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# Scientific Papers

### [1] Medical Conferences in the next millennium: Just point and click

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The agenda of medical conferences is overwhelmed with meetings in different specialties. Even in the same specialty, there are too many conferences being held all over the world, all at the same time. Physicians all over the world are expected to keep up-to-date, and attending conferences is of great importance to exchange results and ideas. However, with over 7,000 upcoming medical conferences in 100 countries, no one can attend all conferences in his own specialty. Moreover, less than 70% of the time spent at these conferences is productive. Shrinking research budgets and travel grants make it more difficult for physicians to meet at international conferences. In obstetrics & gynaecology there are more than 100 conferences scheduled for the year 2002.

Recent advances in the computer industry, especially in both hardware and software, have provided a new accessible way for increased academic productivity. The most striking tool nowadays is the Internet. The Internet is a large collection of networks that are tied together so that users of any of the networks can use the network services to reach users on any of the other networks. Internet services are now available on a 24 hours, 7-day a week basis. The number of users in the world has increased enormously in the last few years.

Teleconference refers to communication between two or more individuals through the use of electronic equipment in different or remote locations all over the world through satellite video conferencing. This enables all parties to view the other in real time. The development of real-time teleconferencing software has enabled the Internet to be used as a cost effective infrastructure for conferencing using audio and video. Internet teleconferencing software can be used to hold "virtual" meetings, during which participants around the world can share ideas, as done on some news broadcasts, but on a much wider basis. Videoconferencing, either in a specially designed room or directly in front of your computer at home, opens up huge possibilities for cost reduction in the medical industry. Expected total savings over current paradigm are estimated to be more than millions. These saving are derived from saved travel time, expenses. Being still in his environment while attending an international conference on the Internet is an attractive point to physicians. Many more doctors in the developing countries of the south, particularly in Africa, could join in this new advancing technology rather than attending formal conferences in other areas of the world, which will cost them a lot.

Use of the Internet in medicine has expanded beyond traditional application of simply providing information. There were a number of successful trials worldwide in teleconferences that have been developing rapidly. Successful transmissions were performed from Pontiac, Michigan, to Laguna Hills, California, and Buenos Aires, Argentina, and participants actively interacted in audio and video formats in real time with a delay of 0.5-2 s. The broadcasting computer station was also able to receive real-time video and sound from the distant computers, allowing complete interaction between both parties over the duration of each transmission session. Average broadcast time was 1.5 h +/- 30 min, and the cost of each

transmission were equal to that of a regular local phone call. In another trial, live video and sound from the 11th World Congress of Anaesthesiology in Sydney, Australia were broadcast over the Internet. The broadcast lasted for four days, during which a functioning combination of computer hardware and software was established. Technical issues relating to broadcast of these real time signals over ISDN links and the Internet itself were addressed. Over 200 anaesthetists from around the world were able to 'attend' the plenary sessions via the Internet. In the field of assisted reproduction, the first global Internet conference was hosted on blastocyst culture and transfer.

Live-broadcasted videoconferences have excited many doctors who have expressed their deep interest in such technology. The experience gained in web based virtual conferences suggests that the Internet will find increasing use as a medium for medical congresses within the next few years. Large groups or outof-country meeting participants can join over the Web with a standard browser and Internet connection. If used properly, the Internet can provide a fast and cost-effective way for attending medial conferences. First, you have to register on-line for instant access or request more details online. Then, you can choose among any of the sessions offered and search the fully registered conferences for details of main topics, keynote speakers and specialist workshops. During the oral talk, you can see live slide presentation and submit written questions. Even, if you could not join the live-broadcasted conference, the oral talks and lectures of the conference with sound and pictures can be stored on the net on demand under the address of the specific organization or society.

The technology of Web conferencing software tends to work well with the most commonly used Web browsers that are rapidly and progressively developing. This means that it will get better. In particular, user interfaces will improve as JavaScript, dynamic HTML. Web based videoconferences will let the speaker manage his own meeting and view online participant lists. He can also track people who have watched his recorded presentation and create online usage reports when he needs them. Web based conference packages can be priced according to the number of days you attend, so you can pay for just what you need and no more. Global competition will increase and prices will be forced down. In addition, web based videoconference will be able to offer exclusive banner advertising either on the main site pages or targeted pages which will be visited by conference participants Finally, it should be noted that your computer must meet the following hardware requirements: For Windows 95, Windows 98, or Windows Me, a Pentium 90 processor with 16 MB of RAM (a Pentium 133 processor or better with at least 16 MB of RAM is recommended). For Windows NT, a Pentium 90 processor with 24 MB of RAM (a Pentium133 processor or better with at least 32 MB of RAM is recommended). 56,000 bps or faster modem, ISDN, or LAN connection, sound card with microphone and speakers (sound card required for both audio and video support). Video capture card or camera that provides a Video for Windows capture driver (required for video support).

In conclusion, the use of the Internet in live-broadcasting medical conferences in low cost, and accessible technology provides a potentially valuable tool for different organizations and societies in holding their conferences. Doctors from the developing countries to which the authors belong to wish this dream come true. This is practically exemplified by the use of a comparative analysis of the prices and cost-effectiveness ratio in developing and developed countries by using teleconferencing to save institutions precious time and money in securing the importance of continuing education for their staff. These examples include a prospective comparative study of this practical use in Egypt.

### [2]

# Healthcare direct-marketing in the age of cyberspace: A close look into the relationships between the Internet, electronic mail and healthcare

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The important issue at hand is how the Internet, and specifically the different e-mailing services, can be used to fulfil the important task of direct marketing in the field of healthcare. The real question was: "Could the revolutionary processes occurring in the world of 'cyber this' and 'cyber that' affect the way a healthcare provider does business?"

In the past, direct marketing could only be done through bulk mailings through the local post office. The pros of this option were it allows a large number of the target group to receive offers, announcements, etc. all at the same time. Unfortunately it also had many drawbacks, mainly a relatively low return on investment (ROI). Therefore, a new more cost-effective technique had to evolve to substitute this form of communication with customers/ clients, or potential customers/ clients. These issues are very evident in the healthcare industry since a service, not a product, is being offered. This is how the email services came in to help give life back to this time-old tactic.

Using emailing techniques as a tool for a direct marketing campaign has never been more effective, or promising as today. "At its heart, opt-in e-mail allows health marketers to forge a stronger bond between the organization and the consumer than is possible using traditional media," says Kevin P. Richardson, President of MedRocket, Inc., a healthcare marketing directed company. "E-mail remains the simplest, most-used, and arguably the most useful Internet tool. It is one of the most versatile vehicles a communicator has at his or her disposal. Even without a Web site, an organization can use e-mail to communicate with its customers."

Before entering the realm of technology based marketing, it is essential that we enumerate the different types of email campaigns used, so that a closer look into each can be provided. The main types of email techniques include: Autoresponders, Web-based forms, Opt-in e-mail, Unsolicited e-mails, Database-enabled content and last, but definitely not least Viral marketing.

By efficiently and effectively using the different e-mailing services, healthcare organizations can maintain an interested client group, a good customer relationship image and most importantly protects the organization's web site from being closed down by the host for spamming (or sending un-solicited mail).

The criteria for classifying any mail correspondence as solicited or spam is according to different criteria denoted by each mail server. The range differs so widely from sending an email to more than X number of recipients at one time to be being as harsh as to having any word in the correspondence being CAPITAL. Therefore, if this paper were sent to 50 different email accounts at the same time, some servers would consider it to be spam. Others would consider it to be spam only because the word capital is written in all capital letters. In this manner, the consequences of spamming has not only affected the organizations that take up this non-ethical means of propagating information, but also the very privacy and security of our mail boxes have become threatened, not by hackers, but by our own mail servers.

In conclusion, it is fair to say that cyberspace has created a new media that healthcare management must learn to control if they intent on maintaining a competitive advantage over their rivals. The process of sending electronic mail to customer/ clients, or potential customer/ clients, must not be neglected. Electronic mail provides freedom, versatility, low cost and high return on investment as compared with any other healthcare marketing plan. It therefore should be introduced into the marketing mix of all healthcare provider organizations, even if they do not posses a site on the World Wide Web. Given the many advantages and limited disadvantages, a properly constructed marketing campaign using electronic mail as its backbone can produce a high return on investment and strong marketing response.

## [3]

# MOBIlearn: Exploring new ways to use mobile environments and devices to access basic medical knowledge

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*Introduction:* The MOBIlearn project, co-funded by the European Commission and prospectively by the US National Science Foundation (NSF) and AU Department of Education, Science and Technology (DEST), is strategically positioned to provide relevant research outcomes. It explores new ways to use mobile environments to meet the needs of learners, working by themselves and with others. An innovative "open mobile learning abstract framework" will support new forms of organisational learning, using ambient intelligence, context awareness, location-dependence, personalization, and instant messaging. State-of-the-art mobile devices will be available. Part of the focus of the field trials covers "learning to interpret information sources and advice" by acquiring medical information for everyday needs. The high connectivity and functionality may lead to new group behaviours, akin to the SMS phenomenon.

*MOBIlearn: project scope:* The integration of new technologies in education and training is in essence a culturally driven process, with the need to bring about change not only in people, but also in the entire learning environment. This is a key part of the MOBIlearn project. The need for this socio-technical element in projects has now been recognised in the new eLearning Action Plan [1]. This is a part of the comprehensive eEurope Action Plan [2] for European adoption of digital technologies, in which a basic objective is for education systems to use developments in information and communication technology. Another important part of the MOBIlearn project is the free circulation of knowledge, in forms that are appropriate for individual users. In recent decades political and social progress has emphasised the need for free circulation of knowledge, as the most advanced answer to the increasing needs of new skills related to new technologies and new socio-economic models formed by the Information Society.

The recent "e-mobility 2001 EU Information Society" International Conference on mobility in the Knowledge Economy [3], convened in Goteborg in preparation for the European Council, highlighted priorities that we shall explore: the need to define new work paradigms (e.g., mobile worker) together with innovative models for their social, economical, cultural and environmental deployment, while preserving the local nature of content (national and regional) and cultural heritage. At the same event it emerged that the sustainable social and economic deployment of such models within the Information Society of the third millennium will see a key role of new technologies for mobile access to knowledge. On these social and technological premises, the MOBIlearn project aims to improve access to knowledge for selected target users (such as mobile workers and learning citizens), giving them ubiquitous access to appropriate (contextualised and personalised) learning objects, by linking to the Internet via mobile connections and devices, according to innovative paradigms and interfaces.

The Goteborg Conference also underlined the need for pilot experimentations and applications for the fast spread and uptake of envisaged models and related services to preserve Europe's leadership in the exploitation and innovation of mobile technologies. The need for this is becoming urgent. Thus, the MOBIlearn project is justified in two ways: its pioneering research and development directly targets priority areas for the knowledge society, and its exploitation directly addresses the need for Europe to stay dominant in the important area of mobile applications.

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To deliver these crucial results, the MOBIlearn project will exploit a partnership that is truly international, capable and influential, including well-known Universities with a large user-base (such as the Open University and the University of Birmingham), and calling on expertise from two US World-level academic institutions (Stanford University and OKI/Massachusetts Institute of Technology). The project consortium also involves mobile operators from four countries (Telefónica, Cosmote, Deutche Telekom, Telecom Italia), European-leading commercial organisations (Space Hellas, Giunti Ricerca, Emblaze Systems, Peter J. Bates) and World-class mobile devices manufacturers (Compaq, Nokia), and Australian on line learning content providers (education.au) enabling them to communicate with each other and exchange information at all levels.

The partners bring a real cross-disciplinary know-how, with expertise in pedagogy, adaptive interfaces, collaborative learning, context awareness, business modelling and e-learning technologies. The scope includes studies of conceptual models and new methodologies, with prototypes to implement them. These will be evaluated in trial application fields set up and managed by international partners participating within the MOBIlearn project. The objective is to improve the knowledge level of individuals through cost and time optimisation of learning processes. In particular, one of the representative groups that the project will focus on includes citizens as family members, to have simple medical information for everyday needs. Access to basic medical knowledge will to enable support for anywhere and anytime interventions. The certified knowledge basis will be provided by the European Resuscitation Council (not a partner, but a member of the MOBIlearn Special Interest Users' Group), which already trains non-specialised citizens in basic medical procedures (such as Basic Life Support), with quick reference, audiovisual procedural guides and VR simulations

*Expected results* : The MOBIlearn system will investigate ways to meet user needs and build knowledge spaces. The MOBIlearn project has international relevance by proposing the conception, development, experimentation, and exploitation of new models of learning, via next-generation mobile networks, through: - creation of pedagogical paradigms to support learning in a mobile environment (such as collaborative learning, organisational learning, dynamic knowledge creation in a group); - new architectural layouts to support creation, brokerage, delivery and tracking of learning and information content on mobile networks, which extend existing systems; - selection and adaptation of existing eLearning contents for mobile devices, enabling automatic multi channel and multi device versioning; - realization of new business models, based on existing success-cases (e.g., DoCoMo iMode), for self sustainability and deployment of the conceived solutions beyond the research timeframe within Europe's Knowledge Society of the third Millennium.

*Conclusions*: The goal of the MOBIlearn project is the creation of a virtual network for the diffusion of knowledge and learning via a mobile environment where, through common themes, it will be possible to demonstrate the convergence and merging of learning supported by new technology, knowledge management, and new forms of mobile communication. This also creates a virtual point of mobile access to content that could be used at a European and International level. A subsidiary goal is to develop deeper understandings of the social processes and interactions that arise when connectivity reaches a critical point, so that we are alert to the possible emergence of "ambient intelligence" equivalents of the widespread take-up by users of SMS.

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### [4]

# From web sites to e-communities: The Internet and mental health service users: An empowerment process?

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The Internet is a powerful tool, offering a whole range of possibilities for people concerned about mental health issues, especially service users. This relatively new medium has already had an effect on the way that people can access information about their diagnoses, treatments and health care options and its importance is set to increase as the availability of the Internet expands each year and Web sites become more sophisticated.

It is no longer the case that service users have to be reliant solely on information provided by their clinicians or other health care professionals. This process of information democratisation has been an increasingly important feature in the relationship between service users and professionals over the last forty years and the Internet is speeding up this process. The Net has become a place to get a second opinion; share experiences with other people who have the same problems; carry out personal research into diagnoses and treatments and find out about patients rights.

From being a predominately US based medium it has now become an important means of disseminating information for many agencies (from national organisations to local user groups) in many countries, especially in the developed world. The availability of internet based information sourced from different countries of origin is important not only because the dominance of the English language on the Internet is diminishing, but also because there are inevitable cultural differences in the way mental health issues are tackled and services provided.

The importance of the Internet as a source of information for people with mental health problems appears to be increasing. As the Internet has become more sophisticated there has been a rapid increase in the number of sites aimed at service users worldwide. As the number of Internet subscribers has grown so has the number of visits to mental health sites. Although, statistics on the level of usage of the Internet as a source of information by mental health users is difficult to extract, the indications are that it is increasing. The surge in the development of sites is a consequence of the potentially high numbers of people organisations can reach through the Internet.

Further, the cost of reaching a mass audience is no longer prohibitive (it does cost something, but it is affordable even for small organisations and individuals) and imaginative, well-constructed sites with something to say, can make a considerable impact.

The Internet then, can be considered a great equalizer, a tool for the empowerment of service users and a potential means of breaking down the stigma of mental illness in the wider community. Having said that, it would be wrong to say that is a problem free innovation. Although, as the saying goes, "information equals power", it does depend on the quality of the information being provided. Is it authoritative? Is it accessible to the layperson? Is it helpful? Is it accurate?

This presentation is based on my experience of researching web sites worldwide, and determining their value as sources of information for the mental health community. For the last two years I have been

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working for a UK based national mental health charity, providing the content for a new web site called Connects: The mental health portal (www.connects.org.uk).

In conclusion this presentation will seek to:

- Review service user-orientated mental health information and consider whether its availability can be considered a positive development.
- Consider the value of the Internet in promoting the interests of people with mental health problems and specifically those of us who are using mental health services.
- Examine the implications for society as a whole in using the Internet as a tool for addressing the misunderstandings, prejudice and stigma facing people who use mental health services.
- [5] Role-based authorizations using mobile agents in healthcare organizations

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*Introduction:* In healthcare information systems (HIS), the security threat is being considered as an important aspect. These systems should guarantee patient privacy and data security. With the use of Internet and Intranets for sharing valuable information among the medical community, the security problem becomes more significant as healthcare professionals rely upon the accuracy and the availability of the data these systems store. The dilemma of obtaining, using and sharing healthcare information to provide care while not breaching patient privacy, is therefore a serious concern [1].

Also one has to acknowledge that information concerning a particular patient might be distributed in different information systems, which makes its retrieval more time consuming and complicated, while a healthcare provider is trying to achieve the best treatment for the patient. The patient information needs to be readily accessible to all authorized healthcare professionals, in order to guarantee the suitable treatment of the patient, as well as the quality of the provided medical services. We support therefore the use of mobile agents designed to move among these HIS over an Intranet and get valuable information for the doctor. Mobile agent technology is a convenient way to acquire (detect, locate and accumulate) such valuable medical information.

As the sophistication of mobile agent software has increased over time, so have the associated threats to security [2]. In this paper we focus on access control issues concerning mobile agents that are used in healthcare organizations. We introduce the idea of role-based authorizations for the travel mobile agent, as it is more nature for an agent acting on behalf of a medical stuff member to achieve a local role at every host visited, after presenting the necessary credentials.

*Materials and methods:* Mobile agent technology offers many undeniable benefits in distributed computing, such as strong remote interaction over untrustworthy networks and dynamic customization both at servers and at clients. A mobile agent is an autonomous software program that can move from location A to location B carrying out specific tasks at the command of its creator. The program chooses when and where to migrate. It can suspend its execution at an arbitrary point, transport itself to another machine and resume execution. Using mobile agent technology we have moved from huge centralized computing devices supporting static applications, into client-server environments that allow complex forms of distributed computing. Such a technology offers a valuable advantage, as it does not require the treating doctor to spend precious time looking information for its patient. After launching the agent it can go back to its main duty and collect the information gathered at a later time.

In such healthcare distributed systems, authentication and authorization procedures are complicated by the fact that a request may originate on a distant host and may traverse multiple machines and network channels that are secured in different ways and are not equally trusted. When an agent arrives at a specific platform, the host has to decide what privileges to grant to the requested agent. Instead of using the traditional method of access control via an access matrix we introduce the idea of acquiring a role from the local medical role hierarchy. This is a direct use of Role-Based Access Control (RBAC) approach, but with a flexible method of selecting the appropriate role every time an agent arrives at a hosting platform.

The driving motivation for RBAC [3] is to simplify security policy administration, while facilitating the definition of flexible, customized policies. Though RBAC continues to be an evolving technology, the basic RBAC mechanisms provide a valuable level of abstraction to promote security administration for mobile agents. Access decisions are based on the roles individual users have as part of a healthcare organization. Roles represent the responsibilities, the tasks and the qualifications associated with a healthcare organization. Moreover RBAC offers an adequate model for the healthcare environment as the different roles a physician could undertake (through its dispatching agent) are almost well established and well understood among the healthcare community.

In addition, we propose the use of the emerging privilege management infrastructure (PMI) and the relative attribute certificates (ACs), as a means of extending a public key infrastructure (PKI) to allow users or other issuers to control how their authority is entrusted to software that operates on their behalf [2]. So, an individual authenticated physician may pass his role authority by using his private key to digitally sign an AC, which is capable to encode not only the message digest of the software, but also the role (privilege) and the policy passing on.

Moreover, we express the protection the agent must receive in conducting its activities by evaluating the current situation. The decision, which role the host is willing to release for the agent, has to be based on different criteria. First we take under consideration the principal who is responsible for the migration decision. This might be the previous hosting platform of a HIS, or the agent itself. Another criteria is the method of migration, this might be via hand off (a role hand his authority off to another role) or delegation (a role is combining his authority with another role). If we combine the previous, we have four different migration results, which give four different types of roles that the host will be willing to give. We also have to take under consideration that the hosting platform has to trust the host from where the mobile agent initiated or alternately the previous host from where the agent arrived. We discuss the different opportunities of medical roles that the agent is capable to posses, deriving from the different methods of migration.

*Results:* The main contribution of this paper was to conduct the security problem a mobile agent is facing thorough out its journey in HIS, by the use of role-based authorizations. We also consider the fact that an agent acting in a healthcare environment must have limited privileges and as the matter of fact no modification privileges. This limitation guided us to propose a parallel role-hierarchy especially designed for a visited agent, with no modification privileges for all roles. Depended of the migration method the agent might acquire an exact privilege role, an additional privilege or a limited privilege role.

*Conclusions:* A health-care information system must depend and operate on the basis of a clearly defined set of user roles to both internal and `external' users. In our approach we propose a flexible policy for assigning a role to the requested agent, which can be seen as `external' to the local information system.

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Information management becomes harder with the increasing flood of information - not only in medicine. The user needs systems which take a preselection of the information provided and which report periodically to him on their own. The Open-Source Project "PubMed-Bots" bases on a Opensource WAMP / ACCESS Environment and retrieves its content from the PubMed Knowledge-Base at the NCBI. A similar approach is also performed by services like http://www.pubcrawler.ie/ and http://www.biomail.org.

The objective of the work was to design a simple Open-Source Bot Software to allow not only a periodical email/browser update of certain PubMed Topics based on a specific user profile, user keywords. The System should also be able to process recent user feedback and modify the user and system profiles depending on the feedback. The system was designed as a simple web-interface, where users can login and configure their profile consisting of:

- 1. Treated diseases & Applied procedures,
- 2. Their medical fields of work (from a list of branches),
- 3. Their interest areas (from a list of branches),
- 4. Favoured information sources (Journals) Keywords form MeSH.

The actual System Lists were test-configured especially for cardiology topics. The single diseases & procedures and the branches where filled with the common PubMed Tags: Special Author names Keywords, MeSH major topics, Title Words, Text Words Journal names

For each user the system is able to submit a request computed from both the individual profile and the corresponding common profile. A user can then see a weekly update of new abstracts form PubMed. A Grading on "usefulness" of the single papers by the user can then reconfigure the individual profile depending on certain algorithms by adding single keywords or by adding "negative" lists of journals or keywords.

With 9 doctors over a period of 4 weeks showed good results in the first runs, but also showed up that the system performance in generating the lists gets very low with complex profiles. Per Profile in an overnight Session the System was busy in average for 8 minutes with each profile.

Overall the approach seems to be useful - the "worth" of the system may lie in the generation of the profile for some special medical branches. The Source-Code of the main system without implemented profiles may also be useful for an Open-Source approach initiated by the authors.

### [7] Implementation of virtual patient record architecture use case scenarios

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A Virtual patient record (VPR) is an ideal Electronic healthcare record (EHR) that is a decentralized and contains heterogeneous and distributed medical and clinical data [1]. In addition a VPR is feasible through the use any information and telecommunications platform such as Internet and is ported to the end user via a user friendly and transparent environment (GUI). In order to create a VPR, a series of prerequisite are needed such as thorough design, a Master Patient Index (MPI) [2], well-formed and structured data, a strong security policy, a code of ethics, and a Middleware structure for heterogeneous data manipulation. Extensible Markup Language (XML) is a Web standard that was introduced by the World Wide Web Consortium (W3C) and has become today the major driver towards heterogeneous system integration for any industry solution [3]. As a consequence the healthcare sector was also affected and many efforts [4-8] are in progress in EHR metadata coding. This work is based on our efforts to create an XML Schema that operates as an interface between different heterogeneous patient record structures. The XML Schema structure is based on standards such as HL7, DICOM, VITAL, GEHR and prENV 13606-4. We are testing our technological platform by implementing various healthcare scenarios and using state of the art java components and XML based technologies.

The architecture of the application, consists of a relational database (or a series of data distributed in various databases) for the storage of patient data, a server application (web server) that processes client requests and produces the XML documents and a client application (standard web browser) which provides a view of the data to the end user and the capability to edit and post the data back to the server application. The server application communicates with the databases to retrieve the data of a specific patient and produces the XML document that will be sent to the client.

The whole system is based on Java and open source technologies. The server application is implemented as a web application consisting of Java Servlets and Java classes. The client application consists of a web interface based on Javaserver Pages (JSPs) running on the web server, and XSL documents retrieved from the web server that are used to transform the XML document into HTML on the client. Furthermore, the generation of the HTML view is accomplished by XSLT transformation of the patient data XML documents with automatically created XSL stylesheets. The automatic generation of XSL stylesheets and templates is based on XML documents describing the document classes and their contents.

The XSL stylesheets for the creation of the HTML view (GUI) of the patient data XML document is also automatically generated based on the XML document describing the document classes and additional XML documents describing the HTML form view of the data.

The Resulting system is a flexible web based interface to access multiple instances of a patient medical record. In that sense, a doctor can have a complete history of his patients by using a simple web browser that simply and securely communicates with a web server dedicated to unify the disparate piece of a complicated puzzle: a patient record. By using this system the end user can view and even post data to a distributed electronic healthcare record that can cover all type of medical records: primary care records, homecare scenarios, telemedicine scenarios, clinical records located in hospital institution, etc.

The XML schema that is validating the XML documents created by the system as described earlier is unlimitedly expandable to incorporate any type of medical data and future developments. The important issue of security and privacy is handled by the implementation of personal security environments (PSE) through a Java Cryptography Extension (JCE) tool, for each user of the system. This PSE is using PKI infrastructure to encrypt and decrypt data, which is compliant to both HIPAA guidelines and the European Directive 95/46/EC on data privacy.

In matter of interoperability and expandability the virtual patient record created is simply expanded by incorporating new distributed databases by assigning Java beans to the database's fields and connecting them to XML document tags defined in the XML schema. As a consequence the system is driven by its own Java bean healthcare toolkit that acts as the physical data middleware. This pilot has been tested with three homecare scenarios in conjunction with a standard primary care patient record database. We are planning to assess this system with many more scenarios, by introducing features such as emergency telemedicine, hospital information systems, smart card setups and other information system involved in the deployment of healthcare networks.

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At this point this architecture is tested and assessed for its interoperability, its expandability, its usability and its user acceptance. The use of XML based technologies is the drivers towards the incorporation of new technological features such as Web services, voice technologies (via VoiceXML), and wireless services (PDAs and Cell Phones) in the near future.

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### [8] Clinical quality management tools in an intranet: A two-year experience

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*Introduction*: Guidelines and standard operational procedures receive growing attention in German hospitals for various reasons. The first major reason is probably the requirement for evidence based clinical decisions. Another major reason is the shift toward a DRG based reimbursement for inpatient treatment (DRG: diagnosis related groups). In fact, the German legislature has prescribed that hospitals must make explicit their quality assurance measures. In 2000, we have begun operation of a departmental intranet for the presentation and retrieval of quality guidelines, which are supposedly relevant for the everyday usage of clinicians. At a very early stage, we have decided to base this solution entirely on Lotus Notes Release 5 (Lotus Domino).

*Materials and methods*: The intranet is available within the Medizinische Klinik I (Med I) of the Center for Internal Medicine. Med I serves the specialties Pneumology, Endocrinology and Metabolism, Gastroenterology/Hepatology, Infectiology and Intensive/Emergency Care. The department is responsible for the non-surgical emergency admissions to the University Hospital. There are 137 hospital beds and 12 ICU beds; 55 physicians of all levels of proficiency are employed full-time. In 2001, 5000 patients were treated as inpatients. The intranet is shielded from the general medical network of the whole hospital by a router. The only connection to the Internet is a "Metaframe server" which provides Internet access through another firewall.

*Results and implementation:* The relevant information is kept on a Windows NT server as Lotus Domino Databases or HTML documents. Currently, we offer document databases about standard operational procedures and about general quality assurance mechanisms in the hospital. Guideline documents provided by the German "guideline agency" AWMF are integrated as HTML source code. Moreover, information about local resources is presented. This includes a lab test directory, a directory of

in-house medical counselling services, major telephone numbers, shift plans and rotation plans. Lotus Domino Release 5 requires that the system designer decides early in the implementation process on the preferred client. We are currently using the Lotus Notes client. All information might be viewed through an Internet Explorer, but optimal results for that mode of access require additional programming. Our integration of external HTML documents was technically straightforward. We decided, however, to keep the keyword information regarding national (HTML) guidelines in a Lotus Notes database because of the searching facilities of Lotus Notes. The coupling of the Lotus Notes part of the national guidelines database and the HTML source code was achieved by an individually written PERL program. The introduction of the Metaframe solution - providing restricted access to the internet - has increased the popularity of the clinical intranet greatly. Users report that access to common internet sites and literature databases has been beneficial to their clinical work. (Alternatively, this might have been beneficial to their happiness with the work environment). It turns out that users appreciate standard interfaces (i.e. any MS Internet Explorer) lot more than excellent non-standard interfaces such as the Lotus Notes client. In this two-year experience, the major advantages to the Lotus Notes / Lotus Domino based solution have been the ease with which new document databases can be defined ,out of the box", providing excellent search and indexing mechanisms. While the pure power of the Lotus Notes programming facilities might be intimidating to the novice, Lotus Script programming has turned out to be manageable given that adequate support is available. The major disadvantage has been the non-standard client interface and the difficulty of searching across heterogeneous databases.

*Discussion:* We have demonstrated the feasibility of constructing a viable intranet with significant medical information at a very low cost. The users have accepted this intranet, but the additional "goodie" of firewall-secured Internet access has greatly contributed to positive acceptance. Many users view the Lotus Notes client as too foreign, and likewise the usage of authoring tools in the system is not accepted unequivocally. Clearly, a move toward more standard looking interfaces should be considered. Security measures and functionality should not be sacrificed in that next step, however.

#### [9]

# A confidence space on the Internet thanks to the HONcode: WRAPIN («World-wide online Reliable Advice to Patients and Individuals»)

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An Internet research firm estimates that nearly 36.7 million adults visit 15,000 health Web sites to learn more about their personal health issues or to purchase products online [1]. By the year 2005, that number is expected to rise to 88.5 million citizens visiting medical and health Web content. The accuracy of any medical document is crucial. Indeed, the consequences of false information and bad advice can be serious and even irreversible [2]. The growth of medical information of any kind has become so extremely huge that it is impossible to ask experts to manually verify each document [3]. Thus, the quality of medical and health information on the Web is unsure and heterogeneous. Since its creation HON is devoted to distributing trustworthy and reliable medical and health information on the Internet to citizens as well as to healthcare professionals all around the world [4]. To improve the trustworthiness of medical and health documents, HON initiated in 1996 the deontology code called HONcode [5, 6]. The code is mostly based on three major pillars: (1) well-defined authorship, (2) references to other sources of information and (3) clear distinction between what is publicity and what is of scientific extraction. HONcode principles are a de facto standard on the medical Internet. HON has set a HONcode community, which counts 3,400 Web sites. These have been HONcode accredited and display the active

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and dynamic HONcode link on their sites. The principles are strengthened with application, tracking and enforcement tools. Regular and random review of HONcode accredited sites dispose Web masters to upkeep the right ethical standard. This article will describe the five years of activity of the HONcode. It will also show that throughout biannual surveys, the wise user prefers to visit HONcode certified sites with additional content from scientific databases such as MEDLINE. However the user needs to access evermore specialised, complementary, detailed, remote, exhaustive and reliable scattered medical and health databases. This expansion of HON services is the expected result of the WRAPIN project (Worldwide online Reliable Advice to Patients and Individuals) of the European Community (IST-2001-33260).

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### [10]

# **ProMISe - Project Manager Internet Server: Implementation of a complete tool to design and manage both structure and data of multi-center disease registries and clinical trials over Internet without software development costs**

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ProMISe (Project Manager Internet Server) is an Internet-based, secure application for the Design, Maintenance and Use of (clinical) data management projects. Developed at the Dpt of Medical Statistics of the LUMC, it is currently in full production. Using ProMISe, the design and implementation of single and multi center data management projects can be performed without any programming effort, thus allowing the project coordinators and users to fully concentrate on the clinical aspects and logistics of the study at hand.

In the way a word processor provides a generic tool to produce an unlimited variety of text documents, ProMISe is a generic program which allows a Designer to create and maintain an unlimited number of data management projects over the Internet.

For each project running under ProMISe there is a "Designer", responsible for the structure, the Dictionary of the project itself. This person will "translate" a clinical protocol (a paper coding form) into an electronic one and thus into an Internet based data management project. The Designer is a user with special access rights and usually a clinician (project coordinator) with some "feeling" for data management (in our situation being trained and guided by the responsible biostatistician, who will also make sure that the resulting structure closely resembles the structure needed for the intended analyses).

Normal users are associated with centers and registries. Usually centers coincide with hospitals or departments therein. Users belong to a center and each of them has his/her own user name and password with associated access rights varying from "statistical overview only" to "full data management access" (complying with all privacy laws currently in force in the EU). A Registry is a kind of "virtual" center and an inherent property of the concepts realized in ProMISe. A Registry could for example be the union

of a number of centers ("national registries") or a certain subset of patients (e.g. according to a disease classification).

The entire process of designing, activating and maintaining a data management project in ProMISe does not require a single line of programming. ProMISe is a computer program which writes computer programs. It is a systematic approach to data management in clinical research avoiding repeated and unnecessary spending of precious research money on the development of basic and intrinsically identical computer software for data management. The Designer of a project merely provides, in a systematic and menu driven way, clinical and structural information to the design part of the ProMISe software. On that basis, the ProMISe designs modules then creates the entire infrastructure of the project (that is all tables, indexes, content, web pages etc etc) within a few minutes. In this way it is possible to have a complete multi center study running everywhere in the world in a few days!

The architecture of any ProMISe project is transparent and open to other applications. For instance a patient information website could be allowed to extract statistical info from one of the data tables of a ProMISe project to display a table with the current number of treatments having been performed for a set of diseases.

One of the current production applications is for the European Blood & Marrow Transplantation group: 500 hospitals and around 3000 members. The application covers the field of hemato-oncology and collects information on the sequelae of bone marrow transplantation in Europe in over 10 different diseases using about 2000 variables. The data base contains over 160.000 transplants and nearly 300.000 follow-up records. Apart from access by all individual hospitals (some of them enter data themselves, others send in data on paper which are entered via ProMISe at a central location by the central Registry) there are over 10 disease related Registries (to them the data base appears as containing only one specific disease) and a number of National Registries (Registries dynamically defined as the collection of patients in centers in one specific country). Other examples will be given during the presentation; they include randomised multi-center studies and International registrations for various diseases.

Using ProMISe our department can set up almost any clinical research data project over Internet providing a common interface to data management and allowing all participants in all clinical fields to profit from modifications and improvements triggered by the numerous users in the various projects. Some properties of any ProMISe project:

- 1. Data Entry forms
  - Dynamically created in real-time
  - Menu guided data entry (mouse and/or keyboard)
  - Unlimited quality control
  - Unlimited help files Reports
  - Columnar, Status, Statistical, Missing, Survival- and Log-file reports
- 2. Administrative participating centers;
- 3. Users currently on-line;
- 4. System documentation available to all users
- 5. Paper Coding Forms
  - Created by any user
  - Full control over layout; reflecting the current data input electronic counterparts
  - Partially filled paper coding forms can be used e.g. to obtain follow-up information
- 6. Backups and conversions
  - Backup of data available as Microsoft Access file at any time
  - Full conversion also to Excel, Word (mail-merge) and SPSS writing out the entire dictionary and creating fully documented SPSS system files

- Seamless integration of local private data management projects with the central, internet based project using standard Microsoft Access features (like linked tables)
- 7. Project Creation
  - Web based interface for the (relational) structure covering: Item properties; Coding System; Chapter and Section divisions; Logical Tests (quality control), Warnings (unlikely situations) and Jumps (skipping of non-applicable items and sections); Help files
  - The Clinical Dictionary is maintained in transparent tables; can be made available to other applications in real time; can be changed/extended at any time during the projects life time; all modifications fully automatically executed Project Maintenance
  - Web based maintenance of Users; Centers; Registries; Help files
  - Bulk data upload (maintains relational integrity of the project even if partial data are uploaded; full reporting on changes)
  - Separate data tables and Dictionary for testing within the project
  - Full information on all user activities (logon, execution of programs); all data modifications (old value, new value, date & time, user name, IP address) are logged.

### [11] Internet in Primary Care: How Polish family physicians and their patients use the Internet

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Internet, a brilliant donor of every kind of information, is a quickly developing medium in times of comprehensive informatics technology and computerization. The increasing role and the use of Internet in medicine is an incontestable fact. Primary care is the basic medical area where the Internet applications could be successfully implemented both from doctors and patients sides.

*Objective:* To access how Polish family physicians and their patients use Internet; to find out whether and how often they have used it, what they are looking for, what are their expectations and personal attitude to it, , if they know and use any medical Internet sites, how evaluate the quality of Internet information and the security and confidentiality of transferring data.

*Materials and methods:* Retrospective analysis obtained from a specially designed questionnaire. One hundred family doctors who had been trained in the Department of Family Medicine in 2000-2002 years and three hundred of their patients were asked to fill out the questionnaire.

*Results:* Replies were received from 90 family physicians (90% response rate) and 180 patients ( 60% response rate). 80% of respondents, both doctors and patients, are familiar with the computer; the remaining 20% of them don 't use the computer at all. They use computer mainly at home (44% of family doctors, 30% of patients), but also at work (31% of doctors and 20% of patients) and some of them at home and at work (20% and 29% respectively). 64% of Polish family physicians and 67% of their patients are Internet users. Family doctors mainly look for professional knowledge and advice (72%), then information (57%) and some of them entertainment, friendship (16%) and profit from various Internet services (14%). Patients first of all look for high quality information (75%), but also for professional knowledge (66%), make new acquaintance, play games (31%) and use Internet services (11%). The personal e-mail account reported 55% of doctors and 45% of their patients; one quarter of respondents use regularly at least two e-mail accounts. Patients considerably more often are Internet users; they usually use it every day for 1-2 hours. Doctors use Internet 1-2 times a week for 3-4 hours, respectively. Nearly 70% of Polish family doctors profit from web medical sites, the most popular are

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Medline and Medscape services. In opinion of 60% of doctors Internet is an essential tool in daily medical practice; they appreciate high quality of receiving medical records.

