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Synopsis

The changing scenery of patient records

Looking at the papers selected for inclusion in the Yearbook Medical Informatics 2003, one is confronted with the changing scenery provided by research and development of patient records. These changes include new perspectives on the role of the patient him/herself as custodian of the medical record, and research from the social sciences underscoring that technology is often not the limiting factor in getting the electronic record implemented and accepted. Other papers in this section show that some topics remain in the forefront of research: how can we support coding and how do we deal with multilingual environments.

In their paper "Personal Health Records: Evaluation of Functionality and Utility", Kim and Johnson examine the Web sites that provide personal health records for patients. In most western countries we have delegated the role of custodian of the medical record to the medical community. In line with the increased emphasis on patient empowerment and involvement, it seems only logical that patients are also given an active role in managing their own medical record. Provide patients with the opportunity to create on a website their own, personal records; they can subsequently grant

access to the care provider. The idea is simple and appealing.

In other parts of the world, it would be considered strange if a medical community would hold on to the medical record. In India, as was pointed out by one of our students who came from there, it is common that the patients carry their own paper medical record with them. When the patients visit a physician, they hand over their record to the physician who adds notes to that record and returns it. I recall the Indian student asking me what is new about this idea of a personal medical record on the Web – my response, for lack of better, was "the technology".

In their study, Kim and Johnson test the claims made by the providers of websites for personal health records. The design of the study is compellingly simple. First, take stock of the claims made by the providers of the Web sites in their promotional material. Second, take a concrete example (albeit in this case a fairly complicated example). Finally, see if it works. The results are sobering. The promises and claims of the industry are not met. One might be tempted to respond with a sarcastic statement such as "Only fools believe the claims and promises of the software

industry". That, however, would do injustice to this study. Certainly, the websites examined in this study showed many shortcomings. That, in my mind, is not the essence of the paper. For me, the paper posed a question I had never asked myself before: Given the same set of medical data, what is the difference between patient entry and physician entry? Or, in the words of the authors: "Of principal concern is the fact that the entire process of data entry assumes that individuals can accurately categorize and prioritise their own medical information." This thought-provoking paper deserves reading. It supplied me with the question I should have asked our Indian student: In your hometown, who writes on the patient-held paper record, the patient or the physician?

In their paper "Adoption of Smart Cards in the Medical Sector: The Canadian Experience", Aubert and Hamel report an evaluation study that examines the factors influencing the adoption of smart cards in the medical sector. Using methodology from the social sciences, they examine the introduction of smart cards in the complex and interwoven setting of the health-care delivery system. Their conclusions will not surprise the

experienced researcher in medical informatics: technology is not the limiting factor, the system must be of direct benefit to the user, and the system is beneficial only if the information on the card is complete.

The paper underscores that the implementation of smart cards (or, for that reason, patient records) is no longer limited by the technology. Poor technology will kill a project. Good technology, however, does not guarantee success. Even better technology will still not guarantee success. In order to better understand the success or failures of our systems, medical informatics will have to collaborate with the social sciences. Although the methodology employed by the social sciences may be foreign to many researchers in medical informatics, we stand to gain from the collaboration.

The paper also illustrates the danger of separate communities addressing the same issue. In the past years, several initiatives have attempted to introduce cards with varying degrees of success. Aubert and Hamel do not make a single reference to these initiatives. Moreover, in the discussion section, the natural place to discuss how this work relates to the work of others, the authors do not discuss related work in medical informatics – the discussion is a summary of their findings without any attempt to relate their findings to the work of others.

In their paper “Evaluation of a Method that Supports Pathology Report Coding”, Hasman, de Bruijn and Arends revisited a classical theme: The accuracy of coding by physicians. One of the purposes of electronic record is to use the data in those records not only for patient care but also for other purposes, such as research or management. Understanding the accuracy of the codes found in records is of paramount importance. The paper, as many other papers, documents the struggle researchers have to identify a “silver standard” because a gold standard, the truth, is not available. The silver standard is, for lack of better, based on agreement between experts. In this study, the authors conclude that the system, when judged against the silver standard provided by pathologists, does not function optimal. At first glance, their results are disappointing. The authors, however, report a second finding: despite the limitations of the system, the agreement among pathologists increased when the system was used during coding. This intriguing conclusion begs further research into how the system influenced the coding-process of the pathologists. Given the role of coded data when using medical records for a wide variety of purposes, increasing agreement is important. The paper shows that even if a system codes sub-optimally, its usage improves the quality of coding by physicians (that is, under the assumption that agreement is an indicator of quality).

The final paper in this section is entitled “Building a Controlled Health Vocabulary in Japanese” by Liu and Satomura. In the scientific community, English is the lingua franca. The most widely used coding systems and controlled vocabularies are in English. Countries that rely on other languages often use translations of these English coding systems. Liu and Satomura built a standard clinical vocabulary for the Japanese language. The authors report that Japanese medical terms mainly come from western medicine. Their use of SNOMED, therefore, is not surprising. Building controlled vocabularies is a daunting task. Having to build a controlled vocabulary and at the same time having to incorporate work done in a total different language adds layers of complexity. The paper provides the reader with a flavour of the many issues that need to be addressed in that context.

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