one research assistant, a software developer and 2 medical doctors)	-Data collection for hepatitis patients through well-conducted survey through mobile phone.	-Development and testing of system -Identify RHW to carry of this survey
Lack of knowledge of Rural Health Workers (RHWs) on Hepatitis and its preventive care	- Majority of RHWs work in isolation as there is not system in place to connect them with doctors in urban areas or connect them with information using ICT.	- Developing SMS services which will play an important role to build their capacity in domain of hepatitis or other communicable diseases.	- Pre and Post evaluation survey of selected RHWs knowledge on hepatitis. -Conduct workshop and mentoring of RHWs on hepatitis especially on preventive care that can be taken to avoid hepatitis.	- Identifying of local RHWs for our project. - Training of RHWs on SMS services. - Testing of mobile ready hepatitis surveillance service.
No system in place to monitor and track the spread of Hepatitis (live) or any other communicable disease in area	- No record found on tracking of hepatitis in the area.	- GIS version being tested and implemented for electronic patient data.	- The accurate visualization of patient data suffering from hepatitis on GIS map.	- Enter the electronic medical records or SMS records of all patients to EMR system for the mapping purposes. - RHWs are able to retrieve definition, symptoms and preventive care on all kinds of hepatitis.

Project implementation: understanding the chain that leads to results

The goal of the project is to develop first ever electronic Real-time hepatitis reporting and surveillance for rural communities of Mardan. The project is designed around mobile phones using Short Messaging Service (SMS), Multimedia Messaging (MMS) and Internet based devices (PCs/laptops running standard web browser

software). The solutions will go a long way in building local knowledge and research in Pakistan and will be replicable for other preventable diseases in Pakistan.

We have singed a contract with NRDP to replicate the project at Narowal through Software As A Service (SAAS) model and also train Rural Health Workers at this district on using mobiles for healthcare from this year. We are also in process of signing a contract with CDRS (Comprehensive Disaster Response Services) to replicate the project in Swat and other project sites. This data collected through our system from all the implementation sites will be shared with stakeholders so that extended research, preventive care and health policies can be carried out for rural Pakistan.

Our system takes into account that the users will have minimal knowledge of computer technology and therefore will be easy to use with little or no learning curve. The system also supports both Urdu and English languages so rural communities are able to understand and operate the system as well. For example: Health Workers are able to report the hepatitis cases in real-time to our central server by using commands such as “Disease” and also can retrieve the definition of all kinds of hepatitis using command “Medical Dictionary” through Short Messaging Service (SMS) and therefore also strengthen their knowledge by querying the medical doctors at UM Healthcare about different type of hepatitis. In order to further assist RHWs we have added an additional service called “Help”. This service will enable RHWs to instantly retrieve all the system commands with example query for each command. This service has been proved extremely helpful for RHWs in the field and they also do not have to carry the manuals with them as they can retrieved commands easily through one signal SMS. Moreover, we also aim to make our research and finished solution available to non-profit sector in Pakistan and to Ministry of Health, so that better monitoring and tracking of communicable diseases can be done in Pakistan.

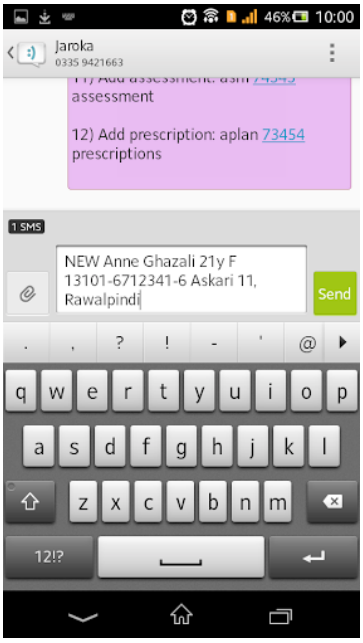
Till now, male and female both (only the ones with authorized access) are able to use the system for entering and retrieving patient’s data by using cell phones or laptops. This has a positive impact on UM Healthcare which shows that not only men are capable of using the system but women are equally able to do the same. Both have access to latest information which helps that stayed updated and empower them to provide necessary care to the patients.

First Quarter:

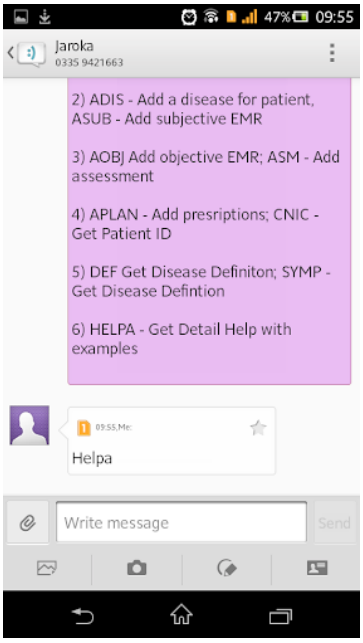
During the first quarter project planning and management took place i.e. discussions on which team needs to be recruited and why. What work would be assigned to the team research assistants and Medical staff. Which equipment’s should be purchased and how much will it cost. Furthermore, we achieved our milestone by updating our software system “Jaroka’ by bringing certain very important and beneficial changes into our system. We also purchased laptops and SMS GW (Short Message Service Gateway) and installed other needed equipment at project site. In the same quarter recruitment of two research assistants and 2 medical doctors took place. Finding a female doctor was a big struggle because the absence of a female doctor resulted in decrease of female patient registration and increase in the diseases concerned with female. After selecting a Female medical doctor, meeting the requirements of UM Healthcare Trust the ratio of female patient influx have gradually increased and now we are able to tackle the diseases female patients are going through.