Patients look for information related to health only occasionally, 71% of them do not know and never use medical web sites; they think Internet is very uncompleted health information resource and they doubt if it could help them in solving their medical troubles. Only 8% of patients would like to be consulted regularly by 'Internet physicians' (if it would be possible), 22% of them only in exceptional cases; the remaining 70% of them don't believe /don't trust such consultations or have no opinion about it. Both family physicians and their patients are afraid of security and confidentiality of transferring by Internet medical data.

*Conclusion:* Internet is an important tool willingly used by majority of Polish family physicians and their patients. Both doctors and patients the most often look in it for high quality information. Doctors don't use Internet so often as their patients; however they assess the credibility of medical information much higher. Patients like to benefit from Internet for various purposes but in the same time they weakly trust in Internet medical resources and are afraid to be treated remotely by 'Internet physicians'.

### [12]

# Ask doctor per email - A modern health service among Finnish university students, carried out by general practitioners

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*Background:* Finnish Student Health Service (FSHS) is a foundation providing university students preventive health care, medical care, mental health care, and dental health care services at 16 health centers. Since 1993 FSHS has produced health services also per email; at University of Tampere started then an email service for health counselling. This study covers the action of a nationwide health service for all university students. It is located at Helsinki health center, carried out by two General Practitioners. "Ask Doctor per email" -service functioned at the period of time 1.9.2001 - 31.5.2002 as an open and unprotected email-service. GP's gave instructions and advice on health and illnesses and answered students' questions in 1-3 (week) days to senders' personal email address.

*Objectives:* To explore the question-answer material to characterize a modern eHealth service, the main topics of the questions and answers, and its users.

*Methods:* Statistical analysis (Microsoft Excel) of a random sample (n=812) of all questions sent to the service (N=2437). As comparison material functioned a question- answers material from the period of time 1998-2000 (n=1480) from FSHS counselling email service in Helsinki-region (the first and second years of its existence). The diagnosis-data (in an electronic medical record-system, Medicus\*) of all FSHS-GP's nationwide from the year 2001 was compared with the topics of "Ask Doctor per email" - service. I also made a questionnaire study (in www-environment) for users of "Ask Doctor per email" - service (at the period of time of 6 weeks), (n=260).

Results:

- 1. The number of send questions is continually growing; annual growing rate is 1.5.
- 2. A big difference in the activity to use the service exists in respective cities and between male and female; the students in the big cities and female students are active users.
- 3. The main topics existing in the "Ask Doctor per email" service differs from the diagnosis registered at consultation hours; hot topics for the former are: family planning, contraception, sexual health, general symptoms and signs, and dermatological problems.

- 4. If the "Ask Doctor per email" service would not exist, 38% of its users would make an appointment for consultation hour, but 24% of users would not use any professional health service.
- 5. Over the half (54%) of the answers contains an advice, information, or a suggestion to self-treatment without a request to make appointment for a consultation hour.

*Conclusions:* The growing interest of use of electronic, email- and internet based health services (eHealth services) makes us as health professionals responsible to guarantee the adequate function, quality and role of the new forms of services to avoid them to be new forms of medicalisation. EHealth services planed and organized well and utilized vice can benefit both the users and producers; critical analyzed data and experience of the new modern form of eHealth services is certainly needed.

### [13] Knowledge attitude and practice of the Internet in Nigeria

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A questionnaire based cross sectional study was undertaken o determine the knowledge attitude and practice of the internet among Nigerian doctors living in Enugu, the capital city of Eastern region of Nigeria. Of the 535 doctors questioned, only 35 had regular access to the Internet. Of the 35 doctors who had regular access to the Internet, only 3 used it for their medical practice. The others used it only occasionally. Four hundred and twelve doctors believed that the Internet had a role to play in routine management of patients in Nigeria. Lack of access to the Internet was a major limiting factor to the use of the facility for medical practice in Nigeria.

It can be seen that the use of the Internet for medical practice in Nigeria is still very rudimentary. Very few doctors use it for their every day life or for medical practice. Efforts should be made to increase the awareness of the use of the Internet among medical practitioners in Nigeria, and to increase its availability. This is important in-order that a wide segment of the population who live in the developing world is not left out of this race for knowledge.

*Methods:* Questionnaires (paper) were randomly distributed to medical doctors practising within Enugu metropolis. Five hundred and thirty five (535) questionnaires were distributed in all, and 530 were returned and used for analyses These questionnaires were distributed to doctors practising in Enugu, Nigeria, incorporating their ages, rank, specialisation and level of practice. Their access to the Internet was sought for their daily use and for the practice of medicine. Their views on the use of the Internet and its usefulness to them were also obtained. Among those who used the internet, an attempt was made to know what use it was put to ,i.e. whether it was used for routine consultation, investigation, obtaining results or treatment. Their views on its usefulness in the future were also determined.

*Results:* Of the 535 doctors questioned, only 35 had regular access to the Internet. Of the 35 doctors who had regular access to the Internet, only 3 used it routinely for their medical practice. The others used it occasionally. Four hundred and twelve medical practitioners believed the Internet would be relevant to medical practice3 in a developing country such as Nigeria.

*Conclusions:* The use of the Internet for medical practice in a developing country such as Nigeria is still very rudimentary. Very few doctors use it for their every day life or medical practice. A large proportion of doctors still believe that it is not relevant to medical practice in Nigeria.

[14]

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# Managing complexity: Using the Internet to support and improve inter-jurisdictional health information standards

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Increasingly, efficient and effective population health requires multiple health jurisdictions to share health related data in order to plan and coordinate their activities. Sensitivities associated with bioterrorism have increased the stress for rapid action and a renewed improvement in the working tolerances between inter-jurisdictional population health information systems. A key requirement of any multijurisdictional population health information sharing strategy is the development and maintenance of technical, semantic and policy interoperability within the system defined by the collective union of each participating jurisdiction's boundaries. To achieve interoperability in this context requires high levels of information harmonization within and between the participating jurisdictions. This paper describes the current efforts of the Peer-to-Peer Standards Development project an ongoing research initiative addressing the development of information management and sharing processes that increase interjurisdictional interoperability. The Info-Structure Division of the Centre for Surveillance Coordination directs this work within Health Canada.

The Peer-to-Peer Standards project is focused upon the development of processes and technologies that support useful and sustainable population health information standards within a Pan Canadian context. The process is intended to assist health professionals using different intra-professional, intra-organizational, and intra-jurisdictional health data systems in developing meta-data repositories that improve the inter-professional, inter-jurisdictional utility of health data related to population health. This intensely complex task is accomplished through a process directly supported by a series of Internet based tools that work to support and coordinate the actions of participating health professionals and their organizations.

The presentation discusses the findings of the experimental trials of the Peer-to-Peer Standards process run from the spring of 2001 to the fall of 2002. The experimental trials of the Peer to Peer Standards process include: 1) a Pan Canadian Communicable Disease minimum data set; 2) a Pan Canadian data system for monitoring adverse vaccine events; 3) a Pan Canadian data system for monitoring immunization; and 4) a regional health authority meta data repository for the sustainable support of standards, policies and guidelines relating the individual professional activities of twenty-seven regulated health professions to a developing clinical informatics system and the electronic patient record which are expected to support population health decision making.

### [15]

### A transcontinental telemedicine platform for cardiovascular ultrasound

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*Introduction*: This paper describes the design and implementation of a transcontinental telemedicine platform for echocardiographic applications The developed solution provides a local resource efficient digital archive and a simple-intuitive sharing system, enabling the local acquisition, storage and visualization of DICOM cardiovascular ultrasound sequences. The system also includes a telematics platform capable of establishing cooperative telemedicine sessions between the Cardiology Departments of the Central Hospital of Maputo (Mozambique) and the Central Hospital of V.N.Gaia (Portugal). The communication relies on nx64 kb/s ISDN channels allowing both real-time and store and forward sessions promoting in any case the remote access and sharing of clinical data.

*Background:* Echocardiography is a rather demanding medical imaging modality when regarded as digital source of visual information. The date rate and volume associated with a typical echo poses several problems in the design and deployment of systems with acquisition, archiving, processing, visualization and transmission functionalities. We know that, for example, an echocardiogram study can produce a volume of 54 MB when considering a frame rate of 25 fr/s, and a minimal sampling matrix. Digital video compression is a technology of the utmost importance when considering key issues like storage and transmission times. In this case, given the time-space redundancy that characterizes this type of video signals there are important gains by choosing a compression methodology that copes with both intra-frame and inter-frame redundancies. The definition of an adequate trade off between compression factor and diagnostic quality is a fundamental constraint in the design of both the digital archive and the telecommunications platform.

Design and implementation: Both clinical partners are equipped with echocardiography machines including standard DICOM output interfaces, videoconference platforms and was installed a network infrastructure with two server computer in the Eduardo Mondlane Medicine Faculty. The Portuguese Medical partner provided the clinical training and is ensuring the remote support to diagnostics and therapeutic decisions, in offline and/or real-time sessions [1]. The referred clinical modus operandi, the distance factor and the extremely limited telecommunications resources available, imposed us the arduous task of planning and implementing an innovator and cooperative system based in a secure-efficient telematics infrastructure between both parts.

*Image compression:* The novelty of our approach starts by embedding each storage server with highly efficient MPEG4 encoding software. Since MPEG4 is not a DICOM native coding standard, subsequent image transmission, decoding and reviewing is accomplished through a DICOM private storage and transfer syntax mechanisms enabled between storage servers and review clients equipped with in house developed echocardiography oriented viewing software. In order to achieve full compliance all the other DICOM information elements and structure were kept unchanged. With its new object based and other improved coding algorithms MPEG4 offers an impressive trade off between image quality and compression factors spanning a wide range of bit-rates. Two parallel studies were carried on assessing both the image quality when blindly compared with the uncompressed originals and when compared with competing coding standards such as conventional JPEG [2], JPEG2000 and MPEG1 [3]. The former was conducted by a series of expert observers and the latter was based on the usual mean square error metrics.

The lack of physical telecommunications structures between the two interlocutors, with minimum technical requirements, takes us to the inevitable space segment through satellite communication services. The project consortium has opted for portable terminals INMARSATB, allowing ISDN 64Kbps point-to-point connections and permanent availability. The operation method equated has take in consideration the primordial necessity of establishing emergency session in real time. The utilization of eventual alternative telecommunications platforms as the public ISDN (not available in Maputo) or Internet (quality-of-service not acceptable) was also contemplated. The expected resource to a shared network obligated the implementation of security mechanisms in the transmissions (SSL-128bits) as well the resource to digital signatures supported by public key infrastructures (PKI) and digital certificates.

*Results:* Our MPEG4 encoding strategy taking full advantage of object texture and shape coding and inter-frame redundancy led to results that clearly points to an overall storage boost. With more than 1200 studies performed (Gaia) so far, we can say that file sizes of 15 to 30 frames cine-loops with Doppler colour coded information, rarely exceed 200 KB and typically reaching 100:1 compression factors. Even for a heavy work-loaded echolab these settings will make possible to have several years of online primary storage. At same time, and concerning the echo transmission aspect, this method allows a low-cost and time-efficient telemedicine communications solution between Maputo and Gaia. As our quantitative and qualitative figures of merit image quality is kept at high standards without ever impairing its diagnostic value. For compression factors of the same order of magnitude competing coding standards will lead to a moderate to severe decrease in image quality.

Concerning the clinical scenario, the project contemplates two type of utilization to this transcontinental telemedicine platform: - An interactive scenario that occurs in real-time for improved decision support, which can be programmed or used in emergency cases. This scenario is video conferencing based, and the physicians can exchange opinions and/or viewing the patient echocardiogram. - The offline session is the other possible scenario, and can be conference-based teleconsultation for offline analysis of clinical cases, or analysis of transferred exams files (DICOM-private-syntax). In the last case the physician in the Maputo can select echo images sequences, make annotations, append extra comments and send over ISDN lines to the Gaia Hospital. This information is stored in one dedicated server and accessible by the cardiovascular ultrasound specialists. Both methods can be used at same time, the physician in Gaia can open and examine a clinic record file previous send by Maputo, and use videoconferencing equipment to face to face consultation and decide the therapy.

*Conclusions:* The emergence of MPEG4 as a coding standard for multimedia data with object based and other enhanced encoding facilities appears to be a good alternative for the cost-effective storage and transmission of digital echocardiographic sequences. The developed software provides a seamless integration with the traditional DICOM entities, boosts the storage capacity up to the level of several years of online availability while preserving the image quality at high standards. The overall result is a cost-effective system with improved workflow and generalized user satisfaction.

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### [16] A multi-service patient data card

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*Introduction:* The world globalisation process is increasingly promoting peoples' mobility, creating a higher dispersion of patient clinical records and forcing even more the healthcare providers to take measures to promoting the share and remote access to patient clinical data. In these scenarios, a Patient

Data Card (PDC) is unequivocally providing a way to store and transport patient's administrative and clinical data. This paper proposes and describes a Multi-service PDC that integrates, beyond these common characteristics, a new set of functionalities that allow handling well patient mobility. The Multi-Service PDC allows the storage and management of: a) resident clinic-administrative data, b) structured hyperlink to remotely access distributed patient records, and c) digital credentials that are a key-point to implement and perform a solid user identification and authentication.

Materials and methods: Current PDC implementations are typically restricted to specific environments and goals, and are mainly applied just for administrative purposes or for a particular clinical usage. Identification card, diabetes card and emergency clinical data card are expressive examples of this situation. Considering large-scale utilization, the most generalized PDC implementations are restricted to identification and administrative purposes, in countries like Germany or Slovenia. Also, the currently reduced utilization of clinic-administrative PDC is primarily explained by its limited storage capability and also by the lack of common policies that enforce the wide use of an interoperable information structure. One recent example of effort to define a standard contemplating administrative and emergency clinical data is the G-8-Netlink[1] consortium. The Multi-Service PDC was modelled and developed in order to provide five complementary services: - Administrative data support, - Emergency Clinical support, - PDC owner verification capability (including biometry), - HyperLink base [2], build upon the URL schema and that allow to link to distributed Electronic Patient Records (EPR), - Patient digital credentials support and management. The patient administrative data and the emergency data are structured following the G-8-Netlink specifications to ensure the PDC interoperability at international level. The option for this recommendation was due to its advanced work concerning the healthcard dataset specifications, and yet it input to the current ISO TC215-WG5 standardization activities. Using the ISO8825 data encoding and follow the G-8-Netlink card dataset it is guaranteed the compatibility with G-8-Netlink systems and issued cards.

On the HyperLink zone it is possible to store, to search and to reference accessible Web EPR locations. We can see this feature of a mobile clinical patient homepage. This is achieve through a structured implementation of a hyperlink associated to remote clinical patient data, creating, by one side, a truly distributed EPR system and promoting, by the other, the idea of a virtual unique and universal EPR. Any institution with EPR available on a web environment can write on the card a self digitally signed hyperlink referencing this information. The pointer includes an electronic record address(URL), the issuer institution identification and digital credentials references, as well some coded clinical details (information type, code disease – ICD 9, free text). All the structured hyperlink dataset was defined in ASN.1 and follows an ISO8825 data encoding implementation. This HyperLink model is tailored to open, widespread, and heterogeneous environments such as the Internet.

The Multi-Service PDC is supported by a cryptographic token, allowing the store and management of patient digital credentials and is also capable of digitally sign/verify messages with the patient private key. Digital certificates are an excellent tool to perform strong identification and authentication. This concept is based on Public Key Cryptography (PKC), and allows establishing a trust relationship, or certification, between its designated subject and a reliable certification authority (CA). A higher level of security and unrestricted mobility can be granted to the whole certification system through the use of smart cards as possession tokens, i.e., they have the means for storage the user's secret key and digital certificate.

The confidence on security issues depends strongly on the trust we have on digital certificates, on private key storage and how it is verified that the correct person is the owner of the private key. Contemplating these demands, a PDC hosted by a crypto smartcard must implement card owner verification procedures. The first identity proof is related with the patient physical card possession. However, to access local and remote patient data the authentication is made through the patient private key that signs a host-side challenge and proof the user identity. The user private key is unique and

securely stored on the card, protected by a PIN and/or biometric device. The Multi-service PDC supports PIN verification but it is actually prepared to acquire and store two distinct card owner fingerprint templates. It is important to emphasize that this apparently too strong security mechanism is useful not only to prove the user identification but yet to avoid unauthorized access to the card.

The PKC based authentication requires a patient digital certificate that is unique, trustworthy and widely accepted, at least in Healthcare institutions. However, the proliferation of certification authorities, each issuing a distinct digital certificate and recognizing as valid only those certificates that they issued themselves, imply that the user will have to store many certificates. The obvious solution to this problem can be envisioned in the form of governments' policies to establish certification authorities' chains that are recognized as a path of trust in distributed computer systems such as the Internet. Preventing this lack, the Multi-service PDC can store and manage multiple patient credentials, with an innovative storage method that optimises the card capability [3].

*Results and conclusions:* The Multi-service PDC product represents a cost-efficient solution that provides a high patient data mobility and implements a flexible model to distributed EPR access over open and heterogeneous environments as the Internet. Strong securities enforcements and completely scalable utilization are other achievements of the proposal. The trial phase has been realized on a recognized centre of excellence in Portugal – the Gaia Central Hospital Cardiology Department. This unit provides public healthcare services to a 350.000 population universe, but in some cardiac specialties receives patients from all hospitals of the north of Portugal.

### [17]

### A proposal for improving ICU assistance through intelligent monitoring and supervision

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*Introduction:* The supervision of patients at a hospital's Intensive Care Unit (ICU) requires a complete real time monitoring of the patient's clinical evolution. Various monitoring and control systems have been developed in order to provide this monitoring and improve the use of available the human and technical resources.

The latest advances in monitoring have led to the creation of complete systems that, equipped with certain IA-using modules, offer an intelligent supervision of the patient's physiological parameters and contribute to the diagnosing. These systems also use the Hospital Information System (HIS) to provide local and remote access to relevant data.

Finally, the generalisation of the communications networks has made it possible for users outside of the HIS to access the system and interact with it, turning the system into a complete Telemedicine system.

This paper describes the main characteristics of a tele-supervision system, developed by our research team, which improves and enhances the monitoring and control tasks of doctors and nurses. This system covers the whole process, going from the intelligent acquisition at the patient's bedside to the consultation and visualization of the information stored in the medical database. Thanks to new applications on the PC platform and to the web interface, it even becomes possible to visualize real time physiological signals, stored signals and part of the patient's clinical records.

*Materials and methods:* The global system has a client/server architecture, with client computers at the patient's bedside and a central system that gathers the data and supervises the client systems.

The local applications obtain and visualize in real time the signals of the patient's physiological parameters. The central subsystem, which has total control over all the connected local subsystems, receives the signals from the local applications and visualizes them in a similar way. The system also

disposes of multimedia applications that facilitate the collaboration between physicians during the diagnosis: a complete videoconferencing system (following video compression protocols (H.323)), the visualization of graphic archives such as X-rays, etc.

Within the scope of our Telemedicine system, and with the aim of improving the interaction between man and machine, we have designed and implemented a three-dimensional visualization module that represents the data collected by the monitoring devices at the patient's bedside. These data are previously processed so as to reflect, in the virtual environment, the evolution of each monitored parameter through the object it influences.

A 3D visualization module improves the interaction with the user and provides remote supervision of the patients that are connected to the Telemedicine system. This module makes it possible to represent, in a visual way and in real time, the array of variables that are found in an ICU patient and obtained by a bedside acquisition system. The 3D visual environment shows the evolution of the variables and signals, produced during the patient's monitoring, by a change in colour, luminosity, or size of the objects. It can also visualize the numeric values that were obtained for each organ.

Also, we have included a module of distributed agents, developed according to the FIPA standard, that improves the bandwidth distribution and the use of the resources available within the telemedicine system network. Each agent of each network computer incorporates a rules system developed with OPS/R2. Among the functions of this control module are the following: management of the workload between the available resources (task distribution between various computers, launch of distinct processes using threads, control of the workload of each computer, etc.); assignation and modification of the data transmission priorities, according to the available bandwidth; implementation of reaction mechanisms in case of asynchronous events; etc.

Once classified, the data that proceed from the client systems are used by the knowledge rules of the knowledge based system to assist the decision-making process (developed in OPS/R2). These rules inform the system about situations that are dangerous for the patient, the causes of produced alarms, incompatibilities between data from different sources that may indicate instrumental problems, artifacts, etc.

The information thus collected by the telemedicine system is stored in the database that is integrated in the hospital information system (HIS), which allows the access to the clinical records of the ICU patients. This information may be used by the clinical staff (through the web or the tele-supervision system) as well as by the medical expert systems.

The stored data also include the acquisition control variables and the physiological signals and parameters obtained from the medical devices connected to the patient. This makes it possible not only to follow-up the information concerning the patient's clinical record, but also to show the evolution of the stored signals in a graphical way. We have developed a specific applet that visualizes these signals from the medical database access system through the web. The database also collects all the information related to the manipulation of the patient, the administered medication, the expert's comments and diagnoses, etc. The combination of all these data will allow us to observe the patient's evolution and analyse his reaction to applied treatments.

*Results:* This work presents an intelligent supervision system applied to critical units. It pretends to improve the quality of the assistance and follow-up of ICU patients by means of the following assets: a complete telemedicine system integrated in the HIS; the inclusion of knowledge modules with access to medical databases; the development of a network tasks management and distribution system that optimises the use of available resources; the implantation of network bandwidth management mechanisms; and the implantation of an ergonomic environment of 3D visualization or the access to the information through a web server.

*Discussion:* With a view to future advances and improvement, we have taken special care, in every stage of the development, to incorporate knowledge-based systems and implant standards wherever

possible. Currently, the system is being evaluated in the Meixoeiro Hospital of Vigo and the Hospital Universitario of Santiago de Compostela.

### [18] Quality assurance through digital pathology: The eQual project

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*Introduction:* Digital Pathology is the name with which currently all those techniques related to the digitisation of histo- and cytologic images are identified. In particular, it refers to the digitisation of the complete glass slide (called "digital slide"), which is a recently available feature due to the storage and performance of modern computers [1]. Part of the quality assurance process in Pathology is carried out through aptitude tests made usually on glass slides, which should be examined by the subjects and their answers should then be compared with the consensus diagnoses of an expert panel. This is in turn achieved by making glass slides circulate among Institutions, or by gathering together people to be examined in sessions occurring during Congresses or seminars. Examples of the cited approaches are the NEQAS UK breast screening scheme and the European QUATE aptitude test [2]. In Italy, healthcare quality assurance is carried out at regional level, under the control of the regional Healthcare System. Unfortunately, glass slides are unique and fragile, thus it is difficult to have the people examined on the same material, in particular when it is of cytologic kind. As at present strong limitations are imposed to quality control programmes by the nature of the diagnostic material (NEQAS: six months of specimen circulation for every session; QUATE: on average, about 50 tested subjects per year, in Europe).

A solution comes with digital pathology: as digital slides can be replicated and distributed through networks or removable media, they could overcome the glass slide uniqueness and fragility. The present paper proposes a scheme for quality assurance based on digital pathology, studied inside the eQual Project.

*Methods:* The process of digitising a complete slide is based on the scanning of the slide with a robotized microscope. Briefly, a matrix of images is acquired with a high magnification objective, and the complete digital slide is obtained by bringing the images together; the total storage needed may be up to 30GB if uncompressed, 1GB if compressed. The latter data may explain why this is a recent technology. Cases acquired this way might be accessed through specific clients able to display the right images on demand, by giving the pathologist a microscope-like interface. However, once panel-selected cases are acquired in such way, they can be distributed using either the Internet or optical disks (CD or DVD), and they can be the basis for quality control, which can be implemented through the following steps:

1) Distribution of examination cases though the Internet or, for the sake of performance, on CD/DVD Rom; 2) Examination session carried out through an Internet connection, by means of a form containing the questions to be answered according to the quality control scheme; such form may follow the guidelines studied by the QUATE project [2] 3) Additional data can be collected regarding the behaviour of the subject undergoing examination, e.g., in cytologic screening, log of slide areas visited (useful to understand failures and errors).

*Results:* We adapted two digital slide acquisition tools and viewers previously developed to the needs of quality assurance (i.e., including a timer in the viewer, adding a form to be filled for examination,

logging user activity). The data collected this way are then remotely sent to the eQual server, which is a web-accessible database with case, user and examinations data. The server can be accessed by an administrator, which will find examination data and their comparison with case data (available in structured form). Furthermore, a graphic tool is able to show the administrator the examination pattern followed by the user on a slide thumbnail (either as overlay or as play-back of actions). The tool is actively under test by five cytotechnicians in two pathology Institutes, and it has been proposed for a regional quality assurance programme.

*Discussion:* Telepathology and digital pathology are interesting although often underestimated ancillary techniques in pathology, due perhaps to the fact that there is no "killer application" currently available (the most important one is remote consultation, often seen as a luxury application more than a basic one). On the other side, quality control application has always been constrained by the physical features of glass slides (i.e., uniqueness and fragility), which do not really allow the daily implementation of quality control programmes. In this specific field, digital pathology can make the difference. Connected to this, continuing education though digital pathology can also become a useful application. The main issue is still represented by the different levels of computer literacy among personnel subject to testing, which cannot influence the rating obtained in the test. This can be overcome with appropriate user interfaces, and if needed with training.

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#### [19]

### Techniques for the web of telemedicine services: Open telemicroscopy through SOAP

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*Introduction:* In the future of the World Wide Web there will be also the availability of the so-called "web services" [1], i.e., network-accessible functions that can be called from any software. This approach is usually based on a new class of protocols written in XML. In particular, SOAP is a lightweight protocol defined within the World Wide Web Consortium for invoking methods on servers [2]. SOAP defines a vocabulary in XML that allows heterogeneous components to collaborate to perform services. Furthermore, web services are usually described by means of XML-based formats (like WSDL) [3], which are a sort of publication of the access interface.

The web services approach is a step forward in respect to technologies such as CGI, servlets, serverside scripting, because it provides a much more powerful interface into servers, which become easily accessible from specific software.

SOAP and, in general, web services, may be seen as a technical solution for those telemedicine applications still not standardised in their protocol aspects. In fact, the exchange of data at the basis of telemedicine applications might be done by invoking remote calls on a server hosting the data, and eventually carrying out exchanges more complex than usual client-server transactions (i.e., multiple responses, asynchronous services, etc).

The present abstract describes the use of web services for accessing a remote microscope through the Web. Although webmicroscopy by itself it is not a new application, it is suitable for demonstrating the

usefulness of web services in the field of telemedicine, with the added value of an open and interoperable approach.

*Methods:* The objective of the study was to design a SOAP-based protocol for accessing a robotized microscope through the Web. Such a protocol may be also useful for accessing a "virtual" microscope, i.e., a set of stored digital slides. The latter will be a crucial application in the future, for teaching and quality control. In order to to that, a preliminary analysis of the possibly robotized components of such a microscope has been made, which had as output an abstract XML description of a typical microscope, based on a specifically designed DTD or on a XML-Schema. This descriptive structure includes hardware features of the microscope (stage limits, objectives, etc), useful for correctly configuring the remote interface.

The protocol has been then implemented by referring to such structure, following the SOAP approach.

*Results:* The server side for the designed protocol has been implemented using ApacheSOAP; the client side is at present constituted by a Java application. The server side is at present connecting to a virtual microscope. For the description of the microscope, an XML schema has been developed, together with the WSDL description of the provided service. The access to the microscope functions is provided by a main method, plus a number of shortcut methods which allow to directly carry out the most frequent actions (i.e., stage movements, objective change, etc.).

*Discussion:* SOAP appears an interesting technical solution for implementing open protocols in telemedicine, when still not available. In fact, developers might maintain their own data structures, while using XML for interfacing them with other services.

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### [20] AN RDF-based proposal for digital pathology cases on the Semantic Web

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*Introduction*: The forthcoming evolution of the World Wide Web towards the Semantic Web will add new technologies to the already available ones, with the aim of giving wider automatic processing to web-stored information (1). Technologies include XML (2) for interoperability, RDF (3) for semantic markup, and higher-abstraction reasoning applications (1). Among the possible applications of such evolution, we identified also the markup of telemedicine data in a field currently lacking of any standard, i.e., telepathology; we modelled data and developed a couple of software applications to demonstrate the feasibility of the approach.

*Method:* In a telepathology process, the case exchanged between interlocutors is centred around images, but includes some data and features depending on the case source (i.e., electronic medical record, glass slide) and author, some others determined by the image technology used for its delivery, and finally

some more information, which highly depends on the specific aim that caused the case creation and delivery. Thus, we may distinguish among basic case information, image information (including technical details), and aim-oriented information.

Such information may be represented by metadata associated with the case, where the case is in turn a set of images (just still images, or digital slides, etc) plus clinical history, plus author and indexing information. In the present evolution of the Web towards the Semantic Web, metadata can be represented by means of RDF (Resource Description Framework), which provides for semantic constructs suitable for metadata, in XML syntax. Furthermore, parts of the metadata needed for describing a resource (non only online) are already standardized under the Dublin Core initiative (i.e, Creator, title, Date, etc).

As a preliminary step, we developed a generic model for digital pathology cases, including the concepts of image, plane and stack. Two different technical solutions –the most diffused, i.e., static telepathology and digital slides- are comprised in the model. From this, we developed a specialized metadata vocabulary, to be used together with the Dublin Core metadata for characterizing the cases. Starting from that, either still-image based cases and digital slides may be easily described through RDF.

*Results:* Software for adding RDF resource descriptions to digital slides has been developed and added to an already existent system for digital slide acquisition, as well as to a Slide Viewer. In this particular application, where a single digital slide is made up of thousands of images organized in folders, RDF may help in making the storage structure accessible and interoperable. Furthermore, a static-telepathology based system, previously able only to provide HTML cases, has been enriched with RDF descriptions following the developed model.

*Discussion:* We claim that using RDF (with the proposed approach) in addition to any kind of case storage may give a novel form of interoperability for digital pathology cases, even in the lack of standards that currently characterizes telepathology. This is obtained thanks to the added metadata, which regard not only library information like Author, subject, etc, but also technical information on the storage structure used, up to file naming conventions and folder names. This will help in the forthcoming applications of telepathology, and in particular quality control and education (4), where interoperability is crucial.

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### [21] The W3E guidelines for medical web applications for the elderly

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Over the last decade the wealth of clinical information available on the Web has increased. A great number of sites have been developed that allow patients to access information related to their medical conditions and/or communicate with their health care providers. Although the Internet seems to have a great impact on the health care sector and empower patients to become more active in the care process, the fastest growing segment of the US population (i.e., people over the age of 50 years [1]) are at a disadvantage because designers of both software and hardware technology fail to consider them as a potential user group [2].

Designers of a system that targets elderly patients should aim to increase its functional accessibility. An "accessible" application aims to maximize the number of potential customers who can readily use it [3]. A functional limitation describes a reduced sensory, cognitive or motor capability associated with human aging, injury, or disability that prevents a person from functioning in a context where other people in the population can function [3]. The frequency of functional impairments increases with age. Aging can affect vision, the information retrieval and processing capacity, reduce the speed of precise movements, and increase the variance in their timing [4]. Aging also decreases the attention span and causes changes in the amount and quality of information extracted from displays [5]. Functional impairments of the elderly population are not the only challenge is user inexperience with the technology. Although the elderly population has the highest penetration rate for telephones, it is behind all other age groups with respect to computer ownership [6].

This paper presents a set of guidelines (W3E) that was developed for the design of web applications for the elderly. These guidelines are based on an extensive literature review, existing work for general applications such as the Resource Guide for Accessible Design of Consumer Electronics [3] and the web content accessibility guidelines W3C [7] as well as practical experience with web based applications for the elderly [8]. The guidelines intend to address not only general usability principles but also the functional limitations and user inexperience of the specific population (thus, for each of the guidelines there is detailed documentation reporting the area it addresses and its rationale). The guidelines cover the following areas:

- 1. System Interface
  - Simple and Clear web pages
  - Alternatives for Different Tasks
  - Elements of Proper Visual Display
    - Simple icons
    - Concrete and distinguishable symbols
    - Large buttons with text labels
    - Large font size of text
    - No light or subtly patterned background
    - Conservative use of colors
    - Sufficient brightness
    - High contrast between darker and lighter colors
    - Avoidance of fluorescent colors
    - Viewing a page through a piece of yellow cellophane gives an idea
  - Help Features and Constructive Error Messages
    - Context sensitive help
    - Error messages that provide constructive advice and offer suggestions
  - Clear Navigation Mechanisms
  - Avoidance of Sound Effects
  - Elimination of Distracting Features
  - Inclusion of Users in the Design Phase
- 2. Training Support
  - Sufficient Training
  - Personalized Training

– Education about the Value of Online information

### 3. Content

- Choice of links to sites that provide educational material and meet a detailed set of criteria.
- The final selection of sites must be reviewed by health care providers for readability, accuracy, and appropriateness of content.
- Avoidance of Deep Hierarchy in the Information Structure
- Appropriate Electronic Communication between Patient and Provider

### 4. Security

 Security is a great concern of medical web based applications. It can be accomplished by utilizing several mechanisms depending on the scope and specifics of the application. Such mechanisms include encrypting techniques, access controls etc.

It has been demonstrated that elderly who utilize the Internet to send and receive email or play games, show an actual improvement in activities of daily living [11]. Technology can facilitate the involvement of patients in their own medical care, but it can also become a barrier if they cannot easily and effectively use it to meet their needs. The presented set of guidelines provides a framework for the design and implementation of accessible web based applications for the elderly.

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### [22] Can the Internet play a role in reducing the global burden of infertility?

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This paper examines the role that the Internet can play in reducing the global burden of infertility with emphasis in developing countries. In particular, it discusses potential advantages and disadvantages of its

use in promoting infertility prevention and equity of access to treatment. While the Internet can address and possibly eliminate geographical and in some cases financial barriers, its global utilization in the field of infertility is faced with a series of technical, ethical, political and clinical challenges.

Infertility is the failure to have a live birth after one year of unprotected coitus. Estimates of infertility prevalence vary widely amongst regions. It is estimated that globally up to 90 million people are infertile at some stage in their reproductive lifespan. The majority of those with infertility live in developing countries, with rates of secondary infertility up to 30%. A large percentage of infertility in developing countries is caused by infection and therefore efforts to prevent ascending reproductive tract infection, and infections related to childbirth and abortion can result to reduction in infertility. For those with non-infection related infertility, treatment remains the only option, which has become synonymous with costly and sometimes ethically controversial assisted reproductive technologies (ART). Access to ART is virtually unavailable in many developing countries. Even in developed countries, reimbursement policies, laws, and ethical norms restrict access.

Online information on the nature of infertility, on the diverse ethical views about infertility treatment, the gap between demand and what is available, and the high costs have played a critical role in the way the debate on these issues has evolved. Internet utilization in the case of infertility has grown rapidly in the last few years and the term "e-infertility" has been coined to describe the numerous web-based sites, applications, and databases that deal with infertility. The type of online information varies in terms of accuracy, quality, target group and provider. On-line information on infertility treatment and ethical guidelines are provided by medical associations such the American Society for Reproductive Medicine, (ASRM) or the European Society for Human Reproduction and Embryology (ESHRE), by patient/consumer groups, religious organizations etc. Clinics provide online information on their success rates and available options for gamete donors or vendors. Pharmaceutical products are advertised on the Internet and addressed not only to the medical community but also to the general public and in particular to infertility couples. An outgrowth of this development is that consumers are not only seeking out health information sources; they are also taking an active role in developing and maintaining online resources and in some cases establishing networks for information access and infertility treatment that bypass conventional authorities (e.g., sites providing egg donation matching).

Internet can, and has, already, contributed to the empowerment of the consumers worldwide. Many institutions also use their websites to assist consumers in filtering and evaluating online information, such as the Human Fertilization and Embryology Authority (HFEA) in the UK, or the Centres for Disease Control (CDC) in the US. Information flow has also the potential to strengthen research capacity and improve the quality of infertility care, especially in developing countries by eliminating geographical or in some cases financial barriers. Such is the objective of a large initiative launched by the World Health Organization and the world's six biggest medical journal publishers that establishes free online access to these journals in about 70 developing countries. Finally, the Internet can play a critical role in promoting infertility prevention through reproductive health education. In this context, web-based educational initiatives can contribute significantly to disease prevention.

However, since the current digital divide between developed and developing countries is more dramatic than any other inequality in health or income, it can be argued that such inequality will be reflected on e-infertility. Further, e-infertility could also expand the digital chasm between developed and developing countries. The vast majority of people in developing countries have no access to the Internet and much of the information they might find is irrelevant to them. As Internet utilization increases in the developed world, people without access to modern communication technologies are increasingly being excluded from education, healthcare, and the means to improve their own lives.

Another concern associated with Internet utilization in the case of infertility treatment is that it can allow the spread of misleading information that serves the interest of certain stakeholders or contributes to false expectations and inaccurate perceptions. It can also provide a tool for activities that exceed legal and/or moral boundaries such as the buying and selling of human gametes and embryos, commercial preconception or "surrogacy" contracts. The wealth of online information and the variety of data sources can confuse and overwhelm consumers and create a demand that cannot be met.

While recognizing such limitations, it is important to emphasize that the potential of the Internet to reduce the burden of infertility remains significant. However, to reach the maximum benefit, we propose that e-(in)fertility operates within the following scheme:

The utilization of the Internet should be designed to reflect the principles of: • relevance of information to the population in need • cultural appropriateness and sensitivity of the information • technical and financial sustainability of applications • multi-directionality of the data flow (flow not only from developed to developing countries but also from developing to developed countries and perhaps most importantly among developing countries themselves).

