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Developing Health Surveillance Networks: An Adaptive Approach

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ABSTRACT

The research literature on public health information and communication networks shows enormous promise and tremendous obstacles. There is a great deal of evidence to suggest that when electronic health information systems are widely employed, and clinical information is easily shared, trained individuals can track and monitor health status, and avert acute events that can potentially affect an individual or a population. However, the research literature also leaves unresolved important questions about effectiveness versus efficacy: that is, whether health information sharing can achieve compliance on a large scale, particularly across social, political, economic and geographic boundaries. For this reason, we propose adaptive healthcare information networks to collect, process and disseminate health information and reduce medical errors. This research assesses existing electronic health monitoring initiatives in the United States and worldwide, and discusses their progress and limitations. It identifies how healthcare information networks could be improved by the application of innovative theories and technologies, such as complex adaptive theory, expert systems and grid technology.

INTRODUCTION

Networks have the property of being both ubiquitous and absent. That is, they are everywhere in general, but in a literal sense it is hard to point at, for example, the Internet. This is a reminder of how networks exist topologically and some suggest networks must be increasingly understood as simultaneously technical and political in nature[1]. Ideally for healthcare, network models should be flexible, with the ability to adapt to the management of the health of populations and capable of disease surveillance and early identification of disease outbreaks.

Communication networks have already revolutionised information communications in the 21st Century. The first major paradigm shift is the rapid expansion of Internet communications. The second is the diversification of access methods, as

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represented by cellular phones, personal digital assistants (PDAs), personal computers (PCs), etc. and developments in high-speed access technologies. Clinicians nowadays commonly use laptops (notebooks) and PDAs for medical management. Health specialists, especially those working in the community are helping to drive the expansion of mobile data communications in healthcare. This creates a new setting in which new principles and materials must be discovered to shift health information technology so that it can address modern issues including freeing patients from the restriction of being treated in fixed locations. Ideally, modern technologies should be able to support a global framework that can address key issues including: health system complexity, quality of care, health inequalities (disparities), urbanisation, emerging infectious diseases and bioterrorism.

THE CHAOS THEORY APPLIED TO HEALTHCARE

Previous work has demonstrated that systems that are interactively complex (various components that tend to behave in nonlinear ways) and coupled (lacking spatial, temporal, or other patterns of buffering) are prone to failure. Tan and colleagues[3] have analysed how the parts of networks connect and interact to achieve outcomes, and through their research have identified factors and challenges to consider when designing future-oriented healthcare networks. Their work discusses a chaos theory view of healthcare systems. This view divides the causes of chaos into internal and external origins. Each origin is further subdivided into a human or individual level, an organisational level and a system level, and stages ranging from static to chaos. When either etiology, internal or external, surpasses the static stage, the potential for error increases.

Ideally, a health information framework should support and facilitate interventions to shift and maintain the complexity towards the static stage. In addition, it is very important that healthcare information systems are created with checks and balances to prevent system-induced chaos.

Conceptually, a global health information system should provide efficient access to patient information, comprehensive surveillance, expert systems to facilitate decision-making and computational power. Information networks can be used to manage the complexity of healthcare. The adaptive system theory identifies the following concepts that should be incorporated when developing future-oriented information and communication networks[3]:

- *Accept uncertainty.* The best way to deal with turbulence is to attempt to understand it, not control it. Healthcare information networks should gradually redirect natural flow.
- *Healthcare systems are unpredictable.* It is necessary to take the time to research existing systems at the process level to help identify the small changes that have the most overall benefit.

- *Feedback loops improve performance.* These should be implemented at all times and be direct, rapid, specific, and constructive, indicating both good and bad performance.
- *Standardisation with flexibility.* This is important in maintaining care quality in static stages. It should, however, be avoided for rare processes.
- *Quicker response time with backup redundancy at the edge of chaos.* The time at which relevant patient information is retrieved and reported is crucial to the reduction of medical errors[4,5]. In addition, a shortened cycle time can be increasingly important at the edge of chaos.
- *Intelligent and effective leadership is essential in the chaos stage.* Someone must be in charge and if feedback loops are absent, they must be put back into place.

