[QUOTIENT]

Final Report

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On-line Search Behavior
For Medical Information

Feasibility Study

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The Office of Communications and Computer Systems (OCCS)
Applications Systems Branch

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Matching Search Technology to User Expectations: Identification and Evaluation of End-user Behavioral Patterns when Accessing and Retrieving Health Information via the Web

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Introduction

This feasibility study investigated how some members of the general public (health care professionals) look for medical information on publicly available Web sites; and how they **browse** on-line medical resources, including multi-media files and educational materials. A variety of unanswered questions, as well as some emerging and already known human-computer interaction (HCI) factors on human search behavior and cognition, spawned this research. We addressed these with various study methods.

Questions that Guided this Study

- What are some usability criteria for search engine selection?
- How do users cope with ever increasing amounts of information that compete for their attention?
- How do users orient themselves in proliferating Web sites with rapidly changing and evolving content for Medical and Health Information?
- What is the desired format and/or level of language used when communicating medical / health content?
- What other orienting principles can be applied for content organization and to support information searching and **decision making**?
- How do users acquire and pursue complex medical knowledge? - Scientifically proven knowledge and science-based communication is complex. We know that most people will actively avoid complexity, yet they need the information.
- Why don't people access valuable health and medical information when it is in fact available on-line? Why can't they find it?
- Do users know what they are looking for?
- How do users know when they are "done" searching?

The practical outcome focus for this study was to document "Persona" profiles of various health professionals, define basic search scenarios and associated behavioral user strategies, derive practical **sense-making** rules and user decision models and better understand how some of the visitors to various NLM Web sites currently obtain, review and employ on-line medical information.

Study Context: From Data to Interface Design

Once data on the above topics are collected, they will be available for further on-demand analysis and will be used towards the development of usability recommendations for user-centered interface design prototypes of the various Web applications that the Office of Computing and Communication Systems

(OCCS) and their Application Development Web Group will be called upon to implement.

Prototyping

It is anticipated that, once prototypes have been developed employing a user-focused method and using these data, fewer subsequent changes will need to be made to developing Web applications (as evidenced by advocated usability testing), and that this will help to effectively manage cost and development resources and to better satisfy NLM's user constituency, the general public.

Roadmap of Study

As can be seen from Figure1 below, the scope of our activities ranged over three distinct phases and the work was conducted between October 2005 and April 2006. Each Phase built upon the knowledge gained in the preceding one. Hence, our final report addresses each phase of activities in separate sections including (1) The Literature Review Phase; (2) The Interview Phase; and (3) The Focus Group Phase.
At the time of final report preparation, we inserted any comments and notes about data, when topically appropriate, even though the insights and findings were actually collected in a subsequent phase or activity.

Throughout this report we also include summary lists of actionable recommendations for prototype development and implementation. We have marked these with the "🕮" symbol.

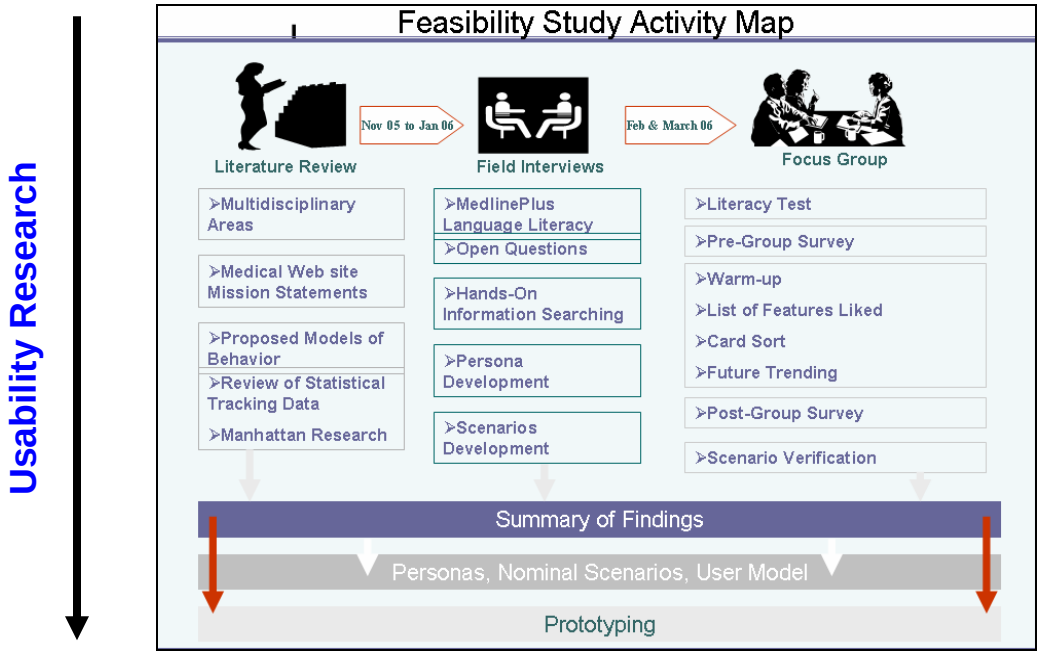

Figure 1. Overview of study activities in three phases organized into the three chapters of this report

CHAPTER I
Annotated Literature Review

The literature from the following domains was reviewed to ascertain existing scientific thinking as input to this feasibility study. Various library resources were scanned for publications with particular focus given to the following interdisciplinary domains:

- Computer Science (Search Engines and Algorithmic Approaches to Information Distilling)
- Library and Information Science (Categorization, Lexical Taxonomies and **Indexing**)
- Cognitive Science (Mental models, decision making under **uncertainty**, sense making)
- Human Factors (Information Processing, Episodic Memory and Ecological Information Architecture)
- Sociology (Cultural Factors)

Identifying **Important** Inquiry Topics

After reviewing several articles for our literature review, the following contribution areas emerged as those having the most "significance" for our topic of user searching of Medical Information on the Internet. We found these topic areas most helpful in providing a foundational framework for further inquiry and activities organization.

From the Communications Literature:

- The Concepts of ***Medical Literacy*** and *Strategic Messaging*
- Web sites as a *Medium for Health Messaging* to the public. This idea supports the concept of mission oriented Web site design.

From the CHI Literature:

- Search Engines, Search Specification, Results Presentation, *Filters and* ***Organizing*** *Schemes*, Workspaces

From Applied Cognitive Psychology:

- Searching for Medical Information as ***Sense-making***.
- Search as a *Long-Term, Goal-Directed & Contextual User Task.*

From Existing Tracking/ Survey Data and corporate research:

- *Who* goes *where*? (Which users access what information?) The "*User Market Place*"

We reviewed nearly thirty articles during the targeted time. However, during the first part of this year (2006) we took note of the fact that many big Journal publications (ACM Communications and others) have published special topic issues on the subject of searching.
Of the originally reviewed articles that seemed relevant, we selected some (see Reference list in Appendix II). Ideas and relevant topics from the articles or materials are listed and issues relevant to the goals of this study are noted.

Issue	Implication – Hypothesis – Finding Confirmed	Interface Design	User Behavior
Further actions (links) after queries are fairly universal [1] and widely expected by users.	When using a Search Engine, users expect interim results, not final destinations.	Query results should point to clearly defined Next Actions	Users expect interactive / collaborative searching.
Misspelling of queries is pretty common [1].	A self-correcting user feedback feature such as **Google**'s "Did you mean…?" is helpful.	Any tool suggesting alternate spellings or allowing searching on suggested spellings will be beneficial.	Typing as user input is fraught with miss-spellings and word selection difficulties
People don't do Boolean Searches [1]. Very few people will employ operators such as AND, OR in their search queries.	Only professional or trained searchers will likely employ these complex query tools.	Simple one-word query entries should yield results.	Some people shy away from **query formulation** and will not readily use a **search box**
Common search engines such as **Google** or Yahoo are the most frequently employed tools for Web searching. Other tools are: subject gateways and specialized search engines. [1]	Most people use **Google** or Yahoo Search to initiate a query.	Site name should be easy to remember and should be properly indexed and marketed	People use **Google** for exploration on what is out there. This is how people find sites that they would otherwise not come to.
Users employ search engines because to them they function like an encyclopedia. [1]	These gateways point them to related, and not so related, topic areas, and open up a world of to-be-discovered information.	If branding the site is important then make sure when people are on your site they have a good way to get back to it.	People like subscriptions and getting informed about new developments. Use **RSS** to get people back.

Table 1. - Contributions from the **Communications** Literature about Medical Information Searching

Sense-making

Sense-making is the cycle of pursuing, discovering, and assimilating information over time [12] during which people's conceptualization of a problem and their search strategies may change.

Issue	Implication - Hypothesis	Interface Design	User Behavior
There are several military research projects which refer to human **sense-making**.	Searching for Medical Information is seen as an attempt to reduce **uncertainty**.	In a list of results basic content and or scope information should be included to distinguish one item from the next.	Users will attempt to reduce **uncertainty** over time by re-checking and refreshing information and adding to their current knowledge store.
Sense-making is akin to having to integrate partial information from diverse sources over a certain time course (as in command & control situations and remote monitoring)	Informational value of **message**s comes in different elements over time. They can only be properly evaluated when a bigger picture already exists (**sense-making** has occurred)	User effort in accomplishing searching over time should be reduced via implementation of tools that support this activity.	Search for relevancy can occur in longitudinal fashion over time. Facilities should be provided to easily store and review already accessed items.

Table 2. Contributions from Applied Cognitive Science: Sense-making through Web Searching

Cognitive Schema

A Schema is a cognitive structure an individual uses to receive, filter, and process information and to integrate new information and experiences into a collection of coherent knowledge, past experience and attitudes.

Issue	Implication - Hypothesis	Interface Design	User Behavior
Interactivity and **feedback** loops are necessary ingredients to performing human searches.	Provisions should be made in the results list interface to allow people to refine search results.	Simple tools for search that allows users to "interact" give evaluative feedback to a search) should be included.	Users cognitively anchor at the current results and prefer to stay on a single path of inquiry (not 'restart' when encountering 'dead' ends)
Users have a personal Health schema (7) which motivates their search behavior	People will pursue information on the basis of what they already know and how they feel about something.	If new information needs to be communicated people will need to be motivated to look for it. It needs to be pushed to them.	People will typically not approach items that they know nothing or little about. They will seek advice from trusted or 'expert' sources when there is a personal need only.

Table 3. Topics Reviewed for Cognitive Modeling of Human Medical Information Searching

Modeling Search

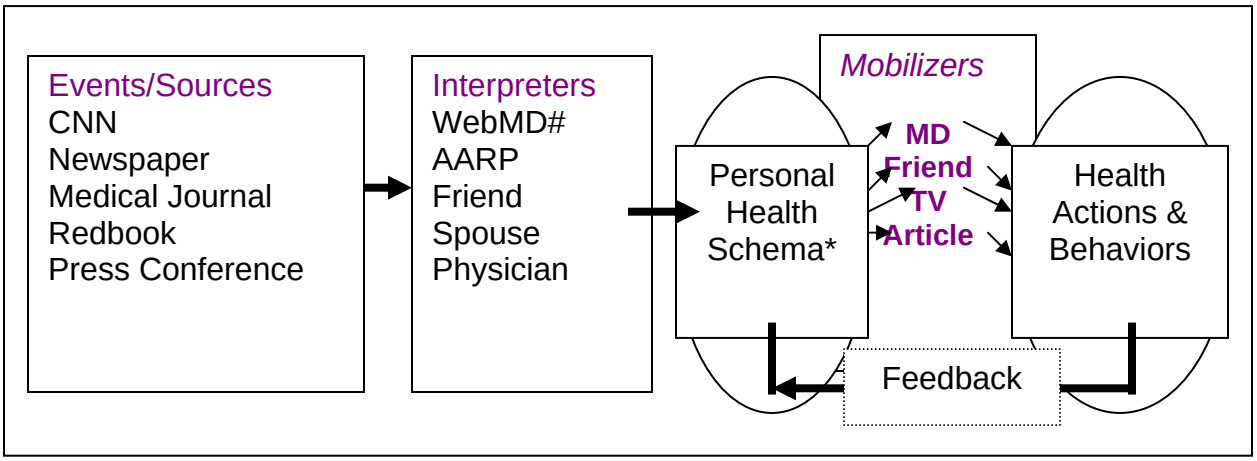

Figure 2. Simplified general (hybrid) model of biomedical communication from the perspective of the communicator (adapted from [7])

Message Content and Search Target

One of the most basic design issues for Web sites is what content will be presented. But also, design needs to consider what other **messages** will be conveyed. Here is what others in the literature have indicated that people will look for:

- Detection of early warning signs of diseases and conditions
- Assorted topics enabling users to make sensible personal decisions (diet, exercise, health maintenance activities)
- Knowledge about how to treat various illnesses and infections (those that virtually all children and adults encounter in the course of their lives). There are systematic variations in **interest** for health topics based on life-cycle, life-style, **literacy**, and family context. [7]

Annotation: Predictive "health history" (based on demographic, i.e. life-cycle statistics) can be used together with a user's personal profile and task goal identification statement to focus search on **retrieval** of specifically applicable target content.

- News and information is often discussed with family and friends and co-workers and the final acceptance, retention or **use of information** is influenced by intermediaries. [8]

Annotation: Virtual family and virtual friends provided on internet discussion (chat) boards or via expert **Pod -casts** could serve a similar mediating purpose.

- Pharmacists and nurses are mediators, particularly for older people.
- **Specialized Web sites** (by disease) synthesize information and provide patient and family oriented information about the diagnosis and treatment of diseases. [7]
- Some Advocacy Organizational Web sites provide biomedical information, policy information, and actual services. [7]

Annotation: The fact that people like organization-based non-profit sites was also reflected in our interview findings. **WebMD** was another frequently mentioned site as it is a commercially based "health portal". Factors such as easy-to-remember site names (URLs) and clear mission statements, as well as useful (service oriented) content all serve to drive **user traffic** to these types of sites. A motivating force for return behavior is one-stop shopping - however, similar to aversions to large outlet retail stores, people will not likely visit "we-have-it-all" sites unless these are well segmented and organized into user access friendly areas (meeting user needs).

Competing **Message**s [7]

It must be remembered that Web site visitors will visit many different Web sites and they also do so in the context of being bombarded with **media messages** via other channels. Medical information **messages** competing for **user attention**, and mentioned in the literature are:

- Food advertisements
- Drug advertisements
- Stories about medical discoveries
- Discussions with friends and families about health problems (if you are an educated adult, and not currently a parent, and not a senior you won't discuss problems with family and friends, but will seek health professionals' opinion) [5]

Annotation: Some health care professionals from our focus group specified that they needed content regarding newly marketed "**Nutraceuticals**", and their safety regarding interaction with prescription drugs that people may be taking. They mentioned that this is an **important** area that governmental Web sites should address and "push" with appropriate educational materials.

Use of "Found" Information

Access to Web content for Medical information occurs within an individual's larger task set, this is the information usage context. Various factors that influence user behavior are mentioned in the literature relating to user context:

- Exposure to health information alone is not adequate for effective communication; individuals must retain information for recall and use. [5]
- "The information seeking process is influenced by specific and general prior knowledge and by the costs of the search behaviors. Once knowledge is acquired, decisions about the adequacy and usefulness of the information may be influenced by the level of expertise of the information source and by the **relationship** of the source to the information seeker." [6]

Annotation: Our **interview participants** employed the "expert heuristic" to a great extent – based on recommendations by educational institutions, the **media**, or other **rules of thumb**, they tended to evaluate the quality of the source only initially, and once deemed trust-worthy, they would return there repeatedly and feel comfortable because they had been there in the past.

New Information versus Supplemental Information

A distinction can be made between to-be-found content that is brand new (likely to be a rare event) and content that is used as reference material:

- Current health information consumers use the Internet or World Wide Web to obtain additional information concerning health information about specific topics such as cancer or alcoholism that they may have heard about. [5]
- The likelihood of the consumers going to the Internet for additional information on health topics is greater than their consulting all print and broadcast media combined. Going to the library for additional information was also mentioned as a primary source of additional information. [5]

- Use of the Internet for additional information is strongly related to level of education. [5]
- The World Wide Web contains an ever-growing number of sites devoted to health and medicine in general, as well as to specific diseases. [5]
- Men more so than women (statistically significant) recalled reading news articles about cancer or heart disease or about alcoholism and mental health. [5]
- Personal experience with an illness is directly related to the ability of an individual to recall stories about health information (75% recall for people personally involved (family member) versus 51% without personal involvement.) [5]
- **Age** and health awareness are related. Fewer than half of adults aged 18 to 24 recalled hearing a story about heart disease whereas over 80% of adults aged 65 and older recalled that they read or heard a story about heart disease. [5]
- Higher levels of education and biomedical **literacy** correlated positively with health information consumption (more so than age demographics). [5]

Individuals look to physicians or other **health care providers**, the library, or the Internet, to obtain **additional disease information**

- Individuals rely on both **formal and informal** sources of health information. Formal sources include family doctors and other health professionals; **informal** sources include friends and relatives and commercial and **media** sources include television, newspapers, and **magazines**. [5]
- Highest importance ratings for preventive health information sources were associated with physicians, spouses, and nurses, while television, **magazines**, and other **media** sources received substantially lower ratings. [5]
- In 1994, older women health information seekers ranked **magazines** (both articles and advertisements) highest as their primary source for health information (next to television and newspapers. [5]

Annotation: Content specifically geared toward the older female demographic together with women's potential role as family care givers might be supported on a special area within NLM's Web sites. The "style" of content could be similar to that of **magazines** with **colorful** pictures and useful current content including to-do lists.

Targeting the **Message** to the Audience by Demographic Group

Annotation: Part of the challenge of Web design for government organizations is that, generally, "the public" is used as an undifferentiated **audience target**. In this large user target group, ultimately, everyone is included. Hence further differentiation along **message** significance categories should be made in order to maximize **interest**.

- Young adults - rely most heavily on other people for health information [5]
- Parents with children at home – television is the primary source of health information for this group [5] followed by **magazines** and news articles.
- Older adults **aged** 60 or higher – senior men and women were equally likely to be health information consumers but retention and recall varied strongly with educational attainment. (Cumulative advantage of education). No differences by race or ethnicity in this group. [5] Family and friends served as a primary source of new information on diseases.
- Other men and women (outside of the above categories) – one fifth report that they would go to a library to find additional health information. [5] Neither men nor women would seek information on alcoholism/ mental illness from friends or family.

All information consumers (SUMMARY [5]):

- **FORGETTING** - Only half of all American Adults can recall any medical information that they have heard or read in the last 2 months (**Latent versus Active consumers**)
- **FILTERING** – most American Adults effectively "**filter out" information** they don't focus on currently – Concern about health and related information is not universal.
- **CONSUMER SEGMENTATION** – the more education, the less reliance on television for health information.
- **PARENTS WITH CHILDREN** – rely heavily on television
- **INTERNET IS NOT A PRIMARY SOURCE FOR ALERTING TO NEW HEALTH INFORMATION** - Internet and library is used primarily for additional information finding, not as a primary alert source of information.

Health Information Communication Strategies – Single Disease Sites

Many examples exist where association or foundation medical Web sites have content about only one disease category. These are typically visited by individuals who look for more detailed **disease specific** information.

- Web sites for single diseases or conditions (most often hosted by a related organization-affiliated site, for example: The Juvenile Diabetes Association (JDA) or, the National Association for the Mentally Ill (NAMI)) [7]

ANNOTATION: It is conceivable that site content found in **MedlinePlus** could be organized along disease categories and their likelihood, severity, etc., where users would find sought after resource links such as Go-Local Information, association links, Clinical Trials information, Drugs used to treat that disease.

Future Trends in Human Information Searching

- Substantial convergence among **media** and major modifications in the ways that individuals acquire, store and utilize information is predicted. [7]
- Increasing Specialization of Content Providers. [7]
- A substantial portion of adults will increasingly rely on **informal learning** resources to remain knowledgeable about health topics. [7]

Web searching research is a young area and not many publications have emerged to describe how people search for information.
Spink [1] used transactional log analysis to define trends in people's search behaviors and reported the following:

- People still mostly make short and simple queries. [1]

Annotation: A brief inspection of NLM's logs and WebTrends statistics for the **MedlinePlus** site and other NLM sites confirms that most search queries consist of single words. Few visitors to this site employ multiple words or AND/OR connectors.

- A shift in topic targets from entertainment to business information presumably reflects available on-line content more than being due to demographic shifts. [1]

Annotation: In other words, the availability of on-line business content was the winner statistically for most visited on-line content, motivating overall search target browsing rather than any user or market-driven originating health goal categories. Medical searching was not mentioned nor was a distinction made between private and publicly funded sites.

Anticipated future developments and trends for Search engines [3]:

From "Nearly Complete and **Automated**" Searching, To Improved Ranking Quality of Results[1]

The following characteristics define literature references for search engine related attributes:

- Refers to self-organizing, economic or chaotic models of search spaces.
- Mentions features such as specialized themes, localized search services, **customization**.
- Continued importance of meta-tagging, Dublin Core standards[2] is predicted
- Multiple presences of "bad" search services is predicted
- Multi- and Meta-**media** search engines with pattern recognition capability is seen as the way of the future.
- Continued emphasis on more search engine "intelligence".
- Prediction: More complex queries will be possible but the human-computer interface for these will be more difficult to use.
- Hybrid Meta-Search engines with combination **indexing**
- "Level 4" search engine "dark matter finder" – concept of "deep searching"
- Dialogue-like searching is mentioned
- Meta-search engine with semantic text analyzer is discussed.

Annotation: The Dialogue-like searching reference made here acknowledges the more active role a user could play in narrowing down search goals. This is an approach with appeal based on several user-centered issues such as better human-computer task assignment based on the idea of collaboration and **successive refinements** leading to better search results (in complex search situations where such refinement is needed).[3]

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1 An unpublished paper by Kirthi Venkatraman and Renate Roske-Shelton: "Vigilant and Guided Search: A new Search Paradigm (in preparation 2006) addresses various approaches for improving search outcomes.

2 The Dublin Core Metadata Initiative (DCMI) is an organization dedicated to promoting the widespread adoption of interoperable metadata standards and developing specialized metadata vocabularies for describing resources that enable more intelligent information discovery systems.
Mission and Scope The mission of DCMI is to make it easier to find resources using the Internet through the following activities:
Developing metadata standards for discovery across domains,
Defining frameworks for the interoperation of metadata sets, and,
Facilitating the development of community- or disciplinary-specific metadata sets that are consistent with items 1 and 2

3 A recently discovered **blog** paper titled "Focused Crawling: The Quest for topic specific portals" http://www.cse.iitb.ac.in/soumen/focus/ names the "exploding volume of Web publications" and "specific portholes" as two major future trends.

User Behavior **Modeling** for Searching

This area of applied research has been spawned by a recognition that user search behavior on-line is an **important** topic deserving of study. Only initial attempts at modeling have been reported in the literature and these have almost exclusively addressed **exploratory human searching**. Other attempts at describing human behavior in searching appear too new to be published as yet.

Much attention in modeling has occurred on the system side. With the aid of defense monies, progress appears to have been made on the **data-mining** front (see References [14] and [16]).

- New aspects of behavior are recognized when people search on-line spaces but these are not yet identified. [1] There are currently no good theoretical models of user search behavior.
- Past decade has brought the "big bang" in the **amount of on-line information** available for processing by humans [4]
- On today's Web, most of the information is still intended for human consumption [4] as opposed to that provided for other automated crawlers of information.
- Tim Berners-Lee, James Hendler, and Ora Lassila described the "grand vision" for the Semantic Web in a Scientific American article in 2001[4] where ordinary Web users instruct their "personal agents" to
    - talk to one another,
    - talk also to a number of other integrated on-line agents for example,
    - to find doctors that are covered by their insurance;
    - to schedule their doctor appointments to satisfy both constraints from the doctor's office and their own personal calendars;
    - to request prescription refills, ensuring no harmful drug interactions; and so on. [4]

Annotation: The recent flurry of vendor activities offering various collaboration tools also seems to capitalize on the idea that "good results" come from multiple agents. Perhaps a community-inspired feature on a Medical Web site might include a collaboration chat room – where "have you seen this, heard this" markers could be placed by site visitors (automatic content links) to recommend strongly liked areas of a site to others. Amazon.com, for example, employs a reader rating system which helps users decide to buy a book or not. This feature is replicated in e-bay's vendor and buyer rating systems giving users presumed

[4] Berners-Lee, T., Hendler, J., and Lassila, O. 2001. The Semantic Web. Scientific American 284 (5): 34–43.

"collective" additional information. The on-line Science publication also includes a reviewer rating scale for each of its articles and asks: "Please indicate how strongly you would recommend this article to your peers".

- Increased importance of "ontology definitions": Users can infer new facts from ontology definitions that were not put in explicitly. Ontology is a **formal** description of a domain, intended for sharing among applications, and is expressed in a language that can be used for reasoning. [4]

Interface Design Support Features

[7] Questions communicators of content should ask: How should the content be described to the consumer in terms of scope, level, intermediaries, and goals?

- Currently, support features are limited to supporting people's querying construction to get them to more complex and interactive searches. [1]
- People will do successive searching over time.

Annotation: Integration of information by the user over time is something that should be supported by a search interface. Longitudinal support of users via search histories is advocated. This type of search was discussed by our health care **study participants**. Particularly medical specialists, researchers and medical students engage in this kind of longitudinal search behavior.

- Support via search histories is currently being researched (see U. of Maryland; June 2005 workshop). [1]
- Supporting user multi-tasking behavior. [1] This is another desirable feature of search interfaces – remind the user what he/she already searched on; where they have been.

Future Trends in Human Information Searching

The development of tools to help people manage **floods of information** is one of the emerging areas of active development in today's "digitally ubiquitous" society.
Tools for **information visualization** or so called **visual workspaces** [11] help to **organize personal information "geographies**". Such usage maps are created via accumulating trails of a user's activity (activity history) as they evolve over time. Presumably peoples' activity remains stable enough to provide feedback inputs.

Sense-making as a search activity refers to a user's task of making sense of incomplete or poor information before reaching a sufficient understanding of the topic to be able to ask the right question.

Annotation: The theme of asking the "right questions" prior to consulting with an expert is a recurrent one in the literature concerning medical information **communication** and was also substantiated via our interviews. People indeed perform searches with the goal of being able to formulate "intelligent" questions. Providing content concerning advice on **what "Questions to Ask**" is highly desired by the public.

Nature of Searching on the Internet

Much of an individual's internet search activity is assumed to consist of small-scale **fact finding** --- inquiries which can be resolved in a minute or two with perhaps a single query to a good search engine [11]. Other searching such as a **recurring interest** in a topic and pursuing longer-term complex searches over time may in fact require hours or days of continuous searching, requiring hundreds of changing queries. (see "search" definitions in Appendix !).

Metrics for Searching Behavior

- Measuring the effectiveness of **Information Retrieval** (IR) systems traditionally has involved recall and precision **measures**.
- The concept of precision does not necessarily relate to the **effectiveness of searching**. [1]
- Needed are user-centered **measures** with good face validity. [1] These should take into account the usefulness of the information accessed towards reaching the users' goal.
- Number of Web sites visited [2] is one metric of search (breadth versus depth of search space).
- Number of search terms used in search queries [2] is another indicator of topic definition.

Search Units of Analysis (Methodology)

- Transaction log analysis [1] provides insight into search behaviors.
- Mixing qualitative and quantitative data [1] in search research is a necessity.

Important Research Questions for Search and **Information Retrieval**

Research into **Information Retrieval** (IR) for available on-line text databases has evolved from applications such as digital libraries to more recent interests in **indexing** multi-media content. Accordingly, Boolean logic approaches to text matching user queries have been supplemented with interest in the topics of **automated** retrieval models, query processing, term weighting, and **relevance feedback**.

According to the National Science Foundation's (NSF's) Center for Intelligent **Information Retrieval** (CIIR) in 1995, the following 10 topics were listed as the most **important** research areas [9]:

Topic 1 - Integrated Solutions

📖 [5] Search tools should be seen as part of a larger information management context. This includes user access and provisions for dealing with multi-media, general work/life flow and social aspects and purposes for using the information. Desirable are standardized approaches and common tools that can be used across applications. Common solutions for ranking search results and dealing with **uncertainty** and profiting from contextual profiles will be required.

Topic 2 - Distributed **Information Retrieval**

Among identified issues in need of research is access to the best databases in a distributed environment, and for the user to view results as a uniformly ranked list.

Annotation: Associated user issues concern a user's understanding of the ranking **criteria** employed by the search tool. **Explaining** the **ranking criteria** to users is an **important** feature in usability. In fact we strongly recommend that consideration be given to provide users with control over various ranking and sorting tools for results lists.

Topic 3 - Efficient, Flexible **Indexing** and Retrieval

Search efficiency is a frequent topic among search engine vendors [9]. Metrics such as query response time and **indexing** speed are major concerns of

[5] 📖 Book symbol indicates findings that the authors believe to be important for eventual interface design.

software vendors. Future directions point to more work in multi-user concurrency control, update, and recovery strategies.

Annotation: Interestingly, in our user interviews, we found that the subjective user experience when waiting for search results is that a longer search time is associated with the supposition that many more resources are being scanned by the search engine. Some participants mentioned "further away targets" and thought that "more thorough" and thus overall more comprehensive and better search results were being generated, when the computer responded slowly via wireless network access. A controlled study regarding user perceptions regarding waiting times and attributed "power" of search engines would be of interest. The perceived "power quality" of a search tool appears diminished when it brings back quick results. (Consumer research in service operations such as restaurants has previously shown that "level of service" is rated highly when the timing of results was seen as just right, i.e. not too soon and not too slow).

Unlike system or service provider concerns about efficiency, user-centered parameters include overall query effort and **cost of searching**, which result in differential user **behavioral patterns** such as "careful **query formulation**" or "rapid-fire" engagement of search tools.

Annotation: We found evidence for this with our **interview participants**. They basically followed these behavioral characteristics with most people being on the "careful **query formulation**" side. This indicates that there is room for improvement in the area of supporting users with **query formulation**. A new book[6], discovered post-study, investigates this shaping of user behavior.

Topic 4 - "Magic"

Vocabulary mismatching is a major source of information **retrieval failure** [9]. A user may describe their information need in quite different terms than what has been indexed in documents. Tools such as **automated** vocabulary expansion, semantic **indexing** and other automatic thesaurus **tools** have been helpful. Commercial approaches such as "Others have requested…" or, "most frequently requested features" are helpful in guiding people to what they should be looking for, and what words they should employ in their query.

[6] "**Ambient Findability**: What we find changes who we become" by Peter Morville, O'Reilly, 2006

Annotation: In the medical application domain the problem of **vocabulary mismatches** between indexed documents and query terms employed is magnified and related to an individual's **medical literacy** in addition to their own **query formulation** model of words that a search engine may require or need in order to find targeted or relevant information. In our interviews we made an attempt to find information on people's "**rules-of-thumb**" for formulating queries.

Topic 5 - Interfaces and Browsing

The interface is a major part of how users evaluate the **effectiveness of searching** [9]. The goals for interface design are that the system is easy to use and that results are understandable. Task functions that the interface must support are: **query formulation**, presentation of retrieved information, feedback, and browsing. All of this is to be accomplished in a conceptually simple way. One of the newer areas in this domain is research in information visualization.

Annotation: As with other information presentation schemes, those interfaces that match the way people think about information and searching, will be most successful, because they benefit from user's existing knowledge and skills of how to get around in the search space and what to expect, thus avoiding confusion and encouraging use and re-use.

Topic 6 - Routing and Filtering

Filtering relevant information from multitudes and volumes of other information can be achieved via comparison of newly added documents to archived **interest** profiles. Information documents that match specified criteria are then automatically sent out to users. Invitations to visit a Web site to access newly added information also falls in this category. Other, more recent services such as **Really Simple Syndication (RSS**) serve their diverse user communities in this way. Particularly, **news services** attempt to match and customize channel subscription and **pod-casting** services to meet user **interest areas**.

Annotation: Matching interest areas of a user seems of immediate benefit. However, it is still unclear how individuals will manage their personally configured "information filters". Will they continue to specialize, or will they want to be informed about items they may be interested in but lie outside their current

"**profile specification**". Information and knowledge comes from ever increasing **relationships** among topics which are not well described by simple subscription theme lists. "**Interestingness**" of an informational item, in large part, comes from its novelty in addition to its inherent resonance (evident affordance) because of previously specified needs. A user's medical condition, or her place in her own life-health history, in addition to other personality traits, may determine which of these competing directions she will likely embrace or pursue at any one time. People as well as their information needs are largely dynamic and constantly evolving.

Annotation: There is a problem with labeling content on a Web site as "new". The reference is typically Web site centric (newly added content by the organization) when it in fact needs to be user-centric, i.e. "things in our collection YOU have not yet looked at".

Topic 7 - **Effective Retrieval**

Research on **information retrieval** has produced a number of **effectiveness of search** metrics. The most frequently mentioned are recall and precision. A system that performs well on queries but makes it difficult to recover from mistakes will be unacceptable [9]. This will most likely be the case if the user does not understand and is not afforded any explanation of why a **"bad" result** occurred.

Annotation: We observed this kind of **"bad result" failure** on a variety of NIH.gov sites with almost all of our **study participants**.

Topic 8 - **Multi-Media Retrieval**

Techniques are being developed to access image, video, and sound databases without text descriptions. Multi-media **indexing** for retrieving pictures are of limited utility due to being highly context dependent and differ between applications (**visual** content versus language **processing** content). Many research groups seem to be working on solutions to this problem.

Annotation: In our interviews we found that in many cases it had not even occurred to our **study participants** to try to search for training materials that

were in other than text formats, while at the same time acknowledging that this might be useful. In some instances, when prompted to search for any video or sound clip on any of NLM's sites – many clicks were required for users to find even just one of the many multi-media offerings. Better "marketing" of this interesting content is recommended. Previous usability research[7] has suggested that when people know that this type of **media** is available, they prefer browsing it visually, instead of reading textual content or transcriptions (text content consisted of biographical sketches whereas film clips contained "personalized anecdotes" and "why" information).

Topic 9 - **Information Extraction** – New Trends

There is currently much renewed interest in information extraction technologies.[9] The Department of Defense sponsors a workshop and conference in **Sense-making**, while formerly the Advanced Research Projects Agencies (ARPA) sponsored **Message** Understanding Conferences (MUC) . How to develop rules for automatic systems to track and **extract knowledge** beyond simple items such as names, research topics, etc. and alerting interested parties to the "added value" embedded in the internet content of available knowledge data bases are all targets for research. User interface tools are being developed to support data analysis, browsing, and mining.

Annotation: Initial discussion about user needs within health management involving other organizational entities addressed in the current issue of ACM [10] seems to align closely with these "intelligence" application efforts. Interface functions that serve to combine and support personal record keeping, appointment scheduling, and communication and messaging with **health care providers** and first responders are current developments.

Topic 10 - **Relevance Feedback**

This refers to the process of the user providing feedback about the accuracy of search results, which in turn allows a system to create a new query based around the feedback provided. In practice [9] users typically will only pick a single document as indicating **relevance** and will use this function as a way to **browse** to content that is not otherwise obviously related to their initial query.

[7] NLM OCCS Usability Study for the Local Legends Web site (2005).

Annotation: This behavior is precisely what we observed in some of our sample hands-on searches with **interview participants**. It seems that users are willing to look at most any information that appears "recommended" to them. This is a kind of **"proximity effect**" and suggests opportunistic browsing for information, where first-up information (visually acquired first) will be considered by users even if the surface structure of the item (i.e. title etc.) may indicate that the document has nothing to do with a user's initially put forth search goal.

Questions: **Important** for Research

- How universal are search behavior findings? [1] Typical related questions concern the stability of the query and search behavior and how much influence the interface has over the behavior.

Nine Questions: **Important** for Consumer **Communications [7]:**

1. What do you want to communicate and what actions do you want the consumer to take? (Alert or enhance appreciation?)
2. Whom do you want to receive this **message**? (Prioritize possible audiences)
3. What **media** or sources are likely to transmit the **message** to the **targeted audience**? (Television serves to alert- Web sites provide additional information)
4. What is the likelihood that the targeted recipients will hear, read, or view the **message**? (Salience is a key factor in determining what gets read). [7]

Annotation: Salience appears to be a wide-open research area with respect to biomedical information.

