

Application of Technology ■

Interactive Computerized Health Care Education

SUSAN W. McROY, PhD, ALFREDO LIU-PEREZ, MS, SYED S. ALI, PhD

Abstract The Patient Education and Activation System (PEAS) project aims to prepare people to take a more active role in their health care decisions. In this paper, the authors describe their work on the Layman Education and Activation Form (LEAF). LEAF is designed to be an interactive, Internet-based system for collecting a patient's medical history. It is unique in that it gives patients access to educational information when it is most pertinent, while they are attempting to complete a form. It avoids overwhelming the patient, by providing information only when it is likely to be relevant. The system avoids asking irrelevant questions or providing irrelevant facts by tailoring the content of the form to the patient's responses. The system also uses the patient's answers to suggest questions that the patient might ask a doctor and provides online resources that the patient can browse.

■ JAMIA. 1998;5:347-356.

The Patient Education and Activation System (PEAS) project aims to prepare people to take a more active role in health care decisions. With the collaboration of the Department of Medicine at the University of Wisconsin Medical School (Milwaukee Area Clinical Campus), the PEAS project group has been developing a coordinated set of computer programs for educating patients. The group is investigating strategies for helping people identify their health care concerns, learn what actions they can take, and verbalize their concerns to health care professionals. These strategies address the problem of how to present relevant information efficiently and effectively. This is accomplished by a multimedia computer interface with intelligent tutoring and intelligent discourse processing.

One goal of our design has been to create an architecture that would alleviate the problem of misunderstanding and miscommunication between patients and computer systems. Ultimately, we hope this will

also alleviate miscommunication between patients and their physicians. Such breakdowns in communication can arise because of differences in vocabulary or differences in beliefs about the significance of different states of health. Moreover, errors in understanding can proliferate, because people interpret each new fact on the basis of their understanding of old facts. To address these concerns, computer systems (and people!) must not ask patients to make choices without providing them with the opportunity to obtain clarification.¹ In addition, systems must avoid overwhelming their users with too much information at once. As in human conversations, computer systems should allow a dialogue with users, in which each participant takes a turn and then gives the other party a chance to accept it or ask for clarification. In this way, misunderstandings can be detected and addressed before communication breaks down completely.²

This paper discusses an architecture for patient education that we have developed for the Layman Education and Activation Form (LEAF). LEAF extends the normal activity of filling in medical forms by including education activities that will help patients understand medical terminology and various health care-related issues. At any point during an interaction with LEAF, patients can access facilities for explaining the terminology of the form (through the Definitions module) and for learning about topics that they might want to discuss with their doctor (through the Dialogue module) (Figure 1.) Unlike a hypertext-based system, which presents the same information to ev-

Affiliation of the authors: University of Wisconsin-Milwaukee, Milwaukee, Wisconsin.

This work was supported by grants IRI-9523646 and IRI-9701617 from the National Science Foundation and by a gift from the University of Wisconsin Medical School, Department of Medicine.

Correspondence and reprints: Susan W. McRoy, PhD, Professor, Department of Electrical Engineering and Computer Science, University of Wisconsin-Milwaukee, P.O. Box 784, Milwaukee, WI 53201. e-mail: <mcroy@cs.uwm.edu>.

Received for publication: 5/14/97; accepted for publication: 2/3/98.

LEAF

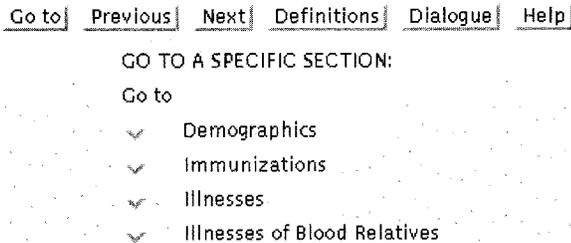


Figure 1 LEAF's user interface.

everyone, LEAF is interactive and tailors its content to each patient's responses.

For example, suppose a patient has indicated that she is female, childless, and has a family history of heart disease. LEAF will dynamically filter irrelevant parts of the medical history form, such as those related to breast-feeding. (This customization is important because irrelevant parts of the form are especially likely to contain terminology that is unfamiliar or confusing.) If asked for advice (via Dialogue), LEAF will offer tailored information about prevention and treatment strategies for heart disease and suggest questions for the patient to ask the doctor. Similarly, if asked for a medical definition, LEAF constructs a customized definition based on the health history given by the patient.

