Community empowered disease monitoring for shared care, rapid diagnosis and outbreak detection in Pandemics : Extending Sahana framework as a social networking tool for disease surveillance

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Sahana framework architecture

Sahana Disaster Management System consists of 6 *core modules** and 11 *optional modules* to manage various aspects of disaster situations. Core modules function as framework features and necessary for the integration of other modules. Even though optional modules depend on core module functionality, these modules can function independently form each other facilitating selective deployment.

Main functions of various Sahana[4] modules can be summarized as follows.

- Situation Mapping(GIS)* - Mapping activities on a GIS map providing current situation awareness
- Missing Person Registry - Report and search and manage missing persons
- Disaster Victim Registry - Traces internally displaced people
- Organization Registry - Coordination of the relief organizations' activities
- Request/Aid Management - Tracks requests for aid and matches them against donors who have pledged aid
- Shelter Registry - Tracks the location, capacity and composition of shelters
- Web Services Sharing of information with other Sahana instances and third party systems
- Inventory Management Management of relief aid and inventories
- Messaging Module* - E mail and SMS based text messaging to groups
- Volunteer Management Manage coordination of volunteers
- Aid Catalog Management of catalogs and measurement units
- Reporting System* - Various reporting functions based on Sahana system
- Synchronization* - Data exchange between Sahana instances
- User Preferences* - Customization of Sahana deployments
- Administration* - Module, user and activity management options
- Financial Management Handling of financial resources
- Damage Assessment Information for handling damages sustained by a disaster incidents

Sahana has a language translation feature embedded in the system for the easy localization and it has the ability to change look and feel 'on the fly' when being accessed online by PDA (portable digital assistant) and other mobile devices.

Sahana can be deployed as a high end web server as well as a portable application runs on the USB mass storage devices (USB pen drives), independent of network access. It also installable in OLPC[5] as a robust disaster management tool.

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4. http://www.demo.sahana.lk
5. **OLPC** (One Laptop Per Child) : This FOSS project primarily focused on providing low cost laptop for the children of developing countries and known as the ***Hundred Dolor Laptop***. This laptop has mesh networking, embedded camera and low power consumption making it a suitable device to be used in disaster situations **(**http://www.laptop.org/en/laptop/start/**).**

Background and Rationale

Disease surveillance using computer systems with laboratory based epidemiological data[6] is not a totally new concept in the health care informatics. Recently it was found that *social networking*[7] through internet could be a source of information in disease spread monitoring. However it was much debatable that how reliable is the informations received through public information sources for this purpose. If there is a way to authenticate and verify the information source, social networking will also be an effective source of information on disease surveillance parallel to conventional information sources. Other advantage of this approach is that it will empower the community based approach of improving health status.

There are many advantages of an online disease surveillance systems[8].

- Wider and timely access to the system through internet
- Possibility of rapid analysis of information using intelligent computer applications as well as manual analysis
- Easy and customizable graph and report generation ability
- Easy role based sharing of information and responsibility in management of preventive aspects of the disease
- Automated diagnostic assistance to rural/less resourced centers
- Ability to provide therapeutic guidelines and useful informations rapidly
- Easy monitoring and mapping of situations with GIS based spatial map tools
- Ability to monitor range of surveillance centers by a center of excellence for their activities
- Promoting participation of the society in community empowered health care system
- Function as a health information system for the health care professionals and general public
- Ability to prepare the health care system and community by early prediction of disease out breaks
- Long term use for community statistics purposes
- Ability to conduct drills and continued health education programms

Though there are many advantages of a such system, there could be a risk of fraud access and information miss use if system security is not up to the standard. Since the patient data should be treated as confidential information, such security breach may lead to breach of medical ethics and would have legal implications as well.

Other risk is the reliability of information sources, those do the reporting of cases. This problem is specially applicable to the social networking applications and proper measures should be taken to check the validity of the data and authentication of the users. Developer of any such system should concentrate on above mentioned problems with due care.