5. What is the likelihood that targeted **message** recipients will accept (believe) the **message** and incorporate it into their health schema? [7]

Annotation: Expected variations depend on personal health assessment, endangerment and **risk**, and expected level of control (ozone layer depletion versus diet impact).

6. What intermediaries or groups will improve the likelihood that a **message** is received and believed? [7]

Annotation: Personal value structures come into play here such as perceived quality of the source, or the nature and relative strength of the **relationship** with the mediator etc. This might determine whose advice or recommended action is taken.

7. What is the likelihood that the targeted recipients of the **message** will take desired actions? (The process of mobilizing beliefs into actions).
8. What groups or intermediaries might improve the likelihood that the target recipients will take the desired action? [7]

Annotation: Friends and other mediators who have been diagnosed with diseases can motivate others to take action.

9. How will you know how many of the **targeted audience** hear the **message**, accept or believe it, and take the desired action? [7] Recommends going from focus groups and small design studies to more elaborate full "**message** cycle" assessments.

CHAPTER II:
Interview Activity Report

Findings from User Interviews

In preparation for our interviews we developed several probe items and question sets to insure that we would spend the interviewee's time effectively and that we would be able to collect information most relevant to our study's "searching" focus.
Towards this purpose we divided each interview into distinct activity areas:

- Introductions – collection of pertinent participant data
- Web site **Medical Literacy** Testing
- Structured Interviewing based on Interviewee **Interest**
- **Hands-on** "show us" **interface walk through** of one or two search scenarios

The Table below shows the demographic mix of the people Quotient staff interviewed on behalf of OCCS.
We sought to achieve a fairly representative sample of actual and prospective NLM government Web site visitors.

Interviewee Demographics

	Doctors	Nurses	Researchers	Patients	Pharmacists	Students (Medical)	Other	Totals
Male			1				1	2
Female	1	3		1	1	2		8
18-34		2	1			2		5
35-54	1				1		1	3
55-64		1		1				2
>65								0
No of Interviewees	1	3	1	1	1	2	1	10

Table 4. Interview Participant Demographic Mix

Interview Participants

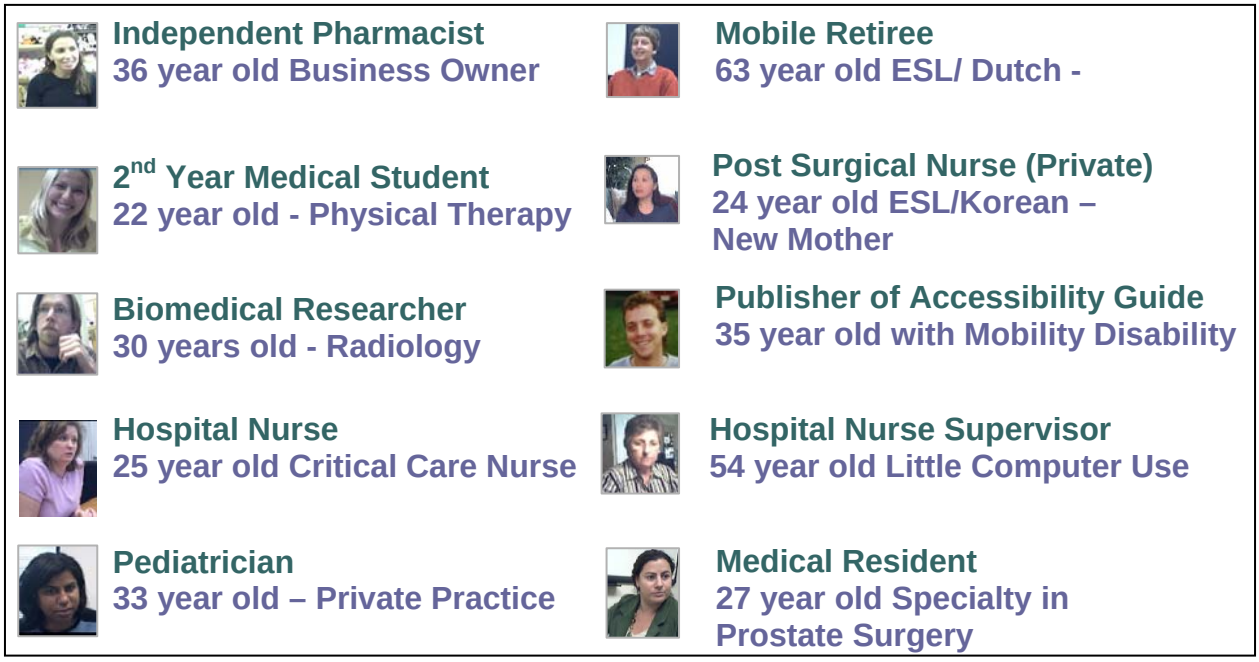


Figure 3. Interview Participants: Mix of Gender – Range of Ages – Professionals involved in Healthcare

Description of Basic Interview Procedure

Upon confirmation of the interview appointment participants were e-mailed the Pre-Interview Questionnaire shown.

[QUOTIENT] Pre-Interview Questionnaire Form

Instructions: "Please fill in as much of the following information as you can before meeting with us."

Name	
Age (Circle range)	**18-34 35-54 55-64 >65**
Gender (Circle)	**Female Male**
Ethnic Origin - Please specify	
What is your Primary Language? Secondary Language?	
What is your highest level of education attained?	
What is your current level of personal health? (Circle most applicable)	**Poor Mixed Excellent**
What is your Profession / Job Role? Briefly describe your primary responsibilities	
How do you rate your self-health knowledge? (Circle most applicable)	**Know Almost Nothing Basic Terminology Educated Consumer Expert involved in health field**
What medical Web sites do you go to? Please list the top three URLs in order of preference	
What other information / resources do you use to obtain medically related information?	
Why do you want (search for) medical or health related information?	
What type of information do you want? (Please describe)	
How do you know you have the right information?	
Who do you talk to when you need know more?	
How do you deal with ever increasing amounts of new medical information?	
What do you do with the information you find?	
Concerning drug-related information, please describe your need?	
What is your most frequently occurring need for information?	

Figure 4. Pre-Interview Questionnaire Sample

At Interview time, the interview moderator(s) adhered to the basic protocol and method outline shown in Figure 5.

1. **Carry out medical literacy test. (5 minutes)**
2. **Follow-up with any questions that arise from the pre-interview questionnaire. (15 minutes maximum)**
3. **Start formal questions:**
    a. **What would you say was your main aim in accessing health information on a Web site?**
    b. **How frequently do you use such sites?**
    c. **How do you go about finding health information resources?**
    d. **What is your favorite source of medical information – what is your favorite Web-based source?**
    e. **Do you use different medical sites for different searches or do you always use the same one?**
    f. **How do you go about searching within health information resources?**
    g. **What are the best aspects of medical search methods?**
    h. **What are the worst aspects of medical search methods?**
    i. **How does searching medical sites compare to any searches you have carried out on other Web sites. (20mins @ 2mins+ per question)**
4. **Verbal Protocol Analysis of two searches. (20 minutes)**

Verbal Protocol Analysis Instructions:
Please walk us through a recent search you have carried out on the laptop provided. The laptop is set up to track which screens you choose, but in addition I would like you to comment on your search progress. Starting with finding the site, identify where you are going and for what purpose. At each page let us know why you are there, and where you expect to go to next. Identify all expected and unexpected outcomes, letting us know which is which!

We would like you to do this on the site of your choice, and then on the MedlinePlus government site.

Figure 5. Basic Interview Protocol and Critical Interview Elements

During the Debrief, participants received a nominal **remuneration** for their trouble and they were also invited to send the moderator more information on anything that they forgot to mention, if they so desired.

Results from Pre-Interview Questionnaires[8]

Participant JL - **Results from Pre-Interview Questionnaire**

Participant – (JL)	
I#	**I1**
Age	35-54
Gender	Female
Ethnic Origin	Caucasian
What is your Primary Language? Secondary?	English
What is your highest level of education attained	Grad School
What is your current level of personal health?	Excellent
What is your Profession/Job Role?	Registered Independent Pharmacist
Please describe your Primary Responsibilities	Meeting prescription needs Running pharmacy and general store
How do you rate your self-health knowledge?	Expert involved in health field
What medical Web sites do you go to?	Don't use other than EPIC site
What other information/ resources do you use?	Drug Facts and Comparison Ref Book. Supplier **magazine** – Drug Topics
Why do you want medical or health related information?	Consultation on drugs and symptoms
What type of information do you want? (Please describe)	What is drug for, what class, type, interactions, contra-indications
How do you know you have the right information?	Trust in references, also ask pharmacists and supplier
Who do you talk to when you need know more?	Supplier on both regular and homeopathic remedies
How do you deal with ever increasing amounts of new medical information?	Automatically from supplier by summaries with side effects. Update references
What do you do with the information you find?	Respond to patient queries by copy, leaflet or verbally
Concerning drug-related information, please describe your need?	To respond to patient queries, check prescriptions
What is your most frequently occurring need for information?	50/50 patient queries and own knowledge

[8] **See summary matrix for all verbal reports to these and similar questions in Appendix IV.**

Summary of Interview Points for JL

- Packaging of information could be better, better presentation.
- Search needs to be quicker overall than looking up information in a reference book.
- NLM / **MedlinePlus** need links from EPIC (independent pharmacists).
- Job difficulty is constant interruptions.
- Need to be able to pick up where left off.
- Also searches are time-dependent.
- Likes spell checker as has learned to shorten terms to avoid misspelling.
- Rapidly got fed up when search didn't produce relevant results.

Participant HE - **Results from Pre-Interview Questionnaire**

Participant – (HE)	
I#	I2
Age	55-64
Gender	Female
Ethnic Origin	Caucasian
What is your Primary Language? Secondary?	Dutch English
What is your highest level of education attained	Some College - Flight Attendant Training
What is your current level of personal health?	Mixed
What is your Profession/Job Role?	Retired Flight Manager - Boating First Mate
Please describe your Primary Responsibilities	Manage financial and social affairs
How do you rate your self-health knowledge?	Educated Consumer
What medical Web sites do you go to?	None directly - uses **Google** or Ask Jeeves search or look-up on any medical association site
What other information/ resources do you use?	N/A
Why do you want medical or health related information?	Personal and family use
What type of information do you want? (Please describe)	Anything relevant to personal problems e.g. heart, knees, epilepsy
How do you know you have the right information?	Generally accepts sources as being acceptable - experienced at searching. Checks with Doctor if doubtful
Who do you talk to when you need to know more?	Family Doctor
How do you deal with ever increasing amounts of new medical information?	N/A
What do you do with the information you find?	N/A
Concerning drug-related information, please describe your need?	N/A
What is your most frequently occurring need for information?	For personal and family reasons, curiosity - once or twice a month

Summary of Interview Points for HE

- Would be useful if gov medical sites were on “toolbar” (one single site for all).
- Some dot gov sites are not very commercial in appearance (lack of color and pictures).

- Believes that commercial sites are more biased.
- Likes to check results one at a time which can be time consuming. When she gets a list of results by site (links to other sites), she prefers not to go to most.
- Can be distracted from original search by news items that look **interesting**.
- Isn't interested in registering with a site to get information (doesn’t want to fill up scarce e-mail resources – (cost)).
- When prompted, thought that a "shopping basket" to put in likely **items of interest** would be useful.
- Also would like a "compare" button to show up matching items in different site searches
- **Not interested** in professional papers (too academic).

Participant AT - **Results from Pre-Interview Questionnaire**

Participant – (AT)	
I#	**I3**
Age	**18-34**
Gender	**Male**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**MS**
What is your current level of personal health?	**Excellent**
What is your Profession/Job Role?	**System Administrator / Medical Researcher**
Please describe your Primary Responsibilities	**Project researcher for MRI**
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**WebMD, PubMed, Wikipedia,**
What other information/ resources do you use?	**Primary care physician, Google, friends and family**
Why do you want medical or health related information?	**Research work, because I like to be healthy , and personal curiosity**
What type of information do you want? (Please describe)	**Causes and treatments of diseases and conditions** **Primary research the same**
How do you know you have the right information?	**Look at the source** **Look for verification by others**
Who do you talk to when you need know more?	**Research colleagues** **Primary care physician, friends and family**
How do you deal with ever increasing amounts of new medical information?	**Distil it the best I can; look for review papers or summaries from reliable sources**
What do you do with the information you find?	**Read it?** **PDF to folder; print out forms for some uses; book mark, uses delicious site**
Concerning drug-related information, please describe your need?	**Find out about clinical trials, side effects, alternatives**
What is your most frequently occurring need for information?	**Research followed by personal or family ailments**

Summary of Interview Points for AT

- Never used **MedlinePlus** before.
- Thinks Medical sites have poor search syntax.
- Doesn't use advanced search features.
- Avoids links prescribed for researchers on any site.

- Doesn't like to use keywords.
- Does use e-Medicine.
- Thinks **Google** is a good “filter”.
- Does not like ‘natural language’ type searches.
- Does not use About.com.
- Is a dictionary user.
- Likes Firefox as a **browser**.
- Uses Babblefish if translation is needed.
- Likes spell checkers.
- Is not concerned about identity theft.

Participant RH - **Results from Pre-Interview Questionnaire**

Participant – (RH)	
I#	**I4**
Age	**35-54**
Gender	**Male**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**BA Sociology**
What is your current level of personal health?	**Excellent (paraplegic)**
What is your Profession/Job Role?	**Executive Director Access Information Inc. Disabled persons guide.**
Please describe your Primary Responsibilities	**Respond to inquiries on accessibility**
How do you rate your self-health knowledge?	**Educated Consumer**
What medical Web sites do you go to?	**Google, Ask Jeeves, WebMD sometimes**
What other information/ resources do you use?	**Doctors handouts articles**
Why do you want medical or health related information?	**To keep self healthy (wheel chair bound)**
What type of information do you want? (Please describe)	**Typically on heart and working out, plus general interest For enquirers access to information on disabilities**
How do you know you have the right information?	**Formulates what is wanted, and structures search on that basis. Comparison**
Who do you talk to when you need know more?	**Uses specialist physician s, for instance urologist Own doctor for spinal chord related material**
How do you deal with ever increasing amounts of new medical information?	**Feels it is an advantage in that there is always new material out there, Simply searches for what he wants**
What do you do with the information you find?	**Mostly for personal use and to give out to people. Otherwise uses material for Web site. Doesn't bookmark**
Concerning drug-related information, please describe your need?	**Not often, has researched homeopathic drugs for health benefits Antibiotics from doctor**
What is your most frequently occurring need for information?	**Mostly for information relating to exercise and spinal injuries**

Summary of Interview Points for RH

- Doesn't like having to log in.
- Doesn't like pop-ups and missing links on medical sites.
- **E-bay** and Amazon.com user.

- Thought **MedlinePlus** was "sharp" attractive, more like a library - not as precise, lots of good information.
- Likes **Google** because he thinks that it usually comes up with relevant results.

📖 Thinks a “word" catcher would be useful.

📖 There should always be a **summary**.

- Thought **WebMD** was more like “a dictionary” - too big, no links, nothing worth clicking except for one very basic result.
- The Web links found were old, some were very old (one had an article on Christopher Reeve, that was very **out-of-date**. It had nothing on "living with spinal cord injury" (his search choice).
- When searching for Letrazol, got only **foreign language results**, although **Google** did ask if English was wanted which he considered useful. One English language result turned out to be in Chinese when selected.
- Usually uses single search words.
- Likes **MedlinePlus** much better than **WebMD**.
- **Google** never pointed to **WebMD** in any of the searches he did.

Participant SJ - **Results from Pre-Interview Questionnaire**

Participant – (SJ)	
I#	**I5**
Age	**18-34**
Gender	**Female**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**BS - Biology**
What is your current level of personal health?	**Excellent**
What is your Profession/Job Role?	N/A
Please describe your Primary Responsibilities	N/A
How do you rate your self-health knowledge?	**Educated consumer**
What medical Web sites do you go to?	**Ovid, Medline, Google**
What other information/ resources do you use?	**Textbooks, medical journals, databases**
Why do you want medical or health related information?	**School related purposes (papers, projects, presentations)** **Personal information (curiosity)**
What type of information do you want? (Please describe)	**Physical therapy related, information about body systems, muscles, nerves pharmacological cross referencing**
How do you know you have the right information?	**N/A**
Who do you talk to when you need know more?	**Professors, fellow students**
How do you deal with ever increasing amounts of new medical information?	**Strategies taught in school, continue reading and learning as it is discovered**
What do you do with the information you find?	**Try and integrate with what is already known**
Concerning drug-related information, please describe your need?	**Learning about pharmacological agents (analgesics, NSAIDS, opiates**
What is your most frequently occurring need for information?	**PT information for learning purposes.**

Summary of Interview Points for SJ

Unavailable due to **time constraints** – May be produced via analysis of existing stored recording **media**.

Participant LD - **Results from Pre-Interview Questionnaire**

Participant – (LD)	
I#	**I6**
Age	**55-64**
Gender	**Female**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**BS Certified (Nursing) 4 year + exam state board**
What is your current level of personal health?	**Mixed**
What is your Profession/Job Role?	N/A
Please describe your Primary Responsibilities	**Tax Accountant**
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**SGNA, ASGE, NIM** **PubMed, Yahoo - health**
What other information/ resources do you use?	**Journals - SGNA** **Nurse Spectrum**
Why do you want medical or health related information?	**As a health professional** **Also for family members**
What type of information do you want? (Please describe)	**Research information - keeping up-to-date** **Answer patient queries, need level of detail down to Doctor**
How do you know you have the right information?	**Credentials - if NIH, trust John Hopkins Institution to verify sources**
Who do you talk to when you need know more?	**Expert in field** **Physicians - even if in different field** **Family physician**
How do you deal with ever increasing amounts of new medical information?	**Filter by using professional sites for reviews** **Belongs to Chesapeake Nursing Society** **e-mail within group on gastro** **NOVA, Delaware, MD DC**
What do you do with the information you find?	**For patients make copies for handouts, also instructions on standard information** **Does not file**
Concerning drug-related information, please describe your need?	**Not a lot, mostly for own needs and gets info from hospital**
What is your most frequently occurring need for information?	**75/25 professional to personal**

Summary of Interview Points for LD

- Dislikes sites that ask for fee.
- Likes easy to see and read materials.
- Relatively inexperienced, but has bought on-line, and just goes slower when unsure.

- **Used back button a lot** to navigate.
- Thought **MedlinePlus** was **too much text**, and not directly applicable to what she was looking for.
- Felt that long search times, with little to show for, were tiring and would rather just ask someone else.
- Commented that NLM site doesn't show summaries.
- Would like to see better groupings, e.g. , surgical, medical, current issues.
- Hates the hot bars, pop-ups as these slow her down more.

Participant CG - **Results from Pre-Interview Questionnaire**

Participant – (CG)	
I#	**I7**
Age	**18-34**
Gender	**Female**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**BSNursing**
What is your current level of personal health?	**Excellent (Pregnant)**
What is your Profession/Job Role?	**Senior Clinical Nurse (NCII)**
Please describe your Primary Responsibilities	**Medical ICU at Johns Hopkins Hospital**
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**MicroMedix, PubMed, up-to-date, Cinahl?**
What other information/ resources do you use?	**Books, journals, Hopkins protocols (electronic)**
Why do you want medical or health related information?	**For professional, patient and personal reasons**
What type of information do you want? (Please describe)	**Patient /pt family education, disease specific knowledge, drug information, journal articles**
How do you know you have the right information?	**I use the Hopkins (my employers) intranet to find Web sites and content – they have Tab list of approved sites**
Who do you talk to when you need know more?	**Fellow nurses, physicians, clinical nurse specialists**
How do you deal with ever increasing amounts of new medical information?	**I forget a lot of it!! Have to go back multiple times**
What do you do with the information you find?	**Share with others - verbally or provide hard copy**
Concerning drug-related information, please describe your need?	**Learn about the drug, in the ICU we always are hanging multiple drugs at one time with limited places to infuse so drug compatibility is a huge thing**
What is your most frequently occurring need for information?	**Drug information, disease specific information**

Summary of Interview Points for CG

Unavailable due to **time constraints** – May be produced via analysis of existing stored recording **media**.

Participant JC - **Results from Pre-Interview Questionnaire**

Participant – (JC)	
I#	**I8**
Age	**18-34**
Gender	**Female**
Ethnic Origin	**Asian (Korea)**
What is your Primary Language? Secondary?	**Korean English**
What is your highest level of education attained	**BSN**
What is your current level of personal health?	**Excellent (3 month old baby)**
What is your Profession/Job Role?	**Nurse Post- operative**
Please describe your Primary Responsibilities	**Plastic Surgery Unit**
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**Hospital Web site, Nursing Spectrum, Women's Health**
What other information/ resources do you use?	**Manuals, procedures, emergency preparedness, Personal notebook, text books, medical dictionary, nursing magazines**
Why do you want medical or health related information?	**Patient investigation Personal knowledge**
What type of information do you want? (Please describe)	**Patient symptoms specifically for post-op trauma and patient history**
How do you know you have the right information?	**Carefully check background against patient notes**
Who do you talk to when you need know more?	**Pharmacist, Nursing Supervisor, Patient for background**
How do you deal with ever increasing amounts of new medical information?	**Prefers to use journal articles as they are directed. Finds data overwhelming tries skimming through**
What do you do with the information you find?	**Print out and store in folder, add to note book. Does not store electronically**
Concerning drug-related information, please describe your need?	**To look up medications for side effects, interactions, will check with colleagues**
What is your most frequently occurring need for information?	**Patient follow-up, personal reasons e.g. pregnancy**

Summary of Interview Points for JC

Unavailable due to **time constraints** – May be produced via analysis of existing stored recording **media**.

Participant JM - **Results from Pre-Interview Questionnaire**

Participant – (JM)	
I#	**I9**
Age	**18-34**
Gender	**Female**
Ethnic Origin	**Caucasian**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**College; MD in May 2006**
What is your current level of personal health?	**Excellent**
What is your Profession/Job Role?	**4th year medical student** **About to take up residency in hospital**
Please describe your Primary Responsibilities	
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**PubMed, Medline, MdConsult**
What other information/ resources do you use?	**Detailed medical information; clinical investigation trials**
Why do you want medical or health related information?	**To better serve my patients and to self educate**
What type of information do you want? (Please describe)	**Detailed medical information; clinical investigation trials**
How do you know you have the right information?	**Certified**
Who do you talk to when you need know more?	**Physicians**
How do you deal with ever increasing amounts of new medical information?	**Try and read some of it**
What do you do with the information you find?	**Print or save it**
Concerning drug-related information, please describe your need?	**Adverse reactions, cost, interactions**
What is your most frequently occurring need for information?	**Ongoing education** **personal information**

Summary of Interview Points for JM

Unavailable due to **time constraints** – May be produced via analysis of existing stored recording **media**.

Participant DL - **Results from Pre-Interview Questionnaire**

Participant – (DL)	
I#	**I10**
Age	**35-54**
Gender	**Female**
Ethnic Origin	**African American**
What is your Primary Language? Secondary?	**English**
What is your highest level of education attained	**Medical Degree, Fellowship school, Residency**
What is your current level of personal health?	**Excellent**
What is your Profession/Job Role?	**Pediatrician, behavioral and developmental**
Please describe your Primary Responsibilities	**Health care for children, community practice**
How do you rate your self-health knowledge?	**Expert involved in health field**
What medical Web sites do you go to?	**CDC, Medline, aap, journal – pediatrics chadd, Hopkins, children's hospital, vaccine, food allergy Web site**
What other information/ resources do you use?	**Journals, medical newsletters, Washington Post (patient recommendations) PDR – desk reference, text books, Barton Schmidt**
Why do you want medical or health related information?	**Knowledge, addressing rare issues, patient advice (Kennedy Krieger Web site)**
What type of information do you want? (Please describe)	**General view for patients – NIH, .gov, parenting issues, studies, cutting edge**
How do you know you have the right information?	**Known entity, multiple searches, keep to recognized sources**
Who do you talk to when you need know more?	**Specialist in field in the area, colleagues in practice**
How do you deal with ever increasing amounts of new medical information?	**Targeting strategy, using AND searches**
What do you do with the information you find?	**Save some articles, electronically, verbally and hard copy to patients**
Concerning drug-related information, please describe your need?	**PDR plus updating, Herriott Lane drug reference book**
What is your most frequently occurring need for information?	**Continuing Medical Education Journals Searches 3 hours/week**

Summary of Interview Points for DL

- Believes commercial sites are faster and have better links.
- Medical sites are more work.
- Tells patients to use the WHO site.
- Could not find NLM on NIH site.

- Thought NLM site not user friendly.
- Not heard of PubMed central.
- Wouldn’t want to have e-mail contact with patients.

Results from **Medical Literacy** Test for **Interview Participants**

The results for medical **literacy** of our **interview participants** are shown in *Table 5. Web Site Medical **Literacy** Results for **Interview Participants***. Please refer to the methods discussion for this test in Appendix III, entitled: "From Medical **Literacy** to NLM Web Sites - **Literacy** Test Development Method".

	Term	I1 Independent Pharmacist	I2 Patient	I3 **Medical Researcher**	I4 Disabled Adviser	I5 2nd Year Medical Student	I6 Nurse Mgr Community Hospital Dept	I7 Nurse Critical Care	I8 Nurse	I9 4th Year Medical Student - Resident	I10 Medical Doctor - Pediatrician	Totals
Easy	Exercise	X	X	X	X	X	X	X	X	X	X	100%
	Bone	X	X	X	X	X	X	X	X	X	X	100%
	Eyes and Vision	X	X	X	X	X	X	X	X	X	X	100%
	Stomach	X	X	X	X	X	X	X	X	X	X	100%
	Heart	X	X	X	X	X	X	X	X	X	X	100%
	Heartburn	X	X	X	X	X	X	X	X	X	X	100%
	Depression	X	X	X	X	X	X	X	X	X	X	100%
	Birth Defect	X	X	X	X	X	X	X	X	X	X	100%
	Antacid	X	X	X	X	X	X	X	X	X	X	100%
	Gene	X	X	X	X	X	X	X	X	X	X	100%
Medium	Reflux	X	X	X	X	X	X	X	X	X	X	100%
	Valve	X	X	X	X	X	X	X	X	X	X	100%
	Ulcer	X	X	X		X	X	X	X	X	X	90%
	Phobia	X	X	X	X	X	X	X	X	X	X	100%
	Metabolism		X	X	X	X	X	X	X	X	X	90%
	Osteoporosis	X	X	X	X	X	X	X	X	X	X	100%
	Mutation	X	X	X		X		X	X	X	X	80%
	Myopia		X	X				X	X	X	X	60%
	Colitis		X	X	X		X	X	X	X	X	80%
	Hemophilia		X	X		X	X	X	X	X	X	80%
Hard	Sphincter		X	X		X	X	X	X	X	X	80%
	Gastroesophragial						X		X		X	30%
	Autosomal Dominant			X		X		X	X	X	X	60%
	Leukodistrophy										X	10%
	Keratotomy			X				X			X	30%
	Squamous			X		X		X	X	X	X	60%
	NSAID	X	X			X	X	X	X	X	X	80%
	Sucralfate	X						X		X	X	40%
	Ibandronate											0%
	Hemachromotosis						X			X	X	30%

Table 5. Web Site Medical Literacy Results for Interview Participants.

Observations and Lessons Learned from Interviews during Discussion Phase

The interviews provided a rich set of information concerning people's use of on-line medical information, their attitudes and biases, their professional and individual usage of Web site searching for **needed medical information**.

Reported Reasons Why Interviewees Looked for Medical Information

- Continued Professional Education
- Service Provider Excellence
- Learn More About Personal Conditions
- Look-Up Family Conditions
- Staying Healthy
- Drug Information
- Rare (Little Known) Diseases
- Locate various Useful Web Resources
- General Curiosity

Table 6. Set of reasons why interviewees looked for medical or health related information

How much "Search Confidence" do **Health Care Providers** Generally Have?

People view themselves as search novices. They frequently don't feel that they are "in control" and report much uncertainty with on-line information gathering. Our interview participants were not always sure how to classify themselves in terms of search expertise. They typically rated themselves much lower or reported themselves as less frequent searchers when compared with a colleague or family members. (This despite showing considerably advanced skills in searching during the hands-on portion of the interview).

Searching takes Time – Health Care Professionals don't have Much Time

People reported not having enough time in their daily work practice to locate information routinely. Participants reported that they depend on other, more traditional sources such as Journals, Reference Books, and Vendor Representative Communications for professional information. Typical frequencies of searching are, once a week to once a month. When traditional sources showcase or recommend a Web site, most interviewees say that they would be inclined to go there.

🕮 **Marketing and promotion of on-line resources** should employ traditional paper **advertising media**.

When Is a Search Done?

Searching was typically viewed as a kind of perpetual educational activity where scarce time resources are spent on behalf of patients or in preparation for specific health care system provider and receiver scenarios (before a Doctor visit, etc.).

Searching To Find Questions to Ask

People search for medical information so that they can ask useful questions of others. One of our interviewees even suggested that medical information be specifically accompanied by **FAQs.** She termed this feature jokingly "FAQ to Ask" (FAQTA).

📖 Provide **Frequently Asked Questions for medical content** similar to those provided by service providers concerning software downloading or use.

Observations and Lessons Learned from Interviews during Hands-On Searching

Looking for Quality Only (Quality Heuristic)

A quality heuristic is an adapted or learned rule used by searchers to select items that they will further search on. Some frequently employed quality selection factors used by our interviewees were:

- "item-is-from-known-big-name"
- affiliated institutions
- recency-of-**date**-shown

The acceptability of the date is determined, based on a given personal criterion, where the time period of interest is variable but should be within a "**currency time window**".

📖 **Shelf-life** of information is an **important** design element and users will pay attention to dates included with medical information.

The **Total Number of Items in Results Paradox**

An "approach" behavior seems to be dictated for result items with low reference counts – several of our interviewees spontaneously shied away from selecting the class or category of listed resources that had the indicated **largest number of hits**. There seems to be a trade-off between perceived effort for looking through many results, (categories with high counts), and the relative ease of looking at a more peripheral category, but one with fewer entries. Many people seem to be more inclined to look at, or interpret, large counts as places that they want to avoid. This is because they anticipate that they will have to expend more time. Our collection of video clips that were produced from this study, include a segment where a user selects a lower count category on the **MedlinePlus** Web site for these reasons.

📖 Too many results are not necessarily good for guiding users to what they want.

🕮 Table of Interview Summary Points: Toward User Interface Design Recommendations
• Any user search typically starts with **Google**! • The Benchmark: the entire **search experience** needs to be shorter in duration than the time it would take to **look up** information in a reference book. (**MedlinePlus** should be available as a **toolbar search** for health professionals) • Content Access could be organized by role of the user (separate area for physicians, nurses, researchers versus lay people; general educational materials versus case study professional articles and content) • Always provide a topic preview **summary** describing what the content (article/text) contains. • Mark applicable content "Easy Read" or "Professional" to guide people • Mark content with original language (if the article is in Chinese) indicate this in the English language abstract reference • On MedlinePlus, participants avoided going to areas that have large numbers (of **hits**) associated with them – they will go to the smaller sets first. Provide results in a prioritization scheme – in a staggered & "more" fashion • Show all video and alternate **media** materials together in a "multi-media" room for broadband access, (i.e. – a keyword search on "pod-cast" should produce a list of available MP3 files, a keyword search on "tutorials" should produce a list of available NLM tutorials). • Provide **FAQ** –like (what to ask) topics about diseases, drugs, treatments • Provide "**Blog**"- like content by medical experts discussing major current topics • Provide links to on-line educational multi-week "courses" and give CEU credits • User Search is contextual - It is motivated by specific "Need scenarios". These need to be addressed. • Users either have fairly specific goals – they want to go to something again, or, they are engaged in some larger educational purpose – want to learn about something. We need to provide tools for these goals. • Web sites need to address **user goals** on the entry page (! see next) and every other page • Users are willing to explore and are "**waiting for suggestions**" from an expert or a "certified" organization • **Google** and **WebMD** are successful because they tell people where they might want to go, what to do next • Never have **zero results** on any search query without directing the user to a different area. In other words, guide users to give alternate queries. • In general, enable people to go from general to more specific knowledge without backtracking or re-directing them • Users look for "real" news (anything new that requires updating of existing knowledge is of **interest** to professional **health care providers**) • Both medical search novices (general population) and research experts repeat their searches over time. • Allow people to "manipulate" knowledge elements (**shopping** basket – book case **metaphors**)

Table 7. Interview Activity Summary

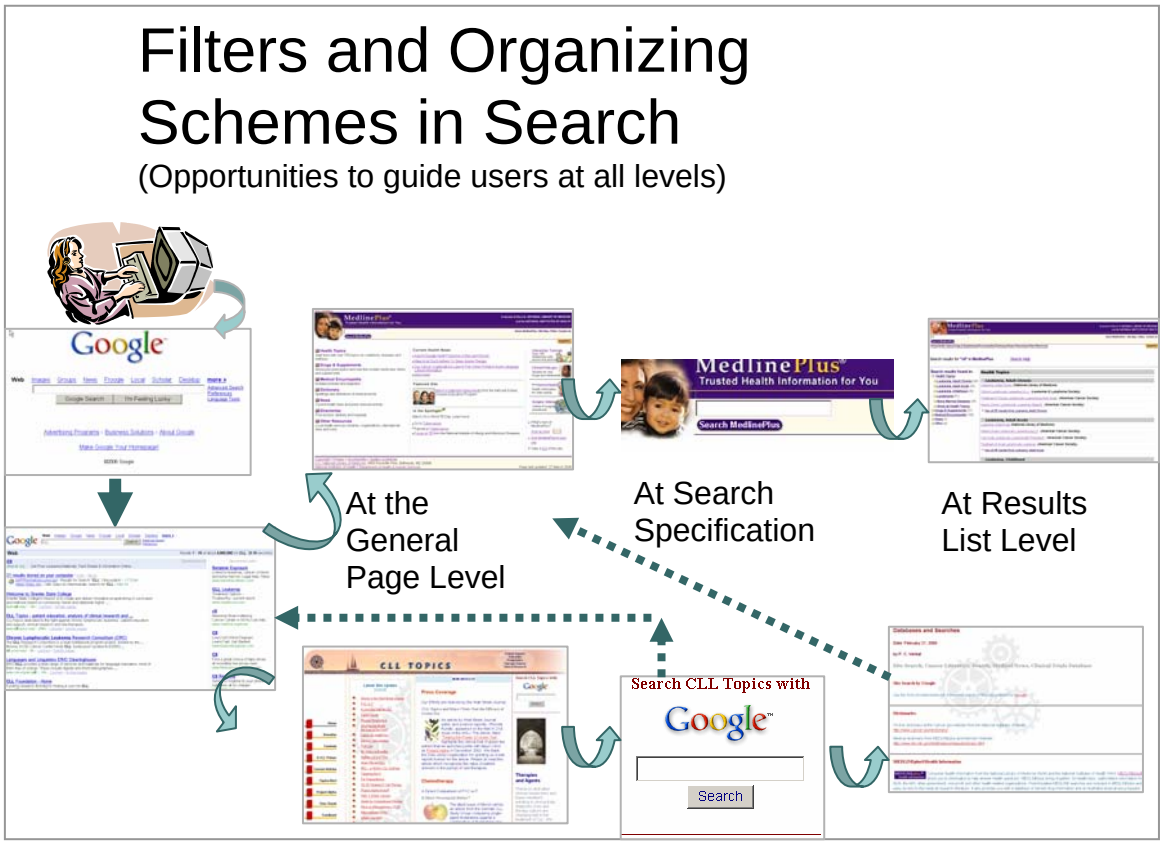


Figure 6. Filters and Organizing Schemes in Searching Found Via Interviewing

📖 Opportunities to Guide Users at all levels exist.

General Search Patterns

Many of the interview participants indicated that they usually start their searching with a general search engine such as **Google** rather than going to a specific site. They mentioned that they would only do the latter if they were trying to access something very specific (a specific research article, for example, that they already know about, would lead them to go to PubMed, or any other "publication type" site.)

📖 For health care professionals search is an instrumental activity and not an end in itself.

Where Health Care Professional Users go to find Health Information

Our interview participants indicated a variety of Web sites "they would typically go to" in order to find health information. While the sites are too numerous to list here individually, they can be categorized into the types shown below. Professional health care givers seemed to particularly like sites that had specialized content for "members

only" sites with password access for doctors, or sites with educational materials useful to give to patients.

