Expanding the Scope of Health Information Systems

Challenges and Developments

K. A. Kuhn[1], S. H. R. Wurst[1], O. J. Bott[2], D. A. Giuse[3]
[1]Institute of Medical Statistics and Epidemiology, Munich University of Technology, Germany
[2]Institute for Medical Informatics, Technical University of Braunschweig, Germany
[3]Informatics Center, Vanderbilt University Medical Center, Nashville, TN, USA

Summary

Objectives: To identify current challenges and developments in health information systems.

Methods: Reports on HIS, eHealth and process support were analyzed, core problems and challenges were identified.

Results and Conclusion: Health information systems are extending their scope towards regional networks and health IT infrastructures. Integration, interoperability and interaction design are still today's core problems. Additional problems arise through the integration of genetic information into the health care process. There are noticeable trends towards solutions for these problems.

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Keywords

Health Information System, Information System, eHealth

1. Introduction

In 2002, the International Medical Informatics Association (IMIA) Working Group on Health Information Systems (HIS) analyzed HIS challenges and recent developments [1]. Among the challenges were a lack of generally accepted measures to describe a HIS and to predict its performance [2], the lack of a shared vision, of comprehensive definitions for national infrastructures, and of top level guidance and direction [3]. Furthermore, the integration of HIS into health care professionals' work practice was considered an old and well-known, but still central, challenge [4]; the paucity of documented HIS success stories, paired with abundant failures, was a deterrent to new HIS implementation. Closely related to this aspect, socio-technical issues were ranked highly important in the interactive and communicative HIS environment [5]. Patient empowerment was identified as a current key issue to improve the practice of health care by patients becoming active participants in their own care process, selecting interventions and assessing outcomes together with their physician [6]. To guide HIS architects and to identify concrete benefits, more evaluations were considered necessary [1, 7].

Since 2002, the potential of information technology to improve patient safety has been further elaborated [8, 9]. Bates and Gawande have argued in favor of tools to improve communication, to make knowledge more readily accessible, to assist with calculations, to perform checks in real time, to assist with monitoring, and to provide decision support [10]. Current research activities are directed toward health knowledge infrastructures, including decision support systems and grid computing, wearable and implantable personal health systems based on biosensors, and also toward the integration of data from molecular and genomics medicine [11]. The scope of „health information systems " has been extending from regional networks to a more global „eHealth" perspective [12], integrating concepts from medical informatics, public health and business with an emphasis on internet-based applications and patient empowerment. Besides health care professionals and administrative staff, patients and health consumers are increasingly recognized as users of health information systems [13]. Enhancing the use and distribution of health information through the internet and related technologies, eHealth comprises a technical development as well as an attitude of global thinking to improve health care

locally, regionally and worldwide by using information and communication technology [14]. Some of the 2002 visions have come closer to reality, including seamless support and tracking of communication, and integrated management and resource utilization and tracking [15].

2. Current Developments

2.1. Continuity of Care, Patient Empowerment, and eHealth

Recently, discontinuity of care and the need for improved continuity have been studied more intensively. Continuity of care has been defined as "an organizational principle, where one or more health care providers deliver several health care services to a subject of care" [16]. In CEN prENV 13940, the concept has been described as a part of integrated care together with shared care and seamless care. Shared care has been defined as the situation "where two or more health care providers jointly co-operate to provide health care services to a subject of care for a continuing health issue" [16] and seamless care as "a quality principle, focusing on the timely and appropriate transfer of activity and information, when responsibility for the delivery of health care services is wholly or partly transferred from a health care provider to another" [16]. Coleman and Berenson [17] have described the challenges resulting from short time intervals between a patient's discharge from one setting and his/her reception at another setting. Unplanned transitions, unanticipated medical problems, and transitions during nights and on weekends, are occurring so fast that neither formal nor informal support mechanisms are available for

health care professionals who may not even have a relationship with the patient. Discontinuity occurs when „transitional care" fails and care cannot be continued by colleagues without an increased risk of medical error. It has been shown that at least one medical error occurred to 49% of patients after discharge [18]. In a Canadian study, adverse events happened to 19% [19, 20] of discharged patients. Of these adverse events, 30% were classified as preventable, and another 32% were classified as ameliorable events. These events were related to an increased risk of rehospitalization [18].