Second Quarter:

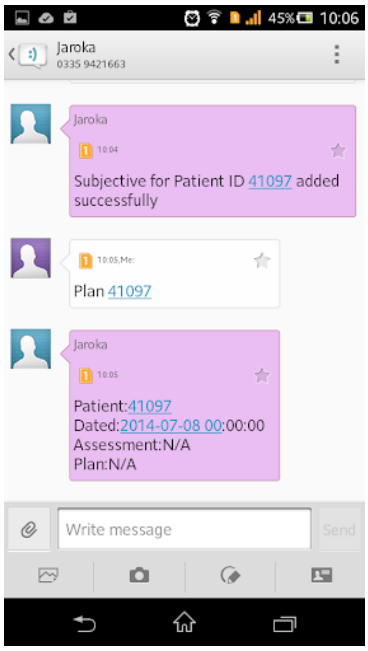
During the second quarter, the electronic medical record system was customized according to the users requirements to handle queries related to Hepatitis for registered patients. Our development team closely worked with team at UM Healthcare Trust to develop SMS services. During this process, feedback from medical doctors, nurses and Rural Health Workers were collected so that best possible SMS services can be designed. Following the SMS services, the team worked on GIS Map module.



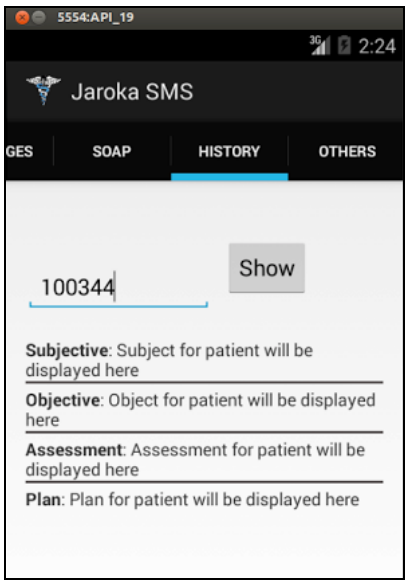
Patient registration SMS



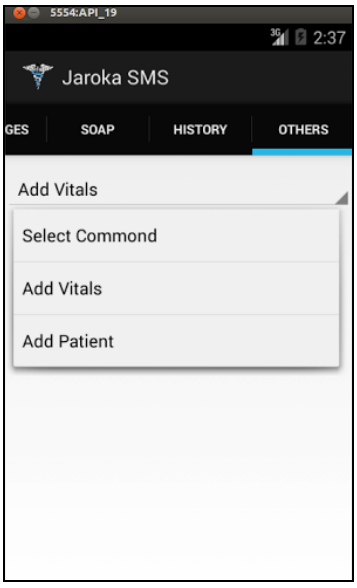
Help Command- SMS



SOAP Record SMS



SMS Smart phone application



SMS Smart Phone application for vitals

Third and Fourth Quarter

According to the work plan, third and fourth quarters were dedicated to the training of RHWs, data collection from the field, surveillance of the data and analysis of the data but due to the sensitive security condition in Mardan, KP, the activities were delayed. The government demanded authorized 'No Objective Certificate' from NGOs involved in data collection. This impeded the timely implementation of the project activities. Since our team could not collect data from the field without the proper permission from concerned authorities, we continued to collect data at UM Healthcare Trust hospital of registered patients. The patients with Hepatitis positive were referred to the city hospital and were also offered consultation from medical doctor. Also the medical doctors also took preventive care sessions with patients with any of family members being Hepatitis

positive. We also arranged interactive awareness sessions for the female and children patients on Hepatitis, its prevention and other vector borne diseases. It was the first time any awareness seminar was arranged for the female of the area.

Fig 4: Hepatitis Awareness Session (UM &Right To Play)

Fig 5: Play based Session on Hepatitis Prevention

Final Quarter- Extension Phase:

During the extension phase we collected data from patients through mobile devices. Our male RHWs went to field to collect data from male members of the communities where as our female RHWs collected data in Hujra, a central place where all females were gathered. Due to the sensitive security constraints and rigid cultural issues, we were extremely careful to avoid any unpleasant situation during data collection. Contact tracing was performed of all infected patients. Additionally, the index patient (the patients infected with Hepatitis)'s contacts were identified and notified for Hepatitis tests. Moreover, the data of all patients was plotted on GIS Map.