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6. Mark A. Hoffman et al., Multijurisdictional Approach to Biosurveillance - Kansas City, Emerging Infectious Disease Online (www.cdc.gov/eid)
7. *Social Networking* : Web based application, through which people can share the ideas and keep on touch with each others by using email, chat and internet based messaging(IM).
8. Harvard School of Medicine - Children s Hospital Informatics Program, Biosurveil lance: Using Informatics for Public Health by Kenneth D. Mandl, MD, MPH

Almost all the health hazards, regardless of whether it is man made or natural, could be monitored using online Biosurveillance systems. However the Biosurveillance assisted by social networking is more applicable and useful in pandemic situations which affects the wider community with a high spatial involvement.

With considering all the above facts, the proposed system will be mainly focused on two disease entities. Namely those are **Avian influenza** and **Autism**. The rationale for selecting those diseases will be explained below in more details.

Avian Influenza

Avian influenza is a viral disease, caused by H5N1 virus and well known for its high mortality rates (approximately 60%) all over the world. The condition is aggravated by its robust nature of the virus, shorter incubation period and difficulty to contain by conventional methods.

According to the WHO Influenza Pandemic situation assessment, following facts have been reveled[9].

- Risk of pandemic is great
- The risk will persist
- The evolution of the threat cannot be predicted
- The early warning systems are weak
- Preventative intervention is possible, but untested
- Preparation is the best protection
- Reduction of morbidity and mortality during a pandemic will be impeded by inadequate medical supplies

Further aggravating the situation there are instances of evolution of highly pathogenic variants of H5N1 virus[10, 11] in many places of the world.

Considering all these facts Avian Influenza can be considered to be a priority in all over the world without any doubt. Extracts form **World Health Organization's *Global Influenza Preparedness Plan***[12] will indicate the need of effective and efficient global information sharing model as follows.

- Develop tools to estimate Influenza seasonal and pandemic disease burden, and the public health value and cost-effectiveness of interventions, including seasonal vaccination.

- Work with national authorities and other partners to coordinate a research and monitoring programme for the human animal interface, and use data collected to assess the risk of human infection with animal influenza viruses.

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9. Responding to the avian influenza pandemic threat , Communicable Disease Surveillance and Response Global Influenza Programme , WHO (WHO/CDS/CSR/GIP/2005.8)
10. Gilbert et al. Anatidae Migration in the Western Palaearctic and Spread of Highly Pathogenic Avian Influenza Virus. Emerging Infectious Disease. Volume 12, Number 11 November 2006 (cited October 2006).
11. EMPRES Watch: Updated situation of Highly Pathogenic Avian Influenza (H5N1) in Asia. August 2006. (http://www.fao.org/docs/eims/upload//211696/EW _asia_aug06.pdf)
12. WHO Global Influenza Preparedness Plan (WHO/CDS/CSR/GIP/2005.5)

- Develop or review interpandemic or pandemic guidelines and tools for detection, investigation, rapid risk assessment, reporting and ongoing evaluation (e.g. monitoring outcome of containment measures), of clusters of influenza-like illness.

- Develop guidelines and tools to assist countries in ongoing monitoring of information, for assessment of impact and resource needs during the pandemic phase.

- Collect pandemic preparedness plans from countries and make them available to other countries.

- Keep a global inventory of key manufacturers of key products

- Provide information to facilitate risk communication related to influenza.

- Plan and test capacity for meeting current and expected future international information demands, among others by maintaining a web site.

- Develop feedback mechanisms to identify emerging public concerns, address rumors, and correct misinformation

- Establish global case definition for reporting by countries

- Collect, synthesize and disseminate information on the global situation in collaboration with partners.

- Enhance alertness for additional cases and encourage active human case-finding

- Provide background information regarding the effectiveness of recommended measures.

- Identify needs and encourage international assistance to resource-poor countries.

- Promote intensification of disease surveillance in countries not yet affected, to the maximum extent possible.

- Accelerate and enhance situation monitoring and assessment activities in pandemic alert period, phase 4, to a maximum.

- Forecast trends for the first pandemic wave (affected regions, risk groups, health-care resource needs,impact, etc.).

When it comes to information flow and data sharing, Avian Influenza has more hierarchical *bottom up data flow* structure (also see Autism section below). Information regarding case detection and management will flow from community level to higher level of health services administration in national level. Sharing of information is only with cluster of trusted organizations and though online case notification can be allowed.

Top down data flow can be used to alert community on disease control plans and situation awareness. More complex information like therapeutic guidelines and laboratory investigation data can be delivered to health care professionals and administrative level in a timely manner with a online system.