OBSTACLES TO CLINICAL INFORMATION SHARING

To achieve the goal of global information sharing, there must exist smaller, localised units, which contribute to a distributed framework. The lack of a nationalised healthcare provider may be the most important limiting factor when implementing health information systems in many countries. For example, Joel White, a member of the US Government's Subcommittee on Health, House Committee on Ways and Means, stated in 2002: "*The multitude of healthcare information systems currently available are discrete and do not communicate with one another. In addition, vast bodies of medical knowledge and data do not exist in an electronic format that is usable by a decision support system*". In general, health information systems in hospitals and other established practices cannot monitor patient results, analyse them according to best practices, or provide the necessary information to clinicians caring for patients.

In many countries such as Canada, it has been widely recognised that one of the keys to service improvement in national healthcare lies in the integration of medical information systems. However, even with a central provider, the system is fragmented into autonomous units and many heterogeneous data sources currently exist. Although people are aware of the benefits of medical information integration, disagreement exists on how such integration can be achieved[6].

The movement towards electronic medical information systems is still limited in several countries. In economically poor countries, few if any governmental healthcare personnel are usually assigned to rural areas where much of the population may live. This raises logistic problems when designing comprehensive healthcare monitoring systems to ensure that necessary data will be collected and entered into computerised databases for use in determining global heathcare needs and issues. Even simple factors such as the absence of electricity in remote areas act as serious impediments to the collection of vital data for analysis. Information sharing initiatives should do their best to ensure network participation is inexpensive, accessible, and flexible.

A MODEL FOR INFORMATION SHARING: INTERNATIONAL COLLABORATION BASED ON VIRTUAL PATIENT RECORDS

Many suggest the first step towards comprehensive information architecture is the electronic medical record. For example, establishing a global network of distributed patient records may facilitate the surveillance of infectious diseases. Currently there are several initiatives to build a new information architecture that will enhance and extend the quality of healthcare worldwide[7]. Internationally accepted standards currently exist for the exchange of financial information, and health information could move across networks just as easily, based on international standards that provide the appropriate privacy and security.

A number of organisations are working towards standardising object interfaces for healthcare applications at a global level. This includes the Object Management Group (OMG), a not-for-profit consortium of 700 software vendors, developers and users, the European Committee for Standardization (CEN), the United Nations rules for Electronic Data Interchange For Administration Commerce and Transport (UN/EDIFACT), the Joint Working Group for a Common Data Model (JWG-CDM), Health Level 7 (HL7), American Society for Testing and Materials (ASTM), the Computerized Patient Record Institute, and others[7]. Only some of these approaches are object-oriented.

The HL7 Standard for Clinical Document Architecture

Healthcare monitoring systems using EMRs as essential units, will find it is very important that they are semantically normalised with relevant clinical data. HL7 Version 3 is a standard that specifically deals with the creation of semantically interoperable health information[8]. HL7 is an ANSI-accredited standard developing organisation whose major function has been the development of standards for clinical and administrative healthcare data. These standards have been increasingly adopted in many countries[6]. Early HL7 standards focused on the fine-grained message structures for cross-organisational integration of medical information systems. In this latest version, HL7 has developed a more course-grained, document-oriented information standard, called Clinical Document Architecture (CDA)[9]. CDA is a document markup mechanism that defines the structure and semantics of clinical documents (such as discharge summaries and progress notes). The HL7 Reference Information Model (RIM) is composed of a set of standards, of which CDA is one. In this format, clinical care is administered on the basis of clinical decisions made from essential pieces of patient information, such as demographics, diagnoses, laboratory results, medications, allergies and other adverse-event history[10].

INTEGRATING PUBLIC HEALTH INFORMATION AND SURVEILLANCE SYSTEMS

When considering the requirements for a model to integrate public health information into disease or symptom surveillance systems, several important factors that should be addressed are:

- Fragmentation of healthcare systems
- The burden of collecting and reporting medical data
- Any information gaps that may exist among the system's constituents[11].

In the United States, the general focus has been on improvements at the state and federal level. These initiatives have focused on developing EMRs, supporting the development of data standards to increase health information system interoperability, patient safety, reducing medical errors and paying for performance. Although, it is easier for the government to use a state/federal approach, many health systems, and their described needs are better expressed in less discrete regions, which may even overlap or readily change and may not be accurately represented with this approach.

