DESIGN DECISIONS FOR A LOW LITERACY HEALTH SURVEY USER INTERFACE

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Abstract

The American health care system relies heavily on information supplied by patients to administer efficient and effective patient care. Unfortunately, most standard patient intake forms are incomprehensible for the 94 million American adults who are functionally illiterate. This inability to communicate health factors can adversely affect the ability to receive proper care. Studies have shown that the use of computers as an alternative strategy for retrieving information from patients can be advantageous for both patients and health care providers. This paper details the background, methodology, results, and design decisions of a series of usability tests conducted on an interface designed to collect health information from a low literacy population.

Headings:

Graphical user interfaces (Computer systems)

Human-computer interaction

Literacy

Touch screens

Interactive computer systems

Surveys – Computer software
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Introduction

To administer efficient and effective patient care, the American health care system relies heavily on information supplied by patients. The ability of a patient to communicate their ailments/symptoms, medical history (personal and family), and other medical information is vital to proper care. The mechanism currently used to acquire this information is standardized patient intake forms. These forms are completed by the patient and submitted to the hospital or health care provider upon each visit. These standardized intake forms are designed to elicit the necessary patient information to direct the examination of the patient so that the health care provider can properly diagnose and treat the patient. Unfortunately, most standard forms are incomprehensible for the 94 million American adults, about 1/3 of the US adult population, who are functionally illiterate (National Adult Literacy Survey [NALS], 1992). They are unable to comprehend, retain, and apply information acquired through reading, writing, and speaking (Davis, Meldrum, Tippy, Weiss, & Williams, 1996). In an article on health literacy, Davis et al. (1996) focused on the relationship between poor literacy and poor health care. The authors further stated, “while 1 in 5 adults cannot read the simplest brochure, the majority of health information is written beyond the reading comprehension of the average adult” (Davis et al., 1996, p. 95). Moreover, “patients are not likely to volunteer information that they have difficulty reading or understanding” (Davis et al., 1996, p. 96). These communication factors can adversely affect the ability for patients to receive proper care.

Health care facilities are well aware of the problem and realize that steps need to be taken in order to address the problem of literacy in health care. Davis et al. (1996)
make several recommendations for improving communication between health care providers and patients. Their recommendations to health care providers include: avoiding information overload, slowing the rate of speech when communicating verbally; providing information through audio, video, or multimedia mechanisms, and using additional aids including pictures, stories, "catch" phrases and, mnemonics (Davis et al., 1996).

Baker, states, "We're not going to be able to solve this [problem of poor literacy and poor health care] simply by rewriting information— we need to go to alternative strategies (Keflides, 1999, paragraph 11). Past studies have detailed the use of computers as an alternative strategy for relaying information to patients, but most do not deal directly with interviewing low literacy patient using computers. Mayne, Martin, Morrow, Turner, and Hisey (1969) detailed the use of mark-sense answer sheets in conjunction with computer-generated questionnaires. The study showed that using computers to present questions to patients could be advantageous to the patient as well as the health care provider. Slack, Hicks, Reed, and Van Cura (1966) compared handwritten patient interviews to those conducted by a computer. The authors were attempting to produce a system that would “require no physician time and provide a standardized and consistent method for taking medical histories” and “store responses for retrieval for purposes of research and patient follow-up observation” (Slack et al., 1966, p. 194). The results of both aforementioned studies were very positive and supportive of the use of computers to gather patient information effectively.

Recently, a pilot study conducted by Duke Family Medical Center (DUMC) and Lincoln Community Health Clinic (LCHC) revealed several advantages of computer-
based medical questionnaires over paper-based questionnaires. In the study, named MADELINE (Multimedia Adaptive Data Entry and Learning Interface within a Networked Environment), participants responded favorably to an automated user information system; however no personal information was collected and only 22 subjects were interviewed. The results showed low literacy patients were able to more easily and effectively interact with the computer-aided questionnaire, without assistance, than they were with the paper-based questionnaire (Lobach, 1998). This study suggests that some other advantages to computer-based questionnaires include collecting more complete information at a higher quality and at a lower cost than traditional methods (Lobach, 1998). If this approach to patient data collection is to be effective, it must be determined how to design computer-aided surveys for low literacy populations.

DUMC, LCHC, and the University of North Carolina – Chapel Hill have initiated a full-scale project based on the initial pilot study previously mentioned. This study is trying to confirm and expand on the findings of the pilot study. One portion of the MADELINE Project has been the task of designing and testing a user interface for a low literacy population. This paper details the development and usability testing of the first two prototypes for this project.
Literature Review

In order to explore the topic it is necessary to gather literature from three areas. The first area is the problem of illiteracy. Information in this area is vital to describing the current state of literacy in America and detailing the potential needs of the population in which this interface is intended. The second area is current health care practices. This area will focus on the feelings of health care professionals toward patient illiteracy and different measures they have taken to address the needs of the low literacy population. The third area is user interface design. This area will discuss current user interface design studies for low literacy users.

Problem of Illiteracy

Studies have shown that there is a need in health care settings to make information transfer appropriate for all levels of literacy (i.e., literacy sensitivity). Literacy assessments of the American adult population have revealed that significant portions of adults have limited literacy skills. According to the results of the 1992 National Adult Literacy Survey, 21% to 23% of the 191 million adults in America demonstrate literacy skill at the lowest level, level 1 (see appendix A). They are unable to read a prescription label, thermometer, or a note from a doctor (NALS, 1992). Of the 26,000 people surveyed, 25% to 28% demonstrated literacy skills at the next level, level 2 (see appendix A). Individuals at this level are able to enter limited background information on simple forms (NALS, 1992). About 50 million American adults who perform at literacy levels 1 and 2 encounter significant challenges comprehending information from complex or lengthy documents and performing quantitative tasks.

“Literacy is more than just the ability to read words; it is an ordered set of skills that are
called into play to accomplish diverse tasks. Fifty percent of level 1 and 2 adults reported getting a great deal of help from family members or friends in completing everyday literacy tasks, such as filling out forms” (Sutherland, 1999, p. 2).

This assessment also suggests that it could be anticipated that individuals with a high school education or less read 3-5 grade levels below their highest completed grade (NALS, 1992).

Low literacy can negatively affect an individual’s health and health care. Patients are often required to take charge of aspects of their medical care such as administration of medication, monitoring of their medical condition, maintaining a calendar for follow-up appointments, reading pre-printed health information brochures, and filling out different types of patient forms. All of these tasks require a level of literacy higher than 1 and 2. An example of how low literacy can negatively affect patients can be found in a survey conducted at two public hospitals in Los Angeles (979 participants) and Atlanta (1680 participants). The researchers found that fewer than 60 percent of the diabetic patients knew what a normal blood sugar reading was (Williams et al., 1996). Barriers such as this can severely limit the person’s ability to care for him/herself. In order for patients to overcome these types of obstacles and receive adequate health care, health care providers must attempt to address the literacy needs of the low literacy patient population.

**Health Care Practices**

The introduction of a computer system to aid with the dissemination of health education and patient information can potentially be very disruptive to the daily operations of the health care system. Patient and health care providers have to adjust to new methods of communicating with one another that may not be comfortable. But,
studies have shown that current mechanisms are inadequate, and there is a desire for change.

Health professionals agree that the current system of giving and receiving information from patients is inadequate. They have shown strong support for computer usage, among other tools, as a mechanism for assistance. JoAnne Schwartzberg, director of the department of geriatric health and the American Medical Association’s Council on Scientific Affairs said, “Obviously, we can’t teach them [the illiterate] to read when they’re sick, but we can teach them to communicate better. But how? Multimedia? Oral instructions? This is something that needs to be studied further” (Ziegler, 1998, p. 57). And Baker of Case Western points out, “[we] are still approaching this problem the same way we did 20 years ago. It’s time for a different approach” (Ziegler, 1998, p. 57). These types of opinions have led to several research papers and experiments using computer systems to aid in health education and provision of health care.

Computerization of medical functions can benefit the health care provider and the patient (Bates et al., 1999). A computer system called Physician Order Entry (POE) was designed to create complete, unambiguous, and legible patient prescriptions to aid in correcting prescription errors. Built into the system was the ability to assist health care providers by recommending drug frequencies and dosages, and issuing warnings about potentially harmful drug combinations. Before POE, all prescriptions were handwritten and transported manually and let to a high frequency of adverse drug events (Bates et al, 1999). The cost to a health care facility for an adverse drug event can be more than $2,000 per event (Bates et al., 1999). Although most adverse drug events are minor, some can be fatal. POE was evaluated over a 10-year period and the results were
positive. Dose errors dropped 81 percent and medication errors dropped 86 percent (Bates et al., 1999). These results show that the health care profession can greatly benefit from the integration of computerized functions into their environment. Although POE did not directly involve the patient, it does detail the general benefits of using computers to aid in health care systems.