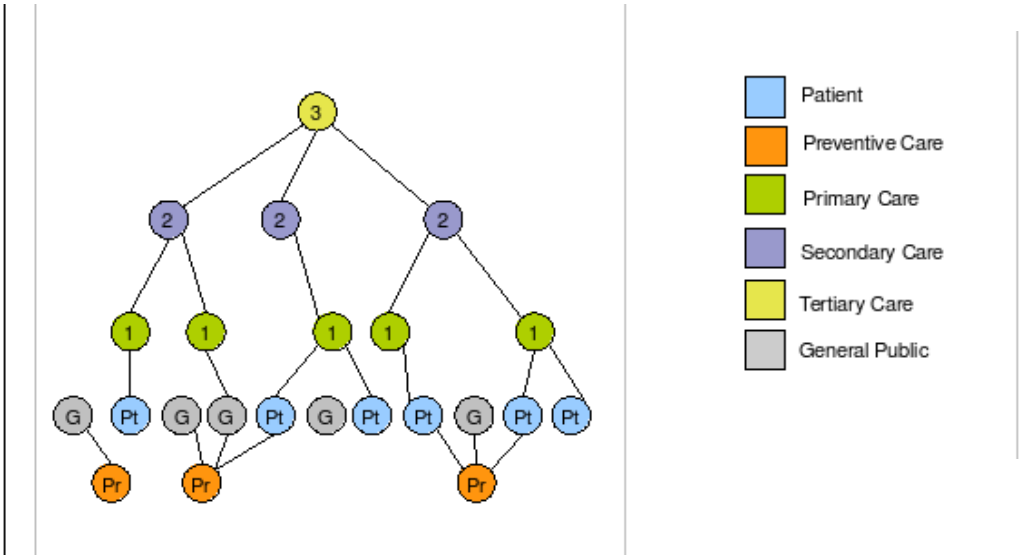

Fig 01: Social Networking model of Avian Influenza like acute and management is more hospital centered illness.

If countries or institutions wish to share relevant informations with other organizations or institutions in a international level, it is also easily possible through a online disease surveillance system with various levels of user access.

It was felt that after improving some of the existing features and developing new features to the current framework for disease surveillance functionalities, Sahana Disaster management System would be capable of fulfilling the above mentioned requirements of WHO action plan for Global Influenza Preparedness.

Further to this, being an **Free and Open Source** Product, Sahana is available for *free of charge for deployment and access to software source codes for further development* under LGPL open source license. These features will allow Sahana to neutralize the technical and financial gap for deployment of such system and it will make it acquirable even by an underdeveloped country.

Autistic Disorders

Autism is highly heritable, although the genetics of autism are complex and it is generally unclear which genes are responsible. In rare cases, autism is strongly associated with agents that cause birth defects. Other proposed causes, such as childhood vaccines, are controversial and the vaccine hypotheses lack convincing scientific evidence. The number of people known to have autism has increased dramatically since the 1980s, at least partly due to changes in diagnostic practice; the question of whether actual prevalence has increased is unresolved[13].

In a multiple source surveillance program in the United States, the prevalence of autism in 8 year olds was found to range from 1 in 3003 to 1 in 94 in different States, with an average rate of 1 in 150 or 6.6 per 1000[14].

Findings in a population based longitudinal study in Taiwan - compared to birth years of 1996-1999, the rate of autism increased by 14% during the period 2000-2004, where as newly diagnosed mental retardation decreased by 42% to 50% over the same period[15].

About 10% of cases can be explained by genetic syndromes and chromosomal abnormalities, but genetic studies have not provided substantial insight into the 90% of cases where autism is idiopathic. The twin and family studies indicate that very likely there are 3 to 12 susceptibility genes for autism acting synergistically[16].

Considering all these factors, it is apparent that the number of cases reported with this childhood developmental disorder is increasing at a alarming rate. How ever, the exact cause/s for the Autism is yet to be investigated.

One of the main problem faced by the researchers are lack of proper database which continuously monitor the relationship of the cases with possible aetiological factors. If there is a sharable model for a childhood developmental disorders, it will be beneficial to analyze the relationship with the causative factors national level as well as globally in an international level. As mentioned in the Avian Influenza section above, if sharable database model with open web framework is available it will help countries to maintain national level *childhood developmental disorder* knowledge bases. Further to that it will encourage nations to share non-confidential informations among participatory level for more regional and international level studies.