Participants mentioned visiting the following types of sites during our interview sessions. Generally, they fall into one of these five categories:

Five General Types of Medical Content Sites Mentioned

1. "**Brand New Unknown Sites**" (more used by non-professionals or for searching for personal reasons) – However, medical professionals will visit these sites when they are mentioned to them by patients, or when a professional association, **magazine**, or other communications outlet "recommends" the site.
2. "**Affiliated Sites**" – sites that users know of because they are currently, or have been in the past, affiliated with that institution professionally or personally. Examples: John Hopkins Hospital Internal Web site, George Washington University Hospital or Stanford Medical Center Site. These sites typically require password access for medical content information.
3. "Educational Institution - University Sites" – University sites and/ or their on-line library resources that specialize in particular aspects of medicine or medical **communication**.
4. "Non-profit Association – **Disease Specific** Organizational Sites" – Public sites that have extensive **disease specific** content
5. "Foreign Sites" (typically foreign government or academic institutions) – sites that have content that is either in a person's first language or sites that have geographical location specific medical information not otherwise available or applicable (tropical diseases, etc.)

Noteworthy was that very few of our participants mentioned NLM's sites or any of the NIH sites, and if, it seemed more as a courtesy to the moderators since they understood that this was the sponsor organization for the research.

Annotation: NLM sites must compete for **users' attention**!

In our interviews, for example, our pediatrician participant mentioned the following list of sites that she would go to in order to find relevant information: (this list also includes some sites she went to on the topic "CLL" [9] in the talk-out-loud on-line search walk-through):

- http://cdc.gov – for Bird Flu Pandemic Information
- http://www.chadd.org/ - to provide patient's parents with resources for Hyperactivity Disorder
- http://www.hopkinsmedicine.org/ - for patient consultation (access by physician's special area)

[9] **"CLL stands for Chronic lymphocytic leukemia (CLL) and was the disease keyword that one of our first participants searched on. The study team subsequently asked other participants to search for information concerning this disease example, as if they had been "asked by a relative to look up critical information".**

- http://www.kidshealth.org/ - as a resource reference site for parents

Search Scenarios Described in the Interviews

Various search scenarios were decided on as walk-through examples by the interview participants. Participants reported searching for the following "items":

- Keyword search on "CLL" to find out more about this diagnosis
- Urology – PSA value high - prognosis **interest** for Quality of Life
- Exercise Information for **Disabled Individuals**
- Information on Ultrasounds and Pregnancy
- Find out News in Medical Imaging
- Look for Spanish Language Educational Materials
- Exact Spelling of a Drug
- See what might be of **interest** in the "Medline Site"
- Any NLM site to find materials on parenting
- **WebMD** site information on bird flu
- John Hopkins Home Page Area for Nurses – Find **Patient Education** Materials
- George Washington University Home Page Area – schedule of educational events and health seminars

Producing Search Scenario Descriptions

One of the many goals of this study was to gather information concerning valid search cases that can serve as test-scenarios for potential prototype usability testing of new NLM interfaces and Web applications.

Both the interviews and later focus group **survey** questions provided information on scenarios that could be used. Here are two scenarios in the participants' own words.

Search Scenarios: In Their Own Words

These quotes came from participant statements in our subsequent Focus Group follow-up **survey** phase. Statements were entirely voluntary and were made after the participants had had time to think about their own search habits.

"12. [Optional Question] **Using your own words**, please describe either a typical or an unusual situation that you encounter where you will **look up** medical information. (Be as specific as you can, regarding the entire scenario. Describe the context, **technology**, the information type and nature of content you are looking for and how you approach your search.) [Your detailed information will help us provide example scenarios that we may use to test new designs and **content** when building new search interfaces.]"

Figure 7. Question asked to produce Search Scenario "Using Your Own Words"

Scenario Description (Person 1 "**Using Your Own Words**"):

"The night after the meeting [refers to focus group held] I got on **Google** to **look up** Ionized Calcium. I was not searching only for the meaning but also for a detailed,

physiologically broader, yet organized presentation that I can easily mentally absorb for future use and education of peers and patients. After typing in the topic on **Google**, I was queried for clarification. I then clicked the suggested topic again and was taken to 6 sources with additional directories numbered 1-10 for further search should I need to do so. If I recall correctly, some of the sites were so disorganized in their presentation that I went immediately to another. I ended up with 4 sites that I liked for each unique reason ranging from quantity of the presentation, organization, **color**, depth and the complexity of the content. I was forced to make notes as I moved from one source to the other. I ended up spending the most time especially during the conclusion and summarization of my search at the source that was easiest to comprehend, **colorful**, (blue) and chronologically presented in accordance with human anatomy and physiology. I think that some of these distinctive qualities in presentation of a topic or subject are the primary force that either drives one away from a Web site or keeps one spending most, if not all of their search time on a particular Web site, only to turn around and revisit for some more or never again!"

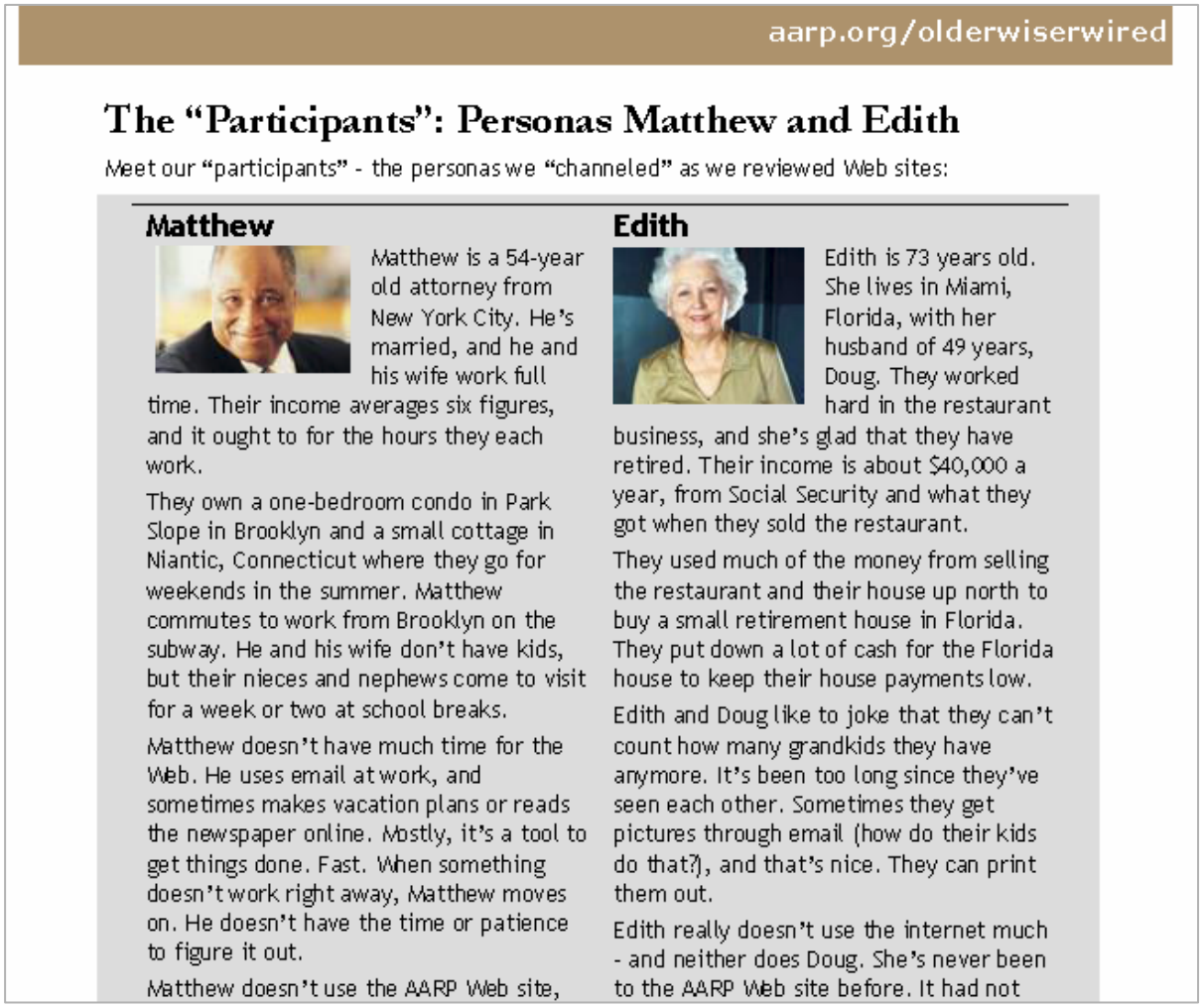
Scenario Description (Person Two "**Using Your Own Words**")

"Often, when looking up medical information, I will be doing it for my own information, to study, or for a project. I will first go to **Google** on my personal computer and use key words such as "Osteoarthritis" to find background information on the topic. I usually try to use Web pages from organizations (for instance if there were an arthritis foundation - I probably am making this foundation up, but you get the idea). Then I will try the search again in **Google** for a little more detail such as "osteoarthritis and treatment." I will look at the first several results and I can usually find enough background information in the first few sites offered (usually an organization / foundation). If necessary, I will look at up to about 30 Web sites on **Google** before I go to my next search engine. Then, for more detailed information, I will go to my school's library where I can access databases. (I like to get all the information I need with one or two library visits, so I do the preliminary searching ahead of time on **Google**). When I get to the database I usually choose Ovid/ Cinahl / Medline, because I was taught to use it and I understand it. I will enter the generic keyword again "osteoarthritis" and then I will do another search on my topic of **interest** such as "physical therapy intervention." Then I will combine the two searches. If I get no results I will try a new search such as "Osteoarthritis and treatment" or I will just enter "osteoarthritis" and narrow the search by clicking on subheadings "and treatment". It is always frustrating when you do a search like this one and you get no full-text articles as a result. But usually I can find other keywords or ways of searching to fix the problem. Personally, I will hardly ever consider an article if I can not find the full-text for free within a few searches."

Persona Development for Use in User-Centric NLM Web Site Development Work

Persona development is a fairly standard tool employed by usability professionals to facilitate user-centered design. Persona construction helps interface design goal **communication** within IT development groups and with sponsor agencies. This is used because Persona's communicate user needs in a much more memorable way than typical interface specification documents.

A good example of Persona use is given by a usability group involved with the AARP (American Association of Retired People) Web site (aarp.org/olderwiserwired). Their award winning design had to accommodate a wider constituency specified via these examples. (They used more of these).



aarp.org/olderwiserwired

The "Participants": Personas Matthew and Edith

Meet our "participants" - the personas we "channeled" as we reviewed Web sites:

Matthew

Matthew is a 54-year old attorney from New York City. He's married, and he and his wife work full time. Their income averages six figures, and it ought to for the hours they each work.

They own a one-bedroom condo in Park Slope in Brooklyn and a small cottage in Niantic, Connecticut where they go for weekends in the summer. Matthew commutes to work from Brooklyn on the subway. He and his wife don't have kids, but their nieces and nephews come to visit for a week or two at school breaks.

Matthew doesn't have much time for the Web. He uses email at work, and sometimes makes vacation plans or reads the newspaper online. Mostly, it's a tool to get things done. Fast. When something doesn't work right away, Matthew moves on. He doesn't have the time or patience to figure it out.

Matthew doesn't use the AARP Web site,

Edith

Edith is 73 years old. She lives in Miami, Florida, with her husband of 49 years, Doug. They worked hard in the restaurant business, and she's glad that they have retired. Their income is about $40,000 a year, from Social Security and what they got when they sold the restaurant.

They used much of the money from selling the restaurant and their house up north to buy a small retirement house in Florida. They put down a lot of cash for the Florida house to keep their house payments low.

Edith and Doug like to joke that they can't count how many grandkids they have anymore. It's been too long since they've seen each other. Sometimes they get pictures through email (how do their kids do that?), and that's nice. They can print them out.

Edith really doesn't use the internet much - and neither does Doug. She's never been to the AARP Web site before. It had not

Figure 8. AARP Example Personas

For our own purposes at NLM, the interviews for this study yielded the necessary contextual materials for constructing brief Persona Information Profiles. We reviewed our interview transcripts, (or tapes), and noted particularly memorable events for some

of the individuals. We then wrote a profile which included the following informational elements at a minimum.

Our goal was to produce information sheets that were approximately one-page in length for easy reference; including these content sections:

- **Background**
- **Sources of Information**
- **Internet Experience**
- **Medical Web Sites Visited**
- **Medical Search Experience**

Together with assigning a fictitious name and a picture we arrived at the some of NLM's potential Web site visitor Personas shown below.

The main thing to remember is that persona's don't necessarily represent a single user, instead they are a "representative type of person" established as a target user for Web site development purposes.

What Persona's are: Fairly detailed description of a user with characteristics drawn from one or many actual user observations and behaviors.
How Persona's are used: Serve as a "standard" user to design to - "Will our design satisfy this type of user?"
Where Persona's are used: Help to communicate and specify user requirements to developers.
When Persona's are used: As "User test cases" for proto-type designs one method of initial usability testing and for heuristic walk–through.

Interview Results – Personas

Persona 1: Alfred Talbot, **Medical Researcher**

*"Correct spelling is seemingly trivial but in the medical research domain it is an important aspect of formulating a successful search query. I like a spell correcting capability for the **search box**."*

Background

Mr. Talbot is a 30 Year-old American male with advanced academic credentials who works as a systems administrator and biomedical researcher in the area of Magnetic Resonance Imaging (MRI) at a large government research facility. His medical knowledge is narrow but extensive in his own field of research. He uses the computer every day for his work and conducts on-line searches; both for primary research and for personal reasons (he is curious and also wants to maintain his health).

Sources of Information

Alfred, when searching on-line for medical information is usually looking for the causes and treatment of diseases and conditions. His primary professional sources of information are those internal to his Research Institute. Scientific verification of findings is important to him and he keeps up to **date** with colleagues and conferences, although he feels that the latter are poor at posting items and articles electronically. He feels that PDF (Adobe) formatting of articles is the way to go. He is interested in the latest links and always searches for the most recent documents and news.

Internet Experience

Alfred uses the Internet for work and has also made on-line purchases using Amazon. He is an accomplished and frequent on-line user. His major concerns are that he has control of the search and results can be verified. He is not concerned about having to register at sites or with problems of identity theft. He rarely bothers to follow **foreign language links**, but has occasionally used Babblefish to translate summaries of foreign research articles in his field.

Medical Web Sites

His usual sites for searches on health or medical information are **WebMD**, PubMed and Wikipedia. Although he uses Wikipedia, he realizes its limitations as well as strengths due to anyone being able to post changes to it. Alfred also uses **Google** as a filter for new links, which may not appear in the medical listings until accredited. He has also used e-medicine. He uses MeSH (medical Subject Headings) from the NLM site to cross-reference medical terms that he is unfamiliar with. Alfred does not use **MedlinePlus** as he does not currently feel that it has "clinical **relevance**".

Medical Search Experience

In terms of searching for medical information, Alfred's past experiences have resulted in a bias against "thematically organized" links – such as NLM's "Researcher" link. He was more frustrated then helped by Web sites that missed the mark. He also doesn't like searching on just assigned keywords of an article as he feels that he is second-guessing the editor's choice a lot. He would much rather search the **full text** with a phrase query of his own choosing. His **strategy** when searching for an unfamiliar medical topic is to look for a review article written by someone else.

Persona 2: Robert Hess, Executive Publisher of a Disability Guide

Spontaneously exclaimed about **MedlinePlus** results for **"exercise health paraplegic"**: "What a sharp and attractive site, it has a lot of good information, like a library should, but not as precise".

Background

Mr. Hess is a 35 Year-old, American, Quadriplegic male who is the Executive Director of an Accessibility Guide published for disabled persons residing and working in the Washington, DC metropolitan area. He is in good health, but very conscious of the importance of exercise for people in impaired mobility situations like himself. He uses a laptop computer extensively every day for his work, and although he is "manually-challenged" does not use any special accessibility devices or programs.

Sources of Information

Outside of his daily working use, Robert usually looks for informative content on health and exercise for the disabled. He may also **look up** specific disabilities he is unfamiliar with when a disabled person rings or e-mails him seeking advice.

Internet Experience

Robert uses the Internet for publication work activities and has also bought products on-line using Amazon and **e-Bay**. He prefers using large well-known commercial sites for making purchases, as they are quicker to respond and easier to use.

Medical Web Sites

He feels that medical Web sites are generally "too technical" for the average user and prefers to use **Google** for most of his searches. His other top Web sites to visit for searching are ncpad.org (National Center on Physical Activity & Disability), **WebMD** and About.com. Although he uses the **WebMD** site, he is critical of its performance. (It threw up some very old links, including one on Christopher Reeves (recently deceased) that was out of **date**).

Medical Search Experience

In terms of searching for medical information, Robert does this frequently as part of his work as well as for personal reasons (about 95% for personal use). He is constantly looking for health and exercise related information for paraplegics. This gives him broad knowledge on the main areas of the body relevant to his disabilities. However, he also looks for information on a wider range of disabilities so that he can respond to inquiries to his Guide publication. Robert's main **strategy** for searching is to use **Google** to find the most up-to-**date** links in his own knowledge area. He uses **WebMD** for getting information on unfamiliar disabilities.
When doing his own search using the key-words "exercise health paraplegic" on NCPAD he got two "good" results. Mr. Hess was pleased that these were new items of information he had not seen before. He feels that **Google search results** could display summaries of items found rather than just showing the words searched for highlighted. Search engines should also provide a "**word catcher**" to show exactly where in the link content the words matched are located – often the words matched are buried somewhere in text.

Persona 3: Dr. Diane Lobe, Community Pediatrician

When viewing information on NLM's MedlinePlus site Dr. Lobe asked: "What is the *'Plus'* in MedlinePlus?"

Background

Dr. Lobe is a 37 Year-old, African-American, female physician practicing in the United States Mid-Atlantic Region. She works in a large community health care practice. Diane likes to meet and treat her patients in person because she cannot always rely on the parents giving her relevant information. "With children you never know - their health can change just like that and they can get in bad condition very quickly."

For this reason she will not employ e-mail to communicate with the parents of her patients, although she is aware that they and other physicians are using the internet a lot. She also does not want to get into a work backlog-type situation and does not use e-mail for liability reasons.

Medical Information Searching

In terms of searching for medical information, Diane's past experience as a research specialists with a large Clinical Center proved frustrating and time consuming. There she spent a lot of time trying to find specific publications on health topics and clinical trials. When she looks at **search results** now, she only seeks out very recent information from reputable organizations or known academic institutions.

Sources of Information

Diane likes being in a setting where there are a wealth of experts and medical specialists available for consultation. "This [Washington, D.C. metropolitan area] is a good region to practice in, all you have to do is make a phone call and others (various experts) are there to help and they do graciously offer their knowledge". She also has access to academic institutions in other parts of the country and will use their Web sites (sections for physicians and **health care providers**) to find information. Among these "trusted" good sources are Stanford University's Health Center site, John Hopkins Clinical Center, and the University of Michigan's Health Center for physicians. Dr. Lobe conducts on-line searches in order to see what the parents of her patients that come to see her with unusual requests "are talking about". Recently a "nervous but confused" parent wanted to know if they should have their child immunized against Avian Flu based on what they read in a newspaper.

Internet Experience

Dr. Lobe uses the internet at home and at her office for professional administrative reasons but has also bought toys and made other personal attire purchases on-line. She believes that commercial sites are typically much more efficient than medical resource sites. Diane will typically **look up** information about specific drugs and information about available treatments on-line. Her main **strategy** for searching is to be as specific as possible in her query keywords and she almost always will specify at least two keywords with an AND (example: Avian Flu AND Tamiflu) in the **search box**. Diane spends a large amount of her time on-line with activities for her advanced **continuing education** courses.

Medical Web Sites

Diane's top Web sites to visit related to her practice are: for Children and Adolescents (CHADD), the Food Allergy Network, a Birth defects site, a Philadelphia Children's Hospital site. Dr. Lobe likes to go directly to special areas for Physicians and Health professionals, but will research more general health information sites when she is looking for references that she can give to the parents of her patients.

Persona 4: Jean Marsfield, 4th Year Medical Student & Surgical Intern

Quote: *"It's not a medical Term, but people use Google all the time!"*
Regarding the question, when is a search done? She replies: ***"There is no 'done'… because, how do you know that there isn't something else out there?"***

Background

Ms. Marsfield is about to start her medical residency in Buffalo, New York. Her medical research specialty is Urology. As a surgical intern she will perform and assist with minor operations, will write prescriptions, discharge patients and coordinate their long-term follow-up care. Jean is outspoken and says that she has very little patience when it comes to locating something that she knows exists but for some reason she can't get to on-line.
Jean feels that medical information sites are not as easy to use as commercial sites when it comes to navigating them. She says "it's very easy and comfortable to use **Google** Search to see what pops up", and she emphatically continues; "it produces the exact same results! Sometimes it produces results that you wouldn't find otherwise- information that is not as scholarly but that is "good" for some other reason – it's all relative!"
Jean feels that searching for medical information is generally more stressful than she would like it to be. This is because it usually takes more time than she planned on. "If you are not sure of the information that's out there and if a patient is involved, you are going to keep looking for that one piece of information that tells you why not to give a drug to a patient… because if there is just one reason, then as a physician, you better know why."

Internet Experience

Jean uses a PDA and has access to the internet "all over the teaching hospital and Medical Center Complex". She considers herself strongly computer literate. As of January 2006 she had not subscribed to any **RSS** feeds and does not really know what these are. Jean works in the specialty area of Urology and frequently finds potentially relevant articles and abstracts in German or French. This is where her searching for information typically stops: "I wouldn't have something translated – I would use it if I could read it, but I would not necessarily pay a fee for a translation."
When she gets too deep into searching for Journal articles on-line, she says that it happens a lot that she gets a result that is "totally extraneous to what I am looking for."
At that point Ms. Marsfield's **strategy** is to **abandon** her **search** and start all over again with the top-level home page **search box**, where she will enter some of the keywords she noticed in the result items of her previous **search results**.

Sources of Information

Jean uses PubMed to find articles but has never before encountered PubMed Central (PMC) nor does she know what PubLink is. **MedlinePlus** is also not a regular site destination for her. She goes to PubMed when she knows a specific article she is looking for because "I'll know I'll find what I'm looking for fast". She has learned to look for some type of official stamp of approval such as the NIH logo on medical Web sites which tells her that here is information she can trust.

Medical Web Sites Visited

For drug-related information Ms. Marsfield goes to the Drug Resources Guide (DRG), the Merck Manual, or a drug company's Web site. She cautions: *" you really have to look at what you are reading and analyze it closely, if it's a good article or a bad one and who it's funded by – in case*

of the drug company you need to take a close look at what they are comparing their data to and what they haven't published yet (left out)."

Medical Search Experience

Her most frequent searches involve finding recent Journal Articles that contain Clinical Trial information. – She often uses her password-protected Journal search site available from her Medical School [uses OVID search engine] searching with simple Key words to find relevant and recent publications. For broad text-book like background information she will go to sites like www.mdconsole .

Desired Web Site Features

Jean thinks that having full Journal articles available would be nifty and she says that having a type of electronic folder (in a library) where you could have your own research files stored and gain access to it easily would be wonderful. "Because when you are doing research you are comparing things from different sources and referencing different articles." She wants the ability to highlight and annotate articles she reads.
On the PubMed site Jean reads through the list of findings and judges each with respect to relevancy, recency, and origin.

Web Site Catalogue and Review of Sample Sites Mentioned by **Study Participants**

Where do health professionals and other educated consumers **search** for medical information? What are the features and missions of the sites used? These questions were addressed to our **study participants**. We asked them to list and go to some of the sites they had visited in the recent past. About 20 % of the resulting site destinations are shown here. More can be gleaned by analyzing the original taped transcripts of the various interview sessions (We employed Moray software for recording these).

The following Web sites were inspected for overall mission statement and intended audience content and we also paid attention to a site's overall organizational approach for displaying and/or advocating medical information.

The sites sampled here represent only about 20% of all the various sites mentioned by our **study participants** as sites that they use a lot to **look up** medical information on behalf of others or themselves. This relatively broad landscape of resources available and accessed points to a lack of standardization for on-line medical information resources. We expected more convergence on only a few resources which had established themselves as "places to go".

Site 1 - http://www.cdc.gov/ (Mentioned by pediatrician interviewee)
Government Site - Inferred Purpose: Control and Prevention of Epidemic Diseases

- Health Topics
- Safety Topics
- Publications
- Images
- Statistics
- Specialized Topics
- Seasonal
- Global
- Resources for Businesses

Site 2 - http://www.chadd.org/ Provides science-based, evidence-based information about AD/HD (Mentioned by pediatrician interviewee)

Specialized Resource for Attention Deficit and Hyperactivity Disorder
Provides:

- Definition
- Mission Statement
- News
- Court Rulings
- Resource Center
- Support Groups
- Phone Numbers
- Area for Professionals
- Fund Raising
- Educational Materials (Store)

Site 3 - http://www.hopkinsmedicine.org/ Provides information for Health Care Professionals by Role (Mentioned by pediatrician interviewee)

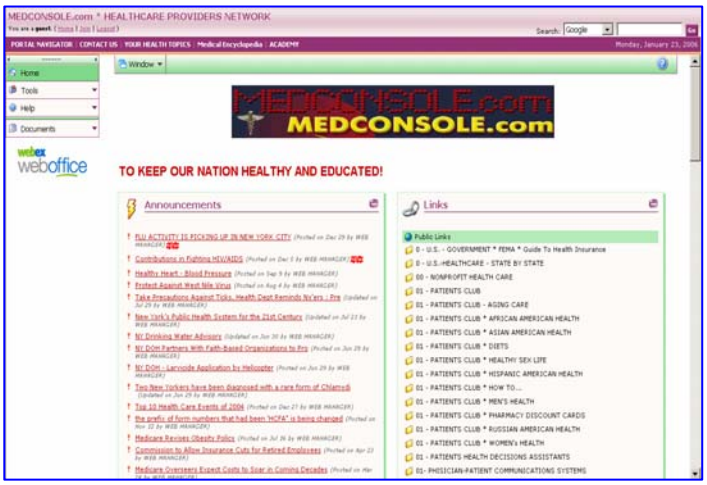
- Provides access to physicians for consultation with patients [HAL]
- Weekly Medical & Health News
- Specialized Info by role
- Send to a Friend and Print this Page Functions
- **RSS** Feed
- Weekly Med and Health News Pod cast
- Audio News
- Hopkins Publications
- Health Topics from Allergy to Women's Health

Site 4 - http://www.kidshealth.org/ Provides **specialized sites** for parents, kids, and teens – Nemours Foundation (Mentioned by pediatrician interviewee)

Provides:

- News
- Parental Guidance and Education
- **Games** for Kids

Site 5 - http://healthproviders.webexone.com/login.asp?loc=&link= Health Providers network (Pediatrician mentioned) "To Keep Our Nation Healthy and Educated"

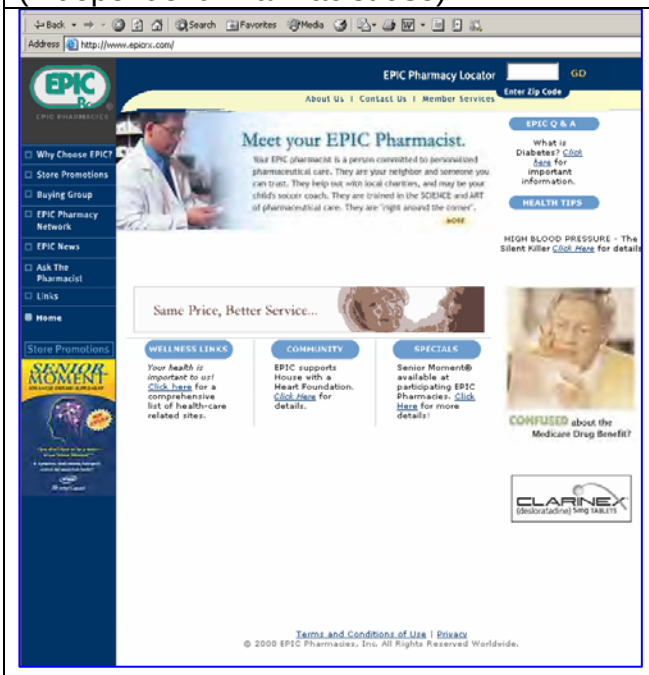


- Health Topics
- Links to Patient Clubs
- New Article Links
- Health Provider Network Links
- Insurance Company Credentials

Site 6 -www.google.com Used by every interviewee at some point. Whether to keep up-to-**date**, used as a "cover **search**", preferred to going directly to medical sites, familiarity and ease of use.

- Most people used **Google** for entering search queries

Site 7 - **http://www.epicrx.com/** **EPIC Pharmacy Locator**
(Independent Pharmacist use)



- Has member pharmacy home pages linked to this site
- Keeps up-to-**date** on drug issues
- **Wellness Information**
- **FAQs**
- Health Tips
- Pharmacy resources

Site 8 - http://www.webmd.com/ - **"Better Information, Better Health"**
Used by disabled interviewee for own use health information

- Mentioned by others and in the literature
- Has a Symptom Checker
- Top-12 Health Topics
- "Interactive Check-ups"
- Healthy Living
- Advertisements
- Pregnancy and Family
- A to Z Guides
- Support Group Membership
- Cooking Recipes
- Drug Information ("Medicine Cabinet")
- Search Tutorial
- **WebMD** University – 4 week courses
- Now Playing Videos – Stocking your Pantry
- Health Centers (Focused Topics) etc, etc. many more well-organized features

Site 9 - http://www.rxlist.com/ "Providing fast, reliable information to both the consumer and medical professional". A specialized link provided on the **WebMD** site.

- **Drug Name Searching**
- Top 200 US Drugs
- Medicare Information for drugs
- Breaking Health Alerts
- Alternatives Tab

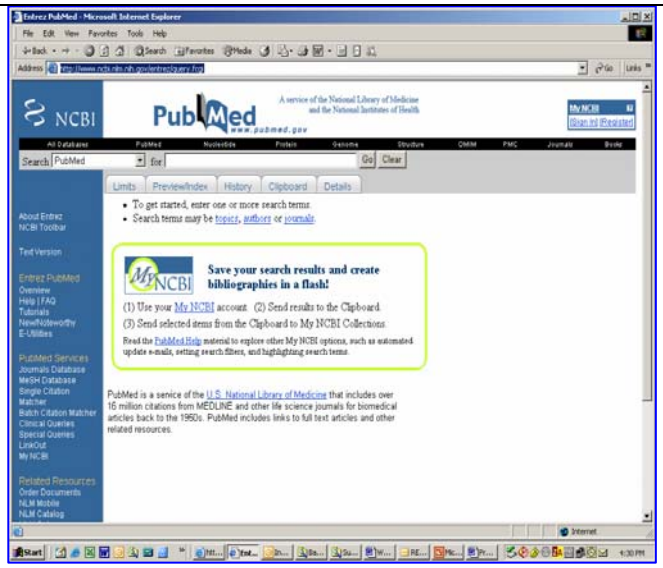
Site 10 - http://en.wikipedia.org/wiki/Main_Page "the free encyclopedia that anyone can edit." (Researcher frequented site)

- Researcher likes this "open" nature of the site – he realizes that the approach has strengths and weaknesses in that whilst powerful, anyone can post any comments true or false
- Sign Language
- Current Events
- Requests Donations
- Today's **Feature Article**

Site 11 - http://www.emedicine.com/ "Easy Access to the Minds of Medicine" (Referenced by Researcher Participant)

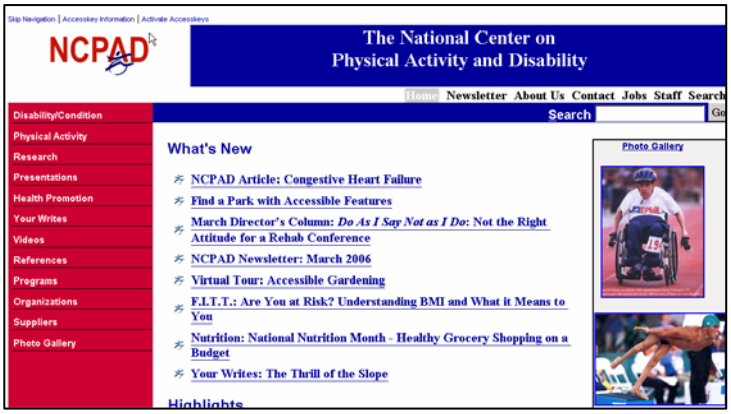
- Featured "Resource Centers"
- News Headlines
- **Patient Education**
- Resources for PDAs
- **Disease Spotlight**

Site 12 - http://www.ncbi.nlm.nih.gov/entrez/query.fcgi (Researcher mentioned site - the only 'government sponsored' site mentioned by anyone to find medical information). "PubMed - A service of the National Library of Medicine and the National Institutes of Health".



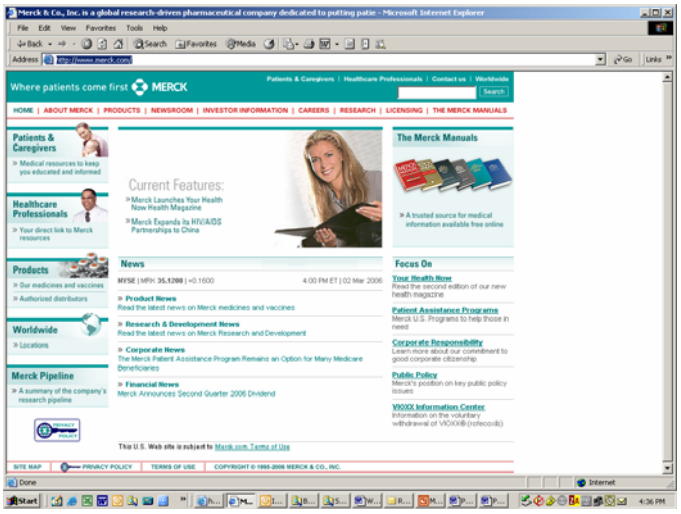
- Searching for Medical Publications/Articles
- Tool for saving searches
- Menu of Databases
- (PMC – Pub Med Central) could not be found by others
- Some free full-text articles

Site 13 -http://www.ncpad.org/ (mentioned by Publisher of a Disability Guide)



- The National Center on Physical Activity and Disability Organization Web site
- News articles on disability related topics
- Specialized Equipment Vendor Resources
- "Your Writes" – features articles written by disabled folks or their family members or car givers

Site 14 -http://www.merck.com/ "Where Patients Come First"
(Referenced by 4th year Medical Student)



- **Summary** of the Company's research "Pipeline"
- Product Information
- Special Area for Health Care Professionals
- News and Current Features
- Addendum t Merck Manual and Drug Information

Site 15a – http://www.cinahl.com/ "Cinahl Information Systems – Leaders in delivering current and comprehensive health care information
(Mentioned by Nursing Participant)

- Provides a library of Resources
- A Store
- "Find a host of health care Web sites by subjects with links"

Site 15 b - http://www.cinahl.com/

Summary: Analysis and **Inspection of Web Sites** Mentioned

Our brief review of these sites produced the following Interface Design Observations and Common Practice Prototyping Guidelines:

- Home Pages should include a “Tag Line” or Mission Statement for the sites where purpose and **audience targets** are clearly addressed.
- Site ownership should be clearly identified and cross-links to related sites containing relevant content should be provided.
- The navigation elements (links, menu items, tabs, etc.) listed on a Home site should be reflective of the potential site visitor goals.
- News and Highlight Focus are becoming fairly standard prominent features.
- Site **Search box**es should be prominently placed, particularly when not many navigation targets are made available.
- **Advertising** is typically displayed on the right-hand side of Home – Pages. Since users try to ignore ads, this screen location should be reserved for items of lesser importance.
- Sometimes the only visual object content is displayed inside of ads. Regardless of accessibility concerns with visual objects, screen content interest can be generated using **graphics** generously; but they must be appropriately tagged for accessibility to be compliant with Section 508 guidelines.
- Banners, tabs, **colored** background blocks and outlining is used to define major page areas where text content resides. This could be distracting and interfere with understanding.
- Any text that appears is very brief and strives to be “thematically informative”.
- Headlines are freely used to organize Navigation target items.
- Pages are typically time-stamped to indicate freshness.
- Clarity is achieved via content organization which was evident on most of these sites.
- The one government site showcased here has problems due to organization-centric abbreviation usage (PMC for PubMed Central).
- Special Index Keys for menu selection was a feature included on the site targeted for disabled users.

