The design of effective health-related Web sites is becoming increasingly important as the Internet continues to grow as a delivery medium for health information. As these sites are developed, the importance of a user-centered approach to design is recognized by informaticians:

Groups producing information materials must start with needs defined by patients, give treatment information based on rigorous systematic reviews, and involve multidisciplinary teams (including patients) in developing and testing the material.¹

In this paper, we present a user-centered model for this type of Web site design. The model includes techniques for needs assessment, goal/task analysis, user interface design, and rapid prototyping. Each of these techniques can be used to produce effective solutions across multiple content arenas.

To show how these techniques may be used, we detail their application in the design of a family health history Web site, Health Heritage (http://www.HealthHeritage.net). Funded by the Robert Wood Johnson Foundation, the purposes of this Web site are:

- To assist patients in recording and maintaining their family health histories in a secure, confidential manner, and
- To support primary care physicians, through analysis of family health histories, identification of potential risks, and provision of preventive or treatment recommendations.
Background

We set out to develop the Health Heritage site for several reasons. First, collection of family health history has been advocated for targeting individuals at risk for specific diseases and for identifying patterns of disease and other health conditions in families. However, primary care physicians (PCPs) do not always collect complete family health histories or use them in any systematic way, because of limited time, inefficient collection methods, and related factors. Compounding this situation is the fact that patients often do not have complete health history information for their families.

A second motivating factor was the emerging importance of genetic medicine, with the sequencing of all human genes by the Human Genome Project. It is predicted that genetic testing and counseling will be included in the scope of practice for PCPs, although physicians may have had little training in genetics and may not appreciate its relevance to their practice.

A third influence was the potential of computer and Internet technologies to meet pressing needs for health care, continuing medical education, and consumer health information. These new technologies have been used for decision support, patient management and, most recently, patient self-management and self-care. Computers offer the potential to simplify the collection and interpretation of pedigrees and referral guidelines. Coupled with the Internet, computers make possible sophisticated continuing education, including the provision of “just-in-time” support (during the course of patient care) for physicians.

We undertook the development of the Health Heritage Web site to address some of these needs. In the sections that follow, we describe our methods and how we implemented them for the design of the Health Heritage Web site.

A Model for Web Site Design

Figure 1 shows a modified framework for our user-centered design model. Each component is described in the paragraphs that follow.

Assess, Analyze, and Select Needs

How can developers of new tools and resources ensure that their creative, resource-rich, visually appealing, and easy-to-use products are actually useful to the intended populations? They can do so by...
basing their design on a thorough needs assessment, an inquiry process supported by numerous design methodologies. Needs assessment can be used to explore what is currently occurring and how individuals feel about it, and it can identify potential solutions.

There are a variety of techniques of collecting needs information, including qualitative and quantitative approaches. (Qualitative approaches include examining existing materials and sites, conducting interviews and focus groups, and observing practice, whereas quantitative approaches include surveys and rating scales, among others.) These methodologies are frequently used in tandem. When it is not clear what needs exist and how they might be measured, however, qualitative methods are most useful.

For Health Heritage, the stakeholders included our end users—PCPs and patients—as well as medical specialists, geneticists, genetics counselors, and informaticians. Our methods included document review, interviews, focus groups, surveys and observation. All interview, focus group, and observation sessions were audiotaped and transcribed for later analysis. Our data sources are described briefly in Table 1.

As needs data are being collected, needs analysis begins. For all qualitative data, we take a naturalistic approach, using content analysis to identify themes expressed by respondents and noted in document reviews and observations. As the themes emerge, we test them as other needs data are collected and analyzed. Those that are confirmed are then used to categorize needs data in a conceptually clustered matrix. This makes it possible to identify the relationships among the themes and make comparisons between them for different respondent groups. It is