Families with Autism suffer various financial difficulties due to the natural history of the disease as well as the treatment and rehabilitation costs. The main goals of

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13. *Newschaffer CJ, Croen LA, Daniels J et al.* (2007). "The epidemiology of autism spectrum disorders". *Annu Rev Public Health* 28: 235 58.doi: 10.1146/annurev.publhealth.28.021406.144007. PMID 17367287

14. *Autism and Developmental Disabilities Monitoring Network. Prevalence of autism spectrum disorders in multiple areas of the United States, 2000 and 2002: community report 2007; Centers for Disease Control and Prevention*

15. *Chen CY, Liu CY, Su WC, Huang SL, Lin KM. Factors associated with the diagnosis of neurodevelopmental disorders: a population based longitudinal study. Pediatrics 2007; 119: 435-443*

16. Rutter M. Aetiology of autism: findings and questions. Journal of Intellectual Disability Research 2005; 49: 231-238

treatment are to lessen associated deficits and family distress, and to increase quality of life and functional independence. No single treatment is best and treatment is typically tailored to the child's needs. Intensive, sustained special education programs and behavior therapy early in life can help children acquire self-care, social, and job skills; claims that intervention by age two to three years is crucial are not substantiated. Available approaches include applied behavior analysis, developmental, and structured teaching. Educational interventions have some effectiveness in children; the limited research on the effectiveness of adult residential programs shows mixed results[17].

Treatment is expensive; indirect costs are more so. A U.S. study estimated an average cost of $3.2 million in 2003 U.S. dollars for someone born in 2000, with about 10% medical care, 30% extra education and other care, and 60% lost economic productivity. Publicly supported programs are often inadequate or inappropriate for a given child, and unreimbursed out-of-pocket medical or therapy expenses are associated with likelihood of family financial problems. After childhood, key treatment issues include residential care, job training and placement, sexuality, social skills, and estate planning.

In the management of Autism, community based approach will play a major role. If a child with a developmental disorder is considered, management of the child is done by a collaborative effort of several parties, which includes patient's family, health care workers, social workers, speech and language therapists etc. The relationship of those parties can be represented as follows.

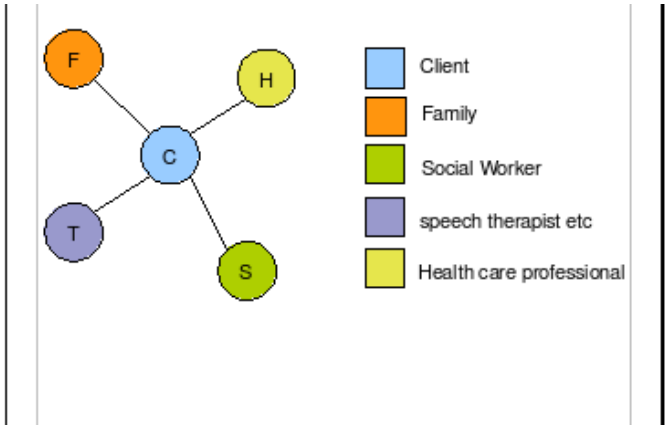

Fig 02: Schematic representation of relationships among the affected child and care givers.

When community has several patients, it creates a network which consists of patients and people interested in particular patients. Each relationship is built around a child who suffering form the disease as shown above.

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17. Ganz ML (2007). "The lifetime distribution of the incremental societal costs of autism". Arch Pediatr Adolesc Med 161 (4): 343 9.PMID 17404130

There are various links among care givers, and there might be certain degree of similarity between the socio economic problems encountered by various nodes of this social network.