Lewis (1999) discussed the results of a literature synopsis that focused more on computer-based approaches to patient education and treatment. In her article she detailed several advantages to computer-based approaches to health education for patients such as “just-in-time” availability, a private learning environment, support for decision-making processes, potential for individualization of information presented, and the ability to simulate life experiences (Lewis, 1999). Additionally, she detailed studies that showed patients’ preferred to reveal personal information to a rather than health care staff. Two studies in particular reported on the use of health interview programs designed to present customized interviews and individualized patient information.

One study Lewis described was the Be Well! System (Slack, Safran, Kowaloff, Pearch, & Delbanco, 1994). This system was designed to promote healthy lifestyles for hospital employees. Employees logged on to the system, enter data about medical history and personal habits, and receive suggestions for behavior changes they could make to improve their health. Upon completion of the interview, employees were asked a series of questions to evaluate the session. The results were encouraging. The majority of the 1281 people who completed the interview responded favorably. Most (97%) found the system easy to understand and 37% indicated that they would prefer the computer interview to a doctor or nurse (Slack et al., 1994).
Another study described by Lewis detailed the use of a touch screen application for the education of patients with brain injury. It received tremendous support from health care professionals, patients, and patient family members (Patyk, Gaynor, Kelly, & Ott, 1998). In the study, 75% of the respondents (i.e., health care professionals, patients, and patient family members) indicated that using the touch screen applications was “non-threatening” and “allowed for control of pace and content of the material” (Patyk et al., 1998, p. 86). Patients and family members commented, “the touch screen methodology, format, and instructions made it very user-friendly and easy to understand even though they were not computer literate” (Patyk et al., 1998).

The Be Well! System and the touch screen application showed that the introduction of computerized systems into in health care is advantageous and well accepted by the patient. Lewis (1999) concluded that these types of computer systems can encourage patients to interact more with their care provider, as well as, think more about their health.

As stated in the introduction, a pilot study done by Duke University Medical Center and Lincoln Community Health Clinic details several advantages of computer-based medical questionnaires over paper-based questionnaires (Lobach, 1998). The study consisted of 22 patients with literacy levels of 1 and 2 (16 – NALS level 1, 6 – NALS level 2) (see appendix A for NALS level definitions). According to the findings of the study, the participants were eager to use and responded favorably to an automated user information system. The participants evaluations indicated that they were more comfortable filling out the computer-aided survey (6.6 average on a 7 point scale) than paper forms (4.2 average on a 7 point scale) (Lobach, 1998). Participants’ comments
suggest that they could more quickly and accurately complete the computer-aided survey. They emphasized how helpful having the questions read to them was. For the health provider, the electronic collection of data makes it readily able to be analyzed. This study showed that there are advantages for the patients and health care providers to using computer-aided questionnaires to gather information from participants.

The aforementioned articles detail patients’ attitudes toward the integration of computers into the health care system. Patients have shown enthusiasm about interacting with computer applications designed to assist in their health care. Results from the studies have shown computer applications are successful in reducing errors, educating patients, and contributing to a more efficient health care experience for the patients. There is strong support for the implementation of additional computer aided devices to assist with patient to provider communication, patient education, and overall efficiencies in the health care system.

**User Interface**

The purpose of the MADELINE project is to design an interface to replace a paper survey already in use. A study conducted by Beebe, Mika, Harrison, Anderson, and Fulkerson (1997) attempts to replace a paper and pencil questionnaire with a computer-aided survey in a school setting. Although a school-based survey from a health-based survey, the design issues discussed by Beebe et al. (1997) are similar to those of the MADELINE project. Beebe et al. incorporates seven essential features into the design of the computerized version in order to make the computer and paper versions comparable. Those features are scrolling, jump screen, automatic next, quitting, keyboard response, help, and progress meter. Scrolling is the ability to move back and forth through the questions sequentially. This is inherent in the paper survey, but due to skip patterns this
is not easily addressed in computer surveys. Jump screen is the ability to “jump” to a specific question for another question. Again this is very natural for a paper survey, but several factors must be considered with implementing this functionality in a computer survey. Automatic next is the mechanism with which you to the next question as soon as the response is provided. Use of the keyboard to indicate an answer does not translate well to pencil and paper survey. Help is available in both the paper survey and the computer survey, but the computers have a variety of media for display. Finally, a progress meter is apparent with the paper survey but not necessarily available to the user with computers. Several of these factors described by Beebe et al. (1997) have been considered in designing the MADLINE interface. The authors acknowledge that it is virtually impossible to create a computer questionnaire identical to a paper/pencil survey. They recognize that there are advantages that computer surveys have over paper ones. The computerized survey allows for skip patterns to limit the amount of questions each respondent must answer, reduces data preparation time, reduces non-response, and potentially reduces survey costs in the long term (Beebe et al., 1997).

Beebe et al. (1997) describes some of the nuances of their interface design, but these features are common to most interface designs. The features mesh with basic design concepts posed by IBM such as: simplicity – keeping the interface simple and straightforward; support – enabling the user to accomplish tasks using a sequence of steps that is naturally used; safety – keeping the user from entering erroneous data; and satisfaction – creating a feeling of progression and achievement for the user (IBM, 2000).

A research project conducted by faculty at the University of Glasgow in the UK detailed a touch screen health information system designed to provide health information
and feedback to the public in various communities in Glasgow and Clydebank, England (Jones, Navin, & Murry, 1997). The system, named Healthpoint, included touch screens, color graphics and cartoons. The system was installed in two phases, in public locations such as supermarkets, libraries, and post offices. The result was a product appealing and attractive enough to hold the attention of the general public users (Jones et al., 1997). The results of the study showed 40,842 user-episodes within a population of 46,920 potential users (Jones et al., 1997). A user-episode is described as accessing the system but the results do not consider a user who accesses the system on multiple occasions. The article does not detail any user issues and only discusses issues regarding regular system maintenance. However, the authors indicate that the use of the system within the population was positive and fairly steady (Jones et al., 1997).

**Summary**

There is literature that shows the effect of literacy sensitivity in health care settings, but none that discusses the use of computers as a method of extracting information from a low literacy population. The literature that addresses literacy sensitivity tends to focus on health education and the redesign of current written materials, creating more effective communication methods, and the use of visual aids, rather than probing for patient information.

Through this literature, it appears that literacy is a major issue for about 1/3 of American adults. This population must have health care; regrettably they have barriers for adequate health care due to their literacy level. The literature also shows that health care providers recognize that literacy is an issue. Providers have shown tremendous support for modifications of current methods of health information communication. They seem to be very open to the introduction of computers, as well as other types of patient
support. There are design standards for interface design, but there is essentially no
guidance for designing interfaces for low literacy populations. It is hoped that this
experiment will lay a foundation for future low literacy interface designs.
Design and Testing of an Interface for Low Literacy Users

Part of the MADELINE project is to design an interface for a low literacy population to replace the currently used paper patient intake form (see appendix B for the questions included in the survey). The interface should allow the user to answer questions more thoroughly and accurately. It should also disseminate health education and training to the user through use of the interface. This section will describe the preliminary design of the first prototype, its usability testing, the design of the second prototype, and its testing.

First Prototype

The design of the first prototype was based on system requirements and perceived user needs. The interface was designed to be placed on a kiosk type of computer placed in emergency rooms, clinics and other hospital admissions facilities. The design had taken into consideration that this was a web application. This was especially important when considering web file transmission times and multimedia support mechanisms. The initial design was done in Cold Fusion and HTML. The content (questions, responses, and help information) of the interface was based on the cognitive response interviews conducted by MADELINE researchers, but could be modified to meet the needs of the users (Sutherland, Campbell, Hyrwna, Lewis, & Ornstein, 2000).

The first decision for the initial design was layout. The layout consisted of four frames: question, response and navigation, help, and title (see Figure 1). These frames compartmentalize the screen to promote uniformity of the questions. The consistency of
the layout should aid the user with navigation of the interface leading to increased user comfort.

<table>
<thead>
<tr>
<th>TITLE FRAME</th>
</tr>
</thead>
<tbody>
<tr>
<td>QUESTION FRAME</td>
</tr>
<tr>
<td>RESPONSE &amp; NAVIGATION FRAME</td>
</tr>
</tbody>
</table>

*Figure 1: Initial Layout*

From a technical perspective, the frames allowed the segmentation of information and functionality. The programmer can change a single area of the screen without having to reload the other sections of the screen. For example, if a user requests the definition of a medical term, the answer can be placed in the help frame without having to retrieve an entirely new page from the web server (which is standard HTML functionality). The use of frames also improves web response time because it does not reload an entire page each time the user goes to another question or asks for help. This layout design simplifies the interface, and allows the user to look in the same places each time for the question, help, or responses, thus aiding in navigation.