Table 1

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<tr>
<th>Needs Assessment Data Sources: Health Heritage</th>
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<tr>
<td><strong>Document review:</strong></td>
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<tr>
<td>- Existing family health history instruments were used to craft a master health history collection instrument.</td>
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<tr>
<td>- The master instrument was evaluated by 18 primary care physicians (PCPs) and medical specialists, who used it to record their own health histories and the history obtained from a case study. Strengths and weaknesses were identified.</td>
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<td><strong>PCP interviews and focus groups:</strong></td>
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<td>- Two initial interviews were conducted with PCPs, to learn about current practices with health history collection, what information should be collected, and what issues are important to PCPs.</td>
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<td>- Two PCP focus groups, led by a trained moderator, focused on the meaning of health history, how it was collected and interpreted, and what kinds of support would help PCPs use family health histories in their practice.</td>
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<tr>
<td><strong>Patient interviews and focus groups:</strong></td>
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<td>- Six patients from a primary care practice were interviewed over the phone to learn their understandings of and experiences with family health histories. They were also asked to relate their feelings about Internet security.</td>
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<td>- A trained facilitator led two patient focus groups. Participants drew their family trees and discussed difficulties in doing so. They evaluated a health history survey used in a family practice and reflected on their own doctors’ collection of health history. Finally, they indicated what they would like to have in a health history Web site and their willingness to use such a site.</td>
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<td><strong>Patient computer-use survey:</strong></td>
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<td>- A computer-use survey was used in two medical practices. One was a family practice that served a population of patients of mixed socioeconomic status (n = 44) and the other was a gynecology practice serving a middle-class, white, female population (n = 91).</td>
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<td>- We solicited information about access to computers, e-mail, and the Internet and about level of comfort in use of a computer.</td>
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<td><strong>Interviews with other stakeholders:</strong></td>
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<td>- Throughout the needs assessment, the design team conducted a series of interviews with members of other stakeholder groups, including genetics specialists in oncology and pediatrics, medical specialists in neurology (two) and cardiology, medical informaticians, and the project’s principal investigators.</td>
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<td>- These persons helped us identify other needs that were not immediately apparent to the PCPs and patients and lent support to some of the perspectives voiced by PCPs and patients.</td>
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<td><strong>Observations:</strong></td>
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<td>- We observed the “gold standard” in operation—family health history collected by skilled genetic counselors via audiotaped sessions.</td>
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<td>- To better understand how specialists use family health history information, we observed interactions between patients, genetic counselors, and an oncologist during three counseling sessions at a cancer genetics clinic.</td>
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<td>- As a result of these observations, we were able to identify specific strategies used to solicit health information that patients may not immediately recall.</td>
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also possible to quantify the frequency with which various themes are indicated in this corpus of data. These analysis techniques are standard for qualitative data\textsuperscript{21,23,24} and lend themselves well to needs analysis.

Data from surveys and other quantitative measures are analyzed, using conventional descriptive statistics. These outcomes add meaning to the qualitative findings, providing indications of degree and illuminating aspects of the situation that would not otherwise be apparent.

For the Health Heritage project, the design team leader used the themes confirmed in the data to code each piece; a tag indicated the respondent group (PCP or patient population, medical specialists, informaticians, etc.) supplying each piece of information. Each theme was further broken down into sub-themes, as shown in Table 2.

The needs identified in both types of analysis are further examined, to select and prioritize those to be addressed. Considerations here are organizational goals, the consequences of needs not being met, and the available time, budget, and expertise for project. It is also important to identify the barriers users may face and incentives they may associate with use of the future product; these will be important factors during design of the product.

Because we were developing Health Heritage in response to a funded grant proposal, certain parameters in this project design were already specified for us. We had already determined that we would be developing a Web-based product to collect and eval-

