M-Governance:
A Mobile Computing Framework for Integrated Disease Surveillance in India

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Abstract: *A critical aspect of preventing an outbreak of a communicable or non-communicable disease is the early detection and investigation of such disease. With most outbreaks starting in small clusters, if a cluster is detected and investigated early, its spread could be prevented. The Government of India launched the National Programme for Surveillance of Communicable Diseases (NPSC) in 1995 with the goal of creating a sustainable and efficient disease surveillance system that could detect and respond in a timely manner. While disease control programmes have existed for diseases such as Malaria, Tuberculosis, Leprosy, Lymphatic filariasis and HIV/AIDS, locally prevalent infectious diseases were not part of any system till this programme started. It is well accepted that a decentralized disease surveillance system, with strong emphasis on local action for disease control, is the most effective bulwark against the spread of outbreaks. Mobile computing and other information and communication technologies have a significant role to play in the deployment of early detection and medical intervention systems.*

Keywords: M-Government framework, disease surveillance, tuberculosis control programme, public health-care, mobile computing, ontology, citizen identity.

1. Introduction

A generally accepted definition of surveillance in public health practice, promoted by the Centres for Disease Control (CDC, Atlanta, US), is given as follows (Thacker & Birkhead, 2002):

> "Public health surveillance (sometimes called epidemiological surveillance) is the ongoing systematic collection, analysis, and interpretation of outcome-specific data essential to the planning, implementation and evaluation of public health practice, closely integrated with the timely dissemination of this data to those who need to know. Outcomes may include disease, injury, and disability, as well as risk factors, vector exposures, environmental hazards, or other exposures. The final link of the surveillance chain is the application of these data to prevent and control human disease and injury."

Disease Surveillance is a basic tool for the field epidemiologist and surveillance data provide a scientific basis for an appropriate health-care policy, disease control decisions, and evaluation of efforts, and allocation of resources in primary health-care.

In this paper, the authors have proposed a mobile computing framework for disease surveillance that integrates the best practices from the medical fraternity with the potential of embedded, mobile information and communication technologies to create an architecture that is scalable and replicable.

2. Background Material

Disease surveillance is an important aspect of any public health-care programme that serves two essential purposes, one of which is monitoring the progress of ongoing medical interventions for disease reduction, and the other is for the early detection of outbreaks to initiate investigative and control measures (John, 2002).

Health-care professionals at the Christian Medical College (CMC), Vellore, India first initiated disease surveillance through a card-based questionnaire in a community outreach programme in the neighbouring districts. Subsequently, the National Institute of Communicable Diseases (NICD), New Delhi established a pilot model of disease surveillance in several other districts of the country in 1996 based on the Vellore model and tried to replicate it at the national level. CMC recognized a major flaw in the NICD model due to the non-participation of the private sector in primary health-care. The Vellore model had already addressed this through the inclusion of the private sector health-care initiative as a critical element in the disease surveillance chain. This has been successfully replicated in Kerala, the southern-most state of India, and is a classic example of a well-run, and scaleable disease surveillance system (John, 2002).

The system defines the procedures for clinicians to examine patients and report the diseases that are required to be reported to the District Health Officer through a set of pre-formatted cards. Clinicians fill up cards for a range of pre-identified diseases that include vaccine-preventable diseases such as polio, diphtheria, measles, tetanus and whooping cough and outbreak-prone diseases such as cholera, encephalitis, hepatitis, malaria, meningitis and typhoid etc. The system is also periodically revised to include other reportable diseases that might be locally prevalent. The system has proven to be quite effective in detection and control of outbreaks within the geographical region covered by this system and has found to be sustainable (Heymann, 2004).

While manual disease surveillance systems and procedures have been effective in localized pilot studies, a coordinated national effort is required which recognizes the advantages of decentralized networks for locally specific disease detection and intervention control activities, along with the advantages of a centrally controlled network of medical experts, and medical and research laboratories. The objectives of any effective integrated disease surveillance system are (Thomas, 2002):

- The establishment of a decentralized system for timely and effective medical interventions in response to health challenges at different administrative levels in the country
- The establishment of standardized mechanisms for information sharing across other disease control programmes and stake holders, and avoidance of duplication
- The introduction of decentralized decision making
- The integration of private and public health-care agencies and other health-care stake holders for effective surveillance activity
- The use of Information and Communication Technologies (ICT) for data management, feedback and information dissemination to improve response times for medical interventions

Field epidemiological data would be used for:

- Case detection
- Outbreak detection
- Trend monitoring
- Priority setting
- Response targeting
- Analysis and presentation of surveillance data

3. A framework for an Integrated Disease Surveillance System

This section presents a conceptual framework that logically replicates the manual models of disease surveillance by mapping the manual processes onto mobile devices. A communication-oriented mobile device to provide early access to surveillance data, replaces card-based manual reporting procedures. Validation of data occurs at the source of input, which is critical to the success of a disease surveillance system. Invalid or incorrect data can potentially result in faulty analysis and the consequent failure in detection of disease.