A prototype implementation of LEAF has been built using the JAVA programming language and is publicly available over the World Wide Web.* This prototype demonstrates the functionality of LEAF and its ability to tailor the information that it provides. It also demonstrates the portability of LEAF. Along with the form itself, LEAF provides a short questionnaire that allows users to participate in an informal (and anonymous) evaluation of LEAF. This information has given us insight into how real patients might react to LEAF and where design improvements should be focused. The objectives of the prototype are limited in scope (to establish the proof-of-concept). For example, the current project does not address the problems of verifying the accuracy of the medical information that is provided. Any medical information provided is for illustrative purposes only, and should not be taken to represent the views of any of the PEAS project participants. The LEAF prototype demonstrates the feasibility and cost-effectiveness of patient-tailored computerized interfaces to medical information.

Background

Motivations for LEAF

LEAF aims to help bridge the communication gap between patients and their doctors. Patients are being asked to take a more active role in their health care. Patients must therefore be prepared for the increasing amount of information that they will receive describing their options and possible courses of action. This preparation includes a better understanding of medical terminology. Although the resources available to health care professionals may be limited, computers can help by giving people access to medical information outside the doctor's office and by adapting the presentation of information to suit the individual's interests or expertise.

To adapt the presentation of medical (or any type of) information to each user, a system must have information about the user and must be able to reason about which parts of its knowledge apply to a given situation. Ideally, a system will monitor each patient's interaction with the system and build a profile (called a *user model*) of the patient. As the system collects this information, it can use it (as well as the current state of the task) to modify the questions it asks and to customize the educational materials it presents. For example, it may choose to elaborate the core definition of a concept with specific information relevant to a health condition that the patient has. This customization is facilitated by organizing the knowledge base into small units of text that are indexed by facts about the patient or goals the patient might have. LEAF's design provides this type of flexibility.

In designing LEAF, we considered previous methods for collecting medical histories from patients and presenting educational materials to them. The results of our investigation supported the need for a system such as LEAF and motivated some additional design constraints that have been incorporated into the prototype. In the remainder of this section, we consider some of the lessons learned from prior work. We then discuss the architecture that has been developed.

Traditional Medical History Forms

For reasons of generality, typical medical history forms contain questions and sections that might be irrelevant to any particular patient. They can also be confusing if they are worded awkwardly or contain medical terminology that is unfamiliar to patients. At the start of this project, we evaluated a number of such forms. We found questions about the health of the patient's spouse, which are irrelevant if the patient is single. We found sections that were intended "for

*It can be reached by pointing a JAVA-capable network browser to <http://tigger.cs.uwm.edu/~alp/LEAFV1.1/leaf.html>.

administrative use only." We found potentially ambiguous questions, such as one that asked patients "To what extent are you experiencing difficulty in the area of:" and presented "apathy, lack of interest in things" as an area. Our evaluator found this confusing, because he felt that he could either respond "no difficulty" because he never feels apathetic, or he could respond "no difficulty" because he found it easy to be apathetic. (This confusion is especially easy for non-native speakers of English.) Finally, none of the medical forms that we examined provided explanations of the diseases or medical terms used, relying on the strategy that if patient's have not heard of a disease then they have not had it. However, this is not a good assumption for non-native speakers. Moreover, even native speakers may confuse terms that sound alike, such as "constipation" and "obstipation."

Computerized Medical Forms

Computer programs for collecting patients' medical histories offer the possibility of suppressing parts of the form that are unnecessary for individual patients and including information that will help them respond to the questions more accurately. Researchers and clinicians have been experimenting with computerized medical forms since the 1960s.³⁻⁷ This and subsequent work confirms that medical interviewing by computer can be as reliable as the traditional medical form and that patients enjoy using it.

For example, HealthQuiz is a computer program, developed by the Clinical Practice Enhancement Project (CPEP), that gathers health-risk data from patients and provides feedback to both the patient and physician concerning guideline-based suggestions.^{8,9} These suggestions include possible immunizations or diagnostic tests. In experiments with HealthQuiz, 89 percent of patients found the computer enjoyable to use and 85 percent considered HealthQuiz important to their care. Previous studies by CPEP examined the reliability of different methods for gathering various types of health information from patients. They found that consistent preventive care information can be obtained when patients use a computer. In addition, patients were *more* likely to be candid about risky health behaviors when communicating with a computer than with a human interviewer. As in LEAF, HealthQuiz filters questions on the basis of responses to earlier ones. Unlike LEAF, however, it does not support questions from patients about the terminology it uses.

Customized Medical Explanations

Another potential benefit of computerization of medical history forms and educational materials is the

possibility of customizing the content of these materials to individual patients. Several studies have shown that customized information is more effective than generic information. For example, in a study targeting smoking cessation, 30.7 percent of patients who received tailored health letters reported quitting after six months versus 7.1 percent in a control group (who received a generic health letter or no information).¹⁰ In a similar study targeting nutrition, total fat intake decreased 23 percent in the tailored group but only 9 percent in the non-tailored group.¹¹ The primary difficulty is in automating the customization process. Here we discuss three systems that have shown that automatic customization is possible and effective.