Another design decision was the color scheme. Our original design consisted of five colors: blue, yellow, black, white, and gray. Blue and yellow were used for the navigation buttons; black was used for the lettering; white was used for the background of the response and navigation frame; and gray was used for the background of the title,
help, and question frames. Statistics show that about 8% of all males and 0.5% of females have some level of color blindness. Most have perception defects for red, green or both (Heath, 1996). Perception defects for yellow and blue are the second most common form, but they are extremely rare (Heath, 1996). It was determined that this color scheme would not be a problem for patients with color blindness.

Smooth navigation is essential to an effective interface. For the initial design two buttons handled survey navigation. A blue button was used to go to previous questions, and a yellow button was used to move forward to subsequent questions. Each button had the text of its function and an arrow indicating the direction in which the button would take you within the survey. The navigation buttons were placed in the response area centered at the bottom of the screen (see Figure 2).

![Figure 2: Initial Layout with color](image-url)
In addition to basic layout and navigation, additional functionality was needed for help functions within the interface. The help frame was provided to assist the user in completing the survey by displaying help text, showing video clips, or playing audio clips, on demand. This was a very important part of the interface because of the special needs of the low literacy population. Additional buttons were needed to activate these help functions. A gray and black toolbar was created for the task. The toolbar was broken into five adjacent squares. Two squares contained video and audio icons to represent video and audio functions, and the remaining squares were left blank for future help functions. The help toolbar was placed in the title area to allow for the necessary space in the help area for video clip dimensions (see Figure 3).

![Figure 3: Initial Design w/ help icons]

Help text is displayed in the help frame to aid the user in understanding words and/or health terms that were deemed difficult or uncommon during the cognitive
response interviews. This help text is displayed at the same time the question text is displayed. Audio help is provided in the form of audibly reading the questions and responses to the user. Video help is provided to give health education to the user about selected topics pertaining to the question. The help toolbar only appears when that type of help (i.e., video or audio) is available.

For this project, it was not enough to simply design an efficient navigation system; the project demanded the use of touch screens with patients who are not only low literacy, but also have little experience with computers. Touch screens replaced the mouse for this system. Therefore, several of the HTML form objects posed a design challenge, since they were too small to provide an adequate touching area. Consequently, the design had to be modified to use images and hyperlinks instead of form objects. For example, the back and next buttons previously mentioned are not actually buttons, but images that mimic the functionality of buttons by use of hyperlinks. The help toolbar also consists of images and hyperlinks that perform similarly. These workarounds were created because of the touch screen aspect of the system specifications. For text input, a standard keyboard was to be used.

Question response options were greatly affected by the lack of availability of form objects. Again, through the use of images and hyperlinks, we were able to emulate radio buttons and check boxes for the response options. Each response option would have a corresponding numbered image next to it (see Figure 4). This numbered image would serve as the designated touch point for a given response. Touching of the numbered image would display a check next to the numbered response option (see Figure 5).
Through the hyperlink and Cold Fusion logic, radio buttons and check boxes were emulated successfully.

Figure 4: Initial Design w/ Numbered Responses
The decision to use numbered response choices was consistent with the notion that people of low literacy are more likely to recognize numbers than letters or words (NALS, 1992). After having the question read to them, NALS (1992) argued that the user might more easily remember the number instead of words. Numbering the response options, in conjunction with the audio/video clips, should aid the user in selecting their desired responses.

Each numbered image was sized 40x40 pixels, and plans were made to test if this size was adequate for a touch screen application. The tool bar and navigation buttons were sized to be 40x100 and 40x60 pixels respectively, in hopes of testing them also.

The user interaction with the question responses of the interface is central to the user completing the patient intake form. The questions and responses were standardized to be consistent throughout the survey. The questions were of six different types based

<table>
<thead>
<tr>
<th>No</th>
<th>Cold/Flu</th>
<th>Headaches</th>
<th>Stress/Fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>Depression</td>
<td>Diabetes</td>
<td>Asthma</td>
</tr>
<tr>
<td>Eye concerns</td>
<td>Smoking Concerns</td>
<td>Pregnancy</td>
<td>Birth Control</td>
</tr>
<tr>
<td>GYN concerns</td>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
on question text and the allowable responses. Each type is described in Table 1, with an example of the question and a few possible responses.

<table>
<thead>
<tr>
<th>Types of Questions</th>
<th>Example</th>
<th>Possible Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Select one response (no default answer)</td>
<td>Are you male or female?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>2) Select one response (default answer)</td>
<td>How long have you smoked cigarettes?</td>
<td>Don’t smoke (default), &gt;1 year, 1-5 years, 5-10 years, 10+ years</td>
</tr>
<tr>
<td>3) Select one or more responses</td>
<td>Has anyone in your family had diabetes?</td>
<td>Mother, Father, Sister, Brother</td>
</tr>
<tr>
<td>4) Select one response and options include a response of “other” with a textbox</td>
<td>How often do you take you medication?</td>
<td>Once a day, Twice a day, Other</td>
</tr>
<tr>
<td>5) Select one or more responses and options include a response of “other” with a textbox</td>
<td>Who do you live with?</td>
<td>Mother, Father, Brother, Sister, Other (with textbox)</td>
</tr>
<tr>
<td>6) Textbox only</td>
<td>What is your name?</td>
<td>textbox</td>
</tr>
</tbody>
</table>

Project requirements stated that a 17-inch monitor would be used with a resolution setting of 1024x768. It was determined that the available space of the response and navigation area could support 15 responses and maintain sufficient spacing for all additional objects (i.e., number response images, text, and navigation buttons).

A final issue considered in the initial prototype was the possibility of automatic forwarding to the next question when a response was made for any questions of type 1. Two design possibilities were considered. The first was to allow the user to choose an answer, and require them to press the next button to move to the next question (i.e., the navigation was consistent with the other question types). The second was to allow the
user’s answer to automatically forward the user to the next question. After looking at both of these choices and creating a mock up of each, it was determined that the second design would have the advantage of decreasing the number of touches needed to complete the survey. With roughly 52 questions for males and 65 questions for females, the first design would require the user to touch the screen approximately 100 times for males and 130 times for females. We calculated that automatic forwarding could possibly reduce the number of required user touches by 20-25%. As a result, everywhere it is possible, the response choices would automatically send the user to the next page and avoid use of the navigation buttons. Although this design conflicts with the design goal of consistency (Grudin, 1989), it was considered advantageous to reduce survey completion time.

The initial prototype consisted of 32 questions selected from the list of patient intake form questions (see appendix B). The selected questions represented the first four question types and were selected to provide feedback on how the users would interact with the different question types.

The initial prototype was completed and ready for testing November 14, 1999. Although the initial prototype design was not driven by user suggestions, it was designed in light of user responses to the cognitive response interview questions.

Usability Test of Initial Prototype: November/December 1999

The usability testing of the initial prototype was conducted on November 16, 1999 and December 5, 1999. A total of five interviews were conducted (Nielsen, 2000) and the average educational level for the participants was 11th grade.
The testing of the interface was conducted at Pickens Family Health Clinic and Lincoln Community Health Clinic, both located in Durham, NC. Patients from the clinic were recruited from a booth set up in the lobby of Lincoln, except for one patient from Pickens who responded to a flyer posted in the lobby of Pickens. Signs posted on the booth advertised the usability test (see appendix C). Patients who inquired were screened for eligibility. To be eligible, patients had to have 12th grade education or lower and indicate that they had low computer skill by answering two computer skill questions (see appendix D for the text of the questions). If a patient did not qualify, they were given a water bottle for their time. Patients who were deemed eligible were scheduled for an interview that day. The interviews were scheduled in one-hour intervals and filled on a “first come, first serve” basis until all the necessary time slots were filled.

At their scheduled time, each patient was given two copies of the consent form detailing the project and the interview requirements (see appendix E). They signed a consent form, gave it to the interviewers, and kept a copy for future reference. The interview was conducted by two interviewers, one to conduct the interview and another to take notes. In addition, the interviews were video taped (consent was included in the patient consent form previously mentioned) to allow for additional analysis. Patients were asked to describe their thoughts and opinions about the interface, in addition to any changes they would recommend. Patients could refuse to answer any information or to discontinue the interview at any time. Patients were paid $25 dollars after the completion of their interview. The interview notes were compiled to help determine the needed alterations or enhancements to the interface.
For the most part, the patients were very receptive to the interface, as well as the goal of the project. The users, after some initial assistance from the interviewers, were able to complete the survey and generally seemed pleased with the interface. Several users commented that they thought the system would be “useful” and the interface was “easy to use.” One user in particular indicated that he thought it was fun and commented that “the computer aspects could be educational.” In general, the users seemed to be engaged with the text of the question rather than with the mechanism through which the question was presented to them. This indicated that the initial prototype was reasonably usable.