The logical administrative unit for disease control is the district headed by a District Health Officer (DHO) assisted by primary health-care workers to be equipped with mobile devices capable of land-line or wireless connectivity. In this way, the Integrated Disease Surveillance System has minimal impact on current, manual processes and does not appear to be disruptive of current workflows.

The components of the framework for the Integrated Disease Surveillance System are:

- Data Capture Module
  - Patient Registration Module based on Ontology for Person Identity
  - Smart-card based Identity and Demographics information
  - Surveillance Data Collection
- Disease Information Exchange
  - Based on Ontology for the Disease Vocabulary
- Surveillance Module
  - Detection and Analysis of Events
  - Pathogen Identification
  - Prediction & Monitoring
- Security and Authentication Module
  - Data Encryption for information security, confidentiality and privacy
  - Smart-card based authentication procedures for access to confidential information
- Communication and Messaging Module
  - GPRS or CDMA based data communication with backend services
- Alarms and Responses
- Training, Information Dissemination and On-line Help

Some of the modules are backend processes that would be running on the server. The mobile device is used for Data Capture, Validation, Security & Authentication, Communications and Messaging. The backend services consist of Detection, Prediction, Analysis, Modelling and generation of Alarms and Responses.

3.1 The Role of Ontologies in Disease Surveillance

An important aspect of the disease surveillance framework is the capture of existing knowledge about processes and work-flows and its mapping into an abstraction that can be translated into a set of services, and the sharing of this knowledge across other disease surveillance programmes and stake holders. Formal representation of knowledge is based on conceptualisation that is an abstract, simplified view of the objects, entities and relationships that define a particular domain of knowledge. Ontology is an explicit specification of this conceptualisation. It formally defines a common set of terms that are used to describe and represent a domain (Gruber, 1993).

Some of the common reasons for developing Ontologies are (Noy & McGuiness, 2002):

- To share common understanding of the structure of information among people or software agents
- To enable reuse of domain knowledge
- To make domain assumptions explicit
- To separate domain knowledge from the operational knowledge
- To analyze domain knowledge

An integrated, mobile disease surveillance system must provide automated sharing of information across various application software agents to improve the cross-functional service delivery mechanism and reduce response times for service delivery. An Ontology for Citizen Identity would be useful across the entire range of potential health-care applications requiring demographic data and personal identity. This ontology will cover the classification of citizens based on various sub-classes such as personal identity describing demographic information about each participant citizen, family structure and relationships, individual health-care records, and employment status for access to health-care services and entitlements. Another ontology for diseases will form the basic vocabulary of diseases under surveillance and enable the sharing of information in this domain.

3.2 Classification of Diseases for Disease Surveillance

A disease surveillance system should also be capable of handling a range of diseases that may be broadly classified as shown below, along with a few typical examples (John, Samuel, Balraj & John, 1998):

- Vaccine preventable diseases
    - Poliomyelitis
    - Diphtheria
    - Measles
    - Whooping Cough
    - Tetanus
- Out-break prone diseases
    - Cholera and cholera-like diseases
    - Encephalitis
    - Leptospirosis (Fever with bleeding)
    - Acute viral hepatitis
    - Malaria
    - Meningitis
    - Typhoid
    - Dengue and dengue-haemorrhagic fever
    - Acute dysentery (amoebic or bacillary)
    - Varicella
    - Mumps
- Control programme based diseases
    - Tuberculosis
    - Malaria
    - Lymphatic filariasis
    - Leprosy
    - HIV / AIDS
- Other diseases
    - Reproductive tract diseases
    - Acute respiratory infection

Some of the above diseases have been successfully kept under surveillance, using manual methods (John, Rajappan & Arjunan, 2004).

While Ontologies have traditionally been used in AI and expert systems for the representation of knowledge, these can also be applied to a diverse range of applications that require sharing of information. In the context of an integrated disease surveillance system, we propose to develop ontologies for diseases based on the above-mentioned classifications because current manual systems cover these diseases. This approach will enable easy sharing of information across other programmes and health-care professionals.