Work processes, objectives, values and hierarchies influence the implementation process of a health care information system. The diffusion of a medical information system will depend on the degree of agreement between the conceptions reflected on the system's design and the realities into which it is introduced. Therefore, many challenges are involved in the design and implementation of infertility related web-based applications for developing countries. These include the design of user interfaces that address different degrees of user experience and familiarity with the web and have a culturally sensitive content, network architectures that enable easy and quick access for all users, data security, and platform independence that accounts for different hardware and browser versions and local operation system settings. Systems governed by the proposed principles should aim at three key targets: reproductive health education; consumer empowerment; strengthening of research capacity in low resource settings.

### [23] Internet video for medical research communication

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*Introduction:* Several institutions of higher education have implemented digital video broadcast and Internet streaming. Although several technologies have been developed three streaming methods (Real, Windows Media, and QuickTime streaming) dominate the market. In the present study we demonstrate and compare the use of Windows Media and QuickTime streaming in a medical research seminar.

*Background:* In many years the web was practically reserved for text and images. As bandwidth increases, however streaming video offers obvious potentials. Most researchers and educators agree that face-to-face communication and teaching can not be fully replaced by e-communication. However, medical research conferences, seminars, and workshops require participants to spent both time and money travelling. Electronic transmission (broadcast or streaming) may allow participation by at least part of an audience without expensive travelling costs and participation becomes possible for an audience who would not be able to afford travelling. In medical education, streaming video offers access to an audience beyond the reach of conventional university teaching. Important issues include compression and video quality vs. bandwidth; cross-platform and cross-browser compatibility issues, security issues and firewalls; legal issues including the controlling of access; economical issues (production, streaming, and viewing). However, many more aspects i.e. pedagogical, aesthetical and dramaturgical are also of great importance for effective communication.

In the present project we have tried to isolate some of the difficulties and have tested a number of possible solutions. We have successfully produced and implemented examples using Windows Media and Darwin (QuickTime) streaming

*Materials and methods:* For video recording we simultaneously used two DV cameras for two different views and two different encoders: Sony DSR PD150 and TRV900E with Sennheiser EW100 wireless microphones. Real-time broadcast was done while recording on mini-DV tapes. Encoding for broadcast was done with Windows Media Encoder with the WM8 codec in two simultaneous streams on a Dell workstation. The other camera was connected to a Mac G4 based computer running Quicktime broadcaster with MPEG4 encoding for the QuickTime 6 player at 150 Kbit/s. Streaming was done by a Windows Streaming server, running on a Windows 2000 server, and a Darwin streaming server, running on a Linux server. All software for encoding and streaming was either part of Windows or free to download. Editing and off-line encoding for on-demand web-streaming was performed with a Windows 2000 video workstation running Media 100 iFinish software, mixing video and sound from both cameras. Production of web pages and synchronization of video with PowerPoint presentations was done using Microsoft Producer. For QuickTime video was produced for a separate browser window and PowerPoint slides were exported as web pages for browsing in a separate window.

*Results and discussion:* We were able to successfully broadcast and record a 2-hour research seminar of the International Epidemiology Association (IEA) held at the University of Aarhus in June 2002. Windows and Internet Explorer (IE) users could choose either the Windows Media or QuickTime streams, Mac and Linux users could view results from the Darwin streaming server using either IE or Netscape browsers. PowerPoint files were available for download prior to the broadcast.

After the seminar the video materials were edited and placed on the respective streaming media servers for on-demand viewing (see: www.hivideo.au.dk/iea ). In addition a CD with all contents was produced.

We kept bandwidths between 100-300 Kbit/s to allow web streaming on ADSL and faster connections and to avoid too heavy loads on the streaming servers with several simultaneous users. The audience in our test setting was limited in number and we did not experience performance problems with encoding or streaming. We conclude that once video recording and editing hardware is available, low budget yet high quality video encoding, broadcast and on-demand streaming can be setup both on Microsoft and on Linux, open source platforms.

### [24] Modelling medical operational knowledge for e-health applications

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*Introduction:* Medical applications and electronic healthcare have special requirements that conventional relational database systems cannot satisfy. To name but a few: Electronic patient records need modelling based on complex objects such as component hierarchies, image data and structured texts. E-health applications should be able to represent complex objects directly and implement them effectively. Relational databases simulate complex object by joining relations, an approach that complicates modelling and results in performance problems. Healthcare applications use text, graphics and image archives. Therefore they should be able to model, store and manipulate extensive multimedia data efficiently, while still operating at a reasonable speed. Relational systems are good at handling number and string-based data, but have difficulty dealing with the types mentioned above. In the case of medical knowledge derived from imaging data, hardware limitations mean that all this knowledge may not be possible to reside in main memory at any given moment, in which case tailor-made storage and access techniques are required. The system described in this paper uses the technological advances in

information technology in order to influence and improve healthcare practice by enabling the modelling, direct representation and flexible use of medical knowledge that supports the use of complex objects and multimedia content. It aims at significantly reducing the complexity of the development of distributed healthcare systems and e-health applications.

*Materials and methods:* Aiming at overcoming the problems and limitations mentioned above, our approach follows the FDM (Functional Data Model) for the modelling of medical information. The resulting system is (i) persistent, by means of the back-end functional database, and (ii) interoperable by means of XML. (a) Unlike the relational model which is record founded, the functional approach is based on graphs, and as such, it provides a finer semantic granularity which facilitates data modelling. Complex data structures are supported, allowing the use and manipulation of complex objects and multimedia content, the two most important elements of medical data. Missing or incomplete information is also efficiently handled. (b) On the client interface front the system was designed to be fully XML compatible, adhering to XML's principal features of structure, extensibility and validation (by means of DTDs rather than schemas). The feature of compatibility was of high priority as it guarantees the interoperability between our system and other existing e-health applications. Furthermore, the issue of validation was deemed especially relevant to medical applications, as it allows for agreement on a common format for interchanging data among independent sources.

*Results:* A prototype system following the above design and specification has been implemented with a back-end functional database and a query-specific XML compatible web interface. The modelling of medical information follows thus the functional paradigm, incorporating complex objects and multimedia content into a compliant schema. The fundamental schema transformation rules between the functional database and XML have been established [1], and the implementation of a basic translator framework has been carried out [2]. This grants full interoperability between our system and other medical data banks over the Internet, since most existing relational or object-relational medical systems in use are also XML compatible. The implementation of the two-way prototype translator between the functional database and XML has been done by means of a server-based Perl/cgi script running on a SPARC Enterprise 450 Solaris 8 platform which supports an Apache Web server (chosen for its open source and for allowing safe connections of medical data through SSL). The Perl/cgi script interfaces the back-end database and formats the query output. The local client receives the XML-formatted web data, translates and stores it in the back-end database. The data can then be queried, updated and even sent back over the web, reformatted into XML.

*Discussion:* Internet based medical applications include electronic patient records, databases of clinical practice and literature, distance-learning type applications, decision-making tools for diagnosis and optimal treatment selection etc. Patients internet support groups and education packages revolutionise the traditional patient support, while terms such as telemedicine and teleconsulting (but also cyberchondria) find their way into our everyday lives. All of the above applications rely on the fact that it is easier and cheaper to move data than people and/or other resources. Medical operational knowledge can be grouped by its type and source. The type of medical information varies from simple numeric and string-based data residing in traditional RDBMS's, to text, graphics and image data. The source of this information can be as widespread as the web itself. These are the exact parameters our approach aims at: treat medical data in a uniform way regardless of its type and source of origin. Once fully operational, the proposed system will be able to gather data from a variety of different sources, model it into flexible complex objects and store it locally to be queried and manipulated at will. Having finished the prototype phase, we are currently negotiating testing the system with UK NHS (United Kingdom National Health Service) data, which will put to the test the performance and delivery, and prepare the second phase of implementation.

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### [25] Using Internet health resources in tailored patient education

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*Introduction:* In the context of health education, tailoring is defined as the adaptation of education materials to the features and needs of a specific individual. Although tailoring is a largely computer-assisted process, the Internet has thus far been viewed only as a delivery channel. Little is known with respect to the use of Web-derived content in tailored patient education programs. In our project STructured Evaluated Personalized Patient Support (STEPPS), we are exploring the challenges and requirements of incorporating health and medical information available online in a strategy for tailored or personalized patient education. The application domain of STEPPS is post-discharge care of burn patients. In this paper we describe the methodology we employed in developing a domain-specific test collection of Web content, aimed for use in conjunction with electronic patient record data; we report our findings and discuss the challenges of implementation beyond the experimental stage.

*Methods:* Prior work in the field of tailored patient education has relied almost exclusively on locally produced and therefore controlled resources. In order to be able to experiment and investigate the use of Web derived content in STEPPS, we created an offline collection of pertinent Web pages. The creation of this test collection took place in three phases:

- 1. Identifying the target areas of interest: This phase corresponds to the determination of end user information needs, on the level of a specific patient population (in this case, of burn patients). For this purpose we used the following sources: a) scientific publications on burn patient education programs and needs b) experiences of local burn care teams c) findings of a national project aiming at defining education and information needs during hospitalization of burn patients d) consultation with representatives of the national burn patients' organization and e) the Web itself, by recording the topics covered on web sites dedicated to the area of burns and reviewing the issues raised in their Frequently Asked Questions section.
- 2. Locating the pertinent web pages: We aimed to create a collection representing a 'cross-sectional' impression of the Web pages a regular user would retrieve at a specific point in time, while searching for information on the identified areas of interest. Therefore, we chose for a search strategy that would emulate the behavior of 'average' Internet users. For each topic, we developed variations of simple search queries (ranging from one to four words), both in English and Dutch. Consequently, we used these queries with the CopernicPro® meta-search software, a commercially available program which allows for batch downloading of the retrieved material. The Internet searches for English language sites took place during the period February to June 2002, across a number of popular general-purpose search engines and directory services (such as AltaVista, AOL, MSN, Netscape Network, Google, Yahoo, Lycos, LookSmart etc.). Searches for sites in Dutch are currently under way.
- 3. Organizing the collection: We first exported the results of URL's retrieved by CopernicPro® to an Access database. We then pooled the pages we retrieved through several, partly overlapping

queries per topic and removed duplicate results, to create sub-collections of unique pages. Subsequently, the pages were indexed with the Collexis® software, using the UMLS Metathesaurus 2001 as indexing vocabulary, in order to facilitate coupling with the electronic patient record.

*Results:* Through the aforementioned process, the following thematic areas were identified: a) wound management and related problems (sleep disturbances, itching, etc), b) scarring management (prevention with exercise and pressure garments, etc.), c) pain relief, d) physiotherapy, e) psychological problems (such as post-traumatic stress disorder) and f) nutrition and growth issues. Corresponding collections of Web pages were created, plus an additional collection, covering the topic of burn injury in general. The initial number of English languages pages retrieved over the seven thematic categories of interest exceeded the total of 130.000 pages. On average, one third of the pages in each sub-collection were duplicates, after removal of which, the collection consisted of approximately 92.000 unique pages. More detailed results per thematic category, as well as representation of type of host sites (educational, commercial, governmental etc.) in the collection, will be presented alongside the results of the Dutch language pages.

*Discussion:* In spite of the wealth of health and medical information available online, the use of Web content in tailored patient education remains largely unexplored. We have described the methodology we employed in creating a test collection of Web-derived material, as part of a system for personalized or tailored education in burn care. Drawing on the wide array of health resources available on the Internet to support a patient education program could provide a solution to several problems inherent to the use of paper-based, locally produced materials, such as storage, accessibility, adaptability and easiness of update. Challenges that need to be addressed in this context are the accuracy and relevance assessment of the content, the suitability to local practices and standards, the currency maintenance of the collected material, as well as issues of intellectual property rights.

### [26]

# A guideline-based co-operative work framework integrating medical knowledge management services for heart failure care delivery

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*Background:* Information and communication technology (ICT) represents a significant change agent in the medical community. The development and the integration of innovative ICT tools to effectively manage the Medical Knowledge (MK) is one of the more relevant challenges for near future. The development of innovative information technology tools can support the process of creating, sharing, disseminating and exploiting the MK amongst the different health care organisations. Guidelines (GLs) are one of the methods that try to solve the issue of transferring the results of the bio-medical research into the clinical practice, providing a series of recommendations based on scientific evidence that would constitute the best practice. However, the development of good GLs doesn't ensure their use in practice. Several studies have shown that the compliance with the GL can be improved when GLs are integrated with an Electronic Medical Record so that patient-specific advices can be delivered at the right time and place, improving clinical performance. Moreover, it has been shown that organizational constraints, whose communication amongst hospital Health Care Professionals (HCPs) and between hospital specialists and General Practitioners (GPs) represents one of the more relevant aspects, can impair the

implementation of GLs. The co-ordinated action of HCP's in patient care delivery is a key factor for an healthcare organization. Therefore, not only computerised GLs (establishing "what to do"), but also organisational aspects (establishing "how, by whom, and by what") have to be taken in consideration. Workflow management systems could be a suitable tool to address organisational issues.

Based on the above, the project "A guideline-based shared care through a computer-based cooperative system for the management of heart failure (e-Heart Failure)" started last May in the Telemedicine and Medical Informatics Laboratory of ITC-irst, funded by the "Fondo Unico per la Ricerca" of the Autonomous Province of Trento, in collaboration with Fraunhofer IBMT, University of Pavia, University of Trento, University of Firenze and the Health Care Service Trust of the Province of Trento. The project lasts three years and finds its clinical basis on the project "T.Ri.P.P.S. II" funded by Italian Ministry of Health, currently in progress in the Province of Trento, that aims to foster the integration of all the actors involved in the management of Heart Failure Patients (HFPs).

Aims: The general aim of e-Heart Failure project is to design and develop a general computer-based co-operative work framework for providing MK management services for delivering guideline-based shared care and to evaluate this approach in a clinical setting for managing HFPs on the territory of the Province of Trento. As heart failure is a complex pathology involving several specialists in the patients' management (hospital physicians, outpatient nurses, GPs and the patients themselves), the co-operative framework is being designed in order to address all the MK management issues seen above, so as to support the people involved in the care process providing specific services directed to the different classes of users. Actually, innovative ICT tools will be developed and integrated in the framework in order to allow to healthcare providers to represent and exploit guideline-based clinical and organisational knowledge. The core of the framework is a flexible ontology-based distributed Electronic Medical Record (EMR), built using Internet and distributed object technologies, supporting the storing, the retrieval and the exchange of multimedia clinical information. Such EMR will allow rapid integration of new medical knowledge with no changes in software architecture. Moreover, medical knowledge representation issues are being addressed by formalizing the GL's MK in an electronic format and developing an integrated GL engine interacting with patients data and with the user interface to effectively exploit the computerised GLs, giving patient specific support guiding the HCP in forming his/her decision. A guideline-based Careflow Management System (CfMS) will be designed and embedded into the framework to fully exploit the GL and control its execution and outcome in order to address organisational issues. A teleconsultation tool will implement a virtual communication space allowing to healthcare providers to communicate by an embedded patient specific messaging system.

*Methods:* GPs, nurses and clinicians of the Cardiology, Gerontology and Internal Medicine Wards of the two main hospitals of our Province (the S. Chiara Hospital of Trento and S. Maria del Carmine Hospital of Rovereto) are involved in the project.

The cooperative framework is based on web-based client server architecture. The client side of the system is a standard web-browser. Data are stored in a relational database accessed through the web server. The network infrastructure is an intra/inter hospital wide area network (WAN) connecting the hospitals' wards. GPs' surgeries and patients' homes are connected with the main WAN through Internet. Secure Socket Layer (SSL) protocol will ensure secure communication between the clients and the web-server. The system is being developed using eXtended Markup Language (XML) technologies, Microsoft COM+ distributed objects and Active Server Page. XML is the data transport format between the Web server and the browser so that is possible to dynamically redefine the presentation interface on the client side by using different style-sheets for different users. XML is also used as the language for formalising electronic guidelines used by the integrated GL engine object.

*Results:* With the e-Heart Failure project, which involves several scientific disciplines, such as telemedicine, medical informatics, and artificial intelligence in medicine, we want to verify 'if' and 'how' innovative ICT technologies can contribute to support the integrated and shared management of HFPs.

Therefore an evaluation phase is scheduled for the last year of the project. The results of the project, properly disseminated through congress communication and research papers, should provide a basis for further improvements in scientific and applied research in medicine. Until now, a first version of the Electronic Medical record has been developed and deployed in the clinical setting to allow to GPs to begin collecting data of their hearth failure patients. Moreover, a first prototype of a GL integrated engine is being developed in our laboratory and tested on heart failure GLs. More services will be added in an incremental fashion in the course of the next two years.

## [27] Peer-to-Peer: Does this new technology have a future in the healthcare area?

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Advances in technology are the enabling building blocks for future IT solutions. One of the last movements is the Peer-to-Peer (P2P) paradigm. P2P means to empower the user on multiple level of work and to leverage software that uses idle resources on the "edge of the internet", hence at the user. Many information services are moved from central servers back to where the information comes from. In the same way resources like space on hard drives and computing power on users computers is used. This facilitates many services and enables a complete new way of working in the fields of communication, collaboration and resource sharing. All major software companies are doing research in this field, as it seems to help in solving some of today's problems. The whole research is tremendously pushed by the business challenges in the media industry, where the P2P paradigm has had the power to attack established business models and threaten some big media companies (like CD label, publisher etc.). The healthcare sector is yet slightly touched by the P2P paradigm: there is software available that uses idle resources on computers to do computations for the design of special drugs against cancer [1,2] in a similar way as one looks for extraterrestrial intelligence (in the SETI@home project, [3]).

In this paper I will outline P2P technology and sketch its impact on the media industry. In the following chapter I argue that the effects in the media industry shouldn't be considered to be bad in general but offer the possibility to learn from it to use P2P for the own purpose. So, the question how healthcare could benefit from using P2P applications. If we understand the character and the benefits of P2P, we will be able to benefit from using it. But beware because P2P is not a general-purpose "weapon", it doesn't work in all cases and even if it fits to the needs, it has to be finely tuned. But the problems where it fits – being in media industry, healthcare or another matter - are solved "quite good".

The power of P2P Media industry faced a big challenge during the last years. The combination of the MP3 music data format in combination with advanced networking abilities of modern programming languages (like Java) made it possible to share pieces of music just as easy as writing an Email or downloading a program from a website. Quite a long time the music industry didn't realize the threat for the CD business. Each person just downloaded the music she wanted to hear (instead of buying the CD). And because these systems were designed with the "internet spirit", downloading music was free. When the major CD labels felt the decline in the number of CDs sold, it was much too late: nearly every modern song was immediately available for free download on the P2P music exchanges like Napster or Gnutella [4]. The only thing that the user offers to the community is – in general – some space on its hard drive and the right to download files from the own computer. This enabled a very efficient way to move files from one computer to another, without using a central server. Other P2P applications use the idle CPU of the client computers to perform complicated computations. In general P2P applications deal with communications and collaborations and sharing resources [5, p. 23 for overview]. The systems are

distributed in a way that a central server is not needed any more. This architecture fits much better to the somehow "chaotic" structures of communities and offers each of the members (the peers) an increase in possibilities and performance. The media P2P case shows that using the P2P paradigm in a correct way offers a enormous potential to enhance today's solutions.

Is P2P an issue in the healthcare sector? The question if P2P will have impact on the healthcare sector could not be negated [5, Chapter 15]. Even if things are different from the media case, we find similar structures like Communities of Practice, the need to exchange files (prescriptions, healthcare data records), to communicate and collaborate; security is an issue to be discussed, too, and so on. So, if considering the characteristics of P2P applications, P2P will play an important role in some areas of the healthcare sector.

One case to be mentioned considers the group of "patient peers". Health portals resemble the way of how to use P2P software. Think of building reputation of the primary care physician in the patient community [4, chapter 17]: by using P2P software, opinions will be gathered on an application where the patients can discuss illnesses, treatment, about the physician, about its office etc. So there will be an increase in quality since there is a information pool that can be used by the patients (when choosing a physician) and - of course - by the physician (he will use it as a means to get feedback on his work). The result of such a tool will be better transparency. This is only one single aspect of enabling the patient with a "P2P means".

If considering the eHealth issues like "reliability on special pieces of information", "patient empowering" or the "informed patient", especially when considered with the question of costs then also the physicians could take advantage of the P2P paradigm. Lets think of a scenario where a patient asks the physician to comment on an article from a newspaper ad. Probably this physician is not the first to answer the question, but in general she is not able to get this answer from her colleague. So, when using P2P knowledge management systems, one could easily put the answer into the forum, where a general professional opinion could be discussed and published. This would be a possibility for the community of physicians to tackle the increasing information flood and hence offering a superior service in today's world of information overload.

Summary P2P is a new paradigm of software enabling the user with unforeseeable possibilities. The users of the music market use the P2P software to get access to a service of superior quality: delivery of songs right to the home PC. The media case shows the power of this new kind of software when being used in the right environment. As we saw from a few cases, healthcare indeed is and will be a niche for P2P solutions in the healthcare system. Depending on how the different communities are using the P2P systems, it could be a threat or of great benefit for the user – being it the patient or the physician. And as the field of P2P systems is still young, many other applications will emerge, helping to solve problems that we never thought of being able to – always considering that the characteristics of P2P fit to the solution.

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Web enabled applications have become more popular in many fields. On-line applications are being used everywhere, starting from e-commerce, passing through doctor-online and pharmacy-online, ending with e-education or distance learning. Using multimedia adds an order of magnitude in getting the benefits of knowledge cognition especially in the medical field. Medical training, anatomy and physiology, virtual surgery, videoconferencing networks, online resources [Hofs 2001]. Medical Training: multimedia enables interactive health care training, medical references are using multimedia, professionals and consumers benefit, and teaching tools can simulate actual patient encounters. Anatomy and Physiology: examples for available products are: Anatomy and Physiology videodisc, National Library of Medicine's Visible Human Project, and The Dynamic Human. Virtual Surgery: rehearsal of complicated procedures possible, simulators teach motor skills and cognitive knowledge necessary for procedures, and laparoscopic surgery. Videoconferencing Network: Videoconferencing connects hospitals, allows patient diagnosis and treatment through video conferencing, and transmits medical images and clinical procedures. Online resources: medical journals(online journal of current clinical trials), medical databases(MEDLINE), government institutions (National Institute of Health), and medical communities (WebMD).

This paper presents the author's experiments in applying the Internet to develop the ways of teaching and educating his fellows. For each course, the author assigns an e-mail account to receive and discuss the assignments and the fundamentals, builds a home page and puts his lectures and full activities. Each student should build his/her home page and puts the assignments after sending its URL to the assigned email. The author manages each course through the Internet. The course management includes: contacts, syllabus, lecture notes, lab activities (experiments), assignments, projects, tutorials, database that includes the performance of each students (each student has assign a PIN number to access his record to know the status of his/her performance), the ideal solution of each problem, the odd cases and ways of handling it, statistics of each exam, and helping tools.

This methodology has some pros and cons. About 25% of students do not attend lectures (they depend on the existence of all activities on the Internet). Students can find the lecturer and discus with him whatever is difficult, interchange thoughts, and solve any problem. 7.5% of students reply to requests of the lecture within the first 7 hours, they reach to 30% by the end of the day, after two days they reach 70%, about 15% do not care (most probably they fail to pass the course). The previous courses' results showed the following: 2% got the full mark, 34% got an "A" (including the full mark students), 24% got a "B", 15% got a "C", 18% just pass, and the rest failed to pass.

The responses from the author's fellows encouraged him to use that way in all of his classes (through the last three years). It can be strongly said: applying this way in the medical field will satisfy all objectives of the education and will save money, will improve physicians' skills at no risk of real experiments on human patients. Chatting and discussion groups will add an order of magnitude on the benefits of that experiment.

Loading courses on the net, a part of distance learning, is named courseware. The other part of distance learning is the management part. This management part starts with registration phase of a degree and ends with the phase of giving the diploma to successful student. Between these phases, there are some other managerial/administration phases (e.g.: follow up student performance, exams, funding affairs, ...etc.). All those phases use web-enabling tools (like: ASP, or JSP) to connect the web pages into the

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university databases. We train our B.Sc. students on the web enabling concepts and building a project in the last 10 hours of the "Multimedia course- http://www.h-elmahdy.net/multimedia/" lab.

As a result of this experiment, Ain Shams University (Cairo, Egypt) has selected the author of this paper (Sep. 26, 2002) to be the vice chair of the University Network to plan and deploy the mentioned education system.

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## Principles and scenarios of automated email routing and request-tracking: A field-study with 4 different systems

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Similar to Call Center techniques like "skill based" routing, different techniques can help to pre-route incoming email to the most competent agent or doctor in a clinical setting. Our objective was to evaluate incoming emails from a general / surgical clinic on their contents and the possibility to match them into different categories. In addition we evaluated different technical methods to do so.

For the Evaluation 282 consecutive incoming Patient Emails were taken and categorized into a certain scheme "by hand". Spam-Email was not included in the Evaluation. With this categorization we tried to interpolate and evaluate 4 different methods for Email pre-routing:

- 1. Simple Classification of the request into 4 categories "by hand"
- 2. Automated Sorting with a simple Keyword-based System
- 3. Automated Sorting with SerWare Private Brain Software
- 4. Sorting with an AIML-based Agent from the Healthbot.Net Project

In our own classification, results showed that most Emails (128 Emails / 45% = Class I) where requests on certain procedures and illnesses from doctors (12%) and patients (33%), second most there where Emails regarding an already planned and upcoming visit to the clinic (22% = Class II) only from patients, third most there were simple requests for information material (18% = Class III), fourth most (9% = Class IV) there were specific requests on treatments afterwards & questions on the doctors letter. 6% of the Email could not be classified.

For the simple Keyword-based System we set up a database with around 800 treatments and illnesses keywords and their synonyms and typos. The setup was independent from the content of the Emails. With the System there was nearly no differentiation between class I, II and IV Emails and a very basic but good classification according to different illnesses in each class. 23% of the Emails where mis-categorized to

Class III due to missing keywords. With the AIML-based System there was a very near result to the keyword-based system due to the very simple AIML-patterns for this example. With the small set of Emails also the SerWare System could not differentiate between Classes, but did a good job on grouping Emails by same and also new keywords.

An Analysis of the answers of Class I Emails showed, that for the number of 128 Emails no number of more than 2 answers could be grouped to "equal" answers.

Our actual conclusions from the different systems were that mechanisms seem to take grip only if a system takes influence at the different steps of the workflow. A system of formula-based entry and tracking-numbers for coherent requests seems to be very feasible. For the new requests concerning medical content a keyword-based system with a self-learning component seems to be feasible. A higher number of Emails has to show, if a component for pre-configured answers could be possible in the medical field.

#### [30]

## Designing natural speaking smart bots for patient screening and education: The HealthBot.Net project

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Patient education is associated with several desirable outcomes like greater satisfaction and compliance of the patient. This work attempts to use a natural speaking software bot for education, screening and data entry purposes in chronic and acute disease management. The Platform Healthbot.NET was set up for this purpose and allows groups to set up bots via a web interface.

For the Programming of the Bot we used the Artificial Intelligence Meta Language (AIML) in Combination with an interface built in PHP4. For the Deployment a variant of the ALICE Program D and a Cocoon/Apache Server was used. The Linguistic Analysis of the Bot/Patient Interview was performed over a Special Parser plotting a map of the conversation's topics. One objective of the platform was to give patients independent possibility to access information speaking "natural" Language and being guided in entering structured data. Second objective was to provide a conversation overview and screening objective for the doctor to allow a more focussed and individual patient interview.

The resulting platform allows to setup of the bots brain using keyword pattern matching, matching synonyms and determining communication pathways and conjectural questions. The Bot was trained on therapeutic catheter ablation in AV-Node Reentry Tachycardia patients before a rhythmologic catheter ablation. Patients had the chance to have conversation with the bot before the treatment. In a following Doctor/Patient Interview a Map of the Bot Conversation was provided for the doctor. Doctor and patient had to fill out a questionnaire after the interviews. For our study patients were divided into two groups - one group had only a doctor interview, the other had both interviews. Results with n=26 patients in both groups showed good acceptance of the bot conversation. Patients having the bot conversation asked 8.7 questions in average, while the bot failed to answer properly an average of 2.9 questions. In the doctor interview patients having had bot conversation surprisingly had an interview with the doctor being graded as "more detailed". The Conversation Plot was graded by 5 the doctor as "useful" and the interview was "more focussed".

Our results encourage our approach in training a bot for specific patient education. Over the Web-Interface two independent groups could be invited to setup an own bot. Our first version seems to stimulate patients for a deeper and more detailed understanding. For future aspects of the bot patient monitoring and continuous health education could be feasible with the provided tools. A very interesting future component could be the integration of interfaces to hardware (like a glucose meter or blood pressure meter) and the combination with speech technologies (voice in/output).

## [31] Teledermatology: The patient's perspective

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*Introduction:* Teledermatology (dermatology through the Internet) is an alternative to busy outpatient consultations. While health care providers and authorities look for technical standards, explore legal issues and adaptation of Internet technology in health care, patients are already seeking for information on the Internet and approach doctors daily through e-mail [1][2] Until now, most teledermatology studies involved a general practitioner (GP) as an intermediate between the patient and dermatologist [3][4]. The GP provided the digital images and patient history to the specialists and communicated their answer to the patient. Because of capacity problems in Dutch GP's and the patients' clear willingness to use Internet technology [2] we have introduced a teledermatology system where the patients are the main information providers and receivers. We have investigated the feasibility and accuracy of this new model of care. Important part of the feasibility study was the patients' opinion about the approach. In this article we describe the main patient expectation and satisfaction results.

*Materials and methods:* Patients were eligible if they were able to provide electronic images and history of skin complaint through the Internet. Before visiting the outpatient dermatologist they had been referred to by their GP, study participants were reviewed through the study website by a board certified dermatologist. Within one day, patients received a structured answer through the same website. Within 2 days subsequently, they visited their own dermatologist for the actual diagnosis and treatment. During the first visit to the website, patients filled in an expectation questionnaire consisting of both multiple-choice and open questions. In the open questions patients were asked to explain their answers to the multiple-choice questions and to indicate good and bad aspects. The identical questions were asked again after receiving advice from the online dermatologist, but before the live consultation in order to evaluate satisfaction.

*Results:* Of the 105 patients who participated in this study, 93 (88.6%) completed the expectations and 90 (85.7%) the satisfaction questionnaires. Eighty patients (76.2%) completed both questionnaires. Before the teleconsultation, 62.4% patients thought teledermatology was "good' or "very good". This was 76.7% after the teleconsultation. After the teleconsultation 52.2% of patients had confidence in the answer of the online dermatologist as compared to 34.4% at onset. The best aspect of teledermatology, according to 41 patients who completed the satisfaction evaluation, was the speed of receiving an answer. Patients also indicated that they had more time to think about the history of their complaint when filling in the complaint questionnaires at home. This made them more aware of their symptoms. The fact that diagnostic and therapeutic information was displayed on their own screen, gave them the opportunity to re-read it and understand it better then during a traditional live consultation. The major disadvantage of teledermatology was the lack of personal contact and interaction with the doctor. Eighty-six percent of patients indicated a wish to be seen by a live dermatologist after the teleconsultation, but considered teledermatology as a good preparation tool for the actual live consultation.

"I get the feeling that I have a more active role and I like that. I am more aware of my complaint and my expectations."

"It is distant (pleasant!)."

"It is nice to have the diagnosis in black and white. You can read it several times." "You have to describe your complaint in detail which can probably improve the diagnostics."

Fig.1: Some of the patients' answers on the question about their opinion towards teledermatology.

*Discussion and conclusions:* Patients mentioned various advantages for teledermatology, but remained reserved and preferred a live consultation with a dermatologist. Teledermatology as a consultation preparation and communication model was welcomed by most patients. For this study we used a simple website. Adding interactive features and personalizing it (e.g. with the name and photograph of the dermatologist) might improve the adoption of patient mediated teledermatology. We conclude that teledermatology, could not only become a potential time saving tool, but also a way to improve the communication between the patient and doctor. They both have more time to think about, write and read medical information, independent of time and place. Based on our results, we believe that this new model of care deserves more attention and we completely agree with Mair et al. [5] who emphasis that further research is necessary for a wider introduction of telemedicine.

*Acknowledgements:* We would like to thank all patients who participated in this study. Special thanks to dermatology assistants and call centre members who included the patients. Dermatologists: T. W. van den Akker, F.B. Blog, M.T. Bousema, M.Brakman, I. Cairo, M.B. Crijns, R. Damstra, C.P. Glade, A.Glastra, A.M.J. van der Kley, R.J.J. Koopman, C.R.R. Kuiters, C.J.G.R. van der Harst-Oostveen, C.W. den Hengst, C.J.M. Henquet, M. Nahuijs, B.P. Nanninga, M.A. de Rie, C.J.G. Sanders, P.M. Steijlen, C. Timmer, P. Velthuis, J.E. Zeegelaar.

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## Designing knowledge management systems using XML, XSLT, and MPEG-7 – The GridSET catalogue

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Capturing knowledge in electronic information systems has been proven difficult over the years. One problem is the rigidity of information systems. During the recent years, XML has been proven a suitable framework for creating structured data and information structures that provides great flexibility. In previous publications we have shown that XSLT, the extensible Stylesheet Language, is a powerful tool for linking XML-descriptions of different sources together [1]. Despite its name, XSLT is not a stylesheet language, but a programming language that can transform collections of XML-documents in new

collections. It can be used to build XML-based search en-gines, self-configuring XML-editors and more. We have applied that for managing a telemedicine magazine, and several other web sites [2, 3, 4].

In this paper we describe how we can use MPEG-7 [5] based classification schemes to describe multimedia and programming items related to a medical training package called GridSET. The advantage of our approach it that - It is based on standards - It is easy to implement because of the use of XML, XSLT and MPEG-7 technology - Classification schemes can easily be added and changed. - The user can view the same information using different classification schemes

GridSET [6] is an e-learning environment. It consists of software, both specially developed and publicly available, and tools to help courseware developers. It has been used to implement three surgery training courses. These also are built from a number of reusable components. GridSET was developed in the EU funded project WebSET [3]. To make as much of the items as possible reusable, we created a catalogue of all the items. This is called the GridSET Exchange. In this catalogue, each item is de-scribed by a meta-data entry. This entry is described in MPEG-7, the new ISO standard for describing meta-data about multi-media objects. MPEG-7 is formulated in XML. Part of the meta-data for an item can be described using classification schemes. MPEG-7 includes a number of standard schemes but also has a mechanism to describe new classification schemes, and tell, using Xpath, where they may be used within an item description.

We used these basic MPEG-7 classification scheme descriptions to develop an XML editor that is automatically generated for an item [7]. When an item property is described as a classification scheme entry, a number of pull-down menus is generated describing the whole classification scheme. Also the description of the item in the hierarchy, to which the author has already made his choice, is displayed.

A user of the information can list all items with "classical" means, like a standard word search. But in addition he can list all items in the catalogue projected over the classification schemes. The classification schemes present his knowledge. By projecting the items on top and in relation to these schemes, he can use his existing know-ledge to gather new knowledge.

New classification schemes can be added easily to our system. They have to be ex-pressed in MPEG-7, which is not difficult, because XML-tools can be used to produce them. Once they are available, they can be registered with the application. Once registered, the user can select the one he wants to use for a specify property. The author and user of the catalogue can use different classification schemes for the same property. Hence, an author can use his knowledge to enter information about an item, while a user can use his different knowledge to view the information.

The technology has been implemented for the GridSET Exchange web site. Classi-fication schemes have been added for the form of the item (programme, VR object, image, etc), where it should be used, the intended audience, whether the item has been certified and how it is available. The schemes implemented currently are rather simple. In future work, we will try to use existing larger classification schemes.

In another area, that of Grid computing, we have applied the system to build a large catalogue [8]. Because Grid computing is an emerging area of technology, no well-defined taxonomies or classification schemes exist. There the flexibility of our system to adapt the scheme and immediately see the result proves to be useful.

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## An interactive web-based system for Uterine Fibroid Embolisation (UFE) facilitating education, patient information, pre-assessment and follow-up

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*Introduction:* This paper evaluates a purpose-designed web-based information system and a web-based interface for pre-assessment and follow-up of patients undergoing uterine fibroid embolisation (UFE).

*Materials and methods:* Uterine fibroids are the most common benign (non-cancerous) pelvic tumours in women. About 40% of women have fibroids by the age of 40. Fibroids develop in the muscular wall of the uterus and depending on their size and location may cause heavy uterine bleeding (menorrhagia), pain or problems with passing urine or bowel movements. Fibroids may also interfere with fertility either by preventing implantation of the embryo or by interrupting a growing embryo. Treatment options for fibroids include the administration of drugs, or surgery, which but not cure the fibroid. UFE is a relatively new treatment option performed by an interventional radiologist. It is a minimally invasive procedure where a tiny incision is made in the groin and a catheter is inserted into the femoral artery. The catheter is guided through the artery to the uterus while the radiologist watches the procedure using X-ray (fluoroscopy). Then thousands of tiny polyvinyl alcohol (PVA) particles are injected through the catheter into the artery that is supplying blood to the fibroid. This results in cutting off the blood flow to the fibroid and causes it to shrink in size.

A patient assessment is made prior to the procedure and it involves a gynaecologist in order to make the diagnosis and exclude if possible contra-indicating pathology. Pre-procedure imaging by means of magnetic resonance (MR) imaging is necessary to determine size, exact location and number of fibroids. There is a 30-day post-embolisation follow-up, then another one in 6 month's time and another in a year's time. These follow-ups are carried out by the radiologist and involve a set of questions answered by the patient.

The system is designed using Dreamweaver and Flash providing a graphical user interface (GUI) making it more user friendly and easy to use. In order assure security of the patient's information, the access to the web system is made via secure HTTP (https) where the information sent over the connection is encrypted using the SSL protocol. There is a provision for the system to be linked to the current hospital information system (HIS), so that assessment and follow-up feedback forms can be routed back to doctors.

