

Usability Issues in Developing a Web-based Consumer Health Site

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ClinicalTrials.gov is a Web-based system intended for a diverse audience, including patients, family members and other members of the public. Throughout the system design and development process, our decisions have been driven by usability concerns. We first describe the overall design of the site, including the home page, which provides a site overview and rapid access to the information contained within it. Next we discuss the data presentation format which has been standardized in spite of data coming to us from many different sources. We provide a detailed description of the search and browse features that are intended to simplify the complexities of medical terminology and support information discovery. We conclude with a review of our evaluation activities and future plans.

INTRODUCTION

We have recently developed a Web-based system for clinical trials information called *ClinicalTrials.gov* [1]. The system is a National Institutes of Health (NIH) resource that became available in February 2000. It provides patients, families, health care professionals, and members of the public easy access to current information about clinical research studies. The first version contains information about some 5,000 clinical trials, most of which are supported by the NIH. The work was initiated as a result of the Food and Drug Administration (FDA) Modernization Act of November 1997, which requires the establishment of such a registry [2]. Because the system is intended primarily for the public, a variety of usability issues needed to be carefully considered and addressed. The system must be easy to access and use by people with varying experience in Web-based searching and with widely varying medical knowledge. Further, the information retrieved needs to be presented in a readily understandable form as well as being appropriately placed in the overall health care context. As is the case in all system design and implementation, it is important to involve users of the system throughout the development and enhancement process.

SITE DESIGN

Since the primary audience for our site is members of the public, we spent some time early in the project investigating a number of existing consumer health

sites. We looked at the features that seemed to work, and others that we felt either introduced undue complexity or were otherwise undesirable for our purposes. We conducted extensive literature searches and compiled a bibliography of work on clinical trials issues, including a variety of consumer issues. This preliminary work informed our design of the *ClinicalTrials.gov* site, with all design decisions being driven by our desire to create a site that would be fully accessible to consumers, many of whom would be seriously ill.

We designed the home page to provide an overview of the site and to allow rapid access to the information contained within it. Figure 1 below shows the current home page.



Figure 1. *ClinicalTrials.gov* homepage

The brief explanatory text describes the purpose of the site and answers the questions "Where am I?" and "What does this site do?" A navigation bar provides rapid access to seven top-level pages. Because people use different strategies for accessing information [3], both search and browse capabilities are supported. A prominent search box is available

near the top of the screen. This simple search mechanism provides a broad, recall-driven capability designed for use by the typical visitor. The focused search capability, on the other hand, is precision-driven, and clicking on this link takes users to a form that allows them to search by specific data field (e.g., location, condition, and trial identifier). Two browse options allow users to explore the data through different filters (by condition and by sponsor). Finally, users who want to get a better understanding of clinical trials, as well as general information about health issues, are provided with links to high quality health resources.

The overall architecture of a Web site can be described as depth- or breadth-oriented [4]. The appropriateness for a particular site depends on factors such as the goals of the site, the nature of the information, and the intended audience. Depth oriented sites contain deeply embedded interior pages that often contain highly specific content. Breadth oriented sites, on the other hand, give users a high-level overview when they first enter the site and then provide easy access to next level pages. Because *ClinicalTrials.gov* is a data repository aimed at helping patients and health consumers rapidly find comprehensive and accurate information that is technical in nature, it uses a combination of these approaches. Figure 2 illustrates the architecture of our Web site.



Figure 2. Schematic showing the number of moves (arrows) from the *ClinicalTrials.gov* home page (shaded circle, center) required for users to reach lists of study protocol titles (icons).

Because searches are query driven, paths from search forms to data require very few moves (1-2 mouse clicks). Results pages list the study protocol titles, together with a listing of the values of key data

elements (i.e., recruitment status, brief title, and conditions) of the retrieved documents. If the topics of the documents are too broad or narrow, users can quickly recover by returning to the search form with a single move and proceed to modify their queries. When searching, the results are determined once a query is submitted. Browsing, on the other hand, is directly influenced by contextual factors. That is, users may encounter something of interest along the way to their original goal or anticipated destination [5]. Thus, because browse paths are designed to facilitate exploration and discovery, the number of moves required for browse is greater than search. Overall, the site architecture emphasizes breadth over depth; a maximum of four links need to be traversed from the home page to reach a detailed study page.

MANAGING AND PRESENTING THE CONTENT

Data are currently provided to us from some twenty-one groups at the NIH, and in the future, we will be receiving data from many other groups in other Federal agencies and the private sector. For the user, it is most important that the data be presented in a clear and consistent way, no matter where the information originated. We worked with our NIH and FDA colleagues in the establishment of a set of standard data elements and a standard way of sending these to us [6]. As a record is added to the system, it is assigned a unique identifier, which consists of the prefix “NCT” followed by eight digits.