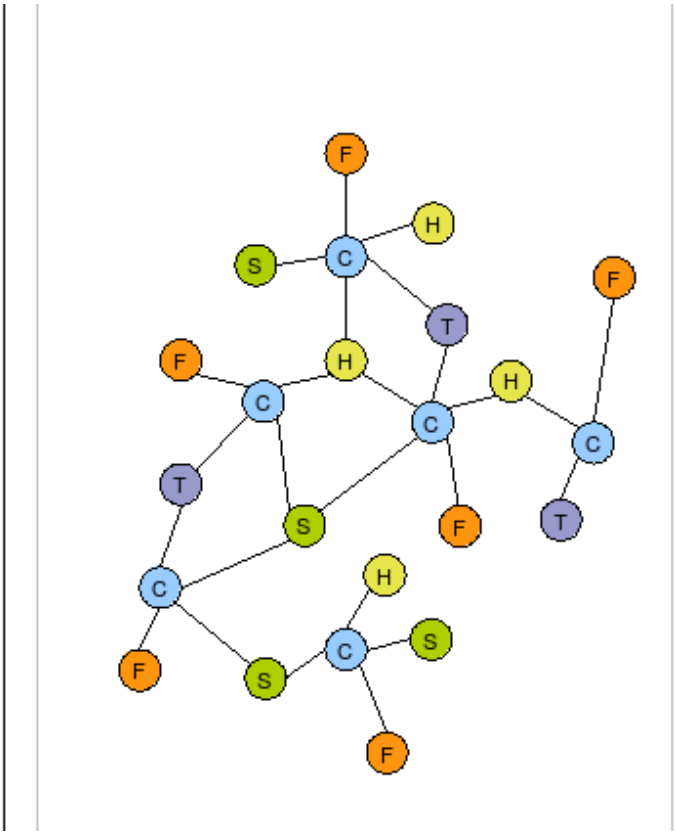

Fig 03: Social networking model for the Autism like Childhood developmental disorders where management is more community based.

If there is a system which allows sharing of information among a group of individuals based on interest towards a particular child (e.g. parents of a child, family doctor and speech therapist), it will be very useful in management of the child.

If the confidentiality of the child and the family is preserved to desired level, disease management information can be shared among parents of many children with similar symptoms (e.g. Stereotypy, self injury etc) and similar developmental and social problems. This will help educating parents about disease and its outcome, managing financial difficulties as well as management experiences to overcome their socio economical problems. This will enable affected families to build their own '*self help*' network and will strengthen the community participation of management[18].

18. Compton Autism and Special Need Kids Meetup group (http://autism.meetup.com)

How ever most of the current web based social networking applications doesn't provide desired level of privacy for patients or their families.

Not only in coordinating families with autism and similar diseases, this kind of social networking applications can be used in managing 'post traumatic stress' and socio-economical impact in a mass scale disaster situations as well. This kind of web applications seems to be used for 'post traumatic stress disorder' in military veterans as long term management of the problem behaviour[19, 20]. Again the level of privacy is questionable in the web based applications available so far.

None of the already available systems follows the free and open source model of a FOSS disaster and health information management. Hence, it makes such systems unusable in a *humanitarian deployments* or as an *information sharable system*. Further to this there won't be a an emergence of FOSS framework and continuous development of the system with the help of like minded developers around the world.

If information sharable common framework is available for the disease surveillance of the Autism and other childhood developmental disorders, it will aid uncovering more informations on the aetiological factors and causative agents[21]. This will in help disease prevention activities and hence reduces financial losses in family perspective as well as in national and international level.

18. http://www.myhealth.va.gov
19. http://www.seamlesstransition.va.gov
21. *Rutter M. Aetiology of autism: findings and questions. Journal of Intellectual Disability Research 2005; 49: 231-238*
22. *Schechter R, Grether JK. Continuing increases in autism reported to California's developmental services system: mercury in retrograde. Archives of General Psychiatry. 2008; 65(1):19-24.*

Extending Sahana framework for disease surveillance

As discussed above in great detail there is a need for a web based, social networking enabled open source disease surveillance systems for general use. Since disease outbreaks are common in disaster situations, it is important to be able to function in disaster management and disease surveillance capacities simultaneously.

Sahana framework can be easily expendable to achieve this objective as follows.