Migraineur is a system that provides customized information to patients suffering from chronic or acute migraine headaches.¹² It consists of an interactive history-taking module and an intelligent explanation module. The history-taking module collects information from patients prior to each visit, builds a user model, and summarizes the patient's status for their physicians. The intelligent explanation module produces an interactive information sheet containing explanations in everyday language that are tailored to individual patients, and responds intelligently to follow-up questions about topics covered in the information sheet. This information sheet contains generic text that is presented to all patients, customized text based on an analysis of the user model, and text that, when selected, will show patients questions they might ask about the words in a specific context. The information presented to each patient depends on the discourse history. As a result, the system can avoid repeating the same response, even if the patient asks the same question more than once.

The most important difference between Migraineur and LEAF is that LEAF will provide customized information while its model of the patient is incomplete, whereas Migraineur can only do so after knowledge acquisition is finished. This requires motivated users who are willing to provide a history prior to being helped. Also, Migraineur's knowledge acquisition component does not allow users to ask for medical definitions or for help with the form while they are still working on it. Migraineur's ability to track the discourse history is unique. (This ability is part of the design for LEAF, but it is not part of the current prototype.)

HealthDoc uses the patient's medical information, physical characteristics, and medical diagnosis to create a document with medical advice tailored to the user.¹³ It differs from LEAF in that it is intended to be used by health care professionals (rather than patients) and, like Migraineur, it does not integrate the

task of acquiring knowledge about the patient with the task of generating educational materials.

The work of Jimison et al.,¹⁴ like Migraineur and HealthDoc, uses a model of the patient to generate customized educational materials. These materials explain therapy decisions in terms of the patient's own condition, medical history, and lifestyle (sedentary or active). The system includes or omits therapy explanations depending on the contents of the patient model. It does not support questions about the explanations it provides.

Systems to Be Used at Home

One goal of LEAF is to prepare patients for subsequent discussions with a health care professional. Ideally such a system should be usable by people over the Internet, without any outside assistance. The feasibility of this idea is demonstrated by the Comprehensive Health Enhancement Support System (CHESS), a system that people can access from their home.^{15,16} CHESS provides access to a variety of services, including a compilation of answers to commonly asked questions; a dictionary of health-related terms; a database of articles, brochures, and pamphlets; a tutorial to show users what health and social services are available to them; a database of real-life accounts of people coping with health crises; facilities for anonymously contacting health care experts (*Ask an Expert*) or members of an appropriate support group (*Discussion Group*); and programs to help users assess their lifestyle, think through hard decisions, and develop a plan of action to implement their decisions.

The primary difference between the design of LEAF and the design of CHESS is that, in CHESS, each component is separate from the rest, so that, for example, a person who is using the assessment tool could not look up a word in the dictionary without leaving the assessment program. Also, CHESS does not build any model of its users or their interaction with the system, providing the same information to everyone. Moreover, tools that collect information about the user (e.g., to perform a risk assessment) cannot make this information available to other components. As a result, users of CHESS tend to confine themselves to those components that are personalized and dynamic (*Ask an Expert*, *Discussion Group*) but not wholly automated.

Design Objectives

LEAF combines three tasks: collecting medical information about patients, providing information about the vocabulary and use of the form, and directing patients to additional educational materials that might

be of interest. We anticipate that such a system would be used by a person who is waiting to see a physician or who is at home considering a visit to the doctor. Such a person will not always know what they do not know or what they will need to know to understand the choices that a physician might ask them to make.

LEAF has been designed to minimize misunderstandings and to help patients reach the most relevant information efficiently. The design supports these goals by allowing separate tasks to share information about what the patient is doing and what facts the patient has already told the system. Wherever possible, the system suppresses irrelevant questions and information. It also allows users to switch between tasks easily without causing the system to "forget" what it has been told. For example, while working on the form, the patient has access to definitions of medical terminology, links to online resources, and instructions for filling out the form. Moreover, the information provided by these services is tailored according to which parts of the form the patient has completed or is currently working on.

System Description

The Implementation Platform

This section describes a prototype implementation of the Layman Education and Activation Form (LEAF). This implementation achieves the design that we have discussed. In addition, the implementation has been developed to maximize its portability—we want LEAF to be usable from a variety of locations using a variety of computer hardware components. The solution that we have selected is to build a system that could be run using free and widely available programs for accessing the Internet, such as Netscape's Navigator or Microsoft's Internet Explorer. Such a program can be used to access files at a remote location on the Internet or used on a stand-alone machine that is running another program called a "server."