*Results:* Patient information in the form of question and answer is provided through the web-based interface in order to familiarise the patient with the procedure and educate them about it. The pre-

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assessment questionnaire is also provided and can be filled by the patient on-line and submitted to the interventional radiologist, in order to plan the procedure and in collaboration with the gynaecologist make the diagnosis and plan pre-procedure imaging needed.

*Discussion:* The web-based interface for providing patient information, pre-assessment and follow-up of women undergoing uterine fibroid embolisation is a simple efficient way of gathering important information. It also beneficial to women by providing a complete up to date accessible source of information which helps relieve anxiety and assists in the process of informed consent, educating them and answering all the questions they might have prior to the procedure.

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## [34] Developing electronic care plans for multi-agency use across the Web

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Electronic Care Plans have been developed for multi-agency use across the web. These Care plans have been designed from the original paper version but the need to make these available to a larger range of practitioners was the driver behind creating an electronic version. These Care Plans needed to be made available to practitioners with specific responsibility for the individual patient and eventually for the patient themselves. The agencies involved include primary and secondary care and social services. The Care Plans have been developed for use with Mental Health patients but their structure and component sections could be changed for other patient groups. It is particularly important in the Mental Health Service as several different agencies are involved in the patient's care and the patient may need emergency or crisis care.

The Electronic Care Plans have been designed with Harrow Unified Mental Health Services, and have been based on their original paper version, but with some improvements due to the greater flexibility of the electronic system. These care plans are now being used across this service and within their own intranet system. Plans are to extend this and allow the GP's access to their own patients Care Plans, although the confidentiality arrangements still need to be completed. Consultant psychiatrists, social workers, CPA managers, care co-ordinators and IT professionals all formed part of the team that created the electronic form, which was then tested with real patients.

The Electronic Care Plans were then developed with an IT software company to produce the final version. This has been written in XML so that it is compatible with any future developments and so that the data can be loaded from the existing legacy systems. This was considered to be very important, as data already in the system such as the patient's demographics, including their GP and Hospital contacts could be pre-loaded, which should reduce the workload of each care co-ordinator responsible for creating and inputting the Care Plans. Each screen of the Care Plan fulfils a specific function such as, Patient demographics, Core team, Mental Health and Physical needs, Crisis Plan, and Patient and Care co-ordinators agreements. The presentation will include an outline of each of these screens together with an indication of the method of completing them. It will not contain any patient identifiable data.

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The Care Plans are now available across an Internet connection, which is firewalled, and at present only within the NHSNET. As the practitioners within the HUMHS service are all on NHSNET it has been possible for all the secondary care and social care practitioners to gain access to their own patients. A matrix of security levels has been created to set up permissions within the clinicians to ascertain exactly who has specific rights to access specific patients Care Plans. As different practitioners may need to access patients files in a crisis situation these overrides (with audit trails and reasons) have been included, for more senior staff. The next stage will be to make these available to the A&E staff, again for specific patients, as the need arises and then link the system to the GP systems.

The link to the GP systems is likely to be more time consuming as each of the GP's has different software and set-ups on their computer systems. However the GP's will be given access within the hospital environment for their own patients, such as at the individual patients care review and via the Care co-ordinator. This is expected as being prior to their being given access to this information at their desktop.

The presentation will include information on the confidentiality and access arrangements and will cover the future developments of the system. Finally a discussion of the problems encountered and some of the solutions will be delivered, prior to opening up the discussion to the audience.

The Care plan system was developed over a time span of approximately 12 months during which time there were three iterations of the system, with changes to the screens, layout and structure, before the final version was accepted. It should be remembered in any computer-based project that there would be (and usually should be) development time and iterative developments. The comparatively short time frame was possible because of the basic paper version which was already being used and the commitment of the specific team, without this it would have taken much longer. There will also be future changes to the system over time and it is expected that the whole Care Plan system will evolve through time and that increasing links will be made to other systems as these come on line.

The Electronic Care Plans are part of the plans for a larger system, which has been planned, and has been funded by "Invest to Save" government and matched local funding and with some additional development money from the Social Services. The need to create a unified Care Plan which included each patients care records was dependent on the creation of the Unified service which enabled all practitioners in the patients care team to be able to access the same security and computer intranet. Future implications for this are that, with the requisite high security controls, these Care Plans could be transmitted to other agencies, perhaps even in other geographical areas who take over the care of a specific patient.

Acknowledgements should be made to the team from HUMHS who were instrumental in developing the system and the system designers who produced the final version to our specifications.

### [35]

#### Web supported education and teaching: Lifelong learning in telemedicine: KOD project

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*Introduction:* As a consequence of the multi-disciplinary nature of the Telemedicine it is difficult to find contents and suitable material to fit the trainees objectives. Furthermore the role of Internet on Medicine and Telemedicine teaching is going to be decisive in the XXI century. On this context the KOD project (Knowledge On Demand IST 1999-12503), try to provide a suitable environment capable to use Internet for efficient lifelong learning. The main achievements include innovative tools, adaptive environment, efficient information update and selection of items according to user demands. Using this

technology the CATAI is developing a Telemedicine training demonstrator, able to deliver adaptive contents to the different learner categories.

*Materials and methods:* Technically, the main idea behind the KOD is the creation of a vertical learning portal (VLP) to design, develop, modify, retrieve, search, broker, interchange, re-use and access educational adaptive e-content; to this aim the KOD consortium is building an e-learning environment following the main standards; KOD is based on XML and is IMS, SCORM, IEEE LOM & LIP and Dublin Core Standard compliant; and pretends to be interoperable and portable.

KOD includes innovative approaches like "Agent technology" like KRADLE for brokering and repository publishing purposes, EM2 for Educational Metadata Edition and Generation (metadata are XML tags to classify contents). The Adaptive environment includes a Learning Management System to monitoring and managerial purposes, this tool examine the learner profile and the assets available in the repository and then decide which of them are suitable for a particular learner.

KOD also incorporates its own editor, to support authoring purposes, called KOD packager; this tool allows the authors design, develop, edit or modify packaged contents. An efficient assets update tool is included inside the Packager to classify, export, re-use and adapt raw assets in XML, to be then stored into a repository. The initial telemedicine contents processed by means of the above technology is the so-called BoK of Telemedicine published in the only existing textbook of telemedicine.

The Current demonstrator is built around "KOD knowledge units", a set of assets and topics grouped by a certain subject criteria; the core units telemedicine are "Fundamentals" and "Specific Telemedicine Applications". The "learning objects" of each knowledge unit are structured in this way: an Overview of the unit, a number of contents in several formats (.doc, .html, .ppt, etc.), a reference section, FAQs, Summary and Test Section. Each learning object and some of their contents are tagged with metadata that will enable the system to select the suitability of a content to an specific user profile, KOD has adopted the Felder-Silbermann learning styles model; which is used through an small questionnaire to determine if a particular user is visual or verbal, active or reflective, sensing or intuitive, is interested in IT or in Medical issues; the system will use this information to decide which contents should be presented to a particular person, this is the reason the contents are covered by a "skin" of metadata (basically describing and classifying those contents) and through navigational rules (designed by the authors) the system use the knowledge on an specific user to check an asset metadata and decide if the content suits the preferences and objectives designed to that particular individual. In terms of Agent and Authoring features the system allow back end users to remotely access the material for updating and delivering purposes by means of KRADLE. Basically, the systems keep information on the assets stored in many specific machines, wherever they would be. When an agent is looking for contents the system request response from the repositories, then the targets can be retrieved or delivered or whatever would be necessary to doing on it.

*Results:* The 130 students who tested the tool during the X Winter Course of the CATAI reported very positive impressions and interesting statistical results. The more relevant are related with the designed policies used in such courses, specially referring the use of SCORM for reveal sequentially the previously hidden contents: they found particularly disgusting this policy due to the fact they prefer to know the exact amount of material in order to elaborate an studying strategy. (They must be taken into account a 70 % were medicine students and a 25 % were IT Students, both very used to deal with huge amounts of information). They also prefer not to be tested on an issue to check their previous knowledge, the most of them (98%) reported an interest in material that match their goals and they prefer material written in their mother tongue.

*Conclusions:* According to the feedback of the Attendants of the CATAI X Winter Course KOD Packager features for learners were considered very positively but, in terms of Authors features, the IT students received the tool warmly and some of them found it excessively complex to deal with; However, it must be considered the available version was still under development. In other hand the user's pre-

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evaluation on desired features for learners reported very interesting results and corrections to be done in the previous design of the demonstrator, specially in a crucial aspect like navigational rules; demonstrating once again the importance of testing every stage of a project and not only the final one avoiding in this way the irreversible consequences of preconceived misconceptions.

Glossary XML = Extended Mark-up language IMS= Instructional Multimedia System Global Learning Consortium SCORM= Shareable Content Object Reference Model LOM= Learning Object Metadata LIP= Learner Information Profile KRADLE=KOD Reusable Adaptive Learning Content Exchange Broker technology EM2= Educational Metadata BoK = Body of Knowledge of Telemedicine - Ferrer-Roca O. Sosa-Iudicissa M. "Handbook of Telemedicine". IOS-Press Amsterdam. ISBN: 90 5199 413 3 2nd Edition. 2001 FAQs = Frequently Asked Questions

#### [36]

## A new approach to medical compliance at home: The MEDICATE project PART I – The home unit

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This paper describes the research and the analysis that motivates the development of a health automation system for European homes, as part of the EU funded MEDICATE project. This project aims at developing an innovative yet simple to use automation system in the form of an intelligent home unit for solid medication dispensing, connected to a pan-European network of medical service providers, pharmacies, physicians, and home care groups. The European Community funded this concept in May 2001 (IST-2000-27618). This paper reports on the findings of the first year of the project, in particular on research, functional, and non-technical issues related to the specification, design and development of the intelligent home unit.

The strength of the device described here is premised on the trust relation that ties patient, physician and pharmacist, and improves on it by providing continuous supervision of medication intake by the patient. This device is personalized for the needs of each individual patient, thus creating a link between the pharmacy, the physician and the patient's home through Medicate control centre. Personalization consists of enabling prescription check against allergies and drug conflicts, enforcing specific rules about timing of medication assumption, developing audio and visual reminders tailored to patient's disabilities, and adapting to patient's compliance habit he device consists of a fixed part and a mobile part, thus allowing for short stays outside the home. The main goals guiding the development of the home unit are:

- 1. Modular for easy reconfiguration and support of a variable number of oral medications,
- 2. Programmable by telephone directly by the control centre,
- 3. Capable of dispensing oral medications in any combination and time sequence,
- 4. Capable of generating audio, visual and voice reminders at medication time,
- 5. Trained on the patient's voice to understand simple spoken commands,
- 6. Monitoring treatment concordance and informing the control centre of any non-concordance with treatment,
- 7. Automatically requesting medication refills to the service platform,
- 8. Conforming to Health and Communication Standards at national and EU levels.

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The device will interact with the patient at home with audio, visual and voice messages to remind them of the need of taking a medication at a specific time. It will also be able to monitor the presence of the medications in its delivery receptacle, thus detecting when medications are taken. If medications are not taken within a prescribed amount of time, it will automatically remove the medications form the delivery receptacle, thus preventing the acquisition of medications at the wrong time, and will inform the control centre of a non-concordance event by automatically contacting them via telephone.

This device bridges the gap between hospital care and home care, by providing simple monitoring tools that can autonomously request support via telephone from medical personnel in cases of non-concordance with prescribed drug treatment. The device will use low cost consumer electronic components, and will have state of the art communication (supports TCP/IP protocol, XML, Bluetooth, and GPRS) and processing capabilities, that will make it very user friendly to patients and medical personnel.

There are a number of advantages to be gained by continuously monitoring the medication adherence of patients, especially elderly patients. These benefits can be grouped into the two main categories of therapeutic and economic benefits. Treatment can be better maintained, thus enhancing its efficacy. This in turn would reduce the risk of under or over medication, and the associated risk of hospitalisation. Complex drug regimens could be prescribed more safely without the risk of danger for the patient, i.e. instances of drug contradictions can be avoided. Finally, medical personnel would work under less stress, since the robotic device will alert them at the insurgence of a non-adherence situation. To reach a consensus on the features of the home device, an extensive state of the art and of the practice analysis on the issues related to pill dispensing has been conducted, including:

- 1. Research of design safety for the medication delivery module,
- 2. Research of similar approaches addressing the same medication
- 3. Issues (from an academic, technological and market perspective),
- 4. Development of reliable monitoring and communication software,
- 5. Selection of appropriate warning methods,
- 6. Design and fabrication of low cost, highly reliable electronics,
- 7. Design and implementation of patient and other stakeholder interfaces.

This paper reports on the outcome of these studies and on the system design, which results from the trade off analysis of the factors affecting the development of a successful medical home automation product.

## [37]

## The Internet through the eye of breast cancer patients and their families – Or the dilemma of credible and usable websites and the patients' needs

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*Introduction:* Breast Cancer Websites were observed from the patients' eye with the focus on German Websites concerning content, usability, trustworthy and interactive options. The expertise was part of a bigger study in breast cancer by the "Deutsche Krebshilfe" (German Cancer Aid), named "FORMaCa". Purpose of the study is to give transparency to the circumstances of diagnosis and therapy of breast cancer in the German healthcare-system from the diseased women's point of view. The study is conducted by Wilfried Jacobs, head of the AOK Rheinland – Die Gesundheitskasse, a German health

insurance company. The study includes various approaches, for example + for one year every week to every two weeks a female gynaecologist gives a phone call to 20 women, who recently got the diagnosis breast cancer and interviews them about their present-day experience, thoughts and feelings, + 100 women, who suffer from breast cancer between 9 and 18 months, are interviewed about their personal experience and feelings looking back to the process of diagnosis and therapies, + in an expertise websites concerning breast cancer were reviewed from the focus of patients and their families or friends, who need help or want to get information for the patients.

*Objectives:* To determine which national and international websites are available for breast cancer patients and their families in Germany and how usable and trustworthy they are viewed by the patients needs.

*Study design:* Compared to other studies of a similar subject the selection of relevant websites was diverse. The search engine Google was only one option to generate the list of websites. Because the intention was to examine websites through "the eye of the patients" the search word "breast cancer" was too broad or too narrow. To consider the complex illness breast cancer and the complex questions of breast cancer patients we had to widen the search. In a secondary attempt to enlarge the list of websites we considered the web links of three German patient oriented non-profit-portals mamazone.de, inkanet.de and krebs-kompass.de. Finally we have chosen 188 websites, mainly from Germany or German Spoken. Because the US-American Breast Cancer Movement is much more ahead as well as the Internet is we took some important US-websites into account, and some Dutch and British websites. The type of organization (medical society, support group etc.) or the type of publisher/editor (commercial, lay man etc.) was not relevant. Very important was not only to look at websites which were "officially" trustworthy (in a sense of having a "quality medical label") but also we considered websites, which had many users and were rated to be "authentic". Extremely important were common criteria of usability because medical laymen have to understand a website from two sites: medical and navigational wise. The survey was done in July/August 2002.

*Methods:* To discover the breast cancer patients' needs we examined three most popular communities on the German Web: brustkrebs.net, krebs-kompass.de and inkanet.de. The questions and remarks of the patients were put into more than 10 different subjects: "diagnosis", "finding a 'good' doctor/hospital", "second opinion", "therapy", "therapy studies", "check-up", "reconstruction", "coping", "alternative medicine", "soul", "pregnancy", "support by family, professionals", "social status/work", "dying" etc.. We finally ended up in looking at websites beyond medical themes including social issues, nutrition as well as for end of life care and spiritual themes.

Every website was checked by content, trustworthy, interactivity and usability. Content contained the primary and secondary target group and the actual themes of the website. Trustworthy contained whether the website was participating in quality labelling or was certified of any kind. Interactivity meant to look for interactive tools of websites like chats, boards, mailing lists etc. Usability included e.g. site navigation, design, technical availability, site map and search, wording.

## Results:

<u>Content:</u> As expected we found that the patients and their families can find many websites which deals with breast cancer in general. A part of this huge amount of possible information there is a gap of information, which is tremendous too. The demand of information for patients is only partly covered in the (German) web. The websites for patients, which are first diagnosed, seems to be okay but could still be improved. We discovered that important themes were nearly completely missing at the German Websites: Breast reconstruction, dying, nutrition, partnership and sexuality, alternative and complementary medicine, patient guidelines, patient education, spirituality, pregnancy with or after breast cancer. Also there was not a single website focusing specially on the questions of the care takers (families and friends). The information gap was partly filled by private websites from survivors, e.g. www.brustwiederherstellung.de, a website about the reconstruction of breasts done by a German Patient.

The websites of medical societies hardly focus on the patients' needs. If at all they had a very poor offer of patient oriented content or links. Mostly patients were seen as a secondary or tertiary target group. Patients and families have to "collect" the needed information on various websites, so "surfing" (and the ability to "surf") is absolutely necessary in order to get a clear idea. Concerning the type of organizations we found that support groups offered the most important interactive tools. Websites of medical societies and cancer information centres did not offer any interactivity at all. Mailing lists (in the USA very frequently used by patients and their families) are not common yet in the German Breast CancerWeb. Probably for law reasons the websites of German pharmaceutical industry offered only few usable information for patients, to get detailed information e.g. on drugs German patients have to leave the "legal" way of research and swap to Swiss or US-American Websites. There is no commercial breast cancer site in Germany as there is in the USA.

<u>Trustworthy</u>: There were only four German Websites who took part at "afgis" (German programme for quality health information in the Web) or any other kind of "proven" information.

<u>Usability</u>: Only two German websites were within the common criteria's of usability. Nearly all websites had a poor navigation, hardly any website had a site search or site map. To find out who produced / published the site the users very often had to look around for a while, the classical legally demanded "imprint" was not widespread. The Font size was often fixed too small and/or in too light colours. Especially websites of support groups and medical societies were navigated and designed badly probably because of the lack of money and/or know-how.

It was remarkable to see that "official" German websites from cancer information centres and medical societies have hardly any useful links for patients. There are list of links in the web but they were offered by patient organizations.

*Conclusions:* Compared to the German Websites the US-American Internet is still way ahead in content, usability and interactivity. Information for breast cancer patients and their families are offered by many different communities of interests and they hardly work together. The support scene is very heterogeneous, too. The health system in Germany is still very hierarchical and very difficult to understand for layman. The German Web mirrors that.

### [38]

### The electronic version of the Portuguese medicines handbook "Prontuário Terapêutico"

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Introduction: "Prontuário Terapêutico" is an official handbook for medicinal products published every year by the Portuguese agency of medicines INFARMED (Instituto Nacional da FARmácia e do MEDicamento). It main goal is to offer to the health professionals a tool for rational prescribing of medicines. "Prontuário Terapêutico" holds all the medicines that have permission to the introduction in the Portuguese market. The electronic version of this handbook appeared as a complement to the original annual paper version in a collaboration of Faculty of Medicine of Porto with INFARMED. The information about medicines in this electronic version is automatically updated from the INFARMED main database of all medicines and health products. The main goal of the development of this on-line version was to improve even more the access to medicines information. This on-line version allows several types of searches in all the information about medicines and includes searches in all the texts of the handbook. The official web site is http://www.infarmed.pt/prontuario/.

*Materials and methods:* The application was developed using HTML, scripting languages such as PHP (Server Side) and Java Script (Client Side) within the Apache Web Server and with Oracle as DBMS. Its implementation and development comprised the following phases:

- Database design and data importation. In this phase, tables, relationships and indexes were studied, defined and created. Data was transformed from it initial book format into the new defined electronic format,
- Browsing, searching and listing mechanisms implementation. A prototype was initially developed and evaluated taking into account its speed, intuition, easy of use and functionality,
- Data visualization. Outputs were based in the following aspects: intuition, coherence and completeness,
- Printing and exportation of data,
- Data editing tools, for updating and managing data,
- Web design. The design is simple, ergonomic and, as far as possible, fast. Several questions about graphic, colours and iconography were considered.

*Results:* The application is based in a philosophy similar to the paper version. It is possible to distinguish two different types of utilization: one restricted – based on a specific search, limited to medicines designations (international common designation or commercial name) and related specific information (indications, adverse reactions, posology, etc.); and other extended – including several others ways of searching, browsing and listing, such as the onomastic index and the index of contents. The first one consider a faster and, eventually, more intensive utilisation (e.g. to immediately obtain information for prescribing). The second one, mainly used for knowledge update, allows general searches and browse through the chapters' structure. The developed application has the following functionalities implemented:

- Possibility of hierarchic browsing.
- Possibility to search for medicines (generic or commercial name) or for laboratories. Results include indications, contra-indications, adverse reactions, interactions, presentation, posology, price, etc.,
- Possibility to search in all the texts of "Prontuário Terapêutico",
- Possibility to sort the obtained results by designation, price, laboratory, etc.,
- Printing results in a proper format,
- Mechanisms for update and management of data,
- Browsing through the onomastic index,
- Browsing through hyperlinks dynamically created in the texts that includes references to other chapters or to medicines that exists in the database,
- Specific searches for generic medicines and for laboratories.

*Discussion:* With this on-line version the National Health Service have an informative space that can be an advantageous option for health professionals that need to quickly find updated technical, scientific or administrative characteristics about some medicines. This on-line version has many obvious advantages in comparison with the paper version. The process of creation and implementation of the on-line version of "Prontuário Terapêutico" led to the detection and rectification of several inconsistencies and the systematisation of recommendations for the conception and implementation of future editions. The created database is now being used in others national applications related to electronic prescription of medicines. Analysing the logs it is possible to see an increasing utilization of the on-line version. Comparing to 2001, in 2002 the average of visits per month is 28% higher (1129 vs.1443) and the average of web pages visited by month increased 38% (10638 vs. 14716).

### References

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#### [39]

# A 5 year update of the K.O.A.L.A.<sup>TM</sup> Internet-based learning portfolio database and description of user's characteristics

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*Methods:* Data entered from July 1997 to July 30, 2000 on the Internet based KOALA system by Obstetrics and Gynecologic residents. High volume users were characterized as > 500 cases overall or >100 cases/year if only one year of use or >300 cases/year if more than one year of use.

*Results:* 170 residents entered a total of 44,023 cases. Of these cases entered, 10,046 had a critical incident. High volume users were 26.5%, moderate 18.2% and low volume users 55.3%. In entries with a critical incident, resources used were staff feedback 13% for high volume users compared to 4% for low volume users, clinical expert 33% for high and 20% for low volume users and Medline, 18% for high compared to 3% for low volume users. High volume users were more likely than low volume users to ask questions related to attitude p<0.001 and self-assessment p<0.001. High volume users were more likely to register a critical incident of learning p<0.001. In addition, a practice change was more likely to be recorded if linked to a critical incident p<0.001. Obstacles encountered during this study were computer access, integration of the Program into the evaluation process, establishment of discipline of reflection on cases and faculty development.

*Conclusion:* Although this study was not mandatory and not part of the final in-training evaluation (FITER), the usage of the KOALA Knowledge Management System can benefit a program in gathering educational data and demonstrate users trends and characteristics. The study suggests that high volume users demonstrate some of the characteristics of self-directed learners and life-long learners.

## [40] Combination of patient informing and disease management - First experiences from Germany

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A target of the German health reform in the year 2000 was the introduction of integrated care. However, measures regarding this were realized hardly till now. So corresponding concepts shall be pushed more strongly, and in addition evidence based approaches (e.g. guidelines) shall be integrated into the treatment series and nets by a new health reform. A result of this politics is the introduction of the so-called Disease Management Programs (DMPs). With their use and the guaranty of structured treatment processes the quality of the medical care of patients with chronic diseases shall be improved. Expectations from it are to achieve a considerable improvement of quality of life for these patients and the reduction of the appearance of resultant damages. The participation is voluntary for the patients. In an initial phase corresponding programs for diabetes mellitus, coronary heart disease, breast cancer and asthma are provided, since 7-1-2002 a legal order has taken force for diabetes mellitus (and breast cancer) at first.

Newest elevations show that about 150 million people are afflicted with the metabolism disease diabetes mellitus worldwide, up to the year 2025 it will be increased on about 300 million. The therapy of

this popular disease requires an active cooperation of the patient independently of the diabetes type. Assumption for it is that the patient is provided with the latest medical information and supported at the use of health software. The modern, informed patient would like to be included in medical decisions and therapies and act on own responsibility - this is basis for a successful realization of the DMP concept again. But present problems of acceptance by patients don't have to be rejected by the hand. Fear of data misuse, missing transparency and a bad information technological networking are the main causes for it. The question is, how this situation can be improved. The decisive keys for cooperation of the patients are enlightenment and informing. While some of the aspects mentioned above are only politically soluble, patients can be supported at participation in the measure by the use and combination of modern information technologies.

At use of electronic media the acceptance of the information supply by the users depends on the representation of the existing medical knowledge considering the structuring of the knowledge, quality of the information, orientation on the target group, clarity and meaningful user guidance. How this was realized in a disease management program for diabetics, the authors would like to represent an electronic case history and its combination with some components to the patient informing process particularly.

A good user interface is distinguished primarily due to the following qualities:

- Monotony (habitual use),
- Low number of steps (information units) for the solution of the task,
- High efficiency.

In this concrete case the layout of the program was realized so that as many criteria as possible could be considered for supporting a good user guidance in the system. The homogeneity of the layout was obtained by color design and the same order of the individual elements. Therefore the recognition effect by the user increases. To avoid misunderstandings it was renounced of the often used multistage menu structure with different placing (e.g. dropdown menus). That's why this logic doesn't disclose itself to unpractized users. A sub-structure was chosen which is organized logically and thematically so that the user can interpret the target information correctly. Supplementary notes or context sensitive helps, for example, offer further support at the use of the program. By the imbedding of context-dependent status information, use of control elements, like list fields and option buttons, and offering of specifically search functions a high degree of operator convenience is obtained.

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## [41]

## The growing and development of intranet services in a hospital context: The case of a clinical and research institution in Italy

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Hospital Information Systems are traditionally divided into three main areas: the Administration Network (older and more consolidated), the Clinical & Sanitary Network (rapidly evolving: think of the systems for the archiving, retrieving and transmission of biomedical images (PACS)) and the Scientific Research Network (relatively new in hospitals not historically involved in Scientific Programmes).

In the Internet era we face a radical change in this scenario with a deep revolution caused by the new possibilities of interaction and integration of the three traditional components. Now, with the growth of institution wide Intranets, users can employ simple (web based) and uniform (XML based) consultation and management tools for their data, ignoring the many sided hardware & software world which effectively produced them. In the first stage of its development the planning of an intranet in a Hospital context focuses mainly on an effective and timely business communication (very important for multi site institutions); this is achieved by a series of services like paperless document flow, statistical reporting of the clinical activity, electronic clinical case sheet, telemedicine data flows, etc.

From this viewpoint the case of the IRCCS Casa Sollievo della Sofferenza, an Italian hospital and research institution, is atypical and give rise to original solutions. In this case, in fact, the first developed and active service was a web-based system to access the electronic editions of scientific journals. The web based system, implemented with client/server technology (using the MS Active Server Pages architecture and the SQL Server DBMS), allows (only) authorized users to directly access the e-journals avoiding the typing of the username and password in the editor access form (these data are stored in a shared database invisible to users and posted to the editor's site via a form located inside the intranet and filled with the respective data in the database). The whole system hides the complexity inherent in the different ways the editor site authenticates the subscribed user (username & password, IP address, both, etc.).

The statistical analysis of the accesses to the web system reveals an enormous interest in researchers and physicians who habitually used to connect to the e-journals available on the Intranet from their workstations. The sudden availability of the full text (without physically going to the library and waiting for an available librarian) is surely the main factor of success of this model, which, with no doubt, increased the overall quality of the medical education in the institution.

Another important field of impact of an Hospital Intranet is personnel education: we developed a section containing electronic materials (text documents, interactive simulations, slide presentations, etc.) concerning courses on management of risks and safety in the work places, in addition to medical knowledge resources.

The next step will be the evolution of the intranet from a means of information/consultation to a complete instrument of hospital business communication. Concerning this, we are implementing a number of Intranet based services for the management of internal processes (as an integrated service for the management and monitoring of the departmental ordering and purchase of drugs, in addition to a distributed reporting of the departmental clinical activities to the Central Management) and for supporting clinical and scientific activities for evidence-based medicine (an online periodically updated database of clinical and pharmaceutical data is currently available to users). The final step will involve the connectivity of the Intranet towards the external world, making its contents reachable from remote locations with notebook and PDA, and with the publication of parts of the contents in the official web site of the hospital institution.

### [42] Internet-based prenatal records: Moving Obstetrics into the 21<sup>st</sup> century

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The prenatal care environment presents a unique need and opportunity for the implementation and acceptance of electronic medical records for several reasons. First, prenatal care is typified by largely routine, high volume, and brief encounters with relatively healthy patients. In many care settings,

particularly large teaching institutions, which care for the highest-risk patients, this care is delivered by rotating, anonymous providers with little knowledge of the specific patient, as well as varying levels of knowledge and expertise. It is exactly this type of environment that can lead to untoward variability, errors, and oversights in the delivery of care. Second, the conduct of prenatal care, including its vocabulary, is fairly well-defined with practitioners already comfortable entering data into a record, which is largely structured, that is an island set apart from a patient's "main" record. Third, the logistics of making paper-based information available to inpatient facilities is both tedious and expensive, especially when that information may be most crucial, namely outside of regular business hours, and when the patient is not anticipated to present in labor. And finally, the fact that the records of office-based prenatal care are crucial to the inpatient obstetric management of these patients makes accessibility of these records of major importance.

The current paper-based system, which has not changed significantly in several decades, is seriously flawed in its ability to achieve these objectives. Central to remedying the current state in prenatal care is the requisite transformation of prenatal care information currently held captive on paper to a discrete digital form that allows wider access, common vocabularies, clinical decision support activities, and improved information design.

eNATALSM is an online, browser-based system which can be implemented via several models, ranging from an Application Service Provider subscription model, suitable for smaller practices, to an enterprise model which is more appropriate for larger implementations. This system has been in use in our solo obgyn practice since June 2001, and has simplified and streamlined several crucial tasks in the delivery of prenatal care in the following ways:

- Accurate determination of EDD

A crucial task specific to prenatal care is accurate determination of a patient's estimated date of delivery (EDD). This assessment is made using several pieces of information, taken from history (menstrual history, LMP), physical findings (uterine size), laboratory findings (date of positive pregnancy test), and ultrasound. eNATAL displays, in one location, all data elements that contribute to EDD calculation, allowing for coherent calculation of this all-important parameter.

 Identification of risks and problems
 Any abnormal values in history, physical, or test results are linked to specific risks and problems. These suggested risks and problems are presented to the provider for validation along with their supporting evidence, for clinician validation or deletion. If validated, the risk or problem becomes part of the permanent record, and, for risks, a risk-specific care plan in enacted.

*Delivery of intended care* Simply identifying patient risks will not improve outcomes unless care plans for those risks are reliably executed. eNATAL provides an automated passive reminder system based on a patient-specific list of care items, each associated with a particular gestational age. These reminders are displayed prominently at the appropriate gestational age, with overdue items highlighted. The clinician must take specific action to indicate that a particular item was performed, discussed, refused by the patient, or deleted, in the event the care item is no longer applicable or relevant.

- Sharing of information The prenatal patient will visit the practitioner's office an average of 14 times during a finite 8month period. Depending on the practice, these visits may be at different locations, and with different providers. The patient will also present, at an unpredictable day and time, to labor and delivery or to an emergency room. Because this application is accessible via the internet, global information sharing is assured. Security is accomplished by 128-bit data encryption, using SSL, thus assuring HIPAA compliance.

#### - *Reduction of liability/increasing defensibility*

We are pleased to report that this capability of the system has not yet been tested in our practice. The fact that eNATAL creates a legible historical record documenting prenatal care can be beneficial in the litigious society in the US. Further, the logs of risk identification and care processes, which include the reasoning behind disposition of specific items, as well as being date and time stamped, will improve the chance of defending one's clinical decision process.

As a by-product of our use of this application, data is generated about the information retrieval patterns of practitioners, and the conduct of prenatal care. We analyzed data from user logs automatically generated weekly by the system, to evaluate patterns of usage by patient and by practice roles. During the 12 month period of the study, 181 unique patients were entered into the system. Patient charts were accessed a total of 4967 times by staff and physician, for an average of 27.5 events per patient, with a minimum of 1 and a maximum of 66. Table 1 outlines the breakdown of these encounters with the chart by practice roles:

Clinical Staff	3258	66%
Physician	1483	30%
Hospital Staff	151	3%
Consultants (MFM)	52	1%
Administrator	23	0.5%

For the first 6 months of this study period, we also evaluated the specific chart modules that were accessed. Table 2 summarizes that analysis:

1312	29%
1213	27%
551	12%
435	10%
334	7%
243	5%
226	5%
103	2%
76	2%
4493	100%
	1213 551 435 334 243 226 103

We will specifically discuss issues that arose during implementation, the ongoing effect of eNATAL on office workflow, and the implications of this data to future enhancements of online prenatal records, including patient access, expansions of clinical decision support, and design modifications of the product.

### [43] Using consumer segmentation to examine effectiveness and utilization of health education tools

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Compare Your Care (CYC) is an interactive, Internet-based tool designed to educate consumers about their chronic health condition, the national treatment guidelines for their condition, and their doctor's level of adherence to these guidelines in treating their illness. Ideally, this tool will strengthen the doctor-patient relationship, and ultimately the health of the patient, through increasing the accountability of both

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the patient and the doctor in the proper treatment of the condition. Use of this tool, however, implies a certain level of activation/motivation on the part of the consumer. With the motivation to use CYC and comply with the tailored feedback and consumer ratings, we hypothesize changes in the doctor-patient relationship and subsequent improvement in health outcomes for individuals as well as movement toward a more consumer-centered health care system.

This presentation will demonstrate a model of consumer activation in health care consisting of four types of patients/health care consumers: Independent Actives, Doctor-Dependent Actives, Doctor-Dependent Passives, and Independent Passives. Each segment has been shown to represent a distinct type of person in relation to their use of health information and services, and will be described in the presentation. These segments are determined by responses to a 10-item, Likert scale survey. Support for the scale's psychometric and external validity on the general American population will be presented.

Understanding the different consumer activation segments and their different approaches to health care can help researchers document the effectiveness of e-health education tools, as well as assist marketers design relevant health messages for their target audience(s). Preliminary investigations have shown that different types of health care support tools appeal to different consumer activation segments. While Internet-based tools are more likely to be used by Independent Actives, phone-based support systems led by doctors are more likely to be used by Doctor-Dependent Actives.

Ultimately, our organization will use this segmentation model to test the effectiveness of CYC to enact health attitude and behavior change, as well as improvement in the doctor-patient relationship. Future research will be discussed.

## [44] Technology and innovation assists healthcare in a developing country

## David Green On-Cue, South Africa

*The project:* Using the web and the text message service of the GSM standard reminders are sent to assist patients with medication adherence and to reduce workload of health care providers in a government clinic in Cape Town, South Africa.

*Background:* Tuberculosis is an increasing public health problem in Cape Town. Poor adherence to treatment regimens results in a low cure rate and an increasing incidence of multi-drug resistant tuberculosis. Current usual care is to directly observe patients for all or most of their doses in the short course regimen. Direct observation has been shown to be no better than self-supervised care. Further, Directly Observed Therapy (DOT) has not been shown to improve outcomes of care.

DOT places a considerable burden on the human resources of health centres. Adherence interventions are required that improve adherence and decrease the workload of the staff at health centres.

*The system:* Prompted Self Administered Therapy (PSAT) is a system whereby selected patients are released from the requirement of direct observation and are prompted by the text message service of the GSM standard to take their medication daily. A pilot project testing the practical functioning and acceptability to patients of PSAT has been successfully completed at one site in Cape Town. Cell phone use is remarkably wide spread in South Africa.

The web is used as an interface to load patient details into a secure database. A custom built application then determines timing and content of messages and sends these to patients cell phones. This effectively makes the system and application service provider or ASP.

Open source and free technology has been used throughout the system. The operating system is FreeBSD, database is MySQL, the application is written in Python, the web server is Apache. Total

development costs, excluding time, are about US\$1000. It currently costs about US\$1 per patient per month to run the system.

The rationale behind the programme is:

- 1. Those with cell phones are more likely to be literate and to have some form of income to pay for the ongoing use of the phone (these two factors have previously been shown to be associated with better adherence)
- 2. Cell phones are more likely to be with the patient at any time than a custom reminder device.
- 3. From the subset of patients with cell phones, the responsible sister determines those with the greatest motivation to adhere and with needs (such as employment circumstances etc.) that make it difficult for the patient to be observed for all doses of the treatment.
- 4. The patients give the go ahead to be placed on the system and are issued with an agreed quantity of medication to return in time for continuous therapy.
- 5. They are loaded onto the SMS system via a simple web based form and the SMS's are sent automatically from then on, ending at the appropriate time, without further intervention from the health personnel.
- 6. The decreased numbers requiring daily observation increase the staff's time to focus on those who may be poorly compliant for whatever reason (note: this intervention is aimed at improving overall compliance, not just in the group selected to receive SMS reminders)

## [45] The Internet in connecting electronics health record mobile clients

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The European Center for Medical Informatics, Statistics and Epidemiology - Cardio (the EuroMISE Center - Cardio) was focused on new approaches of designing of electronic health record (EHR). In the first EHR pilot application - MUltimedia Distributed Record (MUDR) we include the possibility of mobile patient data accessing by physicians outside of their consulting rooms. The development of new advantages is mostly based on experience gathered in the European project I4C-TripleC. The two-layer architecture used in the "Open Record for Care" (ORCA) developed within this project was in the MUDR extended to a three-layer architecture consisting of a data layer, an application layer and user interfaces. By virtue of the defined communication interfaces based predominantly on HTTP, HTTPS, XML and WAP protocols, it is possible to use clients for various purposes like medical data entering and their visualization, statistical data processing or mobile data accessing. These clients may be connected over the Internet from anywhere in the World which enables easy sharing of patient data. In the MUDR we are using an extensible set of services at the application layer, which transforms the command-response based XML to documents conforming the HTML or WML language. These utilities are mostly implemented as pre-processors in form of programs conforming to the "Common Gateway Interface" (CGI) or as HTTP Server modules.

