

Communications in Medical and Care Compunetics

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Future Visions on Biomedicine and Bioinformatics 2

A Liber Amicorum in Memory of
Swamy Laxminarayan

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Health Informatics: A Roadmap for Autism Knowledge Sharing

Ron Oberleitner, Rebecca Wurtz, Michael L. Popovich, Reno Fiedler, Tim Moncher, Swamy Laxminarayan and Uwe Reischl

Abstract With the prevalence of diagnosed autism on the rise, increased efforts are needed to support surveillance, research, and case management. Challenges to collect, analyze and share typical and unique patient information and observations are magnified by expanding provider caseloads, delays in treatment and patient office visits, and lack of sharable data. This paper outlines recommended principles and approaches for utilizing state-of-the-art information systems technology and population-based registries to facilitate collection, analysis, and reporting of autism patient data. Such a platform will increase treatment options and registry information to facilitate diagnosis, treatment and research of this disorder.

Keywords Autism · Patient information · Patient observations · Information systems technology · Population-based registries

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1 Background

Autism spectrum disorder (autism) is characterized by a range of neurological anomalies that typically include varying degrees of communication deficits and repetitive negative social behaviors. A tenfold increase in the incidence of autism over the past 15 years has been documented and is regarded as a significant public health concern. Despite the documented increase in the incidence of autism, the cause(s) of this disorder and appropriate treatment remain mysterious. The NIH road map emphasizes the need for developing phenotypic signatures based on available evidence including documentation of behavioral, clinical and genetic traits, as well as contributions by the basic sciences and applied bioengineering such as medical imaging outcomes, auditory phenomenology, neuroscience, and brain modeling studies.

Current population-based databases include a number of cross sectional studies sponsored by the CDC (Autism and Developmental Disabilities Monitoring Network [ADDM Net] and NIMH). These involve partnerships between a variety of governmental agencies, universities, and leading nonprofit organizations. Database initiatives that have been spearheaded include the Autism Genetic Resource Exchange, Autism Treatment Network, and Autism Tissue Program. Each of these offer contributions to the understanding of autism, but have significant limitations