For reasons of network security, applications that run from network browsing programs cannot write files on the local machine. Moreover, for portability reasons, we do not want files to be written on the remote machine either. LEAF addressed both of these concerns by generating new screens dynamically and communicating this information to the interface program directly.

The implementation of LEAF is composed of a number of programs written in JAVA, C, and the hypertext markup language (HTML). JAVA is an object-oriented programming language that is well suited to building user interfaces because of its portability and the avail-

ability of ready-made code for implementing forms. The core medical history form presented by LEAF is a JAVA program that can be run by any "JAVA-aware" browser. HTML is a language for specifying the format of a document and for creating links between documents; LEAF uses it in the presentation of customized medical definitions and context-sensitive help. C is a general-purpose programming language; it is used to write CGI (common gateway interface) scripts that can be executed by the browser software. LEAF uses these programs to generate new HTML documents dynamically, on the basis of the user's interaction with the system.

In the remainder of this section, we consider LEAF's overall architecture and the implementation of the modules that LEAF comprises.

Architecture

The architecture of LEAF has been designed to integrate three tasks: the collection of information about patients, the explanation of how to use the system, and the selection of educational materials that are most likely to address patients' concerns. Each task is managed by independent modules that share underlying knowledge sources. In addition, because the program is run from a browser, the architecture has been refined to include a separate module that controls the look and feel of LEAF's interface while providing access to the modules that control its content.

Figure 2 shows the information flow between different LEAF modules. The user communicates with LEAF through the Interface module. The Context-Sensitive Help module provides information that explains use of the form, such as how to navigate between screens. The Knowledge Acquisition module controls the medical history form and updates the User Model with

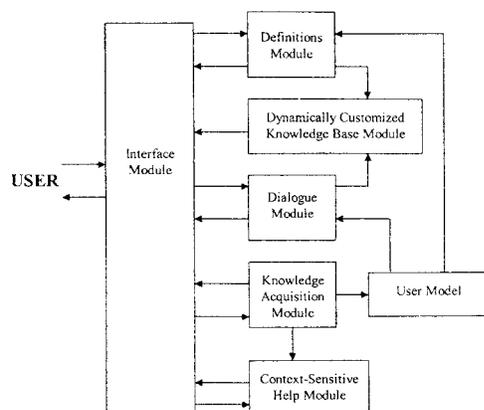


Figure 2 General architecture of the LEAF system.

the information provided by the patient. It also uses this model to customize the form. The Dialogue module generates a list of suggested topics that are likely to interest the patient, given the current state of the user model. The Definitions module generates a list of customized medical-term definitions that have been constructed within the Knowledge Base module, given knowledge passed from the user model.

Interacting with LEAF

The interface to LEAF consists of a window with six buttons above it, as shown earlier in Figure 1. Three buttons help the user navigate the medical history form: <Go to>, <Previous>, and <Next>. The rest of the buttons: <Definitions>, <Dialogue>, and <Help>, are used to access other modules. All output produced by LEAF is displayed using this interface, so the patient always has access to all the modules. An explanation of the functionality provided by each button follows:

- <Go to> displays a list of pages from the medical history form. This list changes as the user provides more information. LEAF will display the page selected by the user. (One section of the medical history form is displayed at a time.)
- <Previous> shows the previous page of the medical form. If the user is on the first page of the form, pressing this button will show them the last page of the form.
- <Next> shows the next page of the medical form. If the user is on the last page of the form, pressing this button will show them the first page.
- <Definitions> provides access to the Definitions module (described later). When a patient selects this action, LEAF shows a list of medical terms that it can define. Selecting any of the medical terms from the list causes LEAF to display a window with a definition of the medical term in hypertext. Patients can navigate the definitions by clicking the buttons <Back> and <Forward> in their Web browser.
- <Dialogue> displays a list of relevant topics for the patient. Figure 3 shows the topics that would be suggested for a female patient who has indicated that she has one of the risks of breast cancer and has a history of alcoholism and diabetes.
- <Help> shows context-sensitive help on how to use LEAF.