Analysis: **Importance** of Web Site Language Level

Web site **literacy** is a combination of a person's skill with:

- Educational Background (Problem Solving Style)
- Computer user experience and training (**Computer Literacy**)
- English **Literacy**
- Medical Domain **Literacy**
- Cultural and Social Factors such as **age**, heritage, and religion which can all influence attitudes toward the "medical domain"
- And disease "experience", i.e., personal contact with certain diseases and related therapies and procedures.

When designing Web site content an effort needs to be made to match Page Content to the skills of its intended visitors. Our brief foray into medical **literacy** showed that "language level" is really a BIG issue which can not be ignored as a main faction in communicating medical knowledge.

Some of our **study participants** even commented on this important and yet frequently overlooked Web site variable.

Notable Quote by a Health Care Professional:

"This is way too 'technical'… definitely not where I will want to go"

📖 An attempt should be made to present content in a way that can be "understood" more easily by the **target audience**.

Language **complexity** is magnified as a factor when **user demographics** indicate that English is a second language for an increasing number of scientifically trained medical staff who may want to avail themselves of NLM's resources.

Figures 9, 10 and 11 support the write-up for illustration on a Web site of the concept of "**Cognitive Obscuration**", i.e., failure to finding target content searched for because elements of the page can not be understood. It is not necessarily only a function of the power of a search engine or the size of the computer database resource holdings when search fails. Language itself can often be the culprit for the user making the necessary distinctions and decisions for finding appropriate search targets.

Implication: Roughly half of the medical **terminology** that is shown on NLM sites, such as the **MedlinePlus** Web site, is not familiar to people. Only half of what is shown can actually be understood by many site visitors.

Illustration of **Cognitive Obscuration**

Refer to Appendix IV for more detailed information on **cognitive obscuration**.

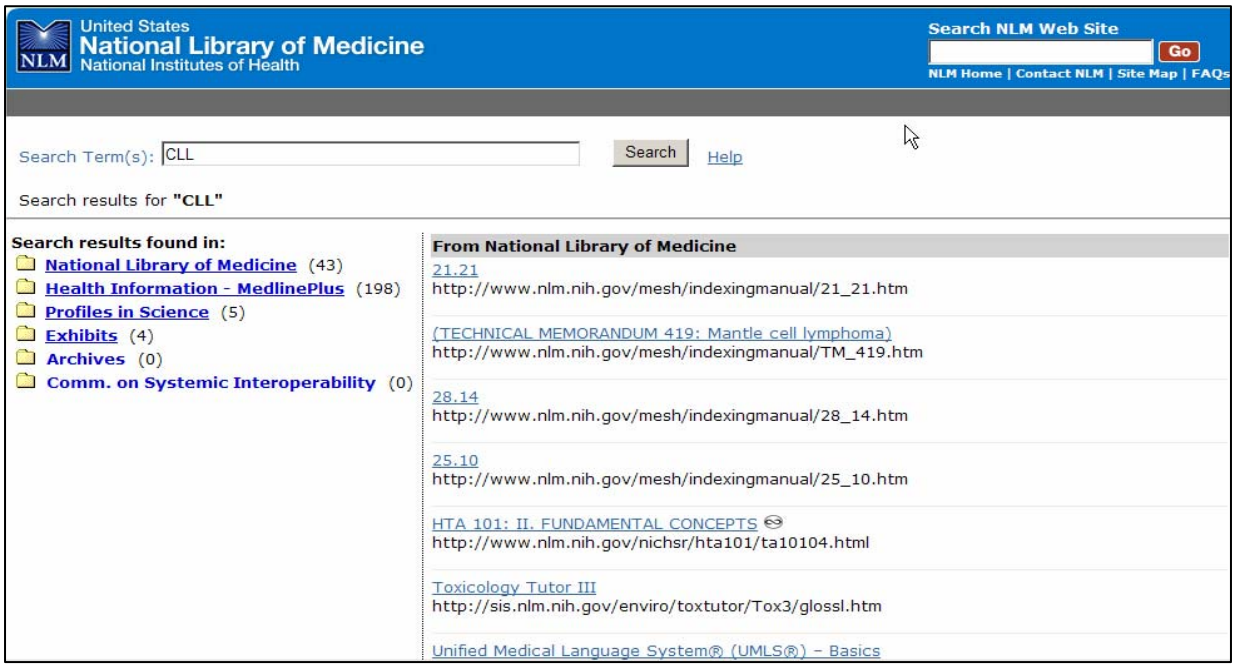


Figure 9. Screen Representation of the Search Results Page for "CLL" from NLM's MedlinePlus Page.

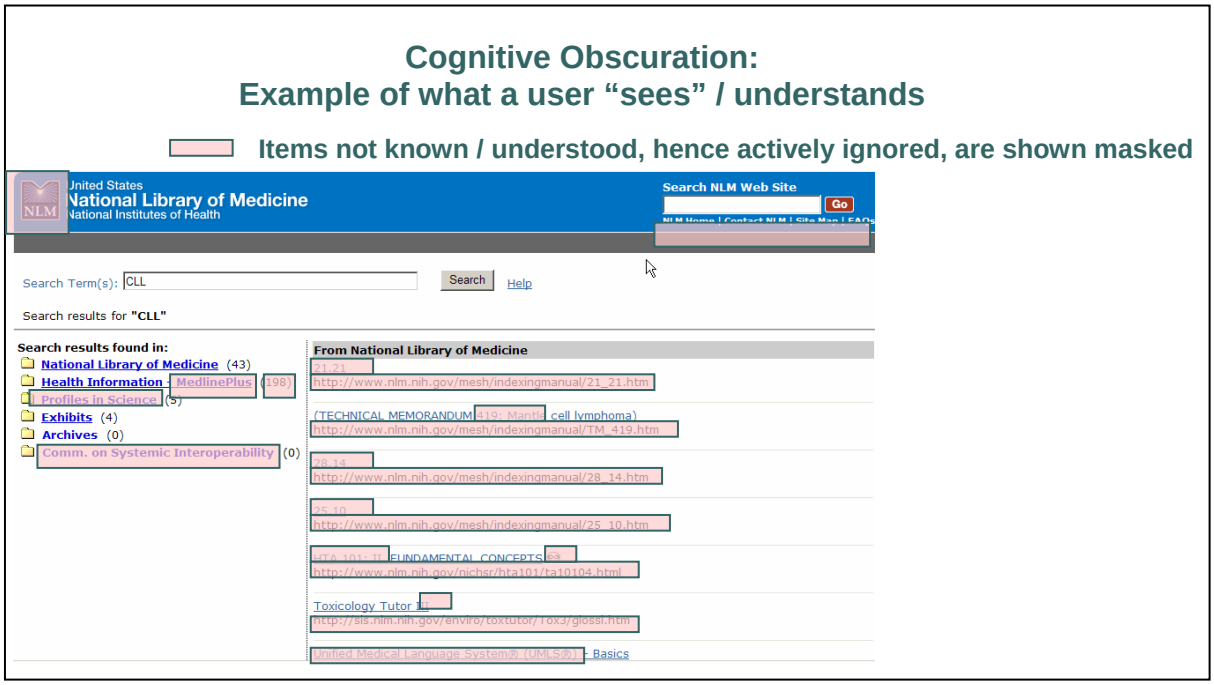


Figure 10. **Cognitive Obscuration**/Cognitive Masking

NLM Search Results Page
Half of the content is "cognitively obscured" due to Language and Ambiguity

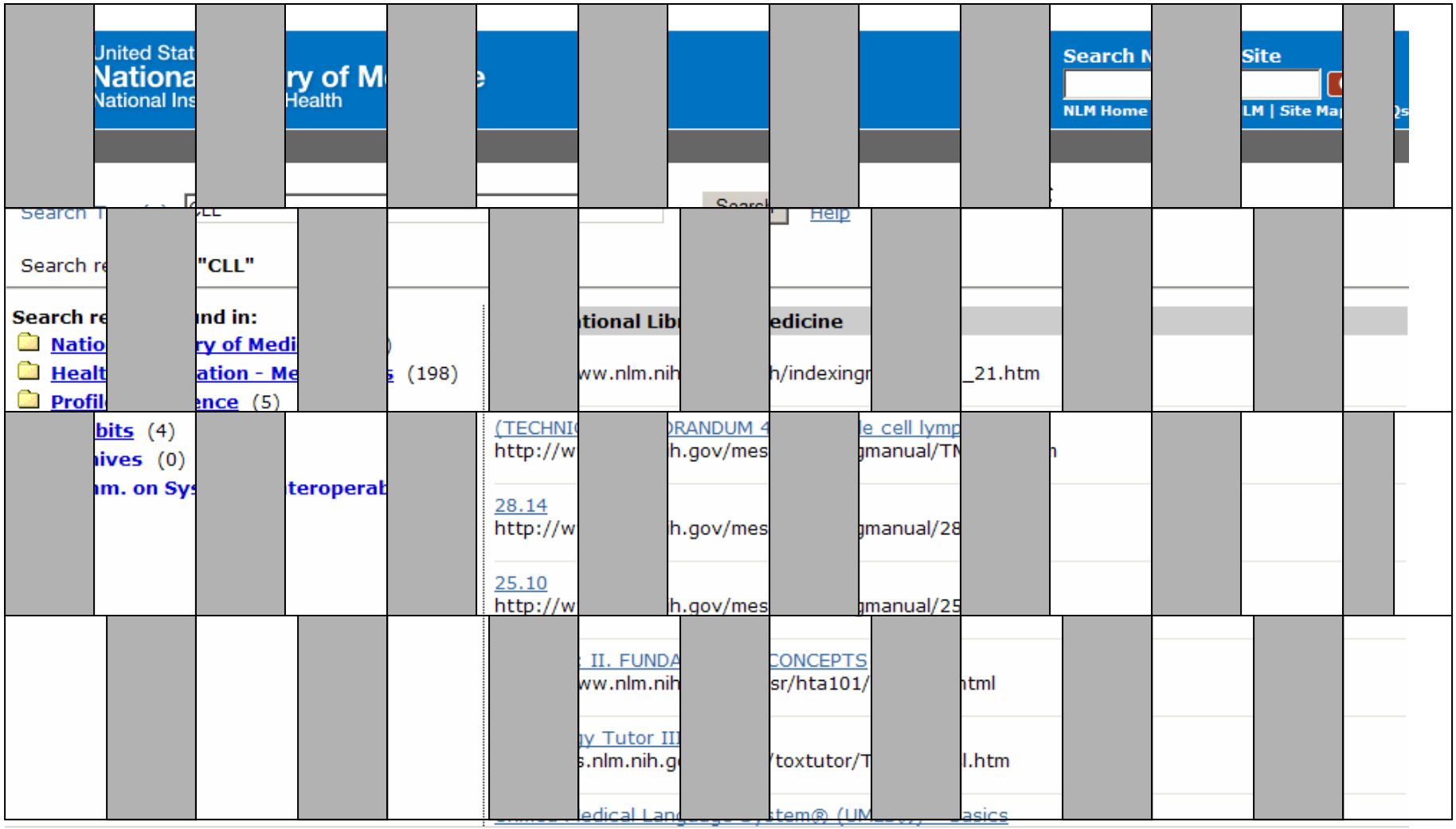


Figure 11. Illustration (Moderately Educated General Web site User):

🕮 Results from Hands-On Search Activity with Interview Participants (General Interface Guidelines)

- **Avoid Abbreviations** of all kinds, standard or not - [Example Comm. – in this context, for example, participants thought it stood for Commerce, Communications, or Community – none of the participants choose it as a destination]
- Avoid display of "meaningless" numbers – note "21.21" is not meaningful to the casual visitor. [When participants were asked to guess what these numbers were, they were at a total loss and assumed it was "some kind of library designation like the Dewey Decimal System"]
- Provide a Medical Dictionary for quick look-up of unknown terms
- Avoid displaying long strings of URL page names (**Computer Literacy**) – people tend to "tune out" when encountering this
- Don't prominently display program-centric material **not of interest** to main purpose users (i.e., "Comm. Systematic Interoperability") – create speacialized "corners" for this
- When providing menu choices for navigation, they should be in the expected standard location (roughly left or upper center of a page - not interfering with the **search box**)
- When viewing **search results** – most people read the center list of items (first few) only and didn't pay attention to the surrounding headers or other information
- When displaying "hit numbers" they should be identified as " search engine **hits** or finds" – people in a hurry will have a tendency to migrate toward categories with the lower numbers to further search for relevant results

Notable Quote by a Health Care Professional:

"I don't want to have to look through 198 items – it would take me forever – maybe I'll just take a look at these 4 - (clicked on Exhibit category)"

Themes and Motives Analysis

We inferred the following underlying themes or motives from analysis of our interview data. These either stem from participant's verbal protocol (direct answer to a question, or spontaneous production) or from a review of the Web sites the interviewees said that they use quite a bit and are familiar with. These techniques combine elements of **usability "science"** with a professional marketing perspective, (a burgeoning trend). These are the themes that our set of individuals are familiar with, hence would be likely to respond to favorably, if addressed on NLM sites. There is no reason to believe that these themes would not also have broader NLM Web site user population appeal.

- Control and prevention of disease according to **life-span** (i.e., demographic membership)
- Science-based recent content concerning a certain diagnosed condition
- Insider Information (Medicine by Role) – Access to areas presumably frequented by healthcare professionals like themselves (Virtual Community of **Interest**)
- Information useful for Parents (and Pregnant mothers)
- Information on Exercises and Nutrition for Special Populations (Disabled – Mobility impaired)
- "Instant Access to the Minds of Medicine"
- "The free Encyclopedia" (anyone can post / read articles – Freedom from barriers to communication)
- "Tools not Rules"
- "Give me the words that will get me there" – **Word Recognition** is easier than Word Production (Give me tools for **query formulation**)

Notable Quote by a Health Care Professional:

"Can't you say the gist of this in simpler words?"

Recommendations for Interface Design (Author's Note[10])

📖 A search utility should be able to include aspects of the current self-identified or inferred user context and organize and display found items according to a user-centered scheme.

This may be as simple as providing information related to the type of item, its level and language, and intended audience. Bringing to the fore "**surface feature**

[10] In April 06, a colleague referred me to the following paper from the CHI 2004 Conference in Vienna, Austria; ACM 1-58113-702-8/04/0004: Teevan, J.; Alvarado, C.; Ackerman, M. S. and Karger, D.R. "The Perfect Search Engine is Not Enough: A Study of **Orienteering** Behavior in Directed Search".
A similar point is made and a step-wise approach of human searching is emphasized in our Lessons Learned.

elements" of the items in an organized **search results** list display will go a long way towards allowing people to decide which item to pursue further. It will allow users to apply their selection strategies based on their own experience of what is successful for them. This is a distinctly separate approach from the usual **technology**-centric **strategy**, where search engine "power" is purely defined on the basis of content analytic & algorithmic rule-making; and the vendors of these approaches apply the term "usable" when referring to a simply structured and "nice-looking" display interface.

It seems that a more collaborative and a contextually and user-goal sensitive approach seems preferable where users indicate up front what they are after. Even in top-level Home Page designs the major and predictable **user goals** viz. a vie the site are known and should be addressed in the page's content and navigation architecture.

For example, a usability inspection of the **NLM Home Page** would ensure that **user goals** are addressed. Even a cursory review tells us that when it comes to meeting site user's goals directly and with clarity, much room for improvement in site design exists.

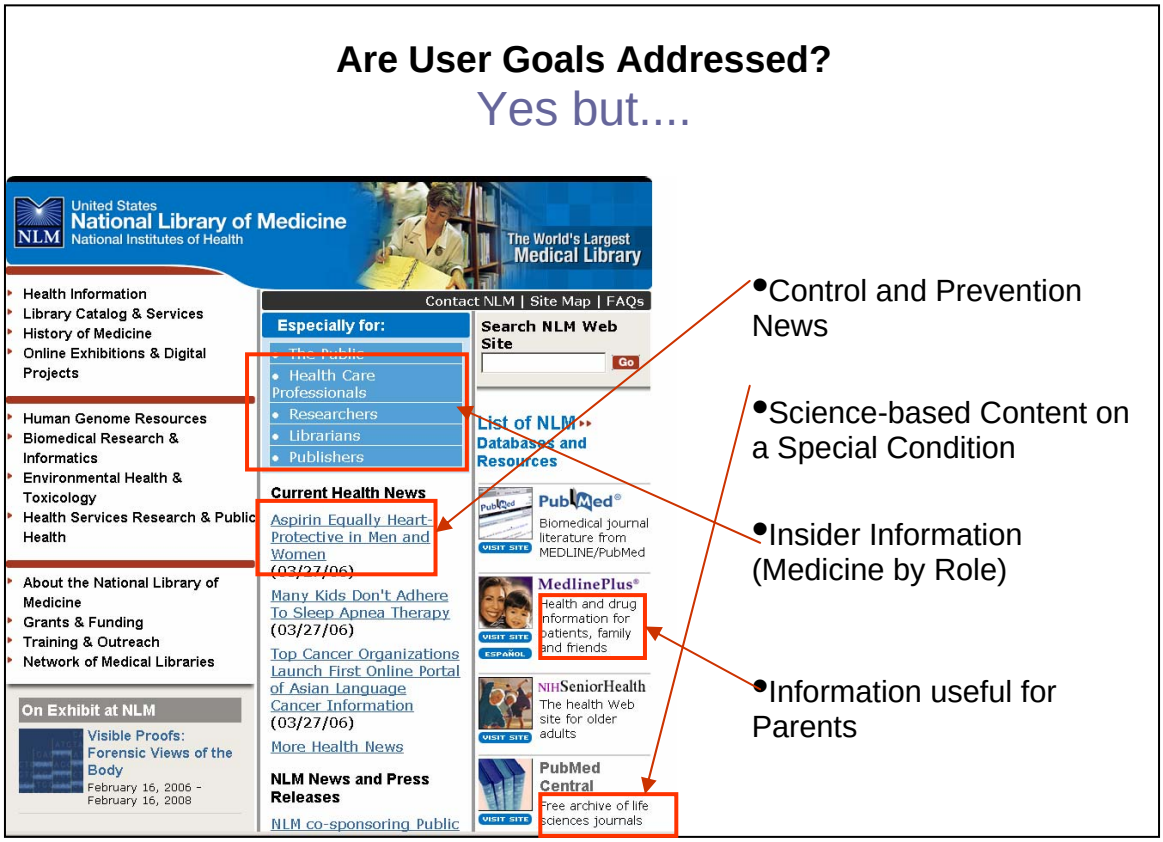


Figure 12. Sample Usability Analysis

NLM Home Page – top level access to NLM content.

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Lessons Learned - Towards Formulating Recommendations

- **User actions are goal-directed** (there is a reason behind searching)
- **Search occurs within a user's context** - search can occur in any of the following contexts: as a critical, a professional, or a leisure activity

📖 **Medical Education Levels of users vary widely** – site content should match this variety but in an organized fashion

📖 **Sites should provide explicit self-improvement opportunities** – some amount of **moderated** educational **content** (sign up if you are a new parent, if you want to stay informed on Bird flu, etc.) this is pulled together by our experts for you

- **Medical Language, English Language; Standard Culture?** - proficiency and information needs of users vary (3rd culture kids)
- **NLM "treasures" must go to the top** – focus on NLM goals for information –showcase content according to needs (requested search)- always have the "best" close by – dictionary; latest news; what others have looked at.
- **From Google to NLM sites** – advertise NLM site missions – and features in professional publications and college campuses – tell users "welcome" and what else they can do on the sites when they come from a **Google** search result link.

Towards Formulating **Search Models**

A simplified Strategic Model of Searching based on a quick review of our interview findings and particularly the detailed Persona 4 information is shown in the Medical Information Grid of Figure 13. It accommodates the following ideas for user strategies and **decision making** for item selection:

Presumed <u>Authority</u> or Expertise

- Users say they are looking for a "Stamp of **Approva**l" from some professional organization on a Web site. But they will read content and visit other sites without apparent **endorsements**.

Have One or Two "Words" in Mind to Start But am Willing to Use Others

- Search for key terms (usually one or two only) – use **terminology** others are using

Look for "Why" Content Items when doing Research while non-professionals look for the "What"

- Search Clinical Trials (inclusion or exclusion) – specifically look for information on “evidence – based medicine” – this means that the user and the content they look for must show their “why”
- Do advanced Searches - Epidemiology

All Employ a “Recency is Better” Heuristic

- Most Recent is presumed to be most relevant

All subscribe to a “Science is Better” Rule but all Will Read Other Materials because it is “Easier” and “Faster”

- Generally look for more specific “evidence-based” medicine
- Technical content is “drudgery and time-consuming”

Ethno-Centric Searching or the World is Local, and, I Read What I Know

- Users don’t typically look at literature from other countries – some of the abstracts are translated

Just-In-Time Searching

- Typically **search scenarios** of a personal nature will be conducted just before visiting with a patient or other event

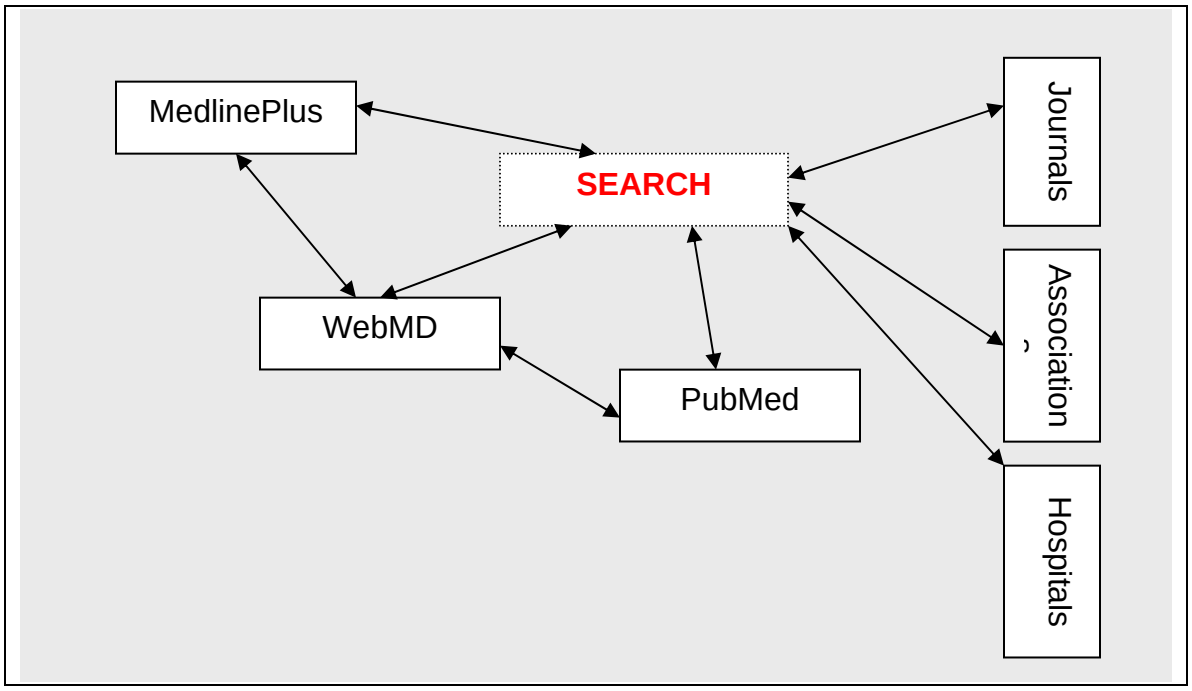

Figure 13: Information Strategy for Searching (Model of Self-Reported Behavior)

SEARCH SCENARIOS FOUND

Evidence for the following four **"Nominal" Search** Scenario Types was found in our Study as illustrated in Figure 14:

(1) The Look-Up
(2) The Find-Out-More
(3) The What's-New
(4) The Explorer-Discoverer

These four scenarios are related to the following search domain levels:

- Levels of Technical Specificity
- Level of Technical Knowledge
- Level of Complexity

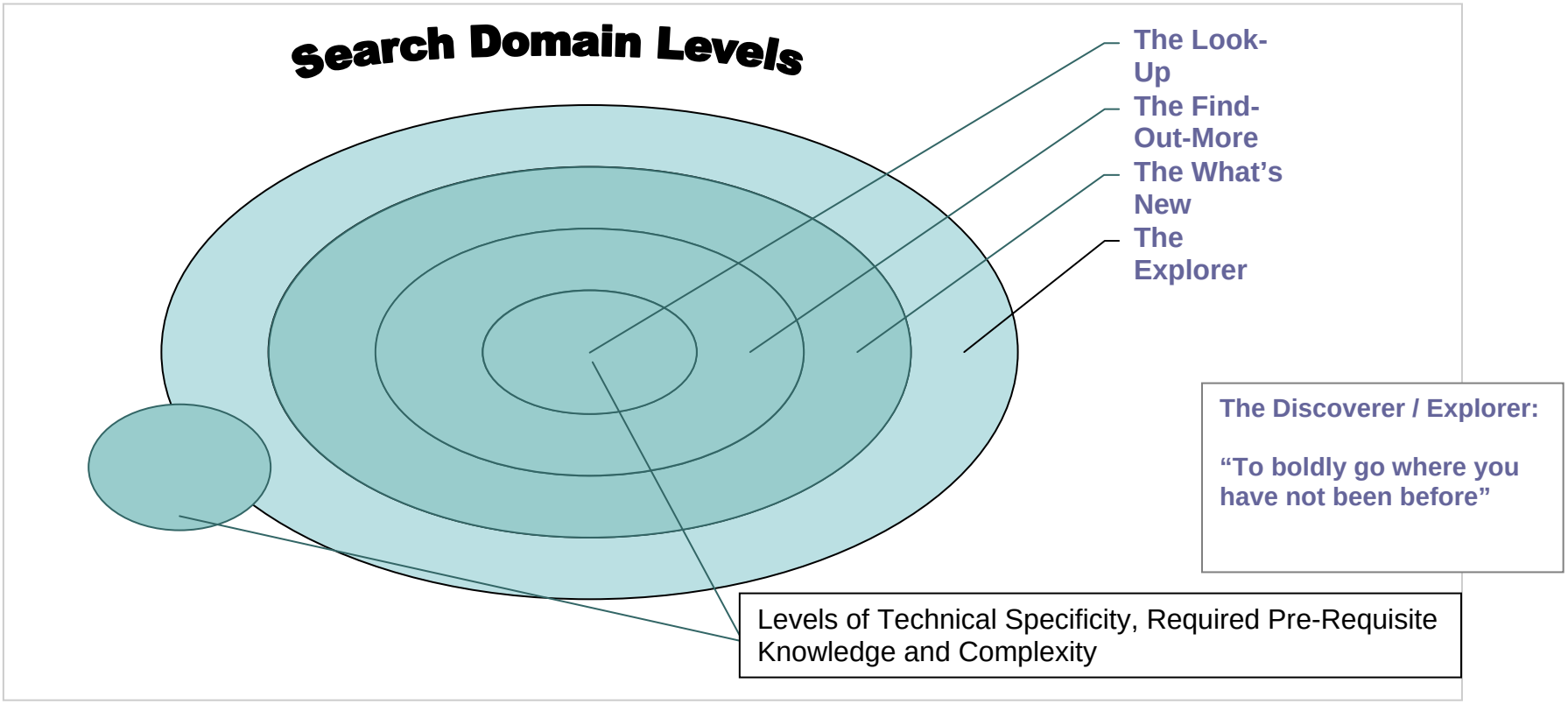

Figure 14. Search Scenario Types

The Look-up Scenario:

Find out what a particular disease name or abbreviation means.

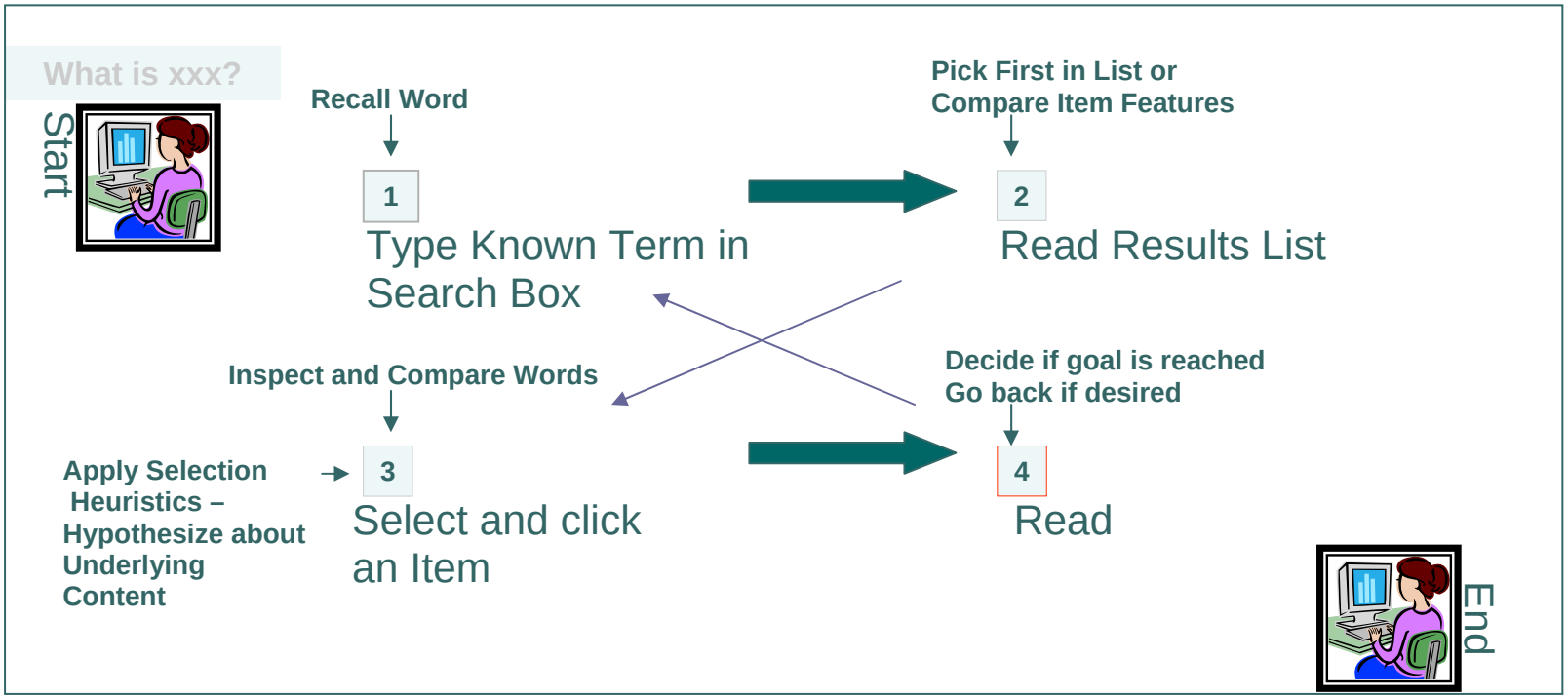

Figure 15. Search Scenario (1): The Look-up

The Look-Up Scenario: Recommended User Support Features

- **Recall Aiding** – alphabetized lists of disease names
- **Search Box Prominence** – Standard Upper Left or Center in Site Banner
- **Spelling Error Tolerance** – **automated** spell correction & search extension –"did you mean XYZ?"
- **Results List Prioritization** – Exact Match on Top – give short Definition along with name
- **Highlight** - matched word in results list items and content
- **Allow Filtering at Results List Level** – Provide tools for reducing results list length (recommend show only top 5 results and have "more" button; **less is more for most searches – users will actively avoid large numbers of results to go / look through**)
- **Show Next Step Options** – help users decide what to do next; display action options: sample other items; search again (additional term), store (download) this result, e-mail, print items, show related content, learn more, read latest news articles...etc.

The Find-out-More Scenario:

Find out information about a newly diagnosed condition for a friend.

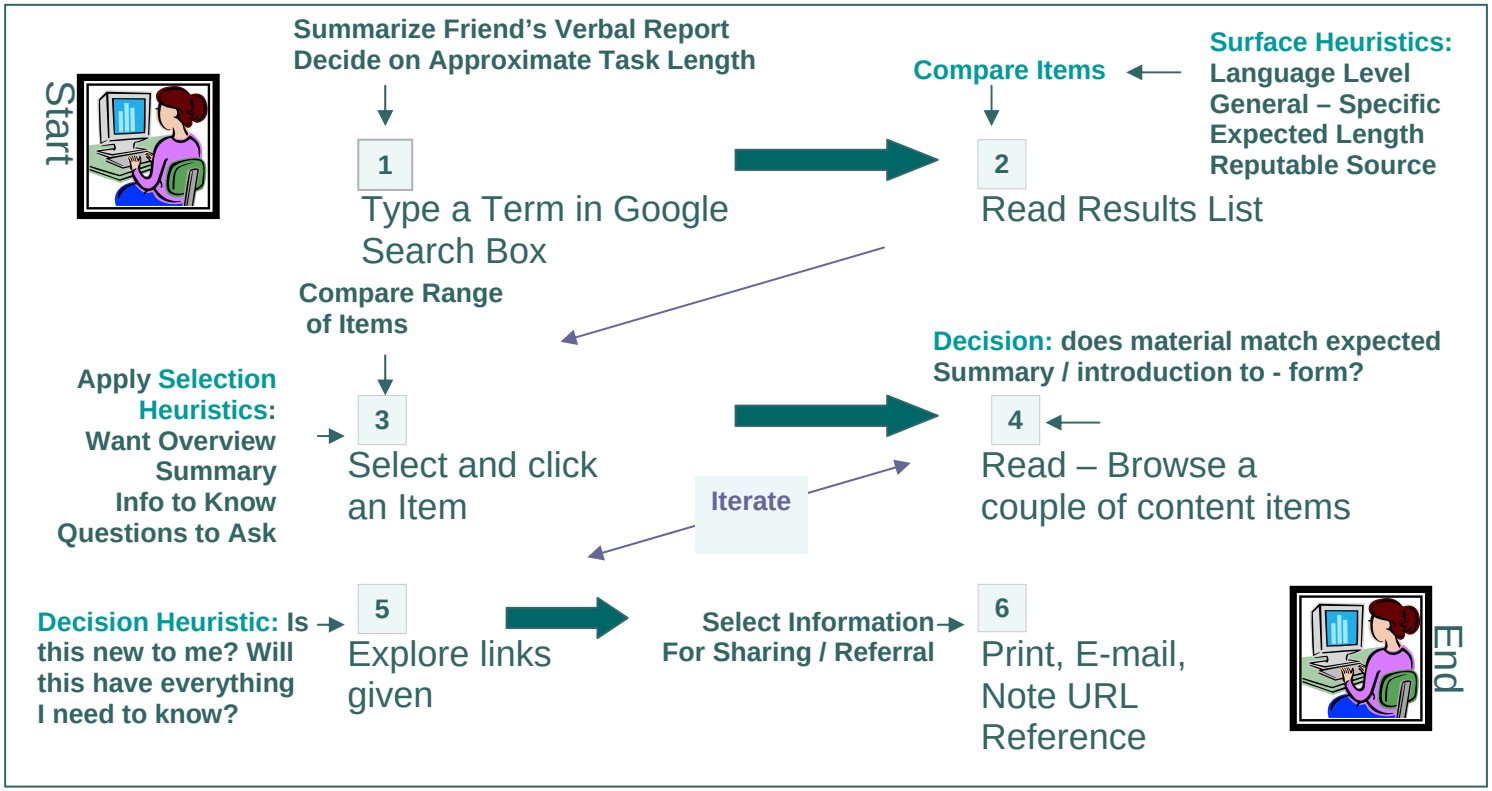

Figure 16. Search Scenario (2): Find out More

🕮 **The Find-out-More Scenario**: Recommended **User Support Features**

- Suggest Alternate Words and category menus to Search – Self-Education areas, and/or Hand-out Materials must be one of the categories of information sought
- Source Identification – clearly identify mission and site originator type (NIH – NLM resources etc.; other Government Information, Non-Profit Association sites, commercial resources)
- Identify **Date** of Information Always – "Newness" Matters – users want the latest and greatest
- Content organized for 'the Basics" and "Detailed" – the basics should guide people further with suggestions
- **Site Prominence** – NLM sites need to show up prominently in **Google** results lists [Mission of **MedlinePlus**? To guide users to good information]
- Best questions to ask of **health care providers** – show a list of questions that are relevant to the specific medical condition – also show questions always to ask/know
- Results List Prioritization – Basic Level Content & Advanced Language Content should be clearly marked in results lists (similar to **media markings of content**)
- Bring videos and other special content **media** as a results type – could also include how to approach a newly diagnosed disease – what resources are available where on the site
- Allow Filtering for **media** at Results List Level – Provide tools for: a) viewing all video type materials available – b) filter for: with/without **graphics** – c) more information on surface structure of items – length – type of content – language level, etc)
- Show Next **Step** Options – help users decide what to do next; go – SUM Results – **explain** the prioritization scheme and show top items only; search again (site versus search on results), store (download) this result, e-mail, print items, show related content, learn more, read latest news articles...etc. – desirable is a shopping cart type feature which allows a user to collect bits and pieces of information suitable for printing with link resources indicated
- Strongly Recommend – There should always be one item in response to any search that NLM recommends! If no recommendation is possible – list content with the most hit rates over the last 2 weeks – or content that was added last for a general topic area (assume people want to **look up** a disease area"
- Go Local Resources – should be advertised in results sections (part of next step guidance)
- Organize disease content along common areas of searching: "Diagnosis", "Prognosis", Treatment", "Drugs", "The Latest News", "Research Activities", "Community Resources" "Exercise and Health for..."