\begin{table}[ht]
\centering
\caption{Needs Assessment Themes and Sub-themes: Health Heritage}
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\hline
Four major themes identified through the qualitative analysis process: \\
- Goals/assumptions for the Health Heritage project \\
- Collection of family health history \\
- Other functions of the Health Heritage tool \\
- Policy/confidentiality/security/liability \\
\hline
Sub-themes identified for the theme "Goals/assumptions for the Health Heritage project": \\
- Definition of stakeholders \\
- Characteristics of current primary care physician (PCP) practice \\
- Implications of the Health Heritage tool for PCPs \\
- Implications of the Health Heritage tool for patients \\
- What PCPs want \\
- What patients want \\
- What specialists want \\
- Barriers to collection of family health histories \\
\hline
Example of needs analysis data catalog, in matrix format, for the sub-theme "What PCPs want": \\
\begin{tabular}{ll}
\textbf{Need} & \textbf{Source} \\
PCPs want to want to be alerted to & PCP Focus Group 2/9/99 \\
patients’ risks. When a risk area is & \\
unfamiliar, PCPs want assistance with & \\
interpreting the & \\
risk and providing care & \\
PCPs want risk information and & PCP interview 1/6/99 \\
recommendations based on & PCP Focus Group 2/9/99 \\
quantitative epidemiology & \\
\end{tabular}
\hline
Example of thematic summary\textsuperscript{*} for the sub-theme "What PCPs want": \\
- Evidence-based risk information and recommendations; efficient delivery. \\
- Risks and recommendations for each patient, based on quantitative epidemiology; accurate family histories to drive the risk prediction algorithm; possible replacement of health risk assessment form (some patients do not fully respond, dislike having to update). \\
- Information on diseases and conditions that PCPs know little about. \\
- Increased efficiency and quality of care without increase in PCP time, unless time is billable: "We don’t have a lot of time like researchers do. Our days are full." \\
- Some see review of the tool output as similar to a review of laboratory results. If something significant is found in the risk assessment, they will bring the patient in for an office visit. However, others may not review the risk assessment and recommendations unless there is an office visit. \\
\textsuperscript{*}Data for each thematic need area were systematically reviewed and summarized. A sample summary is shown here.
\end{tabular}
\end{table}
Validating assumptions about users and environments:
We wanted to design a tool that would serve the medical practice of tomorrow but would not completely lose sight of the capabilities of today. An early concern was the prevalence of patient computer access, so we paid special attention to the results of our computer use survey. We found that a surprising number of patients had access to computers (80% at home and 59% at work) and the Internet (67% at home and 50% at work), felt comfortable using this technology (75% felt either “extremely” or “somewhat” comfortable), and had e-mail accounts (71%). As a result of the positive response, we felt comfortable retaining the assumptions for a Web-based tool.

A discrepancy between initial project goals and identified needs:
While attempting to design for the medical practice of tomorrow, we found that most PCPs voiced needs from the practice of today. Primary care physicians wanted printable output from Health Heritage that they could include in a patient’s chart; they were less interested in online displays of patient pedigrees and risk data, since most did not have access to computers in their examination rooms. So the project team struck a compromise, addressing the need for printable output while still endeavoring to explore the use of interactive computer-based displays to present information in interactive ways that might enable new understandings of the data presented.

Table 3

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<th>Validation of Assumptions and Discrepancy Identification: Health Heritage</th>
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Goals and component tasks are then analyzed by breaking down the goals into subordinate parts. The goal or task analysis stage is sometimes referred to as an “information processing analysis.” To achieve this goal, what does the user need to know or be able to do—what tasks need to be undertaken? For each task, what are the subordinate components and individual actions? The result is frequently a flow diagram detailing the goal/task analysis (Figure 2). The goal statement and task analysis form the basis for the Web site’s functional requirements (Table 5), which are lists of required characteristics.

### Design and Develop Solutions

Once the goal and related tasks are fully understood, the project team can begin the Web site design. We brainstorm about the experiences we want to create for the users as they go about achieving the goals we have set, keeping in mind the barriers they face and any incentives on which we may be able to capitalize. We apply what we know from learning and psychological theory in this process. As we begin to visualize the Web site, we start to adapt the flow diagrams (produced during the previous task analysis) to develop a blueprint for the Web site.

For each page in the projected Web site, we create storyboards that suggest the content and layout of the page and the functionality and navigation controls to be provided. The graphic design is purposely ignored until the contents and functionality are finalized. Holding to the principle that “form follows function,” the look and feel of a Web site are developed after its functionality, to better support it.