When users access a record in the system, they consistently see a record structure that contains four high level elements: *Purpose*, *Eligibility*, *Location and Contact Information*, and *More Information*. These four high-level elements impose a structure on data that have come from a large number of sources and might otherwise be heterogeneous in presentation. At the top of each record the user will find the title, the recruiting status of the study, and its sponsor. The purpose section, in addition to a prose summary, also includes a table that allows the user to see at a glance what condition is being studied, what the intervention is, and what the phase of the trial is. Just below the table, there will often be links to possibly relevant MEDLINE^{plus} topics [7]. The eligibility criteria give the age and gender of participants who might qualify, together with specific criteria expressed in text form. Location and contact information includes names, addresses, and telephone numbers of those who are conducting the study.

The final *More Information* section may include URL’s for related sites, links to MEDLINE® citations that are relevant to the study, and links directly back to additional information for that trial

on the data provider's Web site. Since the links are made at the individual record level, they function as "just-in-time" information, helping users place the sometimes quite technical information in context. The information that patients find on the site should be a good starting point for discussions with their physicians. Together, they can evaluate potentially appropriate studies for which they might be eligible in the context of their overall care.

SEARCH FUNCTIONALITY

In order to provide support to users as they search our site, we have developed a terminology server that assists in the following ways. The server

- defines and enforces a flexible query grammar;
- expands terms with their synonyms;
- expands words with their lexical variants; and
- generates alternative spellings for unknown words.

The general search strategy is to generate several alternative forms of the query. If the original query produces results, the alternative queries are not executed. Phrases are initially searched as is, i.e., all the words must be found, in the original order, and adjacent to one another. Phrases are then relaxed into an <and> clause and, finally, into an <or> clause. For example, if the search for the phrase "advanced lung cancer" produces no results, a second search for the intersection of each of the individual words is performed. If that search produces no results, a third search for any of the words, anywhere in the document, is performed. This last search is so broad that the results are accompanied by a note suggesting that the search be reformulated. In all cases, the search strategy that was actually used is displayed on the results page, providing feedback to the user.

Within each of the query versions, the terminology server expands recognized terms into an <or> clause of whatever Unified Medical Language System (UMLS) synonyms are found in the data [6]. For example, the query "Lou Gehrig's disease" is expanded to include the synonyms "ALS" and "amyotrophic lateral sclerosis", both of which are found in the clinical trials data.

Word variation is performed in a similar manner. Variants are generated by the UMLS lexical programs. If a user enters a word that is not recognized as a word in the database, the terminology server offers several nearby alternatives that actually occur in the data. An n-gram algorithm [8] finds alternatives that have many letter pairs in common with the unrecognized word. This approach finds, for example, "heart", "heat", "hart", and "haart", as

alternatives for the misspelled "haert". A metaphone algorithm [9] offers alternatives that normalize phonetically to the same form. Vowels are dropped and similar sounding consonants are grouped together. Finally, a look-up table provides alternatives for known common misspellings. The quality of all the alternatives is evaluated and ranked, and only the best alternatives are presented to the user.

Browse is a useful alternative to textual search. A traditional text-search interface demands that the user think of and type in search terms. If no matches are found, users might worry that they chose poor search terms, or that they spelled those terms incorrectly. In other words, that the system didn't understand what they wanted [10]. One goal of a browse interface is to avoid this problem. Browse starts by presenting a small set of top-level categories. The user selects the desired category and is then presented with a new list of subcategories, and so on, until the desired information is found.

A browse interface lends itself to user discovery by showing what the system has instead of just asking what the user wants. Whereas a text-based search engine can do an acceptable job without any real knowledge of the data being searched, a browse engine must be able to place each data point in a conceptual hierarchy. An important aspect of our browse capability involves taking an arbitrary disease or condition name from our incoming data and mapping it into the National Library of Medicine's (NLM's) Medical Subject Headings (MeSH). For example, a study whose only condition is "mesothelioma", and whose text makes no specific mention of any other diseases would normally be missed by a search for "cancer". Using synonymy to assist the search is not feasible, since performing a text-based search on all possible synonyms for all possible kinds of cancer is undesirable. Instead, at data ingest time, we annotate this study with all ancestors of the MeSH term "mesothelioma", a list which includes "adenoma" and ultimately the top-level category "neoplasms", which is itself linked to the "cancer" subtree.

Since browse demands navigating through a large concept space, the user must be able to do so with as little visual interference as possible. The pages should be identical in structure so the user is not surprised when following a link. Moving up and down a large hierarchy will quickly leave users wondering "Where am I, and how did I get here?" -- particularly if they are not where they want to be. We show the full browse path at the top of every page in the browse hierarchy. The current page is shown prominently, and each ancestor is hyperlinked

to that exact level of the tree, so that users can quickly back out of a subtree.