Building a Model of the Patient

The Knowledge Acquisition module collects medical information about the patient and stores it in the user model. The mechanism used for collecting this infor-

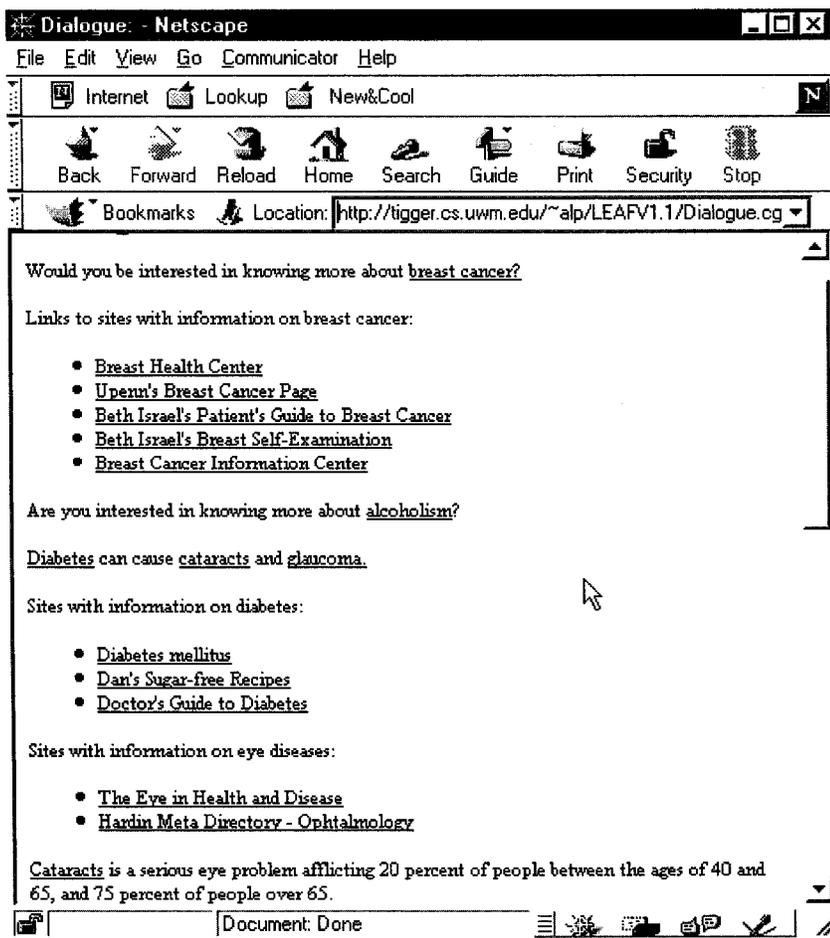


Figure 3 A Dialogue screen.

mation is a medical history form consisting of three components: a generic form with questions for all patients, a form with questions for women, and a form with questions for men over 40 years of age. The generic form consists of questions on demographics, the patient's previous illnesses, and previous illnesses of the patient's blood relatives. The customized form for women includes a questionnaire about risks for breast cancer. The customized form for men includes a questionnaire about benign prostatic hyperthrophy (BPH).

Users of LEAF can fill out the medical form in any order. As they do so, the information they provide is used immediately to customize the form. Thus, questions and sections may appear (or disappear) as soon as an answer is given. For example, in the absence of any information from the patient, LEAF suppresses questions about breast cancer; however, as soon as a patient indicates that she is female, the form is extended to include a questionnaire on the risk factors for breast cancer. Similarly, LEAF does not ask any questions about breast-feeding unless the patient has indicated that she has children. If she does, then new

questions are added to the risk-factor form immediately. The information provided by other components (such as Dialogue and Definitions) will also improve immediately, as they have access to any information that has been added to LEAF's model of the patient.

While LEAF is running, information about the patient is stored (within the program itself) as a user model.[†] User models capture the system's knowledge about the user.¹⁷ This information may be static (based on a stereotype) or dynamic (based on the user's interaction with the system). LEAF's user model is constructed dynamically. At present it takes into account only the information content of patients' answers to the medical history form. This includes demographic information like age and sex, reported illnesses and immunizations, and illnesses of family members. Mirroring the form itself, it also includes specialized

[†]For reasons of privacy, all information about the user is discarded as soon as the program terminates; however, LEAF could be modified to save this information.

structures for representing the risk factors of female users for breast cancer and the BPH symptoms of men. Other factors that might be added are the sequence of actions of the user and the user's apparent level of expertise.¹⁸

Generating Customized Information

Customized educational materials are provided to the patient in the form of medical definitions and suggested questions and topics. The list of suggestions is presented by the Dialogue module in HTML format, with links to definitions or other resources (see Figure 3). For example, if a female user reports at least one risk factor for breast cancer, LEAF will ask "Do you want to know more about breast cancer?" and provide links to the definition of breast cancer and to sites that provide more information about it. Also, when a suggestion references multiple definitions, such as how diabetes can cause cataracts and glaucoma, LEAF provides links to information about these topics as well. The links are all active from LEAF, so users connected to a network can access these sites by clicking on them.