Nevertheless, some problems with the interface were identified through researcher observations and user comments.

- None of the patients felt that the interface was readily intuitive. They had trouble getting started. The first question was “What is your first name?” Users did not know to touch the text box in order to place the cursor there for typing. One user actually said their name out loud. Users also placed both their first and last name in the single textbox, totally disregarding the question text. It was only after some initial coaching that the users were able to figure out how to respond to the first question. Patients were able to retain this knowledge after the second or third question.

- The help area instructed the users to enter their social security number in the format 999-99-9999. All users entered their social security number without the dashes despite the help text. When asked about it, the users indicated that they did not notice the text in the help area.

- Throughout the survey, users had difficulty touching the responses. Some patients touched the words instead of the numbered square. Also, users had to touch the screen several times to get the response they wanted. Interviewers also had trouble touching the responses. The interviewers were not able to determine what percentage of this problem was due to the size of the response touch area and what percentage was the touch screen software. Nonetheless, the difficulty with touching the screen was evident throughout the survey.

- Several users unchecked the default answers throughout the survey. We mentioned to the users that the question had a default answer. They indicated that
they would rather select their answer themselves and this was evident by their actions. One user asked why it was already checked.

- Periodically users would wait for the question to automatically move to the next question. There were a few single response questions in which the users were required to press the next button. The users indicated that they thought the question would forward automatically by pressing the answer since similar questions behaved in this manner.

Several design decisions were made based on comments by the user and observations of the interviewer. These decisions were implemented prior to the next phase of usability testing.

Decision #1:
- Placing the first and last name textboxes on the same screen
  Rationale:
  Originally the questions for entering the patient’s name were in two parts (first name and last name) on two different screens. This seemed to cause confusion for the users. Users would type their whole name in the first screen, and either realize their mistake on the second screen or just type their name again on the second screen. For ease of use, we placed the two text boxes for first and last name on the same screen.

Decision #2:
- No default answers
  Rationale:
  Patients often did not comprehend that the answer was pre-selected. After a few instances of this problem, the interviewers inquired and the consensus was that the patients wanted to check their own answers.

Decision #3:
- Enlarge the size of the response choices number images
  Rationale:
  The number images used to respond to the questions were 40x40 pixels. We found that patients were having trouble (through the touch screen) selecting their choices so the number images were enlarged to 50x50 pixels.

Decision #4:
- Auto forwarding on *all* single answer questions
  Rationale:
  There was some confusion by the patients as to when auto-forwarding would and would not occur. Therefore, all questions that do not allow multiple answers (including questions with the “other” option) would be auto forwarding.
The second prototype incorporated these decisions. In addition, an increased number of questions were included to test user completion.

**Second Prototype**

There were two major influences on the design of the second prototype. The first was design decisions based on the interviews of the initial usability testing. The second was modifications to the content resulting in changes to the question types. This section will focus on the influence of these two factors on the design of the second prototype.

As noted in the Design Decision #2, above, the first round of usability testing indicated that the use of default answers was inappropriate for this user group. In addition, several question types identified for implementation in the first prototype were combined as one question type for further development (i.e., types 3, 4, and 5 listed in Table 1 were combined). The final change was to add two question types: one to handle multi-part questions and one to handle question with a large number of response options. The question types as implemented in the second prototype are described in Table 2.
Table 2
Questions types (second prototype)

<table>
<thead>
<tr>
<th>Types of Questions</th>
<th>Example</th>
<th>Possible Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Select one response</td>
<td>Are you male or female?</td>
<td>Yes, No</td>
</tr>
<tr>
<td>2) Select one or more responses and options</td>
<td>Who do you live with?</td>
<td>Mother, Father, Brother, Sister, Other (with textbox)</td>
</tr>
<tr>
<td></td>
<td>include a response of “other” with a textbox</td>
<td></td>
</tr>
<tr>
<td>3) Textbox only</td>
<td>What is your name?</td>
<td>textbox</td>
</tr>
<tr>
<td>4) Multi-part questions</td>
<td>Which family members have had a stroke?</td>
<td>No, Father, Spouse/Partner, Mother, Child/Children, Other (with textbox).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>How old were your family members when the</td>
<td>Selected options from the previous question with a textbox for age 38 response</td>
</tr>
<tr>
<td></td>
<td>first stroke occurred?</td>
<td>options available</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Questions with a large number of response options</td>
<td>What are the main health concerns you want</td>
<td></td>
</tr>
<tr>
<td></td>
<td>addressed at this visit? *Choose all that</td>
<td><em>Choose all that apply.</em></td>
</tr>
<tr>
<td></td>
<td>apply.*</td>
<td></td>
</tr>
</tbody>
</table>

A first content related issue was multiple part questions (question type 4). They were tested in preliminary form in the first prototype, but the second prototype enhanced their relationship. It was deemed necessary that the different question parts share information and use that information. For example, information from part A of the question is needed to determine the text and response options for part B of the question and so on. The responses for part A and B need to have a one to one relationship for future analysis. In the initial design, they had no direct relationship and were simply two
questions (see Figure 6). This modification would require that some information be stored in the database and some logic be built into the second prototype.

![Part A

Figure 6: Original Screen for Cancer Question (No direct relationship between family member and cancer type)](image)

![Part B

How old were they when the first heart attack occurred?](image)

The initial design for multiple part questions was modified, adding a processing loop for each. Each multiple part question would have two additional questions added to it, an opening and closing question. This allowed a relationship to be formed between the responses (see Figure 7).
Figure 7: Modified Question
(One to one relationship between the family and cancer types)

Although this solution increases the total number of questions for the survey, it allows for a strong relationship between the answers. This solution sacrifices the usability of the interface in order to increase the accuracy of the data being collected.

The second content related issue was the handling of questions with a large number of response options (i.e., questions of type 5). In the design of the first prototype, the hope was that the number of responses options would be reduced to 15 or less. This was not the case, and in the second prototype a solution for handling these question types implemented. The solution combined multiple pages of responses with utilization of the
help area. More clearly stated, if a question had more responses options that would fit on one screen, then the first 15-18 responses were put in the response and navigation area. As the user made selections from the response options, the text of the option would appear in the help area as an indicator to the user of their selection. The navigational “Next” button was replaced with a “Next List” response option. After the user had selected all his or her options, the “Next List” button was touched. A second set of response options (i.e., those further down the list) would appear in the response and navigation area. The user would select from the new list of response options. All of the previously selected options would still be listed in the help area for the user to see. In addition, any newly selected response options would also appear in the help area. The user had the option of touching the “Previous List” button to return to the first set of responses. By pressing the “Next” button available on the second screen of response options, the user indicated completion of the question and proceeded to the next question (see Figure 8).
Figure 8: Question with more than 15 response options

The second prototype consisted of 49 questions for males and 52 questions for females representing 75-80% of the total questions. The selected questions represented all of the original and the new/modified question types. This round of usability testing would provide user feedback to the new/modified question types. In addition, the testing
yielded a respectable estimate of survey completion times. The second prototype was completed and ready for testing December 15, 1999.

Second Round of Usability Testing: December 1999

The usability testing of the second prototype was conducted on December 16, 1999. The recruitment procedures and testing protocols were the same as those used in the usability testing of the first prototype. Six interviews were conducted and the average educational level for the patients was 11\textsuperscript{th} grade.

As with the first round of interviews, the patients were very enthusiastic about the system and interested in what the project was trying to accomplish. Users offered new criticisms about the design and some recommendations as to how it could be modified to make it better for them.

- On the questions with a large number of response options, users were uncertain about how to remove from the help area items they had selected.

- Although they had no problem understanding how to navigate and answer the questions with a large number of response options, they commented on the inconsistency of these questions when compared to other questions in the survey. One user also commented that “Next List” was not intuitive and they would understand more easily “more choices” or “more”.

- When selecting options from the drug list (see Figures 9 and 10), patients often did not use the intermediate letter to select their drug. For example, if the patient were searching for the drug Tylenol, they would choose the "T" option instead of the "To" option. The "To" option would display a list of available drugs starting “To”. Instead the user selected T, and did not see Tylenol in the list. They then selected the “To” option located on the “T” drug list.

- Users need additional help for terms such “dosage” and “physical activity”.