Not only between institutions or from an inpatient to an outpatient setting, but also within a single health care facility, discontinuity of care poses a threat to patient safety. It has been shown that cross-coverage of medical inpatients was associated with a 5.2-fold increased risk of an adverse event, which could be reduced through implementation of a computer application assisting in cross-coverage [21, 9]. Analyses of the communication process during handover among doctor shifts [22] suggested that in the majority of the cases there was no standard or formal procedure; the process was unstructured, informal, and therefore error prone. Another still prevalent in-house problem is insufficient follow-up of abnormal test results [23].

Patients' demand for participation in medical decisions has been increasing. In order to help patients understand potential risks and benefits of a procedure, and select the option that best accommodates their personal needs, information has to be coupled with high-quality decision counselling. The 2005 working symposium of the American Medical Informatics Association's college of Medical Informatics discussed system characteristics, tech-

nical architectures, benefits, barriers to and strategies for the adoption of personal health record systems for patients and consumers [24]. Helping patients to understand their own medical record remains a challenge [25]. Offering customized information of proven quality according to the patient's individual informational needs may be a key success factor for computer supported patient empowerment [26, 27]. Although there are concerns on the quality of information, especially the results of misinformation on practitioner-patient relationship, the utilization of the internet might meet demands to support patient empowerment [28, 29].

Worldwide, health IT infrastructures are being built up in order to improve quality of care and to empower patients. In 2003, the health ministers of the EU member states made a commitment to the development of national and regional *e*Health implementation plans [30]. In this declaration, eHealth has been characterized as "the use of modern information and communication technologies to meet needs of citizens, patients, healthcare professionals, healthcare providers, as well as policy makers" [30]. The Healthcare Information and Management Systems Society (HIMSS) defines eHealth with a focus on its effects on the patients status "as the application of Internet and other related technologies in the healthcare industry to improve the access, efficiency, effectiveness, and quality of clinical and business processes utilized by healthcare organizations, practitioners, patients, and consumers to improve the health status of patients." [31].

Several European countries have started to implement health IT infrastructures. In the UK, the Connecting for Health (CfH) project, one of the largest public sector and health IT projects in the world, is aiming to the implementation

of an "integrated IT infrastructure and systems for all NHS organizations in England by 2010" [32]. Finland is implementing FinnWell [33], comprising an electronic patient record systems, interoperability, e-prescribing, e-referrals, home care, telemedicine, decision support, standards-based systems, component-based systems and home monitoring systems. Germany has started an ambitious project to build a national infrastructure with health professional cards, patient cards, and electronic prescriptions, finally aiming at electronic medical records. Denmark currently implements the National IT Strategy for the Danish Health Service which will be completed by 2007 [34]. In the Netherlands a national IT institute for healthcare was founded in 2002 to establish a national healthcare information system architecture with an electronic health record system as a core component [35]. In other countries, regional and/or national projects have been started.

The Telemedicine Alliance, a consortium comprising ESA, WHO and ITU initiated in 2002, is building a vision for the provision of eHealth to European citizens by supporting several groups and organizations contributing to standardization like the "e-Health Standardization Coordination Group" (eHSCG) [36]. The European Institute for Health Records (EUROREC) [37] represents a permanent network of national centres (PROREC) to promote the adoption and extended use of standardized electronic health care records through quality and affordable added value services to the European market, health care providers, governments and patients. An initiative for a European Health Insurance Card has become part of the eEurope 2005 Action Plan [38] of the Commission of the European Communities. This action plan for European eHealth comprises national

and regional road maps by 2005, common approaches for patient identifier and interoperability standards for EHR and messaging by 2006, boosting investments in eHealth by 2006, deployment of health information networks until 2008 and a legal framework and certification of qualifications by 2009 [39]. A yearly ministerial conference and exhibitions is held to ensure progress and cooperation between the member states and the European Commission. On the request of the European Commission and in connection with the eEurope 2005 action line CEN/ISSS has created an open CEN/ISSS Focus Group to investigate eHealth standards requirements. Beginning of 2005 the group published a final report with 15 recommendations concerning current and future standardization issues in the eHealth domain [40].