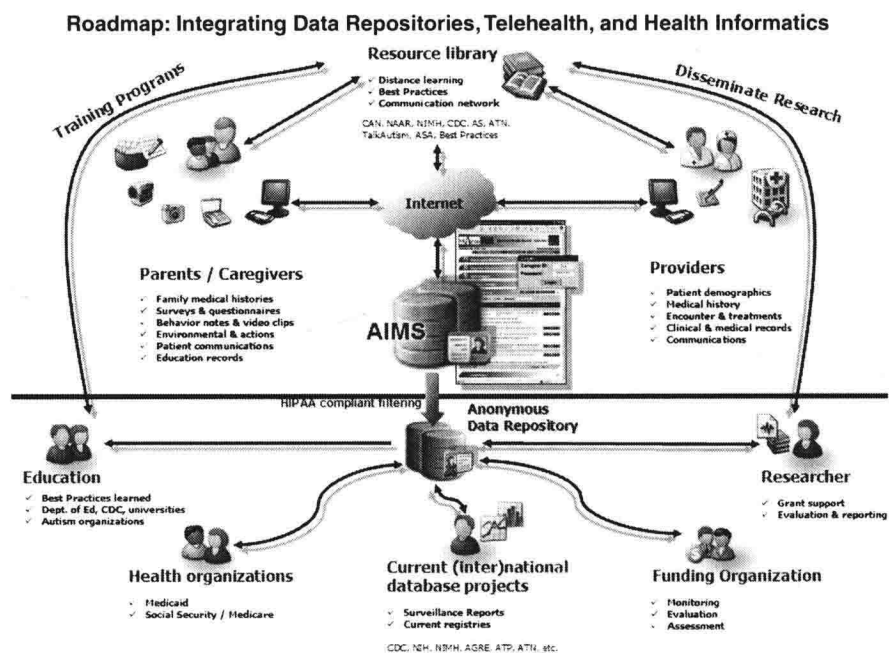


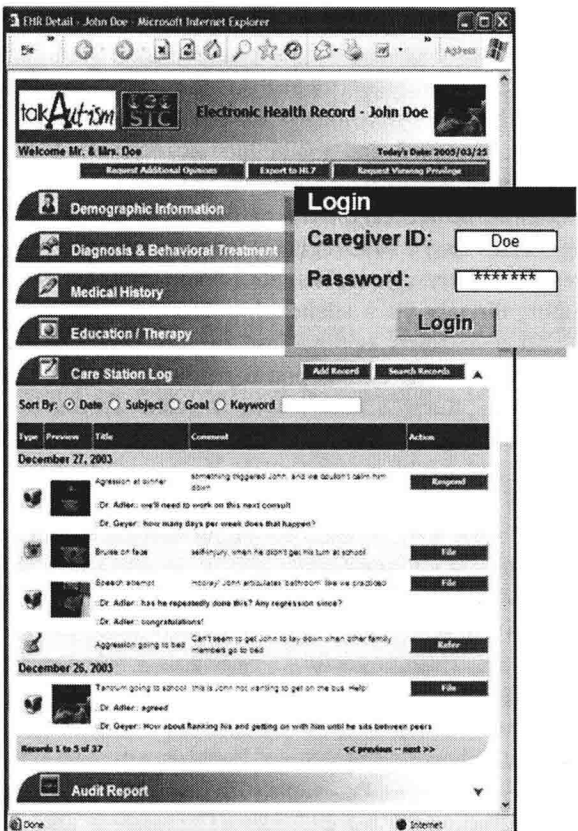
Fig. 1 Illustration of AIMSTM to service patients, parents, and healthcare providers, while supporting researchers, health organizations, and funding agencies in understanding more about autism spectrum disorders

in terms of ease of use, costs to build and maintain, and interoperability with other database projects.

In the National Institute of Mental Health's April 2004 *Congressional Appropriations Committee Report on the State of Autism Research* [1], the authors list the following obstacles, among others, to understanding the causes of and treatments for autism.

- Lack of a national autism twin registry that would allow researchers to access a large sample of well-defined twins where at least one twin is affected by autism.
- Lack of multi-site, high-risk population studies (i.e. pregnancies and infant siblings of individuals with autism) that would allow for increased knowledge about risk factors, early development of autism, and enhanced characterization of the disorder.
- Need for enhanced mechanisms to involve voluntary organizations, industries and potential donors in all stages of research design and implementation.

Fig. 2 Sample view of an autism EHR as developed by e-Merge/TalkAutism (Boise, ID) and STC (Tucson, AZ)



The shortcomings related to a lack of information resources can be overcome by the design and implementation of a longitudinal, person-based autism registry that would leverage the benefits provided by telehealth and the benefits offered by an interoperability infrastructure which integrates and builds on information already generated by the above-referenced initiatives. This paper outlines a vision for such a registry.

Complementary to necessary in-person examinations, the value of telemedicine and information technology to support the evaluation, diagnosis, and treatment of autism by the community of parents, health care providers, educators, and researchers has been outlined [2] (Fig. 1). To date, the ability to create a sharable information resource to support the diverse community of stakeholders is limited. The following illustration provides the concept for a new Autism Information Management System (AIMS). This system is designed, in part, to create a complementing patient registry that will be interoperable in relation to the current database initiatives, while providing a platform of sharable information to support the mission and goals of the various stakeholders.

1.1 Caregivers and Providers

The primary concept for the AIMS is a “Parent/Provider driven Person-Centric Information Environment” enabled by a web-based electronic health record (EHR), designed and maintained to enhance treatment options for caregivers. Caregivers would own the data and would have final jurisdiction in matters of access by providers. Providers (clinics, health professionals, therapists, specialized educators etc.) and caregivers (parents, other family members, paraprofessionals, respite workers, therapists, etc.) could complement in-person visits by communicating directly via a telehealth platform.

To help foster optimal use of this EHR, the system should incorporate an always-updating online portal resource library tailored to the caregivers and providers. Such a library will increase access to distance learning, updatable resource directories, and online communication forums involving other caregivers and health professionals is optimal to provide support and incentive to update the EHR.

An EHR can be used to capture and transmit patient behavior in a natural environment via input into text, and data capture devices like stethoscopes, or even cell phones and videophones. For example, images and video clips from a digital camera can send data linked to the treatment activities, milestones, or concerning behaviors. This can facilitate patient case management by providing visibility and insights into episodes that occur in their natural environment, and will allow a provider to remotely evaluate situations occurring at the moment of concern, and without delays or distractions found in a typical office environment. This type of system minimizes the impact on the individual with autism while maximizing the utilization of the provider. The system also offers the opportunity of the

parent/guardian to record accurate information in a timely fashion, which is of utmost concern to most.

By providing such support and communication benefits, the platform is also a convenient medium for researchers to request voluntary information to facilitate research via surveys, questionnaires or with unique data capturing technology (Fig. 2). And as seen in other applications of telemedicine, there is savings realized by reduced travel for both professionals and families, comparable satisfaction to inperson visits, and advantages of accurate case documentation—all contributing to justify the technology hosting fee for this platform.