As we create storyboards, we reference guidelines for good user interface design. The guidelines we use address content design and the design of navigation and user input. (Guidelines for design of the “look and feel” of the site are considered later.) We have

### Table 4

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<th>Additional Project Goals Identified: Health Heritage</th>
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<td>Patients and physicians will be able to learn more about family health history, disease and epidemiology, and health care as part of the history collection and evaluation process.</td>
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<tr>
<td>Patients will be better prepared to communicate with their physicians during office visits.</td>
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<tr>
<td>Patients will be drawn back to the Web site to update their health histories, in part because of special features such as printable family trees and automatic e-mail birthday reminders.</td>
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developed our set as the result of many years of practice, which includes design, development, and evaluation of multimedia products; evaluation of successful educational and informational products; and reviews of the literature on instructional design, interface design, and usability testing.26–30

A complete listing of these guidelines is available on the Web, at http:/ /kinzie.edschool.virginia.edu/UIguide.html. The recommendations provided by Nielsen are also useful to keep in mind.31,32

For the Health Heritage site, we designed two separate interfaces, one for patients and the other for PCPs. Patients needed to be able to create a family tree, record health history for each family member, draft questions to ask their PCP during the next office visit, and access the prevention and treatment recommendations generated by the Web site on the basis of their family health history. In addition, we wanted patients to be able to receive reminders of birthdays, anniversaries, and special events.

Primary care physicians needed to be able to quickly access and review family health history information for each patient and review the resulting prevention and treatment recommendations generated by the Web site. To provide educational opportunities for both patients and PCPs, references for diseases and recommendations were provided, as were glossary entries for many medical terms.

We faced special design challenges as we implemented the user interface guidelines to meet these user needs. We describe two of these challenges here.

In the first design challenge, which concerned the intended audience and site objectives, we were attempting to meet the needs of two very different populations, but some of their needs were held in common. For example, we made the advantages of the site explicit to the first-time visitor (patient and PCP) without requiring registration, by providing this information:

- A rationale for collection of family health history
- Identification of advantages of Health Heritage for collection of family health history
- Graphic examples of what users can produce

The second design challenge concerned the structure of the site. We knew that physicians and their patients would use the site only if it was very easy to do so. We knew we had to collect and display complex information in as clear and simple a manner possible, in formats that would be understandable to all parties. Finally, we felt it was important to embed additional, supporting information for physicians and patients in an easy-to-access manner. Figure 3 shows, for example, a Web page providing health care recommendations for a patient and the pop-up definitions that users can obtain by simply clicking on an unfamiliar term with the mouse.

As the design emerges, it is refined through rapid prototyping—an early, iterative, method of staged development and evaluation. Repeated cycles of prototype development, evaluation, and revision take place. We rely predominantly on two evaluative techniques during prototyping—cognitive walkthroughs and user testing. We often use “think aloud” protocols with both of these techniques, in which a user is asked to think aloud as he or she uses the prototypical site to accomplish a goal.33
Cognitive walkthroughs, involving evaluation of a site design by a group of the designers' peers, help determine the ease with which a user might perform needed tasks. We base these evaluations on heuristics such as our user interface guidelines or those advanced by Nielsen. Issues requiring attention are noted in these sessions. To help us determine which issues are worthy of our attention, we go further, asking evaluators to judge how important an issue is for the effectiveness of the Web site and indicate how difficult they feel it would be to address in revision (Figure 4). The product of these two measures is used to rank order and select the issues for revision.

User testing can also be conducted at early stages. Users are in a unique position to provide early, authentic feedback—they know what they need and want and can respond to the design when they can "try out" the site for themselves. The inclusion of users as evaluators is also critical for another reason: Design experts are often experienced technology users and can frequently overlook problems that more novice technology users will have with a Web site.

The Health Heritage Web site evolved considerably through the paper prototyping process. Seven PCPs participated in prototype evaluation sessions, as did 19 patients. Between these sessions, results were cir-
culated and discussed among members of the design team and project specialists. All Web pages underwent numerous revisions, with each revision bringing the page closer to addressing users' needs with the best possible user interface.