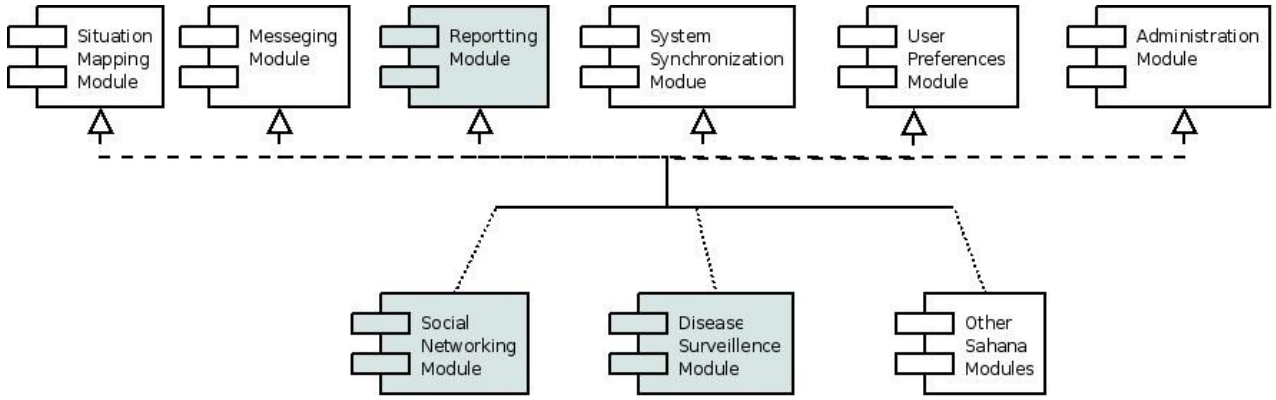

Fig 04 : How new modules depend on Sahana core modules

In this model, 6 Sahana core modules (Situation Mapping, Messaging, Reporting, System Synchronization, User Preferences and Administration) will be used as framework feature. Other Sahana modules can be installed if necessary. This will enable the system to work as a disease surveillance system alone or as a components is a general disaster management system.

Features of ***Reporting module*** are under developed in the current Sahana system. So the current features necessary for epidemiological statistics will be kept in the Reporting module, while other functionalities being moved to the relevant modules to reduce the complexity of the user interface. This will provide a data sharing interface with user levels and access control.

Two new modules, Social Networking Module and Disease Surveillance Module are proposed to add to the current Sahana framework to enable social networking and disease surveillance activities.

Social Networking Module is responsible for making connection among members of the community interested. This will allow system to go beyond the conventional web link capacity, enabling it to maintain *personal relationship* with the person responsible for the linked resource. Features of XFN[23] (XHTML Friends Network) and FOAF[24] (Friend Of A Friend) will be explored and used in combination with expert system features to develop a intelligent module beyond the common capabilities of a such system.

23. http://www.gmpg.org/xfn
24. http://rdfweb.org/foaf

Such a system is more capable of helping relevant parties to make new contact based on their common interests.

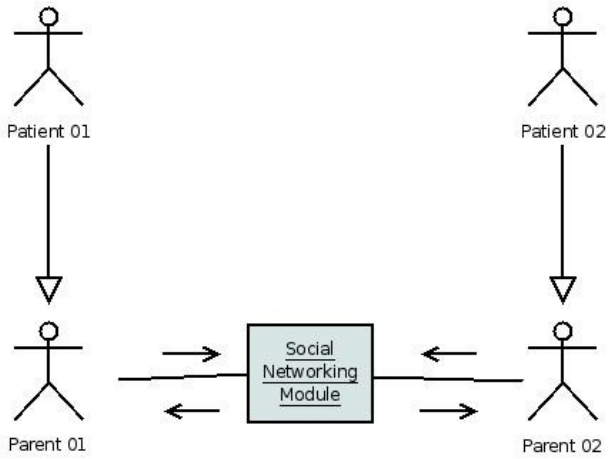

Fig 05: Social networking, connecting 2 parents

As shown above, when a parent has a child with some form of developmental disorder, system has the capacity to suggest him/her another parent with a similarly disabled child. This will allow both the parents to share management experiences they have about the disorder and automatically a net work of similarly disabled children will be developed facilitating patient education through peer experience. A health care worker may facilitate group discussions, providing them more informations if it is within his/her field of specialty.

Disease Surveillance Module is mainly responsible for following functions.

- Intelligent diagnosis based on *therapeutic guidelines* given by a center of excellence
- Rapid and automated detection of relevant disease cases even without the presence of a specialist of a relevant disease entity (This will allow centers with less human resources to function efficiently in disease out break situations)
- Detection of cluster of similar patterns in time and space
- Providing GIS module the necessary information for geo spatioal mapping of cases
- View and analyses the data stored in the database to monitor diseases outbreaks and activities of a health care network

All the above features will be enabled only through secure log in and access control with user levels. This security feature enables the system to handle confidential and sensitive patient informations without allowing access by unauthorized personnel. It will allow deploying organization to share data with wide range of users, local,

national and even international level through internet or any other data sharing mechanisms available in the Sahana framework.