In 2004, the US government published the report "The Decade of Health Information Technology: Delivering Consumer-centric and Information-Rich Health Care", and initiated a 10-year plan to build a national electronic health information infrastructure on basis of the "National Health Information Infrastructure" (NHII) [41]. The US Federal government [42] is acting as a facilitator in the plan, working with commercial, medical, political and other stakeholders for realizing e-prescribing standards in 2006, and an Electronic medical record for "most Americans" to be deployed by 2014 [43].

In Australia, HealthConnect has been proposed as a national health information network [44] by the Australian Government, in partnership with the states and territories. Test implementations have been operating in some territories since 2002 and work on a staged implementation has already begun. The Health Information Strategy for New Zealand (HIS-NZ) [45] aims at imple-

menting a national health information network until 2009. Hong Kong intends to realize a Hong Kong health information infrastructure until 2007, South Korea's E-Health action plan runs until 2009, Bangladesh started Integrated Rural Health information System (IRHIS), its first national e-Health project, as a private sector initiative [46], and Fiji realized an Patient Information System (PATIS) [47]. Malaysia has started to develop a telehealth platform initially constituted of four applications: a national consumer health portal, a lifetime health plan project, a continuing medical education portal and a teleconsultation network [48].

2.2. EHR Diffusion and Costs

Health care has become a major economical factor. In Europe, the health care sector employs 9.3% of the total workforce in the EU, i.e. more than 15 million people, compared to 13 million in retail and 13.3 million in business services. While health care expenditures worldwide are around $3,500 billion, the expenditures for health technology are estimated at $220 billion, and for eHealth at another $220 billion. Current funding of European Commission-BME/eHealth for the information society, life sciences and nanotechnologies programs is approximately $660 million [11]. Even today, eHealth is already the third largest industrial pillar of health care, after the pharmaceutical branch and medical devices, and its market is likely to correspond to 5% of health care expenditure within the next 10 years. In the US, on the basis of existing and expected requirements of critical information technology functionalities in 5 years, the costs of a national health information network in the US was

estimated at $156 billion in capital investment over 5 years, which would correspond to 2% of annual health care spending for 5 years, and $48 billion in annual operating costs for providers, functionalities, and interoperability functions. Approximately two thirds of the capital costs would be required for acquiring functionalities and one third for interoperability, while ongoing costs would be more evenly divided between functionality and interoperability [49]. On the other hand, electronic health care information exchange and interoperability between providers, hospitals and medical group practices, independent laboratories, radiology centres, pharmacies, payers, public health departments, and other providers could yield a net value of $77.8 billion per year once fully implemented and standardized [50]. The clinical value of such an extensive interoperability would likely add further value.

Recent publications on health information systems, nursing documentation systems, computerized medical records systems, and physician order entry systems reported mostly on successful solutions. E.g., clinicians reported ease of use according to record keeping time, savings in documentation and response time and a general decrease in time spent on documentation in comparison with paper [51]. Furthermore, it has been shown that the adoption of telemedicine services in various areas, including accident and emergency, was at least partially successful [52]. After implementation of an EHR, time needed to find patient information tends to decrease [53]. One retrospective, serial, cross sectional study revealed a reduced use of ambulatory office visits in favor of telephone calls after introduction of an EHR system while maintaining quality of health care [54]. A randomized prospective study

concerning the use of clinical and administrative information to detect errors in care and deviations from best medical practice, and to mitigate their consequences, showed a reduction in hospitalization, medical costs, and morbidity [55]. The combination of an EHR system with computer generated physician reminders for health screening in elderly patients produced a positive effect on clinical outcome especially for not-yet established screening tests [56]. Through savings in drug expenditures, improvement in utilization of radiology tests, better capture of charges, and decreased billing errors, a positive financial return on investment to the health care organization may be achieved [57].