Using this facility, more application complexity can be moved to the second layer of the MUDR, which simplifies the user interfaces and enables to communicate with clients in form of web browsers, Pocket, Handheld or Tablet PCs, PDAs or mobile phones. It is important to conform to special conditions of these devices. Compared to personal computers we have to adapt to smaller and often just monochrome display, aggravated controlling possibilities, lower memory and computing power, slower data transfer etc. Taking note of these constraints we are preparing a solution, where the patient data will

be pre-selected at the application layer using physician's specifications together with the semantic knowledge about the stored patient data. Using this technique just the selected relevant data will be transformed according to the needs of the mobile clients. The other attributes will be enabled on a special demand. Therefore the required amount of transferred data will be lowered which will lower the needed communication speed as well.

As the first MUDR mobile module we are developing a special utility at the application layer, which transforms the MUDR application interface (MUDR API) to a special form of HTML. This HTML must conform to the limited possibilities of small web browsers used internal in mobile devices. This portable and universal solution we are testing by using the Nokia Communicator as the MUDR Client, whose browser does support neither tables nor frames.

### [46] Is it possible to predict the death of a medical website?

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*Introduction and objectives:* Several authors have demonstrated that the World Wide Web has certain stable organization and behaviours that follow some mathematical models. In this sense we have found that certain webometric indexes, such as the number of incoming links and their yearly increment, could be reliable quality markers of paediatric web sites. Our aim in this study was to find out whether or not those indexes can also predict the disappearance of web pages.

*Methods:* Follow-up study of four years (1998-2002) of a sample of paediatric web resources selected from eight evaluation and ranking directories of the Internet. Several variables were studied on their capability to predict the disappearance (death) of the web resources. The main variables were: number of incoming links and their yearly increment, number of daily visits to the pages, number of pages per site, type of domain (.edu, .com, .org, or .net), changes in the URL of the web pages during follow-up, and rate of compliance of the pages with the quality codes of the Health on the Net Foundation (HON), British Healthcare Internet Association (BHIA) and the American Medical Association (AMA). The webometric indexes were calculated in 1998, 1999 and 2000 by means of the search engine Infoseek.

*Results:* 363 URL's of paediatric web resources were compiled in 1998, 65 web sites and 298 web pages. At the end of follow-up 163 resources had disappeared (13 sites and 150 pages). Dead and survivor pages did not show statistically significant differences regarding their n° of daily visits, or the type of domain. On the contrary, survivor pages received during the follow-up a higher number of inbound links than the pages that disappeared (p < 0.01). In addition, survivor pages showed a higher yearly increment of inbound links (p<0.001), and were more compliant with the quality criteria of HON and BHIA than the pages that disappeared (p = 0.005). Both groups of pages did not show differences regarding their compliance of AMA guidelines. On the other hand, web pages that did not suffer changes in their URL's showed a four-fold probability of dying than those whose URL changed during the follow-up. We could not find statistical differences among the dead and survivor sites regarding the studied variables.

*Conclusions:* In this study we have found that web resources that disappear and those that survive on-line show different patterns regarding certain variables. That is, the higher number of inbound links

and the higher compliance of HON and BHIA quality criteria by a web page, the lesser probability of disappearance. It is very interesting that a webometric index such as the number of incoming links, an equivalent to a citation on printed media, acts as a prognostic indicator. Further studies must clarify if by analysing this webometric index and others we could predict the death of a medical web resource, and, eventually, to plan strategies that avoid its disappearance.

#### [47]

# Tacit requests to explicit contracts: Opportunities for knowledge management in surgical pathology

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*Background:* The corpus of medical knowledge is increasingly partitioned between medical specialties, creating problems for those specialties that regularly interact with other areas of medicine. One such field is surgical pathology, the branch of pathology that involves the analysis of biopsies and surgically resected tissue and organs. Specimens arrive in a pathology laboratory from various clinical services, and for each one, pathologists are expected to meet particular information requests by performing certain pathologic analyses, and communicate that information back to the clinician in a complete, meaningful and timely pathology report.

In order to meet these information requests, pathologists have information needs of their own. Most obviously, they must be aware that an information request exists. They also must have relevant knowledge about each specimen type and the clinical specialty of origin. At present, the main means used by clinicians to communicate such information is the pathology specimen requisition. This system is subject to the same problems faced by other kinds of paper-based communication, such as illegible writing, incompleteness, transcription error, and data in the wrong field.

*Objective:* To determine the extent to which information requests in pathology are tacit, and what effect such requests have on pathology report quality and patient care.

*Materials and methods:* Setting - Tertiary teaching hospital Study Design - Retrospective description. A series of 100 consecutive surgical pathology reports from the May 2002 workload at Oregon Health & Science University Hospital was analyzed by an experienced pathologist. Measures - Perceived clinician information request(s) and their nature (implied vs. explicit), data used to meet information requests, and source of that data.

*Results:* Information requests were explicit in 15% of cases (explicit and complete: 13%, explicit and incomplete: 2%), and implied in 85% (5% became explicit after the clinician called to request additional pathologic information). Information sources used to arrive at a diagnosis were: specimen gross description and/or histologic findings in 100% of cases, admission and discharge records in 100%, the specimen requisition in 69%, clinical documents in the electronic medical record in 10%, most common external source, and verbal information from the clinician in 6%. Information on the requisitions was frequently incomplete or in the wrong field, but missing information could often be extrapolated from the supplied information.

*Discussion:* An experienced pathologist could meet almost all the information requests, even though the requests were mostly tacit and the input frequently incomplete. The clinician considered the pathology report unsatisfactory in 5% of cases, prompting a request for additional pathologic information. The high success rate was largely attributable to the simple nature of most information requests ("What is it?") and the pathologist's ability to piece together the clinical context from the sometimes scant information available.

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Responding to more complex information requests ("What about it?") was facilitated by a report template or checklist pre-negotiated with the clinicians. These templates represent externalized knowledge and an explicit "information contract" between the clinician and pathologist, which stipulates the required content and format of the diagnosis. Not all the knowledge associated with these paper checklists was externalized, however. The use of templates was dependent on the pathologist's recognition of a particular specimen type and recollection that a template exists for that specimen type.

Currently, involvement of the pathologist is important in the pathology workflow to bridge deficiencies in hospital information sharing that result from the problems of paper-based documentation. In one sense, it is an error-tolerant system in that one can still complete tasks despite incomplete input. However, in the sense that it depends heavily on an individual's knowledge and human memory, the current system is also vulnerable to error.

Knowledge management systems can help pathologists practice more efficiently and reduce errors by recognizing scenarios, then retrieving and presenting relevant knowledge at the point of need. In order to realize this potential, considerable work lies ahead: externalization of more clinician information requests and expert pathology knowledge, formalization of explicit information contracts, and mapping of all to a standard knowledge structure for easy situation-specific retrieval.

*Conclusions:* Information requests in surgical pathology are often unstated or incomplete, poorly organized, and otherwise garbled. Existing paper-based systems rely on human expertise to bridge documentation deficiencies and are vulnerable to error. Knowledge management is a potential solution, but will require considerable developmental work.

## [48] Evaluation of Internet courses for cancer patients

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*Background*: The Cancer Information Network for patients and their families named INKA exists since 1996 and was the first German-language non-profit information project of this kind. INKA arose from cancer patients' needs for information and exchange about their illness. The Internet represents a method and the instrument of information exchange. The function of the Internet is to provide a communication and information platform, on which patients with questions; requests and answers get in contact (www.inkanet.de). INKA also enables patients to use research tools to take more active control of the healing process. In co-operation with the VHS Hamburg West, a public adult education institute, the course "Internet for patients and family members " took place from 1998 to 2002. The concept spread rapidly over the VHS Hamburg and even beyond the actually targeted interest group. Again and again multiplicators, advisors and professionals contacted INKA to get information about the conception of the course. This gave the impact to evaluate the Internet courses.

*Objectives:* The aim was to give a fundamental knowledge to small user groups and to evaluate the structure of participants, their reasons to join the Internet course and the effect on their healing process. This kind of Evaluation of Internet Courses for cancer patients is the first in Germany.

#### Study Design:

<u>Participants:</u> A total of 40 users attending 10 Internet courses were asked to fill out a questionnaire on the day of the course and were sent in a second questioning after three months.

Setting: VHS Hamburg West, Germany

The INKA Internet course in Hamburg was evaluated over 1 year. Standardised, anonymous questioning developed from B. Hoeldke M.P.H. supported by a student-working group "Health Science" at the University of Hamburg.

*Results*: 65% of the participants attended the course in a treatment break or a rehabilitation phase. 78% of the participants had no references from their physician to the possibilities, which the Internet offers. Considerable 70% said they had access to the Internet and more than half of them already have some experience in the use of this medium. 1/3 of the asked ones said that their physician has too little time for talking or they had not the courage to ask questions. Concerning the question how the participants had informed themselves so far about their topic, information from patient brochures and books was most important even compared to a consultation by the physician. First they want to learn to deal with the Internet in order to find therapy explanations, supplementation methods, addresses and contacts. They want to become active and share experiences. Besides practising information research the personal exchange between the participants was an important intention. The participation in the Internet course fulfilled the expectations fully and completely. The concept of the course ensured that all participants felt 100% accepted. In the second questioning after three months those participants evaluated the attendance of the course as a successful entrance into the research of health information with the help of the Internet. Beyond that the course had a positive effect on personal security and self-certainty in dealing with medical experts. The results show that the asked ones prefer printed media as the most important source of information and if we consider the communication between physician and patient does not lead to a feeling of support, the Internet offers a solution to cover the existing deficits.

*Conclusions:* The concept of INKA to offer cancer patients information and exchange is successful. If the perspective of patients, they can step self-confidently with their health interests into the dialogue with their physician. To find acceptance is a relevant parameter of quality in the Internet. The combination of self-help and information via the Internet provides "the best of both worlds" for the consumer. The necessary tools to find relevant health information from the Internet can easily be acquired by patients and physicians.

### [49]

## Successful disease management using health telematics: Two years of experience with "Forum-Telemedicine"

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*Background:* Education for asthma patients should improve self-management of this chronic illness. It should also reduce the amount and frequency of acute in-patient treatment and of exacerbations. Nevertheless it is unclear as to how to stabilize this learning success in the long term.

*Goals:* Using an interactive and personalized follow-up educational Internet platform (www.forum-telemedizin.de), research was carried out on 50 children and youths to determine whether, following a standard asthma education course, the Internet as a media is appropriate and accepted by the patients for ongoing follow-up training.

*Methods:* From July 2000 to February 2001, fifty asthmatic kids aged 10 - 17 participated in an acceptance study. After having attended a standardized asthma education course, participants were offered Forum Telemedizin's individualized, interactive follow-up training program. This allowed them to review and deepen their disease-related knowledge and to develop practice in behavior-related situations. Furthermore it allowed patients to participate in the framework of a virtual community with one another and with doctors, to manage their Peak-Flow reports and therapy plans online, and much more.

*Results:* In the acceptance study 40 (80%) patients used the Internet tool. 10 (20%) patients had no Internet access and therefore could not use the platform. The number of pageviews rose steadily from 978 (average of 1.7 pageviews per patient / day) initially to 4596 (average of 7.1 per patient / day) by the end of the acceptance study period.

Kids generally judge FTM positively; in particular the game and chat modules were extremely well accepted. Their self-efficacy improved noticeably and the children felt they were better prepared to cope with their disease.

FTM helps make it clear to the patients that it is largely their own participation that can lead to improved disease management.

*Conclusions:* These results show a high acceptance of this personalized, Internet-based follow-up educational platform that, thanks to an individualized approach, can contribute toward increased self-empowerment, thus leading to long-term educational success.

The currently running evaluation study with over 500 patients shows astonishing results. Preliminary data will be given during the oral presentation.

#### [50]

## An objective, but indirect, measure of the quality of the information shared in online support groups

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Online, patients actively share information with each other in addition to passively receiving it from Web sites. In this study, we propose an objective, though indirect, measure of the quality of the information shared in online support groups and apply it to three sample public message boards.

*Objectives:* At the conclusion of this presentation, the participants should be able to evaluate the quality of the information shared in an online peer support group.

*Methods:* Seventeen categories of information were proposed. One public message board hosted by the author and two others known to him were selected. The focus, geographical location, and type of administration of each group were different. The author trained a psychiatry resident in the categorization process by giving her an explanation of the categories and seven annotated examples. Inter-rater reliability was "substantial" (Cohen's kappa = .80 and .76 in two preliminary trials). We divided between us the first 100 "posts" to each group in July 2002 and categorized the information therein.

*Results:* The original 17 categories were consolidated into 5 to eliminate, for statistical reasons, low-frequency categories. The final categories and the range of the proportion of each type of post across the three groups were: personal experience, 55 to 79%; general information with its source, 1 to 20%; general information without its source, 11 to 39%; opinion, 17 to 37%; and disclaimer, 3 to 8%. In each category except disclaimer, each pair of groups was compared using the chi-square test with Keppel's modification of Bonferroni's correction, and 8 of those 12 comparisons were statistically significant (ps = .0000048 to .046).

*Conclusions:* An objective method of characterizing the information shared in online support groups is to determine the proportion of posts with personal experience, general information with its source, general information without its source, and opinion. This is an indirect, but straightforward, measure of the quality of the information. When applied to a sample of three public message boards, statistically significant differences were found in each category. Objective characterizations of online support groups may help patients choose between them. One size does not fit all, however; "high quality" information may constitute better evidence, but may also feel less empathic.

## [51] Web based e-procurement mechanism in the Healthcare marketplace

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The Internet is fast becoming a standard office procurement tool for many medical practices. Just about anything can be purchased online, from large medical equipment to rubber gloves and pharmaceuticals. Gone are the days of leafing through outdated paper catalogues, filling out forms and realizing a product is on back order when the shipment arrives. Online ordering gives the purchaser real-time information on the product, and the process can be done in minutes. Apparently, the solution for the more efficient procurement of medical supplies is e-procurement. E-procurement offers physician practices and ambulatory facilities several notable advantages: convenience, efficiency, broad selection, favorable pricing, information on new products and even more. But wise office managers will ask a few important questions up front, to make sure the method fits their particular objectives. The cutting edge of e-procurement involves applying software technologies that have some of the highest return-on-investment: optimization and business rules.

The OPUS project creates an efficient e-procurement mechanism that enables hospitals and pharmaceutical suppliers to electronically exchange contractual information, aided by the technologies of optimization and business rules. OPUS mediation service provider grasps the market opportunity, as this triggered by consumer's request, offer the participants the ability to dynamically constellate with other medical suppliers, and promote collective competition among the constellations. Appropriate settlement modules address the necessary contractual and/or value sharing arrangements spontaneously or dynamically. OPUS modules, entailing the various business perspectives, policies and market rules, resolve any apparent conflict. The dynamic pricing module dismantles the generated product and disseminate the value among the implicated partners

*Objectives:* The main objective of the project is to create an efficient e-procurement mechanism where hospitals and pharmaceutical suppliers will be able to exchange contractual information (orders, characteristics of orders), using electronic means and specifically the Internet and the World Wide Web, aided by the technologies of optimization and business rules. Optimization and business rules address some of the roadblocks in e-procurement systems. These technologies can help meet buyers' needs and bring a higher level of efficiency to key tasks such as formatting multi-supplier catalogs, costing out indirect procurement alternatives, optimizing the sourcing of indirect goods and services, mapping approval processes and following the progress of specific purchase orders.

*Methods:* The OPUS project introduces a new framework, in order to sufficiently support the Dynamic Value Constellation form of medical supply arrangements. OPUS addresses the healthcare supply chain in a unified approach and proposes an innovative procurement environment based on optimization algorithms. Innovation can be seen in three different aspects, namely: Content, Planning and Price clearing. Current leading e-procurement solutions concentrate in the dynamic binding of buyer requests and seller offers. This does not fit at all with the requirements of the healthcare sector. The solution that OPUS proposes is a reverse auction optimized procedure. More specifically, OPUS content in the form of product-purchaser catalogues (as opposed to product-supplier catalogues) will be dynamically administrated by being in a central repository containing item and supplier information. Item

interrelationships have to be meticulously modeled in this database. Other procurement critical item attributes will be also encoded (e.g. item expiration time). Content management research will be conducted in the following areas: a) Define templates in order to effectively link the items descriptions with the supplier products. b) Explore and develop techniques to support the groups of item indexes from the consumers' requests. OPUS planning features are based on analytic processing of information in the form of: a) Supplier information that encodes the supplier scoring, response times, historical data and b) supply allocation analysis and supply risk analysis. In the case of healthcare and in the context of a generic European healthcare model OPUS proposes the following axis of optimization of a) the price clearing mechanism b) the procurement planning process on a multi-resolution scale, that is on hospital level, regional level, national level. The OPUS system aims to exploit on technology framework built over the Internet.

*Results:* As e-procurement solutions have been implemented by numerous organizations in various industries during the past five years, new areas of cost savings have emerged such as a) Reduced Administrative Costs b) Curbing Off-contract Purchasing c) Transforming the Purchasing Function d) Reducing Errors, Rework and Dispute Resolution Costs. The implementation of the e-procurement mechanism in the Healthcare marketplace that OPUS suggests, entails gaining significant competencies for the buyers, the suppliers, the end customers and the system developers.

*Conclusions:* The evolution towards an e-procurement environment that benefits the business-tobusiness market requires new approaches that take advantage of the efficiencies of Internet-based services. OPUS offers end-users quick, easy, and broad access to more real-time information, thereby allowing customers to shop directly and comparatively. Sales and marketing activities will shift toward reaching customers through on-line promotions, electronic catalogues, and real-time ordering capabilities. Distribution may achieve greater economies of scale through public warehouses, or virtual distributors, who "pick" and deliver a wide variety of products that support a variety of industries in addition to health care. Expanded delivery capability will need to be developed to service different and diverse customers. Direct delivery, use of pre-determined pick-up points, market-based service centers, and third-party order picking/delivery are several approaches that can be geared to individual customer needs.

## [52] Security issues for XML based health information systems

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*Introduction:* XML is a data format for structured document interchange on the Web, which is used to create data structures that can be shared between and among disparate and otherwise incompatible systems. The IT community agrees today that XML is to be a common meta-language that will enable data to be transformed from one structure to another.

No doubt, XML is state of the art technology. But, how secure are XML applications? This question is very important especially for Health Information Systems that share sensitive data because security is a key issue, which must be taken into account from the very first steps of the design process of those systems.

In this paper, we examine the security problems related to XML data and present our approach for enforcing security policies in XML based Health Information Systems

*Objectives:* The objectives of this study are the definition of the security problems of XML Information Systems, the security requirements and the security policies for XML Health Information systems.

*Methods:* Our methodology has been based on the study of the XML data model, on the identification of the security requirements of XML Information systems and on the proposal of a suitable security policy, which is based on Role Based Access Control. The development procedure has been based on the corresponding approaches on the classification of multilevel secure object-oriented database and from our work and experience on the Internet security policy for health information.

*Results:* The proposed security policies for the usual relational and object-oriented databases or hypertext documents are not however sufficient to support in a flexible and efficient mode the security requirements in XML Information systems. The above approaches do not consider the particular characteristics of XML data, as for example the partial absence of schema, the existence of connections between data fragments and the data structure of XML documents. XML data is not object-oriented and the data hierarchies represent part of relationships, which require specific techniques different from those applicable to the hierarchies in the object-oriented model. Also, the lack of a management information system able to support access and integrity constraint rules in XML environment, introduces new protection requirements. In addition, the existing security models for the relational and object-oriented databases do not usually take into account the additional security needs that arise from the use of Internet and they are not easily integrated with the existing Internet security technology.

Main protection requirements for XML based Health Information systems that influence the definition of the policies for their access and exchange are related to the following characteristics of XML and subjects accessing them:

- 1. Access control. The access control components decide whether a subject can access a particular resource (object).
- 2. Granularity. Granularity considerations in XML Information systems call for the support of an Access Control Policy on individual elements (fine-grained) as well as on the whole portions of a document (coarse-grained).
- 3. Propagation. The XML data model is essentially an ordered labelled tree and the data exists in an ordered hierarchy. Thus permissions that specified on an object (e.g. element) can be propagated to the nested objects (e.g. sub-elements and text nodes), too.
- 4. User authentication. Verification of the identity of users.. Document authentication. Document authentication refers to the fact that security policy must provide evidences that the XML document or fragment is that, which is claimed.
- 5. Signer authentication. Signer authentication refers to the ability to identify who signed a XML document, or fragment.
- 6. Communication security. Communication over insecure links is typically the case in a XML information system. Thus there is a need to employ mechanisms that provide the required communication secrecy and integrity.
- 7. Non-repudiation. It is important for some applications to provide evidence of actions.

A security policy for an XML based Health Information system, which is distributed over the Internet, must encapsulate flexibility, decrease the security administration overhead and enhanced protection from unauthorised information disclosure. The proposed security policy for XML based Health Information Systems, takes into account and exploits the specific characteristics of XML data. The proposed approach incorporates the flexibility of Role based policies, using roles, inheritance and permissions on objects and enforces negative permission and subject location constraints and propagation of authorizations. In the proposed security policy, subjects can be referred to on the basis of their identities and on the associated Role. The security objects are the targets of the security protection and can be the elements, attributes or the entire document. We use the Xpath Language in order to identify the security objects within a document. For example, the path expression /patient\_Record/Personal\_data/Complaint[@id="c\_12'], identifies the complaint where id is c\_12. Our access control enforcement confirms the three-tier architecture with thin clients. Also, It is performed on the server side, regardless of whether other

operations (e.g. presentation) are performed by the server side or by the client module. The requested XML data computed by the access control mechanism and transferred to the client as the result of its original request. This implementation prevents the accidental transfer to the client of information it is not allowed to see.

*Conclusions:* In this paper, we study the security problems of XML Information Systems, the security requirements and the security policies for XML Health Information systems. We achieved to implement a secure environment with flexible security administration. The next step of this study is to enforce the digital signature technology in order to achieve, document, user and signer authentication.

#### [53]

## Implementation challenges and approaches to keep protected health information private and secure

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Creating and maintaining an environment of privacy and security of protected health information (PHI) is not an easy task in an industry where timeliness with accessibility to PHI directly impacts human lives and efficient patient care. Current and proposed US regulations regarding the privacy and security of PHI have broad sweeping implications with regards to clinical and commercial use and disclosure of PHI. In healthcare, as we continue to foster and promote open use and sharing of health information for a variety of well meaning and well intended uses, well meaning and well intended legislation for the use and disclosure of PHI presents a myriad of operational challenges to those who create and share PHI on a daily basis. This presentation will discuss these legislative issues, current and future impacts surrounding the continued use and disclosure of PHI created in the US but shared domestically and internationally, current reaction, reception and remediation plans regarding mandated privacy and security initiatives and suggested, balanced approaches to achieve mandated compliance without diminishing the ability to optimally deliver patient focused care as well as continue to share health information to help other patients around the world.

## [54] Knowledge management in medicine through extreme collaboration

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*Introduction:* The trend in healthcare in the United Kingdom and in Europe has become increasingly patient-centric as the ageing population number increases and the focus is directed at community-based care as well as in-home patient care. This demography change also brings with it such chronic ailments as diabetes (the type-2 class) which shifts the bulk of the disease monitoring and management responsibilities to in-home and to the patient who is increasingly recognised as an active member of a team along with the appropriate healthcare professionals. There are also instances of rare paediatric metabolic diseases at the opposite end of the age line, which require similar in-home monitoring, and management [1]. Combating these diseases within the framework of evidence-based medicine requires

major research effort in the area of knowledge management with the Internet playing the pivotal role in the collaborative effort.

Material and methods: Our research reported here is focused on identifying and developing the key processes in knowledge management that drive the team effort that we refer to above. We recognise that the main challenge in knowledge management within a team environment is knowledge sharing and to meet this challenge we introduce a knowledge sharing concept called extreme collaboration which derives its basic tenet from an agile methodology called extreme programming (XP) The XP framework has been successfully applied to software development where changes in requirements are easily accommodated and which is based on a few key elements among others such as metaphor (shared story), refactoring ( restructuring as required to reflect changing requirements), collective ownership, paired working etc.. and underlines such values as simplicity, continual communication and feed back. Although a form of extreme collaboration has been attempted in space mission design activity [2] which has a specific end result, our version of extreme collaboration (XC) framework in the areas mentioned above operates on a life-cycle with three key knowledge management processes - knowledge acquisition, knowledge generation and knowledge integration. In order to implement this life cycle, we classify the knowledge in each of the disease domain as consisting of experiential knowledge and documented knowledge. The former refers to the undocumented personal/professional experiences of each member of the team including the evidence-based practice and the latter refers to the more formal clinical information such as the tests results obtained through biochemical, physiological, radiological examinations. Both these knowledge forms appear as models, which basically are metaphors and can, be updated or refactored to reflect the changing conditions thus keeping the life cycle live and active. The stakeholders in the life cycle are the members of the team, which includes the patient, clinical and allied professionals. The latter are dieticians for the diabetic and paediatric cases. The proposed prototype system uses XML interface operating under two other healthcare technology standards, HL7 and CORBAmed.

*Results:* We will first present examples of models based on Petri Net and Bayesian Belief Network formalisms [2] that represent experiential and documented knowledge components for type-2 diabetes and paediatric metabolic disease classes showing diagnostic, developmental, therapeutic, dietary views and explain how these are used to structure the knowledge acquisition, knowledge generation and knowledge integration processes. We will show snap shots of the extreme collaboration life-cycle with a team of skate-holders, and explain the attributes of the agility of the three knowledge management processes. We will show through snap shots how XML, HL7 and CORBAmed standards facilitate the operation of extreme collaboration within the team. We will also draw attention to an on-going knowledge management research work in Malaria under extreme collaboration framework and the role of intelligent agents in this effort. *Discussion:* and Conclusion

We will argue that the extreme collaboration framework illustrated in the above section should facilitate knowledge sharing at local, regional, national and international levels in an Internet environment and should help to incorporate personal experiences and best practices in a knowledge management lifecycle. We will conclude by highlighting the advantages of using three healthcare technologies, XML, HL7 and CORBAmed in any knowledge management task in medicine.

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# A study on patient satisfaction analysis using data mining technique in a spine hospital

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Due to recently changed environment, some hospitals have suffered reduced profit problem and many patients' request better medical services. Therefore, many hospitals have adopted CQI (Continuous Quality Improvement) and TQM(Total Quality Management) for quality management and more and more hospitals have a plan to start QI activity.

For OI activity, objective analysis is essential for acquiring useful information, so the importance of quality evaluation is increasing. Patient satisfaction is the most useful information that is reflecting overall outcome, process, and structure and it is including concepts of cost and technical aspects of medical services and doctor-patient relationship.

Data mining is a discovery process for new relations, trends and patterns between multiple entities using pattern recognition technique, statistical methods, and mathematical algorithms. Recently, there are some cases using data mining technique for analyzing medical service utility, disease patterns and hospital management in medical area.

In this study, we used data mining techniques for analyzing patient satisfaction, and we could acquire very useful information for QI activity in the hospital. In the near future, we are expecting for developing more systematized QI activity model based on patient satisfaction and this model will be integrated with cyber hospital system based on Internet including EMR/OCS/PACS.

## [56] **Teleslide.com:** A publishing server for pathologists

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[55]

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Materials and methods: Since the 90's French pathologists have been very active for individual and collective publications over electronic media. Particularly case reports and posters sessions have been fully digitized (images and texts - images are the basis of case discussion for morphologist -) and a unique yearly CD is produced and is sent to each member of three scientific society (IAP, FSP, ADICAP). The same cases are also made available on server. Both for providing new services and for production simplification purpose a new set of applications has been developed and is opened to everyone at teleslide.com server.

Results: Three services are being provided:

*Case publisher* 1.

> It allows the production of an organized multimedia folder associating images, individual datasheet and the case description text. Those who use standardized image workstations (ADICAP standard) may export their documents straight to the server. The produced folders are stored at the server site and may be used by their author for link with forum discussions. Special features - Text may be organized within different chapters as needed for a scientific communication - A keyword search

allows lesional code selection; the code may be linked to the folder document or to individual images. This feature makes easy the translation of code in local language and code allows efficient multicriteria search. - Wide field images useful for providing good slide representativity while discussing complicated cases may be associated to each folder.

2. Interactive forum

The forum provides classical features. Anyone may manage his own forum through the Forum Manager. He has room for describing the aim of the forum in an unlimited size memo. He may decide who is authorized to participate and if message publication has to be checked. The forum user can manage his individual profile for each forum he attends. The standardized multimedia folder, which has been stored by Case Publisher, may be attached to any question or answer.

3. *Static publications* 

One time a subject has been fully discussed within an interactive forum or within physical meetings, it may be synthesized through validated folders and then published on the publication section. That section will provides shortly a multi-criteria search system based upon folder description (scientific society, authors, index medicus keywords, lesional codes, title, etc.).

*Field Review:* This server has been mainly used for meeting preparation since mid 2002. It has been very helpful both for participants and for chairmen. On the publisher side it allows pre-production and validation by authors and reviewers, but it is more demanding for chairmen and authors. In counterpart Web publishing may occur shortly after physical meetings and data are available for the yearly CD production. At the end of 2002 we will be able to present six months of service running.

*Discussion:* Today service seems promising, however, a lot of new features should be added for developing attendance at an international level. We are planning a set of new features, but we are seeking for new suggestions. All cases, which have been published since 1996 will be added to the publication section (> 1 000 cases illustrated by >10 000 images involving 500 authors, IAP, FSP, FGHC, ADICAP editorial committee). As an International opening is wished, Menus are written in English, but content are produced in the author language. Here are some possible improvements: Other cases published through an identified editorial committee could be added, as far as they are produced on the standardized format.

Even if each case is published in the author language; an English summary could be asked to each author or committee. Lesional codes are made available by ADICAP in French, Portuguese and Spanish and soon in English. Keywording and code wording could be made possible in any of these languages. Other improvement would concern more intensive use of a new document format which allows viewing and annotating large fields images (virtual slide). It would be particularly helpful for the cases which lead to a diagnostic variability and which have to be studied at an international scale.

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# MedCIRCLE - The collaboration for Internet rating, certification, labelling, and evaluation of health information

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MedCIRCLE is an EU-funded semantic web project, that builds on, expands and continues work on rating health information on the Internet piloted within the MedCERTAIN project. In the course of the MedCERTAIN project, we developed the standardized metadata vocabulary HIDDEL (Health Information Disclosure, Description and Evaluation Language) to evaluate and annotate health related websites. The aim of MedCIRCLE is to further develop and refine this vocabulary, and to develop technologies and networks to guide consumers to trustworthy health information on the Internet. In the course of the MedCIRCLE project, we modelled the HIDDEL vocabulary as an ontology and the partners of the project founded the MedCIRCLE collaboration: University of Heidelberg, AOUMED - Agency for Quality in Medicine (ÄZQ), COMB (Medical College of Barcelona) and CISMeF, a gateway developed at Rouen University Hospital. The three latter organisations are gateway sites for consumer health information and evaluate and annotate health information on the WWW using the HIDDEL vocabulary (technically supported by the German Research Center for Artificial Intelligence DFKI GmbH). The metadata of the annotated websites are expressed in XML/RDF and will be made publicly available. These metadata allow intelligent agents or client-site software to harvest information and opinions about the trustworthiness of health related websites. The collaboration intends to help people, patients and professionals to identify health information useful to them, e.g. by ensuring interoperability of rating services, identifying common standards for recommending websites and exploring possibilities for decentralised, distributed rating systems by creating a network of evaluators, taking into account the power of the Internet as a networked environment. Other subject gateways, accreditation or rating services are invited to join the MedCIRCLE collaboration to weave a global, collaborative, open semantic web of trust for health information.

*Acknowledgements:* The MedCIRCLE project is funded by the European Union under the Action Plan for Safer Use of the Internet The collaboration consists of: the University of Heidelberg, Department of Clinical Social Medicine; COMB (Medical College of Barcelona), Spain; CISMeF, University of Rouen, France; AQUMED - Agency for Quality in Medicine (ÄZQ), Germany.

[58]

## Promoting regional networking of welfare in eastern Finland: The Netinformation project

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*Background:* The Netinformation Project (2000-2006) is a subproject of the Sonetti Programme in which the five hospital districts of Eastern Finland co-operate in developing information exchange and communication between hospitals, primary health care centres and municipal social workers. The Kuopio University Hospital is the main operator in the project, which represents a population of 681.000 inhabitants in an area of 85.585 km2.

*Aims of the project:* The main target of the Netinformation Project is to create a flexible regional information system for social and health care services. In order to facilitate the interaction between professionals, organisations involved in public social and health care in Eastern Finland will be unified into a comprehensive electronic service, with high quality professional information distributed via the Internet.

In addition to providing technical solutions, the project will reorganise the professional information to ensure its high quality, actuality and accessibility. It will design and build a dynamic portal for networked information, and organise the content production and maintenance. It will bring guidelines, publications and reports into extensive use, and administer documents by means of metadata. It will promote communication and thus develop a model for work and education for social and health care professionals.

*Results:* To analyse the nature and amount of existing information, a study was carried out at the Kuopio University Hospital. Altogether 4546 treatment and operational guidelines were identified. Close to two thirds of them (62%, N=2839) were described to have at least some common significance. Out of these guidelines, 900 (32% of all) did already exist in an electronic form.

It became obvious that the handling of information should be based on standardised metadata to be easily retrievable and updated. Metadata represents the content, structure, and logistical information of documents and other information objects. It is structured data about data, descriptive information about an object or resource. Metadata is used for discovery and administration of data. The Dublin Core Metadata Element Set was chosen for the standard of the metadata for the guidelines. It is used to supplement existing methods for searching and indexing Web-based metadata. With 15 descriptive semantic elements it defines the properties of objects for Web-based resource discovery systems. The Dublin Core was created to provide a core set of elements that could be shared across disciplines or within an organisation needing to organise and classify information. The thesauri to be used in indexing the guidelines are the General Finnish Thesaurus, maintained by the National Library, and the Finnish version of the Medical Subject Headings, translated by The Finnish Medical Society Duodecim.

To test the feasibility of the metadata standard and the thesauri in clinical setting, 163 guidelines of the neonatal intensive care unit and the maternal unit were described and added to a database. The clinical personnel successively performed the work under the guidance of an information specialist.

Based on the results and a survey among health care professionals in the Northern Savo Hospital District, the following issues were decided to be developed at the project in order to create an infrastructure. 1. To install a regional network, extranet, for the hospitals in secondary/tertiary medical care, health centres in primary health care, and social work in communal administration. 2. To build up a regional network portal for the whole welfare sector. 3. To encourage the publication of the local treatment guidelines in electronic form. 4. To provide the electronic documents with metadata, which describes the contents in the terms of indexing and classification. 5. To establish an organisation to support the production and maintenance of the networked information. Networks of substance experts, an information specialist and secretarial services are the corner stones of the organisation. An editorial board of experts in each area draws the content policy lines.

*Ongoing development:* The pilot version of the portal was published in June 2002. The main target for the ongoing development is to build up a so-called "Dynamic Integrated Desktop" (DID). DID is planned to be a secure, personified desktop that integrates public and professional data with carefully selected and secured patient data. Technical and logical solutions on integration will be based on the use

of de facto standards and vocabularies. User identification will be based on the use of public and private keys.

The characteristics of the regional network are being developed in the following issues. 1. The security of the data will be guaranteed. 2. The IP characteristics of the data network are being developed in order to be able to transfer multimedia material. 3. Centralised archiving of digital radiological images is made possible by rapid transfer capacity. 4. Wireless network connections are applied to information transfer in health and social care between organisations as well as between citizens and organisations.

*Discussion:* It was defined for the Netinformation Project that the portal includes general knowledge in the field from various sources, that the handling of information is based on standardised metadata, including indexing and classification and a universal URN identifier, and that the portal can be customised for each user. After the pilot phase the characteristics of the portal will be developed further. This includes sophistication of the use of metadata, search software and customisation, integration of different information systems for parallel use of patient information, development of the handling of multimedia material, personal identification with the electronic signature, etc.

The network will be made to cover all hospitals, health centres and municipal social work units in the area. The network in each hospital district is an independently administered entity, thus creating five regional networks in Eastern Finland. The are, in turn, combined into one jointly used extranet. The advantage of the network will be the wide geographical coverage.

[59]

# A framework for representing and executing a clinical practice guideline for the management of high blood pressure in pregnancy

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*Introduction:* In this work we describe a framework for representing and executing clinical practice guidelines (GLs) and we focus on a particular application. The core of the framework is a tool called new-GUIDE, able to represent a GL with both a graphical language (for the flow of actions) and a formal language for writing rules and building abstractions, both qualitative and temporal. The very first step for a GL formalisation is the interpretation of the natural language text where the GL itself is written. It is well known that this is a difficult task, leading to different representations for different people reading the same text. To facilitate the text interpretation, we use Unified Medical Language System (UMLS) as a standard for terminology and, we developed an ancillary tool, Medical Text Markup (MTM), that is a mark-up tool for the free text representation of the guideline.

*Methods:* The "National High Blood Pressure Education Program Working Group's (NHBPEPWG) report on high blood pressure in pregnancy" proposed a GL for the classification, differential diagnosis and management of patients with high blood pressure in pregnancy. It provides recommendations for managing patients and also provides the principles on which recommendations are based. We have done a formal representation of the tasks and abstractions mentioned in the GL using UMLS, MTM and new-GUIDE.

