

# Web as Medium for Patient Access to Electronic Health Information

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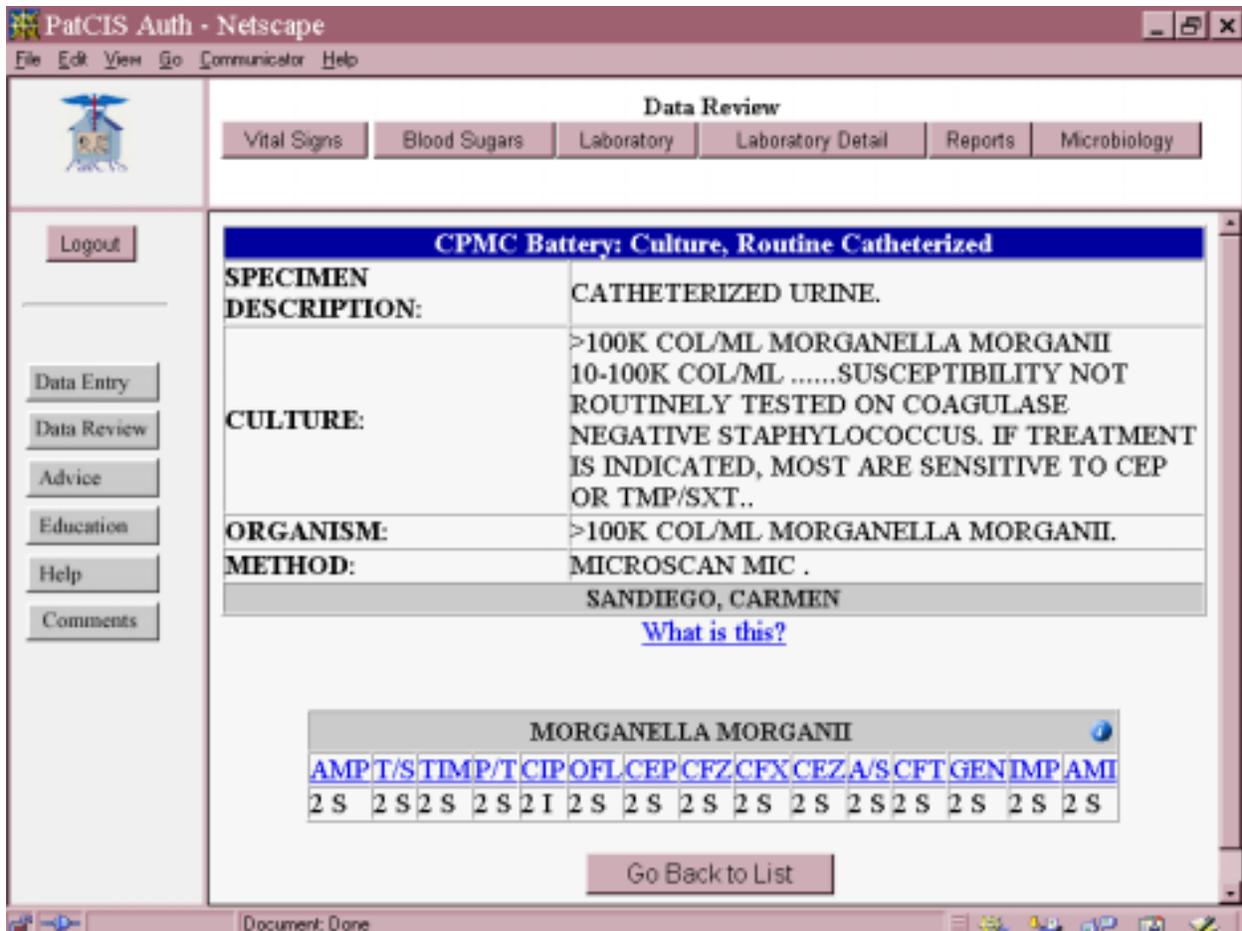


Figure 1. Sample PatCIS Screen

Despite plans for pending privacy legislation to include provisions for patients' access to their electronic health data, little is known about how they would use such data, and it is likely that patients will need help understanding these data. In the absence of appropriate tools to help with interpretation, they may turn to their care providers for help. This may foster better communication between patients and providers, or it may place an additional burden on the relationship. Opinions on both sides are mostly conjecture until formal studies can be done.