Nevertheless, adoption and diffusion rates for electronic health records are still low, ranging between 5% and 39% with a predicted increase of 15% to 30% per year in the US, with significant differences especially in ambulatory EHR to other countries like Sweden with 90%, Denmark with 62% or Australia with 55% [58]. To collect more precise data on this, the World Health Organization recently presented a metric to measure the diffusion of EHR [59]. Various reasons [58] for this low adoption comprise financial and safety issues, but also organizational and technical difficulties. Misalignment of incentives, delays in standards adoption, limited demonstrated value of EHRs in practice, limited purchasing power among providers, variability in the viability of EHR products and companies [60], and a still volatile market were also described as reasons. In absence of a clear business case for interoperability between EHR implementations, there is a need to coordinate, promote and provide new incentives for relevant standards, and to educate the health care community.

2.3. Mobile Systems and Ubiquitous Computing

A promising solution to improve human computer interaction and to adapt systems to users' needs could be the use of portable computer technology like handheld computers or tablet PCs. The use of mobile devices is likely to improve information access, enhance workflow, and promote evidence-based practice to make informed and effective decisions directly at the point of care. Handheld computers are increasingly being used in health care, and applications of handheld computers can be found in areas of communication [61] documentation, medical reference [62], and access to patient data [63]. Physicians are often enthusiastic about the possibilities of mobile technology, but in the end, usage and acceptance are still low [64]. Handheld computers are limited in their capability on storing and retrieving data, so tablet PCs might be more applicable [65]. Major obstacles to adoption include usability, security concerns, and lack of technical and organizational support [66].

Nevertheless current research on mobile computing focuses on its next level of pervasive computing, where mobile computer devices will monitor their environment and offer services adapted to changing contexts. An example is the location dependent presentation of patient information when the physician is near the patient's bed [67]. Ubiquitous computing combines mobile and pervasive computing, surrounding the user with technology that provides him or her unobtrusively with information and services dependent of the environment and relevant to particular context. Currently explored scenarios for application of ubiquitous computing are home care and monitoring e.g. [e.g. 68, 69], assistance for health professionals

[e.g. 70, 71, 72], and the self-organization of health care institutions [e.g. 73]. Sophisticated new human-computer interfaces and especially wearable systems are key technologies of ubiquitous computing in health care [74]. The latter are characterized by miniaturized electronic sensor systems invisibly integrated into clothes or small computers worn on the body and equipped with sensors for context awareness. Wearable systems aid in monitoring the patients' health state, environment and therapy over time, so patients can receive care whenever they need it [75]. They help in modeling and recognizing user activity, state, and the surrounding situation, a property referred to as context sensitivity. Applications in health related domains are [76], in particular, health monitoring through portable ECG, blood pressure or pulse monitoring systems, mobile treatment, and administration of drugs to chronic patients. Beyond wearable systems, assisted living systems like smart houses to care for the impaired or elderly at home are subject to research on ubiquitous computing in health care [77, 78]. Such systems might prove useful in improving the quality and reducing the cost of caring for the aging population [79]. In this context technologies like Radio Frequency Identification (RFID) may help with a better understanding of cognitive workflow through situational awareness of events, timing, and location of healthcare activities [80] or, just as barcodes, improve safety if used for identification of patients, providers, medications, or lab results [81, 82].

2.4. Bioinformatics Data

The field of bioinformatics has exploded during the last decade, and significant impact on preventive, diagnostic, and therapeutic measures through genomics and proteomics data are expected. Information systems will play a double role in this context: Knowledge resulting from genomics, proteomics, and metabolomics ("omics") research needs translation into diagnostic and therapeutic solutions, while systematically collected and coded clinical data will play an important role as phenotypical data for researchers [83]. The multi-dimensionality of the required data and fast adaptation to new requirements poses challenges on medical informatics. Data organization becomes a strategic target due to the increasing volume of genomic data and the well-known complexity of clinical data. There is need for a complete shareable, reusable knowledge model for representing the biological system [84].

By cost-effective high throughput laboratory methods, significant opportunities to study genetic factors have become available. Access to large samples of patients or from the population is realized through biobanks [85]. In many countries, biobanks have been established, beginning with the biobank in Iceland with 270,000 people [86], followed by the Estonian project with 100,000 people [87]. The UK Biobank [88] will involve at least 500,000 men and women aged 45 to 69 years from the general population of the United Kingdom. The Japanese biobank comprising 500,000 people [89] has been started and now a biobank in the US [90] with 500,000 or more individuals is discussed. Further biobanks are under construction worldwide. Concerns regarding data privacy for this new type of data are subject to current research [91].