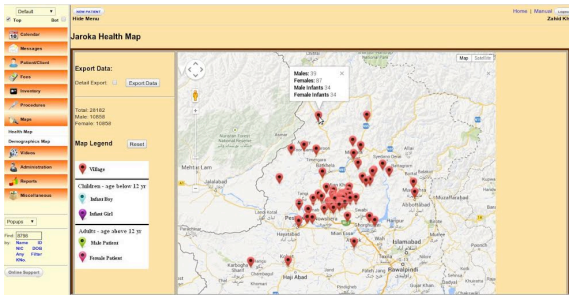


Fig 6: Patients plotted on GIS

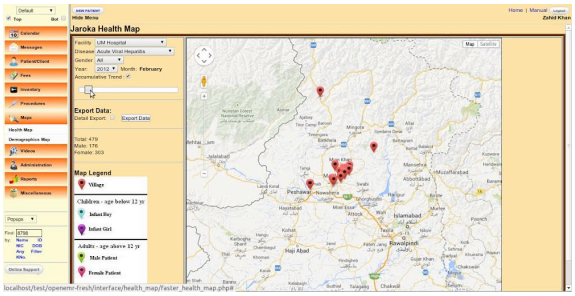


Fig 7: Patients plotted on GIS-category-wise

Please use the table below to report about project implementation…

Input	Project activities	Outputs	Outcomes	Timeline	Status	Assessment
Allocating Financial cost with human and material resources	Project planning and management	Project plan document organized and shared with Project PI, co-PI and Team Lead	Clear idea of resources and cost	First month	Complete	Project plan document has been developed and is followed to conduct future project activities

Price check and comparison for best suited equipment	Purchase of required equipment including laptops SMS Gateway and mobiles.	2 laptops purchased where as 1 SMS Gateway and 25 mobile phone order has been place and will be delivered this month.	Basic equipment for research and coding available	First and Second Month	Complete	Project site setup for the system development and software installation being done.
Advertisement for hiring of medical doctor at UM Trust Hospital	Recruitment of a male and female medical doctors	1 female and 1 male doctors hired to conduct the project activities at hospital	High influx of female patients due to the presence of female doctors. Our female doctor treated 35 patients, out of which 25 were hepatitis infected.	First and Second Month	Complete	Hiring of female medical doctor as well as female staff is a huge challenge in Mardan (a conservative area of Pakistan). After a rigorous selection of the doctors, more patients are visiting facility and asking for counseling for hepatitis. Our doctors are actively providing their input to our system.
Advertisement for hiring of research Assistance	Recruitment of research assistance	1 Research Assistant hired to conduct research of project related issues and tasks.	Comprehensive Research on the issues of hepatitis in Mardan.	First and Second Month	Complete	Since through research is being carried out by our research assistant, an evidence-based material will be formalized to be shared with our stakeholders when the project completes.
Advertisement for hiring of System Developer	Recruitment for Software Developer	1 Software Developer hired to develop the Hepatitis Surveillance System	Our developer will develop a complete Hepatitis Surveillance System by end of the project	First and Second Month	Complete	Our developer is working closely with the team in Mardan and Islamabad to develop a system that caters the needs of the users.
Purchase equipment and free open	Commissioning and installing of all	A project working site at hospital with all the equipment connected	System development will take place	Second and Third Month	Complete	It was a challenge to install and

source software	equipment to make site operational	and working	utilizing the set infrastructure at project site			commission all the equipment in rural areas but we achieved it in short time as we already have a good communication infrastructure in place at UM Trust hospital.
Project proposal	Conduct detailed research and finalize project milestones	Detailed document containing research goals and project milestones	Whole team actively provided their input for the project document. All the SMS services finalized by team are extremely important to make project successful.	Third month	Complete	Input from team members belonging to various backgrounds including medical, ICT and administration helped to efficiently design SMS services. The research is an on-going part and will be conducted throughout the project.
SMS services that are in demand with regard to communicable diseases and patient data to be mapped on GIS	Develop SMS services and GIS Map	SMS module and GIS Map's user requirements documented	5 SMS services simple format and GIS map user requirements are documented after discussion with team members and keeping in view the prospects of future projects	Third and Fourth month	Complete	Both SMS formats and GIS map's requirements consider on ground realities and will be implemented on real data for the first time in Mardan rural areas. The GIS map will make the data visualization of all patients with hepatitis and other diseases very convenient.
5 SMS services Format and GIS map Version 1	Testing the first version of solution	Observation/Feedback document of the services and Map	Identifying the ambiguities and revamping the SMS services and GIS Map to make the system	Fifth Month	Complete	The testing and assessment of the system is being done in teams. This module is taking more time as our next steps are

