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Synopsis

Integrated Information Systems

This section of the Yearbook contains a diverse collection of nine papers under the heading Integrated Information Systems. The problems and systems they describe are quite different, but they have in common the fact that each addresses one or more issues involved in integrating or bringing together health information and the people who use it, including consumers, patients, clinicians, epidemiologists, researchers, and policy makers. Two of the papers discuss use of internet by consumers seeking health information and advice, two are concerned with improving prescribing practices, two address two sides of the identification coin: assuring accurate identification of patients to link data in separate repositories, and assuring effective concealment of patient identity when aggregated data is handed over for research; finally, three papers describe systems for using internet technology to enable sharing of information for disease surveillance or clinical research.

Bringing Together Consumers and Health Information

The availability of health information for consumers has exploded through the use of the internet, but with the increase in quantity has come an increased concern about quality of information. One approach that has been

offered to address this concern is the use of instruments or scales to rate the quality of the information found through web searches. Jadad and Gagliardi [1] identified and evaluated quality rating instruments currently in use on the internet. These authors were able to identify 47 such instruments, 33 of which provided no information about the criteria used in their ratings. Of the remaining 14, 9 appeared to have been developed specifically for health information sites, 8 reported results in summary form, either as numbers or graphic analogs (e.g. stars), and 5 provided instructions for use. None provided any information on formal evaluation of the instrument with respect to the reliability or validity of the criteria used to rate information. Given the dynamic and complex nature of information use on the internet, the authors question the feasibility or desirability of attempting to provide meaningful evaluations of the information available to consumers. The authors note that, "Despite its obvious benefits, the increase in availability of [health] information could also result in many potentially harmful effects on both consumers and health professionals who do not use it appropriately."

Another intriguing aspect of internet use by consumers has been the phenomenon of consumers submitting unsolicited requests for health information and advice from physicians unknown to them. Eysenbach and

Diepgen [2], noting that there has been much speculation about the potential benefits or harms from this practice but that little data is available, investigated this issue among visitors to their website, <http://www.derma.med.uni-erlangen.de>, a comprehensive dermatology information source maintained by the Department of Dermatology at the University Hospital of Erlangen. They examined 209 consecutive unsolicited email requests in English or German from nonprofessionals seeking advice from physicians in their department. In many cases the age, gender, or country of origin of the requester could not be determined. The majority were from persons who appeared to be seeking a second opinion regarding their condition, with many requesters expressing frustration with previous care. Three quarters of the requests contained specific questions, including questions about diagnosis, cause, treatment, and complications. One third asked for general information about a condition. In the investigators' judgment, a) about one half of the requests would not require a physician's input to respond, such as requests for contact information for referral; b) about one quarter could be answered by a physician without seeing the patient; and c) about one quarter could not be answered without more information or a visit with a physician. The authors discuss many concerns about this phenomenon, including confidentiality and security, anonymity and au-

thentication, licensing and liability, reimbursement, and the potential impact on patient-physician relationships, noting that these issues must be addressed before appropriate use of email-based telemedicine can be defined.

Improving Prescribing

Two papers in this section are concerned with integrating information systems to improve prescribing practices. Schiff and Rucker[3] provide a useful overview of the potential benefits of computerized prescribing and a discussion of inhibitors of progress toward achieving their goal that "all medications should be prescribed on a computer interacting with 3 databases: (1) the patient's drug history, (2) a scientific drug information reference and guideline database, and (3) patient specific information, including age, weight, allergies, diagnoses, and relevant laboratory results." The paper outlines eight key areas in which computerized prescribing might transform care processes and patient outcomes, including (a) point-of-care decision support that integrates recommendations, guidelines, and standards of care into the prescribing process; b) patient participation in the prescribing process, allowing "a dialogue among patient, provider, and computer," exploiting the computer's ability to display cascading levels of display as required; c) screening for interactions, including drug-drug, drug-disease, and drug-allergy interactions, to reduce potential adverse effects; d) integration with laboratory systems to provide relevant patient specific data at a point where it can improve prescribing decisions; e) dosing and timing support to reduce dosing errors, which are among the commonest and most avoidable prescribing errors; f) facilitating patient education about medications, coordinating team participation by clinicians, pharmacists, nurses, and patients; g)

supporting ongoing postmarket surveillance for adverse effects; and h) capturing feedback about patient response to therapy, especially where this may suggest adverse effects.

One real-world example of the benefits to be realized by electronic prescribing is the report by Monane et al. [4] on a system linking physician, pharmacist, and computer to improve prescribing for the elderly. Taking advantage of a centralized prescription benefits management program that provides mail-in pharmacy refills, they examined the impact of a computer system to trigger re-examination of prescriptions with high potential for adverse effects in the elderly. Expert recommendations drawn from published sources were adopted by the service's independent medical advisory board and incorporated into rules for computerized drug utilization review (DUR), using the service's prescription data and self-reported patient health information collected in a separate survey. During the one year study period, 2.3 million patients filled at least 1 prescription through the service, and the DUR system triggered 43,007 alerts among 23,269 elderly patients, prompting 24,266 pharmacist initiated contacts with prescribing physicians and 5860 prescription revisions to a more appropriate agent. Reasons given by physicians for not changing prescriptions included 55% saying they agreed with the intervention but it was not applicable, 41% disagreeing with the intervention, 3% agreed with the intervention but did not change due to patient views or convenience, and 1% gave no explanation.