For example, we developed ten different versions of the patient's home page during the paper prototyping process. In the early prototype (Figure 5, A), a number of competing functions were vying for attention. Through prototype evaluation, we were able to provide a more primary focus for the functions, which guided users through the tree creation and history entry. We moved these functions from the lower right of the page to a more prominent location and added embedded roll-over text messages informing users about what these functions did and how they operated (Figure 5, B and C).

Only so much can be determined from evaluation of a paper prototype for a Web site. When the programmers began developing the Web site and implementing the undergirding health history evaluation algorithms (a complex undertaking), we had to freeze the Web site design to enable them to produce a functional site.

**Figure 5** Evolution of the paper prototype for the patient's home page.
When the first computer-based prototype was completed, we resumed evaluation, beginning with a pilot test involving 105 persons (50 used Health Heritage and 55 received usual care). We obtained some encouraging findings. Although persons who used Health Heritage spent a considerable amount of time gathering information about family history (mean, 12.6 hr; range, 1–120 hr), they were generally satisfied with Health Heritage:

- 94 percent found it easy to create the family tree,
- 70 percent found it easy to make changes to the family tree,
- 75 percent found the glossary helpful,
- 92 percent were satisfied with how the site looked,
- 77 percent found the overall quality of the site either good or excellent,
- 76 percent would recommend it to friends,
- 70 percent agreed or strongly agreed that it was easy to get from one part of the site to another,
- 54 percent found it not at all difficult to complete the family health history; only 4 percent found it very difficult.

Health Heritage was compared to usual care, with reference to a gold standard (genetic counselor), to measure the accuracy and completeness of the family health history gathered. When completeness and accuracy of family member and family health history identification were measured, Health Heritage was found to be an improvement over usual care. Further analysis is being undertaken to compare the risk information generated by these two methods.*

We followed the pilot test with a cognitive walkthrough, to clearly identify issues that needed to be addressed in the Web site revisions (Table 6). These issues were confirmed or discounted through user testing with both patients (n = 36) and physicians (n = 4), and a list of needed revisions was created.

We tested the subsequent revisions to the site a final time with 20 persons, to confirm the usability of the site, and made a few final revisions. Final changes were made to update the health history evaluation algorithms and recommendations, using the latest scientific evidence, and the site was completed (Figure 6).

### Implement Solution and Realize Goals

A critical time period for users occurs early in their use of a Web site. If they perceive that some short-term needs are met, they are likely to adopt the site. If they adopt the site and use it, there is a reasonable probability that their long-term needs will be met or, if not met, at least positively influenced. This is the success for which every Web site developer hopes.

### Discussion

The techniques described in this paper allowed us to focus specifically on what the physicians, patients, and project stakeholders felt was most important. The Web site design was based on needs assessment and analysis, on goal and task analysis, and on guidelines for effective user interface design. The design was refined as it was developed through early user testing in a rapid prototyping process. This made significant evolution of the tool possible while the design was still paper-based and guided important revisions after a functional computer prototype was developed.

The result is a Web site that is that is demonstrably easy to use. It is also effective in identifying a family’s relatives and health conditions and providing individ-

*These and other pilot test findings are the subject of a forthcoming paper.
ualized risk assessments and care recommendations. Case studies on other products report similar successes for user-centered design. A future research need in this area is the collection of more extensive usage and outcome data, to enable cost/benefit analyses that will further validate this approach.

In the meantime, what is the risk we take if we do not follow a user-centered design process? At risk is the success of the project, and failure is an expensive and time-consuming way to learn about the importance of meeting user needs with a good user interface. This risk is clearly identified in this thoughtful assessment, by Lawler et al., of the failure of a $500,000 system implementation:

Our effort to implement a [computerized medical information system] failed, ultimately because of cumbersome procedures, the risk of “getting lost” in the system, and the inflexibility of the system, all of which produced user resistance.

With a user-centered design model, these failures do not need to happen.

References

1. Coulter A. Evidence-based patient information is important, so there needs to be a national strategy to ensure it [editorial]. BMJ. 1998;317(7153):225–6.