			efficient.			completely based on these modules.
Identification of RHWs and volunteers for data collection from field through mobiles	Held focus group discussions, meetings and training on using mobile services for Hepatitis surveillance data collection from field	RHWs trained on using Jaroka mobile services	Enhanced knowledge of entering and accessing patient data through mobile devices. Also empowered with knowledge on Hepatitis and its preventive care	Six onwards till March 2014 (due to the factor beyond our control but they were collecting data of patients visiting UM Trust)	Complete	The training of RHWs on mobile services is complete and now they are ready to visit the target villages/fields to collect data
Meeting with stakeholders and decision makers	Held meetings with key stakeholders and decision makers from target villages so that data collection process can be carried out smoothly	Key stakeholder extending their cooperation for data collection at target villages through mobile phones	Key stakeholders oriented on the project and the impact of services for target population	March 2014	Complete	All meetings and discussions with stakeholders and concerned authorities are complete. Our team has their permission to access villages for data collection
RHWs and volunteers sent to field for data collection	Target villages and schedule are allocated to RHWs. All RHWs are given restricted access to the Jaroka Tele-Healthcare System so that they can registered or update the patient record for hepatitis	RHWs collecting data from target villages.	Real time data from the field that will play a curtail role in real time surveillance of hepatitis.	August 2014	Complete	RHWs collected data of the patients from field and from hospital. Female RHWs due to the security concern could not go to the field for data collection hence the data was collected in Hujra (a room where all women gather)
Data Analysis and Reports	Develop and document the results and report of the collected data	A report/document	Real time field results on Hepatitis and its prevention	Fourth Quarter (Extention)	Complete	The data was collected from various villages from people from all walks of life through mobile and was plotted on GIS Map. The contact tracing was also

						conducted by randomly contacting the contacts of index patients.

Project outputs, communication and dissemination activities

Project outputs	Status	Assessment	Dissemination efforts
Human Resource to develop and implement project : Recruitment and hiring of 2 medical doctors , 1 research analyst and 1 software developer	Completed	After recruitment process, 8 medical doctors were shortlisted where telephonic interviews were conducted for final selection. Likewise the hiring of Research assistant and software developer took place on telephones. Finding a female doctor was a great challenge which has been resolved.	The profile of hired HR is shared with UM Trust Staff.
Hardware for project execution site: purchasing of Laptops and SMS GW	Completed	Laptops have been purchased and installed so that software developer could perform software coding and bring necessary changes into the system adhered by project leader	The information on equipment is shared with staff and the site is operational
User Requirements: Input/Feedback from users and stakeholders to develop SMS and Mapping modules	Completed	Stakeholders and direct users of the system including members form local community provided their input for the project modules. These sessions were very productive as it helped cater the exact need and requirements of users for the system.	Documentation of user requirements shared with software development team.
Software: GIS version 1 prototype.	Completed	The first prototype of GIS (both Health Map & Demographic maps) has been tested, integrated with updated records and made live on server. It is currently plotting the electronically registered patients in EMR system suffering from hepatitis as well as other diseases on the GIS map. This demographic information as well as the location of the patient is also available through map.	A systematic collection and analysis of data and the provision of information, which leads to action being taken to prevent and control a disease. For sustainability, the collected statistics will be provided to Health ministry in form of tables and maps, so that necessary actions to prevent the disease can be taken.
Information sharing and dissemination: Strong Industry-academia partnership and building healthy relationships with NRDP (National Rural	Completed	Demonstration of the project was conducted for NRDP and we have successfully signed the contract with them to replicate the project at Narowal, Pakistan through Software As A Service (SAAS) model. This is one of the major accomplishments towards the sustainability of the project. Moreover, we are in process of signing a contract with CDRS in	This data collected through the system is and will be shared with stakeholders so that extended research, preventive care and health policies can be carried out. Also Seminars would be held for awareness campaigns

Development Program) and CDRS (Comprehensive Disaster Response Services)		order to have our system being used in their organization. We have submitted the research paper, "**Hepatitis Surveillance System for rural Pakistan through web and mobile based technologies",** to High Capacity Optical Network and Enabling Technologies (HONET), 2014, Charlotte, USA. Furthermore, our chapter, " Epidemic Tracking and Disease Monitoring in rural areas of Pakistan", is selected for publication at CRC Press/Taylor and Francis Group, LLC. We also presented this project on renowned national/international platforms including National University of Science of Technology (NUST) and Interactive Research Development to present our work.	
SMS Commands: SMS commands to enter and retrieve patient electronic medical record as well as complete information on diseases including Hepatitis has been implemented	Completed	All **SMS services** including the followings can be accessed via mobile phone by RHWs and volunteers during the field visits: **1) Registering new patient** **2) Accessing the Patient ID of already registered patient/search patient** **3) Adding complete SOAP record of the patients (this also includes the disease)** **4) Retrieving complete Assessment and Plan of the patient** **5) Adding disease against a patient (e.g Hepatitis)** **6) Accessing medical dictionary for definition of the disease** **7) Accessing the symptoms of disease** **8) Help- retrieving formats of all commands**	All the SMS commands are easy to use with less typing strokes and are user-friendly. They directly connect to Jaroka Tele-Healthcare system and are available on the field to authorized RHWs and volunteers. For future, these services will play a vital role during humanitarian crisis where most of the healthcare related work in done in the fields.
Key stakeholders involved: Due to the security concerns in Mardan, It was imperative to orient and win confidence of concerned authorities and key stakeholders.	Completed	Regular meetings and discussions were held with concerned authorities and opinion makers of the area to allow us to smoothly collect data from the field.	Key stakeholders and authorities ready to cooperate with us.
GIS Mapping: The Live		All the patients based on location and gender are plotted on map. Through their information **contact tracing** was carried out.	For sustainability purpose the data will be provided to relevant organization through