The Patient Clinical Information System (PatCIS) is a system to provide patients with access, via the World Wide Web, to health data in the New York Presbyterian Hospital clinical data repository<sup>1</sup>. The system allows patients to add data to their records

(blood sugars, insulin doses, hypoglycemia and hyperglycemia symptoms), review data (laboratory, radiology, pathology, cardiology, operative reports, etc.); use automated guidelines (for cholesterol management and mammography recommendations); and access a variety of educational resources. Figure 1 shows a sample PatCIS screen.

The Web offers advantages in three respects over traditional, paper-based approaches: It (1) lowers barriers to access, (2) offers an environment in which to provide tools that can promote understanding of the data, and (3) allows monitoring of access to and use of the record. This paper describes our experience with these three advantages.

## LOWERING BARRIERS TO ACCESS

Although patients have the right to obtain copies of their records, PatCIS gives patients dynamic, timely views of their records. For example, a patient who has blood tests done on a weekly basis can review the tests the day they are done. PatCIS also provides a level of organization (by report type) that is not available in the paper record. This allows patients to see, for example, all their lab data over time, rather than having to thumb through several inches of paper looking for relevant reports.

Concerns about access may be raised because many patients do not have access to the Web. Although educational and language barriers exist (as they do with the paper record), Web access is now available in public libraries, lowering the economic barrier.

## INTEGRATION OF INFORMATION RESOURCES

Given that the record is in electronic form and that resources are available to help patients understand health issues in general and their data in particular, opportunities abound for bringing online resources to bear. For example, the linkage between health records and MEDLINE is well recognized<sup>2</sup>. We incorporate such access in PatCIS in several ways. "Infobuttons" pass patient data to online resources automatically. For example, in Figure 1, if a user clicks on the "i" icon to the right of the organism name "Morganella morganii," the system will pass the organism name, as part of a search strategy, to PubMed. Similarly, if the user clicks on one of the antibiotic sensitivity names, the system will carry out a search of a drug monograph database. Also, clinical guidelines are integrated so that data from the patient record (such as cholesterol or mammography data) can be extracted and passed to the guidelines to expedite the generation of appropriate recommendations.

Care must be taken, however, to avoid the traditional dual problems of hypertext systems: disorientation and cognitive overload<sup>3</sup>.

Disorientation occurs when a user gets lost in the navigational path through the hyperdocument (in this case, moving among and within the clinical record system and the various online resources). Cognitive overload refers to the difficulty users encounter as they try to keep track of the various, nested tasks they are performing as they move among different user interfaces and information paradigms. We address these problems by opening new windows when accessing external resources, so that when users close the resource, they return to their previous place in PatCIS.

## MONITORING ACCESS AND USE

Studying user interactions with PatCIS is a crucial part of the project. We accomplish this through an architecture that manages the users' sessions so that individual applications do not need to track their own use. Briefly, all calls to applications or document links are calls to the PatCIS program, with the address of the desired link passed as a parameter. PatCIS saves the request in a log file and then passes it on to the appropriate application. We currently require that all internal links be managed this way. We also have a technological solution to applying this restriction to *all* Web pages that are retrieved for display from external sources. In this way, we can keep a record of virtually every mouse click the user makes, whether or not it is one of our own applications.

Security is always a concern when dealing with patient data. The security of paper-based systems is often substandard or impractical. In PatCIS, we make use of a variety of techniques to keep the data secure. For example, logging onto the system requires a SecurID token (Security Dynamics, Bedford, MA) that displays a different six-digit number each minute. Users must authenticate themselves with their user ID, password, and SecurID token. The system also maintains a database about sessions to prevent users from changing variables used in the queries, for example, to obtain data about another patient.

We also present some practical approaches to issues that are relevant to a wide variety of Internet-based telemedicine applications. An evaluation of the usability and usefulness of our approaches is presented elsewhere.

## ACKNOWLEDGMENT

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