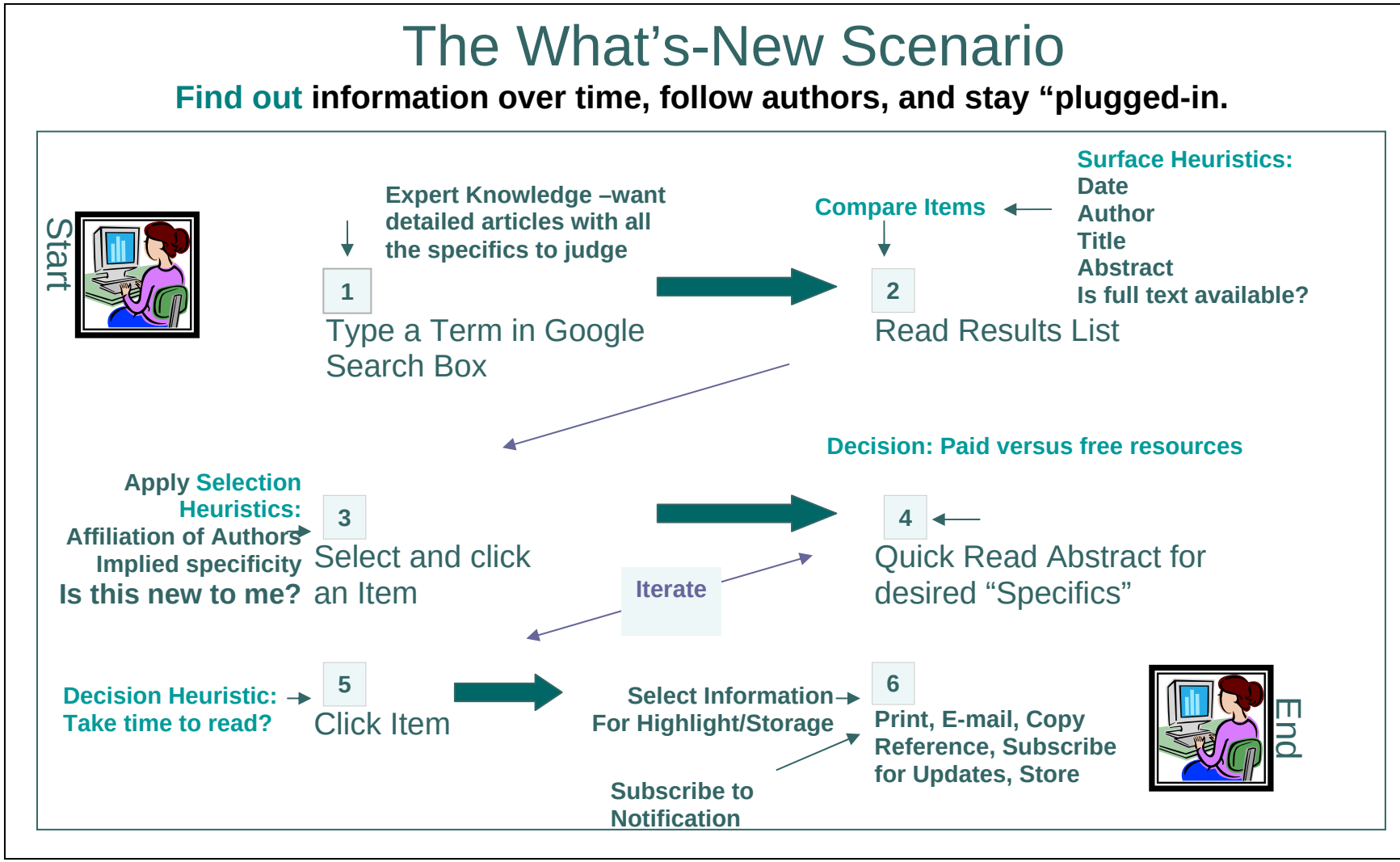

Figure 17. Search Scenario (3): What's New Scenario: Repeated Searching / Learning

🕮 The What's-New Scenario: Recommended **User Support Features** (Extended Learning):

- **Suggest Alternate Words and category menus to Search** – Full-Text Scientific Articles versus News Articles, versus Educational/Support Materials
- **Date of Publication** – must be shown
- **Language of full-text publication content** should be listed in results
- **Affiliation of Authors** should be indicated in results list
- **Professional/ Scientific / Peer Reviewed** versus **Easy Language Reads** should be listed in separate groups, as a filter tool with the search key word
- **Author Feedback / Comment Area** should be provided
- **RSS-like notification of updates** (subscriptions) for publications of interest, and further publications by this author should be provided

Annotation: As this longitudinal search pattern, (occurring over an unspecified length of time), appears the most complex, it is interesting to note that user decisions, given this **search scenario**, regarding whether to approach an item, (look at it further or not), is based mostly on **surface feature** information (i.e. anticipated target content based on past experience is used for selection assessment as opposed to a quick but actual inspection of the item content).

Summary Search Scenario Characteristics

Search Scenario Type	Characteristics	User Support Needs
Look-up	One-Time "Throw-away" results • Memory / Forgetting • Taking the time to finally check it out	Exact Match Highlighting Definition or Meaning Summary of Content Context Occurrences Thesaurus of Terms Needed
Find-Out-More (**Sense-making**)	**Elaborated Search** for Resource Materials	Spiraled Knowledge Marking for Reference Transferring – sharing for collaboration Communication
What's New (Longitudinal Searching)	**Repeated Searching** for Added Info	Integrating Knowledge Learning Applying

Search Scenario Type	Characteristics	User Support Needs
Discoverer / **Explorer**[11] "To boldly go where you have not yet been"	Discovery occurs when **Google** brings up a site or links to a document that introduces the user to a brand new concept or domain area but still of **interest** to his/her overall pursuit or goal	Orienting Tools Map of domain ('planets') <More> Navigation Directions

Table 8. Search Scenario Characteristics

Several as yet unpublished research papers in Human Factors & Cognitive Engineering have discovered that search behavior in humans can be a fruitful activity of inquiry.

The final Model graph below, attempts to fit the initial Search Types we found into a three-dimensional graph, where cognitive sub-activities are represented on the X-axis, and a unit descriptive scale on the Y-axis, and time on the Z-axis. This type of "behavioral path" representation is an example of the type of detailed research work that could lead to further development in understanding human search and/or to develop assessment instruments that provide best fit profiles, or progress status accounts, etc.

More general application interest for detailing behavioral paths, (time course event charts), seems to reside in the burgeoning area of collaborative **sense-making**, where communications between remote robotic agents and a geographically dispersed control team attempt to reduce **uncertainty** and increase factual **knowledge**.

For the purposes of this feasibility study, it is sufficient to indicate that much current, but yet unpublished basic research activity seems to exist on the topic of human searching for information under uncertain conditions.

[11] **A current article by Gary Marchionni entitled "Exploratory Search: From Finding to Understanding" in Communications of the ACM; April 2006/Vol. 49; No. 4; pps. 41-46; shows a variant of this search classification, including the Exploratory search pattern where learning and investigation are presumed to take place. This publication serves as a nice face validation of our study findings and analysis.**

Elementary Model of User Searching

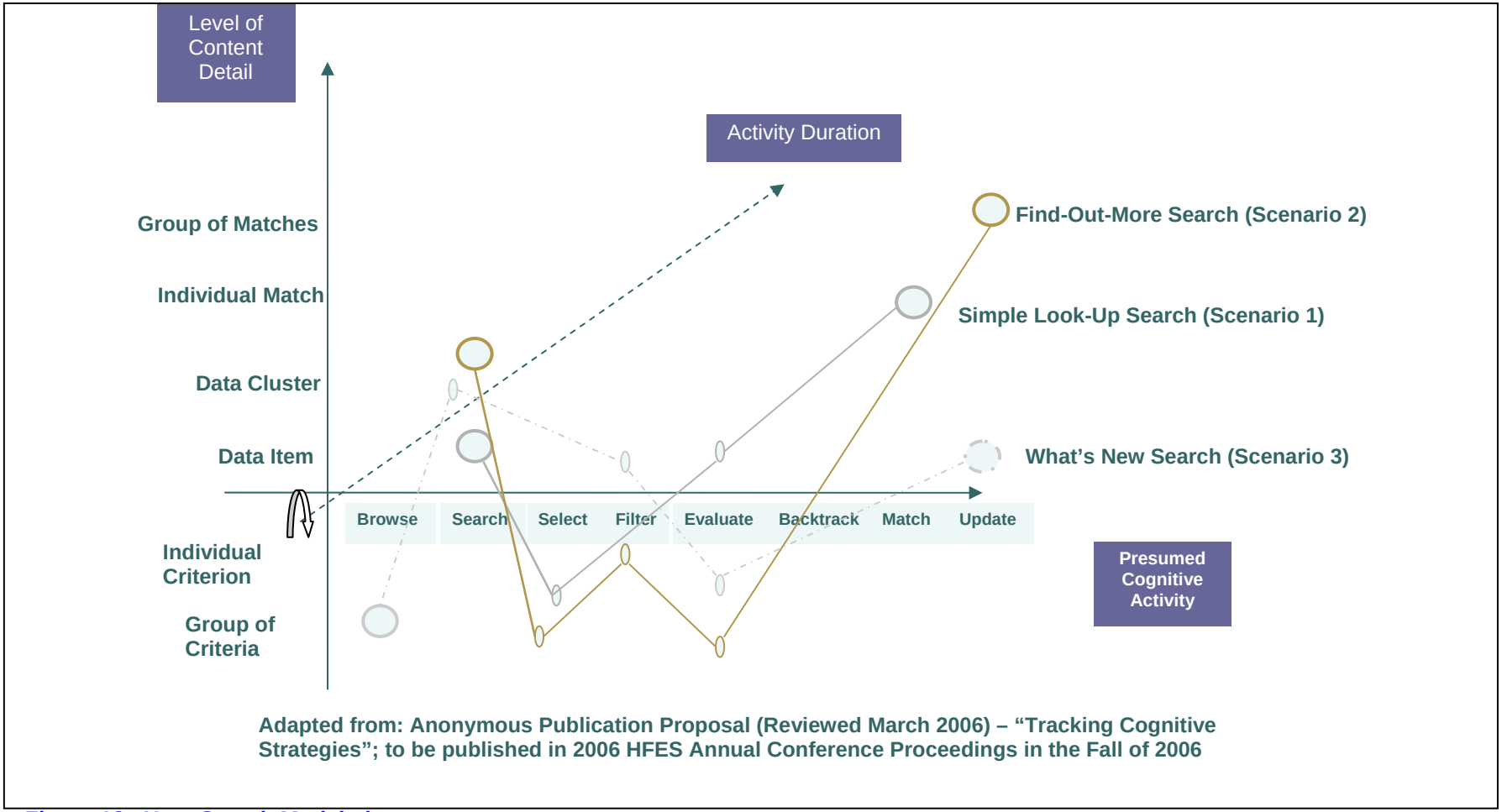

Figure 18. User Search Modeled

CHAPTER III:
FOCUS GROUP PHASE REPORT

The following main topics were addressed using focus group activities as a data collection / study method:

- Useful Web features & tools related to searching.
- What are you looking for on medical health content Web sites?
- How do you organize the information you find when searching over time?
- Life span issues of Information.
- **Terminology** from a card sort.
- Future Trends looked at from the view of what impact they might have on medical information searching.
- What People Want (Discussion on NEED for communicating Scientific Solutions)

Figure 19: Moderated Focus Group Discussion Session

Medical Web Site Search Study Focus Group Plan Notes

Objective

The objective of the overall focus group activities was to investigate user perceptions of searching for information on medical Web sites, and **extracting** medical information. Further, we wanted to develop and "test" some new interface **design concepts** for accessing the information. Emphasis was to remain on finding out more information about "**contextual searching**" (as inputs to search interface design).

Focus Group Composition

Ten individuals involved in Health Care were recruited to participate in a Saturday Morning Focus Group Session held at Quotient Inc. facilities in Columbia, Maryland. Two of the ten had participated in earlier interviews. Eight were brand new to this study.

Pre-Event On-line **Survey**[12] Results

A screening **survey** and on-line background **questionnaire** of a recruited set of focus group participants produced the following results.

Focus Group Health Care Professional Role

Question

Please give us your current Job Title and field of work. Be as specific as possible. If retired - please indicate a job role that you performed the most often in the past. If now a student - indicate Years of study. (Examples: Retired Submariner; 4th Year Medical Student)

Answers	
1.	EMS Lt., Public Service Paramedic
2.	Head Nurse ICU/PACU
3.	Pharmacy Technician
4.	Homoeopathic Practitioner
5.	Secretary/Librarian- Judy Center, Howard County Public Schools
6.	EMT, PT Rehabilitation Aide
7.	4th year medical student
8.	Director of Nursing Assisted Living
9.	First Year Graduate Student for Doctor of Physical Therapy
10.	Clinical Safety Associate (Research Dept of Pharmaceutical comp)

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[12] **Survey Monkey software via subscription from http://www.surveymonkey.com/ was used to prepare the on-line survey and view the results shown. Participants were sent a URL via e-mail and told to fill out the survey prior to coming to the focus group – all 10 individuals complied.**

Focus Group **Age**

Question
Please indicate which age group you belong to:

Answers

		Response Percent	Response Total
18 to 25		30%	3
26 to 35		10%	1
36 to 45		**40%**	**4**
46 to 55		20%	2
56 and above		0%	0
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group Personal Health

Question
How would you rate your current health?

Answers

		Response Percent	Response Total
Excellent		30%	3
Quite Healthy		30%	3
Have Minor Issues		**40%**	**4**
Have Major Issues		0%	0
Suffer Chronic Disease		0%	0
Terminally Ill		0%	0
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group **Interest**

Question

Specialty Area of Study (Primary **Interest** Area Now)

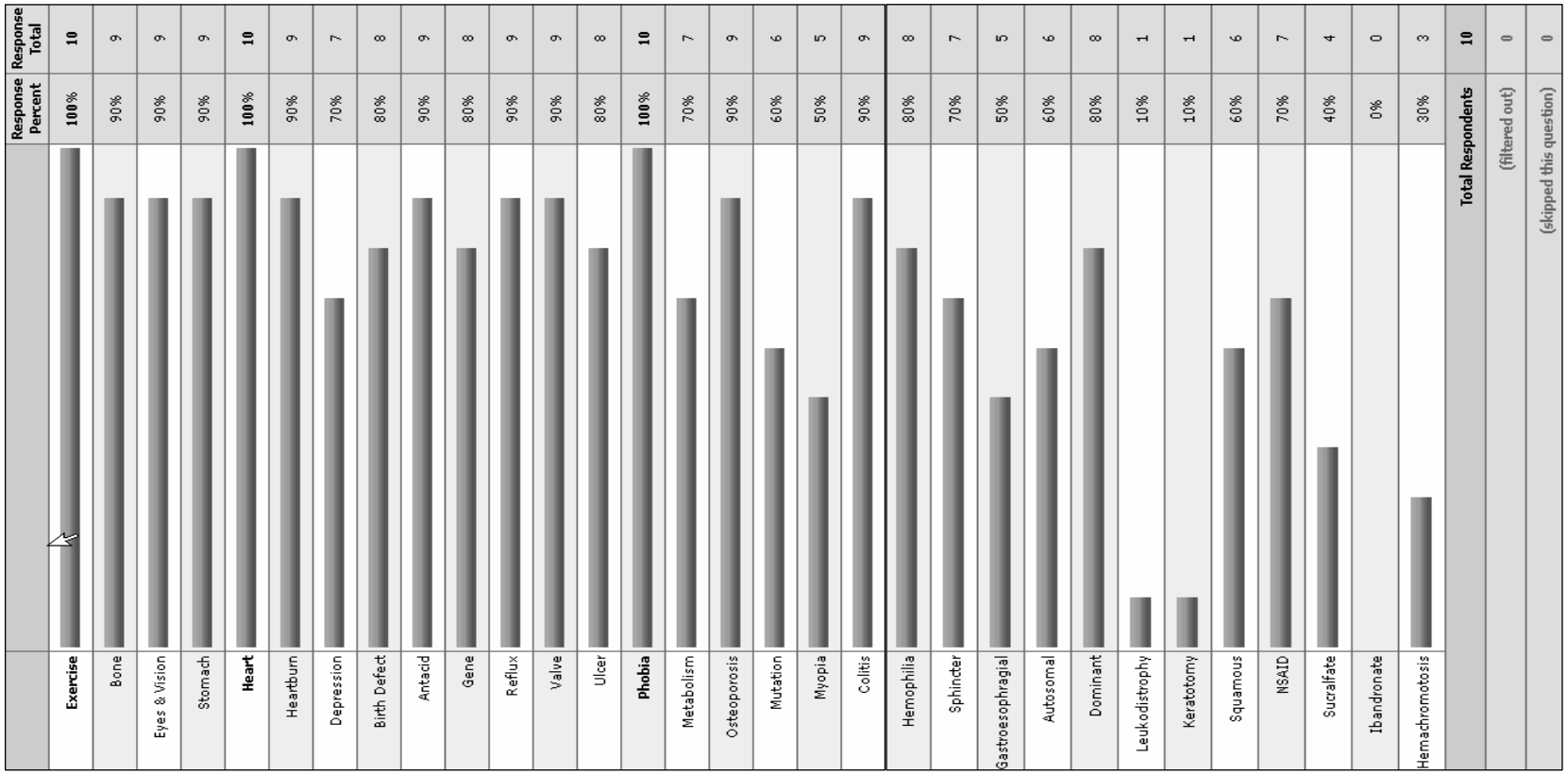
Answers

1. Emergent medicine
2. Nursing
3. Pharmacy
4. Homoeopathy
5. Library Science
6. Emergency Medical Services
7. Urology
8. Geriatrics
9. Physical Therapy
10. Nursing

Questions

Mark all the health related terms or medical **terminology** that you can **explain** to someone else in terms of definition, symptoms, causes and/or behavior.

Answers



Focus Group Level of Formal Education

Question

How much formal Education do you have? (If degree, only mark highest degree earned):

Answers

		Response Percent	Response Total
Highschool		20%	2
2 Year College (Vocational or Associates Degree)		20%	2
4 Year College (Bachelors Degree)		**60%**	**6**
Plus 2 Years University (Masters Degree)		10%	1
Professional Certification (Any such as Nursing, Engineering, etc.)		10%	1
Ph.D. and/or D. Med		0%	0
View Other (please specify)		20%	2
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

OTHER Responses

1.	Critical Care Nursing
2.	some college

Focus Group On-Line Information Access **Frequency**

Question

How often do you look for medical/health information content on the internet?

Answers

		Response Percent	Response Total
Several Times Every Day		20%	2
About Once a Day		**30%**	**3**
Once or Twice a Week		20%	2
Once or Twice a Month		10%	1
Once or twice a year		0%	0
It really fluctuates greatly		20%	2
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group Accessing Medical Journal Articles

Question

Have you ever looked up Medical Publication Information (or found a Journal Article) on-line?

Answers

		Response Percent	Response Total
Yes		80%	8
No		20%	2
	Total Respondents		10
	(filtered out)		0
	(skipped this question)		0

Focus Group Willingness to Pay for Full-text Access

Question

Would you pay $ to have access to full Scientific Journal Articles on-line?

Answers

		Response Percent	Response Total
Yes		10%	1
No		90%	9
	Total Respondents		10
	(filtered out)		0
	(skipped this question)		0

Focus Group Current Access of **Full Text** Articles

Question

Do you currently have free access to Full-Text Professional Journal Articles which you might want to read for Education or Work?

Answers

		Response Percent	Response Total
No		40%	4
Yes- but not for all Journals		20%	2
Yes - I have access through our library but not online		30%	3
Yes - I have full on-line access to any Journal article I might want to read		10%	1
Other (please specify)		0%	0
		Total Respondents	10
		(filtered out)	0
		(skipped this question)	0

Focus Group Type of **Content Sought**

Question

Please describe the type of content or information that you **look up** on-line most frequently (and recently) in terms of medical or health related information. (Examples: How to spell something, information about a disease I heard about, information on what tests are available, how to treat something and so on)

Answers

1. My job as an EMS Lieutenant requires continual presentations on various medical subjects, to operational Paramedics, on a Monthly or greater basis. I often **look up** reference material in preparation for or in response to one of these 'in-service' lessons.
2. Pathophysiology, Post op care, Patient Teaching, Surgical approaches, alternatives to surgical approaches and pharmacology
3. Information on a disease a family member has. Treatment options.
4. New imaging technologies new diseases new courses in health field definition of new **terminology**
5. What certain drugs are used to treat and the possible side effects. When symptoms need to be evaluated by a doctor. Information about illnesses that family members are suffering from.
6. What a medical term means, To gain further information about what medical practices I am taught.
7. Treatment specific to disease processes, information to give patients, **drug** adverse reaction **information**
8. Medications, different diseases and their treatments.
9. Information on a disease I heard about, symptoms, and how to treat it
10. Mostly medical terms and abbreviations along with the definitions. I also **look up** a lot of foreign terms and attempt English translation.

Focus Group Query Type

Question

When searching on-line with **Google**, Yahoo or similar Search Engines to find information, what do you typically enter in the **search box**?

Answers

		Response Percent	Response Total
Only 1 or 2 Key Words		**60%**	**6**
A keyword and descriptor (Half a Sentence or so)		20%	2
Key Terms with AND and OR Qualifiers		20%	2
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group **Computer Literacy**

Question

Please rate your own level of **Computer Literacy**

Answers

		Response Percent	Response Total
1 - New to Computing		0%	0
2 - Casual User (Personal Use Mostly)		20%	2
3 - Frequent User (Both Professional and Personal Use)		**70%**	**7**
4 - Expert Information Searcher (Library Science)		10%	1
5 - Computer Programmer or Software Developer		0%	0
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group On-line **E-Bay** Purchases[13]

Question

Have you ever made an on-line purchase via E-Bay or another auction type site?

Answers

		Response Percent	Response Total
Yes		60%	6
No		20%	2
View Other (please specify)		20%	2
	Total Respondents		10
	(filtered out)		0
	(skipped this question)		0

OTHER Responses

1. Amazon
2. Bought numerous products on-line

Focus Group Government Web Site Use

Question

Have you accessed a Government Web site during the last month?

Answers

		Response Percent	Response Total
Yes		80%	8
No		0%	0
Can't Remember		20%	2
	Total Respondents		10
	(filtered out)		0
	(skipped this question)		0

[13] This question was included because it has become a defacto standard screening tool question within the usability community. Presumably it will screen out beginning internet users or those without sufficient enough experience in using computers to show stable **behavioral patterns**.

Focus Group Recent Government Web Site Destinations

Question

Do you remember what you were looking for and which site you ended up in? (Please be specific)

Answers

1. Navy Medicine on-line, University of Pittsburg, new National Criterion for Paramedic Practice and other items of **interest**. I ended up at both sites.
2. AKO
3. **Food and Drug Administration**. Looking for **black box warning** for anti-depressants.
4. No Can't remember
5. A list of Democratic Senators to see who I recognized and might potentially run for President. Found the most useful list on the official Senate Web site.
6. The Maryland institute for emergency medical systems http://miemss.umaryland.edu/
7. No
8. Tonsil stones Lupus Antiphospholipid syndrome Medicare D
9. State Senatorial Scholarships MVA for driver's license
10. Yes. I was looking for employment and was sent to the USA Jobs Web site.

Focus Group **RSS** Subscription

Question

Do you currently have any active subscriptions to **RSS (Really Simple Syndication)** services?

Answers

		Response Percent	Response Total
Yes		10%	1
No		20%	2
I don't know what it is.		**70%**	**7**
	Total Respondents		**10**
	(filtered out)		0
	(skipped this question)		0

Focus Group Government Site **Interest**

Question

For each of the following topic areas please indicate how likely you are to visit a Government Site with Information Relating to that topic.

Government Site **Interest** Answers

	Not at All Interested in This Topic	Small Interest Only	Moderately Interested	Very Interested	Would Rather go to Non-Government Site for This	Don't Care One Way or The Other	Response Average
Social Security Information	10% (1)	**40% (4)**	0% (0)	**40% (4)**	10% (1)	0% (0)	**3.00**
How to Stay Healthy	10% (1)	10% (1)	**30% (3)**	20% (2)	**30% (3)**	0% (0)	**3.50**
Contact Information for Doctors and Other Medical Professionals	0% (0)	0% (0)	**40% (4)**	30% (3)	20% (2)	10% (1)	**4.00**
Drug Information	0% (0)	0% (0)	20% (2)	**60% (6)**	20% (2)	0% (0)	**4.00**
Medicine in the News Articles	0% (0)	0% (0)	20% (2)	**70% (7)**	10% (1)	0% (0)	**3.90**
Abstract of a Medical Journal Article	0% (0)	10% (1)	**40% (4)**	**40% (4)**	10% (1)	0% (0)	**3.50**
Prevalence of Toxic Sites	**30% (3)**	20% (2)	10% (1)	20% (2)	20% (2)	0% (0)	**2.80**
Identification of Hazardous Materials	0% (0)	30% (3)	**40% (4)**	20% (2)	10% (1)	0% (0)	**3.10**
Topics & Information for Seniors	0% (0)	**40% (4)**	20% (2)	20% (2)	10% (1)	10% (1)	**3.30**
Women's Health Information	0% (0)	0% (0)	**40% (4)**	20% (2)	30% (3)	10% (1)	**4.10**
Men's Health Information	0% (0)	20% (2)	20% (2)	20% (2)	**30% (3)**	10% (1)	**3.90**
Children's Health & Parenting	10% (1)	10% (1)	20% (2)	10% (1)	**50% (5)**	0% (0)	**3.80**
Internal Revenue Service Tax Information	10% (1)	**30% (3)**	**30% (3)**	20% (2)	10% (1)	0% (0)	**2.90**
Senate Web site featuring Congressional Hearing Information	**50% (5)**	10% (1)	0% (0)	30% (3)	10% (1)	0% (0)	**2.40**
Patent and Trademarks Information	**50% (5)**	10% (1)	30% (3)	0% (0)	0% (0)	10% (1)	**2.20**
Food & Nutrition Information	0% (0)	10% (1)	**40% (4)**	20% (2)	20% (2)	10% (1)	**3.80**
						Total Respondents	**10**
						(filtered out)	**0**
						(skipped this question)	**0**

Focus Group Government Site Desired

Question

Please indicate a favorite Government Type Web site or one that you would want to visit:

A. Answers (For Medical or Health Information)

1. PubMed
2. AKO
3. FDA
4. www.nih.com
5. Medicare information
6. http://www.fda.gov/default.htm
7. NIH-related
8. nih.gov
9. Ovid/Medline/Cinahl database
10. Food and Drug Administration

B. Answers (For Other Information)

1. **Google**
2. OUTLOOK
3. Howard County Government
4. -
5. Election information
6. http://miemss.umaryland.edu/
7. None
8. *
9. **Google**
10. National Institutes of Health

Focus Group Features Looked for On Web Sites

Question

Please tell us in your own words what features you look for on a Web site (What do you like? For Example: Good Organization of Topics, Pictures, Easy Navigation, Information for Professionals, a Shopping Cart, etc.):

Answers

1. **Relevance**, good layout, ease of understanding the material.
2. Good organization of topics to ease accessibility, Picture illustrations, Up to **date** and accurate information, Regularly active site, and less complicated and red-taped access
3. Easy navigation. Links need to be clear and easily accessible.
4. Information for professionals interesting topics
5. Clear topic areas; Easy to navigate; A professional look; Secure Web site
6. User friendly but professional, plenty of links that are described
7. Easy navigation, information that is easy to read
8. Easy navigation links. I like to be able to do an internal search without being taken back to cyberspace
9. Easy to navigate, good organization with pertinent topics/headings to click on to access information, Easy to read (**color** schemes that are easy on the eyes), Pictures, credibility of information
10. First and foremost the organization. For the items that I am searching for, I would like to see it within the first sentence of the site accessed. It also is very important to have easy navigation and the site should be user friendly.

Focus Group Desired **Information Content** for **Drug** Sites

Question

If there were a reliable Government type site for prescription **drug information**, what information, if any, would you want to find there?

Answers

1. Everything in the PDR (Physicians Desk Reference).
2. Types, administration info such as dosage, interactions, and access to reliable means for follow questions from the patient.
3. Side effects of drug, what it is used for, usual dosage, description of drug
4. Uses, contraindications, side effects
5. Brand names, Uses, Side effects, FDA approval **date**, and information on the testing
6. Recommended doses, side effects, drug interactions
7. Cost, adverse reactions, dosing
8. Indications and usage including off label information. Drug to Drug/Herb/Food interactions.
9. Common uses for the drug and adverse reactions to it
10. What the cost was before the government plan and what you save on each medication that is listed on the site. Most of us don't save much money by having a plan. I also would like to see the MedWatch[14] site for post marketed medications and how to report reactions to medications. I would also want to see statistics on reliability of the generic versus the brand name. Some folks are allergic to the vehicle or base in which the generic product is produced and I would like to see those types of things listed on the site as well.

[14] **http://www.fda.gov/medwatch/**

Focus Group Concerns about Government Sites versus Commercial Sites

Question

How do you feel about getting information about medical topics from a Government Web site? What are your primary concerns with Government Web sites as sources for information?

Answers

1. That they would be outdated and therefore useless.
2. The information may have been sanitized. In most cases for very valid reasons. Certain information is better left to the non Governmental organization to avoid any such suspicions. The other concern will be getting most current and updated information because of the large bureaucracy
3. Honestly I have never had any problem with government Web sites I have used.
4. They are reliable
5. My main concern is that they wouldn't want to publish anything that could later be used against a government agency and therefore would leave out potentially important information.
6. Current information and updated regularly
7. I am not partial either way
8. No specific concerns
9. Although I haven't had a lot of experience with Government Web sites, I don't have any real concerns with them. I would read the information carefully to see if it was written with some bias, but I don't think I would have any concerns with the information if it seemed valid.
10. Well, I have not had many issues or problems. I hope that the information is not biased in any way.

Focus Group in Their Own Words **Reasons for Disliking Search**

Question

Finally, please indicate what you most dislike about on-line searching for information. Please be specific:

Answers

1. You can get caught in a maze of sites without really finding anything of substance, mainly due to abuse of meta-tags.-
2. Unless someone puts the information right and just as the user asks for it, it is usually difficult to locate a particular piece of information. But overall I am more satisfied than not with current service that the internet provides.
3. I don't like links that appear to lead to the information you need only to be taken to an advertisement.
4. There is distributed information in many sites so to view it completely we have to open many sites.
5. All of the sites that come up that really don't have anything to do with what I'm looking for, but because the search words come up just once or twice on those sites, they are included in the list.
6. When a search brings up **zero results**
7. Takes too long.
8. No comment @ present
9. I dislike it when I can't find what I'm looking for. For instance, if it doesn't give me an option to route me to the correct category and I waste a lot of time looking for what I need.
10. Sometimes the information for professionals is mixed up with lay information. In this situation, searching becomes cumbersome and frustrating. Sometimes you cannot tell which site is a credible site. That is the most frustrating.

Focus Group Participants

Charlie Brown
Head Nurse
ICU/PACU

Garfield
Pharmacy
Technician

Peppermint Pattie
Librarian
Public School

Polly Pocket
Director of Nursing
Assisted Living

Piglet
First Year
Graduate Student for
Doctor of Physical Therapy

Marge Simpson
Clinical Safety
Associate
Research Dept
Pharmaceutical Co

Wiley Coyote
EMT & PT
Rehabilitation Aide

Winnie the Pooh
Homoeopathic
Practitioner

Tinkerbelle
4th year
Medical Student

Elmer Fudd
EMS Lt.
Public Service
Paramedic

Figure 20. Focus Group Participants with Self-Selected Cartoon Names

Focus Group Activities

Warm-Up Exercise

Question: "What are you looking for on a Medical Web site?"
Answers from Participants:

Self-Selected Cartoon Name of Participants	Information about Participants	Answers to "What are you looking for on a Medical Web site?"
Garfield	• from Ellicott City • Pharmacist Technician • took first airplane plane ride at **age** 42 • likes to Crochet	Looks for drug information on the internet
Peppermint Pattie	• from Bethesda • nursing director • likes to crochet • first time on a bike at age 46	Looks for Diagnosis type information
Elmer Fudd	• from Annapolis • a Lieutenant Firefighter	Searches for miscellaneous topics
Wiley Coyote	• from Baltimore • a full-time physical therapist	Searches for specific Internet Information
Piglet	• Baltimore • 1st year Medical Student	Searches sites that are easy to navigate and

Self-Selected Cartoon Name of Participants	Information about Participants	Answers to "What are you looking for on a Medical Web site?"
	• **interested** in Physical Therapy	are well-organized
Tinkerbell	• from Manhattan NY • 3rd year Medical Student	Searches for Information that is easy to utilize
Marge Simpson	• from Pittsburgh • a Nurse working in Cardiovascular Research Area – • relocated to Washington/DC area for Job opportunities	Looks for user-friendly, cross-referenced specific and relevant information
Polly Pocket	• from Virginia • an Information Science Librarian • likes to play "Bonko" a Social Game with dice	Searches for User-friendly Web sites
Charlie Brown	• born in Lagos, Nigeria – • is a Registered Nurse in a Military Hospital Critical Care Unit – • has spent 6 months in Iraq – • started professional life as an Engineer, • resides in the US since 1976	Searches for Medical Information related to **Military Applications**
Winnie the Pooh	• Born and raised in India • is a Consulting Homeopathic specialist	Searches for Information on Medical Imaging Techniques and for topics related to homeopathy

Table 9. Participant Answers to "What you are looking for on a Medical Web site" Question

Summary Table of Typical Search Target Content Mentioned

Professional Role	Described Search Targets	Described Attributes of Search Targets
Pharmacist Technician	Drug Information	
Nursing Director	Diagnostic Type of Information	
Nurse- Cardiovascular Research	Very Specific Information	User-friendly, cross-referenced, relevant
Nurse – Critical Care Hospital	Medical Information related to **Military Applications** Looking for instructional and Reference Materials to have ready for patient care-givers near bed-side	
Fire Fighter EMS Paramedic	Miscellaneous Topics Specific Instructional Materials Ongoing-Education Reference Materials for others	
Full-time Physical Therapist	Very Specific Information	

Professional Role	Described Search Targets	Described Attributes of Search Targets
Medical Student (1st Year)	Information relevant to a particular study project – various purposes	Sites that are Easy to Navigate and are well organized
Medical Student (3rd Year)		Easy to Utilize Information
Librarian Information Science	**Look up** Information on a Diagnosis for Parents or Others	User-friendly sites
Homeopathic Specialist	Information on Imaging Techniques Topics on Homeopathy	

Table 10. Summary Table of Typical Search Target Content Mentioned

Search Strategies

"Discuss things you do when you look for information on-line"

(What is the reason you search on-line?)

There is a difference to be made between long-term ongoing search task goals and One-time search sessions. Also, some people referred to informational content and others discussed "using" information as a material object.