In future work, the Dialogue module will be extended to support two-way English-language dialogue between the user and the system, as in our B2 project.^{19,20} The system will ask questions about concerns that the patient might have (beyond those indicated by the medical form) and will suggest assessment exercises (such as risk assessment) that might help clarify the patient's understanding. It is anticipated that the tool will also link patients to programs that perform these exercises.

Customized definitions are generated when the patient selects Definitions from the main menu. The definitions that are generated take into account the information in the user model. For example, Figure 4 shows two possible definitions of estrogen that a patient might see. This particular customized definition would be given to a female patient who has indicated that she has at least one of the risk factors of breast cancer. Figure 5 shows three possible definitions of heart disease, illustrating how the current context of the interaction can also affect the selection of information. For example, the second definition would be given if the patient were involved in learning about estrogen. In general, definitions may contain text, graphic images, audio, or video images, whichever are most appropriate to the concept being defined.

The content of definitions is provided by the Dynamically Customized Knowledge Base. The knowledge base is organized as a semantic network. A semantic network represents concepts in terms of objects and

The uncustomized definition:
Estrogen: A hormone that can prevent or slow down menopausal miseries, heart disease, osteoporosis, mental deterioration, colon cancer, and aging skin.

A customized definition:
Estrogen: A hormone that can prevent or slow down menopausal miseries, heart disease, osteoporosis, mental deterioration, colon cancer, and aging skin.

Estrogen might increase the risk of breast cancer

Figure 4 Definitions of estrogen that depend on the user model.

The empty-context definition:
Heart Disease: Any of the diseases affecting the heart.

A definition within the context of estrogen:

Heart Disease: Several studies show that there is a link between estrogen and heart disease. An increase in estrogen decreases the probability of heart disease by 50% in postmenopausal women that receive estrogen alone in their hormone replacement therapy.

A definition within the context of alcohol:
Heart Disease: Some studies suggest that moderate consumption of alcohol reduces the risk of heart disease in postmenopausal women and men over 40, where "moderate" means no more than two drinks a day for men and one for women. A drink is defined as 12 ounces of beer, 5 ounces of wine, or an ounce and a half of 80-proof liquor.

Figure 5 Definitions of heart disease that depend on the context.

relationships among them.²¹ Each concept is represented as a node in the network.

Figure 6 shows a portion of the information in the nodes of the semantic network and the relationship between these nodes. Links connect nodes that represent generic information to nodes that represent context-sensitive information. In the current implementation, the nodes of this semantic network consist of HTML files and CGI scripts. Each of these nodes, which can be referenced many times by other nodes, contain general health information, a medical term definition, or a list of questions. Below is a list of the current types of relationships (links) between nodes:

- *Definition:* It links a medical term or other term to its definition, e.g., "Estrogen is a hormone."
- *Definition Answer:* It links a question asking for a definition to the answer to that question, e.g., "What is estrogen? Estrogen is a hormone."
- *Prevention Answer:* It links a question asking how to prevent an illness to its answer, e.g., "How does

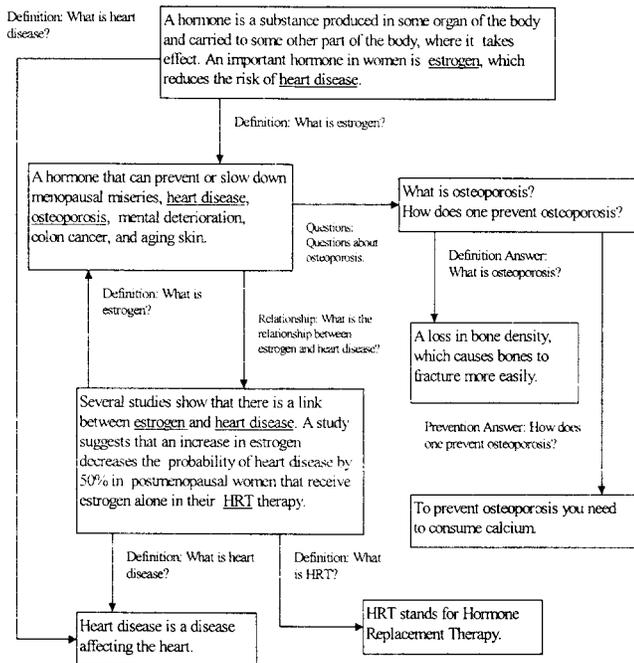


Figure 6 A semantic network.

one prevent osteoporosis? Consume calcium to prevent osteoporosis."

- **Questions:** It links a medical term to questions about it, e.g., "Questions about osteoporosis are: 1. What is osteoporosis? 2. How does one prevent osteoporosis?"
- **Relationship:** It shows the relationship between two things, e.g., "Estrogen can reduce the risk of heart disease."