Organisations and individuals that may use public health data, derive theories and intervention strategies from an understanding of the basic epidemiologic variables of place, time, person and vector. Several categories have been identified by the Centers for Disease Control (CDC) in their report, *Integrating Public Health Information and Surveillance Systems*, for which collected health data can prove useful for the management of the healthcare system and the monitoring of patients[11]:

1. Reports on health events affecting individuals
2. Vital statistics on the entire population
3. Information on the health status, risk behaviours, and experiences of populations
4. Information on the potential exposure to environmental agents
5. Information on existing public heath programmes
6. Information useful to public health but obtained by organisations not directly included in public health practice
7. Information on the healthcare system and the impact of the healthcare system on health.

These guidelines suggest that the information architecture for public health should be scalable, efficient, adaptable, comprehensive and easily accessible, with many views, security levels, and functions.

PUBLIC HEALTH SURVEILLANCE SYSTEMS

A national information system devoted to the surveillance of communicable diseases based on computer networking was proposed in France more than two decades ago. This system was based on electronic surveillance and control of communicable diseases and required the following steps[12]:

1. Timely collection of relevant and appropriate epidemiological data
2. Timely and meaningful statistical and mathematical analysis of data
3. Rapid dissemination of the results to all relevant personnel (including decision makers, healthcare providers, public health officials, and the general public)

Computer networking was identified as being the most useful means to accomplish these three tasks since it connects stakeholders, even when geographically isolated, and makes available the following resources[12]:

1. Large epidemiologic databases
2. Powerful data management capability with highly specialised software
3. Electronic communication facilities (e.g. e-mail and message boards) that allow ready interaction between the diversified components of the system.

Although the concepts still hold and current disease surveillance systems incorporate these requirements, recent designs have integrated more sophisticated facilities for communication and data analysis. For example, artificial intelligence techniques such as Bayesian inference and pattern recognition algorithms have been applied to identify potential anomalies.

Disease Surveillance in the United States

The CDC and local health departments have recognised the importance of state and local disease and symptom surveillance systems. These have been noted as increasing the ability and efficiency to respond to a disease outbreak[13]. Previously, most state health departments received case-reports by mail and then entered the data into an automated system, which could take place weeks after an event. In addition, it is estimated, depending on the disease, that only 10–85% of cases were reported and more than 100 different systems were used to transmit the data to the CDC[13].

Progress has been made since the project was initiated to improve state and local surveillance and transmission of data. In 2000, data was sent to the CDC through secure Internet-based data entry and electronic laboratory results (ELR) reporting. This federal-level framework is provided by the National Electronic Disease Surveillance System (NEDSS), which is part of the broader Public Health Information (PHIN) initiative.

Improvements have been made, but local, state and national public health officials should still continue to improve the timeliness and completeness of disease surveillance. As of April 2005, a total of 27 state health departments and two municipal health departments (New York City and Los Angeles) were entering at least some notifiable disease data using a secure Internet-based system[13]. However, since only just over half of the states are submitting electronic Internet-based data, wide-scale compliance has not been achieved. In addition, to our knowledge, there is no sufficiently established symptom surveillance system for civilians being implemented at the federal level.

Syndromic surveillance systems have been employed in New York City (NYC)[14]. The system is based on information collected from emergency departments in NYC hospitals. In its first year of operation, the NYC Health Department was able to identify an increase in gastrointestinal viruses for all ages, and the arrival of an influenza epidemic. The system was also able to detect single-day spatial signals suggestive of illness clusters[14]. However, none of these anomalies was identified as an outbreak.

Syndromic Surveillance: England and Wales

A commitment to improve surveillance for health protection has been made in the United Kingdom[15]. Syndromic surveillance systems have been proposed to serve as an early warning to detect outbreaks of infectious diseases and chemical or biological poisoning, including those released by terrorists. Data derived from NHS Direct, a system set up to provide direct telephone health advice to the public, has been used for the surveillance of syndromes, and its functionalities expanded to provide an early warning for the potential deliberate release of harmful chemical and biological agents[15]. Outbreaks are detected by a computerised clinical decision support system, which contains approximately 200 clinical algorithms, each with a series of questions related to symptoms. In 2005 the system was evaluated and deemed to be timely, representative, useful and acceptable with low marginal costs, but with borderline flexibility and limited portability[15]. In addition, it has the potential to detect high-risk, large-scale events, but in its current state it is less likely to detect smaller, localised outbreaks.