3.3 Case Definitions

The development of an effective disease surveillance system requires case definitions that balance the competing needs for sensitivity, specificity and feasibility (Buehler, 1998).

Case definitions define a minimal set of signs and symptoms, and additional laboratory investigations that may be required to make a tentative diagnosis of a disease entity for surveillance purposes. WHO publishes standardized case definition guidelines, whereas different countries adapt these standardized case definition guidelines to suit their own localized requirements. Standardized case definitions for multiple diseases under surveillance would also be available on the mobile device through an interactive online help tool.

3.4 A Prototype for Disease Surveillance

While all of the above-mentioned diseases need to be kept under surveillance in any comprehensive and integrated disease surveillance system, India already has well-developed, internationally recognized system in place for the surveillance and control of Tuberculosis.

India's Revised National Tuberculosis Control Programme [RNTCP] is responsible for the technical and operational norms and procedures, planning, establishing a network for sputum microscopy, monitoring, evaluation, supervision, training of personnel, and quality assurance for all TB initiatives in India. In addition, it has established a hierarchical structure of institutions responsible for collection of data for surveillance and analysis of the implementation programmes. An essential element of the programme is Directly Observed Therapy with Short-course Chemotherapy (DOTS) in which a trained peripheral health-care worker watches and supervises the administration of medicines by the patients to ensure that the full course of medicines is taken by the patients on a prescribed schedule (RNTCP, 2001).

The RNTCP-mandated operational guidelines document gives specific formats for collection of TB surveillance data and reporting across the chain of control in the programme hierarchy. Our framework incorporates the process work-flows, data collection and reporting formats and implements it in a mobile device for more accurate and real-time data collection and reporting.

3.5 The Role of Mobile Devices

Mobile devices use screen-based questions and provide guidance to health-care workers to enter data accurately. This screen-based format enables the health-care community to encapsulate medical expertise into the program so that trained primary health-care workers could be deployed for data collection. This can significantly improve the productivity of the primary health-care worker and provide more accurate information to the medical experts, resulting in the reduction of "transaction costs", so critical to the scalability of surveillance systems in a large country.

To facilitate the deployment of mobile disease surveillance services, indigenously developed mobile devices and application software on public domain, open-source Linux platforms have been proposed.

The “Simputer”, a low-cost, mobile device with a small LCD display, and the “Sarva”, a wireless tablet that uses a larger form-factor LCD display are candidate mobile devices. Both devices have a built-in smart card reader, Text-to-Speech capability, multiple connectivity options, and a significant amount of non-volatile storage for handling and storage of large volumes of medical data when connectivity to backend servers may not be available. Built-in rechargeable batteries enable usage in the field for several hours at a time. An external solar charger could be added for extended field use, specifically where reliable power may not be generally available.

Telephony and wireless communication enable the mobile devices to communicate with a server for data updates from the field. Low-cost, memory-based “Smart cards” are proposed for the maintenance of individual demographic and medical records. It is expected that a smart card would be issued to each individual in the target area served by each primary health-care center. The smart card would facilitate the access of specific medical and related data stored on remotely accessible servers.
The wireless tablet has a built-in GPRS modem that facilitates the device to access backend servers from a remote location over the established GSM network and upload data in real-time. The platform provides a Java Virtual machine and Java runtime environment to enable us to develop applications that are essentially platform-independent so that they can be migrated to newer mobile devices as the appropriate technology becomes available.

A mobile, primary health-care worker would typically download from a server the relevant data for all persons to be targeted in her proposed visit, prior to the trip, into the mobile device or in a USB-based storage medium which could be easily carried around on the trip. In the field, the health-care worker would plug the smart card of the individual into the mobile device and pull out the relevant medical record based on the demographic information stored in the smart card. She can then run the screen-based program to collect further data for the individual case. Once the health-care worker returns to the primary health-care center, she can to connect to the backend server and upload all information. This information would eventually be processed and analyzed by medical experts to detect patterns of emerging or imminent disease outbreaks and for recommending the procedures required to localize and control the disease within its cluster. Additionally, data from the results of laboratory tests at the primary health center would also be entered into the system to facilitate early diagnosis and detection of a disease.

The workflow for field data collection is based on established manual procedures to minimize the training of field staff and disruptions that could occur due to the incorporation of mobile technology in the process of disease surveillance. In fact, some of the tedium would be removed from the data collection process.