In the implementation, this information is organized as a set of files that can be revised or extended:

- **HTML definition files** contain core definitions of medical terminology.
- **CGI definition scripts** build customized definitions of medical terminology.
- **Context-sensitive files** contain definitions of medical terminology as they relate to other definitions in context.
- **Files with list of questions** that LEAF can suggest to a patient within a particular context.
- **Files with answers to the questions** that LEAF suggests to patients.
- **Files with treatments** that are associated with particular medical conditions.

Preliminary Evaluations

Based on the design discussed above, we have implemented a prototype using JAVA, C, and HTML. (We have also implemented an all-JAVA version, to investigate how LEAF might be used from a machine not connected to a network.) As mentioned earlier, the current prototype provides much of the intended functionality of LEAF but contains limited amounts of content information. (This information comes from published sources.^{22,23}) With this prototype we have been evaluating the design of LEAF according to two sets of criteria: first, its usability as a system (e.g., its speed and portability); second, its perceived usefulness by patients. Evaluations, which are performed online by users after they access LEAF, provide measures of user satisfaction and directions for future enhancements.

An Evaluation of System Performance

The prototypes have been tested using a variety of hardware (stand-alone, connected to a phone line, and connected to the computer network via Ethernet) and software (Mac OS, Microsoft Windows 95/NT, Linux) configurations. The speed of LEAF depends only on the ability of the user's machine to load and run JAVA; once loaded, interaction delays are negligible and do not depend on the amount of knowledge in LEAF's knowledge base or user model. In practice, the only difficulties that we have discovered involve users who had difficulty in the configuration of their browser software (or fire-wall restrictions) that prevent them from running JAVA programs or CGI scripts. The all-JAVA versions of our program can address these issues, but at some sacrifice in speed. Overall, the tool is clearly portable and loads and runs quickly. There have been no complaints from users regarding system performance.

An Evaluation of User Satisfaction

The ultimate usefulness of LEAF will depend on how well it meets the needs and expectations of real medical patients. However, before significant time and money are spent to collect and validate large quantities of medical information, it is important to verify whether this investment is warranted. Toward this end, as we have been adding more content to LEAF, we have been conducting an ongoing assessment with the cooperation of visitors to the LEAF Web site (including students who have accessed the site as part of a class exercise.) We have also been conducting an evaluation of the questionnaire itself.

The questionnaire (part of which can be seen in Figure 7) asks users to comment on how often they used the

different services provided by LEAF and how useful and understandable they found the information that was provided. The questionnaire also asks users to report their satisfaction with the system as a whole. The surveys are completely anonymous and do not include any information from the medical history form itself. The only demographic information that is requested is the user's gender, because, although LEAF contains some gender-neutral information (such as information about eye problems), it contains proportionately more information on women's health issues.

The results of this survey indicate that users responded favorably to LEAF's design. Overall, of 35 completed user evaluations, 87 percent of users prefer an online medical questionnaire to a paper one; they cite the ease of filling out the form and the links to medical definitions and Internet sites among their favorite aspects of LEAF. Users also like having medical information tailored to their interests: 71 percent found the definitions somewhat or very helpful and 58 percent thought the dialogue sections helpful. Users' chief complaint, in fact, was that they wanted

LEAF to provide *more* customized information in definitions. Users even suggested adding the customized link information provided by the Dialogue component within the Definitions themselves.

Discussion

We have considered the design and implementation of Layman Education and Activation Form (LEAF). When we examined existing medical forms, we found that computerization provided an opportunity for flexibility and customization not provided by traditional methods. Our work has addressed the problem of developing an architecture that would allow patients to move freely between tasks in such a way that the information that they provide, *whenever* they provide it, can be used to improve the amount of customization. The design, being browser-based, is also highly portable. We have also explored the incremental presentation of definitions, where we allow users to specify when they have received enough information.

LEAF allows users to interleave the tasks of filling in

LEAF Evaluation Sheet

The purpose of this evaluation sheet is to help us learn what is good and bad about LEAF.

- Are you male or female?
 - Male
 - Female
- How many times did you access Definitions while you were filling out the form?
- Did you understand the definitions that you read?
 - Yes
 - No
- What do you think of the definitions?
 - Too general
 - Just about right
 - Too specific
- How many times did you follow the link from one definition to another one?
- How many times did you follow the link from one definition to another one?

Document: Done

Figure 7 The LEAF evaluation form.

a medical form with activities that will help them understand medical terminology. Our studies with potential users have shown that having access to medical information while they are working on the form was helpful. One difficulty that we anticipate is adding all the vocabulary and resources that patients will want to access. Currently, the addition of new information requires the assistance of someone with knowledge of computer programming. Future developments will focus on providing tools and specification languages allowing users to create medical content that can be included in future versions of the prototype.