Process and Conceptual Modelling: CRISTAL-EIS

A general logical model for Epidemiological Information System (EIS) has been proposed by the CRISTAL-EIS project and developed at CERN, Geneva. It has been designed to facilitate the bi-directional information flow between laboratories and clinical care centres in a global, consistent, reliable and timely manner. This process model describes an EIS as a distributed system that integrates different forms of data, which can evolve over time in a wide geographic area. This raises the need for a flexible, reliable, and responsive system to handle diverse and large volumes of data[16]. The data model underlying the system is open and self-describing in nature and could be easily extended. The technology is easily portable and can be adapted to other domains such as cancer, diabetes, tuberculosis, etc. Currently, this prototype is being evaluated.

IMPROVING PUBLIC HEALTH SUREVEILLANCE

Modern computational approaches to complex adaptive systems, such as healthcare, requires stakeholders to access a comprehensive mix of high-end computing, networks, sensors, data and visualisation technologies. Globally, healthcare has lagged behind other industries in adopting information technology, and incorporating automated expert systems to facilitate decision-making. The future of healthcare quality depends on efficient access to healthcare information, wide-scale compliance using interoperable systems, and easily disseminating expert level knowledge. Advantages of using a grid approach to connect stakeholders and develop healthcare networks include: response time, throughput, availability, security and/or co-allocation of multiple resource types to meet complex user demands[19]. The future of grid technology, and its underlying points, aligns with the requirements to effectively manage adaptive healthcare networks and improve overall quality.

Public Health Grids

Grid technology is ideal to address today's complex problems that require interdisciplinary collaboration. Moving beyond large-scale parallel clusters and supercomputers lies this emerging field. The grid architecture allows users distributed access, not only to computer resources, but also to high-speed networks, information repositories and archives, and experimental and observational devices[17]. This could be valuable to health specialists, especially those working in the field. In addition, they can provide access to a host of tools, such as expert systems and alert systems with triggering events.

The grid computing paradigm may have the potential to integrate medical information systems, and somehow solve the problems presented by many heterogeneous data sources[6]. Foster and Kesselman describe a computational grid as a hardware and software infrastructure that provides dependable, pervasive, and inexpensive access to high-end computational capabilities[18]. A grid uses standard, open, general-purpose protocols and interfaces, and allows constituents resources to be coordinated, delivering various qualities of service. Advantages of using a grid approach include: response time, throughput, availability, security and/or co-allocation of multiple resource types to meet complex user demands[19]. The future of grid technology, and its underlying points, aligns with the requirements of adaptive networks. Considering the autonomous nature of many populations, the geography that divides us, and the more abstract barriers these networks must surpass, we have a noble goal for the future of information sharing and health information networks.

Distributed Expert Systems

Incorporating expert systems into a health information framework can prove valuable for decision-making support. Several systems, such as the one used in NHS Direct, utilise artificial intelligence to support expert level reasoning. However, there are ethical and legal considerations that need to be taken into account when applying artificial intelligence techniques in medicine. The emerging public health cyberinfrastructure will have to establish governing bodies to set rules and recommendations.

To better understand what benefit distributed expert systems may add to a distributed information sharing architecture, we can examine the contributions of previous expert systems research. There are many notable expert systems that may be relevant to the future of disease monitoring and surveillance and which can be modified or directly incorporated into a distributed architecture.

MYCIN

MYCIN was developed at Stanford University to aid physicians in the diagnosis and treatment of patients with infections. The system diagnoses the cause of the infection and recommends appropriate drug treatment according to procedures followed by physicians experienced in infectious disease therapy. It is a rule-based system employing a backward chaining control scheme. The system has approximately 500 rules and is primarily a goal-driven system, using the basic backward chaining reasoning strategy to identify the nature of an infection. MYCIN's knowledge base is represented as a set of IF-THEN rules with certainty factors. Although MYCIN had a pioneering influence on developments in knowledge engineering and expert systems' research, it also had a number of problems, which were later remedied in more sophisticated architectures[20,21]. It was also never actually used in practice. This was not due to any inherent weaknesses in its performance (in tests it outperformed members of the Stanford Medical School), but was related to ethical and legal issues associated with the use of computers in medicine – if the program gave a wrong diagnosis, who would be held accountable?