mapping of all patients infected with Hepatitis are plotted on the graph.	Complete		SAAS.

Project outcomes

Following are the major outcomes of the project:

1) An innovative real-time Hepatitis reporting and surveillance system that unleashes ICT and mobile technologies to monitor, track and perform contact tracing of index patients. Our system is a systematic collection and analysis of data and the provision of information, which leads to action being taken to prevent and control a disease.

2) A novel system that can easily be replicated for all kinds of communicable diseases.

3) Increased access to healthcare and Hepatitis-related information (particularly for hard-to-reach populations).

4) Capacity building of Health Workers on using mobile technologies (SMS) for data gathering from field. This skill of theirs can be beneficial in during natural disasters in country. Furthermore, they can access latest information on diseases and medical terminologies with SMS commands.

5) Adding value to the prevalent mobile technology. Our system can run on any mobile and network in Pakis

6) Establish strong Industry partnership. We have signed contract with NRDP and currently replicating the project in Narowal whereas we are in process of finalizing the contract with CDRS. We have also partnered with Right To Play, an international NGO, to conducted awareness session on prevention of Hepatitis.

7) Scientific publications in top level international conference and journals. During the project cycle we have published 1 research paper at HONET 2014 and 1 chapter in renowned CRC Press.

8) Attaining National and International Millennium Development Goals (MDG).

9) Sharing of information on various national and international platforms.

Project management and sustainability

In order to efficiently implement our project and to have the maximum impact of our work, we focused to satisfy the basic level needs first. To us the basic level needs include effective leadership, collaborative teamwork, motivation, strong communication, and negotiation. We strongly believe that it is the people on our project team that are the most valuable asset. Since we are working with the people from diverse backgrounds including medical, Information Technology, software development and general administration we make sure that our leaders are skilled enough to handle diversity. Our leaders always make sure to work smarter rather than working hard to get efficient output of the system.

In order to maximize the potential of the human resources of our project, we arrange regular capacity building sessions of the staff both at Mardan and Islamabad office. These sessions are mostly need based sessions for example, Tutorial of Jaroka Electronic Medical Record System, Open source technologies, inventory management etc. We strongly encourage and support our team to also attend free certified online courses for their further professional development. We hold regular meeting and mentoring sessions of all staff members at least twice a week with project manager. All the members have clearly defined work plan and tasks place at our central system “Redmine”. Their progress is monitored daily through this tool. We are making best efforts to include all stakeholders including local community members at Mardan, of our product in development cycle of our system. This strategy is important to inculcate the sense of project ownership among people and at the same time it is helping us to make smarter decisions.

For the recruitment of Research Assistant, Doctors, Rural Health Workers, Software Developer, we followed a defined selection criteria made by selection committee. The selection committee includes Project Managers, Advisors and Project Coordinator. All the candidates are selected purely on merit. To disseminate the

information about hiring we give ads on job portals, our website, social media platforms and relevant groups. The selection committee ensures that the candidates have recognized degree in their respective fields and fulfills all eligible requirements. Each candidate goes through two major interview steps including telephonic interview by HR and interview by selection committee.

We have successfully developed SMS services for the project. These services are designed in close coordination with RHWs, medical doctors and nurse so that their needs are handled efficiently. Since they are involved in the project process, they feel sense of ownership of these services. RHWs especially women are very excited to practice these services during their field visit. Since our disease dictionary module let RHWs and doctors learn about the latest diseases, symptoms and preventive measured, they now feel more empowered and connected with latest medical knowledge.