*Markup of the guideline:* According to the semantic types defined in UMLS, the medical terms are classified into Event and Entity. Event is a broad type for grouping activities, processes and states and Entity is a broad type for grouping physical and conceptual entities. In a system for representing and executing task-based GLs, most of the tasks belong to three of the the UMLS semantic types "Laboratory

Procedure", "Diagnostic Procedure" and "Therapeutic or Preventive Procedure". These fall under the semantic type of "Health Care Activity", that in turn is an "Event". All the other semantic types have formal relationships with these (i.e. "chemical" is linked to "Laboratory Procedure" by the relation "is-analized-by").

The general rule of MTM is that the markup maintains the text flow and highlights sequences of "terms", within the text, that define "paths". Thus, each path defines constraining concepts. For example, Hypertension --- that is present and observable before pregnancy Hypertension --- that is diagnosed before the 20th week of gestation are two paths derived from the text of the guideline that restrict the number of patients to be considered. The terms which are not constraining their parent term are put in a separate path starting from the parent term.

MTM is as much as possible compliant with UMLS: a "term" is a concept found in the vocabulary with its UMLS ID. If the term is not found on the terminology server the user can define his own term. The first-level semantic type for the term mentioned in UMLS is its parent and is marked by "S-" and the term itself is marked by "T-" followed by its UMLS-ID. If the term is user-defined, user must also choose a UMLS semantic type for it. Thus, each term will have a semantic type as its parent element. The two paths mentioned before will appear on the markup in this way:

S-Disease-or-Syndrome-T-Hypertension-C0020538 ----> S-Organism-Function-T-Pregnancy-C0032961 S-Disease-or-Syndrome-T-Hypertension-C0020538 ----> S-Physiologic-Function-T-Gestation-NOS-C0312415

Temporal constraints and, in general, logical operators present in the text are not represented in the markup explicitly, because MTM only wants to show that two or more medical concepts are "in some way" related to each other. The result of the markup is that all the medical concepts mentioned in the GL are put into the proper context, and this facilitates the subsequent formal representation.

*Formal representation of the guideline:* The semantics of new-GUIDE, the tool for the GL formalisation, consists of 8 basic element types: task, decision, wait, monitoring, synchronisation, start, stop, and arcs. Its main features are: 1. definition of composite tasks 2. two types of decision: (a) deterministic, i.e. guided by rules (b) non-deterministic, i.e. let to the physician that can call for a decision support system, if any (like decision trees and belief networks) 3. possibility of representing the fundamental control paths: parallel, sequential, iterative tasks 4. the use of standard terminology servers 5. representation and use of modular pieces of knowledge 6. a formal language for the definition of both abstractions and rules 7. different types of abstractions: (a) qualitative and (b) temporal 8. a parser for the interpretation of rules and abstractions, starting from a virtual patient record, i.e. data mapped into a fixed-structure database from the legacy healthcare system 9. A drug server, that gives the general indications for choosing a drug based on the pathology, interaction with other drugs and the past efficacy or adverse effects of a drug on the patient. 10. Guideline Elements Model (GEM) specifications are incorporated, which help in storing and organising the heterogeneous information contained in GLs. Among these features, we illustrate here the reusability of some abstractions in the representation of the above-mentioned guideline.

*Modularisation and abstraction*: We take the example of the diagnosis of pre-eclampsia. The symptoms accompanying increase in blood pressure are represented with the abstraction "PreEclampsiaSymptomsExcludingBP", defined as the presence of at least one of: "Proteinuria>=2.0gram/day, Dipstick=2, Dipstick=3, Serum-creatinine-level >1.2mg/dl, Platelet-Count<100000cell/mm3, Microangiopathic-Hemolytic-Anemia, Alanine-aminotransferase-increased, Aspartate-aminotransferase-increased, Persistant-headache, Cerebral-Disorder-NOS, Visual-Disturbance-NOS, Persistant-epigastric-pain".

The blood pressure levels for diagnosis of pre-eclampsia is represented as "PreEclampsiaSymptomBP" which is categorised as "Stage III - Hypertension", i.e. "Systolic-Blood-Pressure >=160mmHg or

Diastolic-Blood-Pressure>=110#mmHg". Thus "PreEclampsiaDiagnosis" is defined as "PreEclampsiaSymptomBP and PreEclampsiaSymptomsExcludingBP".

The reason for marking two separate abstractions is that "Stage III - Hypertension" is associated with the "Sixth Report of the Joint National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure" which, in general, defines the stages for hypertension and the method of blood pressure determination. Supposing to have represented also this guideline within our framework, the modules and abstractions defined can be reused in the guideline for high blood pressure in pregnancy.

*Conclusion:* This work shows an application where the GL-markup and the use of standard terminology facilitate the representation of the GL itself, the reusability of modules among different GLs and the rationale behind each task during GL execution.

[60]

## Feasibility of the MedCERTAIN rating of Internet health content

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*Introduction:* Third-party rating and certification of online information resources aims at assisting Internet users to identify and find reliable sources of information. The applicability of this approach in the health domain, however, has been criticised; the independent quality appraisal of Internet health content is much debated. As little scientific evidence exists regarding the feasibility of rating online health content, the discussion has been mainly opinion-based.

In the European Union funded project MedCERTAIN, we set up a fully functional rating service to demonstrate and evaluate a model and technology to create independent third-party ratings of health web sites. Both the model and technology were created with the intention to provide a common, international rating platform that can be adjusted to local needs.

*Materials and methods:* We rated a random sample of 140 Finnish health web sites according to a MedCERTAIN pilot rating process. The sites were evaluated by a group of 60 experts. Each site was rated first by two health professionals (level 2 rater pair) and thereafter by two medical doctors (level 3 rater pair). The raters filled in an online feedback form after each evaluation.

The ratings were accomplished using a ratings management system (Archer), which provides the rater with an evaluation form that contains questions and response options defined in a standardised rating vocabulary (HIDDEL). Both HIDDEL and Archer are novel technologies developed within the MedCERTAIN project.

A set of 22 quality criteria was applied and their significance for the overall rating defined in a Quality Appraisal Table. In addition, the raters recorded 26 descriptive characteristics of each site.

The feasibility of the quality criteria was examined in a focus group study, in which both Internet users and information providers participated.

*Results:* Our pilot rating service produced a total of 418 individual ratings, 289 on level 2 and 129 on level 3. Thus we created a full MedCERTAIN rating of 122 sites (87%) on level 2, and of 30 sites (21%) on both levels 2 and 3. The average total time to rate a site (by 4 persons) was 3 hours and 41 minutes.

The average success rate of the applied quality criteria (i.e. the percentage of sites that fulfilled a criteria) was 54% (range 2 - 94). None of the sites passed the evaluation when all 22 criteria were used,

and the application of only few criteria with highest success rates (6 criteria on level 2, and 4 criteria on level 3) caused over 50% of the sites fail in the overall rating.

The raters sent 350 feedback forms. The average response rate was 61% (45 - 70 depending on level and rating phase). The raters were in general satisfied with the MedCERTAIN technology. The standard rating questions were regarded either easy or very easy to answer in 85% of the cases on level 2, and in 67% of the cases on level 3. Likewise, the raters were satisfied with the answering options and Archer's technical functionality. In general, level 3 raters were somewhat more critical than level 2 raters.

The inter-rater agreement between two members of a rater pair was relatively good. In the context of most criteria used on level 2, the raters had assigned the same or almost the same rating to a site in approximately 80% of the cases. In the context of some criteria used on level 3, the inter-rater agreement was less satisfactory.

The participants of the focus groups found most topics included in the quality criteria either rather interesting or very interesting.

*Conclusions:* The experience from a real-life setting speaks for the overall feasibility of the MedCERTAIN pilot rating model and technology. Internet users and information providers related positively to the MedCERTAIN concept and quality criteria. The raters were satisfied with the rating procedure and the technological tools. We failed to produce level 3 ratings to most of the sites. We anticipate that this is primarily a result of the allocation of raters into fixed rater quartets and of the limited timeline of the project. Most of the evaluated sites did not pass the applied quality criteria, which is an important observation, since the criteria derive from common international ethical codes and quality criteria sets. An equally pertinent observation is that our expert raters recommended sites much more often than the application of rigid criteria would warrant. Therefore, further research and development is required. We have identified some weaknesses and shortcomings that help refining both the model and technology.

#### [61]

# Compare Your Care: A web-based strategy for consumer activation and physician performance rating

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With the overall objective of creating published ratings of doctors' performance quality, using the Internet as an inexpensive and universally distributed technology, the Foundation for Accountability (FACCT) created Compare Your Care<sup>TM</sup> (CYC). This Internet-based innovation is a set of Web-based health care coaching tools that allows consumers to rate the quality of health care provided by their personal physician and provides them with information to help them improve the quality of their own care. CYC tools use the Internet as a medium for consumers to create scientifically valid individual physician ratings. FACCT is in the midst of conducting a five-phase research project to test, refine, and validate this doctor-profiling strategy.

Phases I and II of the CYC project have been completed. Phase I was a mode trial designed to compare Internet versus mail-based surveys of consumers' health care experiences. Phase II tested various strategies to encourage use of the CYC tools by consumers, including promotion through employers, labor unions, medical groups, and patient organizations. Phase III (currently in process) tests the instrument development and metrics of physician rating profiles in a large western state in the US. Phases IV and V will focus on best methods of public dissemination and evaluation of consumer use.

We have been able to answer the research questions from the first two phases of this study, and many of the project findings are encouraging. For example, we have determined that employing surveys online, at least with a subset of the CYC tools, appears to present a viable and low-cost alternative to employing mail-based surveys. Consumers are curious and interested in Web-based strategies for health care decision-making. Consumers respond to a variety of communications, but those from trusted sources and via e-mail are most effective (not surprising given that CYC is a Web-based program). Those who use the CYC tools report that the information provided is of high value to them in their health care decision-making. Users of the CYC tools also report a very strong interest in comparative ratings of individual physicians.

This paper will conclude with a forthright discussion of the broader social, political, and health care quality issues and implications that arise when using the Internet to create provider-level profiles for widespread consumer use.

## [62] Simulated microscopy on a handheld personal digital assistant (PDA)

# Szu Hee Lee, Hseuh Fun Chang, Abdul Rahman Zaaba and Siew Meng Chong *National University of Singapore, Singapore*

Handheld personal digital assistants (PDAs) have become popular for medical education because of their portability and compact size. Recently, simulated or "virtual" microscopy on personal computers (PCs) has been applied to recreate the experience of microscopy of glass slides, by enabling the user to zoom in and out, or to move around or "pan" large digital images in a small window on a PC screen.

In a pilot project, we have constructed a digital image library of pathology images that can be viewed on handheld Pocket Personal Computers (PPCs) by medical students at the National University of Singapore. The images were viewed on PPCs with StrongARM 206MHz processors running the Microsoft® Pocket PC 2002 operating system. The PPCs had 16-bit backlit liquid crystal display (LCD) screens of size 240x320 pixels, that were capable of displaying 65,536 colors. Wireless access was tested on PPCs fitted with compact flash wireless LAN cards operating on a IEEE 802.11b wireless network standard ("Wi-Fi") in the 2.4 GHz spectrum, that enabled internet access at speeds of up to 11Mbps (megabits per second) in defined locations.

Fifty Pathology microscopic images that formed a "core curriculum' for medical students were selected by Pathology tutors. The images were in the jpeg (Joint Photographic Experts Group) compressed image format and ranged from 300x400 to 768x1024 pixels in size, and from 30 to 100 kilobytes in filesize. The images were displayed in a Macromedia Flash® extension template that enabled panning and zooming of the image in an Internet Explorer browser window in the PPC. The Macromedia Flash® plug-in is widely available and is supported on all PPCs that run on the Windows Pocket PC 2002 platform. The user can zoom in or out of the image by clicking on buttons, or pan the image by tapping and dragging the stylus on the surface of the screen. The image library, which included a list of contents and annotations of the images, was uploaded to a server for wireless PPC access. The image library could be rapidly accessed on-line and image quality was judged to be good, by students and tutors, who also felt that it was a useful educational tool.

PDAs have the potential to play an important role in curriculum delivery and clinical activities of medical students and staff. Their compact size is convenient for clinical students who have to move from location to location to see patients. The use of Macromedia Flash® to pan and to zoom an image enables simulated microscopy of large images in a small PDA screen. Network access on a PDA enables large image libraries to be reviewed by users without sacrificing the limited memory storage capacity of the PDA. An important advantage of an image library that can be accessed on a PDA is that it facilitates

"anytime, anywhere" learning. In summary, microscopy simulation of digital images on a PPC could be a useful educational tool for medical students.

# [63] Digital video library for presentation of thoracic medicine resources

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Kraków Center of Telemedicine was found with the aim of developing telemedical applications and tools for the healthcare environment in southern Poland. The range of its activities encompasses developing Digital Video Library of the use in the field of thoracic medicine. Digital Video Library was designed as the repository used for archiving, accessing, and browsing of video medical records. The main part of the repository includes the records of procedures conducted in the thorax: bronchofiberoscopy, videothoracoscopy and cardiac surgery. With the use of Digital Video Library these materials are revealed to physician specialising in pulmonology, cardiology, thoracic and cardiac surgery.

The development process included decision on two crucial issues: the video compression format and video streaming platform. Numerous decision factors had to be taken into account. The compression formats being considered were DICOM as a format representative for medical applications, MPEGs, and several new formats targeted for an IP networking. The factors considered in the comparison process included transmission rates supported, compression rates, and options for controlling compression process.

ISDN technique was chosen as the solution for medical parties accessing resources uploaded to the digital video library. There are several backbone techniques (like corporate LANs/WANs, leased lines or even radio/satellite links) available, however, the availability of network resources for hospitals was the prevailing choice criterion pointing to ISDN solutions.

Another way to provide access to the Digital Video Library is based on radio frequency domain solutions. Data may be transmitted both through wireless and cellular network's data transmission services used as the medical video server transport layer. For the cellular network based solution two communication techniques were chosen: Circuit Switched Data and Packet Switched Data.

The repository of the Digital Video Library is being filled with the video cropped during diagnostic and therapeutic procedures conducted in the departments of Collegium Medicum, Jagiellonian University focused on thoracic medicine. The tools for on-line access to video resources are being prepared that enable the specialist working on the materials and adding the descriptions, both in the form of text and verbal commentary.

The Polish Scientific Research Committee finances the project.

## [64] Real-world solutions to complexities of global healthcare networking

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The cornerstone of an effective telemedicine network is the seamless transfer of medical information critical to sound diagnosis and treatment. Ensuring the quality and integrity of medical information on a

multinational scale presents many challenges. After a decade of experience and more that 12,000 successful studies, WorldCare, Inc., a commercial ehealth company, has developed internal expertise and corporate strategies in order to provide international clientele with global access to premier medical care. Patients, physicians, hospitals, and insurers from around the world benefit from the medical experts of the WorldCare Consortium, a group of top ranked U.S. medical systems; The Cleveland Clinic Foundation, Duke University Health System, Johns Hopkins Medicine and Partners Healthcare System (Massachusetts General Hospital and Brigham and Women's Hospital).

Operating in more than 25 countries presents many operational challenges, e.g., hiring of local physicians to participate in case processing, translation, client awareness and understanding for the second opinion product, establishing standard operating procedures, and determining the required quantity and level of electronic connectivity. This discussion will focus on the challenges encountered and practical solutions used by WorldCare, Inc. to meet the complexities of orchestrating this global healthcare network.

#### [65]

# "...They question the nurses so much more now": Nurses views on patients' use of online health information

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In the UK the current health policy context is driving a shift towards user-involvement and userfocused health care, which demands public and patient involvement at all levels of health-care delivery (DoH 1999; DoH 2000). Patients are no longer playing a passive role in their encounters with health professionals, instead facilitated with the development of online health information they are becoming informed, active agents in the health process (Brooks 2001). The Internet by opening up access to scientific journals, conferences and medical textbooks, previously denied to patients, has the potential to reshape the dynamics of the health encounter (Hardey 1999; Muir Gray 1999; Gillam and Brooks 2001). This proliferation of digital health resources is occurring simultaneously with patients assuming more responsibility for their health and that of their families (Eysenbach 2000). With such a rapid, radical change to the culture of healthcare delivery it is! Surprising to find that beyond anecdotal stories of the heartsink patient armed with Internet print outs, very little is known about how health professionals are responding. Moreover, how nurses in particular are adapting to this change has not been researched.

This qualitative exploration of nurse's views concerning patient's use of online health information attempts to bridge this gap. Drawing on data collected as part of a wider study, the Assisted Electronic Communication Project (http://kmi.open.ac.uk/projects/aec/), funded by the UK Department of Health, Research and Development, information technology strategy. This paper discusses the views of nurses expressed in qualitative interviews and focus groups about the project. These views will be considered within the context of patient health informatics and user involvement.

The nurse's expressed conflicting views. Whilst they acknowledged patient's changing information and communication needs and reflected on how these might be addressed they were concerned about their implications. There were concerns relating to matching demand to available resources and the blurring of professional boundaries. However, there was an underlying concern about their perception that their professional status was being threatened. Views about online communication with patients were also constrained by depersonalisation and their level of understanding of user involvement and patient focused care.

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# [66] WOMAN-II: European network of services for women health management

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Health professionals, working in the women healthcare field, are asking for multidisciplinary approaches and collaborative interactions between different healthcare providers. Women, who face the menopausal transition, report the lack of correct and useful information and lack of coordination between different healthcare providers. Internet is a perfect media for information publishing and the web technologies are the perfect platform for collaborative working environments: using Internet, it is possible to manage large-scale trials, based on a well-organized international collaborative approach, to guarantee the quality and quantity needed to reach scientifically significant data.

WOMAN, a European Commission funded project (1998-2000), produced three main services in the field of menopause, currently being validated within another European Commission funded project, namely WOMAN-II (2001-2003). WOMAN-II represents a network of competence involving European menopause centres of excellence.

The three main services, currently under verification and validation at European level are:

- WOMAN Web Site: a multilingual, high quality informative web-site regarding menopause for women and physicians (www.womanlab.com);
- WOMAN Telemedicine Services: Online Advising and Online Consulting services have been implemented for the interactions between women, GPs/Gynaecologists and Menopause Centres;
- WOMAN EPR (Electronic Patient Record), the Gynaecological module of a complete and integrated web based EPR connecting data coming from the different departments involved in the menopause treatment (radiology, pathology, laboratories). It proposes a European standardized electronic patient record, the basic condition to obtain European databases and knowledge.

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## [67] Towards a virtual patient record based on web services

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*Introduction:* Healthcare delivery involves a variety of activities often performed in more than one healthcare organization (i.e. hospital, health center) and they are interrelated to form inter-organizational healthcare processes. To this end, collaboration and coordination within and between the participating organizations become a vital issue for the quality of service provided to the patients. Thus, there is a need to supply the technological infrastructure that supports the coordination and integration of these processes even in cases where the healthcare organizations involved use heterogeneous systems to support their internal functions. This paper presents a virtual patient record (VPR) framework that allows integrating geographically dispersed medical information within a health district and enhancing collaboration and coordination of authorized workgroups by means of workflow technology and web services. An implementation of the proposed framework is also presented.

*Materials and methods:* Workflow systems in conjunction with web services present a new way for effecting this integration and coordination by automatically routing critical information to the right actors, at the right time in a healthcare process, thus reducing the likelihood of error, delay, duplication or omission. Moreover, workflow technology separates business process and workflow management components from the applications in order to increase flexibility and maintainability [1]. Web services based on the service-oriented architecture framework provide a suitable technical foundation for making healthcare processes accessible within and across healthcare organizations. Web services are attractive components of workflows, because they can be composed dynamically or orchestrated into workflows, and because they are widely available across the network [2].

To illustrate the use of workflow and web services into a VPR implementation, a prototype system has been developed in the context of a health district. For the purposes of this paper, the business process described concerns patient visits to a healthcare center and subsequent requests from a health center physician to a hospital radiology department within a health district, involving all activities from issuing a request for performing certain radiological procedures on patients to making available the results to the requesting physician. This inter-organizational healthcare process involves two participating healthcare providers, a health center and a hospital radiology department and can be realized by composing web services offered by the individuals healthcare providers while taking into account the constraints and the requirements defined for each participating web service.

According to the proposed architecture in each hospital tied to the Intranet there exists a workflow server, a web server and a database server. Health centers are not equipped with a workflow server since the medical request processes are managed by the hospital's Workflow Management System (WfMS). The radiological request generated in the health center is stored in the health center database as an XML document which is also sent to the radiology department of a hospital to instantiate and start the corresponding workflow process. Similarly, the radiological response is stored in the radiology database while it is sent as an XML message to the health center. It is assumed that patients who have received care in any healthcare provider in the health district have a unique patient identification number which is stored in the district's master patient index system.

Data exchange between web services is accomplished using XML and the Simple Object Access Protocol (SOAP) communication protocol. To ensure that patient data are accessed by authorized users only, a role-based authorization model was developed to control permissions for executing workflow activities and for accessing data objects (portions of XML documents) during activity execution. The

model was implemented using the WfMS's authorization features with regard to activity execution and an authorization mechanism, which was developed to control access to data objects. The authorization mechanism is implemented centrally on the Intranet's authorization server to facilitate security administration and contains an authorization database that stores all permissible assignments of users to activities/roles and authorizations to access the XML documents needed during activity execution [3].

*Results:* In our implementation approach, workflow and web services technology were used to realize a virtual patient record system within a health district. As a result, healthcare processes within the boundaries of a health district were automated enabling at the same time healthcare providers to make their services available by using together web services and SOAP. This made it possible for healthcare providers, such as health centers and hospitals, to integrate their healthcare processes over the Intranet, making their transactions easier and more efficient.

*Discussion:* This paper describes a virtual patient record system based on workflow and web services technology and implemented in an Intranet environment. The system provides access to integrated patient information scattered around a health district, enhances collaboration and coordination among various actors participating in healthcare processes and creates an easily accessible record of previously agreed upon courses of medical action. Thus, the system supplies an appropriate infrastructure for creating a virtual healthcare enterprise comprised of geographically distributed and organizational disparate healthcare providers.

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#### [68]

# Experiences with a combination of Oracle Clinical<sup>®</sup> 4 / SAS<sup>®</sup> 8.2 / MedDRA<sup>®</sup> 4 and Business Objects<sup>®</sup> 4: Scorecard comparison to open-source products.

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In Multicentre Studies the collection, organization and statistical analysis of study data requires a sophisticated information support system. An ideal system should be easy accessible and should provide high security. For this reason Remote-Data-Entry is seen as the most promising technology. This way of (Inter)net-based clinical data management is ideal for data entry from distributed locations that have little or no computer infrastructure.

The Authors have experience with some OPEN-Source engineered products set up in a LAMP and/or PHP and ODBC/Office environment and have used professional tools for the management of clinical trials. With the small-sized and flexible Open-Source Software-Packages clinical trials can be managed to a certain extent. Choosing a "professional" environment makes trial control and management more convenient but also much more costly and not in every case more flexible.

The objective of this paper was to develop a scorecard for the evaluation of software & dimension of projects to determine which use of components is feasible. The Scorecard is a three-page questionnaire

with chapters of 1.Needs in Project-Management and Remote-Work Components at Studysites, 2.Determination of Study-Size and Volume of Data, 3. Determination of needed Software-Components, 4.Determination IT-Knowledge for the Project, 5. Special Needs in Hardware and Security. The Questionnaire was developed according to experiences with the Oracle Clinical® 4 / SAS® 8.2 / MedDRA® 4 and Business Objects® 4 Environment and a LAMP/PHP Environment, but was kept very modular and general, so there is no fixation to these settings. A Scorecard System allows determining a Product Recommendation after filling out the questionnaire.

The Questionnaire may be useful for other groups e.g. for determination which environment may be feasible for their single study approach, but also for project planning and further development of the questionnaire.

# [69] Internet-enhanced education of medical students

Mindi K. McKenna

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*Emerging trends in use of the Internet for education of medical students:* 

- Medical students' use of Personal Digital Assistants (PDAs) to check clinical reference data, document patient information, transmit orders and view results.
- Medical school faculty's use of online lectures and other educational resources ·
- Distance learning ·
- Web-based clinical research (patient recruitment, data collection, collaboration on data analysis and publication).
- Online continuing medical education
- Education being provided to some medical students regarding use of the Internet for:
- clinical purposes such as clinical research and professional education ·
- patient care and education purposes such as point-of-care decision support and record-keeping systems, personalized patient web pages to provide pre or post-op procedures and preventive care reminders, in-home monitoring for chronic disease management.
- ambulatory care administration such as scheduling, coding, claims processing, billing, contract management ·
- hospital administration systems for admissions, discharges, procurement and materials management, recruiting and financial control).
- Computer applications and Internet technologies being used in medicine:
- Electronic patient records, clinical decision support systems, electronic prescribing ·
- Automated coding, charge capture, documentation and reporting systems ·
- Speech recognition and web-based transcription services ·
- Biometrics, digital signatures, user authentication and other security applications ·
- Provider-patient communication systems, online patient education, web-based patient services such as appointment or prescription refill requests.
- Medical practice and hospital websites

*Online or simulated online tour:* If Internet access is available at the conference, the presenter will give an "online tour" of various websites being used to educate medical students and healthcare professionals. If not, the presenter will show "screen grabs" examples of such websites. The online tour will include websites hosted by textbook publishers, continuing medical education distributors, medical

schools, business schools, medical societies, professional associations, pharmaceutical companies, clinical research organizations, government agencies, accreditation bodies.

*Case study – Internet-enhanced education of medical students:* The presenter will provide a case study that demonstrates use of Internet technologies to develop medical students' leadership competencies and business acumen as well as their medical knowledge and ability to deliver high quality patient care. The presenter will describe a Masters in Business Administration (MBA) in Health Care Leadership (HCL) program for medical students that uses Internet-technologies to enhance teaching/learning and that teaches Internet use as a key component of the curriculum. The program is designed to prepare future physicians to become effective clinicians, administrative managers and leaders in healthcare.

*How faculty use the Internet to teach medical students:* Examples will demonstrate how faculty use the Internet to enhance in-class and outside-of-class learning, to offer online courses, and to encourage lifelong learning, via:

- Online access to teaching resources including textbook supplements, cases, shared lectures, assessment instruments and other interactive digital media ·
- Use of e-mail, listservs and various applications to collaborate with other faculty inside and outside the university ·
- Posting of course syllabi, schedules, lecture slides, assignments and reference materials on faculty websites ·
- Electronic routing of information to students pre and post class sessions.
- Links to online resources that supplement in-class discussions ·
- Use of listservs to encourage online discussions and debates among students ·
- Use of e-mail to interact with students ·
- Use of computer simulations and interactive case analyses

How medical students use the Internet to:

- Conduct online research to learn about concepts and organizations discussed in class ·
- Conduct online research for completion of course assignments ·
- Conduct online literature reviews as background for publication of journal articles ·
- Submit assignments online ·
- Collaborate interactively with other students and faculty, to debate issues, share ideas, and alert one another to available resources ·
- Collaborate with other students on team projects such as papers and presentations.
- Complete online assessments of their skills, knowledge, attitudes and abilities ·
- Access reference materials such as course syllabi, schedules, lectures and other resources

What medical students are learning about the Internet in medicine: Medical students in this program are not just being taught about currently available Internet-technologies. They are learning about the forces that are increasing technology adoption, such as pressure to reduce medical errors and unnecessary costs, consumer demand, legislative and regulatory changes, growing emphasis on evidence-based medicine. They are learning about the obstacles to technology adoption, such as lack of technical standardization and thus interoperability, turbulence in the vendor marketplace, costs associated with hardware, software, Internet access, training, technical support, and difficulty in documenting return on the investment. Thus the medical students are learning to become proficient users of computers and the Internet, and to become advocates of the various policy, technology, economic and regulatory changes that will ultimately be necessary for mainstream use of the Internet in medicine.

Implications and benefits of Internet-enhanced education of medical students: The presenter will describe how use of the Internet for education of medical students is changing not just teaching methods and pedagogies, but paradigms about teaching and learning. Students are becoming better prepared to

remain lifelong learners. Students are gaining skills to access contextually-specific information when it is needed rather than memorization of general facts for possible future use. Students are becoming more active learners, interacting with computers and people to customize their educational experiences.

The presenter will conclude by describing the key benefits of Internet use for education of medical students. Such technologies do not necessarily reduce faculty time or expense, but they do increase the relevance, adaptability and interactive nature of students' learning experiences. The Internet offers vast resources to students who can use it to access information in real time from literally anywhere in the world. The Internet can broaden students' perspectives by exposing them to various innovations and best practices. And it allows medical schools and other educational institutions to expand beyond traditional geographic constraints.

## [70] Public Trust: More than fulfilling codes of conduct based on self-regulation

#### René G. M. van Melick

## TNO Prevention and Health, The Netherlands

Public Trust is the missing element in nearly all web-based medical applications. Newly developed quality initiatives based on "freshly" designed trust marks, communicated by relatively unknown poorly funded organisations, bear all elements for an early death.

TNO Health Trust, one of the Netherlands (Not for Profit) Public Trust Organisations for healthcare, specialised in medical Internet applications, has develop a "brick and mortar" Public Trust system with a wide scope of application. This system cannot only handle internet-based medical information services (including drug and device information), but also systems for Electronic Patient Records, e-commerce services and more. The heart of this Public Trust system are formed by the 198 essential requirements resulting from 1500 pages of legislation, codes of conduct and more, condensed to a structured 52 page document.

The Essential Requirements describe the minimal requirements for Organisations providing health information, communication and transactions to register their web applications within the QMIC® Public Trust framework including professional Codes of Conduct. Conforming to QMIC® requirements deeming to be relevant for a specific web application in our opinion will form a strong basis for showing evidence of conformity to applicable sections from Directives of the Council of the European Community.

QMIC® Essential Requirements will be updated based on feedback processes from organisations, users and regulatory bodies to optimise the Quality, Safety and Usefulness of QMIC® Certified applications.

In this presentation, the minimal requirements for any Public Trust system will be discussed.

## [71] Technology and quality: Organizing information for knowledge in clinical decision making

## Steven Merahn Elsevier Science, USA

Technology in medicine is more than the Internet or other forms of electronic information delivery; technology is generally considered to be the practical application of scientific ideas to industrial or

commercial objectives - but it is far more than that. The printing press was a revolutionary technology; algorithms and evidence-based medicine also represent technologic solutions. In the broader sense then, technology represents the body of knowledge available to a civilization that is of use in fashioning implements, practicing manual arts and skills and extracting or collecting materials.

*The revolution will not be digitized:* It is this 'anthropological' approach to technology that will permit the optimized use of electronic tools in clinical medicine whether desktop, handheld, networked or wireless; it is not the electronic platform that is the technology, but how we seek to develop and organize information to take best advantage of the features offered by electronic platforms. It's not the implement, but how we fashion it; it's not the materials, but how they are extracted and collected.

The challenges to primary care medicine in the 21st century are many, and the socio-cultural expectations of physicians are extremely high: error free decision making; clinical performance perfection; state-of-the-art practice; high patient satisfaction; quality of life as outcome measure; optimal workflow and productivity; efficient use of resources. It is to these expectations we need to seek technologic solutions

But even the best technologic solutions, while necessary, are not sufficient: the professional community must accept and integrate the technology if it is have any impact. Technologies cannot just educate, but must influence attitudes and behaviors as well. Workflow integration and cultural sensitivity are keys to changing the culture of quality.

*"Wetware" is still more valuable than hardware:* Quality is a function of the management of dependent and independent variables over time. Technology cannot create quality, but can facilitate quality by enhancing the management of variables. While machines may never tire, never forget, maintain speed, retain detail, humans can invent sense and order, craft strategies, understand context, and maintain flexible structures. Optimal human problem solving requires these factors over all others. Technology should support, not supplant the physician; the key to quality improvement is to retain the centrality of the physician's cognitive process as the critical success factor for optimal clinical decision making.

Variability in information delivery leads to decision variability. Technology must be sensitive to workflow integration and focus on minimizing decision variation, which is the largest factor in practice variation, respect the logic (or illogic) of the human problems being presented and allow for the creativity that often is necessary to manage the variation that represents the core of humanness. This is primarily accomplished by focusing on recurring information needs, recognizing practice realities and the time demands and filtering requirements of physicians

*Can technology enhance quality?:* Not all information is optimized for decision support. It is the organizing principles, not the delivery platforms that will make the difference. Benchmarks of technology for better quality must be established. Systems must be designed to support the cognitive strengths and problem-solving skills of the physician; information must be synthesized from expert sources and combined with evidence of 'best practices'; special interfaces and navigation systems must supports the cognitive 'flow' of professionals, and all of these benchmarks must be organized and applicable for real-time utilization. Even as ubiquitous a structure as the search engine may itself be a barrier to optimal technology integration; why should a physician expend valuable cognitive time focusing on the needs of technology (e.g., query structure)? Is the search engine an appropriate benchmark for clinical information system?

Technology-enabled clinical problem solving will: foster efficient decision making by supporting a "best practice" approach; expedite work-ups by improving time and resource utilization; optimizes outcomes by offering evidence-based treatment planning; reduce risk of errors and improving clinical documentation, and support the doctor/patient relationship by providing tools and information for dialogue and education. How we realize these benefits will entirely benefit on how we approach the development of the technologies to achieve them.

### [72] Internet: The third millennium trap

Marcucci Moreno and Giuseppe Lavenia University of Urbino, Italy

*Target of the study:* The authors have tried to appraise the eventual Internet's dependence, its psychopathology effects, and inclination in subjects with "pregressa" psychiatric diagnosis, reasons, and treatment.

Adopted methodology: They have considered 150 subjects by Internet Trap Test made by Italian psychiatrist Moreno Marcucci and the graduating Giuseppe Lavenia. The test has been administered by interviewers and on-line. Besides the subjects have been contacted to obtain information about social-cultural features, personality, current or past presence of medical-psychiatric pathology.

*In quiry's results:* It turns out that the 54% of the subjects have manifested several troubles caused by an internet excessive use, the 3.33% is very near the dependence threshold, the 6% it turns out dependent; the remaining 40% it has found ''normal'' user even if the 5.33% of these subjects are very near the problematic threshold.

*Conclusion:* These results are revealing a high-risk dependence of a "not appropriate" net use. Such problematic seems considerably developed by huge resources that Internet proposes in its interior: chatline, MUD, gambling on-line, virtual sex that tend to increase considerably the involvement in the net.

The subjects at dependence risks generate, with the passing of the time, psychopathology troubles as: distortion of sleep-wake rhythm, humour distortion, heavy anxious state.

Sometimes other phenomena can happen as noticed in a subject of ours considered dependent: he has shown for two days visual hallucinated troubles and agnostic troubles for the faces, this illness has spontaneously receded in the period of 24 hours.

The authors even if they appraise these results as necessary of further studies and appropriations, they think useful to open a debate on eventual defence mechanisms by the unconditional net's use especially on subjects with more risks: children, teen-agers, subjects afflicted by personality's illness.

#### [73]

#### Use of an evidence-based medicine information-seeking model for web design

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The practice of medicine changes constantly, and the rate of change is rapid. Consequently it is difficult for clinicians to learn about new information and innovations, and to decide how best to incorporate these new ideas into their practices, given the vast quantity of information available. Evidence-based medicine (EBM) is the process by which practitioners turn clinical problems into questions and then systematically integrate personal clinical expertise with the best available external evidence as the basis for clinical decisions. To practice EBM, the practitioner is required, amongst other criteria, to search the literature for relevant material, and then to synthesise knowledge and apply findings to each patient. Clinicians thus require fast and specific access to multiple data sources, but the availability of electronic full text documents has substantially exacerbated the lack of time to read the

clinical literature owing to the demands of clinical practice, and is further compounded by the fact that the Web contains much health-related misinformation.

Clinicians therefore require a means of searching the literature that will enhance the retrieval of accurate and evaluated clinical data from ranked resources, the so-called "hierarchy of evidence", whereby the most relevant information is retrieved first from the most likely source.

In this paper the theoretical possibility of linking EBM with information-seeking theory and Websearching theory is briefly explored. The latter two theories from the library and information science field hold the potential to assist health care practitioners to integrate EBM into everyday practice. Although not widely recognised, EBM has a very close connection with libraries. It can in fact be seen as a way of encouraging healthcare practitioners to access and use the professional literature, which is often contained in libraries. As libraries are traditionally seen as containing information more useful to researchers than to clinicians, this view presents a unique aspect to EBM information seeking.

In fact, strong correlations exist between four primary steps in EBM, and the formula commonly used in search strategy design in the field of information seeking. The similarities inherent in these steps suggest that an evidence-based approach to information seeking might enable end-users in the health professions to enhance their searching skills, and to translate the clinical question into an appropriate information-seeking strategy.

On investigation it was found that the model of the clinical-decision-making process in particular accorded well with all six phases of the traditional library-based information-seeking process. Accordingly, a model for EBM Web-based information seeking was devised, which incorporated the clinical decision-making model. This new model was tested empirically for compatibility against both a general Web-based information-seeking model and a methodology for Web site design, and was found to be compatible in both cases.

This paper highlights how, for the first time, the choice of browsing the resources, or actively searching for specific information is differentiated in the search process, and how this choice can be incorporated in a meaningful manner into an EBM portal or Web site design. For the end-user or healthcare practitioner, this emphasises the choices available in the search process of either browsing for general background information, or of searching for specific subject-related information. The difference between these two aspects of information seeking is likely to continue to play a significant part in the EBM search process until such time as a single resource encompassing all aspects of EBM information seeking becomes available to clinicians.

In exploration of the theoretical model for EBM Web site design, it was also found that the so-called "PICO anatomy", which encompasses the four filters of patient/problem, intervention, comparative intervention, and outcomes, could easily be incorporated into an information-seeking template for facet analysis. The translation of a "searchable" clinical question into a more formalised search strategy design, by means of the identification of the key concepts or intent of the clinical search, can thus also easily be incorporated into a portal or Web site for EBM information seeking.