Further research will require the combination of molecular-based technologies, systematic tissue procurement, and systematic data collection in order to identify clinically applicable "genotype-phenotype" associations and to translate them into useful diagnostic and treatment strategies [92]. Major challenges for medical informatics arise from the complexity and the dynamic nature of the data to be combined, the diversity and number of information resources, and a lack of use of standard data and knowledge representation methods. For example, official gene names are insufficient, navigational inconsistencies arise, and synonymy and polysemy cause confusion [92]. Ontology tools such as Protégé-2000, Chimaera, DAG-Edit and OilEd will play a role, but need further development [94].

Integration issues will make demands on data models; new viewing metaphors and methods will be needed to deal with the disclosure of genomic data as they contain much more information on the patient's health status than any other laboratory result and can be used as an unique identifier. It is possibly sufficient to store only significant parts of the sequences, but it will be a challenge to find the trade-off between disclosure and privacy [95]. Although genomic data tends to be more structured than phenotype data, existing models and standards need to be extended to support clinical interpretations within health information systems. The Microarray Gene Expression Data Society (MGED) is working on the standardization of gene expression data annotation and exchange. It developed MIAME and MAGE-OM for describing microarray experiments, MAGE-ML for data exchange and comprises an Ontology Working Group for achieving terminological compatibility [96]. The HL7 Clinical Genomics SIG has been addressing these issues by developing the "Genotype Shared

Model", representing the core genomic data as HL7 RIM objects. A draft for the „Clinical Genomics Dynamic Model" to support exchange of this data with other information systems will be discussed at the beginning of 2006 [97].

3. Challenges

3.1. Integration

Integration of health information systems is still on the move, and significant interoperability issues remain unsolved, which have to be addressed on a syntactic, semantic and terminological level [98]. Integration standards may be distinguished between technical and semantic integration and between data and functional integration, respectively [99].

Broadly applicable generic standards provide a basis for IT systems, where detailed domain concepts can be consistently embedded. The Reference Information Model (RIM) of HL7 [100] is based on a set of six core classes, which build the foundations of a multi-level ontology. The HL7 Clinical Document Architecture (CDA) is based on the generic HL7 RIM and its refinements [101] and seems to be a promising approach for the cross institutional exchange of clinical data and the establishment of an EHR crossing institutional borders [102]. The development of CDA Release 2 was finished in 2005 followed by its approval as an ANSI standard in May 2005 [103].

The Integrating the Healthcare Enterprise initiative (IHE) [104, 105, 106] is an attempt to improve functional compatibility of software components in healthcare. The basic idea is to specify so called IHE Integration Profiles on the basis of well established stand-ards such as HL7 and DICOM to serve as semantic reference for application programmers. Besides working on integration profiles for the domains of Radiology, Cardiology and Laboratory, IHE started in 2002 to focus on the integration of health information systems and their components in general and especially across health care institutions [107]. HL7 version 3 includes similar concepts of conformance testing [108].

To support separation of the modeling of medical knowledge from the implementation of an IT system, the archetype approach has been developed [109]. Enhancing the results of the Good European Health Record project (GEHR; EU AIM program 1991-95) the Australian Good Electronic Health Record project first made use of this two model approach [110]. This project produced experience about using archetypes computationally and led to the EHR specifications and Archetype Description Language (ADL) published and maintained by the openEHR foundation [111]. The CEN ENV 13606 [112] „Electronic health record communication" standard, which is currently under revision for resulting in the five part EN 13606 "EHR communication", also uses an archetype approach. Similar to the archetype approach of openEHR and prEN 13606, the CDA of HL7 also follows a two model approach based on the RIM of HL7 Version 3 and HL7 templates.

The Healthcare domain task force (HDTF) of OMG (previously known as CORBAmed) [113] is working on domain-specific services for the medical environment. Open source implementations for a Person Identification Service (PIDS), a Terminology Query Service (TQS), and a Clinical Observations Access Service (COAS) are already available; development of further services is in progress or planned. Experiences with using these services for the development of eHealth platforms are available concerning multidisciplinary electronic health record systems [114] and regional health care networks [115]. OMG and HL7 started in 2005 an initiative to collaborate in building standard healthcare-domain software components and services interface standards to promote open interoperability across health provider organizations and products [116].