Self-Selected Cartoon Name of Participants	What is the reason you search on-line?	Type of Search
Piglet	usually for a study project in school look for information that fits that purpose – have that purpose in mind – typically a one-time search	One-Time Search – Look-Up
Polly	Looked up information for parents recently – "they wanted me to **look up** information for them, they got some kind of diagnosis from their Doctor – this is a one-time search, a look-up of basic information on a particular diagnosis and doctor put them on a particular drug which I looked up also	One-Time Search – Look-Up
Charlie Brown	I constantly **look up** medical information --- particularly medical procedures for education purposes myself and others – I try to set up some relevant information context for patients – information that can be available bed-side	Constant Search - Discovery
Elmer Fudd	I am looking a lot for specific instructional materials that fit job-related issues (emergency medical)	Frequent Search – Find

Table 11. Participant Answers to "What is the reason you search on-line?" Question

"How do you keep track of the information you find?"

How do you keep track of the information you find?	Category for Keeping track of information found
Use physical folders for papers	Print & Physical File Folders
Have electronic folder organization (especially for educational purpose)	Electronic File Folders
Have Favorite folder organization for procedures and I update these occasionally	Electronic File Folders
Sometimes I print things out so *I can take it into patient rooms or hand it around (in work groups)	Print & Give-Away
Repetitively **look up** the same stuff instead of keeping it	Throwaway
Checklist for Procedures keep around to be able to go back and check it out – make update annotations	Print & Keep Handy
For print-outs "pass around the information for a few days"	Print & Give-Away
Print things out and clip it onto other paper information (chart)	Print & Keep Handy
Save information for proof – for stuff I use a lot – so that I will always have the source for it	Electronic File Folders
Continuously update the information – I give it a **date** – when I looked at it – I consult this original source over time repeatedly	Electronic File Folders
I look for the most current information always	Throwaway
I note the site name/ URL rather than the information in it	URL – Favorite Folders

Table 12. Participant Answers to "How do you keep track of the information you find?" Question

Focus Group Card Sort Results

For the method and items used in the card sorting task, see Appendix VI. Focus group participants were divided into two groups, one sorted headlines, the other sorted single word concepts. The results showed that, the "Single Concept Card Sorters" ended up with four different groups that held between thirteen and nineteen cards each as shown in Table 13.

Table 13. Card Sort Result – Simple Concepts

Single Concept Group Card Sort Results

TREATMENT OPTIONS Group 1	DIAGNOSIS & SYMPTOMS Group 2	HEALTH NEWS Group 3	LIFESTYLE Group 4
	11. Diabetes		
	69. Prostate Disease		
	20. Autism		
	30. Strep Infection		
	23. Malaria		
66. Astra Seneca	2. Sleep Disorder	38. Stress & Hostile Behavior	
13. Pharmacy	62. Cancer	4. Nerve	37. Safety
6. Gene Therapy	33. Anxiety	10. Digestive Tract	61. Nightshift
26. Options	1. Migraine	29. Brain	54. Women
12. Stem Cell	36. Stroke	3. Kidney	60. Elderly
51. Organ Transplant	58. Osteoarthritis	67. Smoking Ban	8. Latino
39. Minimally Invasive Surgery	28. Pregnancy	34. Guidelines	5. Kids
63. Hospital	65. Cataracts	0. Knowledge	68. Daycare
31. Chemotherapy	22. Inflammation	55. Health Headlines	27. Sociability
35. Estrogen	53. Hypoglycemia	21. Bird Flu	32. Love
16. Antibiotic	25. Blood Sugar	7. Health Plan	59. Overweight
24 Folic Acid	52. Impairment	18. Remission	64. Healthy Eating
50. Dialysis	17. Taste	57. Level of Incidence	56. Exercise
14. Drugs	9. Lice	19. Health News	15. Prevention

Table 13. Card Sort Result – Simple Concepts

Headline Group Card Sort Results

Genetics Category 1	Brain Injuries Category 2	Breaking News / Viruses Category 3	Prevention / Education Category 4
35. Genes May Sway BP Drugs' Effectiveness	48. Key Protein in MS May Lead to Therapies	54. AIDS Vaccine Trial Exceeds Expectations	18. Parents Right To Say "Don't Jump on Bed"
49. Left-Handed Women Face Higher Cancer Risk	33. Low Cholesterol Linked to Parkinson's Risk in Men	55. Scientists ID Malaria Parasite Dispersal	45. FDA Steps Up Action on Misleading Drug Ads
15. High-Risk Black Women Need Breast Cancer Gene Test	56. Rhythm Therapy Useful for Bipolar Disorder	3. Clinicians Warned About Clinical Trials	58. More Infections with Long-Term Antibiotics
50. Most Breast Cancer Not Linked to Ovarian Cancer	53. Placebo Effect Tied to Brain Receptor Activity	19. Scientists Say Bird Flu Cases Back Migration Theory	21. Prevention Programs Help People With Heart Disease
5. Women Survive Lung Cancer Better Than Men	59 & 57. Noise Affects How Brain Affects Movement	17. Roche Says Set to Supply Tamiflu for U.S. Stockpile	23. Heart Attack Risk Factors Tied to Kidney Disease
4. Kidney Disease May Have Heritable Factor	39. Stem Cells Aid Spinal Cord Injured Mice	28. Treatment Prevents Defects from Cytomegalovirus Infection	24. Circumcised Men Less Apt to Transmit Chlamydia
	20. Blood Test Gives Early Warning to Brain Injury	52. WHO Official Warns to Prepare for Bird Flu	13. Fruits, Veggies Help Build Strong Bones in Boys
			38. You'll Have Medicare Drug Choices

Table 14. The Headlines Group sorted their cards into 12 distinct categories. Each group held between 2 and 8 cards.

Table 14 continued:

Psychology Category 5	Smoking Category 6	Herbal Category 7	Pediatrics Category 8
34. Eating Disorders, Anxiety Go Hand in Hand	**1. Second-Hand Smoke might Boost Leukemia Risk**	**42. U. S. Women Taking Fewer Folic Acid Supplements**	**47. Stuttering Best Treated in Preschool Years**
7. Marriage, Kids, Career Hits Female Sex Drive	**29. Smokers' Misperceptions Make Quitting Hard**	**2. Ginseng May Lessen Misery of Cold Season**	**43. Mechanism Regulates Tooth Shape**
			37. Kids' Abdominal Pain May Become Adult IBS
			14. Flu Can Be Serious in Kids with Neurological Disease
			27. Moms Epilepsy Medications may Alter Infant Head Shape

Table 14 continued:

GN Cancer Category 9	Diabetes Category 10	Geriatrics Category 11	Obesity Category 12
10. Illness Causes Most Prostate Surgery Complications	25. Diabetes Drugs May Cut Lung Cancer Death Rate	51. Study Urges More Palliative Care Training	8. High Number of Cancers Due to Obesity
12. Men With Testicular Cancer Often Become Fathers	31. Turn Off Insulin Pump During Exercise	22. Older Heart Patients Treated Less Aggressively	6. Obesity May be Advantage After Heart Attack
26. Radiation for Cervical Cancer Impacts Sex Life	60. Diabetic Foot Care Interactive Video	11. Balancing Exercise May Steady Older Adults	36. Patients Unaware of Waist Size Heart Disease Risk
9. New Cervical Cancer Methods Developed		41. Complex Work May Help Ward Off Alzheimer's	44. Low Fat Vegan Diet May Spur Weight Loss
30. Alcohol Raises Breast Cancer Risk in HRT Users		32. Menopause may boost Salt Related Hypertension	46. Being Overweight Hurts Kids' Arteries
			40. Obesity Surgery Appears Safe in Heart Patients
			16. Obesity surgery Outcomes Worse in Older patients

Derived "Medical" Categories from Focus Group Participants

Categories from Single Concepts Card Sort	Categories from "Headlines" Card Sort
Treatment Options Diagnosis & Symptoms Health News Life Style	Genetics Brain Injuries Breaking News Prevention/Education Psychology Smoking Herbal/Alternative Medicine Pediatrics Cancer Diabetes Geriatrics Obesity

Table 15. Derived "Medical" Categories from Focus Group Participants

Participant Comments from Trending Information and **Card Sort** Task

The actual **future trending** Information items are shown in Appendix VII, for the Card Sort Task Method, please see Appendix VI.

The following (partial report only) points were made by Participants:

- Would never look for general concepts – typically get very concrete when searching for information [For example would search for a percentage / the success rate for a specific arrhythmia treatment (Cardiac Ablation).
- When searching on behalf of family members for diseases, users want to know about recovery times – also want to know about **risk**s, how long something takes – average hospital stay
- Need for communicating incidence information – how common is this?
- Most people never heard of Medline or PubMed
- They would want a gateway resource that covers all NIH and NLM sites
- Searching on **Google** introduces people to new sites – they are likely to return to those that they like
- Some people get to know about sites when they are mentioned in a Journal or a site they already visit
- Regarding the **FDA** site --- couldn't find anything on the **Black Box Warning** although it has been in the news a lot the last few weeks – Why isn't the information right there when you go to www.fda.gov

📖 People want a way to find out about NLM's newly featured sites--- they should be better marketed

- People are more likely to search on **Google** first when they look for anything – maybe go to a specific very well known site --- but only if they are very familiar with it ---- some people tend not go to sites they are not familiar with that come up under **Google**
- Wanted are educational resources and seminars for busy health professionals – something that guides them through knowledge where spending time will earn them **Continuing Education** Credits --- is said to be a great low-cost way to further educate yourself (there are on-line tests as well) – for example nursingmatters.edu is a education by subscription site and charges about $40.00 per year --- this is what people would pay for – not for access to Journals alone.
- Those who have installed **Google** on their toolbar will always use it for "reach out searching" = searching for where people have not yet been
- People will use **Google** rather then remembering specific sites to go to because "it is always there" [gives me anything new also – gets me to places I wouldn't otherwise go to]
- Scenario: Head Nurse --- prepare for information needs for a patient well in advance of the surgery

- Regarding identification of the Source of a Web site --- it's not the Web site source that counts for this individual but who has authored the material presented there ---what are their credentials – is the author mentioned? – Is it a Doctor (MD, Ph.D., or what)? – This is much like a textbook model where the author is identified.

📖 A frequent scenario for searching (reported by nurses) is to give family members of patients some keywords or sites to search for. (Pre-Searching)

- People look for very recent information --- in most cases they assume that too recent is a reason why they can't yet find it on a government site (FDA site specifically) – One individual said---this is why I don't trust government Web sites (I don't trust that they show me complete information) because they won't put anything up unless it has really, really been verified--- that process is too slow – other sites (including news) tell me what's happening now…. even though it may not yet be proven
- Some will go to Med Watch to get news type info
- On **FDA** site people want to know about Recalls, Product safety information and Hot Topics "It's just surprising to me that it is not right there when you come to their site [**Black box warning** in the news]" – where other than the **FDA** do they want me to go to? [Government Web sites are not complete]

📖 Drug site should tell user about two types of mandatory Warnings for Pharmacists (1) Can't give drug to anyone else (2) New drug yet unproven or, new info found (black Box Warning)

- There may be some desire for guided searches in the future --- somebody that takes you by the hand and shows you the various items you should consider
- Participant insight: I am **learning** that you do have to take the time for good searching
- As a layperson I always would use **Google** ("the reason I use Medline now is because I looked up something on **Google** and it came up with Medline – that's the reason I use it.")
- The general concepts and names are useful for a situation where you don't know what you are looking for --- it may organize your search space

📖 Organization of search space should be refined with medical factors/facets such as "genetics" and demographic determinants such as "**gender/age/race**" and phases of patient care such as "recovery" or" diagnosis"

Focus Group Comments and/or Opinions

Comments during **Card Sorting**

Word Group: Items tended to fall into either very specific or very general topic groups.
Word group members sorted the items into 4 basic groups

Concepts Group:

- Took opportunity to have more categories
- Tried to put the concepts into the most relevant heading group though it could have fit with several
- For search navigation, they said, that they wouldn't necessarily use these categories they chose for the items
- Abstract of a concept would determine final membership (needed)

Comments during **Future Trending**

Scientific Solutions:

- **Self-medication** will lead to the potential for more drug interactions and other **health complications** as the US consumer seems to demand **multi-use foods**.
- Growing trend: label everything with "**proven and effective"** – this is easy for people to understand and not much thought is involved.
- People are looking for solutions to their medical problems or preventing future medical problems with diet or exercise or other solutions.
- Particularly when it comes to being **Overweight** – this is what creates most of their Medical Problems.
- People will always be looking for easy solutions to their medical issues "quick fixes".

Focus Group Discussions: Themes and Issues Mentioned

Site **complexity** correlates positively with "user friendliness"

- "User-friendliness" concept was explained as sites that have minimal cross-referencing
- Want to print things out to hand to others or keep themselves as reference

A frequent **search scenario** involves looking up information for aging parents

- Drugs newly prescribed
- Interventions

Use of Information Technology by current **health care providers** is widely variable (and somewhat **age**- and role- dependent)

- **Look up** reference type information constantly
- **Look up** research type information over time
- Use of handheld devices – by culture – institutional rules – cost and maintenance is an issue

Means of Saving Information – There is still a need to **hold onto information**[15]

- Saving Searches versus content versus Web sites
- Content to share with others
- Some save URLs of Web sites in Favorite folders
- Some print things out (easy to copy and share with others)
- Some take physical notes (Repetitive Release Dates from a Supplier's Web site)
- PUSH SEARCHING – a tool found at some commercial sites (INPUT) where a saved search automatically signs the person up for all updates and new additions with that keyword or other specified filter configuration

Type of Content Saved/Printed

- Procedural Information (in an Intensive Care Unit)

Desired Tools and or Content

- Courses of Instruction (especially for **continuing education** credit)
- **RSS** feeds to be notified of changes and new national warnings (Black box warnings)

[15] This is likely only a "transitional" behavior and can also be viewed as a coping mechanism for bad search interfaces.

Concept of life-span of the information = Importance of currency of information content (What do you do with it?)

- Desire continuous updates to existing information particularly for drug warning information

📖 All information content should be **Date** Stamped and displayed with a source reference, particularly when printed out.

- Would like to know the release date – how long something has been used already
- Difference between freshness of Web site content and **Date** Origin of Content Item
- **Life-Span** of information for Anatomical info is very long (old is ok-10 years)
- **Life Span** for look-up type info – no more than 2 years old max – better 6 months or newer

📖 Life-Span for all personally relevant information is typically no more than 2 months old

- Validity of Information – Combination of **Age** and Source Consideration

📖 For source of information, the following are important (looked for and looked at) quality **affordances**:

- Reputation of the Web site and/or Author
- Affiliation of the Web site within an Organization
- Provided References – name of Author information or (Expert's Vita)
- Trusted Site Seal Information (Seal at bottom of Page)
- Recommended site via Professional Association Publication
- From News Sources
- FDA site for drug related info – only game in town officially – but pharmacists use their own vendor and distributor drug information sites –
- As part of sales they provide information support
- Desire some kind of NOTICE warning for lay-people- just because it's leading edge and the newest – doesn't mean it's good (tried and true and proven)
- The author of some piece of content may be more important to know than who puts up the Web site (laypeople care about experts but not necessarily on government sites)
- Could have an area on the NLM site that has "content that is too early to be posted on site"--- something like a MedWatch area on FDA site – with subscription service (moderated site is desirable)

FDA Web Site (Comments Related to)

Government sites are not expected to have the most current information ("they have to check every last iota in order for them to post anything – that's the nature of government Web sites") however, users expect some acknowledgement of topics covered widely in the news.

What are you looking for when searching for information On-line?

- Look for Keywords and their translation into another language
- Need to have information in the news addressed at the top of the site [couldn't find anything on "Black Box Warnings" right up front] – nor anywhere else on the site.
- Looking for protocol information – ACLS Advanced Cardiac Life Support – a detailed medical protocol (and certification) for the provision of life support under cardiac care in settings ranging from pre-hospital to hospital.
- Looking for translation into English of **foreign language** medical conditions, terms, ingredients
- Go to "**international sites**" to get "local" information content – medical information relevant to that local area (Prevalence of certain types of diseases etc.)
- Looking up information for the traveling public- encounter people from other places and countries of origin in first responder type of work
- Looking for product type information – ingredients –what is in homeopathic medicines – food stuffs etc. (necessary to know for possible interactions type of info)
- For Drug information – desire to know when type in name of drug– intended for what type of disease circumstance (indications)
- Need all information concerning criticality of an item
- Looking for very concrete type information including prevalence information and treatments (would likely go to **WebMD** for this)
- Looking for on-line information about specific surgeries – alternatives – information about Post-surgery care – Recovery - Prognosis
- Look for Recovery times – **Risks** of Surgery – how long a procedure will take – hospitalization type info

Historical (Chronological) Perspective Desired

- Would like some historical perspective ("so-and-so used to be used for this and that but has now been found to….")
- Would like historical perspective on how to think about **Technology** and disease processes
- Same type of historical context is desired for changes in procedures

Possible Filters for Information (**Too much Information**)

- Something **explained** by specific clinical case
- Emergency Context
- User Inputs reason for viewing the information this determines span of information dates
- Leading Edge of Medical Practice Stuff (some things that are so new that it is not yet proven – no existing procedural process – Entrée into Clinical Trials)
- Rare or More Common - New type – recent disease

> 🕮 **Annotation:** As a proposed prototype design, organize information according to location where in a disease cycle a person is (person can select to see information relevant to Phase of disease or context- pre/post doctor's visit).

Recency of Information

For cardiac conditions and related information, rule out information that is 5 years or older ("we are at the cusp of a revolution in medical knowledge when it comes to heart disease and treatment").

Work toward a Revolution in Information Sharing

- NLM resources are a partnership = shared resources between the public at large and health care professionals

🕮 Making all this information available and accessible is a form of **risk reduction**, however, the information should not just simply be posted – it should also be **explained**!

Information for a **Search Results** List

Look for a percentage indicating (rarity or commonness of a disease or therapeutic approach).

What Users Want from NLM

- Better Marketing of their sites: start with Medical schools in the area
- Give user seminars – position your sites in the marketplace – how are these sites different from others out there?
- Keep **advertising** and **explaining**: Medline versus Medline Plus; PubMed versus PubMed Central
- Position so that results in **Google** come up with **MedlinePlus** first
- Offer CEU credits for people going through a structured educational on-line process accessing and **learning** medical information

- Provide an “Informed [Senior] Health” certificate etc.
- CEU credit model can be found at nursingmatters.edu ($40.00 subscription per year) – people are willing to pay for this

📖 Better **integration** of NLM and NIH – the Portals for each should have What’s New – rotating – self-advertising content

- **Interest** is in finding out what others are reading to….
- Information on how to tell family members (comfort level) --- want to give family members key words to search for themselves --- have an ability to e-mail with go to here
- Want Hot Topics Safety Information that is bundled separately and that fits the context/statistics of the day/week/month respond with content for ---- Anti-Depressant Use in Adolescents --- **Up-to-date** News Topics --- have a short article on your site for this – don’t just link to another site (it takes too much time and requires high cognitive workload: I’m already here just give me the info – you know what I want – don’t send me to the next stop) this is perceived as ineffective and unpleasant.
- Have some kind of explanation of the various types of warnings that are out there – for products – medicines, etc.
- Drug Information for “first-timers” / Classes of drugs and classes of warnings – make severity designations understandable – what has warnings as alerts and what has WARNINGS as mandatory items – **explain** why and the difference?
- Link to FDA site for Recalls and Product Safety information
- Concept of a “Future Guided Search” --- an advanced type search with pre-configured suggested topics and areas to visit given a certain context [“I’m **learning** that you do have to take the time to search carefully”]
- Provide information about who the experts in this area are – the best people, the best places

Quotes relating to **Google** Comments

Notable Quote by a Health Care Professional:

“As a layperson I always use **Google** – even sometimes to find the advertised site I want to go to such as **WebMD**”

Notable Quote by a Health Care Professional:

“That’s the reason I started to use Medline – because it came up as a result on **Google**”

Notable Quote by a Health Care Professional:

"If you don't know what you are looking for then search with **Google**"

Recommended Prototype **Design Concepts** to Pursue

Difference between a **Google** search versus going to a Site directly (would use latter to **look up** very specific/concrete information shared with others) – need to do a value-added design approach and give people a reason for coming to the site.

- Organize information by life-phases
- (**WebMD** uses pain levels, gender and **age**) Known Factors influencing health –Cancer one of those areas that needs to fit everything (a whole set of new rules would apply here)
- Anatomy and related educational materials are the most fixed and durable information elements

Interactive search

The user could be asked **to specify – what's missing from a results list or, what appears to be the best match (give me more like this!).**

Desired NLM Web Site Content
(Post Focus Group Survey Source)

Question: What information do you as a health professional want to see on NLM's Web sites?

🕮 Answers/Recommended Features (In Participants Own Words):

- **Depression and Anxiety** are two topics that should be addressed on a medical site – related discussion on use of anti-depressants
- Address depression in adolescents – in seniors – and talk about treatments for each
- **Have Moderated Seminars** on this – stress the commonness and high incidence – give this information – sometimes that's all that people want to see
- **Topics of the Day** --- make the site "fresh" with this
- Treatment and Therapies should be a major Web site section by itself--- stress holistic aspects at all times not just as an after thought – whenever people seek treatment type information
- Discuss cultural aspects – drug culture in US – and related Psychological Aspects --- perhaps have vignettes that people can identify with
- Address Being Overweight as an issue – discuss **risks** of obesity and solutions --- diet control and management not quick fixes
- Provide some of your own strong "marketing message**s**" that people will listen to you are just one voice in the echo of marketers --- need to tell people that quick fixes are not proven effective ---- items such as new biofoods (Nutraceuticals) --- "Health from Cereals" – it's just not realistic but people are buying those messages
- Make the scientific solutions understandable!
- Have a diet product look-up data base – need to know about the ingredients and potential interactions ----
- Preventive Health in Flavored Chocolates? Calcium? People want to have more information about these OTC products
- Need to advocate that Health professionals (particularly when prescribing medications) ask what sort of products they are taking- there needs to be more awareness of interactions
- Have a Medication Interactions Calculator Tool
- Provide Good Educational Messages --- Science needs to be better marketed
- Talk directly to the user, such as teenagers and other demographic groups – "as a teenager here are typically the issues you will have to deal with" ---- as a "middle aged man you need to look at this information"
- Provide more information that is tied (and **organized**) directly around where you are in your life continuum
- Could use pop-up messages to target messages in a context specific way

Notable Quote by a Health Care Professional:

"People need to be told by your experts that these products are not EFFECTIVE ways to ward off cancer!!! These things (**nutraceutials**) are highly popular and people buy them --- to your experts limitations are obvious but they should talk to these people and tell them."

On the topic of Government Web Sites & Published Health Information:

- Just published a huge volume on Dietary Guidelines - this is absolutely useless to the average lay person. They need a simple step by step approach (Giant 5-Step model) - people want easy to use and easy to apply messages

📖 You could think about providing educational modules in POD casts that can be downloaded by I-pod users --- provide I-pod content – connect with the **technology** these people are using out there

- Provide some form of certification for being a "good (health conscious) citizen" - People want to participate or be a member of something bigger
- NIH Body challenge – could offer Health Club Memberships and other free rewards as incentives to market your message --- set up public kiosks in these settings – advertise that it is here that people should go for good medical/health information

Towards a Possible NLM site Mission Statement

Notable Quote by a Health Care Professional:

"Main objective of a government site should be to use the research that is out there and *help people to better understand the medical knowledge/information that exists* already!"

- Could accomplish this by having experts discuss it on-line
- Be a purveyor of good health information

Notable Quote by a Health Care Professional:

"NLM should get people in the habit of going for good medical information and rejecting the quick fix type."

Notable Quote by a Health Care Professional:

"People are scared out there… Nobody wants to eat chicken anymore due to bird flu news"

News Plus, Not Just the News

Notable Quote by a Health Care Professional:

"The government needs to jump in on top of the news and discuss how to think about it ---"

- Provide an area for Frequently Asked Questions **(FAQs)** that address "In the news type issues this month". (Remember it is new and not just news to most lay users!)
- Provide an area for military issues
- **Explain** about tests that are being given/taken
- **Explain** about scientific solutions to civilians – they are being marketed heavily with so-called Health products
- Inform about packaging how to read labels etc. that they are not regulated
- Picking up products in foreign countries
- Need to know what the products are
- Where you got it
- What it is doing for / to you
- **What has the biggest impact on your health?**
- **What gives the truth? – The internet is now just another form of corporate advertising – people need to understand this better**
- Not FDA approved --- "some will still buy it because they can't afford official drugs" or it's a favorite remedy of their grandmother
- People rely on the information that they get being valid, true and good – but they expect this from the wrong sources
- "Better Information through Scientific Solutions" – sounds to them just like another form of marketing ---

Notable Quote by a Health Care Professional:

"It's about interpreting the scientific data, not just providing the information---- you need to follow through all the way…!"

- "When you tell them --- caffeine and wine may actually be good for you – they will listen – you need to tell them that it is a change from before – and what they should do with the information in their every-day lives." (Address anxiety relief and depression topics.)

📖 Want conclusions not just data points

Discussion Points from Future Trending Focus Group Task

Impact of Demographic Change Discussion

- More elderly consumers
- Longer life-expectancy
- More need for care giving
- Shift to later marriages

📖 Web site content should address these groups --- **there is a whole new user out there now who doesn't understand the information given to them.**

- Technologically sophisticated but not medically literate ---
- Make things simple --- **explain** Insurance and related concepts (Medicare)
- Help **explain** people's options

Notable Quote by a Health Care Professional:

"Health care has become a whole different profession – a large part of my day is spent on the phone with insurance companies where I help straighten out problems that the elderly are having --- they just can't do it themselves"

Notable Quote by a Health Care Professional:

"As an EMT we now get many calls for no good emergencies – but no one else is there to help – our public services are impacted – we end up taking the client to the hospital even though they shouldn't need to go there. "

Notable Quote by a Health Care Professional:

"As a pharmacist this happens frequently – a woman calls and says she needs a refill – when 7 days prior her prescription was filled for 30 days – what has happened? – Have they taken too many medications? – after long telephone coordination with the insurance company and the doctor it is found that the customer has been out of her pain medication (OxyContin a strong narcotic pain reliever - prescribed by another doctor) and had taken the insomnia drug (Ambien) for her pain."

📖 **Must better address Social Service Integration Issues with Medical Health Care Topics**

Notable Quote by a Health Care Professional:

"The information on government Web sites needs to be better communicated – people now don't understand it --- you have to have a PHD or better to even look at it."

- Over time it will trickle down but what is the proper role for the National Library of Medicine in this situation?
- Aid in Understanding
- Talk to differentiated populations in their world, language – do whatever is necessary to make them understand
- Help provide access to the Internet Landscape

📖 The Department of **Ageing** has drug site information – you should put this link information on your site [http://www.aoa.gov/]

- Help people find the information for them – even information that they don't know that they want

📖 The number of physicians in Urology and Geriatrics has remained fairly constant, NLM could help increase and meet this demand (going on campus – promoting fields via their Web sites)

- Certain diseases will be a lot more common – urology is a field that will get a major increase – yet there is no effort under way to get more professional Urologists out of medical schools --- NLM could promote these medical fields
- Another area is Geriatrics – not many young people want to get into this

Notable Quote by a Health Care Professional:

"The common diseases we now know of for elder populations are going to be even more common in 10 years from now."

Notable Quote by a Health Care Professional:

"How to speak with people has become an important professional challenge, yet this is not typically addressed in the educational curriculum of health care professionals – this could be a good highlight topic for health care professionals on an NLM site. --- Your Web site should reflect the difficulties we have with direct interaction with people."

- 🕮 Address the challenges of interacting with culturally different folks

Notable Quote by a Health Care Professional:

"We are seeing a large increase in Spanish populations – for this we need information to give to them in Spanish – most materials that are useful as handouts should be provided in Spanish as well. (Many kids are called upon to translate for non-English speakers) (If you want to reach the older generation you will have to go through the kids to get to them)."

- 🕮 **Any major health topic should be available in other languages (**seeing lots of travelers from other countries) - Military –families and staff want Iraq and other type of local information about diseases
- 🕮 Kids, Parenting and Grand-parenting should definitely be a big area on your site.
- 🕮 **Big topic now should be Allergies of all kinds ---** it's related to the foods as well – this is a timely topic
    - Hypertension management
    - Obesity
    - Topics on drug management – living longer now because of drugs and NOT due to behavior change needs to be addressed

ANNOTATION: Future trending seemed to have worked well in that it seemed to have served as a prompt for what is going on now – participants more easily related current issues using this method. Future trend posters seemed to have helped their recall as prompts.

Last Focus Group Task Discussion: Useful Things on a Web Site – Features You Like

- "Ability to **look up** words I don't know"
- "Ability to (embedded hyperlink) jump directly to a contextual reference (statistical table or another article by a cited author)"

Notable Quote by a Health Care Professional:

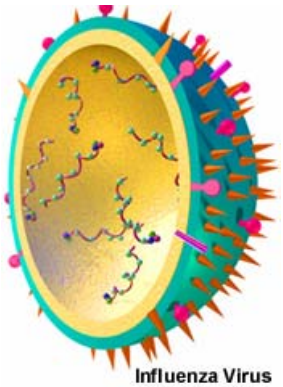
"Ability to easily jump from one 'site' to another –that's how I usually search"

- "Like well-organized left-hand side categories that take you to different sections"

- “On **search box** results listings I like it when I get 2-3 small sentences with each option – some snippet- not too big – that tells me more – keywords are ok but sentences are better”
- “Like a highlight feature – in an article for example I can go through from one instance to the next highlighted word”
- “I like a lot of categorization and more use of **color** to highlight / distinguish categories – that way if it’s done consistently I can more easily find the information I’m **interested** in”

ANNOTATION:

The topic of adding **color** or graphical images to add **interest value** to Web sites to otherwise dry text was mentioned by several participants. Users appear to expect **magazine**-like content, such as the exiting graphic of the Influenza Virus found in a recent Scientist Daily Feed.



Influenza Virus
Credit: NIAID

📖 On NLM site I want to know what other sites are cross-referenced – have these all in a list as a link resource (alphabetized). Let me pull up references really easily – I read some text and you have a link that shows me more detailed data.

- "Bring up a **summary** page for each major topic that gives me the scope and gist of what you've got on the site"
- "For NLM let me know what other sites you've got (NIH site **integration**)"
- "Show me what goes together not something that is totally unrelated"

📖 Don't really like the Amazon feature "you may also be **interested** in" – instead show me the percentages of people reading about what topics – this creates my sense of community and is informative

Notable Quote by a Health Care Professional:

"Bring together people who work in a field – show me the Resources that NIH has to offer in that area."

- "Give me a list of resources – highlight the scientists of NIH knowledgeable in a given field"
- "Good Content Organization of the Page that makes sense – that's why **WebMD** is so successful – it's **colorful** and organized so well – it doesn't give you **too much information** – in contrast there is the FDA site – way **too much** and you can't find anything"

- "Time is critical – need to get around fast – when it's too time consuming it becomes useless"

Notable Quote by a Health Care Professional:

"Give me only the best 100 results not thousands"

- For publications of Journal articles indicate: **Date**-Author-**Relevance**
- Filter other medical information on Care Continuum and Demographics
- Diagnosis
- Treatment
- Age
- Ethnicity
- Want the **search results** organized around each other
- Want origin dates of information
- Let users prioritize themselves as to what is **important** to them.
- Possibly use a second search field for 'Target Area" or have a filter pull down menu
- Allow some searching within results
- Allow search storage – log searches and allow for automatic updates (**RSS** - subscriptions) on those searches

📖 Market NLM sites to **Google** – NLM should always show up on Google searches with medical – health themes

- Create an area for Power Users – allow people to store **search results** here – (like renting a quiet cubicle in a traditional library) (Give them a library icon to click on).
- Dogpile – Model for NLM – search all the NIH and NLM sites at once

Figure 21. DOGPILE Search Model for NLM

- And create custom reference content display for searchers as a result (a Web page where all the links are listed that would get me to topics related to my search)
- The Predacus Model – [http://www.allspark.com] Public Market Square: "we are one"
- Allow people to talk to each other – Discussion of Topics and people with common interests

Recommendations on Portable and PDA devices

- Make Web information formats compatible with portables – these are used quite a bit in medical and research setting– use PDA's at bedside – could have special content for PDA's (see also **RSS** for Warnings)

📖 Make a Portable Anatomy simulator tool available (for point-to **communication** with culturally diverse patient groups – also disabled populations.

- Public tool needed for typing in a drug name and it shows effect on anatomy
- Send any medicine alerts to **PDA** subscribers
- Everything I have ever looked up at a computer I want to have with me – I want to go to one place – log in and get my stuff
- I want to have all of my "stuff" updated automatically – give me the latest you've got on such and such….(shopping not searching)
- Be able to access your electronically stored records (for health care professionals only – wouldn't mind paying for something like this - "My Medical Space")

📖 **Much confusion exists about Medline and MedlinePlus**

Notable Quote by a Health Care Professional:

"What's the Plus in **MedlinePlus**?"

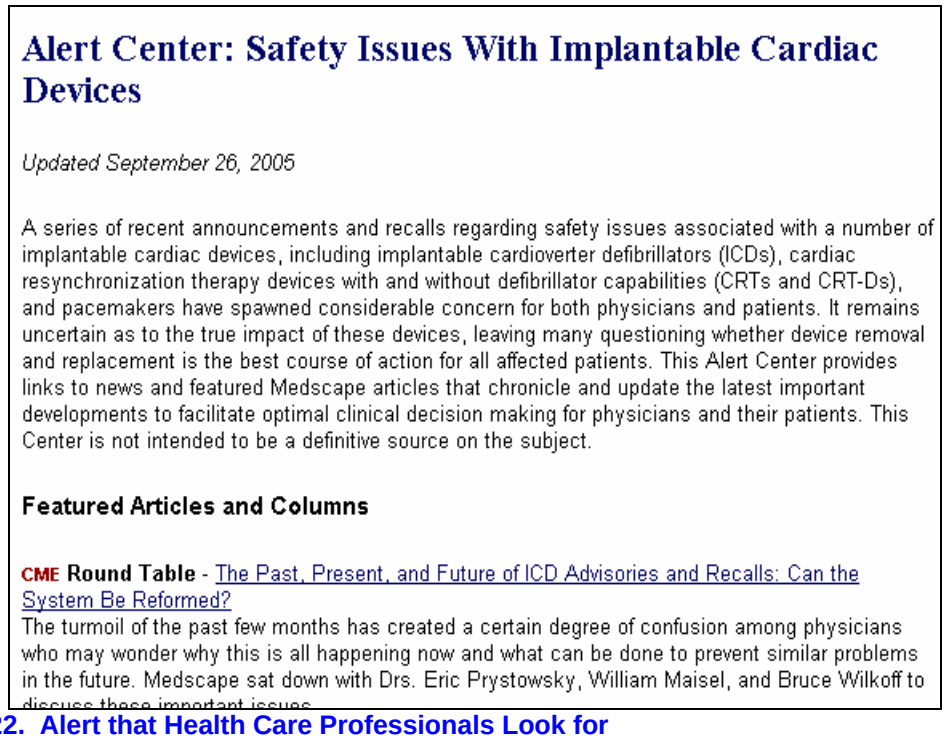
📖 **WebMD uses Games to give educational messages**

- Include immediate Alerts and Safety warnings in the field– EMT example Benzocaine (a gag reflex inhibiting spray used by first responders) would have liked to get the warning right away (see FDA warnings on MedWatch now):

Examples referred to:

Benzocaine sprays
Audience: Healthcare professionals and patients
[Posted 02/13/2006] FDA issued a Public Health Advisory to notify healthcare professionals and patients about adverse events, including methemoglobinemia, associated with the use of benzocaine sprays used in the mouth and throat. Benzocaine sprays are used in medical practice for locally numbing mucous membranes of the mouth and throat for minor surgical procedures or when a tube must be inserted into the stomach or airways. On February 8, 2006, the Veterans Health Administration (VA) announced the decision to stop using benzocaine sprays for these purposes. The FDA is aware of the reported adverse events and is reviewing all available safety data, but at this time is not planning action to remove the drugs from the market. The FDA is highlighting safety information previously addressed by the Agency (see below), has provided other information for the consideration of clinicians in the PHA and will make further announcements or take action as warranted by the ongoing review. [February 10, 2006 – Public Health Advisory – FDA]

Another example of an alert that health care professionals look for:



Alert Center: Safety Issues With Implantable Cardiac Devices

Updated September 26, 2005

A series of recent announcements and recalls regarding safety issues associated with a number of implantable cardiac devices, including implantable cardioverter defibrillators (ICDs), cardiac resynchronization therapy devices with and without defibrillator capabilities (CRTs and CRT-Ds), and pacemakers have spawned considerable concern for both physicians and patients. It remains uncertain as to the true impact of these devices, leaving many questioning whether device removal and replacement is the best course of action for all affected patients. This Alert Center provides links to news and featured Medscape articles that chronicle and update the latest important developments to facilitate optimal clinical decision making for physicians and their patients. This Center is not intended to be a definitive source on the subject.