In addition, it was found that it is possible to use the EBM information-seeking model in order to design access to relevant, ranked resources by subject specialty. This ranking of resources into the "hierarchy of evidence" has now been recognised as one of the greatest limitations to evidence-based practice, specifically in terms of the time taken to do so by the practitioner. A Web site or portal that offers the ability to select the ranked resource with a degree of assurance as to quality, therefore offers a significant advance in the field of EBM information seeking in support of treatment decisions. Furthermore, it is possible to incorporate into these subject-specialty Web pages the ability to link to various help screens of step-by step instructions, should this be required by the end-user, in order to provide "just-in-time" instructions for the use of the specific resource. These instructions are formulated in terms of search practice guidelines, and thus incorporate the clinical decision-making metaphor into the actual Web-site design, in addition to its incorporation into the evidence-based information-seeking

model. The "just-in-time" concept offers the ability to revisit the help screens when necessary at the point-of-need, rather than relying on memorisation or constant revision and training in the use of specific resources.

This paper thus demonstrates how a theoretical EBM information-seeking model can offer a unique approach to literature searching for healthcare professionals, including the ability to incorporate aspects of the clinical decision-making metaphor. The potential for incorporation of this model into Web site or portal design is a critical step towards the widespread diffusion of medical literature searching and the adoption of EBM into daily practice by clinicians world-wide.

#### [74]

## The Health Care TV project: Possibilities of digital television in personal health care

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Digital television (digi-TV) is an emerging platform for a wide variety of services ranging from standard TV broadcasts to interactive services bringing totally new possibilities to the world of television with one of the application areas of these services being health care. The European DVB (Digital Video Broadcasting) and its extension MHP (Multimedia Home Platform) is the most widely adopted digi-TV standard existing today. A DVB-MHP compliant digi-TV system consists of a BSP (Broadcast Service Provider), a broadcast delivery media, an ISP (Interactive Service Provider), an interaction network and the end-user digital receiver (set-top-box) offering a unified solution for digi-TV service provision.

The possibilities of DVB-MHP compliant digi-TV as a platform for media convergent personal health care are researched in the Health Care TV (HCTV) research project at the Digital Media Institute of the Tampere University of Technology in Tampere, Finland. In general digi-TV represents an intriguing platform for health care services utilising the possibilities of a networked multimedia environment with both TV broadcast and interactive communication facilities. The potential health care services on the digi-TV platform range from traditional health care related TV programming enhanced with programme related and integrated added-value services to services utilising digi-TV and as an end-device for providing tele-care solutions (e.g. related to the follow-up of various health conditions) through the interaction network of a digi-TV system. The HCTV project concentrates on the latter type of services with a special emphasis on personal health care solutions and media convergence. Media convergence is a key element in the development of anytime, anywhere available media solutions in health care. A media convergent service platform provides the possibility to optimise end-devices and services according to the needs of individual users and application areas. With these considerations in mind we have developed a media convergent service platform supporting multiple media environments for personal health care applications and have deployed two tele-care research pilot applications, personal follow-up of anticoagulant treatment and asthma self-management, on the platform.

The developed service platform consists of a J2EE based server-side architecture for content and data management in a media convergent setting with web browser equipped PCs and PDAs, various mobile communication devices, and a digi-TV STBs functioning as end devices. End-device platforms utilise the native or especially developed (X)HTML or other hypertext browsers and access the server-side resources using standard Internet protocols. The platform provides full user interaction capabilities for the services.

Follow-up of oral anticoagulant treatment was the original pilot application in the HCTV project and was originally initiated in the spring of 2001. The anticoagulant pilot application was first realised as a web service simulating a real digi-TV experience in a primary health care setting in the municipality of

Ikaalinen. Five self follow-up and ten home-care patients have participated in the pilot with generally positive results both from the user experience and technology point of view. The most significant advantage compared to traditional follow-up has been the enhanced communication possibilities between the patient or home-care nurse and physicians responsible for the follow-up. The original web service was extended to include a possibility to convey follow-up related information in GSM SMS messages and in 2002 an XHTML browser based solution was developed to access the service from a DVB-MHP compliant STB providing a native digi-TV interface to the anticoagulant follow-up service.

The second research pilot study area of the HCTV project is asthma self-management. Asthma is a long-term disease that requires medical and follow-up care. Self-management of asthma involves the patient making therapeutic, behavioural, and environmental adjustments in accordance with advice from health care professionals. Guided self-management of asthma is a treatment strategy in which patients are taught to act appropriately when the first signs of asthma exacerbations appear. Self-management of asthma exacerbations (guided self management) and patient education. The early interventions are peak flow and symptom guided.

In practise a pilot service was developed to be used in guided asthma self-management. One aim for the service was to create a new kind of co-operation communication channel for asthma care. The target was to produce a service for self-management health care of asthma using digital television as medium and the realised self management system was web browser based modelling a digi-TV experience; a native digi-TV interface utilising the developed XHTML browser is to be realised later. The asthma pilot was initiated in the spring of 2002 and the participants were four asthma patients and a physician from the Ikaalinen health centre. The initial experiences of the system have been inspiring.

The self-management service has several advantages in comparison to traditional asthma selfmanagement. It offers better communication possibilities between the patient and health care professionals. The patients gain more support for their asthma related decision making and the health care personnel get a better picture of the patients' condition. The service offers technical support and facilitations for self-management and it combines self-management's two important components: possibility for patient education and self-management of follow-up.

In general digi-TV, as part of media convergent personal health care service provision, offers some unique capabilities, e.g., in terms of the needs of the typical users of health care services. For example, patients on anticoagulant treatment are by average significantly older than the general population. This represents a challenge if tele-care solutions are to be deployed, as older age groups are typically not familiar with IT-based services in general. However, traditional television is a familiar medium also for older age groups and thus digi-TV might prove to be the easiest tele-care platform to adopt for these age groups. In conclusion, digi-TV will in the future provide one avenue for realising health care services as part of media convergent service platforms with personal tele-care being an important part of the service provision.

# [75] CE-net: An intranet portal supporting clinical effectiveness in a large NHS Trust

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Setting: United Bristol Healthcare NHS Trust is a large acute NHS Trust of about 5000 healthcare professionals, across 7 city centre hospitals. An extensive and growing PC network allows for the

development of web-enabled solutions to providing evidence-based information and key resources in support of clinical effectiveness.

*Objective:* To develop an intranet portal website that presents a single access point for healthcare professionals to key information to support effective clinical practice.

*Method:* Developed collaboratively by a team drawn from separate departments (clinical audit, research & development, library, care pathways, consumer involvement), CE-net and it's associated micro-sites are authored in Microsoft FrontPage. By using industry standard web authoring software, the CE-net project is content and user driven, rather than a technical exercise in the latest web technology. The prominent use of a jigsaw as a metaphor for clinical effectiveness is a consistent visual design theme throughout CE-net and it's associated spin-off projects.

*Results:* CE-net was launched in October 2000, and is seen as a key component of the Trust's intranet. CE-net contents include; (a) On-line access to primary research evidence - Medline, Cinahl, AMED etc. available at NHSNet speed from Regional SWiCE databases (b) On-line access to key evidence-based resources - Cochrane Library, WeBNF, Clinical Evidence, Bandolier, EBM Journals, EB-Oncall etc. (c) On-line access to NICE appraisals, local & national guidelines, care pathways, National Service Frameworks, PRODIGY (primary care guidance) etc. (d) How to ... Guides, resources & tutorials, including a quiz with prizes (e) Extensive and relevant up to date links (f) Complementary micro sites for separate components of clinical effectiveness.

*Conclusions:* CE-net complements national initiatives such as the National Electronic Library for Health (NeLH). Future developments may include closer liaison with NeLH, and the sharing of CE-net across Avon, or wider across the South West Region.

*External demonstrator:* Although CE-net is an intranet website, an external demonstrator version with limited function is available at http://www.ubht.nhs.uk/ce-net/

## [76] Emergency department handbook

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I am an Emergency Department Consultant Physician and work across two sites. By the nature of our work we have always relied on a large volume of paper guidelines/protocols/documentation/contact details etc, etc. The old paper based system was very laborious, inflexible, not (particularly) evidence based and was confusing for many. In 1998 we started the on-line Handbook http://www.ubht.nhs.uk/edhandbook/.

The site is different to other emergency medicine sites in that it is written by clinicians for clinicians and acts as a single portal of current, clinically relevant information. It is unique in that the site actively merges best available evidence with clinical guidelines and draws the evidence into clinical protocols and forms. We now have much easier, yet important document control, to ensure the quality of the evidence that we use. The site has become an education focus for medical and nursing staff within the Department and has become an integral part of the functioning of this Emergency Department. Perhaps of most importance is the merging of the above qualities with local details and protocols appropriate to our staff and patients. Web technology has allowed us to provide immediate simple ABC (algorithm) approach to patient care yet support our advice with links to appropriate supplementary evidence should clinicians need further details. We have simplified navigation using search and "chapter" navigation. The evidence guidelines have become integral with patient care pathways and we have used images to enhance information delivery whenever possible. We are now working on personalisation for clinicians in different departments. All the above advantages of the site will be available to a number of different clinicians yet integrating these guidelines with their own local contact details/protocols. The work involved with producing these guidelines, keeping them up-to-date, and the personalisation of evidenced based information is shared amongst many.

### [77]

## Do industry-sponsored web sites adhere to health information standards for the Internet? An analysis of 7 web sites marketing prescription medications for osteoporosis

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*Background:* The U.S. Food and Drug Administration (FDA) in 1997 approved the use of direct-toconsumer (DTC) advertising for prescription medications. Pharmaceutical manufacturers responded with radio, television, print, and Internet advertising for products prescribed for chronic conditions such as depression, seasonal rhinitis, and hypercholesterolemia. Reaction to the approval of DTC marketing and the proliferation of DTC advertisements has been mixed. Proponents of DTC advertising argue that it educates consumers about conditions they may not realize they have, encourages them to visit a physician for diagnosis and treatment, and empowers them to make more informed health care decisions. Critics of DTC advertising contend that it misleads consumers by conveying incomplete and/or inaccurate information, encourages them to self-diagnose illness and request potentially inappropriate medication from physicians, and promotes use of a prescription medications when no pharmaceutical alternatives are available. The FDA has issued broad guidance for print and broadcast media, but no such directives exist for DTC advertising published on the Internet. The lack of specific regulations governing the form and presentation of DTC advertising has compounded the inherent difficulties in evaluating electronic medical media.

Medical Webmasters and editors have developed several guidelines for medical information published on the Internet including the HON Code of Conduct and the eHealth Code of Ethics (eHCE). These treatises outline standards for Internet health information, typically emphasizing such qualities as honesty, accuracy, and responsible handling of users' personal information. These guidelines are appropriate tools for evaluating Internet sites that describe or promote prescription medications because such sites routinely provide condition- and treatment-related information in addition to product information. No research analyzing the degree to which pharmaceutical product sites adhere to Internet health site quality criteria has been published.

Osteoporosis, a loss of bone density and bone tissue occurring in postmenopausal women and elderly men, currently affects 10 million Americans, primarily women. An additional 18 million have low bone mass. The prevalence of osteoporosis will increase as the population ages, and more individuals will need to decide how to prevent or treat this condition. The increasing use of the Internet as a source of health information by affected generations justifies evaluation of Internet sites that describe or promote pharmaceutical products that prevent and/or treat osteoporosis.

*Objective:* This analysis was undertaken to determine whether Web sites for prescription medications uphold standards applied to non-commercial health and medical Web sites.

*Method:* Internet searches using 3 popular search tools (Google, Alta Vista, Metacrawler) were performed to identify Web sites that describe or promote prescription medications for the prevention and/or treatment of osteoporosis. The eHCE was selected as the assessment tool because it includes detailed descriptions of each criterion and examples of how Web sites should implement it. All of each site's pages were printed and the site as a whole was analyzed for its adherence to the seven applicable

principles embodied in the eHCE (candor, honesty, quality, informed consent, privacy, responsible partnering, accountability). The eighth principle, professionalism in online health care, applies to direct interaction between health care personnel and patients via the Internet and thus was inapplicable because DTC Web sites do not provide direct, personalized contact with physicians, pharmacists, and other health care professionals. The eHCE defines quality as "accurate, easy to understand, and up to date." To assess pharmaceutical sites for accuracy and timeliness, statements on product sites were compared with information presented on the National Library of Medicine's MEDLINEplus Medical Encyclopedia osteoporosis page and the National Institutes of Health Osteoporosis and Related Bone Diseases osteoporosis page. When these sources lacked the scope necessary to assess statements on DTC sites, position papers issued by national medical professional associations were used for verification.

*Results:* The searches identified 8 Web sites describing branded prescription medications promoted for the prevention and/or treatment of osteoporosis. Three of the sites identified (Activella, estradiol/norethindrone; Climara, transdermal plant-derived estradiol; Premarin/Prempro/Premphase, conjugated estrogens) provided information about hormone replacement therapy as a treatment for symptoms associated with menopause. These sites were included in the analysis because each provided a section dedicated specifically to osteoporosis; only pages included in the osteoporosis section were analyzed. The home page of 1 site (Cenestin, synthetic estrogens) indicated that the site was under construction, so it was not included in the analysis. All the sites provided information regarding osteoporosis risk factors, prevention strategies, clinical treatments, and product benefits and risks. The sites varied in their use of interactive tools, multimedia elements, brief summaries, and text. Preliminary results indicate some differences in adherence to the 7 eHCE criteria for which sites were evaluated. These differences occurred across the range of eHCE criteria but particularly with regard to accuracy and completeness of information and privacy issues. Final results of the analysis will be presented.

*Conclusions:* Preliminary analysis of 7 pharmaceutical Web sites providing information about products that prevent or treat osteoporosis indicated some lack of adherence to standards applied to non-commercial health and medical Web sites, especially with regard to accuracy and completeness of information and privacy. Specific conclusions will be presented.

#### [78]

# Assessment of utility in self-reported compliance in patients receiving antihypertensive treatment using a tele-monitoring home care system

#### Kristjan Port Curonia Research, Estonia

Patient compliance with prescribed treatment is considered to be a major cause of ineffectiveness in medical therapy. Consequently several remaindering arrangements are available for improvement of adherence to prescription. However, patient sincerity may be put in test if the treatment by itself is disliked. In principle, the erroneous or inefficient treatment scheme prescribed by a doctor may in their own aggravate the non-compliance, as the patients do not experience enough of improvement to find motivation for meticulous compliance. The aim of the current study was to investigate if self-reported drug administration and parallel self-monitoring could be used to vindicate the above dilemma and if the outcome is of any use for treatment adjustment rationale. 50 patients with treated essential mild to moderate hypertension from both genders (age  $51.9 \pm 6.6$ ) were asked to participate in home telemonitoring study.

Treatment effectiveness was defined as adequacy of accomplishing treatment purpose e.g. reduction in a measure of preset indicators of ambulatory self-measured blood pressure (BP) values using semi-

automated BP measurement device (Omron M4). Patients were asked to twice a day (respectively wakeup and evening bedtime) enter the BP measurement result in an interactive data collection device (Docobo Ltd., UK). The same device also inquired for daily symptoms, perceived stress level, and registered patient's ECG. Additionally during every morning patients were asked to confirm intake of prescribed medications for antihypertensive treatment. Doctors prescribing treatment were continuing established course and no inherently new drugs were introduced beyond common practice of normal treatment dosage and drug combination adjustments during the study. Patients were free to decline from suggested regimen of self-monitoring and follow their own rate of usage. However, they were told that the collected medical information would be visible to their doctors. Doctors were free to choose to use provided information for patient's treatment related decision-making.

Antihypertensive drug (AHD) effect was assessed using both a difference between morning and evening blood pressure measurements as well as the absolute BP values. It is reasonable to expect of the long acting AHD administered in the morning to have an effect on the same day's evening BP while the effect would be expected to diminish for the next morning before new dosage is administered.

There are several factors affecting daily BP dynamics outside the expected treatment effect. Evening blood pressure values tend to be higher compared to corresponding morning values. Also daily activities and several socio-psychological factors have impact on the daily BP values. With the aim, to single out the instance of reporting of drug intake as a predictor of BP values, 10 000 day-to-day data points were pooled from 12 months. Using pooled data the influence of other factors on BP was reduced to insignificant background, as there was no other aspect with similar pattern in time that would have been coincided with somewhat random reporting of drug administrations by individual patients.

Patients did significantly differ in their reporting of drug intake. Counting the drug intake by instances of confirmation is an indirect method and therefore we can only state that in 39.4% from all registrations included positive confirmation, and we cannot say that in 60.6% of cases drug was not administered. Overall, patients kept reporting on a relatively constant level throughout the study period of one year.

For whole population on days when drug intake was registered morning Systolic BP (SBP) and Diastolic BP (DBP) did not show significant difference between different instances of drug intake registration while on average both evening SBP and DBP were significantly reduced approximately 1.3 mmHg on the days drug intake was confirmed. The relative change of BP from morning to evening was correspondingly increasing for "not registered" days compared to reduced values for days drug intake was confirmed for SBP. DBP showed a general reduction, but was significantly greater for cases if drug intake was reported.

To assess whether there was any individual difference in response to treatment the patient population was analysed for treatment effectiveness. Patient population was divided according to treatment effectiveness into subgroups using correlation between average weekly morning SBP and duration of the study. Resultant groups were drawn of patients who showed a statistically significant reduction or increase in morning SBP. Third group consisted of patients who did not demonstrate noteworthy decrease nor increase in SBP. As a result study population was split to patients who were treated successfully (called "reducing" group) and those who did not show any effect of treatment ("no change") or those who's BP kept rising despite treatment ("rising").

Population grouping based on treatment effectiveness showed differences in drug registration rate. "Increasing" group reported drug intake significantly less (33%) compared to more successful "no change" (41%) and "reducing" groups (42%).

Relevant to explanation of non-adherence and treatment effectiveness interaction is the comparison of change in daily BP in different success groups. On days with reported drug intake the BP change from morning to evening was 3.4 and 2.8 mmHg for SBP and DBP correspondingly in the "reducers" group, while "no change " group did not show any statistically significant impact of instances of drug

registration. The "increasing" group did show a significant reduction of 1.2 mmHg in SBP on days of reported drug intake.

It is concluded from the above that drug intake seems to be reported "honestly" during a long period, as there is significant difference in BP values between the days when intake is not accounted for. Also, the treatment effectiveness coincides with lower drug intake reporting. The effect of prescribed treatment seems to be negligible in groups of patients. More importantly the most unsuccessful patient group shows signs of lowest compliance, which may be the reaction to treatment ineffectiveness. It is hypothesized that for at least physicians treating hypertension (and possibly other chronic diseases where drug alteration is pertinent) the above patient discrimination gives rationale for potentially more successful treatment adjustments.

#### [79]

# The Internet can reveal previously unknown causes of medical conditions, such as attraction to diapers as a cause of enuresis and incontinence

## Robert A. Pretlow eHealth International Inc., USA

*Background and purpose:* Enuresis (wetting) affects an estimated 200-300 million children, teenagers, and adults worldwide. Incontinence likewise affects millions of individuals. In many patients, if not most, the cause of the condition cannot be found. Dealing with enuresis and incontinence is therefore frustrating for parents and healthcare providers. An interactive website was created to learn more about enuresis issues and to promote a new miniature ultrasound device that monitors bladder volume. This website rapidly expanded into a global website on enuresis, receiving approximately 60,000 users per month.

*Materials and methods:* A multiple-choice questionnaire (poll) was implemented on the website to assess the interest of enuretic individuals in a bladder volume alarm device that would awaken the person in the night when their bladder volume was at the point where enuresis typically occurred, so that they could get up and use the toilet. A surprising result to this questionnaire was that 63% of those responding (n = 128) indicated that they would rather sleep in a diaper than wake up and use the toilet in the night. In light of this result, further questionnaires about diapers were implemented on the website, such as, "How do you feel about wearing diapers for bedwetting protection?", "Do you feel that diapers should be stopped occasionally?", and, "Do you ever wet on purpose, so that you can wear diapers?" Additionally, postings from a message board forum on enuresis were categorized and tabulated.

Cookies were used to minimize hacking of the questionnaires and to avoid a user answering the same questionnaire more than once. Additionally, user IP addresses were logged, and answers with duplicate IP addresses were deleted.

*Results:* A startling result to the questionnaire, "How do you feel about diapers as protection for nighttime wetting?" was that 50% of respondents answered that diapers were a "comfort" to them, and that they did not want to ever stop wearing diapers (n = 179). Those choosing this answer included ages 8 to 61. Only 16% agreed that, "diapers should be stopped every so often for a few days, to provide motivation to learn to stop wetting at night." In response to a questionnaire, "If an alarm did not help your nighttime wetting (like an alarm clock or a wetness alarm), why do you think it did not help?", 49% chose, "I never want to stop wearing diapers, so I really don't care if an alarm can help me to stop wetting at night" (n = 89). A final questionnaire asking, "Have you ever wet on purpose, so that you can wear diapers?" is still in progress at this writing, but preliminary results (n = 40) indicate that more than 50% of children and teenagers wet on purpose to justify wearing diapers. Postings on a message board enuresis

forum (n = 1767 postings, over a period of 26 months) corroborate the results of the questionnaires. Approximately fifty-percent of postings indicate an attraction to diapers. Individuals expressing attraction to diapers typically ask, "Is there someone else out there like me?" Moreover, some users state that the reason they finally stopped wetting was, "... because I was tired of diapers."

*Discussion:* Diaper "fetish", which is a sexual attraction to diapers, appears to be quite common. A search on the term, "diaper fetish" with the Google search engine produces 25,700 results. Emotional attraction to diapers, which is called "infantilism", appears to be nearly as common. Searching on the term, "infantilism" with the Google search engine produces 12,000 results. Web testimonials of individuals with infantilism say that diapers induce a feeling of "security". Emotional attraction to diapers may also be associated with fantasizing about infancy and even using other infantile items such as pacifiers, baby bottles, car seats, cribs, etc.

In light of our questionnaire results and the fact that emotional attraction to diapers and diaper fetish appear to be quite prevalent on the Internet, it can be argued that these behaviors are a significant cause of enuresis and incontinence. Emotional attraction to diapers and diaper fetish should, therefore, be included in the differential diagnoses of enuresis and incontinence.

Medical science seems to be unaware of these behaviors. A search via Medline (U. S. Library of Medicine) on infantilism and diaper fetish produces no articles on the phenomena. Therefore, until the Internet came along, emotional attraction to diapers and diaper fetish were apparently "closet" behaviors, similar to previously closet behaviors like cross-dressing. The Internet has allowed individuals with these behaviors to come forth out of the closet, without having to reveal their identities.

The causes of diaper attraction behaviors and whether they are harmful to affected individuals or to society were not part of this study. Nevertheless, when working up a patient with enuresis or incontinence, a psychiatric consultation may be indicated in order to rule out diaper attraction as the cause. Potentially hazardous procedures and treatments may thereby be avoided. Moreover, underlying psychological problems may be revealed.

*Conclusion:* The Internet, because of its anonymity, can serve as a useful tool for gathering information from individuals with medical conditions, particularly conditions with social stigmas attached. This conclusion is, of course, based on the assumption that Internet users are representative of society as a whole. Nevertheless, information gathered via the Internet may result in discovery of previously unknown causes of such conditions. Further refinement of this new investigational tool is warranted.

#### [80]

# Server artificial intelligence ("Web Bots") for processing of patient monitoring data for automated management of chronic disorders

Robert Pretlow eHealth International, Inc., USA

*Background and purpose:* Proper monitoring and management of chronic disorders such as hypertension, asthma, diabetes, and obesity requires significant healthcare provider time. Moreover, in many countries (e.g. the United States), reimbursement for chronic conditions is inadequate. The Internet offers a potential solution to this problem. Typical patient home monitoring devices can be interfaced to personal computers so that physiologic data is automatically sent to a secure web server, where it can be viewed by the patient's healthcare provider. Patients are enthusiastic about web monitoring, feeling that, "Someone is watching over me". Providers likewise feel that web patient monitoring can be a valuable tool, but again, due to time constraints and reimbursement issues, most providers feel that direct web

interaction with patients is not feasible [1]. It was hypothesized that web bots could alleviate this problem.

Materials and methods: An exploratory study was conducted using a web bot for weight loss management via a website for obese children and adolescents, 1123 children and adolescents, ages 11-18 participated. The web bot utilized the Childhood Growth Chart Database [2] of the U.S. Center for Disease Control and the recommendations of the NIH Expert Committee on Management of Childhood Obesity [3]. The length of the study was 26 weeks. At registration the children input their birthdate, sex, and height, and chose their weight goal and a desired weekly weight loss amount. Subsequently the children logged their weight data at least weekly. The bot analyzed the child's data in real time, compared it to previous data, and generated interactive feedback to the child. Feedback consisted of a trend plot, the child's healthy weight range, information on how far they were from their weight goal, how long it would take the child to reach their goal, and positive or negative comments on their progress. Music and animated graphics were played for achievements. If desired, the bot also could provide periodic summaries to the child's provider and notify the provider when data exceeded ranges set by the provider. Template provider responses, including the provider's photograph, as well as web information links could automatically be posted in a child's virtual care room. Additionally, the children received social support via a virtual community consisting of an automatic "Weigh-in Page" which displayed daily results and comments of all participants.

*Results:* Sixty two percent of participants in the study indicated that they were too embarrassed to directly interact with their healthcare providers regarding their weight problem. Although it was intended that participants would participate for 26 weeks, 42% dropped out before the end of the 26 weeks. Participants who continued for the entire 26-week period lost an average of 14% of obese body weight.

*Conclusions:* A web bot is a feasible method for effecting weight loss in children/adolescents and obviates the need for direct provider interaction. Further augmentation of the web bot intelligence is needed to include dietary and activity analysis. Legal, licensure, and liability issues still remain. Subsequent studies are planned to evaluate web bots for automatic monitoring and management of other chronic disorders. A study to further evaluate the weight loss web bot, with the addition of a web-connected "e-Scale", a pedometer to quantify activity, and limited provider interaction (nursing students), has been initiated. This study will compare the web bot approach with standard office-based weight loss programs. Preliminary results will be presented.

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#### [81]

# BARS: Benchmarking and reporting service implementation of medical application service for quality management in the treatment of diabetic patients

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*Introduction:* Diabetes Mellitus is one of the most widespread chronic diseases. In an ageing population living an increasingly sedentary lifestyle, the prevalence of diabetes is rising rapidly in most

developed countries. Recent estimations predict an increase of the diabetes prevalence in the US from 4% in year 2000 to 7.2% in year 2050 [1]. In the same time, the costs of care for diabetic patients are rising, and have reached \$44.1 billion in 1997 in the US [2] and 15.7 billion € in 1998 in Germany [3]. Recently, disease management programs are seen as the most effective way of healthcare delivery to diabetic patients, simultaneously increasing the quality and lowering the costs of care [4]. A data management and quality assurance module is an essential part of every disease management program [4]. In this abstract we present an application for data management and quality assurance in the treatment of diabetic patients that is designed as an application service.

*Materials and methods:* The BARS (Benchmarking And Reporting System) application service was developed as an N-Tier architecture application using Java 2 Enterprise Edition [5]. Entity Enterprise Java Beans are used to store and retrieve data from the database (Microsoft SQL Server [6]). Business Logic is implemented in Session Beans. Collection of WHO Basic Information Sheets (BIS) is the core part of the BARS application and was presented at the last MedNet conference together with details of architecture used for data entry and storage [7]. In the mean time several new features have been added to the system. The benchmarking part of application service has been reengineered and the administrative part has been implemented. The SQL queries used to produce benchmarking indicators are embedded in a XML structure to facilitate automatic manipulation of queries transparent to the users. A GUI editor for user-friendly generation of generic XML queries has been developed. In this way developed queries acts as quality of care indicators and are integrated in the application service. As each user customizes queries using her/ his own criteria for the query execution, several SQL views are defined for each user and tables in the generic XML query are replaced with user specific views in order to make concurrent query execution possible.

*Results:* A total of 47 diabetes related, user configurable queries have been implemented, classified into three groups: structure, process and outcome indicators. Process indicators are Evidence Based Medicine based, e.g. percentage of patients with hypertension receiving antihypertensive medications. All queries are modifiable via a unique user interface. The user can determine following criteria for the query: centres to be included in benchmarking chart, time frame, diabetes type, gender, age group and duration of diabetes. Results of the queries can be visualized as table or as one of 10 different chart types with numerous visualization options. PDF versions of charts, which are generated on the fly, are available for download on demand. Usage of a state of the art SQL server improves performance. In addition, access to The Cochrane Library of systematic reviews is provided.

Administration of the system is divided in two levels in order to minimize the maintenance effort for the operator and to maximize flexibility of participating centres and their users. Global system administrators generate only baseline data of each healthcare centre and manipulate application level data. Local (centre) administrators can then create and administrate users, classify users in security groups with different access rights and configure other centre-wide administrative data such as measure units in the laboratory.

*Discussion:* At the time approximately 70 000 patients with more than 82 000 BIS are maintained in the database. With the rapid growth of the database (more than 20 000 BIS each year), the application service approach shows all its benefits. Users access the application service with a web browser thus minimising installation and maintenance effort on the user site. A high quality service is delivered with minimal maintenance and operation costs to more than 800 physicians and health care professionals working in more than 400 healthcare centres in Germany and Austria.

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## [82] Analysis of a patient information web site bulletin board; what patients and visitors want to know

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*Introduction:* There is a continued explosion in the number of patient information web sites now covering most disease areas. There are continuing concerns from health care professionals regarding the benefits of web based information systems and the accuracy, quality and impartiality of the information. Patient information web sites are set up and maintained by a variety of sources – health care professionals, institutions, government bodies, health charities and of course, patients – individually or as a patient support group. There can be discrepancies between professionals and patients opinion in terms of content, style and purpose. It can be easy to create a patient information web site which does not take in to account what the patients actually want to be informed about and which questions the patients wish to ask? However, the benefits of Internet based information systems include the ability to include a bulletin board. Thus, it is possible to gain understanding regarding who is visiting the site, why they are visiting and which questions they are asking.

Aim of the study: To examine the messages posted to the bulletin board of a disease-specific patient information web site. To describe the reason for the posted message and its content, in comparison to the Methods examined bulletin existing site content. The study the board of \_ www.kidneypatientguide.org.uk. A multi-disciplinary team of patients, health care professionals and web site designers created this site. Patients determined the style and content, which uses animations to describe the difficult concepts of kidney function, dialysis and transplantation. It is HON registered and maintains a very active bulletin board. In this study, all initial messages posted on the bulletin board were analysed carefully. Follow-up messages were not included in the analysis. The initial messages were categorised in terms of reason for post, originator of post (patient, relative, friend etc) and the nature of the question.

*Result:* 638 initial messages were analysed in this study. Only 26 were simply comments regarding the site, the majority were "appeals for contact" with either a question or a general request for help. Interestingly, whilst 387 messages included an appeal for a response from a health care professional, 512 messages included a desire to receive a response from other patients. Messages were categorised on the basis of the question posed in the message in terms of general questions (e.g. "Can you tell me more about blood pressure?" and "How does peritoneal dialysis work?") and specific personal questions (e.g. "I have diabetic kidney disease, why am I on drug X?", "I only have one kidney, will that be OK if I get pregnant?"). These general and specific questions are presented in terms for whom the question was being asked – themselves, a family member, friend or unknown. General question - themselves 143, family 0, friend 0, unknown 11. Specific question - themselves 241, family 241, friend 84, unknown 50.

The topic covered by each question was also examined – dialysis 121, transplant 55, medication 34, diet 38, finance 16, holidays, diabetes 2, kidney disease 359. This contrasts with the content of the site, which concentrates on dialysis, transplantation, and the general effects of kidney disease.

*Conclusions:* This study has examined the messages posted to the bulletin board of a kidney disease patient information web site. Patients with kidney disease and their carers seek information about their disease, its treatment and the future. Internet based information systems bring added value to this search. This study has shown some important findings of relevance to those creating patient information web sites:

- 1. Visitors to patient information web sites wish to make contact with health professionals but more particularly other patients. This has obvious implications concerning moderation of sites, net security and data protection. Health care professionals cannot ignore this desire and need to include this interaction on patient information web sites despite the difficulties.
- 2. Most questions are specific and personal rather than general. Thus there are problems with the ethics of giving advice and guidance over the internet which need to be addressed.
- 3. The patients' family or friends often pose specific questions. As well as generating the same ethical concerns as above this does raise questions about Internet access for patients.
- 4. Questions were most often asked about kidney diseases rather than dialysis. This suggests visitors are seeking information about the early stages of disease rather than the more advanced problems. An iterative approach to web site design for patient information sites is suggested to allow exploration of what the patients desire to be informed about, their priorities and whether some areas are uncovered. This study examined a disease-specific web site but its findings are generalisable and will be of benefit to others actively involved in designing sites for patients.

# [83] A XML-based tele-dermatology service as patients' management support

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*Introduction and background:* The increasing availability of information and communication technology in healthcare organisation is a pushing factor for the development of innovative applications that could enhance the quality of care delivery while keeping its cost at reasonable levels. Furthermore, as the nowadays patients' care is delivered by multiple operators, thus tools allowing effective management of patients are needed.

In this study we present a web-based tele-dermatology service developed in order to investigate the feasibility of such tool for the integrated management of dermatology patients.

In the Province of Trento, which is a mountainous region in the heart of the Italian Alps, telemedicine application may play a central role for improving patients' quality of life and control healthcare organisation costs. Here work two kinds of dermatologists: "mobile dermatologists" (MoDs), who work in several different dermatology surgeries in the province and "hospital dermatologists" (HoDs), who are specialists working in the central hospital in Trento. In many cases during their practice, MoDs have to decide the care regimen of patients. Traditionally, doubtful cases are directly referred to hospital specialists, and only in few cases they are discussed by phone calls between MoDs and HoDs. A hospital outpatient specialist's visit has high costs both for the healthcare organisation and for the patients, who often need to go to the central hospital from remote valleys. The well-organized management of

dermatology patients, especially of those who need surgery, plays a great role in nowadays care delivery in our region.

*Purpose:* Many studies in literature have proved the effectiveness of tele-dermatology for diagnostic purposes. The aim of this project is the development and the evaluation of a web-based tele-dermatology environment that allows sharing clinical information between MoDs and HoDs, in order to foster the shared care among MoDs and HoDs, possibly enhancing the quality of care.

*Methods:* To achieve this goal, we developed a web application that allows MoDs to gather clinical information in different formats, sharing this information with specialists in the central hospital and consulting specialists for taking appropriate care decisions. Currently, MoDs can collect textual data, both coded and free text, along with digital images too. The textual information collected by MoD includes demographic and past history data. All this kinds of information are then stored in a multi-media database. As the tele-dermatology service is based on Internet technology, the stored information is immediately available to anyone involved in the care delivery.

HoDs can only view clinical data and digital images provided by MoDs. HoDs can then provide either a clinical diagnosis or a therapeutic prescription, depending on their specialties. As our system is mainly focused on patients' management, HoDs can suggest a therapeutic regimen. For example, s/he can indicate where to perform surgery, either in an outpatients' department or in the central hospital, or whether the patient needs day hospital care or a longer hospitalisation.

*Architecture:* The tele-dermatology service is based on a web-based client-server architecture and was developed by using eXtended Markup Language (XML) technologies, Microsoft COM+ and Active Server Page (ASP). The network infrastructure is the Internet. The client side of the system is a standard web-browser (Microsoft Internet Explorer). On the server side, we used Microsoft Internet Information Server 5.0 as web-server and Microsoft SQL Server 7.0 as multi-media database. A Secure Socket Layer (SSL) connection ensures secure communication between the client browser and the tele-dermatology web-server. The user must log on to the system by providing his/her username and password. Depending on user's role, the system shows the proper information. By using appropriate eXtended StyLe Sheets (XSL) it is possible to manage the client presentation layout of XML data, which are retrieved from the server only once. This solution allows performing some data manipulation on the client side, reducing network traffic and speeding up computation.

We developed a COM+ component in order to store the images, coming from the client, into the database as Binary Large Objects (BLOB), and conversely to retrieve them. Moreover, our component creates thumbnails of the full-size images and allows storing them into the database. This solution is chiefly useful to reduce the overload due to full-size image downloading. Actually, the user downloads only the set of thumbnails for a certain patient. By clicking one of the thumbnails with the mouse, s/he can download and view the full-size image. The user can then make some simple manipulation on the image: zoom in and out, panning and scrolling. In our study, MoDs acquire digital images by means of the Camedia Master C3000 Zoom camera, with 3.3 Mega pixels. However, any camera that can acquire digital images and store them in JPG format can be used. The HoDs can view multimedia data with a standard web-browser and then provide their diagnostic or therapeutic suggestions and advices to MoDs.

*Experiments and preliminary results:* In order to evaluate whether such a service could be effective for the management of dermatology patients, we set up the following experiment: MoDs were asked to insert both the diagnosis and the therapeutic prescription and the proposed management regimen as well (MoD's outpatient clinic, hospital outpatient clinic, day hospital, hospitalisation), in addition to the past history data and the digital images. HoDs are able to access only to past history data and digital images and then they can insert diagnosis, therapies and therapeutic regimens. Although the preliminary investigation carried out cannot clearly state the effectiveness of the tele-dermatology service, the first feedback enlightens that MoDs can benefit from the distributed nature of the system. In fact, the system can be used as a central repository of clinical patients' data that can be accessed from any geographical

location. Preliminary results indicate that about 50% (27 out of 52) of patients with diagnostic concordance between MoDs and HoDs would have undergone a different therapeutic regimen, hence indicating that shared patients' management is needed.