- Users had difficulty reading response options with medical terms, such as types of doctors and types of cancers, and disease names such as pneumonia, lockjaw, and tetanus.
• The help area was not obvious enough to users. One user asked for help. When the interviewer pointed out the help area, they indicated they saw it but still needed help.

• On instances when users selected the “other” option, they did not type in the textbox. This contradicts information gathered during the cognitive response interviews, when patients expressed the desire to provide their own responses.

![Interactive Patient Intake Form](image)

**Figure 9: Main Drug select screen**

![Drug list](image)

**Figure 10: Drug list**

Based on the second round of interviews, several design decisions are recommended for future revisions of the interface.
Decision #1:
For questions with more than one page of responses, incrementally number the response options instead of resetting numbered response options on subsequent pages.

Rationale:
Patients had difficulty distinguishing the first page of responses from subsequent pages. It often visually appeared to be the same question because of the reset of the numbered response options, despite the response text. Changing the numbers so that they continue to increment may make it clearer to users.

Decision #2:
Eliminate odd response layouts on questions with a large number of response options (i.e., dangling or leftover responses).

Rationale:
Even though it was initially determined that the number of responses per pages would be 15, some response sets did not distribute evenly across several response pages. Therefore, responses need to be spread across response pages to produce symmetry for question responses and eliminate pages will only a few responses.

Decision #3:
For the questions with a response of "other" (with a textbox), specify a default value that will be sent to subsequent pages if the user does not enter information in the textbox. If text is entered, then that text will be carried to following pages.

Rationale:
Although users indicated in cognitive response interviews that they would like to enter their own answers if their choice was not listed, they often selected the “other” option and proceeded without entering text in the textbox. This caused problems for subsequent pages because of missing information. By sending the text of “other” when they select the “other” option and no text is entered, we will eliminate the problem of missing data.

Decision #4:
Remove additional (in between) letters from initial drug list

Rationale:
For example, patients would choose "L" instead of the shortcut "Li" for the initial drug screen when looking for certain drugs that began with "Lo". By eliminating the "Li" choice for the initial screen, patients will have the ability to navigate the entire L list. This decision will result in some lists that are quite long, but it is believed that this decision will increase the ease with which patients interact with this question.
Decision #5:
Adjust questions with multiple response pages to be the same format as other questions.

Rationale:
Users indicated that the questions with multiple response pages did not look or behave like the other questions throughout the survey. These questions needed to be modified to mirror other multiple response option questions in the survey. This was accomplished by limiting the number of responses on a single page to 15. With this response set size, it is possible to place check marks next to the user’s response just like the other multiple response options questions. The text of the response will not appear in the help area as it did with the second prototype.

Further revisions of the interface and a third phase of usability testing are planned. In these later phases, there are some unresolved issues that should be investigated in future design and testing of this interface.

Future Questions:

• The influence of video and audio assistance to these low literacy patients still needs to be evaluated.

• The complete survey should be tested to evaluate the length of time required for completion. Although 75-80% of the total survey questions were included in the second prototype, the full questionnaire has not yet been tested. This could determine additional modifications if the completion time is too high or the survey is perceived to be too long by the patients.

• In the cognitive response interviews, patients indicated that if their choice was not available in the list of choices, they wanted an “other” option with the ability to type in their own response. However, during usability testing, patients often did not put any information in the textbox. This could have been due to lack of awareness that the option was available or satisfaction with the “other” option alone. Several patients commented on their discomfort with spelling. The phenomenon warrants further investigation.

• Currently, there is no mechanism for stopping the survey and restarting at another time. Because this system will be in a clinic, it is possible that the patient may not finish before they are called to see the doctor. This functionality may be required in future versions of the survey.
Discussion

Designing an interface for low literacy users creates several challenges for a designer. The features of this design are very similar to a design done by Beebe et al. (1998). Below is a table showing their design decisions versus some design decisions made for the MADELINe project (see Table 3).

Table 3
Design features of Beebe et al., (1998) versus MADELINe Project

<table>
<thead>
<tr>
<th>Design Features</th>
<th>Beebe et al., (1998)</th>
<th>MADELINe Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Scrolling</td>
<td>Respondents were allowed unlimited scrolling through next and previous questions using the “Next” and “Back” buttons.</td>
<td>Same as Beebe</td>
</tr>
<tr>
<td>2) Jump screen</td>
<td>Respondents were allowed to return to any previously answered question, go to the next unanswered question, or return to the question just completed</td>
<td>Respondents are forced to use the “Back” and “Next” buttons to navigate to reduce complexity.</td>
</tr>
<tr>
<td>3) Quitting</td>
<td>Respondents needed to be able to quit whenever they wanted and to feel that their answers were not visually secure (due to the openness of the test taking environment). The “quit” button was added to the main screen and later moved to the help screen to prevent respondents from opting to quit too rapidly. Respondents also have the option of saving their data and beginning the survey at the point they exited.</td>
<td>Still to be designed</td>
</tr>
<tr>
<td>4) Use of keyboard and mouse</td>
<td>Originally, it was planned that respondents would use the keyboard and mouse to enter responses. This was rejected because it introduced a visual inconsistency with the paper survey</td>
<td>MADELINe implements a touch screen with keyboard. The mouse was removed since many user have no experience in its use.</td>
</tr>
</tbody>
</table>
Table 3: (cont.)
Design features of Beebe et al., (1998) versus MADELINE Project

<table>
<thead>
<tr>
<th>Design Features</th>
<th>Beebe et al., (1998)</th>
<th>MADELINE Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>5) Auto-forwarding</td>
<td>It was decided not to put an automatic forward to the next question when a response was given. Specifically, a respondent was required to press either the &lt;ENTER&gt; key or “Next” or “Back” buttons to continue in the survey once a response was selected. This was to prevent data errors caused by auto-forwarding to the next question after an erroneous response selection.</td>
<td>Every question that does not have multiple answers automatically forwards the user to the next question. On questions that allow for multiple answers, the user must indicate they are ready to move forward by pressing the “Next” button. The purpose of this navigation scheme is to reduce the number of selections the user has to make. Since they have the option to go back, if they feel they have made a mistake they may go back and correct. This is a preliminary decision, and the MADELINE team is still investigating the merits of this solution and others.</td>
</tr>
<tr>
<td>6) Help screens</td>
<td>Help screens indicate how to complete the survey and are available for tutorials in the event problems arise.</td>
<td>Help screens are designed to display help text and short health educational videos.</td>
</tr>
<tr>
<td>7) Progress thermometer</td>
<td>An indicator for self-administration to allow respondent to assess his/her completion status. This is a feature the paper survey affords you.</td>
<td>Titles of survey sections are indicated in the title area</td>
</tr>
</tbody>
</table>

Despite the differences in environment for Beebe and MADELINE, the features necessary for moving from a paper and pencil survey to a computer-aided survey are very similar. Beebe added some functionality, such as the ability to jump to any question and quitting and continuing later, that are specific to their environment (i.e., test
administrator/troubleshooter). MADELINE does not have the luxury of training or monitoring users, therefore, the functionality had to be more simplistic.

Based on information supplied by IBM, the most compelling design solutions are ones that are simple, natural to use, and completely in tune with users' needs and experiences (IBM, 1999). This concept is essential in user interface design and there are certain basic design principles that were addressed in the design of the MADELINE prototypes. The principles are simplicity, support, familiarity, obviousness, availability, and safety. The goal of the user interface is to empower the user. Below are the aforementioned principles and how they were included in the MADELINE design.

Simplicity: Particularly because the intended users have low literacy levels and little or no computer experience, simplicity was a major factor in the MADELINE interface design. The goal of the design was to provide the user with a straightforward interface and not distract the user with unnecessary functionality. The layout was most affected by this principle. The layout is broken into 4 areas: title, help, question, and response. Each area serves a specific function and does not deviate from that task. This falls in line with the simplicity principle as describe by IBM Ease of Use/Design Basics (IBM, 1999). The consistency of the layout and the functions of the areas help simplify the interface and allow the user to quickly develop familiarity with the interface.

Familiarity: Familiarity is considered a support mechanism. IBM’s support principle says, “The system should allow user to establish and maintain working context, or a frame of reference” (IBM, 1999, paragraph 8). In other words, the interface should
remain stable throughout. Because of the stability of all screens, the user will become knowledgeable about the layout, which will potentially lead to less anxiety toward the system.

Obviousness: Another major contributor to the user feeling at ease is the principle of obviousness. The IBM guidelines describe obviousness as the use of real world representations. When dealing with a graphical interface, the merging of these principles is essential in empowering the user to accomplish the goals of the interface. In this interface, we applied these principles by the use of standard words and icons to represent functions. For example, video with a picture of a camera may help the user understand that these representations allow them to activate a film or video. By using images and terms with which the user may be more familiar, user comprehension is increased and better interaction with the interface is possible.