A specially useful capability of the mobile disease surveillance platform is its ability to perform multi-disease surveillance more effectively through a set of conditional, complex, nested questions, requiring a lower level of training of primary health-care workers in the data collection process. Some biological agents like the *vaccinia* virus in the Smallpox vaccine, can be fatal in HIV-positive patients (Thacker & Birkhead, 2002). Multi-disease surveillance would be necessary to detect such fatal interactions between different disease entities.

Questionnaires can also incorporate pictures and other information presentation aids to facilitate the primary health-care worker in her data collection process and to help minimize variations in the quality of data collected when multiple field workers are involved.

3.6 Location-based Service Delivery

For health-care agencies, whether governmental or non-governmental service providers, it is of paramount importance to be able to quickly visualize and analyze information on a map, in order to trigger rapid and efficient response efforts, based on the ability to determine what areas need to be targeted or evacuated in case of a medical emergency.

The Centers for Disease Control and Prevention (CDC) use a system called, the Lightweight Epidemiology Advanced Detection Emergency Response System (LEADERS) which incorporates a disease surveillance module with a spatial data tool for monitoring data, and an incident management module with a situational awareness tool which is used by emergency health-care personnel to deploy resources (Lantz, 2002). After the recent out-break of SARS in Hong Kong, the Government of Hong Kong has also created a Centre for Disease Control to provide regional support on control, prevention and management of disease outbreaks in future. CDC, Hong Kong is also developing a GIS based surveillance system (Cheung, 2003).

We also propose GIS maps for location and display of critical demographic and medical information to convey the complete picture in a local area. GIS maps are generally available for larger conglomerations such as towns and cities, rather than isolated villages and hamlets, and could be very useful in larger concentrations that are outbreak-prone. But GIS editing tools are now available on mobile devices to enable the creation and use of free-hand sketches or raster-scanned maps where detailed maps may not be available.

GPS-enabled mobile devices could tremendously improve the effectiveness of the integrated disease surveillance system. The proposed mobile device incorporates a GPS Receiver for recording location information and an open-source, public domain GIS package with a programming interface to facilitate the integration of location-based service delivery mechanisms in the disease surveillance system. By incorporating GPS in the device, it would also be possible to record the field visits of the primary health-care worker and improve accountability to some extent.

3.6 Confidentiality of Information

It is the ethical responsibility and requirement of an effective disease surveillance system to maintain and protect the confidentiality of personal identifying information. It is important to prevent willful and accidental misuse of such data for profiling and linkage of sensitive data to any specific individuals. Access to such information is provided through a set of authentication procedures based on a need-to-know basis.

A Smart-card based system is proposed for the implementation of security and authentication procedures. Different levels of access to information can be assigned, based on the security clearance of the health-care personnel operating the mobile devices for data collection and information dissemination. Additionally, individual patient health-care records can be maintained on smart-cards as costs come down.

4. Current Status

A pilot experiment is now being designed to prove the effectiveness and scalability of the integrated disease surveillance model based on mobile devices. A set of ontologies for Citizen Identity and the set of classified diseases are also being developed for forms-based entry and data collection on the mobile device. A smart-card based system of individual personalization is being designed to enable secure, authenticated access to privileged information, while protecting the personal identity of the individual. GPS-enabled GIS is being integrated into the disease surveillance system to enable the delivery of location-based services.

The framework for Integrated Disease Surveillance is currently being implemented with TB surveillance as the major goal since the resurgence of TB, in association with HIV/AIDS, is of particular relevance to India. The complete set of Report Formats of the RNTCP-mandated guidelines is being implemented on the Sarva wireless tablet device to leverage the effectiveness of the mobile technology in reducing transaction costs and response times. An elegant and generic forms-generation tool has also been developed to enable us to develop the various data collection forms quite rapidly.

5. Conclusions

The proposed architectural framework for an Integrated Disease Surveillance System using mobile computing technologies in the Indian context is replicable in other countries. This model recognizes the central role of field medical personnel in data collection for disease surveillance and does not introduce any disruption in that role or established workflow processes. The mobile device is merely a facilitator in improving the effectiveness of field health-care personnel.

The availability of such mobile technology-based integrated disease surveillance systems with consequent reduction in transaction costs due to reliable and validated field data collection, will make it possible to replicate such systems in other developing economies.

Mobile computing technologies have already proven successful for field data collection in a vast range of applications and will play an increasingly important role in delivery of health-care services to the doorstep of the citizen.

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