Featured Articles and Columns

CME **Round Table** - The Past, Present, and Future of ICD Advisories and Recalls: Can the System Be Reformed?
The turmoil of the past few months has created a certain degree of confusion among physicians who may wonder why this is all happening now and what can be done to prevent similar problems in the future. Medscape sat down with Drs. Eric Prystowsky, William Maisel, and Bruce Wilkoff to discuss these important issues

Figure 22. Alert that Health Care Professionals Look for

Two sites **focus group** members discussed:

Site 1 - Medscape

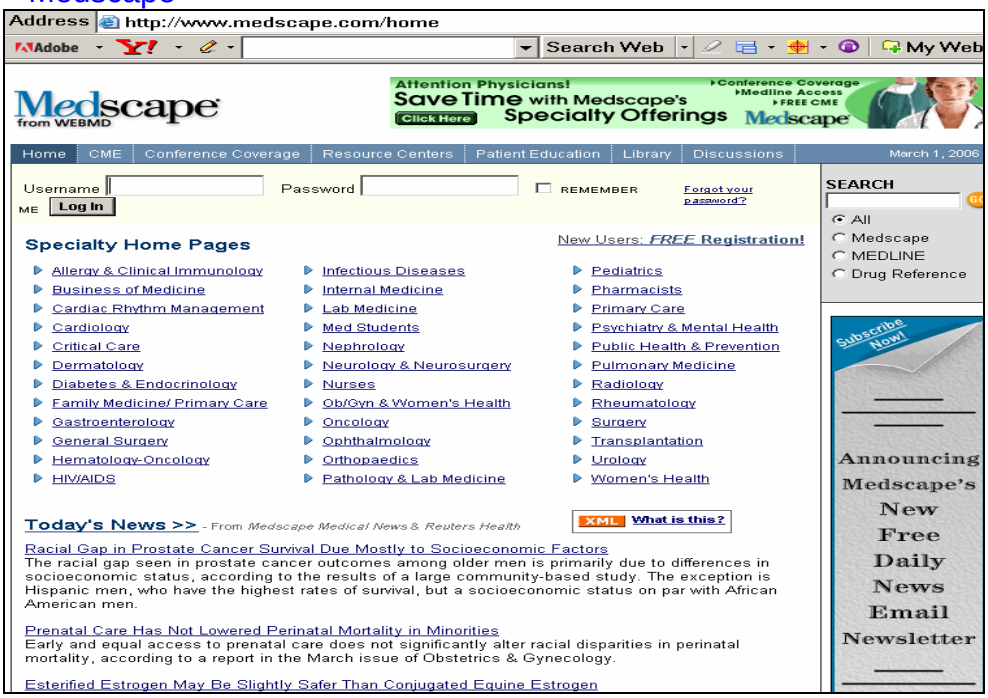


Figure 23. Medscape Site

Site 2 - OVID Gateway for **full text** articles:

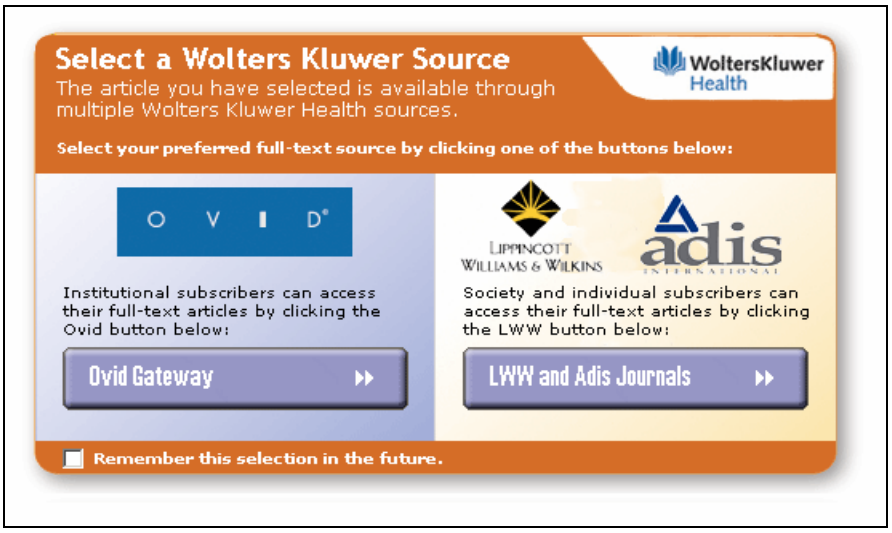


Figure 24. OVID Site

Miscellaneous Topics

- Topic of electronic records --- depends who you are in the health care system – some have very sophisticated private record exchange systems --- their usefulness depends on how many things you need to **look up** at once.

- Paper is still a good and widespread practice.
- Nano **Technology** – the biggest benefit would be to have the capability to carry a lot more information with you at all times.
- Audio and Video on Web sites --- it's a waste of my time – it's a real time-sink --- you need to have lots of time for this --- I could see it for lectures --- you can take time to absorb the information better --- or if you really want to study something --- also may be good for special populations – the disabled --- or even the illiterate could listen to audio. But --- it was thought by the healthcare provider participants that most disabled people would have someone assisting them along with them --- they felt that **technology** couldn't solve all these issues.
- They liked the idea of having educational modules on a site.
- Also thought that broadcasts and Pod-casts by physicians would be a good idea – especially in hospital settings, (example was prostrate surgery).
- There is a definite need for some kind of Information Search Services.

Notable Quote by a Health Care Professional: <Discussion about what patients want>

"I just want something I can take home – take to the doctor to start a discussion".

- Want burning issue updates:
  - Scenario: assess how to improve a condition
  - Read issues that are important
  - Gather information for a report that I can share with others
  - Want to know which technique or treatment works best
  - Want high medical information quality (from a trusted source)

🕮 Advertise NLM sites better

- Participant's idea of an educational focus group: used to promote a new Web site --- hold a focus group on campus as a way to market the site (45 minute to 30 minutes).
- Participants were generally willing to give their name and e-mail address for a list or updates informing them of newest NLM sites.
- "Give people a reason to look at a site – offer something unique --- spend some money on promoting the sites you are building--- so that the general population can access them and knows about them ---- employ TV ads for the general public. And use educational institutions --- All students should get it there – but they don't."
- "Medline – was thinking of CD and not of Medline On-line --- go out and target that generation --- those who went to school 10 years ago or longer – they need to be prompted and shown what is available now – so they

can learn and also feel renewed and keeping up ---- that generation still reads things and is in caregiver roles."

- "The first thing that I look for on a site is a **search box** or something like it – when I don't find what I need --- when it's hard to find what I'm targeting – that's the most aggravating---- sometimes it's there but I don't see it – I'm looking at something unrelated and thinking about that --- then I go to a site map if there is one ---- most of the time I go to **Google** --- that's because it usually works for me.

Notable Quote by a Health Care Professional:

"I need more hands-on **search experience** and **guided training** in where to find what."

- Healthcare professionals serve as intermediaries for NLM information --- they help people understand their situation and they look for support materials to accomplish this.

Transcription of Wall Poster Charts
From Focus Group February 11th, 2006

Transcription Notes: Useful Web features & tools related to Searching

- User friendly presentation and well organized site content
- Allow searchers to indicate **criteria** for narrowing by author, **date**, diagnosis, and language (level as well as foreign types)
- Have advanced search capability in addition to quick searching
- Allow for storing searches (could include registration, if provided free of charge)
- Effective use of **colors**, (and other redundant design elements), to highlight various sections of content on a Web page
- Employ referencing to other sites
- Reference where any data/content came from (e.g. the source of an article or item)
- Include **FAQ**s and allow for questions
- When related to **survey** data allow to display one (1) click detail source data
- Have a version that is printer friendly – one specifically created for printing on 8X11 paper
- Have the site remember what you searched for in the past (often we continue searching on topics of interest – it's not really a one-time shot)
- Like having embedded links in text content (hyperlinks within articles)
- Have a simple **search box** on your site
- Have results laid out as in left side navigation boxes with sub-categories to choose from
- Present search results with 1-2 line content snippet (beginning of sentences). Title by itself is not sufficient.
- In results highlight the words that you searched on and that were found in the article (show the reason why this comes up in search results)
- Saving site searches – but, it would be useful as a tool if it allowed you to save results also from off-site searches
- Allow searching, and test on hand-held computers
- Send alerts to hand-held's – this would be useful for high-demand situations not for the average lay person
- Desire ability to request alerts from Web sites (e.g. new **black box warning from FDA**)
- Typically don't use audio or video content on a routine basis – it is thought to use too much time – however, may use for specific things; time-trading applications such as listening to a lecture

Transcription Notes: Content Looked For

- **Military applications** and issues
- Drug information

- Medical techniques (surgery or therapy)
- Diagnosis
- Lesson Topics
- Detailed and specific information
- Organized, easy to navigate content
- Easy to find information from a reputable source
- User-friendly with minimal cross-referencing
- Information specific to the context I'm searching for (anything that matches the situation)

Transcription Notes: Suitable Content for Medical Professionals

- Homeopathy
- Pharmacy Technician
- Nursing
- Sales and Provisioning
- Firefighter
- Emergency Medical Technician (EMT)
- Physical Therapy
- Aide
- Students
- Cardiovascular Research
- Information Sciences –librarians
- Critical Care Nursing

About Searching

- One time: Project or class related information (External Task oriented searching over a limited amount of time)
- Looking for protocols
- Standards
- Release dates
- Lessons learned- best practices

Transcription Notes: Organization of Information when searching over time

- Employ bookmarks to Web pages
- Store URLs in favorite folders
- Store items electronically on personal PC and using **RSS** update subscriptions
- Print it out – this makes it easy to share with others
- Take manual notes (paper or electronically write into word documents or in notes integrated with **date**)
- Download information to a PDA
- Just remember it – for the latest info always consult the source each time

Transcription Notes: **Life-span Issues** of Information

- Depending on type of data always want the newest and most current
- Recency and newness is a matter of months not years, but it depends on the level of specificity of the topic
- Medical information is perceived as rapidly changing all the time
- For drug information – about 2 years unless drug is new or has issues then want information only that has been posted within the last month or so
- Consider providing freshness updates (For most reference books updates are supplied by vendors/publishers about every month)
- Information related to physiology / anatomy is generally ok with older type information
- CONTEXT determines acceptability of issue **date** --- emergency versus background information – want recency in emergency type situations
- General Preference is for having medical information that dates from the last couple of years [noted was the issue concerning science versus unproven information and established protocols].

Transcription Notes: International Site Use

- About half of the group includes other than US sites as well in their searching for information
- Look at countries with similar protocols
- Journal articles and translations
- Looking for specific local information – medicine specific to that country

Transcription Notes: **Validity / Authenticity** – Disregard or handle with care

- Information that is dated
- Consider the reputation of the site
- Tend to go to specific sites that have passed muster already
- Looking for references provided
- Looking for Certifications of all kinds
- Consult source Journals – recommended sites

📖 Scientific Solutions need to be communicated to the public

- People want quick fixes
- Its become relatively easy to bring the “information product” to market, but not much thought research exists to back it up
- Campaigns advocate reduced fat diet but raised sugars

📖 People will always gravitate to the short version. Easy to understand – this means that medical information should be presented in **QUICK DIGESTIBLE CHUNKS** for the general public

- Healthcare professionals see this as unrealistic – people looking for quick fixes
- **There is an increased need to know about products**
- **There is an increased need to query patients** about what they are taking/eating/doing and why
- Giant's "strive for 5"[16] is an example of a campaign that is simple and easy to follow.
- Government Web sites could follow this example to make them more effective.
- It's all about marketing – more "marketing" is needed where government Web sites are concerned.

Trend: Depression, Unhappiness, Anxiety

- Health outcomes, Productivity, Lifestyle
- Depressed individuals – seek medical help – everyone is a potential future patient
- Depression affects people mentally, physically, and socially, more help needs to be available, such as counseling
- These three topics (depression, unhappiness, anxiety) affect health behavior and disease processes, to **form knowledge** and understanding of these will effect part-time care and interaction
- Depression is a growing trend, affecting lifestyles, new drugs are being developed for the treatment of depression

Discussion on Depression

- Dispense increasing amount of drugs especially for teenagers
- Drugs can affect all aspects of your life
- Depression and related anxiety can decrease productivity, since it affects both caregivers and patients
- Physicians in the future may be more likely to address mood issues
- There will be more use of antidepressants in older populations

📖 Depression should become more socially acceptable to address as an issue

- Can use chat rooms with anonymity for support (**technology** may allow a solution to people knowing that they are not alone)
- Need to take depression into consideration at all times when caring for patients (holistic approach is needed most)
- Need more reliable / reputable information on herbal / natural medicines (there is currently nothing good on government sites)

[16] For example the grocery chain Giant health program "Strive for 5" is an outlet for health communication to the public at the time people buy their groceries (very close to the point of decision making for people) what can be done to get information from government and to the person at the time they make a purchase?

Trend: Demographic Change

- Life Expectancy is being pushed upward, this will impact society and the environment
- Will affect our society and environmental resources, insurance issues, finances, and government

📖 There are now different patient populations which call for more understanding of cultural issues and ethnic differences

- People are living longer – debate about euthanasia, quality of life, having children later and being career minded
- Educated people are not having as many children as less educated lower economic working class creates a huge societal shift

Discussion on Demographic Issues – Ethnic- Cultural Changes

- Need language skills for providing health care to diverse populations

📖 Need hand-outs and information in multiple languages and possible audio/video for non-reading (illiterate) individuals

- Prepare information by use of kids who can then **explain** to adults in their communities
- Dealing with more insurance issues as **health care providers** – need a simpler process
- EMTs are getting more calls for things that are not immediate emergencies but may be -- spend time **explaining** things that they didn't used to have to
- Older patients don't have a familiarity with the internet – they wouldn't use it, if made available. So others are finding info for them (information finder as a new position)
- There is a greater need for professionals for dealing with the huge demographic shifts that are occurring in US (need professionals in Geriatrics, Social Work
- Will see more patients with certain types of illnesses and issues (elder issues, nutrition, obesity, diabetes, etc.)

Trend: Wireless & BROADBAND

How will *Wireless and Broadband* Technology influence the Medical/ Health Care field – how will it influence the use and access of information?

- Allows people the ability to gather information quickly and when needed
- Allows **integration** of multiple systems through common information contents (protocols). It extends the interconnection and **integration** of biomedical information

- People want all of the information and they want it fast. Increasingly, people (patients) feel they have rights to all of the information to make informed medical decisions.

Trend: On-Demand TV, Fragmentation, Being Networked Together

- Increased demand for information results in increased production of fragmented information.
- This could lead to more public misunderstanding of current medical information (and proliferation of erroneous messages) as news agencies like to go for "shock value" and not necessarily provide complete information.
- TV programming could have a really negative influence on the medical field because TV entertainment makes a joke of medical and other related information (could use a weekly accompaniment of "and the real story is…"

Trend: Product and Device Convergence

- Many new medical products and technologies are developing
- With limited funds it is difficult to keep up with current **technology**. Need a trade-in process like with cars --- turn in the old for new --- same thing with knowledge --- and information

Annotation:

📖 SUGGESTED CONTENT – give the historical context for anything that people can "plug into", where they left off, and learn from next generations of **technology** and knowledge organized by "revolution/evolution"

Trend: Gender Polarization: Women

- Hopefully the trend will turn and more research and marketing will be directed towards women
- More medical information being focused on women. There are real differences for men and women – heart disease for example.
- Medicines affected by gender – women have a different set of diseases
- Men have their own different set of diseases

Trend: Seeking Safety

- As the global population increases their travel habits the demand on space/ land/ and general ecology goes up
- Drug Prescriptions for international travel being so frequent, Health Care practitioners must have a broad knowledge of diseases of world wide local regions
- Particularly safety related to medications and therapeutic interventions.

Trend: Identity and Authenticity

- This will affect kidnapping, missing children and should help with properly identifying individuals

📖 Could be misused but also helpful in that a patient **could have complete medical history with them at all times. [WANT and NEED]**

Trend: Embedded Intelligence

- Could be useful in tracking not only motor vehicles but
- Remote Hikers, Miners, etc. Emergency medical services could scan and locate relevant information prior to report of an accident – could increase response times significantly

Trend: Discipline Convergence

- Bridging various scientific fields and specialties could be a mission of government Web sites
- Logical progression of **technology** leading to total biomedical **integration**
- Bio-Informatics – is the slowly emerging health care field

Trend: Nano Technology

- Will enable portability of all medical information to where it is needed
- Storage devices are ever more efficient
- Needs banks of zillions of information objects due to proliferation of internet traffic

Trend: The death of Distance

Bio-simulators –ability to run simulations instead of trials saves tons of Dollars.

Trend: Polarization

- People will decide what they want. The health care field now is influenced/dictated by insurance companies.

Notable Quote by a Health Care Professional:

"Healthcare starts with an individual's insurance company! "

- As people become more involved with their healthcare, they will decide to pay for it themselves (wealthier ones) or look for low cost health care options (poorer population). This trend is already in progress and will impact all. [Analogous to Public versus Private School Education].

Trend: **Really Simple Syndication (RSS)** Time and Place Shifting

- Continual, instant updates of topics you choose
- Increasing Access to more and more content

Trend: Globalization

[Paradoxical effects: local power – lack of innovation - not annotated]

Trend: Brand Experience

[Marketing of patient experiences - not annotated]

What Worked Well in This Research?

Interviews versus <u>Focus Groups</u>

- Focus Groups are good for generating ideas
- Trending Task was used as prompts needed to get at what's going on now with people --- get specific examples that they may not otherwise talk about or report on
- Interviews provided a safer context for people (less brag) and hands-on experience (less frustrating than group search)

🕮 Useful Tools not mentioned in focus group but in Manhattan Research[17]

- Drug Dosage Calculator
- Summary Data Tables on Medical Content?
- Research Modules – also Distance Education Modules [NLM University?] – cost effectiveness
- Need Integrator tools – what does it all mean – sense making
- Clinical Trials.gov (Spanish summary modules) any kind of short form

🕮 Desirable Content

- Caregiver Module
- Information concerning anxiety and depression
- Multi-Cultural perspectives on topics
- Best Practices of Interpretation
- Recommendations of putting the information into practice "On-line Info Care Giver"
- Monthly Newsletters to increase traffic and advertise new Web sites – feature hidden Web "treasures"
- Why won't pediatricians use e-mail with parents?
- Want searchable content related to Clinical Practice Guidelines

Most on-line active disease group is MS group

- http://www.msif.org/language_choice.html global MS resource sponsored by Schering AG in 6 languages (Italian, Russian, German, English, Spanish, and French)
- Most active bloggers are Cardiologists

[17] Manhattan Inc. research report given to an NIH audience circa April 2006.

Final Summary

This research project has yielded an immense amount of data in the form of user originating ideas for user interface design of navigation aids and search functionality and for content.

We have learned that **Medical Literacy**, English Language **Literacy**, and Query formation skills are required user skills for successfully navigating government medical and health information Web sites. We were surprised to find occasionally low self-assigned ratings in all three of these skills when interviewing and discussing issues with a variety of health care professionals.

As interface designers many complementary data points from our study strongly suggest a focus on viewing search functionality within the larger user task context. We were reminded that health care workers of all kinds are time starved professionals who do not typically spend large amounts of time on-line and who like to be alerted to **important** information they may need rather than having to initiate their own searches.

Within the medical domain, the fact that truly 'useful' **information is perishable** and that date information is of great interest to information "finders" deserves the designer's as well as the content provider's attention.

Interface user affordance features such as provided by Date, Authority, Popularity, Commonality, **media** designations and other "eye-ware", i.e., surface structure **interestingness** of graphic images and providing combined **media** type search results listings make information much more easily ingestible for the user searching for information and will ultimately enable users to make 'inspired decisions'[18].

Our collection of video recordings resulting from this feasibility study together with the sample Personas and Scenarios we produced is available to OCCS for further project specific analysis and application.

In terms of the relative value of the types of activities and methods used to derive at this wealth of data, we found that the individual interviews together with the participant's hands-on activity produced best results for interface functionality while the focus group activities yielded superior data regarding desirable topic

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[18] Term used in a published conversation between Peder Soderlind and Peter Morville on societal relationship mapping; found on www.findability.org on 6-12-06. Society mapping is reported as an exercise and a method to increase user information literacy. The purpose is to place focus on the information producers in a society. The feeling of unavailability and lack of perspective that many people experience concerning the amount of information available on the Internet is counteracted through this exercise. Inspired decisions are those made via critical thinking when information is found and used.

areas and content. A combination of these methods together with usability testing of prototyped interfaces is recommended as an **important** tool for NLM Web applications of all types in order to make them truly user and audience centric.

We recommend that this study report be used as an ongoing reference document for NLM Web application interface design and that pertinent usability and content information from our data be reviewed for the various applications OCCS is tasked to develop.

Finally, it should be noted that the participants of this study all had access to modern information technologies. However, there are still relatively large numbers of NLM information consumers who may not even think about the internet as a great source of medical information, because they do not as yet have access to the technology, don't use it often enough, or have been discouraged in the past. These groups will likely need intermediaries to help them access good quality medical information. In turn, it is these intermediaries which can be supported online with practical information that they can then pass on.

APPENDICES

APPENDIX I:
Definitions for "Searching" found via an executed **Google** Search

One Definition: Keyword: "Searching"

> **The act and process of locating information in various sources, for example, looking for a book in a library catalog, looking for articles in databases, or looking for information on the World Wide Web.**
> ublib.buffalo.edu/libraries/help/glossary.html

USER CENTRIC DEFINITIONS

Keyword searching - typing significant words and phrases that relate to a topic into a search engine

Boolean searching - Boolean searches allow you to combine words and phrases using the words (Boolean operators) AND, OR, NOT and NEAR to limit your search [USER-Centric]

Phrase searching - search more than one keyword exactly as written usually by enclosing the terms in quotes to form a phrase

On-line searching - Using a computer to search a computerized database

SYSTEM CENTRIC DEFINITIONS

Field searching - Ability to limit a search by requiring word or phrase to appear in a specific field of documents (e.g., title, URL, link)

Concept searching - The ability of a search engine database's indexing program to determine synonyms of words in the database

Word searching - text of a record in an on-line catalog or database which can be used as a search term in a free-text search to retrieve all the records containing it

APPENDIX II:

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Presentation: October 19th, 10:30 AM - 12:30 PM, NIH Research Festival Symposia Session II - Multidisciplinary Biomedical **Data Mining**

[15] Reference: JIM HENDLER
Semantic Web Tutorial: September 15th 3:00 - 4:30 pm
"Science and the Semantic Web"; Jim Hendler, University of Maryland

[16] Reference: RONALD NEIL KOSTKOFF
Office of Naval Research – **"Systematic Acceleration of Radical Discovery with Text Mining."** Presentation made at NIH – November 17th, 2005. November 17th, 3:00 - 4:30 pm SEMINAR: Systematic Acceleration of Radical Discovery and Innovation in Science and **Technology** Dr. Ronald Kostoff, Office of Naval Research

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APPENDIX III:

Web Sites and Search Engines

Mentioned in the Reviewed Literature

For each particular Web site we sampled its mission statement or a similar site purpose statement found on the home page, when one was found. We also noted any unusual characteristic that was mentioned in the reference publications.

List of Web sites mentioned in the reviewed literature (keyword: "Searching")

Mission Statement Messages	Other Notable Site Characteristics	Web site Address
"Find it all"	Queries studied in [1] were in the Norwegian and German language in addition to English.	http://alltheweb.com/
"Welcome to medifocus – **here is the info you want** - current Medical Guides on Major diseases and conditions"	N/A	http://www.medifocus.com/
"Recently acquired by Pool.com **the domain marketplace"**	N/A	http://inquirus.com/
(Swoogle crawler) indexes more than 300,000 Ontologies and knowledge bases on the Web [4]	N/A	http://swoogle.umbc.edu

Table 16. List of Web sites Mentioned in the Reviewed Literature (keyword: "Searching")

List of Web sites mentioned in the reviewed literature (keyword: "Medical or Health Information")

Mission Statement Messages	Other Notable Site Characteristics	Web site Address
"Brings you objective, trustworthy, and timely health information".	**WebMD** is a for-profit Web site specializing in synthesizing biomedical information for both consumers and health professionals. **WebMD** employs medical editors, reporters and writers who function much as if they were producing a newspaper or **magazine**. In terms of information distribution; it has chat and poses questions via e-mail. [7]	http://www.webmd.com/
"We're here to help"	Juvenile Diabetes Organization Web site [7] "If you or someone you love has recently been diagnosed with type 1 (juvenile) diabetes, we at JDRF can help. Our On-line Diabetes Support Team (ODST) is made up of JDRF volunteers who have "been there" and are available to offer you immediate, one-on-one support. We also provide loads of practical info about diabetes and its management. "	http://www.jdf.org/
Policy, Advocacy, Action – "Inform Yourself, Find Support, Take Action"	National Association for the Mentally Ill Web site [7]	http://www.nami.org/

Table 17. List of Web sites Mentioned in the Reviewed Literature (keyword: "Medical or Health Information")

List of Search engines noted in the reviewed literature:

- Inquirus (Meta Search Engine designed by NEC)
- **Google**
- AltaVista

APPENDIX IV

Summary Table of Interviewee Answers to Moderator Questions

Name	JL	HE	AT	RH	SJ	LD	CG	JC	JM	DL
Age	35-54	55-64	16-34	35-54	18-34	55-64	18-34	18-34	18-34	35-54
Gender	Female	Female	Male	Male	Female	Female	Female	Female	Female	Female
Ethnic Origin	Caucasian	Caucasian	Caucasian	Cession	Causation	Caucasian	Caucasian	Asian (Korea)	Caucasian	African American
What is your primary Language? Secondary?	English	Dutch/English	English	English	English	English	English	Korean, English	English	English
Highest level of education attended?	Grad School	Associate Degree/teachers college	MS	BS Sociology	BS Biology	BS(nursing) and exam state boards	BSN	BSN	College, MD in May 2006	Medical Degree, Fellowship school. Residency
What is your current level of personal health?	Excellent	Mixed	Excellent	Excellent (paraplegic)	Excellent	Mixed	Excellent (pregnant)	Excellent (3 month old baby)	Excellent	Excellent
What is your profession/job role?	Registered independent Pharmacist	Retired flight service director/accountant		Executive Director Access Information, Inc. Disabled persons guide			Senior Clinical Nurse (NCII)	Nurse (post operative)	4th year med student, about to take up residency in hospital	Pediatrician, behavioral and development
Please describe your primary responsibilities	Meeting prescription needs, running pharmacy and general store			Respond to inquiries on accessibility		Tax accountant	Medical ICU at Johns Hopkins Hospital	Plastic surgery unit	Surgical Intern, treat patients, discharge, give drug	Health care for children, community practice
How do you rate your self-health knowledge?	Expert involved in health field	Educated consumer	Expert involved in health field	Educated consumer	Educated consumer	Expert involved in health field	Expert involved in health field	Expert involved in health field	Expert involved in health field	Expert involved in health field

What medical websites do you go to	Don't use other than EPIC site	Google or Ask Jeeves, may finish up on medical site and then use	WebMD, Pubmed, wikipedia	Google, Ask Jeeves, WebMD sometimes	Ovid, Medline, cini, Google	SGNA, ASGE, NIM, pubmed, yahoo health	Micromedix, pubmed, up to **date** cinahl	Hospital website, Nursingspectrum, woman's health	PubMed, medline, mdconsultant	CDC, Medline, aap, journal pediatrics chadd, hipkins, childrens hospital, vaccine, food allergy website
What other information/resources do you use?	Drug facts and comparison Ref book supplier magazine – drug topics	Information in brochures and pamphlets at doctors offices, labs or Medical Journals like the Wellness journal, the Hartford Medical Journal Books on specific medical topics or illnesses	Primary care physician, Google, friends and family	Doctors handouts and articles	Textbooks, medical journals, databases	Journals – SGNA, Nurse Spectrum	Books, journals, Hopkins protocols	Manuals, Procedures, emergency preparedness, Personal notebook, text books, medical dictionary, nursing magazines	Detailed medical information; clinical investigation trials	Journals, medical newsletters, Washington post (patient recommendations) PDR – desk reference, textbooks, Barton Schmidt
Why do you want **Medical or health related information?**	Consultation on drugs or symptoms	To be as best informed about what is good and healthy for myself or family member	Research work, because I like to be healthy, and personal curiosity	To keep self healthy (wheel chair bound)	School related purposes, personal curiosity	As a health professional and for family members	For professional, patient and personal reasons	Patient investigation, personal knowledge	To better serve my patients and to self educate	Knowledge addressing rare issues, patient advise (Kennedy Krieger website
What type of information do you	What is drug for, what class,	**Treatment of rheumatoid**	Causes and	On heart, working out,	Physical therapy ,	Research information	Patient/pt family	Patient symptoms,	Detailed medical	General view for

want? Describe	type, interactions, contra-indications	**Arthritis, prevention of worsening ,medication and research in progress. Personal problems eg heart, knees, epilepsy.**	treatments of diseases and conditions. Research	general interest For enquirers access to information on disabilities	info about body systems, muscles, nerves pharmacological cross referencing	, keeping up to **date**, answer patient quires, need level of detail down to doctor.	education, disease specific knowledge, drug information, journal articles	for post op trauma and patient history	information; clinical investigation trials	patients, NIH, gov, parenting issues, studies, cutting edge
How do you know that you have the right information?	Trust in references also ask pharmacists and supplier	Accepts sources as being acceptable. Check out as many related articles and documentation as possible, look for similarities, differences and specific descriptions. Experienced at searching. Checks with Doctor if doubtful	Look at the source. Look for verification by others.	Formulates what is wanted, and structures searches on that bases. Comparison		Credentials -if NIH, JH verifies source	I use the Hopkins (my employers) intranet to find websites. Tab list of approved sites.	Carefully check background against patient notes.	Certified	Known entity, multiple searches, keep to recognized sources
Who do you talk to when you need to know more?	Supplier on both regular and homeopathic remedies.	Talk to my doctor, specialist and pharmacist (in Canada) or staff at a walk in clinic or the emergency room at a hospital	Research colleagues. Primary care physician, friends and family.	Uses specialist physicians, for instance urologist Own doctor for spinal cord related	Professors, fellow students	Expert in field. Physicians – even if in a different field, family physician	Fellow nurses, physicians, clinical nurse specialists	Pharmacist, Nursing supervisor, Patient for background	Physicians	Specialist in field in the area, colleagues in practice
How do you deal with increasing	Automatically from supplier	It is overwhelming	Distil the best I can;	Feels it is an advantage in	Strategies taught	Filter by using	I forget a lot of it!	Prefers to use journal	Try and read	Targeting strategy,

amounts of new medical information?	by summaries with side effects. Update references	and invites to make notes of specific topics.	look for review papers or summaries from reliable sources	that there is always new material out there, simply searches for what he wants	in school, continue reading and learning as it is discovered	professional sites for reviews Belongs to Chesapeake Nursing Society email within group on gastro NOVA, DE, MD, DC	Have to go back multiple times.	articles as they are directed. Finds data overwhelming tries skimming through	some of it	using AND searches
What do you do with the information you find?	Respond to patient quires by copy, leaflet or verbally	I file them, adding the info to specific topics to be able to review when necessary	Read it? PDF to folder, print out forms for uses, book mark, use delicious site	Personal use and to give out to people. Otherwise uses material for website. Doesn't bookmark	Try and integrate with what is already known	For patients make copies for handouts, instructions on standard info. Does not file	Share with others-verbally or provide hard copy	Print out store in folder, add to notebook. Does not store electronically.	Print or save it	Saves articles, electronically, verbally hard copies to patients

Concerning drug-related information, describe your need	To respond to patient quires, check prescriptions	As to prescription drugs, what does it do, what are the side effects and which work best	Find out about clinical trials, side effects, alternatives	Not often, has searched homeopathic drugs for health benefits. Antibiotics from doctor	Learning about pharmacological agents (analgesics, NSAIDS, opiates	Not a lot, mostly for own meds and gets info from hospital	Learn about the drug, in the ICU we are always hanging multiple drugs at one time with limited places to infuse so drug compatibility is a huge thing	To look up medications for side effects, interactions, will check with colleuges	Adverse reactions, cost, interactions	PDR plus updating, Herriott Lane drug reference book
What is your most frequent need for information?	50/50 patient quires and own knowledge	**For education , what is new / current. In the case of a specific operation it would be good to get a description of a procedure in picture form rather than text Prefer to address a live person with my questions vs internet. Personal/ family**	Research followed by personal or family ailments	Mostly for information relating to exercise and spinal injuries	PT information for learning purposes	75/25 professional to personal	Drug information, disease specific information	Patient follow up, personal reasons e.g. pregnancy	Ongoing education, personal information	Continuing medical education, journals, searches, 3 hours per week

		reasons, curiosity ,once/twice a month								
Summary of interview points	Packaging of information could be better, presentation Search needs to be quicker than looking up in a reference book NLM/MedlinePlus need links from EPIC Job difficulty is constant interruptions need to be able to pick up where left off each time Also searches are time dependent Likes spell checker as has learned to shorten terms to avoid misspelling Rapidly got fed up when search didn't produce relevant results	Would be useful if ,gov medical sites were on toolbar .gov sites not very commercial in appearance Commercial sites are more biased Likes to check results which can be time consuming If a list of results by site prefers not to go to most Can be distracted from original search by news items that look **interesting** Isn't **interested** in registering with a site to get information When prompted thought that a "shopping basket" to put in likely files would be useful Also a "compare" button to show up	Never used MedlinePLus Medical sites have poor search syntax but doesn't use advanced search features Avoids links prescribed for researchers on any site Doesn't like the use of keywords Does use e-medecineGoogle is a good filter Does not like natural language searches Is a dictionary	Doesn't like to log in Doesn't like pop-ups and missing links on medical sites e-bay /amazon user Thought Medline was "sharp" attractive, more like a library - not as precise, good information Likes Google, which comes up with relevant results. Thinks a 'word" catcher would be useful, and should always be a summary Thought WebMD was like a dictionary - too big, no links, nothing worth clicking except for one very basic		Dislikes sites that ask for fee Likes easy to see and read materials Relatively inexperienced, but has bought on line, and just goes slower when unsure Used back button a lot to navigate Thought MedlinePlus was **too much text**, and not directly applicable to what she was looking for Felt that long searches with little to				Believes commercial sites are faster and have better links Medical sites are more work Tells patients to use the WHO site Could not find NLM on NIH site Thought NLM site not user friendly Not heard of PubMed central Wouldn't want to have e-mail contact with patients

		matching items in different site searches **Not interested** in professional papers	user - Firefox Uses babblefish if translation needed Likes spell checkers Not concerned about identity theft Does not use about.com	result.Links were old, some very old (article on Christopher Reeve that was out-of-**date**. It had nothing on "living with spinal chord injury" (his search choice). When searching for letrazol got only foreign language results, Google did ask if English wanted which he considered useful. One English language result turned out to be in Chinese. Usually uses single search words Like Medline Plus much better than WebMD Google never pointed to WebMD in his searches		show were tiring, and would just ask someone else Commented that NLM site doesn't show summaries Would like to see better groupings e.g. surgical, medical, current issues Hates the hot bars, pop-ups as these slow her down more				

APPENDIX V

Cognitive Obscuration Results

Here are the "Cognitive Obscuration" results for our MedlinePlus content sample (http://medlineplus.gov/):

Please note that 100% obscuration means that none of our interviewees indicated that they understood this item to a degree that they could explain it to someone else.

100% Cognitive Obscuration (CO): Not a single person marked this item.