The grid approach, which derives from disciplines such as high energy physics or biomolecular engineering, may also be of use for integration in healthcare. The idea is to offer transparent access to information and computing resources. Application of grid technology may solve many technical problems of eHealth [117], but the concept has to be adapted since its primary purpose in other disciplines is access to computing and not to information resources. Web services [118] reduce the difficulties of integration by providing interoperability of components through web standards [119]. The Open Grid Services Architecture (OGSA) [120] represents an evolution towards a Grid system architecture based on web services concepts and technologies. First use of this technology in life sciences has already been reported [121].

3.2. Workflow Adaptation and Decision Support

During the past few years, the nature of adverse events has been further studied and analyzed [e.g. 8]. The potential of IT-based decision support to prevent adverse events and errors has been investigated and better understood [9, 122, 10]. Computerized Physician Order Entry (CPOE) systems, in particular, have shown a remarkable potential

for reducing adverse drug events. The IOM has argued [75] in favor of a redesign of the health care process, effective use of information technology, coordination of the patient's state of health, therapy, and environment over time and measurement of outcome to continuously improve quality with the aim of reducing errors and improving institutional and process quality.

Recently, however, there have also been increasing concerns that patient care information systems can also foster errors rather than preventing them [123]. A study of a CPOE system [124] identified 22 different error types facilitated by the system. Examples include pharmacy inventory displays mistaken for dosage guidelines, ignored antibiotic renewal notices placed on paper charts rather than in the CPOE system, separation of functions that facilitate double dosing and incompatible orders, and inflexible ordering formats generating wrong orders. Underlying reasons were fragmented display, missing integration, problems with human-computer interaction, and insufficient adaptation to physicians' work practice. Moreover, a systematic review of clinical decision support systems by Garg et al. [125] showed that no other pre-defined study-level covariate was associated with the systems' success than involvement of study authors in the systems' creation and automatic system prompts instead of active system invocation by users. Wears and Berg have commented on these results [126] and identified a persistent discrepancy between clinical work and the model of work on which decision support systems are based.

Altogether, the potential of clinical decision support systems and especially of CPOE systems is high, but significant work on software and requirements engineering, studies of cognitive factors

[127, 128, 129], and evaluations are needed. Adaptation of systems to health care professionals' work practice has to be considered crucial in any case. Success of HIS and user satisfaction are closely related to systems usability. Interface design, organization of screens and displayed information, adaptation to work patterns, availability of visual advices and feedback are of importance. Therefore, design recommendations have been presented [130], and human-centered design methodologies [131] and usability requirements have been elaborated [122].

Understanding organizational structures and, especially, health care processes and work practice is a key prerequisite for adequate health information system design and management. Accordingly, methods and tools for the modeling of processes and organizational structures that affect health information systems are still a field of current work, focusing on process analysis [132], information system design and evaluation [133, 134]. In addition, analysis and design of knowledge-based clinical workflow support utilizing clinical rule bases or formalized clinical guidelines are a research issue. Besides enhancing workflow management system technology [135] methods and tools for guideline modeling [136, 137], guideline management and exploration, and guideline-based care have been elaborated [138, 139, 140]. Seamlessly integrating knowledge based process and decision support with electronic health record systems into health information systems remains an important field of work.

4. Concluding remarks

Health information systems have been developing towards IT-supported regional health networks and further

towards IT infrastructures for eHealth. Together with mobile systems and wearable devices, these infrastructure developments help to come closer to the goal of a health care system which is responsive at all times, providing access to care whenever patients need it, not just during face-to-face visits [75]. Still, however, technical challenges exist, and further developments of component frameworks are necessary. The potential of IT systems to prevent medical adverse events and error is undoubted, but software engineering requirements remain high, and adaptation of systems to health care professionals' work practice is still of eminent importance. More evaluations appear necessary in order to prevent technology-induced errors and also to guide architects in their design decisions.

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Correspondence to:
Klaus A. Kuhn
Institute of Medical Statistics and Epidemiology
Munich University of Technology
Ismaninger Straße 22
81675 München
Germany
E-mail: Klaus.Kuhn@lrz.tum.de