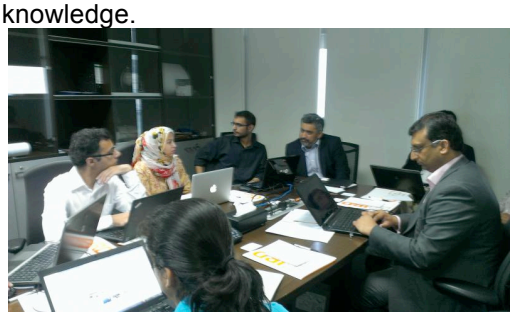


Fig 8: Jaroka Tele-healthcare being presented in Dubai

We believe that our project is sustainable and hold promising market potential, as it will easily replicable and scalable for all communicable diseases all around the world without incurring high cost or requiring new infrastructure. The SMS and GIS mapping services that we are developing can run on any network and mobiles and can be deployed with in no time. It is this real-time collection of critical information from a distributed network of people that partners are already contacting us to implement pilot project at their site. We have already been contacted by NRSP and CDRS to replicate our Jaroka project to their site. We have already signed contract for SOAS SMS and GIS service with NRSP team and soon to sign one contract with CDRS (Paper work going on) . **We consider it an incredible achievement in regard to sustainability**. With ISIF support, we were able to develop a system whose services can be extended to other healthcare stakeholders/potential partners to not just cater hepatitis but all communicable diseases globally. This is a huge impact in the domain of e-health and m-health. Furthermore, with real-time data available, students will be able to conduct more research in rural healthcare, an areas very much neglected in Pakistan.

In addition to the above, UM Trust also had opportunity to present and showcase the project to the Acting Ambassador of European Union, Director General UNESCO Ms. Irina Bokova, Corporate Advisory Council – Social Sector Committee, Chief Minister Punjab at different occasions. Aside from these opportunities, the project especially for its unique SMS services was also nominated to present itself in a provincial event “Punjab Youth Festival's Software and Technology Exhibition”. This event witnessed more than 40 universities and several IT companies. Our project was demonstrated and explained to hundreds of visitors including provincial government ministers and direct adviser to the Prime Minister. Our team network with officials and corporates of top IT companies and academia to find common grounds for mutual projects in healthcare domain.

Fig 9: Project Director, Atif Mumtaz, presenting project at ICT4D Workshop

Challenges and Lesson Learned

The project faced many challenges due to the factors beyond our control which caused delay in implementation of few project activities. In order to handle these challenges, our team worked hard and devised the most suited strategies to efficiently handle the situation:

- **Volatile Security Situation:** Due to the series of terrorists attack in Mardan and its neighbouring districts, it was not possible to collect any kind of data without keeping in confidence concerned authorities and key stakeholders of the areas. Also the image of NGOs or foreign funded project is distorted in conservative areas of Pakistan. Furthermore, due to the target killing of Polio Health Workers, it was nearly impossible for the volunteers or RHWs to roam around the rural area to collect data on Hepatitis. Since patient's registration requires CNIC number (unique social security number) and other personal information it was mandatory to orient local people and opinion maker prior to identity and train volunteers and RHWs on our services. In this regard, we held meetings with stakeholders and involved them in identifying and shortlisting target villages which can be reachable with relatively less difficulty and are safe for local volunteers to travel. More importantly, we choose local people as volunteers as they are the best source of information about the village demographics and also because people are comfortable in sharing their health related data with them.

  While struggling with getting permission from local authorities to execute our project in target villages, we collected data of hepatitis patient visiting UM Healthcare Trust. In this process our para-medical staff played a vital role and also provided consultancies to the patient on preventing hepatitis.

- **Retention of Medical Doctor:** We faced extreme difficulty in retaining the medical staff especially female doctor. Due to lack of basic resources as compared to urban areas, doctors are rarely willing to work in rural areas. Not only that, a major factor of their turn over is salary. They expect and demand what is far beyond our budget for a doctor. That is why we have seen 2 doctors leaving us during this year. Furthermore, we hired a female doctor during this project who hardly served for 3 months. Since the larger chunk of total patients coming to our hospital are women, it is very important to have a female doctor on board so the patients can communicate with the doctors with the least of hesitation.

  In order to handle this challenge, we hired more female para-medical staff members. They were trained on hepatitis and other communicable disease's preventive care and offer consultation to the female patients.

Impact

Our users are now skilled to use the cell phones, tracking and tracing of hepatitis by reaching to the root cause (source) which is playing a vital role in lowering the spread of hepatitis in rural communities, which is the main

vision of this project. With the help of this project, UM Healthcare trust is able to provide better health facilities to the rural communities by informing them about hepatitis and creating awareness in them to take preventive measures for a better life and improved health. It is very difficult to have accurate and- up to date data about patients in Pakistan because systems in Pakistan are not properly maintained for they still use papers for recording patient's history. However UM Healthcare Trust system is very well managed and operated. With the help of UM-Tele healthcare system, patient history and all their previous and latest records are available anytime, anywhere provided a cell phone or laptop or internet is available. For that reason surveillance and contact tracking of hepatitis infected patients is efficiently conducted and positively impacted lives of so many people in different ways.

1. Proper preventive measures taken after the root cause of the disease i.e. hepatitis at present, is known, then it would result in healthy kids.

2. Health is directly proportional with environment. Once people are healthy, environment is healthy and vice versa.

3. UM Healthcare trust adds value and positive impact to this project by making use of 'existing infrastructure and technology". Our project is not expensive but innovative as we always tend to use facilities and provide facilities that are affordable for UM Healthcare trust users and are understood by them for implementing in their lives e.g. for tracking diseases we have come up with the most innovative and cheap services of using cell phones for disease surveillance and contact tracking purposes

4. We plan to share our data with health policy makers, Students, Rural health workers etc. to better understand the disease and have knowledge themselves in order to better implement our project and reach out to as many people as possible to stop the spread of this deadly disease.