1.2 ‘Patient Case’ to ‘Anonymous Data’ Repository

The design of the AIMS targets the need for researchers, health professionals, and educators to collect information about populations of individuals with autism. The vision is to allow anonymous data sets to be built based upon individual patient cases propagated in an individual’s EHR, that can be integrated and coexisting with other database projects. De-identified information will be combined to create an extended knowledgebase to support applied research as well as information sharing of “best practices.” Funding organizations would also be provided the ability to use the information to monitor and evaluate the impact of their service support.

Technical characteristics of this system would follow recent public health information development standards [3] and would build upon the lessons learned in developing population-based registries such as immunization information tracking systems [4]. Specifically, the system would exhibit the following features:

- Would utilize a secure web-based technology to support data collection and information retrieval in an easy-to-use format.
- The information database would be relational and person-centric to support individual case management, individual encounters, and would include treatment-based tracking.
- The system would include appropriate tools needed to capture and link video clips, family observations, and health histories related to time and space (i.e. environmental conditions).
- The system would include the necessary tools to support documentation, research, and reporting.

In order to achieve these goals, the AIMS must have the capability to electronically transfer information in a secure environment. The use of a Master Patient Index (MPI) to uniquely identify patients and to protect confidentiality will be essential. The underlying patient/provider database would contain defining data fields and code sets to support patient management including the following:

- Patient identification and demographics
- Family history
- Longitudinal medical history
- Epidemiologic questionnaires: i.e. exposures
- Time stamped behavior characteristics with attached video clips
- Treatment plans and parent progress reports
- Clinical and medical records

In addition to the core components, the system would allow attachment of added code sets such as:

- Co-morbidity (e.g. ADHD, sleep disorders, etc.)
- School records and reports
- Online treatment survey data
- Family observations of treatment efficacy

One of the essential design criteria will be to guard against information overload. In addition to the controls embedded in the data collection tools, it is recommended that “rule based” algorithms be employed to search for specific criteria, automating alerts for rapid provider notification and assessment.

2 Rationale

The typical health information system is one that is driven by patient encounters and maintained by providers or payers. These types of information systems currently do not support patient nor parent/guardian needs. They do not support research and reporting requirements. As such, additional information systems must be developed for clinical trials, patient registries, and statistical reporting. Resources are duplicated, additional costs incurred, and the ability to share lessons learned is curtailed or non-existent.

AIMS will be designed to collect information from diverse sources, store and share person-based case data and video, and monitor and report all value-added benefits. For example, there could be a module that can integrate school data in parallel. The ability to protect the privacy and confidentiality of individuals, providers, and research initiatives will require that information resources be limited to registered users and managed and controlled in compliance with HIPAA security standards.

The autism caregiver community should be especially motivated to adopt and propagate an accessible electronic health record that is easy to update and offers enhanced treatment for the affected individual(s) in their care. Many families maintain meticulous health history information because they typically visit multiple health providers and must therefore coordinate multiple stakeholders' understanding of their child's medical history. In schools, current best practices frequently require data collection and analysis to determine treatment effectiveness. Various

technology options are appearing on the market to support families and educators in this regard.

There are a number of reasons why a patient-centric autism community telehealth platform is feasible at this time. National objectives have been established through current federal initiatives to facilitate the implementation of electronic health records (EHR). These initiatives require that health care information technology providers work with the community to establish standards for communication and data transfer. The relatively recent use of standard “case” definitions and data elements encourages the development of population-based databases for information sharing about population health indicators. This can directly lead to a better understanding of autism.

The national push towards more extensive use of electronic health records will encourage technology vendors to develop improved next-generation online health records systems. As more health data is created and stored electronically, there will be increasing opportunities to share information and more incentives to establish resources capable of recording longitudinal data on individuals. The impact of HIPAA to support patient confidentiality has also forced the information technology community to focus more on security and thus establish improved methodologies for protecting and sharing data.

In addition to national trends and standard implementation, there are recent examples of registries that have succeeded. Chronic disease and medical registry models including population-based immunization registries are being implemented and maintained by public health departments. These systems acquire data through the participation of both private and public health care providers. There are now technology, business practice and policy solutions available that capture patient demographics and health information electronically. These systems are also available through easy-to-use web-based applications and protect patient and provider confidentially. These systems can be used as models for the implementation of autism-based registries.

3 Conclusion

A strong partnership between parents, providers, and teachers will be necessary to address the challenges of early diagnosis, treatment, and care of the children with autism. New telehealth technologies and electronic medical records storage and retrieval systems offer new opportunities for parents, providers and researchers to communicate their observations and findings to each other. We recommend the development of a new AIMS that will create a complementing patient registry that is interoperable in relation to current database initiatives while providing a platform of sharable information to support the mission and goals of parents, health care providers, teachers, and researchers involved with the autism spectrum disorder.