Availability: The IBM guidelines describe availability as the placement and availability of functionality throughout the survey. This principle is essential to comfort in completing the survey. This was accomplished in this survey by placing icons uniformly across each screen.

Safety: Safety is important for a successful interaction with the user interface. It is your responsibility as the designer to prevent the user from making errors. This can be accomplished through closed-ended questions, data masks, and informative error messages. For this interface, the option of closed-ended questions was employed. This
controls the user input and prevents them from entering unacceptable data. It can minimize user frustration, but not totally because responses may not encompass all possible answers for all users (Babbie, 1998). This mechanism will lower non-responses and prevent the user from entering erroneous data.

Because of our special population, we have to consider some user-centered decisions. McNally states that “each group [special populations] has different needs, abilities, and preferences which must be determined to develop usable systems” (Laux et al., 1996, p. 96). During cognitive response interviews, some individuals with lower educational levels (less than 11 years of school) had difficulty pronouncing or being able to read complex words, such as gastrointestinal, but once read for the individual they can define it and understand the context in which it is being used. To address this problem, appropriate aids for this user population are being created. Text, audio, and video help will be incorporated. These assistants will give the user definitions of medical terms, and health related video clips. They also have the option of having the question and responses read aloud. This should facilitate some of the needs of the low literacy population by empowering them to be able to answer the questions. A touch screen has also been incorporated in the design. It is possible that elderly participants may have poor vision, and so all questions and responses are in large font. A final issue that needs to be considered during interface design is the prevalence of color blindness in the male population.
The MADELINE interface uses IBM’s basic principles and take a user centered approach to design. The use of these principles does not guarantee usability, but they give most designers an excellent starting point.

**Conclusion**

The results of the MADELINE prototype usability testing show patients have a high comfort level with using computers to enter health information. Patients preferred using the computer-aided intake form to the standard paper and pencil intake form because of its simplicity. Although the full help system was not tested, patients commented on the helpfulness of the text help available; they also commented that having the questions read to them when necessary would be of great assistance. These types of assistance can provide for faster data analysis and reduce non-response. Other advantages of the electronic survey are the reduction in the number of questions through use of programming logic, data consistency by means of immediate data validation, reduction in data preparation time, ease in adding or removing questions, and potential reduced cost in the long term.

With over 90 million functionally illiterate Americans, the need for tools to address their literacy concerns is evident. Health care facilities and providers would benefit from a tool to minimize the barriers that have prevented that population from receiving proper health care or relaying accurate medical history. Also, the information from those individuals may be gathered more reliably and with greater efficiency and effectiveness. This type of technology can also be expanded to include things such as health education and health prevention.
Notes

i) The total number of questions can differ based on variation in an individual’s health history.

ii) This differs from other question because a check mark does not appear next to the selected response option
Bibliography


Appendix A

National Adult Literacy Survey

Literacy Levels

Level 1
Reader has the ability to:
• Locate a single piece of information that is identical to or synonymous with the information given in the question, when the text is short.
• Perform a single, relatively simple arithmetic operation.
• Locate a piece of information based on a literal match, or enter information onto a document when little distracting information is present.

Level 2
Reader has the ability to:
• Locate a single piece of information in the text, compare and contrast easily identifiable information based on a criterion provided in the question, or integrate two or more pieces of information when low level inferences are required.
• Locate numbers by matching the needed information with that given, infer the necessary arithmetic operation, or perform a single arithmetic operation, when the numbers and the operation to be performed are stated in the task and the quantities are easily located in the text or document or from the format of the material.
• Match a single piece of information, cycle through information in a document, integrate information from various parts of a document, or generate written information by entering requested information in the proper place.
Appendix B

Draft Final Question Set
Low literacy

1. What is your first name? *Free text*
2. What is your last name? *Free text*
3. What is your social security number? *Free text*
4. How old are you? *Free text*
5. Are you?
   - Female
   - Male

6. Please select any of the following items that you come in contact with in your job that may be causing you difficulties? *Choose all that apply.*
   - None
   - Toxic dust or chemicals (poisons)
   - Heavy lifting/ repetitive or awkward motions
   - Needle sticks/infections
   - Violence
   - Injury
   - Radiation
   - Noise
   - Stress
   - Other (*free text*)

7. Personal Health History
   What are the main health concerns you want addressed at this visit? *Choose all that apply.*
   - None
   - Change in appetite
   - Changes in bowel habits (constipation, diarrhea, blood, pain, tar-like stools, differences in form or frequency)
   - Changes in skin color
   - Changes in sleeping pattern
   - Changes in urinary pattern (pain, frequency, color, difficulty)
   - Chest pain
   - Convulsions or seizures
   - Coughing up blood
   - Depression
   - Difficulties with sexual activities
   - Difficulty handling stress
   - Dizziness
   - Ear disease or hearing difficulty
   - Easy bruising or unusual bleeding
   - Enlarged or swollen lymph glands
   - Eye problems or vision impairment
   - Fainting or loss of consciousness
   - Fevers or severe chills
   - Frequent or chronic cough
   - Frequent or severe headaches
   - Food intolerance
Hemorrhoids or irritation
Important family problems
Intolerance to heat or cold
Joint pains/stiffness
Major life changes
Night sweats
Nose, sinus, mouth or throat problems
Palpitations or heart fluttering
Problems with your work
Shortness of breath
Skin disease or rashes
Stomach pain or bloating
Swelling of hands, feet, ankles
Varicose veins
Weight gain or loss without trying
Other (free text)

8. Please check off each item below that you have now or have had in the past? Choose all that apply

Feedback loop for age or year entry for each selected answer

None
Asthma
Emphysema/ Bronchitis
Pneumonia
Tuberculosis (TB)

Heart Attack
Heart Failure
Heart Murmur
High Blood Pressure
Irregular Heart Beats
Rheumatic Heart Disease.
Stroke

Depression
Nervous Breakdown

Anemia (low blood iron)
Cancer
Other Blood Problems.

Multiple Sclerosis (MS)
Seizures/Convulsions

Chronic Skin Disorder.

Diabetes (sugar in the blood)
Menopause (the change of life)
Thyroid Disease
Other Hormone or Metabolism Problem

Migraine

Gall Bladder Disease
Hepatitis
Infection
Jaundice (yellowing of the skin)
Peptic Ulcer Disorder

Kidney Stones
Renal Disease
Urinary Infection
Arthritis
Lupus
Gonorrhea
Herpes
Syphilis
Other Venereal Disease (STD)

Other (free text)

9. Which operations have you had? Choose all that apply.
   - Appendix out
   - Arthroscopy (scoping of knee or other joint)
   - Endoscopy (scope upper GI tract)
   - Colonoscopy (Colon examined with a tube)
   - Gall bladder removal
   - Heart bypass (CABG)
   - Heart surgery
   - Hemorrhoid surgery
   - Hernia repair
   - Hip replaced/fixed
   - Hysterectomy (female surgery)
   - Prostate surgery
   - Surgery to fix broken bones
   - Tonsils and adenoids removed (T and A)
   - Tubes tied
   - Undescended testicle or other testicle surgery
   - Vasectomy

10. Which hospitalizations have you had in the past? Choose all that apply.
    None
    Change in appetite
    Changes in bowel habits (constipation, diarrhea, blood, pain, tar-like stools, differences in form or frequency)
    Changes in skin color
    Changes in sleeping pattern
    Changes in urinary pattern (pain, frequency, color, difficulty)
    Chest pain
    Convulsions or seizures
    Coughing up blood
    Depression
    Difficulties with sexual activities
    Difficulty handling stress
    Dizziness
    Ear disease or hearing difficulty
    Easy bruising or unusual bleeding
    Enlarged or swollen lymph glands
    Eye problems or vision impairment
    Fainting or loss of consciousness
    Fevers or severe chills
    Frequent or chronic cough
    Frequent or severe headaches
    Food intolerance
    Hemorrhoids or irritation
    Intolerance to heat or cold
    Joint pains/stiffness
    Night sweats
    Nose, sinus, mouth or throat problems
Palpitations or heart fluttering
Problems with your work
Shortness of breath
Skin disease or rashes
Stomach pain or bloating
Swelling of hands, feet, ankles
Varicose veins
Weight gain or loss without trying
Other (free text)

11. Do you currently take any medications? [If no, skip to 15]
   Yes
   No

12. Which of the following medications are you taking? Choose all that apply.
   Clarence will have to get you this list—it is quite exhaustive.