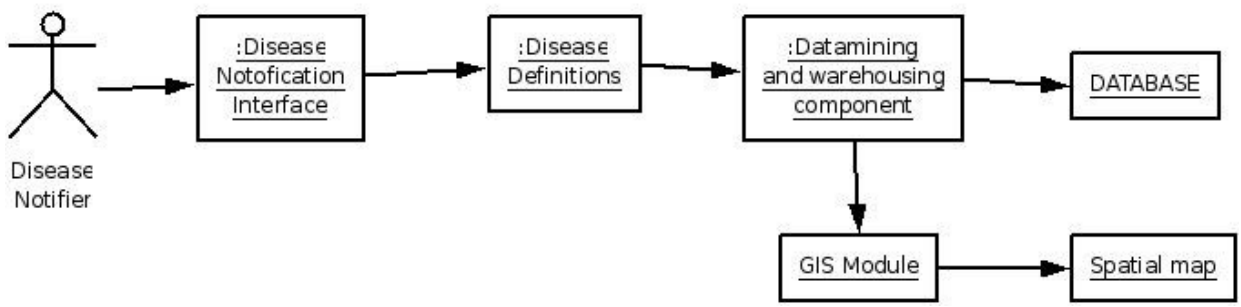

Fig 06: Disease notification data flows

When a disease is notified to the system by any user, depending on the access level data will be written to the database. XML based disease definitions will be used to dynamically interact with the user through a *context sensitive data input* forms. EDXL, HAVE and MML based disease definitions will be used in the above components for that purpose.

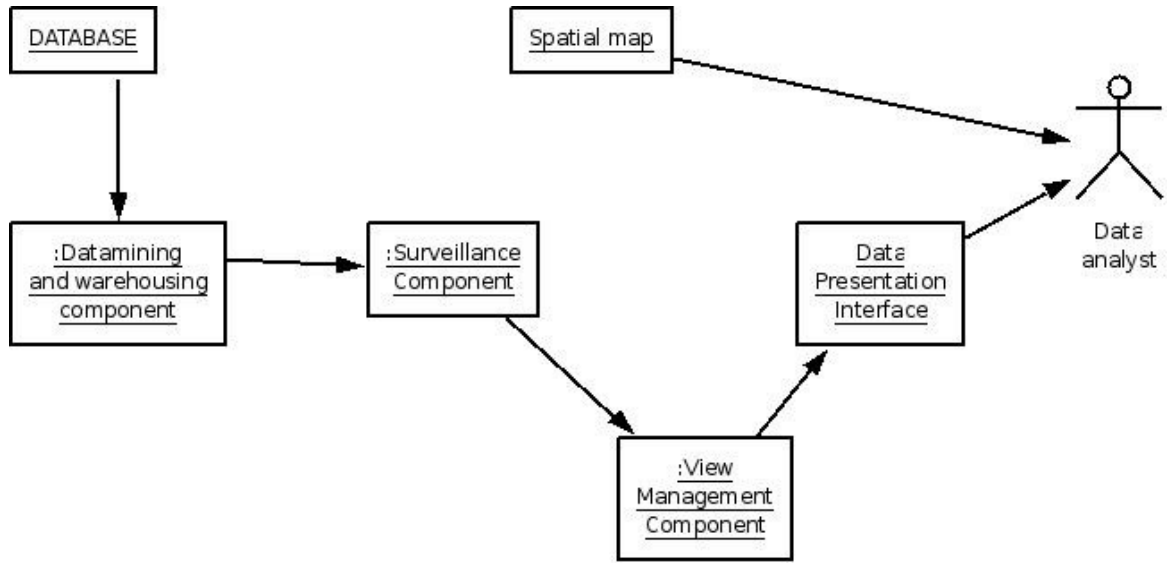

Fig 07: Spacial mapping of cases and data analysis

When data is analyzed (automated or on-demand), data mining and disease surveillance layers will present relevant data to the data presentation layer. Data will be presented to the user using graphical and non-graphical representations with additional features to convert data in to downloadable formats(PDF or Microsoft Office/Open Office compatible spreadsheets) as well as to print as and when

necessary.