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Non-telephone Healthcare: The Role of 4G and Emerging Mobile Systems for Future m-Health Systems

R. Istepanian, N. Philip, X. H. Wang and S. Laxminarayan

Abstract The next generation of “m-health technologies” is a new and evolving topic in the areas of telemedical and telecare systems. These technologies involve the exploitation of mobile telecommunication and multimedia technologies to provide better access to healthcare personnel on the move, by removing the key disadvantage of trailing wires in current systems. These technologies provide equal access to medical information and expert care by overcoming the boundaries of separation that exist today between different users of such medical information. A great benefit to all users will be a more efficient use of resources and far greater location independence. In this paper we will address some notes and future trends in these emerging areas and their applications for m-health systems. Especially we will discuss the role of 4G and emerging mobile systems for future m-health systems. The new technologies can make the remote medical monitoring, consulting, and health care more flexible and convenient. But, there are challenges for successful wireless telemedicine, which are addressed in this paper.

Keywords mHealth · 4G · Mobile Telemedicine Systems

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1 Introduction

Time and space constitute barriers between health-care providers and their patients and among health-care providers. Patients in rural areas, on a space shuttle flight, at accident scenes, en route to a hospital, in a submarine, etc., are often physically remote to appropriate care providers.

Telecommunication technologies have presented themselves as a powerful tool to break the barriers of time and space. With the introduction of high-bandwidth, digital communication technologies, it is possible to deliver audio, video, and waveform data to wherever and whenever needed.

The health-care industry may be poised to adopt wireless devices and applications in large numbers. Wireless technology may provide improved data accuracy, reduce errors, and result in overall improvement of patient care. The number of wireless devices in health-care is expected to triple by 2005, according to a study by Technology Assessment Associates. Wireless-enabled handheld usage by U.S. physicians is likely to climb to 55% by 2005, up from the current 18% [1].

The benefits of the wireless technology can be illustrated in a number of different examples [2]. Patient information can be obtained by health-care professionals from any given location because they can be connected wirelessly to the institution's information system. Physicians' access to patient histories, lab results, pharmaceutical information, insurance information, and medical resources would be enhanced, thereby improving the quality of patient care. Handheld devices can also be used in home health-care, for example, to fight diabetes through effective monitoring.

The major step from second- to third-generation and further to fourth-generation and beyond mobile communications was the ability to support advanced and wideband multimedia services, including email, file transfers, and distribution services, including email, file transfers, and distribution services like radio, TV, and software provisioning (e.g., software download). In general the combination and convergence of the different worlds of information technology (IT), media, and telecommunications will integrate communications. As a result mobile communication together with IT will penetrate various fields of society and especially telemedicine.

4G is expected to support faster- and larger-capacity transmissions, in order to provide high-resolution video and other applications seamlessly in a mobile environment [3].

Mobile telemedicine is a new and evolving area of telemedicine that exploits the recent development in mobile networks for telemedicine applications [4]. It was suggested that the next step in the evolution of telemedicine would be mobile telemedicine systems [5].

2 Overview of Mobile Telemedicine Systems

2.1 Current Mobile Technologies

In recent years there has been increased research on wireless telemedicine using current mobile communication systems, especially in USA and Europe, for conventional civilian and military use [6–14]. However, the increased equipment cost (such as satellite-based systems) and the limited bandwidth of the current generation of cellular telecommunication systems, have restricted the wider use of these systems within the most promising segments of the health care structures in general. However, in recent years some emerging 2.5G- and 3G-based m-health systems with Bluetooth medical wireless technologies have been cited in the literature [2].

2.2 Limitations of Existing Wireless Technologies for m-Health

The current mobile telemedicine systems can be characterised by the following drawbacks:

- The lack of a flexible and integrated telemedical linkage of the different mobile telecommunication options. This lack of linkage exists due to the difficulty of achieving operational compatibility between the telecommunication services and the current mobile standards.
- The high cost of communication links, especially between satellites and global mobile devices.
- The limited data transfer rate of the current mobile telephonic systems (around 9.6 Kbit/s). Specially when compared to the costly new ISDN 1 and Primary Rate Interface (PRI) of less than 2 Mbit/s, or even DSL at 8 Mbit/s [11].
- The limited availability of mobile internet connectivity and information access due to the current bandwidth limitations.
- Healthcare is a very complex industry and difficult to change.
- Organisational changes are very often required for healthcare institutions to benefit from mobile telemedicine.
- Those required organisational changes most likely have an impact on how physicians and other staff members lose or gain power as a result of those changes.
- The short-term and long-term economic consequences and working conditions for physicians and healthcare systems are not yet fully understood.
- The methods of payment for such mobile telemedicine are not yet fully developed and standardised.
- There is a lack of incentive for busy specialists to practice mobile telemedicine because it is seen as yet another imposition for which they are not paid.