13. When do you take this? [For each medication chosen—feedback loop]
   1 time a day
   2 times a day
   3 times a day
   4 times a day
   More than 4 times a day
   As needed
   Other (free text)

14. What is the dose? (free text) [For each medication chosen—feedback loop]

15. Are you allergic to or have you had any bad reactions to medications? [If no, skip to 17]
   Yes
   No
   Don’t know

16. Which medications have caused a bad or allergic reaction? Choose all that apply.
   Aspirin
   Dilantin
   Erythromycin
   Penicillin
   Sulfa
   Tegretol
   Tetracylines
   Other (free text)

17. Other than your primary care doctor what other type/s of doctor are you currently seeing? Choose all that apply.
   None
   Blood doctor (Hematologist)
   Bone/joint doctor (Orthopedist)
   Cancer doctor (Oncologist)
   Ear, nose, throat doctor
   Family doctor or Internist
   Heart doctor (Cardiologist)
   Neurologist
   Ob/Gyn (Obstetrician/Gynecologist)
   Psychiatrist
Rheumatologist
Skin doctor (dermatologist)
Stomach/intestines doctor (Gastroenterologist)
Other (free text)
Don’t know

18. Do any of the following live with you? Choose all that apply
   Spouse/significant other
   Mother/Father
   Sister/brother
   Grandparent
   Child/children
   Roommate
   Other (free text)

Family Health History
*The following questions are about your family health history.*

19. Which family members have had high blood pressure? Choose all that apply.
   None
   Don’t know
   Mother
   Father
   Brother
   Sister
   Other (free text)

20. Which family members have had a heart attack? Choose all that apply
   None [skip to 22]
   Don’t know [skip to 22]
   Mother
   Father
   Brother
   Sister
   Other (free text) [skip to 22 and not 21]

21. About how old was your _________ when the first heart attack occurred? (Feedback loop for each family member checked)

22. Which family members have had a stroke? Choose all that apply
   None [skip to 24]
   Don’t know [skip to 24]
   Mother
   Father
   Brother
   Sister
   Other (free text) [skip to 24 not 23]

23. About how old was your _________ when the first stroke occurred? (Feedback loop for each family member checked)
24. Which family members have had Cancer? Choose all that apply
None [skip to 26]
Don’t know [skip to 26]
Mother
Father
Brother
Sister
Other (free text) [skip to 26 not 25]

25. What type of cancer did your ______ have? (feedback loop for each family member checked)

<table>
<thead>
<tr>
<th>Mother/sister list</th>
<th>Father/brother list</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bladder</td>
<td>Bladder</td>
</tr>
<tr>
<td>Bone</td>
<td>Bone</td>
</tr>
<tr>
<td>Brain</td>
<td>Brain</td>
</tr>
<tr>
<td>Breast</td>
<td>Breast</td>
</tr>
<tr>
<td>Cervical</td>
<td>Colon</td>
</tr>
<tr>
<td>Colon</td>
<td>Larynx or throat</td>
</tr>
<tr>
<td>Larynx or throat</td>
<td>Leukemia/lymphoma</td>
</tr>
<tr>
<td>Leukemia/lymphoma</td>
<td>Liver</td>
</tr>
<tr>
<td>Liver</td>
<td>Lung</td>
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<tr>
<td>Lung</td>
<td>Pancreas</td>
</tr>
<tr>
<td>Ovarian</td>
<td>Prostate</td>
</tr>
<tr>
<td>Pancreas</td>
<td>Skin (melanoma)</td>
</tr>
<tr>
<td>Skin (melanoma)</td>
<td>Testicle</td>
</tr>
<tr>
<td>Uterine</td>
<td>Don’t know</td>
</tr>
<tr>
<td>Don’t know</td>
<td>Other (free text)</td>
</tr>
<tr>
<td>Other (free text)</td>
<td></td>
</tr>
</tbody>
</table>

26. Have any family members had a Mental Health Problem? Choose all that apply
None
Don’t know
Mother
Father
Brother/sister
Other (free text)

27. Have any of your family member’s have/had Diabetes (sugar in the blood)? Choose all that apply
None
Don’t know
Mother
Father
Brother/sister
Other (free text)

28. Have family members had a drug or drinking problem? Choose all that apply
None
Immunizations
The following questions are about your immunization history.

29. When did you get your last tetanus (lockjaw) shot?
   Don’t know
   Never
   Less than 10 years ago
   More than 10 years ago

30. When did you get your last Rubella (measles) shot? [female only]
   Don’t know
   Never
   Less than 15 years ago
   More than 15 years ago

31. Have you had a shot for pneumonia in the last 15 years?
   Yes
   No
   Don’t know

32. Have you had a flu shot in the past 12 months?
   Yes
   No
   Don’t know

33. Have you had a Hepatitis B shot series?
   Yes
   No
   Don’t know

Health-Related Habits
Your answers to following questions will help your doctor assess risks to your health.

34. Have you smoked at least 100 cigarettes in your life?
   Yes
   No [skip to 38]
   Don’t know [skip to 38]

35. Have you smoked a cigarette in the past 7 days?
   Yes
   No [skip to 37]
   Don’t know

36. About, how many cigarettes a day do you smoke?
   Less than ½ a pack
½-1 pack
1-2 packs
More than 2 packs
Don’t know/Not sure

37. How long have you smoked? [skip to 38 once answered]
   Less than 5 years
   5-10 years
   11-15 years
   More than 15 years

38. When did you quit smoking?
   Never smoked daily
   0-6 month ago
   7-12 months ago
   2-5 years ago
   6-15 years ago
   More than 15 years ago
   Don’t know/not sure

39. Do you currently smoke cigars?
   Yes
   No

40. Do you currently chew tobacco or dip snuff?
   Yes
   No

41. Do you drink alcoholic beverages?
   Yes
   No [skip to 43]
   Don’t know [skip to 43]

42. How many drinks do you have in an average week? One drink is 1 beer, 1 glass of wine, 1 wine cooler, 1 shot of liquor or 1 cocktail.
   1-2
   3-4
   More than 4
   Don’t know

43. Have you ever felt you ought to cut down on drinking?
   Yes
   No

44. Have people annoyed you by criticizing your drinking?
   Yes
   No

45. Have you ever felt guilty about drinking?
   Yes
46. Have you ever had a drink first thing in the morning to steady your nerves or get rid of a hangover?
   Yes
   No

47. Have you used recreational/street drugs?
   Yes
   No
   Don’t know

47. In the past 10 years, have you had sex with someone who used street drugs with a needle?
   Yes
   No
   Don’t know

48. Did you have a blood transfusion between 1978 and 1985?
   Yes
   No
   Don’t know

49. In the past 5 years, did you ever drive while drunk?
   Yes
   No

50. In the past 5 years, did you ever ride with a drunk driver?
   Yes
   No
   Don’t know

51. Do you ever ride in the front or back seat of a car without wearing a seatbelt?
   Yes
   No

51. Have you had a new sex partner or more than 1 partner in the past year?
   Yes
   No
   Not sexually active [skip to 54]

52. Do you have any concerns about your sexual activity? (Pain during sex, don’t enjoy sex, or getting a sexually transmitted disease (STD). [male only add troubles having an erection]
   Yes
   No

53. Are you concerned about your weight?
   Yes
   No

54. Are you concerned about your eating habits?
   Yes
   No
55. How many days a week do you get physical activity?
   1-2
   3-5
   5+
   None

56. Do you have a living will?
   Yes
   No

For Women Only
   The following questions will ask you about your breast cancer risk and your gynecological and childbirth history.