The Reportable Diseases System

The *Reportable Diseases System* was developed in 1995, and monitors culture data from a hospital's laboratory system. The system automatically generates a Reportable Diseases form including all relevant patient and clinical data when a culture representing a 'reportable' infection is detected. The languages/shells used to develop and implement this system include: CLIPS, Sybase ISQL scripts, and Bourne shell scripts[22].

GermWatcher/GermAlert

In an initiative to monitor nosocomial infections the *GermWatcher/GermAlert* family of expert systems was developed. These are designed to support infection control specialists in detecting, tracking and investigating infections in hospitalised patients. The system includes a rule-base modelled on local hospital infection control guidelines and the CDC National Nosocomial Infection Surveillance System (NISS) culture-based definitions for nosocomial infections. The languages/shells used to develop and implement this system include: generalized expert system shell (the GermWatcher Engine), CLIPS, Sybase ISQL scripts, Bourne shell scripts.

TherapyEdge

Developed for web-enabled monitoring and chronic disease treatment, TherapyEdge is generally used for HIV management. The system utilises an engine and a knowledge base to assess a patient's current status and generate patient-specific, optimised treatment alternatives for a clinician to review and compare. In this way, the system can be used to generate comprehensive, individualised treatment plans for patients. TherapyEdge is available to subscribers via the Internet[22].

SahmAlert

In 1985, SahmAlert was developed to assist microbiology laboratories with identifying organisms that have unusual patterns of antibiotic resistance. Using a rulebase consisting of criteria developed by local epidemiologists, SahmAlert scans the culture data, identifying which cultures contain organisms with patterns of unusual antibiotic resistance. The languages/shells used to develop and implement this system include: CLIPS, Sybase ISQL scripts, Bourne shell scripts[22].

GIDEON

GIDEON is a commercial product used by clinicians and scientists that is available online and updated on a weekly basis. The system generates a Bayesian ranked differential diagnosis based on signs, symptoms, laboratory tests, country of origin, and incubation period. It can be used for diagnostic support and simulation of all infectious diseases in all countries. A Bayesian matrix processes user input and compatible diagnoses are presented in order of probability, with interactive 'suggestions' for additional discriminative examinations[22].

CONCLUSIONS

Surveying public health requires a wide spectrum of health issues to be addressed including: the identification of vulnerable populations, infectious diseases, chronic conditions, reproductive outcomes, environmental health, occupationally related health events, medical errors and injuries. These health issues may require the allocation of provisions such as prophylaxis measures, educational services, inspection of suspect locations, and control of outbreaks. For all of these activities the accessibility of both geographic and health status information should be efficient, and accurate to best support decision-making. However, the global healthcare system is complex, and composed of an enormous number of interacting parts, which exchange resources from the environment in which they operate. Complex adaptive system theory explores the core fundamentals of the human care process and the interacting components, which consists of an array of stakeholders with different immediate goals. In a modern system this may include: patients, clinicians, clinics, vendors, insurers, governments, hospitals, pharmacies, laboratories, and others. In the 21st century, these components cross countries and impact each other in an unprecedented manner.

If governing organisations cannot securely, accurately, and efficiently collect and share clinical data about epidemiological patterns and healthcare quality, then they are not taking accountability for the public's well-being. It is imperative that communication and standards are open, secure, flexible, low-cost and accessible to any provider or individual that can benefit from the use of health information. Currently, we have many of the tools, but few of the solutions. Current, and future health information initiatives should encourage inter-disciplinary collaboration, and find a feasible and consensual means to implement the strategic vision of interoperable clinical information sharing systems whose demands are not too rigidly defined, but dynamic and for the most part, unpredictable. We believe, with the appropriate system architecture and software tools, the day can soon come, by adopting similar international standards for healthcare information, when electronic information can move efficiently and securely across international borders, easily traversing both the technical and political aspects of healthcare networks.

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