5. The project is also adding value to the mobile devices. RHWs and volunteers who only knew mobile for games, call and SMS will now use this device for their empowerment on latest medical knowledge and effective medical treatment. This is a whole new perspective for them.

Fig 10: Senior patient waiting for her turn for Hepatitis consultancy

Overall Assessment

In rural Pakistan, Hepatitis also known as 'silent killer' is spreading at alarming rate claiming lives of millions of people every year yet it is difficult for health authorities to evaluate its burden and impact. Expect from few hospital in urban areas hospitals rarely have any electronic registration system. The situation becomes more intricate in case of floods and IDPs crisis as the viral Hepatitis exponentially increase and due to the absence of electronic surveillance mechanism it is not possible to track origin of this dangerous disease. Moreover, in Pakistan the key stakeholders and donors usually divert their funds and resources towards high priority polio

eradication and malaria surveillance programs leaving insufficient grant money for developing innovative solution to preventing Hepatitis especially for rural areas.

In unprivileged areas there is low level knowledge on Hepatitis prevention, shortage of competent medical staff, lack of healthcare infrastructures, unhygienic environment and extreme poverty. Majority of population hardly knows any differentiate between different types of Hepatitis and their causes. There exist many myths and misconceptions on its modes of transmission, symptoms and treatment which may be one of the major factors in high rate of Hepatitis infected patient in rural communities. At some places people prefer visiting shrines/religious places for disease treatment due to non-functional health facilities. Moreover, The RHWs in remote communities work in complete isolation and rarely get opportunity to connect with medical professionals in cities or abroad. Furthermore, due to the geographical barriers they lack access to regularly update their medical knowledge. There must exist a mechanism to cater their problem.

For this project we have achieved the following results following the data collection process:

Data Collection:

For this project, we collected data on Hepatitis from fourteen villages including ***Amjad Abad, Bari Kab, Ghazi Abad, Jalal Abad, Jamdher, Jehanzeb Khan Banda, Katta Khat, Miyagano Dheri, Pokai, Sadiq Abad, Saidan Dheri, Toora Banda and Kotarpan,*** located in close proximity of UM Healthcare Trust, Mardan, Khyber Pakhtunkhwa . The study aimed to collect and track information of Hepatitis patients as well as orient infected and exposed individuals on necessary Hepatitis preventive care. The contact tracing technique was performing for all index/infected cases by RHWs through SMS and phone calls. The exposed contacts were further advised to take the Hepatitis test. Our RHWs personally followed up index cases to confirm that contacts have been notified.

Data was collected from all consenting personals without any discrimination of age, gender, sex and social status. Data was collected through medium of web via Electronic Medical Records (EMR) from patient visiting UM Healthcare Trust as well as through mobiles using SMS service from individuals in field.

Results:

A total of 541 persons (from field) including 42% Female patients were attended from 14 villages mentioned in above paragraph. All of these patients live below the line of poverty earning less than $1 a day. A total of 131 (28% of total) people are infected with Hepatitis while 410 individuals have never been tested for any kind of Hepatitis in their whole life. These individual were not sure if they or any of their family members are infected with Hepatitis. Majority of this population was unaware of the types of Hepatitis as well as its essential preventive care. The only know Hepatitis is C.

The maximum age of an infected patient was 80 years where as the average age of patients was 41 years. There were also 4 Hepatitis positive cases of children (50% female) below the age of 10 years. Fine chances are that they may be Hepatitis carrier since birth. The largest number of infected cases were reported belongs at Bari Kab whereas not a single case was reported at Miyagano Dheri as shown in Fig 7. Female accounted for only 37.40% of total infected patients.

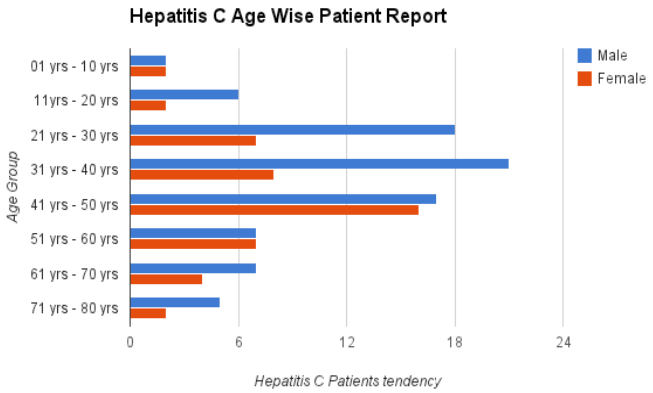


Figure 11: Hepatitis C Patients Age-wise Report

All the index patients were provided oriented on informing and motivating their contacts for Hepatitis screening. This was important for contact tracing. Regular SMS focused on awareness and sensitizations are regularly sent to index cases and their contacts. In few cases RHWs referred Hepatitis cases to UM Healthcare and city hospital.