Suitable artificial neural network model (e.g. WSARE) has to be adopted after being considering the amount of data available as the training set, time taken to perform analysis and restriction of web programming languages as well.

Initially the proposed system will be checked with Avian Influenza and Autism. When a specific deployment needs to cover different disease entities, it can be achieved through customization files (XML) and installing the disease entity sub module. This approach is important since the therapeutic guidelines and disease management is different in different countries. Then deployment team can do the rapid customization of necessary components depending on the user need.

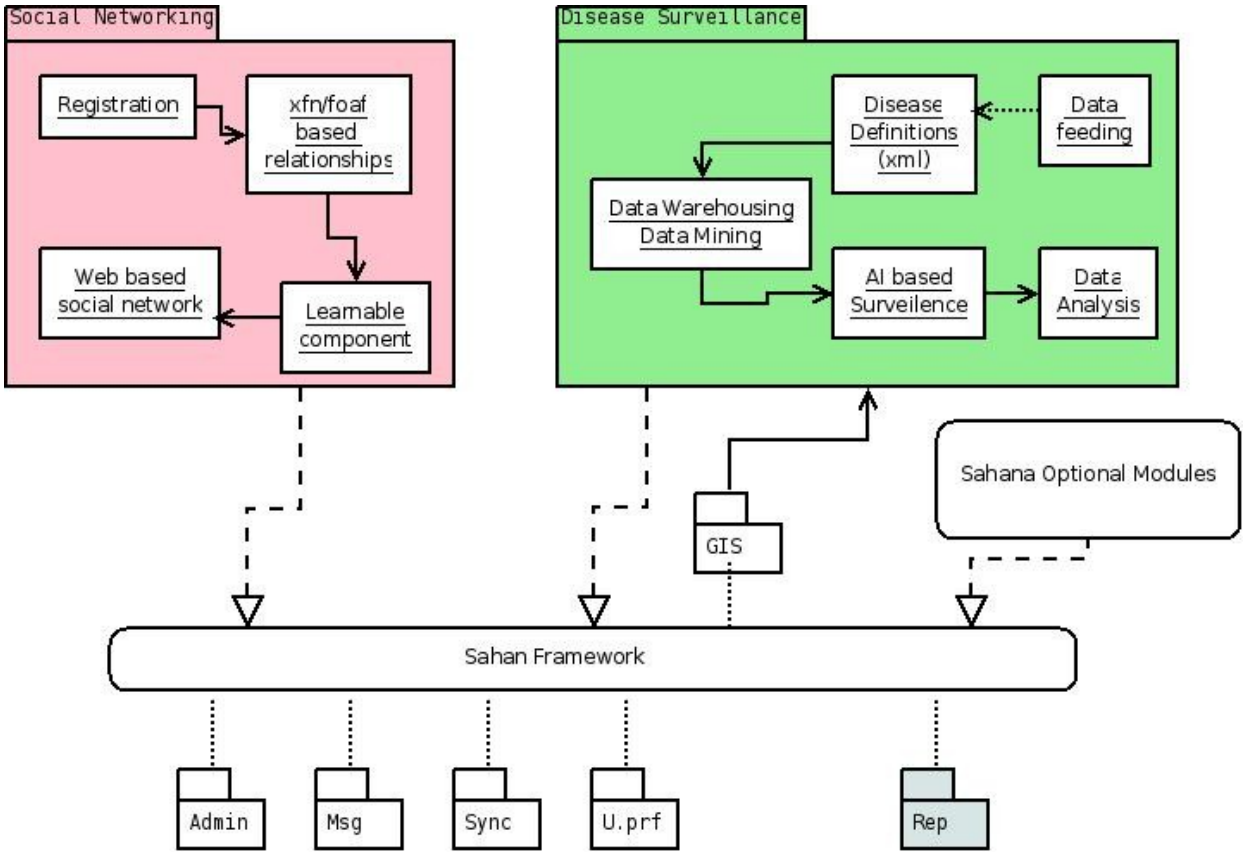

Fig 08:The schematic diagram of the module architecture

This model will allow Sahana modules to be installed as a disaster management system, disease surveillance system or as a integrated system which has both the earlier mentioned features, making is a fully scalable model.