References ■

1. McRoy SW. Misunderstanding and the negotiation of meaning. *Knowledge-based Systems*. 1995;8(2-3):126-34.
2. Schegloff E. Repair after next turn: the last structurally provided defense of intersubjectivity in conversation. *Am J Sociol*. 1992;97(5):129-35.
3. Slack WV, Hicks GP, Reed ER, Van Cura LJ. A computer-based medical history system. *N Engl J Med*. 1966;247:194-98.
4. Slack WV, Van Cura LJ. Patient reaction to computer-based medical interviewing. *Comput Biomed Res*. 1968;1:527-31.
5. Chodoff P, Helrich M. Construction of an automated system for the collection and processing of preoperative data. *Anesth Analg*. 1969;48:870-6.
6. Collen MF, Cutler JL, Siegelau AB, Cella RL. Reliability of self-administered medical questionnaire. *Arch Intern Med*. 1969;123:664-81.
7. Rockart JF, McLean ER, Hershberg PI, Bell GO. An automated medical history system. *Arch Intern Med*. 1973;132:348-58.
8. Hayward RSA, Ford DE, Summerell D, Roizen M, Steinberg E. Randomized clinical trial of a patient-administered computerized preventive care system to implement adult practice guidelines. *Clin Res*. 1992;40:608A.
9. Hayward RSA, Smittner JP, Meyer P, Ford DE, Roizen M, Steinberg E. [Computer versus interview administered preventive care questionnaire: does survey medium affect patient response reliability?] Unpublished manuscript, 1966. Available at http://hirv.mcmaster.ca/cpep/projects/pv/fii_92.htm.
10. Strecher VJ, Kreuter M, Den Beur D, Kobrin S, Hospers HJ, Skinner CS. The effects of computer-tailored smoking cessation messages in family practice settings. *J Fam Pract*. 1994;39(3):262-8.
11. Campbell MK, Devellis BM, Strecher VJ, Ammerman AS, Devellis RF, Sandler RS. Improving dietary behavior: the effectiveness of tailored messages in primary care settings. *Am J Public Health*. 1994;84(5):783-7.
12. Buchanan BG, Moore JD, Forsythe DE, Carenini G, Ohlsson S, Banks G. An intelligent interactive system for delivering individualized information to patients. *Artif Intell Med*. 1995;7(2):117-54.
13. DiMarco C, Hirst G, Wanner L, Wilkinson J. HealthDoc: customizing patient information and health education by medical condition and personal characteristics. Paper presented at: Workshop on Artificial Intelligence in Patient Education; August 1995, Glasgow, Scotland.
14. Jimison HB, Fagan LM, Shachter RD, Shortliffe EH. Patient-specific explanation in models of chronic disease. *Artif Intell Med*. 1992;4:191-205.
15. Gustafson DH, Bosworth K, Hawkins RP, Boberg EW, Bricker E. CHESS: a computer-based system for providing information, referrals, decision support and social support to people facing medical and other health-related crises. *Proc 16th Annu Symp Comput Appl Med Care*. 1992:161-5.
16. Gustafson DH, Hawkins RP, Boberg EW, Bricker E, Pingree S, Chan, C. The use and impact of a computer-based support system for people living with AIDS and HIV infection. *J Am Med Inform Assoc*. 1994;1:604-8.
17. Kass R, Finin T. Modeling the user in natural language systems. *Computational Linguistics*. 1988;14(3):5-22.
18. Cawsey A. *Explanation and Interaction: The Computer Generation of Explanatory Dialogues*. Cambridge, Mass: The MIT Press, 1992.
19. McRoy S, Haller S, Liu-Perez A, Helwig J. B2: a tutoring shell for Bayesian networks that supports natural language interaction. In: Working Notes, 1996 AAAI Spring Symposium on Artificial Intelligence and Medicine, Stanford, Calif: AAAI, 1996:114-8.
20. McRoy S, Haller S, Ali S. Uniform Knowledge Representation for Language Processing in the B2 System. *J Nat Language Eng*. 1997;3(2/3):123-45.
21. Quillian R. Semantic memory. In: Minsky M (ed). *Semantic Information Processing*. Cambridge, Mass.: The MIT Press, 1968.
22. Simons A, Hasselbring B, Castleman M. *Before You Call the Doctor: Safe, Effective Self-Care for Over 300 Common Medical Problems*. Fawcett Columbine, 1993.
23. Wallis C. The Estrogen Dilemma. *Time Magazine*. June 26, 1995.