EVALUATION

Because patients and other members of the public are the primary intended users of the system, we conducted a number of public outreach activities during system development. For example, early in the development process, we presented a project overview to the NIH Director's Council of Public Representatives, an advisory committee that provides direct public input to the director of the NIH [11]. The presentation included four hypothetical user scenarios with preliminary screen designs to illustrate how the system might be used. Later in the development, the prototype was demonstrated at several public events. These formal and informal outreach activities allowed us to focus on a variety of usability issues relevant to our user population throughout the development cycle [12].

Several months before we were ready to make the system publicly available, we conducted a focused test involving members of voluntary health organizations belonging to the National Health Council. More than 60 patients and patient advocates from across the U.S. tested the system over a two-week period and gave us feedback related to the following six questions:

1. *Is the system design sensible? Is the page layout clear?*
2. *Are the messages and instructions provided by the system helpful?*
3. *Does the system work the way you expect it to? (Did it respond promptly? Were your search results on target?)*

4. *What did you like best about the system?*
5. *What did you like least about the system?*
6. *Do you have any additional comments?*

The testers uncovered a number of problems and provided many helpful suggestions. We analyzed the feedback and coded it into three broad categories. A summary of the major findings in each category is shown in figure 3 below.

In addition to involving potential users of the system in testing activities, we evaluated various technical aspects of the system. Usability research shows that 10 seconds is the maximum time Web users are willing to wait for a page to load [4]. Because the system was designed with minimal graphics and uses basic HTML with minimal JavaScript, our tests showed that, on average, system pages load within 10 seconds even at speeds of 28 kbps. Further, to accommodate user preferences, only essential design elements are implemented as server-side style sheets. Users control font type and size, and relative size specifications are used to support different screen resolutions.

We also tested compliance with the World Wide Web Consortium's Web Accessibility Initiative (WAI), through an application developed by the Center for Applied Special Technology [13,14]. The program, called Bobby, automatically checks WAI guidelines for a site, such as providing alternative text for non-text elements (e.g., graphical images) for users with text-only or text-to-speech browsers.

Category	Sample usability comments at an earlier stage of development
Site Design and Layout	<ul style="list-style-type: none"> ▪ Simplicity of screen design and navigation; focus on information content ▪ Text layout, important information at the bottom of the page (off the screen) or "buried" in secondary pages ▪ Understanding particular studies relative to larger health issues, boundaries between the system and linked sites, size of popup windows ▪ Too many jumps to "What is a clinical trial?" information (3 clicks from home page) ▪ Complexity of the URL
Presentation of Content	<ul style="list-style-type: none"> ▪ Labels that were not descriptive ▪ Language in the studies too technical ▪ Help should be separated from User's Guide ▪ Need search examples on the screen and in Help ▪ Comprehensiveness of the site (not enough studies for certain diseaseaes)
Functionality	<ul style="list-style-type: none"> ▪ Precision of search results (relevance of retrieved records) ▪ Differences between search and browse retrieval sets ▪ Difficulty in interpreting browse categories

Figure 3. Summary of usability issues resulting from focused testing

FUTURE PLANS

We plan to continue to evaluate whether user needs are being well served by our system. Together with NLM's National Network of Libraries of Medicine, we will conduct a number of outreach activities, particularly in underserved and minority communities.

During the next few months, we will also create a plan for continued usability testing, including methodologies designed to enhance and refine the interface and content of the system. We recently conducted a pilot test involving a small number of individuals who were videotaped and asked to "think aloud" as they searched for information on *ClinicalTrials.gov*. The pilot has already indicated several areas for improvement. We plan to conduct an online satisfaction survey, and we will continue to monitor and address comments and questions that come to us from users of the site.

CONCLUSIONS

The development of *ClinicalTrials.gov* has been informed by a range of usability concerns. These have been considered during all phases of development and will continue to be addressed as the system matures. Figure 4 summarizes the work we have already done, and includes an indication of what we plan to do in the future. It will be most important for us to know how people are using the system, and what we can do to improve it for their optimal use.

Development Phase	Evaluation and Usability Methodology
Analysis	<ul style="list-style-type: none"> ▪ Created clinical trials bibliography ▪ Reviewed existing consumer health Web sites ▪ Consulted with NIH clinical trials data providers
Design	<ul style="list-style-type: none"> ▪ Evaluated usability features of other consumer health sites ▪ Presented plans to members of the public and other interested groups
Development	<ul style="list-style-type: none"> ▪ Conducted internal testing ▪ Review and testing by NIH collaborators ▪ Conducted user testing with patients and advocates ▪ Conducted Web accessibility testing
Future Evaluation	<ul style="list-style-type: none"> ▪ Formal usability testing with health consumers ▪ User feedback analysis ▪ Web usage log analysis

Figure 4. Summary of usability techniques for iterative development of *ClinicalTrials.gov*

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