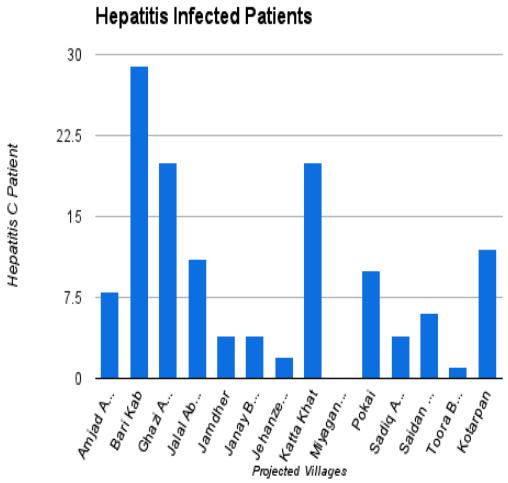


Figure 12: Hepatitis C infected Patients-Village-wise

As discussed earlier, our proposed Hepatitis Surveillance model is an innovative approach to report and track the cases from hospital as well as from field. RHWs using simple SMS/MMS mobile technology can enter patient data and also update her knowledge through any service provider from anywhere in Pakistan. Our model not only identifies and orients patients on Hepatitis and its prevention but also following contact tracing approach tracks Hepatitis back its original source. Our system has great advantages in promoting the early detection of Hepatitis and reducing the necessities of disease confirmation. Since it is built on existing infrastructure and will be offered as a services through Software As A Service (SAAS) approach hence it promises cost effective solution in resource poor settings.

Our solutions will go a long way in building local knowledge and research in Pakistan. We plan to offer our research, data and solution available to government and non-profit sectors so that better monitoring and tracking of communicable diseases including Hepatitis can be conducted in Pakistan. Our novel but easy to use SMS commands can work on any network in Pakistan and on any phone at 24/7. Unlike many other tele-healthcare projects, our SMS services do not require smart phone or any kind of installation. This incredible feature of our

system qualify our services to run anywhere in the world at any event including humanitarian crisis even when internet is unavailable. Since our SMS commands are designed in close coordination with medical staff and other relevant users, it is very user-friendly with less key strokes. During the project implementation, we learned that RHWs do not like long strings of messages. Keeping this in view we have designed simple and easy to remember SMS commands such as new (to add new patient), add (to add patient record), help (to retrieve commands format) etc. These services have added a greater value to the mobile devices and also are playing an important role in strengthening the knowledge of RHWs on healthcare.

We have strictly involved all our stakeholders (medial professionals, community members, Rural Health Workers and our potential partners), who are most likely users of our system in detailed discussion and feedback sessions on SMS services and health map system. This was to make sure that we are designing a need based SMS services and GIS system and which is according to the requirements of users. One of our major lessons was that medical professionals and researchers are very keen to see an online automated monthly disease trends along with other information. Community also suggested us to train and involve female school teachers in order to reach and sensitize maximum children and females in the area about Hepatitis and preventive care. This is very important during our data collection from field.

Our two partners NRSP and CDRS have approach us and are very interested in implement our system for the communicable diseases and preventive care as the result of recent flood 2013 in Pakistan. We have demonstrated the system to NRSP and have sign a contract to implement our system at Narowal. We consider it as an achievement as through these partnerships not only our system will replicate and scale but we will able to test our system in different areas of Pakistan. Furthermore, our staff is feeling extremely motivated and accomplished by this opportunity. Once this project is implemented in different areas, the data and results collected will lay strong foundation of research on hepatitis in rural Pakistan. Furthermore, it will contribute in bringing awareness about hepatitis and other communicable diseases and how to take preventive measures to eliminate or reduce its spread.

We have also submitted the research paper for High Capacity Optical Network and Enabling Technologies (HONET) to be held in Charlotte, USA. Also our chapter on epidemic tracking in monitoring is accepted to be published in CRC Press/Taylor & Francis Group, LLC.

One of the interesting findings of our project is the use of internet by local community. At our facility, with the support from Cybernet, we have made one of our internet connection password free so that community and Rural Health Workers can also use internet on their mobile phones for free even in the field. It is amazing to see that community members especially children are using it for information sharing, educational and business purposes.

Recommendations

We have the following recommendations:

Recommendation for ISIF Asia:

It would be great if we are able to present the project is any of APNIC or ISIF event.

We would really appreciate more networking opportunities.

Recommendations for practitioners:

- In case of SMS services, we have learned that the shorter the requirement of typing, the comfortable health workers is in using the commands/services.
- We highly recommend the involvement of different stakeholders while designing the SMS applications.
- In order to share the project and team progress, we recommend other team members to use an open source project management tool, “Redmine”.
- Data visualization on GIS Map is one of the best ways to not only visualize but to filter large amount of data.

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Please write the project bibliography here…

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