Determining and Protecting Patient Identity

Two papers in this section are concerned with patient identity - one with accurately establishing patient identity

to allow linkage of patient data to support clinical decisions, the other with concealing the identity of individual patients while allowing linkage across disparate databases to support epidemiologic studies. Wang and Ohe [5] describe using the Common Object Request Broker Architecture (CORBA) as the implementation platform to address the first problem. Their two stage process includes a patient identification translation model that maps patient IDs based on patient attribute matching, using computer based human checking to resolve residual ambiguities. The second stage involves dynamic linking of data items based on temporal mapping. The authors emphasize that an important characteristic of their methods is that clinical information systems can be developed independent of one another yet still be effectively integrated.

Quantin et al. [6] propose a method that would maintain the anonymity of each patient while allowing linkage of individual patient data to support epidemiologic studies and outcomes research. Following spell processing adapted to the local language, the first step is irreversible transformation of identification data using a one way hash function that incorporates the Secure Hash Algorithm of the U.S. National Institute for Standards and Technology. The second step involves linkage of data in files which have been rendered anonymous by using a statistical model that takes into account multiple variables, applying to each a computed weight which indicates the reliability of the information provided. Importantly, the authors evaluate their approach linking hospitalization data (388,614 records) and a digestive tumors registry (2847 patients) by comparing the automatic linkage results with a gold standard, in this case the result of automatic plus manual verification of links. They report a true positive rate of 1251/1295 (96.6%)

and a false positive rate of 111/1552 (7.2%), concluding that the method provides satisfactory performance for epidemiologic or outcomes research while assuring the confidentiality of individual patient identity.

Integrating Information Systems for Research and Disease Surveillance

Rare diseases present a special challenge for conducting clinical studies or outcomes research. Few institutions encounter sufficient numbers of patients to conduct meaningful studies, while multi-institution studies must devote significant additional resources to provide the logistic support necessary to ensure uniform data entry and other practices across multiple institutions. Working in the domain of cholangiocarcinoma research, De Groen, Barry, and Schaller [7] developed an integrated approach that could serve as a model for conducting such research in other domains. Their approach is highly integrative, leveraging an existing billing data entry process to identify candidate patients by ICD-9 codes; incorporating human research coordinators to verify eligibility and initiate contact with referring physicians; employing an industrial strength client-server database to ensure such features as data integrity, security, transaction control, and audit; taking advantage of platform independent, World Wide Web technology to maximize flexibility, scalability, and extensibility while minimizing installation and support requirements; and providing links to relevant clinical data in existing laboratory and other clinical information systems to minimize duplication of effort and data entry error. They devote special attention to the clinical data entry process, encouraging local development of web-based templates for data entry in different clinical departments, and providing many fea-

tures to enhance usability, ensure uniformity of data entry, and minimize errors. The authors envision adding additional features in future versions such as ICD-9 based links to information about clinical trials and links to condition related information for patients.

Two papers describe systems for international monitoring of disease activity, using the platform independent client-server technologies of the World Wide Web to maximize distributed real-time access to epidemiologic data while minimizing implementation and support requirements. Snacken, Managuerra, and Taylor [8] describe the extension and expansion of the existing European Influenza Surveillance Scheme (EISS), a collaboration of eight surveillance networks in seven European countries, covering a population of approximately 250 million inhabitants. Initiated in 1992 by the World Health Organisation (WHO) with funding from the European Union, EISS goals include early detection of influenza outbreaks, identification of causative viral strains, rapid assessment of related morbidity and mortality, detection of new strains, surveillance of other respiratory pathogens, and comparison of data among national surveillance networks. The advent of the World Wide Web and its widespread adoption by participating organisations has permitted, with only modest centralised hardware requirements and modest technical support, significant enhancement of EISS functions, including distributed data entry from remote sites with built in security and authentication; real-time access to up-to-the-minute epidemiologic data; graphic displays of influenza data for visualising geographic and time trends in disease activity; enhanced communication among members of participating organisations using email and listserv functions on the EISS server; and provision of tabular summary data in fa-

miliar file formats that can be downloaded for analysis at local sites. Public information including maps displaying recent influenza activity in Europe can be viewed at <http://www.eiss.org/public>.

Another effort to promote and enhance international sharing of influenza data on a global scale is the WHO sponsored FluNet, described in the paper by Flahault, et al. [9]. Like the EISS, FluNet represents an extension and expansion of existing influenza surveillance programs, taking advantage of the widespread adoption of the World Wide Web and its platform independent client server technologies to offer maximum functionality and data access with a minimum of resources in development and support. FluNet permits remote data entry from any of 110 influenza surveillance programs operating in 83 countries, allows real-time access to virologic and epidemiologic data for analysis by participating organisations, provides public access to current influenza information, including graphic and tabular displays for identification of temporal and geographic trends in disease activity. The authors also discuss limitations of FluNet, including potential under reporting of some data, incomplete representation or data from some countries, and the uneven internet performance which may delay (and thereby alter) data entry or interfere with access. Still, the authors point out, the network provides an unprecedented opportunity for global surveillance and early identification of important trends in influenza activity. Public access to FluNet is available at <http://oms.b3e.jussieu.fr/flunet>.

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