   Breast Cancer Risk Assessment History
57. Have you had breast cancer?
   Yes
   No

58. Have you had problems with your breasts?
   Yes
   No

59. How old were you when you had your first child?
   Under 18 years old
   18-23 years old
   24-29 years old
   30-35 years old
   35 years old or older

60. Do examine your breasts at least once a month?
   Yes
   No

61. When was your last mammogram (breast x-ray)?
   Less than 1 year ago
   1-3 years ago
   3-5 years ago
   More than 5 years ago

   Menstrual History

62. About how old were you started having periods? (Free text)

63. Are you still having periods?
   Yes [skip to 66]
   No
64. How old were you when you stopped having periods? [Skip to 68 upon answering] 
   Less than 35   45-49
   35-39  
   50-55
   40-44  
   55+

65. Are your periods regular (at least once a month/every 28-32 days)?
   Yes
   No

66. Are you having problems with your period (such as heavy bleeding, bleeding between
   periods, or periods less than 28 days apart)?
   Yes
   No
   Don’t know

Gyn History

67. When was your last Pap smear?
   Less than 1 year ago
   Less than 2 years ago
   Less than 3 years ago
   3-5 years ago
   5+ years ago
   Don’t know/not sure

68. Have you ever had an abnormal Pap smear? [If no/don’t know, skip to 71]
   Yes
   No
   Don’t know

69. What treatment did you get for your abnormal Pap smear? Check all that apply
   Don’t know
   Repeat pap only
   Coloscopy only
   Coloscopy and some other treatment (freezing, LEEP, laser acid (5-FU), surgery)
   Hysterectomy
   Other (free text)

Childbirth History

70. How many times have you been pregnant? (Include all pregnancies even if ended by
   miscarriage or abortion) [If none, END OF SURVEY] [Do a number line to touch or click
   on, include 0 as the none variable]

71. How many live births have you had?
   0
   1
Male Only Questions

57. Have you ever had surgery on your testicles or undescended testicles? (this should have been captured in #9)
   Yes
   No

58. Have you ever had ongoing pain or swelling in your testicles?
   Yes
   No

59. Do you examine your testicles at least once a month?
   Yes
   No

60. Are you sexually active? [If no, END OF SURVEY]
   Yes
   No

61. What type of birth control do you use? Choose all that apply.
   Condom
   Withdrawal
   Sterilization/vasectomy
   Partner/s takes care of it
   None
   Other (free text box)

Updated on 12/04/99
Created by Lisa A. Sutherland
MADELINE RESEARCH PROJECT

Earn $25 for one hour!

We are seeking patients to complete a one-hour interview about new patient survey forms.

No physical exam involved - just questions.
Appendix D

Usability Interview Protocol
(Low computer skills, Low literacy level)

Screening and Recruitment
Research assistants will recruit five participants at each testing phase via convenience sampling. The project director will get permission from the clinic director, Evelyn Schmidt, to recruit participants at Lincoln Community Health Center at a designated date and time. Research assistants will set up a booth to screen participants in the health center lobby. Eligible participants will be categorized into the low literacy, low computer skills bin if they have (1) a high school education or below and (2) do not meet the following computer screening criteria:

1. How comfortable are you at entering information into a computer?

   ___ Not at all comfortable (do not accept)
   ___ Somewhat comfortable (go on to #2)
   ___ Very comfortable (accept)

2. Of the following devices, software, and systems, check those that you have personally used and are familiar with:

   Set a
   ___ touch screen
   ___ mouse
   Set b
   ___ typing/word processor
   ___ database or graphic design
   ___ accessing the World Wide Web/Internet
   ___ e-mail

   Accept if:
   Mouse + any item from list b = high
   Mouse and touch screen = high

Participants who do not meet eligibility requirements will be given a water bottle. All eligible participants will be scheduled to have an interview completed at the clinic that day. Interviews should be scheduled at one-hour intervals on a first come, first serve basis. As soon as the sample quota has been scheduled for interview, recruitment will end and the booth will be dismantled.

Eligible participants will be asked to sign a consent form indicating that they understand: (1) the purpose of the study, (2) that they will receive 25 dollars upon completion of the interview, and (3) that their participation will be videotaped. Background demographic information will be collected for each participant including contact information, gender, age, and race.

Interview Format
Interviews will be conducted in a designated conference room at Lincoln Community Health Center. Two research assistants will assist in the interview process; one will serve to conduct the interview while the other takes notes. The interview will be videotaped. The videocamera will be set up prior to the subject entering the testing area in a standard fashion to capture the subject’s interaction with the keyboard and screen only. The primary interviewer should explain to the participant that the video camera will not capture their face, but will instead capture their interactions with the computer screen. If the participant does not consent to videotape, the interview will be audiotaped to ensure appropriate documentation of the participants’ responses. (If the subject refuses to be both audiotaped and videotaped, the interview can still take place as long as both interviewers feel comfortable that the responses will be adequately recorded.)

Prior to obtaining participant’s consent, the interviewer will explain the purpose of the research study and will allow the participant to read the study consent form and to ask any questions. The participant will then be given the following instructions:

*The purpose of this interview is to get your feedback on a survey we are developing. We are designing a way to ask medical history questions in clinics like this one using a computer system. Your feedback will help us to create a user-friendly computer-based survey that all patients can use. I know that you do not have that much experience using computers, but that is exactly why we need your help. We want to design a system that people who have not used computers can use. The computer will ask you a set of questions about your medical history, current health problems, and family health history. We would like you to pretend that you are coming to see your physician for an appointment and that you are told to fill out this questionnaire on the computer. We are not interested in your answers to the questions. You can make up answers to the questions if you prefer. What we are interested in learning is how you are responding to the computer system. If, for example, you know what to do, how to input your data, how to move on to the next questions, etc. We don’t expect you to know how to use a computer so you will definitely have some questions and things that you don’t understand. That is exactly why you are here. We want people like you who do not use computers very often to be able to use this computer when you come to the clinic.*

*While I will be guiding you through this process by asking you some follow-up questions, I really want you to pretend that you are completing this on your own. Try to talk out loud anything that doesn’t make sense to you or that confuses you. Remember that there are no right answers. We are just interested in finding out your preferences in designing a system that will be usable to you and most other people with your level of computer experience.*

*Everything that you tell us today will be kept confidential. This means that the information we collect will only be used by us to help us design this program. Do you have any questions for us before we begin?*

The interviewer will let the participant know that they can stop the interview at any time and that the interview process will take between 30 minutes and one hour. The participant will sit in front of the computer screen. The interviewer will open the survey in Netscape. Videotaping will begin as soon as the participant starts to complete the health risk assessment survey.

During the survey, the interviewer will ensure that the participant moves through the survey and will encourage the participant to verbalize their actions. While the interviewer will most likely have to explain to the subject initially how to touch the screen to input data, she should first observe the participant’s uninstructed actions. Whenever the participant does something
incorrectly the interviewer will ask the participant to explain why they decided to do what they did and how the program/ instructions might have been clearer for them. Some examples of probes that the interviewer may use include:

“Why did you decide to do that?”
“What do you think that you are supposed to do now?”
“How would you prefer to give your answer?”

Interviewers should make sure that the participant discusses the following design features over the course of the interview:

- The help function and when/how/why they would access it
- Moving back and forward through the questions
- Choosing more than one answer
- Free text options
- The other response choice

When the last question of the health risk assessment survey is answered or at the end of one hour, the interviewer will let the participant know that the interview is over. The interviewer will ask the participant if he/she had any other comments about the interface that they did not share and thank them for their time. The interviewer will also offer to answer any other questions that the participant may have about the study purposes. Upon completion of the interview, participants will be paid 25 dollars and will be required to sign a receipt indicating that they have accepted this payment. The participant will also receive a copy of the consent form to keep for their records.

Within 48 hours of completion of each interview, the interviewer will file participants’ original signed consent form in Madeline offices and will submit receipts to the Nutrition Accounting Offices. Copies of receipts as well as patient demographic information will also be filed in Madeline offices.
Appendix E

RESEARCH STUDY FACT SHEET

The University of North Carolina at Chapel Hill

What is the purpose?
The purpose of this study is to help develop a new computer-based health survey for patients and doctors to use.

Why have you been asked to take part in this study?
You have been asked to be in this study because you are a patient at Pickens or Lincoln Health Center.

What is this study about?
This study will ask for your opinions and understanding of a computer-based patient health history survey.

What will be done in the study?
You will be asked to participate in an interview. The interview takes about one hour. We will ask about a computer-based health survey designed for patients to complete before a doctor's visit. You will be asked to tell us your thoughts and opinions about the computer-based survey. You may refuse to answer any questions that you do not wish to answer. The discussions will be videotaped in order to have a record of what you have said.

What if you do not want to participate in the study?
You do not have to participate unless you want to. There will be no penalty for refusing to be part of the study. You may stop participating at any time.

Are there any risks?
There are no known risks to participating.

Are there any costs?
There is no cost to participate.

What are the benefits?
You may benefit by learning more about health information. You will also help the clinic to design a better health survey for patients. You will receive 25 dollars for participating in the interview.

Confidentiality:
All the information you provide will be kept confidential. The interview will be videotaped for our records and will only be used for this study. Videotapes will be kept in locked files at the University of North Carolina Department of Nutrition. You may refuse to be videotaped at any time. Your name will not be identified in any report or publication of this study or its results. After review, all videotapes will be destroyed.
Who can you contact to answer questions about the study?
If you have any questions, you may call (collect) Dr. Marci Kramish Campbell at the
University of North Carolina Department of Nutrition (919-966-7230). This project has
been reviewed and approved by the School of Public Health Review Board for
Research Involving Human Subjects.

Signature ____________________________   Date ___________

Printed Name _________________________
Address _____________________________
Phone # _____________________________
Acknowledgements

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