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## [84] e-Health for women via telemedicine

#### Dilip S. Shah

#### Online Telemedicine Research Institute for India

Any nation enjoys fruitfulness of health on the basis of the health of women. We at Online Telemedicine Research Institute are all the more concerned being involved in perpetual research of virtual health possibilities for women especially in countries like India and South Asian region.

The rural and remote of such countries are drastically deprived of minimum health care facilities. To meet the basic and advanced health care requirements we have devised an extra advanced hand handled palm size device called EVENT RECORDER.

PRE NATAL, PREGNANCY, and GENERAL FEMALE health conditions are monitored, transferred and referred to via this device to the super specialist in any part of the world via simple telephone line or any other mode of communication available.

An event recorder is a small hand held battery operated electronic device, which is used to detect and document infrequent and transient symptomatic arrhythmia. Certain episodic symptoms like palpitations, chest discomfort, light-headedness, vertigo, weight, etc could be due to underlying cardiac disease. The ability to record and interpret the ECG quickly during such symptomatic episodes in these categories of patients is a major advancement in cardiac diagnosis. The absence of an arrhythmia during symptoms may help to exclude any major cardiac involvement (arrhythmia) as a cause for the symptoms.

Whenever the patient feels the symptoms, she places the unit over her chest to record the ECG. After completion of recording, the ECG is transmitted trans-telephonically. The ECG is then interpreted by a cardiologist who then advises the further management to the patient, based on the ECG tracing.

Advantages of monitoring via telephone Trans-telephonic surveillance of arrhythmia's affords the following advantages:

- 1. The transmitters are convenient to use and light in weight. Most devices are small enough to fit inside a shirt pocket. Electrode jelly or irritating adhesive electrodes are not required.
- 2. ECG surveillance and monitoring of drug effects may be carried out by instructing patients to transmit their ECGs on a regular basis.
- 3. Evaluation of the patient's rhythm, either routinely or at the time of symptoms, may be carried out immediately. The recorded arrhythmia is thus available to the physician at the time of its occurrence rather than after delayed processing following the return of a Holter recording device.

4. It is superior to Holter monitoring (continuous ambulatory ECG monitoring) as arrhythmias may not occur during the period when the patient is connected to the Holter recorder. The event recorder may detect such transient arrhythmias.

## [85] Empowering patients and doctors via telemedicine

## Dilip S. Shah and Neerja Arun Gupta Online Telemedicine Research Institute, India

The environments like highly competitive and deregulated telecommunication and a range of models and solutions to make telehealth work in different health care situations in most rural, primitive and remote sites are covered in equity of care by Telemedicine thus empowering patients and doctors both.

The Online Telemedicine Research Institute demonstrated a break-even analysis in 3.9 years, when different factors like the lower cost of treating in rural communities, travel time for physicians, and diluted opportunity" costs were considered.

*Re-engineering through disaster telemedicine solution:* Telemedicine was used as a vital tool for re-engineering healthcare effectively during the recent Gujarat earthquake. Tele-consultation healthcare facilities with video conferencing, Information about medical needs, Computation of database on health problems, Tele-monitoring of all patients' care were the prime factors.

*Expedition and telemedicine:* At the height of more than 25000 ft above sea level, through inaccessible approaches and virtually no infrastructure right in the Himalayan Mountains the following was implemented. Kailas Mansarovar and Pithoragargh geographically difficult snowy mountainous regions showed the patients examined live and subsequently over video showed no changes in their diagnosis between methods. This strategic plan was for expanding telemedicine network in most alarming situations of avalanche, frost and snow.

*Telemediicne for mass gathering* – *Maha Kumbh Mela* : Maha Kumbh Fair in January-February 2001 the biggest religious fair on earth involving more than 1 crore people demonstrated savings of \$ 150 per patient when the patient was treated locally instead of referred to specialty care centers. This is the first of its kind of Telemedicine projects in the world. The telemedicine is used for the sake of more than 5 crores pilgrims.

*Telemedicine at alert with defence service:* Army needs specified health care for the reason of its scattered field positions in severe and extreme geographical conditions. Increasingly, whether Army is engaged in special operations units or not, the units are relatively small and modular. It is only natural that civil medicine will be submitted to similar changes under the influence of the modern capabilities generated by various advanced technologies such as remote sensing and imaging, telepresence surgery, virtual endoscopy and virtual reality (VR) surgical simulators.

Accessing inaccessible: In most deficient circumstances almost amidst the deep woods of Assam and Tripura, which are labeled as the most backward civil / tribal communities of North East India for the lack of public health care patients needing specialist consultation and service have to travel long distances to big cities. Today the presence of telemedicine has brought them at par with the any super-specialist protected patient in the world.

*Tele-medi-education:* The system was not used to give lectures, since in those cases communication is entirely one sided and the interactive capabilities are wasted. In the present case the system was used for distributed working sessions, questions and answers, open discussions and references.

Epidemiological surveillance:

1. Epidemiological surveillance through telemedicine

- 2. Preventive measures and diagnosis in the field of epidemiology
- 3. Role of a tertiary cardiac care center in clinical Decision making using trans-telephonic ECG monitoring

*An advanced matter of heart:* The most revolutionary and efficient telemedicine design for tele cardiology has been going on with the DICOM PACS based 3.0 HL7 database standard tele cardiology is rendering services to more than 90 patients a day. OTRI enabled the angio transfer rate to be converted to 1.5 to 3 minutes from 1.5 hours.

*Tele-ophthalmology:* Specially conceptualized tele-opthalmology by OTRI has brought a new world in the field of digital opthalmological treatments. Connecting Bangalore with Chennai and Madurai at Narayan Sankara ophthalmology Institute OTRI has been creating a new world of revolutionary opthalmological solutions. A perpetual nature of project is going on.

As usual all rural and remote: With telemedicine systems and solutions developed by OTRI the reach has been provided where the basic doctor cannot or does not visit all the villages falling under the jurisdiction of particular P.H.C. regularly in a scheduled manner and practice the health care measures. The proposition once mooted by the Union Government, as "Bare foot Doctors" as practiced in China had never been implemented so OTRI took the lead and offered Tele health to the villages as they can be connected to the specialist doctors / hospitals.

Introducing the concept of tele-consultation centers: The concept of telemedicine centers to be connected with super specialist centers all over India and abroad is gripping the general healthcare industry. All sorts of medical data are to be transferred. Local doctors can access Telemedicine without personal investment. Patients save time; botheration of appointment and discomfort of journey Super specialists from all over the world can be approached at virtually no expense

#### [86]

# The role of the Internet in global continuing medical education/continuing professional development: A review of the past and a look at the future

### Laurence Sherman Jobson Education Group, USA

The need for continuous professional education by healthcare professionals is clearly documented. Lifelong learning is therefore an essential component in the career path of these people, most notably physicians. In the United States, most physicians need to participate in continuing medical education (CME) activities in order to maintain board qualification and thus be able to practice in their chosen specialty.

Traditionally, CME has been offered through live events such as presentation at specialty society or association conferences, grand rounds programs, and individual meetings and teleconferences. Additionally, CME credits were available through the use of enduring materials such as written monographs, audiocassettes and videotapes. Recently newer media such as CD-ROMs and the Internet have emerged as delivery vectors for CME. This presentation will focus on the emergence of the Internet as an ideal method for delivering CME, often referred to as electronic CME or eCME, as well as examples of how this is being done.

The Internet, by its nature and design, is a truly dynamic and cost effective method for disseminating information and education to a target audience when compared with traditional methods of delivery. Furthermore, the organic and dynamic nature of the Internet lends itself to both synchronous and asynchronous coursework, increasing the educational options available to the learner.

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The history of medical education on the Internet is similar to the availability of everything else on the web! In my estimation we are in the fourth generation of materials and information that is available. Initially online eCME was restricted to text-only documents. As anyone who has every tried to read a long text document on the web can attest, this can be difficult and at times painful. It was, however, an initial attempt at using what was then a new medium.

As comfort levels with the Internet increased, the materials available became slightly more involved, and had text along with some graphics. Instructional designers emerged as the most appropriate writers of web-based content, as they took into account the properties of the Internet when developing educational coursework. Most notably, text was written in ways that were supported by the size of the screen, and slides emerged as a better method for delivering text – the bullet point replaced the full sentence!

The third generation emerged when audio was added to text and graphics, and the learners were provided with more opportunity for true multimedia activities. At this time, however, the limitations of low bandwidth connections became evident. Learners with very slow connections were unable to hear the audio, or could only hear portions of it. Video, while available only in very limited amounts, was certainly not supported by these slower connections.

Learners had to become more technologically savvy, and the need to download software that was needed to hear the audio was often a limiting factor for participation. At the time, many computers were not pre-loaded with multimedia software as they are today. Slow connections often prohibited even the most eager learner from participating in the online educational activities. Online CME providers needed to constantly monitor the average hardware profiles of their target audience members, and use this information to develop courses that were appropriate for the majority of their constituents.

The third generation ended and the fourth began at about the time we slipped into the new millennium. While there is not scientific correlation between these two events, the temporal relationship is quite interesting! It was at this time that the average eLearner in the United States had a computer with a fast (Pentium II or above) processor, and a 56K bps connection to the Internet. Faster connections such as cable modems were becoming widely available for home use, offering connections at up to 100 times faster than a 56K modem. Home computers were becoming increasingly more sophisticated, and multimedia audio and video software was often packaged with the computer, along with word processing, spreadsheet, and presentation software.

Online CME began to take advantage of the faster connections and ubiquitous multimedia software along with the true dynamic nature of the Internet. Archived activities such as audio slide shows became omnipresent. Live and archived webcasts from national and international conferences became available. Megasites such as Medscape and Physicians Online offered information and education to an astonishing number of online physicians – tens and even hundreds of thousands of American physicians were accessing these sites, and were using them for things as simple as email, and as sophisticated as webcasts and interactive educational activities.

That brings us to what is available today. A search of the Internet for online CME activities will yield search results in the hundreds. All sectors of the education provider community are represented, with quality education being offered by universities, specialty boards and societies, and private organizations. Physicians in need of CME credits for relicensure or board recertification are able to find enough credit hours online to fulfill their requirements.

The types of activities that are available vary and are truly multimedia in design. Live teleconferences are supplemented by web-based slides and graphics; for those unable to dial into these teleconferences, the audio and slides are available in an archived format for use at any time by anyone. Key presentations from conferences are almost routinely webcast, either in audio or video format. Like the teleconferences, these webcasts are typically archived for use by others later. These are two examples of the dynamic nature of the web, and of the cost-effective nature of using it.

Web eCME also uses formats that the physician-learners find comfortable and are used to. Clinical medicine is taught using a case-based approach, and is segmented by specialty and disease. Online educational activities that are in these formats can now be found. There are "virtual hospitals," "virtual clinics," and even "virtual tumor boards." Web sites that are devoted exclusively to case-based teaching have emerged. There is no shortage of eCME!

This does, however, raise the question: "Are physicians using the Internet?" Those involved in eCME have heard this question for as long as eCME has been available. The answer to the question today, is far different from what it was in the past, and the numbers continue to grow. For example, a 1999 survey conducted by the American Medical Association demonstrated that only 37% of the respondents were active users of the Internet. Less than two years later a similar survey revealed that 70% of the respondents were active Internet users.

Similar studies by the Royal College of Medicine in the United Kingdom, and by Harris Consulting demonstrated similar findings in broader survey populations. The target audience members are clearly available, and most are willing to participate in cCME. Between 60 and 95 percent of the respondents of these surveys indicated their willingness to participate in eCME. Another interesting fact is that the average retention rate for an instructor-led class is only 58%. Data show that more intensive e-learning experiences enhance the retention rate by 25 to 60 percent.

The next logical question then is: "If we build it will they come?" The answer to that is not as simple! Web site usage data indicate that physicians will only come to a web site if they know that it exists. Hoping that they find it by chance is not a smart approach. Although many physicians are sophisticated researchers and would be able to find appropriate sites by searching the Internet, they are confined by many variables, most notably time.

Some of the megasites have down an excellent job of building name recognition and have loyal followings, however the CME activities on their sites are often difficult to navigate to. They are often in violation of the "3-click rule" and lose many potential learners because of this.

Other sites are designed and developed appropriately, but do nothing to market the sites to the target audiences, therefore only a small percentage of the target audience eventually participate in the educational activities.

The sites that seem to be the "stickiest" and develop good repeat traffic are those that cater to a small, specific section of the target audience by specializing in specific conditions, therapeutic areas, or specialties. They offer easy to find educational activities as well as other information, links, and services that are pertinent to the well defined target audiences. They also offer frequent updates, education in various multimedia formats, and activities that can be selected based on the learners' connection speeds.

The majority of these sites are in the United States and Canada, but slowly there are sites emerging from the United Kingdom and Continental Europe. Interestingly there is a great deal of international traffic on the US sites, even though most are not marketed internationally. This demonstrates the willingness of the international audience to participate in eCME, and the need for true international sites to be developed.

Finally, what might be the most important difference between eCME and traditional CME is the interactivity. Whether synchronous or asynchronous the educational provider has the opportunity to receive feedback from the learners. This is a valuable tool, and helps to make the education better and serves as a needs assessment for future educational activities. The Internet also permits the use of sophisticated analysis of who is participating in the education, how long they are spending on the site and within each activity, and, when using a post-test, what learning is taking place. Follow-up impact studies can measure the ongoing impact of the education and are conducted easily via email.

In summary, eCME has become an ideal method for delivering education on a global scale. Over the course of the last five years content and sites have become available that take advantage of learner preferences, and, when designed appropriately, provide the learner with education in a convenient and

comfortable format. Metrics are used to determine appropriate use, and interactivity promotes better learning. Online CME will continue to grow and will become the most prevalent form of CME available to physicians worldwide.

## [87] NEUROWEB: A web portal for neurosciences

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The system consists in a medical web portal oriented to accessing clinical information and knowledge in neurosciences. The main objective is to improve the dissemination of information among health professionals and specialists, facilitate access to existing clinical databases, therapeutical/diagnostic protocols and medical guidelines, and gain access to relevant findings for basic research support telediagnosis process and teleconsultation concerning difficult clinical cases in the field of neurology. More specifically, the NEUROWEB portal will allow doctors to:

- Access the latest medical news in neurosciences;
- Access clinical trial news;
- Have links to other useful internet services and sites;
- Access clinical and new research opportunities;
- Share diagnostic and therapeutic guidelines and protocols;
- Organise teleconsulting sessions with specialists in neurology. to improve medical education.
- The main part of the project will be on the technological side, and will include:
- Development of intelligent navigation tools
- Management systems for medical imaging database.

That will imply the need of structuring information and knowledge in neurosciences and neurology, in cooperation between computer scientists and clinicians of hospitals and research centers in neurosciences. The specialists and health professionals in neuroscience will express their needs and define the services they want to obtain through the portal, cooperate in defining how to structure the knowledge it contains, use the portal and continuously improve it. In particular, it will be necessary to:

- Define clinical information procedures and knowledge (protocols, guidelines, etc.) that can be shared by different remote users;
- Define a common basic electronic medical record, including multimedia information;
- Organise clinical data bases accessible to all system users, such as registers and databases in neurology;
- Define the modalities of teleconsulting/telediagnosis sessions.
- The main results of the web portal, which will be hosted in the central server, are:
- Forums for neurologists, health professionals users relating to particular fields (neurology, clinic neurology, etc.).
- Links to other sites with relevant information and knowledge concerning neurology
- Links to main Neurological journals

- Teleconsultation directory of the people (hospitals and specialists) available for teleconferences, teleconsulting, telediagnosis, etc.
- Mail server for participating sites, which will store and then forward e-mail messages
- Access to the special databases to be created within the project.

In general, the benefits for the target of users (researchers, neurologists and health-care professionals) can be:

- Continuous access to clinical information and medical knowledge in neurosciences, useful for daily work of the specialists in their diagnostic-therapeutic processes in care and treatment;
- Teleconsulting, in order to evaluate by "remote" neurological specialists the medical record of a
  patient (evaluation of clinical data and/or images transmitted, condivision of medical information,
  audio-video conferencing, off-line teleconsulting using also e-mail, teleconsulting by means of
  mailing lists and discussion groups or news groups);
- Telediagnosis, if requested, to another clinical structure in order to have for example reports related to radiological images, etc.;
- Clinical trials with the possibility of transmitting and analyzing data product;
- Continuing Medical Education with the possibility to make teleconferencing on neurological arguments requested by doctors participant to this project;
- Discussion forum web based about particular neurological diseases (process of teleconsults/telediagnosis studying together the clinical cases, basic research aspects, complementary clinical support).

# [88] The worldwide Spam epidemic: A call for a systematic approach for attacking the problem

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By 2004 over half of Internet traffic is projected to be Spam and viruses. Without an ongoing intervention against this threat, the Internet is in danger of breaking down and becoming a less effective communication medium. The problem is widely apparent, potentially harmful health products like HGH and "miracle pills", MLM business schemes, pornography and more are in everyone's mailboxes. Technology can help reduce the volume of Spam but by itself cannot solve the Spam epidemic. Spam is not going away. What is Spam to many is some other person's interest. Why shouldn't people make money selling products and services using Spam just because it may be annoying to some? There is a real need to increase the global awareness of Spam, the issues involved with it and its impact upon society and technology. Hopefully, this will lead to a framework of attack that will help preserve the Internet as a means of communication. We propose that an international consensus activity be initiated for this purpose. It likely would take the form of an international congress. The fundamental issues would be identified, approaches, current R&D, social, legal, and political considerations examined. This presentation will focus on the analysis that is being done in preparation for this international consensus activity and some of the preliminary findings.

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## [89] Sexual harassment reduction in society using the Internet

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The legal definition of harassment is "a course of conduct directed at a specific person that causes substantial emotional distress in such person and serves no legitimate purpose" or "words, gestures, and actions which tend to annoy, alarm and abuse (verbally) another person." This vague definition provides little guidance or help either to the person suffers from harassment, or to the person who is unaware of performing act(s) of harassment. Sexual harassment is found everywhere, including the Internet. Web sexual harassment can be easily conveyed through e -mail delivery. It is quite hard to avoid it, besides the toll of time and money consuming to detect its origin. Another source of sexual harassment in the Internet is via the chat. The main way to eliminate sexual harassment is the educational approach. There are numerous courses given in the Internet aimed to managers and employees as well in order to familiarize them with the various aspects of the problem.

In Israel in our medical portal named STARMED, we established an open line in the forum of questions and answers regarding sexual harassment. We offer the surfers a unique opportunity to learn unobtrusively whether they have been harassed, to get a legal advise if needed, encouragement by standing upon their rights, besides explanation why the complains belong or not to the sexual harassment definition. From our experience we know that for each question asked, there are at least ten other people who read the question and answer. The public can add their comments. Normally we are not encouraging this approach. The person who is in charge on the answers, is a professional lawyer, whose expertise is sexual harassment, it helps to keep the forum on a professional basis rather than turning into a chat or a supporting group.

It is too early to conclude our experience, but the initial responses are in favour of our approach. What does it takes to run the program? It should be emphasized that the whole program runs on voluntaristic basis. It is hard to keep professional working for the sake of the community for endless period of time. The program should have more than one person answering the questions. People should get the feeling they are dealing with professional without alternate motives rather than pure help. We are looking forward to expand the program, besides sharing our experience with others.

## [90] Security architecture of the Dutch burn information system

Luc Antonio Taal Dutch Burns Foundation, The Netherlands

The Dutch Burn Information System (DBIS) allows the collection and processing of personal data (medical record and name, address, place and time of birth) over the public network by combining several Privacy Enhancing Technologies such as:

- Biometrics;
- Trusted Third Party;
- Smartcards;
- Public Key Cryptography.

The presentation will focus on several issues concerning the protection of the web- based DBIS environment from unauthorised access with biometrics and public key cryptography.

- 1. Biometric identification methods potentially have a privacy-invading character, since biometric data relate uniquely to an individual. Is it possible to compare live biodata with bio information stored on a smartcard at the office of a trusted third party, or is better to match biodata to the reference on the smartcard on the computer on the employee's desk?
- 2. What is the role of biometric authentication in a public key system where two keys are created :one private and one public? How is the cryptography used in the DBIS environment related to the digital signature?

The DBIS work had begun in 1999. DBIS was completed by the Dutch Burns Foundation in 2002. During the presentation specifically the implementation of specific security techniques are described.

## [91] Supporting the development of evidence-based organisations

Andre Tomlin, Karin Lee Dearness and Douglas S. Badenoch *Minervation Ltd., UK* 

Evidence-Based Health Care (EBHC) has come a long way from its introduction in the early 1990s. The scepticism which greeted its early proponents (Sackett et al.) has been replaced with pragmatism; instead of asking whether we should be practising EBHC, we are now asking how we can practise it. This represents a significant change in attitude, but also presents new challenges to the advocates of EBHC.

Nowadays, a plethora of guidelines and service frameworks set an environment for health care, which is, at least in principle, founded on the best evidence from systematic research. But these "top-down" initiatives still need to be interpreted in the local and individual context.

The ever-expanding array of secondary sources offers a richer than ever source of evidence with which to inform decisions, from quality- and relevance-filtered summaries (as in the Evidence-Based Journals and Clinical Evidence) to comprehensive systematic reviews (as those of the Cochrane Collaboration). Again, however, this evidence needs to be found, appraised, applied to a particular situation and, equally importantly, must be accessible in a form which promotes ease of use.

In summary, there is no "magic bullet" for making health care organisations "evidence-based". Simply providing online access to The Cochrane Library or Clinical Evidence, while undoubtedly improving awareness of and access to good quality evidence, will not solve this problem. To help plot a way forward, it is helpful to describe the objective clearly; here we present a definition of what an "Evidence-Based" (EB) organisation might look like in how it manages information: 1. Routinely deploy evidence from the best available systematic research in making decisions about health care; 2. Integrate EB information into the information resources; 3. Embed the skills of EBHC into the organisation; 4. Establish reliable, secure and quality-assured processes for communicating knowledge and information; 5. Ensure that information systems are relevant and timely to their users' needs; 6. Practice and promote high standards of usability in information systems.

Our definition of knowledge systems has crystallized around these six prerogatives. We recognise that there remain significant barriers, at both individual and organisational levels, to their effective implementation, principally:

- Time: busy clinicians and patients do not have enough time to seek evidence to answer all the questions they have about all health care interventions;
- Lack of integration: evidence delivery systems are not integrated into clinical information systems;
- Access: sources of knowledge are not available to the people who need them when they need them;

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- Usability: poorly designed systems simply present more barriers to the evidence rather than removing them;
- Relevance: what knowledge is available is often irrelevant to the problem at hand;
- Awareness: new publications and resources are publicised unequally;
- Skills: many professionals and most patients are not skilled in finding and appraising evidence;
- Beliefs: often, we separate practice from learning, and regard EB resources in the latter category of knowledge: something to be indulged when we have the luxury of time off from the real world;
- Communication: the right people must share expertise and collaborate on similar goals. This means identifying where the expertise resides in the organisation and establishing channels of communication, collaborative goal setting and progress management.

Clearly, there is no simple solution to this question, but consideration of the barriers has given rise to a new generation of information systems, which will change our conception of health care information in years to come. In this presentation we will outline a number of strategies, currently being implemented in the UK and the Netherlands, to develop effective knowledge systems. The methodology described will cover the following stages:

- Audience research
- Question formulation
- Literature searching
- Critical appraisal
- Authoring/reviewing/translating
- Media creation
- Project management

Sample websites will be presented which aim to answer all of the questions asked by patients, caregivers and healthcare professionals on a specific subject (e.g. depression or breast cancer) by providing the end-user with a summarised and synthesized abstract of the best available evidence.

#### [92]

# Heartweb: A web-based tool for tailoring nutrition counselling in patients at elevated cardiovascular risk

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*Introduction:* Many (family practice based) intervention programs have been designed to help people change their nutrition behaviour. However, despite enormous efforts, patients often find it difficult to reduce their fat consumption in a sustainable way. Quite often do programs have beneficial effects as long as intensive lifestyle counselling is given, while people are not able to maintain their healthy behaviour as soon as the intervention stops. Providing intensive face-to-face counselling for all patients with chronic lifestyle related diseases is extremely time consuming, and requires extensive knowledge from the health worker. Using the Internet for lifestyle counselling may prove useful in overcoming these barriers.

*Materials and Methods:* Readiness to change nutrition behaviour The Stages of Change Model1 has been widely applied in studies aimed at improving health related lifestyle factors. The model postulates

that people can be classified in one of 5 different stages of readiness to change, based on their selfreported current fat intake and intentions to lower their fat intake in the future. Classifying people in stages of readiness to change entails the possibility to better tailor nutrition counselling to the individual needs of patients.

*Heartweb:* We developed a web-based tool to provide stage-matched nutrition counselling and social support to patients at elevated cardiovascular risk. This web site called heartweb.info uses a 'server side' scripting language called Cold Fusion by Macromedia2 to display dynamic information. Support for the scripting language has to be installed at the server-computer that provides web pages to clients all over the Internet. Blocks of scripting code are placed within layout templates (HTML documents). As soon as a client makes a specific request, the blocks of scripting code are instantly translated into dynamic content, usually derived from a database. The syntax code of Cold Fusion is similar to HTML. The scripting language is relatively easy to understand. Web site development in Cold Fusion is therefore fast and affordable, without losing speed, scalability, connectivity, and security. Amongst others, Cold Fusion offers functionalities such as the possibility to insert user-comments made in simple webs forms, session-management, automatically send emails, and generation of server files. User information, discussion boards and project team member information of Heartweb.info is stored in a Microsoft access database that is connected to a web server (Internet Information Server on Windows 2000) through an OLEDB connection.

*Results:* A team consisting of dieticians, family physicians, nutritionists and web designers developed Heartweb. It was designed to contain tailored stage-matched nutrition education messages, a self-assessment tool for dietary fat intake, and a bulletin board allowing patients to interact for social support.

*Tailored stage-matched nutrition education messages:* As was previously done in (web-based3) intervention studies, Heartweb specifically includes a procedure to deal with patients' readiness to lower fat intake. Once every two months patients are presented with a short assessment tool to determine the patient's Stage of Change. This assessment tool is automatically scored, and patients are presented with an information package designed for that particular stage of change. Existing information materials, both web-based and non-web-based were reviewed to develop suitable intervention packages for each of the stages of change.

Self-assessment tool for dietary fat intake: As shown by Oenema et al.4, receiving feedback on a selfassessment tool can be instrumental in increasing patients' awareness of their dietary behaviour. Since awareness of one's problem behaviour is assumed to precede efforts to change behaviour, we hypothesized that the inclusion of a self-assessment food frequency questionnaire might enforce the effects of the Stage-matched intervention.

Online social support: An interactive medium, allowing patients to ask questions and to seek support where and when they wish, may best resemble personalized tailored counselling. This brings limitations upon the use of more traditional (telephone) patient groups in which patients need to set aside a common time to interact. Patient groups via computer networks offer the ability to work at one's own pace at personally convenient times. Furthermore, a computer network allows anonymous expression of feelings. Users can use their full names, or remain anonymous, which removes one of the barriers that normally may block interaction. Heartweb consists in part of a bulletin board, which enabled individuals to post notices on a general forum for all Heartweb users. This informal posting of messages provides a significant avenue by which psychosocial support may be given.

*Discussion:* Heartweb.info was designed to help adult patients lower their fat intake through awareness of their elevated intake levels, through providing them with tailored feedback encouraging them to make changes, and through the provision of an online disease-related social support network. The effectiveness of the Heartweb tool with respect to cognitive, behavioural, and biochemical outcomes of disease is currently studied in Canadian patients with non insulin-dependent diabetes mellitus and/or hypertension and/or hyperlipidemia. Preliminary data will be available in September 2002.

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## [93] The evaluation of the quality of paediatric web sites by parents

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The use of Internet is growing rapidly also among Italian families. The ability to obtain medical information in a short time and directly at home is an important opportunity that parents have to better participate in their children's health. Current literature is full of citations regarding best criteria to verify the quality of the medical web sites. Most of these are created for experts while others refer specifically to the final users.

The aim of this research is to verify the usefulness of an on-line evaluation framework for nonprofessionals, based on some few quality criteria selected from the literature. The evaluation process is allowed by a creation of a web site.

The first step of this study was to select from the literature a set of good web-quality evaluation criteria. After this research, the analysis of these documents allowed the selection of ten criteria: Authority, Contents, Currency, References, Aims Of The Site, Comprehensibility, Target Users, Navigability, Interactivity, Aesthetics Of The Site.

Hence, a joint group of paediatricians and web experts selected five Italian medical web sites devoted to parents in which a clear reference is made both to the aim of the site (provision of paediatric information) and its target audience (the family). The five sites were web.tiscalinet.it/ambupedy/, www.guidagenitori.it, www.ilmiobaby.com, www.ilnido.isnet.it and www.pediatria.it.

To facilitate the evaluation process by parents, a web site was created to allow the filling of the evaluation form with the ten criteria, and the exploration of the sites to evaluate, in the same time. The site was organized to help the users along the evaluation process by on-line supports and guides.

The parents assigned a score ranging from 0 to 4 (worst, bad, moderate-fair, good, best) for each criterion, a global score, in terms of the average of the scores for each criterion, was computed for the considered sites.

Although the evaluation system is in the test phase, the analysis of the firsts data collected from 14 parents, involved in the test of the prototype, shows some significant information: the average of the time used by parents for the evaluation of a site, using the web environment, was 25 minutes; the

comprehensibility of the 10 criteria proposed was easy for all the parents, and all the users involved in the test consider Contents as the more important criterion for the determination of the quality.

The results of the first test shows as this evaluation framework based on the use of a web site can represent a valid alternative system for a quality evaluation of the medical sites, directly from the final users. Improving the usability of the system should reduce the time needed for the evaluation process.

We think that this framework will be tested in more large scale in the next months; we wait these data to make a more significant and complete analysis of the results.

## [94] Use of the Internet to improve clinical response research findings

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*Problem:* In today's world, patients are aware of new medical studies before most physicians. The evening news, the internet and the lay press can provide access to new scientific findings before most physicians can even read a new study, much less formulate an opinion regarding its potential impact on their clinical practice.

Lippincott Williams & Wilkins, together with a team of primary care physicians from Massachusetts General Hospital, worked to design a web-based system to solve this problem for busy physicians. Ironically, the approach involved a web-based authoring and deliver system, use of the very technology that was a primary contributor to the initial problem.

Approach/Solution

A team of 4 physicians reviews primary literature. They select a relevant study, identify its implications for the primary care physician, and create a "Clinical Advisory". In addition, there are also "Patient Advisories" designed as a patient education tool on the same topic. These updates can be posted within 48 hours of publication of the original study in the primary literature, allowing physicians to be prepared when questions from patients begin to flood their offices.

Recent Clinical Advisories include: Mammography, HRT, and Anthrax.

To view all advisories please see: www.lwwmedicine.com.

### [95]

## Using the Internet to combat disease outbreaks caused by bioterrorism

### Jack Woodall

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Successful prevention and control of outbreaks of disease caused by bioterrorism depend upon the same basics as the fight against natural outbreaks: early warning, rapid diagnosis and laboratory confirmation, and rapid communication of the diagnostic criteria, lab results, treatment and preventive measures to both those concerned directly with dealing with the outbreak, and the general public whose cooperation is vital. The Internet is increasingly being used to support all these measures.

Early warning Internet-connected networks have been set up at global, regional, country and local levels. Globally, WHO's Outbreak Verification List (OVL) relies principally on information from WHO offices covering 191 countries, and two other sources: Health Canada's Global Public Health Intelligence

Network (GPHIN) that scours the World Wide Web several times a day for reports of outbreaks, and the independent Program for Monitoring Emerging Diseases (ProMED), which collects reports from over 26,000 readers in more than 155 countries, and posts them 7 days a week by e-mail and on its website www.promedmail.org. ProMED was launched in 1994 by the Federation of American Scientists specifically to monitor bioterrorist acts, even before those were serious concerns in the mind of the public.

WHO operates global reporting networks for specific diseases such as influenza, rabies and salmonellosis, and a regional one for legionellosis out of its European office. CDC supports various lists on which public health and disease specialists exchange current information on outbreaks, in other countries as well as the USA, including VECTOR, ARBONET, Epi-X and GeoSentinel (a global network of 25 travel medicine clinics). These are all more or less closed to the public; in contrast, ProMED is open and subscribing is free of charge. Nationally Brazil and the Netherlands are implementing networks based on the ProMED model, while France and the United Kingdom have networks based on sentinel physicians or laboratories. Many countries have national disease surveillance bulletins on their websites, but these are only updated weekly or less frequently, whereas networks modeled on ProMED send out daily reports.

Locally, the Rapid Syndrome Validation Project (RSVP) connects a number of emergency departments in New Mexico State, USA, to report specific symptom complexes in real time, and other area systems are being set up to monitor pharmacies in the USA for excess demand for specified drugs that may indicate the occurrence of an outbreak. Up-to-date information on specific treatment and preventive measures, including vaccines and therapeutic drugs, is posted on the WHO and CDC websites. The Internet also provides a very rapid means of sending, receiving and amalyzing questionnaires needed for the epidemiological investigation of outbreaks. In June 2002, approximately 6000 persons from the USA and 5 other countries attended an athletic event in Florida. Two cases of gastrointestinal infection with Salmonella serotype Javiana were subsequently identified among them. A web-based survey was distributed electronically to 1100 attendees with known e-mail addresses, and 80% of them replied within 48 hours, leading to the identification of 141 ill persons in 32 states who had attended the event, and of the culprit -- tomatoes in a salad consumed there. Other examples will be given.

The West Nile virus (WNV) epidemic currently spreading west across the USA is providing an excellent test-bed for early warning and communication systems in the USA. The national CDC has provided a standard case definition and laboratory confirmation of samples, while state and local health departments have set up WNV information pages, with maps, and post their press releases on their web sites. There are weekly updates from CDC and Cornell University's Environmental Risk Analysis Program. Standard information from CDC is being distributed through the states to the public on how to protect themselves against mosquitoes, to balance information being spread across the Internet by listservs and newsgroups devoted to the epidemic. Communication is working well, but state and CDC laboratories and getting seriously back-logged in their testing.

Examples of how the Internet has uncovered outbreaks that could have had a bioterrorist origin are many. When Ebola broke out in Gabon in October 1996, ProMED posted the news as soon as it was released by the World Health Organization's (WHO) Regional Office for Africa, 4 full days before it was disseminated on WHO's own outbreak-reporting system. In 1997 a British travel medicine clinic wanted confirmation of a meningitis outbreak in Moscow. Its query was posted on the Internet by ProMED, and confirmation soon came from the Moscow Laboratory for Meningococcal Infection and Bacterial Meningitis. When the worst epidemic ever recorded of Lassa fever struck war-torn Sierra Leone in 1997, the only drug known to be effective against it (ribavirin) was found to be in critically low supply. This led then ProMED Charles Calisher to post a notice that alerted the U.S. Navy to the problem. Enough ribavirin was then secured to protect the fleet that was evacuating expatriates from Sierra Leone following the violent coup d'état.

In 2000 there was a multinational outbreak of unexplained deaths in heroin addicts, eventually traced to contamination of the heroin with anthrax and clostridium bacteria. ProMED relays every report of a confirmed case of anthrax that it can find anywhere in the world, building a database of current natural outbreaks with which to compare future cases. After the anthrax letter attack in the USA, D.A.Henderson, Principal Science Adviser to the Secretary in the U.S. Office of Public Health Preparedness, stated that his office kept up-to-date with developments through CNN and ProMED.

What is lacking at the global level is a system that coordinates and analyzes the information from all the networks mentioned above. The same is lacking for the USA, where -- although military intelligence may be following all the state websites and the newsmedia -- there is no central public system. But the cooperation of the public is essential if the maximum advantage is to be gained from their information and expertise, which is why a free, open, publicly accessible system is needed.

## [96]

## Patient education by using the Internet: The experience with a Turkish health portal

## Hakan Yaman and Aylin Yaman Medical School, SDU, Turkey

*Objectives:* Primary health care services in Turkey are provided by health centers located in rural and metropolitan areas. There is high demand to metropolitan health centers, because of high population density. Contrary to this, rural health centers are not overloaded, but they have difficulties to employ active working doctors, which also compromises health education. Except mother and childcare and family planning no further official health education opportunity is available in Turkey. People of other risk groups demand for appropriate information concerning their health and diseases. Therefore, the World Wide Web (WWW) seems to be a good supportive measure for health education in people, who have access to the Internet. The aim of this study was to investigate the information demand of people, who visited a Turkish Health Portal.

*Study design:* Retrospective, cross-sectional

*Methods:* The user records, between 01.07.2001-01.07.2002, of the Turkish Health Portal (http://saglik.tr.net) have been studied. A needs assessment has been done by a qualitative analysis of the questions forwarded to portal.

*Results:* The average number of hits per day was  $17.360 \pm 1220$ , average no of page views per day was 1908, 992 persons per day visited the portal. Eleven of 992 persons Per day (1.1%) submitted questions to the board of medical consultants. The most frequent topics were women's health, sexual health, overweight and nutrition, men's health, child health, mental health, sports, etc.

*Conclusions:* The topics above need to be addressed in the future and further education lectures and courses need to be prepared. People seem to prefer to ask questions on problems via Internet, which need intimacy. While, new Internet technology for patient education is evolving and problems exist, there is a great promise for educating patients using the Internet. Patient education material that is read, seen, and acted upon over several times is likely to be effective in patients outcomes. Health education via Internet may also be effective in rural areas, which are difficult to access because of climatic and road conditions. Patients, who avoid asking questions concerning personal health, might be encouraged to ask the health consultants anonymously by Internet. There are also drawbacks to health education in Turkey. Although, in nearly all small towns internet cafes provide internet services, people need to buy a PC for personal use. They have to pay for Internet service provision and the telephone bill. Since people in rural areas have other priorities, than Internet, health education by Internet seems to be issues of wealthy people in these areas.