Ibandronate

Definition(s) shown here were found on the Unified Medical Language System ®
"A synthetic nitrogen-containing bisphosphonate. Ibandronate inhibits farnesyl pyrophosphate synthase, resulting in a reduction in geranylgeranyl GTPase signaling proteins and apoptosis of osteoclasts. This agent increases bone mineral density, decreases bone remodeling, inhibits osteoclast-mediated bone resorption, and reduces metastases-related and corticosteroid-related bone pain. (NCI04)"
Source: NCI Thesaurus, 2004_11_17

90% Cognitive Obscuration (CO): Only one out of ten people marked this item.

Leukodistrophy

Web Definition:
"A group of genetic disorders characterized by the imperfect development or maintenance of myelin. Diseases in this class include adrenoleukodystrophy, Alexander disease, Canavan disease, Krabbe disease, metachromatic leukodystrophy, Pelizaeus-Merzbacher disease, Refsum disease, and phenylketonuria."
www.myelin.org/glossary.htm
Also: "defect in the formation and maintenance of myelin in infants and children."

70 % Cognitive Obscuration (CO): More than two thirds don't know what these words mean.

Gastroesophragial

Of or relating to or involving the stomach and esophagus
wordnet.princeton.edu/perl/webwn

Keratotomy

Surgical incision into the cornea
wordnet.princeton.edu/perl/webwn

Hemachromotosis

The disease that occurs as a result of significant iron overload. Hemachromotosis can have genetic and nongenetic causes.
www.cdc.gov/hemochromatosis/training/glossary.htm

60 % Cognitive Obscuration (CO): More than half don't know what this term means.

Sucralfate

A drug used to treat ulcers. It adheres to proteins at the ulcer site and forms a protective coating over the ulcer. Sucralfate is also used to treat mucositis.
www.stjude.org/glossary

40 % Cognitive Obscuration (CO): About half of the participants in our study indicated they knew what these terms mean.

Squamous

(Cells) - Cell type often seen in areas exposed to significant irritation or trauma - e.g. skin.
www.uwo.ca/pathol/glossary.html
Also: Squamous means covered with or formed of scales; scaly.
en.wikipedia.org/wiki/Squamous

Autosomal dominant

A gene on one of the non-sex chromosomes that is always expressed, even if only one copy is present. The chance of passing the gene to offspring is 50% for each pregnancy. Source: Human Genome Project Information.
www.genomecanada.ca/GCglossaire/glossaire/index.asp
Also: Autosomal dominant inheritance refers to genetic conditions that occur when a mutation is present in one copy of a given gene (i.e., the person is heterozygous).
www.stjude.org/glossary

Myopia

The inability to see distant objects as clearly as near objects.
medical.preferredconsumer.com/laser_eye_surgeons/LASIK_glossary.html

20 % Cognitive Obscuration: One in five did not know what these terms mean.

NSAID

A nonsteroidal anti-inflammatory drug, such as aspirin or ibuprofen.
http://www.answers.com/topic/nsaid

Sphincter

A circular band of muscle that opens and closes to allow food or waste to pass.
www.cnn.com/HEALTH/library/DG/00022.html

Hemophilia
A genetic blood disorder, almost always in males, in which blood does not clot properly as a result of an enzyme deficiency.
www.babycenter.com/glossary/H

Colitis
Inflammation of the lining of the large intestine.
www.cnn.com/HEALTH/library/DG/00022.html

Mutation
A change in the genetic material of a cell.
www.biotech.ca/EN/glossary.html

10 % Cognitive Obscuration (CO): Only one participant was unsure about this term.

Metabolism
The chemical and physiological processes by which the body builds and maintains itself and by which it breaks down food and nutrients to produce energy.
www.cytosport.com/science/glossary.html

0 % Cognitive Obscuration: All of the participants marked (understood) these

Osteoporosis
A condition that is characterized by a decrease in bone mass and density, causing bones to become fragile.
www.seniormag.com/conditions/cancer/cancerglossary/o.htm

Phobia
An uncontrollable, irrational, and persistent fear of a specific object, situation, or activity.
www.montefiore.org/healthlibrary/adult/mentalhealth/content.asp

Ulcer
A sore on the skin surface or on the inside lining of a body part, such as the mouth or stomach.
www.spondylitis.org/patient_resources/glossary.aspx

Valve
Structure in a hollow organ (like the heart) with a flap to insure one-way flow of fluid through it.
wordnet.princeton.edu/perl/webwn

Reflux
Backflow. For example, reflux occurs when gastric juices or small amounts of food from the stomach flow back into the esophagus and mouth. Also called

regurgitation.
www.cnn.com/HEALTH/library/DG/00022.html

Gene
A sequence of DNA that represents a fundamental unit of heredity. Most genes encode proteins, but some code for RNA molecules.
www.dphpc.ox.ac.uk/opcgg/glossary.htm

Antacid
A medicine that neutralizes or reduces acidity, especially acidity in the stomach.
www.crestor.com/c/glossary/

Birth Defect
Any defect present at birth; sometimes referred to as congenital.
www.cardiogenetics.org/glossary.asp

Depression
A mental state characterized by a pessimistic sense of inadequacy and a despondent lack of activity.
wordnet.princeton.edu/perl/webwn

Heartburn
Discomfort or pain that occurs in the chest. Often occurs after eating.
www.pregnancy-info.net/newprgnancyarticle13-2.html

Heart
Muscular pump which circulates the blood.
paleo.cortland.edu/tutorial/Glossary/glossary.htm

Stomach
An organ that is part of the digestive system. It helps in the digestion of food by mixing it with digestive juices and churning it into a thin liquid.
www.stjude.org/glossary

Eyes and Vision
There are many types of eye problems and visual disturbances. These include blurred vision, halos, blind spots, floaters, and other symptoms.
http://www.nlm.nih.gov/medlineplus/ency/article/003029.htm

Bone
Rigid connective tissue that makes up the skeleton of vertebrates
wordnet.princeton.edu/perl/webwn

Exercise
The word exercise can mean the following:*A setting in action or practicing.*Any activity designed to develop or hone a skill or ability.*Physical exercise
en.wikipedia.org/wiki/Exercise

APPENDIX VI

Method Description **Medical Literacy** Test Development

We developed our own Web site Medical **Literacy** Test in the following way: Two Human Factors specialists randomly collected five each “medical terms” from NLM’s own **MedlinePlus** Web site [http://www.medlineplus.gov/] going to about three page levels deep. We decided that we wanted to include disease names, symptoms, and biological concepts that represented a broad sampling of human physical and mental ailments that could currently be found via the **MedlinePlus** Web site.

Procedure

Two human factors researchers picked terms randomly from Medline Plus pages. A selection was made for “easy, medium, and hard” medical terms that would include a good range of drugs, diseases, body parts and health topics. A total of thirty one terms were selected and ordered from easiest to hardest - (100% researcher inter-rater reliability). Ten **study participants**, (from educated consumer to health professional), were asked to place a check mark near all those terms for which they could reasonably explain its meaning to another person. Participants did not actually have to provide a definition and only some were asked to read the terms out loud while considering their understanding of them.

This list was then presented individually to five volunteer pilot participants who were educated, non-healthcare professionals.
We hypothesized that our Medical Web **literacy** test would have high face validity if we could achieve the following goals:

- High HF specialist inter-rater agreement regarding term **complexity**.
- The relative **formal** non-medical educational experience of the participants should not correlate greatly with increases in the “**literacy** score achieved”.
- The relative **formal** medical educational experience of the participants, however, should correlate positively with an increase in the “**literacy** score achieved”.
- The achieved **literacy** for this group would be somewhere in the middle category of the rank-ordered list with half of the terms understood and half not marked hence not well understood.

All of these goals were achieved. The results of the test for the non-medical pilot group are displayed in the table below. The test developers were surprised at the

relative “low medical **literacy**” as some participants did not mark perceived “moderate” items such as the meaning of colitis.

Medical **Literacy** Test Results (Non-Healthcare Professionals Pilot):
In order to pilot test the following instructions were given to volunteer individuals. “Please place a check mark against all of the following lists of words from top to bottom that you believe you know the meaning of and could explain to a third party”:

Level	Term	College 2nd Year	BS NW	BS	MS ESL	MS NW
Easy	Exercise	X	X	X	X	X
	Bone	X	X	X	X	X
	Eyes and Vision	X	X	X	X	X
	Stomach	X	X	X	X	X
	Heart	X	X	X	X	X
	Heartburn		X	X	X	X
	Depression	X	X		X	X
	Birth Defect	X	X	X	X	X
	Antacid	X	X		X	X
	Gene	X	X	X	X	X
Medium	Reflux	X	X		X	X
	Valve	X	X		X	X
	Ulcer	X	X		X	X
	Phobia	X	X	X	X	X
	Metabolism	X	X	X	X	X
	Osteoporosis	X	X	X	X	X
	Mutation	X	X	X	X	X
	Myopia	X	X	X	X	X
	Colitis					
	Hemophilia			X	X	
Hard	Sphincter			X	X	X
	Gastroesophragial		X		X	
	Autosomal Dominant					
	Leukodistrophy					
	Keratotomy					
	Squamous					
	NSAID					
	Sucralfate					
	Ibandronate					
	Hemachromotosis					

Table 18. Pilot Results on our Medical Literacy Test collected from five non-health care professionals

This **literacy** testing instrument was subsequently used as a baseline “Web medical **literacy**” indicator for our Interview selection process concerning health care professionals.

Reference Section: Sampled Terms and Their Definitions

Understanding of Web site content by users is dependent on a variety of factors, including level of language content. One concept which may be helpful in explaining and understanding the experience of a user encountering a Web page with language that is unfamiliar is the concept of **cognitive obscuration**. Similar to a partially blind person unable to perceive or see a standard visual picture, cognitive obscuration occurs when the language viewed can not be understood because it is not part of the active vocabulary store the person has to make sense of the world.

APPENDIX VII

Method & Results for **Card Sort** Exercise from Focus Group Activity held on 2-11-06

Two groups of participants sorted 2 sets of 60 uniquely numbered index cards respectively from one of two sets of materials (in the tables, the numbers next to the concepts are the unique concept card numbers). One set, “Set A” of 60 cards held ***Single Concepts*** (nouns) randomly picked from Medline Plus news distribution materials collected over a 3-month period between October 2005 and December 1005. The other set of 60 cards, “Set “B” included complete “headline type” sentences picked from the identical news content.

A List of 60 Medical Terms for Sorting: Drawn from MedlinePlus “Push” Information

Single Concept Names Set A		
1. Stroke	2. Estrogen	3. Guidelines
4. Chemotherapy	5. Love	6. Anxiety
7. Strep Infection	8. Brain	9. Minimally Invasive Surgery
10. Pregnancy	11. Sociability	12. Options
13. Cataracts	14. Healthy Eating	15. Blood Sugar
16. Cancer	17. Hospital	18. Folic Acid
19. Night Shift	20. Elderly	21. Dialysis
22. Overweight	23. Osteoarthritis	24. Organ Transplant
25. Level of Incidence	26. Health Headlines	27. Impairment
28. Exercise	29. Women	30. Hypoglycemia
31. Sleep Disorder	32. Migraine	33. Kidney
34. Gene Therapy	35. Kids	36. Nerve
37. Health Plan	38. Latino	39. Lice
40. Digestive Tract	41. Diabetes	42. Stem Cell
43. Prevention	44. Drugs	45. Pharmacy
46. Remission	47. Taste	48. Antibiotic
49. Health News	50. Autism	51. Bird Flu
52. Stress & Hostile Behavior	53. Safety	54. Malaria
55. Inflammation	56. Daycare	57. Smoking Ban
58. Prostate Disease	59. Knowledge	60. Astra Seneca

60 Elaborate Concept Items – Set B

1. More Infections with Long-Term Antibiotics
2. Scientists ID Malaria Parasite Dispersal
3. WHO Official Warns to Prepare for Bird Flu
4. Study Urges More Palliative Care Training
5. Being Overweight Hurts Kids' Arteries
6. FDA Steps Up Action on Misleading Drug Ads
7. Obesity Surgery Appears Safe in Heart Patients
8. Stem Cells Aid Spinal Cord Injured Mice
9. Patients Unaware of Waist Size Heart Disease **Risk**
10. Turn Off Insulin Pump During Exercise
11. Diabetic Foot Care Interactive Video
12. Rhythm Therapy Useful for Bipolar Disorder
13. Placebo Effect Tied to Brain Receptor Activity
14. Most Breast Cancers Not Linked to Ovarian Cancer
15. Stuttering Best Treated in Preschool Years
16. Low Fat Vegan Diet May Spur Weight Loss
17. Complex Work May Help Ward Off Alzheimer's
18. You'll Have Medicare Drug Choices
19. Genes May Sway Blood Pressure Drugs' Effectiveness
20. Menopause May Boost Salt Related Hypertension
21. Noise Affects How Brain Affects Movement
22. AIDS Vaccine Trial Exceeds Expectations
23. Left-Handed Women Face Higher Cancer **Risk**
24. Key Protein in MS May Lead to Therapies
25. Mechanism Regulates Tooth Shape
26. U.S. Women Taking Fewer Folic Acid Supplements
27. Kids' Abdominal Pain May Become Adult Irritable Bowel Syndrome
28. Eating Disorders, Anxiety Go Hand in Hand
29. Low Cholesterol Linked to Parkinson's **Risk** in Men
30. Second-Hand Smoke Might Boost Leukemia **Risk**
31. Obesity May Be Advantage After Heart Attack
32. Treatment Prevents Defects from Cytomegalovirus Infection
33. Marriage, Kids, Career **Hits** Female Sex Drive
34. Balancing Exercises May Steady Older Adults
35. Fruits, Veggies Help Build Strong Bones in Boys
36. Parents Right to Say "Don't Jump on Bed"
37. Blood Test Gives Early Warning to Brain Injury
38. Circumcised Men Less Apt to Transmit Chlamydia
39. Mom's Epilepsy Medications May Alter Infant Head Shape
40. Diabetes Drugs May Cut Lung Cancer Death Rate
41. Alcohol Raises Breast Cancer **Risk** in HRT Users
42. Ginseng Product May Lessen Misery of Cold Season
43. Women Survive Lung Cancer Better Than Men
44. High Number of Cancers Due to Obesity

45. Men with Testicular Cancer Often Become Fathers
46. Flu Can Be Serious in Kids with Neurological Disease
47. Roche Says Set to Supply Tamiflu for U.S. Stockpile
48. Prevention Programs Help People with Heart Disease
49. Heart Attack **Risk** Factors Tied to Kidney Disease
50. Radiation for Cervical Cancer Impacts Sex Life
51. Smokers' Misperceptions Make Quitting Hard
52. Clinicians Warned about Clinical Trials
53. Kidney Disease May Have Heritable Factor
54. New Cervical Cancer Methods Developed
55. Illness Causes Most Prostate Surgery Complications
56. High-**Risk** Black Women Need Breast Cancer Gene Test
57. Obesity Surgery Outcomes Worse in Older Patients
58. Scientists Say Bird Flu Cases Back Migration Theory
59. Older Heart Patients Treated Less Aggressively
60. Duplication of Provided Items

The groups were instructed to put together those cards that belonged together and to write out header category labels for each of the categories they developed. They were also asked to be prepared to discuss with others why they chose to put cards together the way they did.

Approximately forty five minutes where allotted for this exercise.

Card Sort Results: Terms Organized When Focus Group Participants Worked as a Group

A: Concepts	Assigned Categories - A	B: Headliners	Assigned Categories - B
(30) Strep Infection	Diagnosis/ Symptoms	(58) More Infections with Long-Term Antibiotics	Prevention /Education
(23) Malaria	Diagnosis/ Symptoms	(55) Scientists ID Malaria Parasite Dispersal	Breaking News / Viruses
(55) Health Headlines	Health News	(52) WHO Official Warns to Prepare for Bird Flu	Breaking News / Viruses
		(51) Study Urges More Palliative Care Training	Geriatrics
(59) Overweight	Lifestyle	(46) Being Overweight Hurts Kids' Arteries	Obesity
(14) Drugs	Treatment Options	(45) FDA Steps Up Action on Misleading Drug Ads	Prevention /Education
(37) Safety	Lifestyle	(40) Obesity Surgery Appears Safe in Heart Patients	Obesity
(12) Stem Cell	Treatment Options	(39) Stem Cells Aid Spinal Cord Injured Mice	Brain Injuries
(0) Knowledge	Health News	(36) Patients Unaware of Waist Size Heart Disease Risk	Obesity
(56) Exercise	Lifestyle	(31) Turn Off Insulin Pump During Exercise	Diabetes
(11) Diabetes	Diagnosis/ Symptoms	(60) Diabetic Footcare Interactive Video	Diabetes
(55) Health Headlines	Health News	(56) Rhythm Therapy Useful for Bipolar Disorder	Brain Injuries
(29) Brain	Health News	(53) Placebo Effect Tied to Brain Receptor Activity	Brain Injuries
(62) Cancer	Diagnosis/ Symptoms	(50) Most Breast Cancers Not Linked to Ovarian Cancer	Genetics

A: Concepts	Assigned Categories - A	B: Headliners	Assigned Categories - B
(68) Daycare	Lifestyle	(47) Stuttering Best Treated in Preschool Years	Pediatrics
(64) Healthy Eating	Lifestyle	(44) Low Fat Vegan Diet May Spur Weight Loss	Obesity
(15) Prevention	Lifestyle	(41) Complex Work May Help Ward Off Alzheimer's	Geriatrics
(7) Health Plan	Health News	(38) You'll Have Medicare Drug Choices	Prevention / Education
		(35) Genes May Sway Blood Pressure Drugs' Effectiveness	Genetics
(54) Women	Lifestyle	(32) Menopause May Boost Salt Related Hypertension	Geriatrics
(29) Brain	Health News	(57 &59) Noise Affects How Brain Affects Movement	Brain Injuries
		(54) AIDS Vaccine Trial Exceeds Expectations	Breaking News / Viruses
		(49) Left-Handed Women Face Higher Cancer Risk	Genetics
		(48) Key Protein in MS May Lead to Therapies	Brain Injuries
		(43) Mechanism Regulates Tooth Shape	Pediatrics
(24) Folic Acid	Treatment Options	(42) U.S. Women Taking Fewer Folic Acid Supplements	Herbal
(5) Kids	Lifestyle	(37) Kids' Abdominal Pain May Become Adult Irritable Bowel Syndrome	Pediatrics

A: Concepts	Assigned Categories - A	B: Headliners	Assigned Categories - B
(33) Anxiety	Diagnosis & Symptoms	(34) Eating Disorders, Anxiety Go Hand in Hand	Psychology
		(33) Low Cholesterol Linked to Parkinson's Risk in Men	Brain Injuries
		(1) Second-Hand Smoke Might Boost Leukemia Risk	Smoking
		(6) Obesity May Be Advantage After Heart Attack	Obesity
		(28)Treatment Prevents Defects from Cytomegalovirus Infection	Breaking News / Viruses
		(7) Marriage, Kids, Career Hits Female Sex Drive	Psychology
(56) Exercise	Lifestyle	(11) Balancing Exercises May Steady Older Adults	Geriatrics
		(13) Fruits, Veggies Help Build Strong Bones in Boys	Prevention / Education
		(18) Parents Right to Say "Don't Jump on Bed"	Prevention / Education
		(20) Blood Test Gives Early Warning to Brain Injury	Brain Injuries
(15) Prevention	Lifestyle	(24) Circumcised Men Less Apt to Transmit Chlamydia	Prevention / Education
		(27) Mom's Epilepsy Medications May Alter Infant Head Shape	Pediatrics

A: Concepts	Assigned Categories - A	B: Headliners	Assigned Categories - B
(31) Chemotherapy	Treatment Options	(25) Diabetes Drugs May Cut Lung Cancer Death Rate	Diabetes
		(30) Alcohol Raises Breast Cancer Risk in HRT Users	GN Cancer
		(2) Ginseng Product May Lessen Misery of Cold Season	Herbal
		(5) Women Survive Lung Cancer Better Than Men	Genetics
(59) Overweight	Lifestyle	(8) High Number of Cancers Due to Obesity	Obesity
(57) Level of Incidence	Health News	(12) Men with Testicular Cancer Often Become Fathers	GN Cancer
		(14) Flu Can Be Serious in Kids with Neurologic Disease	Pediatrics
		(17) Roche Says Set to Supply Tamiflu for U.S. Stockpile	Breaking News / Viruses
		(21) Prevention Programs Help People with Heart Disease	Prevention / Education
(3) Kidney	Health News	(23) Heart Attack Risk Factors Tied to Kidney Disease	Prevention / Education
		(26) Radiation for Cervical Cancer Impacts Sex Life	GN Cancer
		(29) Smokers' Misperceptions Make Quitting Hard	Smoking

A: Concepts	Assigned Categories - A	B: Headliners	Assigned Categories - B
		(3) Clinicans Warned about Clinical Trials	Breaking News / Viruses
(3) Kidney	Health News	(4) Kidney Disease May Have Heritable Factor	Genetics
(62) Cancer	Diagnosis & Symptoms	(9) New Cervical Cancer Methods Developed	GN Cancer
(69) Prostate Disease	Diagnosis & Symptoms	(10) Illness Causes Most Prostate Surgery Complications	GN Cancer
(54) Women	Lifestyle	(15) High-Risk Black Women Need Breast Cancer Gene Test	Genetics
(60) Elderly	Lifestyle	(16) Obesity Surgery Outcomes Worse in Older Patients	Obesity
(21) Bird Flu	Health News	(19) Scientists Say Bird Flu Cases Back Migration Theory	Breaking News / Viruses
(60) Elderly	Lifestyle	(22) Older Heart Patients Treated Less Aggressively	Geriatrics

Table 19. Card Sort Results Showing Terms Organized by Participants as a Group

APPENDIX VIII:

Focus Group Activity Materials

Pre-Focus Group Meeting Plan

1. Identification of Meeting Objectives
2. Decide on Focus Group Key Questions
3. Develop Pre Event Questionnaire
4. Plan Individual Session Activities
5. Layout of ground rules for session activities
6. Recruit potential participants and arrange for meeting **date**. Send them a follow-up invitation with a map, proposed agenda, session time, phone number, and request for URL of favorite Web site(s).
7. About five days before the session, e-mail members to remind them to attend and to send go on-line to fill out questionnaire before hand.
8. Dry-run - One day before Event and follow-up with phone calls to participants.

Focus Group Materials Required

1. Two easels
2. Four Post-It style plain paper blocks
3. 12 No-smell marker pens (in assorted **colors**)
4. Index cards – blank or with label adhesive
5. Internet access with projector

Scheduled Session

- One 4 hour session on February 11, 2006, dry run on February 10, 2006.
- Setting and Refreshments: Quotient large conference room, set up so that all members can see each other.
- Provide nametags for members.
- Make refreshments available over the whole of the session, including lunch ordered in.

Moderator Ground Rules

1. Keep focused on the objective – should be displayed prominently.
2. Maintain momentum – if something is not working, stop and go to the next topic.
3. Involve everyone – watch for non-participation.
4. Get closure on the important issues – if necessary agree to disagree, but try and reach agreement not compromise.
5. There is no such thing as a silly question or comment.
6. No grandstanding or hogging air time (see 3).
7. 'Park' interesting but not directly relevant comments.
8. No cell phones – there will be regular breaks.
9. It should be fun as well as informative.

Recruiter Instructions

Objective is to assemble a mixed group of health-care professionals.

1. Desired Characteristics of the mixed group:
    a. Medical experience – doctor, pharmacist and/or nurses (4)
    b. Patient experience (3)
    c. Web design and **search experience** (1)
    d. Library and/or Information Architecture (preferably medical) experience
    e. Also desire a mixture of gender, **age**s, races or national origin

Recruiter Note: in each case it is better that they are complete strangers to one another; there should be no pairs or trios of friends.

Activity Phases

1. Greet - Provide Questionnaires to fill out (pre-session)
2. Introduce Focus Group Agenda (10 minutes):
    1. Welcome
    2. Review of objective of the session
    3. Logistics – recording, refreshments
    4. Review of ground rules
    5. Introductions
    6. Any Questions
    7. Icebreaker Activity
    8. Facilitate discussion around a sample set of questions, in a pair-off

Directive Note: After each question is answered, carefully reflect back a summary of what you heard (the note taker may do this).

Icebreaker Activity Description (30 minutes):

1. Split into pairs (if odd number use one of the facilitators)
2. Find out the following (5 minutes):
    i. Name and place of birth
    ii. Profession or job
    iii. One unusual thing that has happened to them
    iv. One thing you both have in common
    v. What do they want from medical Web sites
3. Each person will report back on the above for their partner in 1-2 minutes
4. Facilitator will note ii and v.

Moderator Discussion Topics

Question: How do you formulate a query session; if you were to subscribe with this query, what source, how long interested (months, years), how many – reader capability (15 minutes)

Question: What do users do with the information they get from medical Web sites? (20 minutes)

Directive Note: Take a 10 minute break after an hour and 25 minutes

Card Sort Activity

60 Medical Items for Sorting – two teams (35 minutes)

1. Two complete sets of card s–one for singular terms words, one for phrase concepts
2. Instructions: Organize into groups that belong together and that would make sense (20 minutes)
3. Discuss – each group explains what groups of cards were created and why (15 minutes)
4. What have we learned from exercise (Facilitator moderates discussion)

Interface Input Activity

Interface Inputs (30 minutes):
Use selected favorite site, or pick one site frequented – medical sites preferred. Discuss why liked – info, organization, content quality, format, utility, feel, and functions.

Directive Note: One hour Lunch after three hours total Focus Group Session Time

Future Trending Exercise[19]

Future trending exercise – implications for medical field and/or your role in it

(60 minutes)

Moderator Reads: "Every few centuries the world changes in a profound way (the wheel, iron, steam, electricity, nuclear) here are some suggested future trends that we have put together. Your job is to be a "visioneer" and imagine how these trends might affect your medical needs or profession:"

Focused Questions: What would the participants want to ask the expert (concerning Medical Information)? Who should the experts be - what are the questions asked. What is it that the participant doesn't yet know about medical or health info but thinks they should or would like to know?

Directive Note: Break for ten minutes.

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[19] **Preparation**: Focus Group Moderators used the following reference materials to prepare for this activity.

The Popcorn Report - cocooning (home), fantasy adventure (virtual worlds), small indulgences (marketing small ticket items), health and safety awareness, cashing out (not saving), down aging, staying alive, the vigilant consumer (expectation), 99 lives (reinvention), save our society – down a thought on the ones they feel are most pressing – try at least five.

An Owner's Manual for the Next Decade - Michael J. Mazarr: - 1. Culture, changing society. 2. Increasingly complex world (science and technology). 3. Work reorganization (7/24, global economy, knowledge era), 4. Global tribes. 5. Changing authority, rise of new information sources. 6. Psychological impact, instability of modern life.

Next Trends for the Near Future - Matathia, Zalman: **www.nowandnext.com** - US of Europe, ubiquity of electronic equipment, rites of purification body and soul, loving and lusting, future of offices, faux money, 360 degree branding, next generation, healthcare, medicine – sleep deprivation, on-line medical information, mobile medical devices, treatment and drugs tailor made for people, diets will be person or group specific, hospitals at home, aging, depression, ethical issues, the next pandemic, memory enhancement, bio-simulation.

Automation Feature Discussion

Moderator collects inputs about useful/needed automation features for consumers (30 minutes):

1. Design/layout of a Medical Wallet Card,
2. On providing Background Personal Medical History
3. How would Search summaries be useful or not?
4. What can you do with search results - discussion about the lifespan of information
5. Personal Medical Assistants:
    i. An editor/ smart form for medical history inputs
    ii. An explanation of what to expect at what **age**
    iii. An explanation of what to expect given a particular diagnosis (what phase of this disease are you in?)
    iv. Self-diagnosis - now what? - What should you do next?

Directive Note: Your question – what haven't we asked you to comment on? (20 minutes)

Directive Note: Conclusion of Meeting: answer all outstanding questions, thank participants for coming, give out remuneration checks, and adjourn the meeting.

Method Note: Total Time not to exceed 5 hours.

The entire session was recorded using Moray Software. However, most focus group products and findings stem directly from wall charts and summaries created throughout the sessions by the moderator team or the participants.

APPENDIX IX:

Materials for Trending Exercise Materials Used

[QUOTIENT]

FOCUS GROUP (2/11/06)
Future Trends
R. Roske-Shelton

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

NanoTechnology

- The science of very small things – Molecular Engineering
- Predicted to effect every industry from toothpaste to car tires
- A major nano-accident is predicted to have occurred by 2025
- Thought to be as big a change in everything (and threat) as Nuclear Weapons are

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Brand Experience

- People increasingly are looking for experiences not products
- This trend is especially true for women
- Ethically based retail products (think fair trade coffee) will flourish

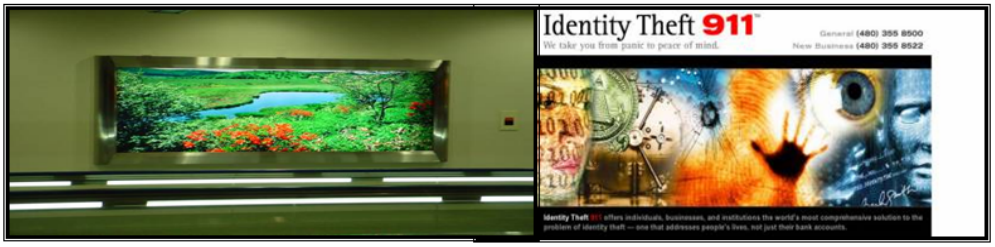
Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Polarization

- By 2015 the Middle Class will have disappeared in most developed countries
- People will look for either low cost or luxury
- High-cost, high-touch exclusivity and personal pampering will be desired
- Traveling low-cost just to splash out extra cash at expensive luxury hotels
- Pay as you go will be well established (Lexus Lanes – Paid Lanes versus Free)
- Tailor-made products for the fortunate few (mass customization for everyone else)

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

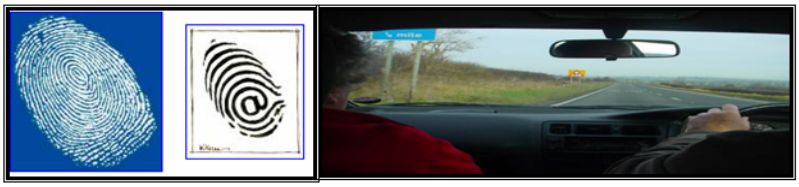
Identity & Authenticity



- Biometrics, verbal signatures, body scanning etc. are all digital means by which you will prove that you are who you say you are
- There is an increasing interest in realness and authenticity
- People will want to know where things and people are from and if they can trust them
- People lead increasingly "fake" lives filling their lips with "Botox", dying their hair blonde, enlarging their breasts, and pretending they are happier than they really are

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Embedded Intelligence



- Car manufacturers are experimenting with fingerprint technology to adjust seat settings, temperature control and radio settings.
- In Spain smart cards open doors and start the engine of your Rental Car
- A prototype "Super car" calls the factory when it realizes something is wrong and orders spare parts
- GPS will tell a dispatcher & the mechanic where you are
- Cars will talk to you, the manufacturer, and shortly talk to each other too.
- So will your refrigerator.
- Remote Monitoring will tell parents where their children are

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Globalization

- The Paradox: The more globalization takes hold, the more powerful small local players become
- Limited-time only products are a result of global market interactions
- Lack of new innovative ideas due to globalization
- Insecurity due to the rate of change in a global world is to some extent generational but whether you're eighteen or eighty there is a general feeling of powerlessness
- The future will be "local"
- The power of the media is no longer limited to National influence alone
- Companies become increasingly stateless organizations responsible only to their shareholders

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Seeking Safety

- In 2002 42,815 people died on America's roads
- Future innovations will include adoption of technologies in warning and guidance devices, sleep alarms, night vision devices, etc.
- Increased interest is in 'safe' destinations – cultural voyeurism – Regional Holidays and religious travel are the fastest growing segments of the tourism market-1,500, 000, 000 airline trips made by the year 2020
- Underground cities are expected to be built in Tokyo, Kuala Lumpur and Bangkok
- Something is happening to the world's weather
- Locally grown and sold foods – Fear of food (BSA) – Growing Food allergies
- Decline of Law and Security at the National Level

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Demographic Change

- The big demographic shift is ageing, a slow change, but a Mega trend
- It's someone's 50th birthday every 8 seconds in the US
- Life Expectancy by the Year 2020 is predicted to be 100+ for many countries
- People marry later or not at all. In the US 42% of the workforce is unmarried.
- Fewer people will be available for work – there will be more competition for workers
- 25% of homes now contain some type of home office
- Increasingly couples aged 60+, other age groups, will travel in flocks
- Voice-lifts and other forms of anti-ageing surgeries, memory recovery and enhancement
- More debate about euthanasia
- Designing product packaging that people with poor eye-sight and old hands can actually open

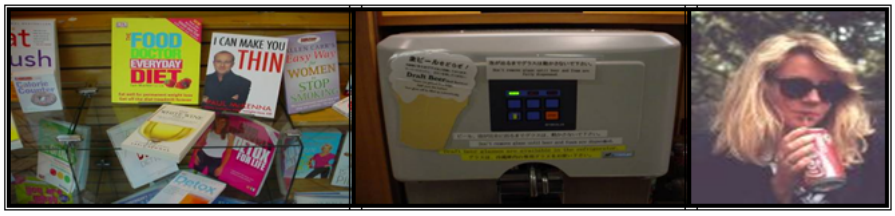
Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Gender Polarization: Women

- Women as the biggest market on earth are largely ignored because most of the world is run by men
- Women buy 65 % of cars and make 81% of financial decisions
- Medicine and Gender
- Women currently outlive men by more than 25% of time
- Dieting is the new Eating (Starvation is a growing trend in the US)

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Scientific Solutions



- Functional Foods, "Nutraceuticals", or "Phood" – combination of old-fashioned food with the very latest pharmaceutical know-how and technology
- Breakfast Cereals that reduce heart attacks
- Bread that fights depression
- Chocolates that fight cancer
- Coca-Cola that reduces Alzheimer's disease
- In the US 2/3 of adults are overweight
- Health food on the Go (Fruit!) mixing healthy food with portability is a continuing trend

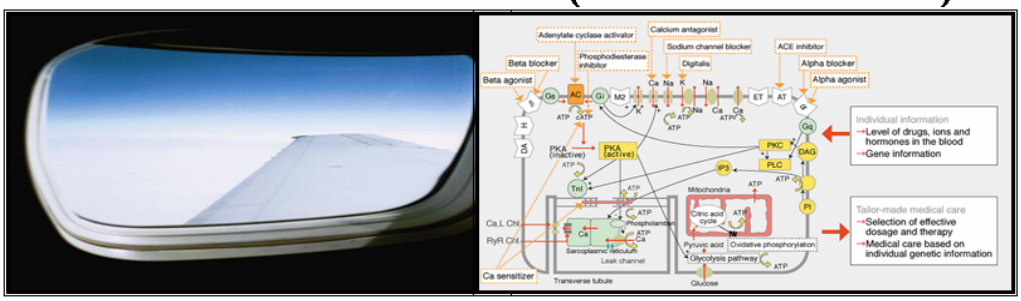
Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Depression / Unhappiness / Anxiety

- A study by Brown Medical School found that men who suffer from depression increase their risk of heart disease by 12-18%
- Individualism, living alone, social exclusion (lack of community)
- Will increasingly be treated as a disease
- Western societies are sleep deprived and as a result people are becoming clumsy, stupid, unhappy, and dead according to Dr. Stanley Coren, (author of The Sleep Thieves)
- In Australia there were 4 Sleep Clinics in 1985 – now there are over 70
- In New York there is a company called "Metro Naps" selling sleep to stressed out people for $14 for 15 minutes
- Materialism, unhappiness and the rise of "spiritualism" (search for meaning)
- Increased promise of "happiness" in advertising
- There are 40 wars in 35 countries going on as you read this
- Nostalgia is a major trend – Speed of Change becomes increasingly unmanageable

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

The Death of Distance (and Realness?)



- The internet has given ordinary people access to new information (far away places)
- We can increasingly model biological systems and processes with computers
- Bio-simulators can be models for designing and testing new drugs
- It currently costs about $900 million and 15 Years to design and launch a new drug

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Product and Device Convergence

- One of the key drivers of global change is convergence of technologies
- Product Obsolescence – throw away your old TV, Computer, and Mobile Phone?
- Get ready for intelligent paint and wallpaper in your house
- Smart Clothing and 3D TV
- E-everything for convenience and cost savings
- In the meantime Office e-mail is reaching plague proportions
- Do it Yourself (We can't be bothered) – Book your own flight, check in and out via a TV

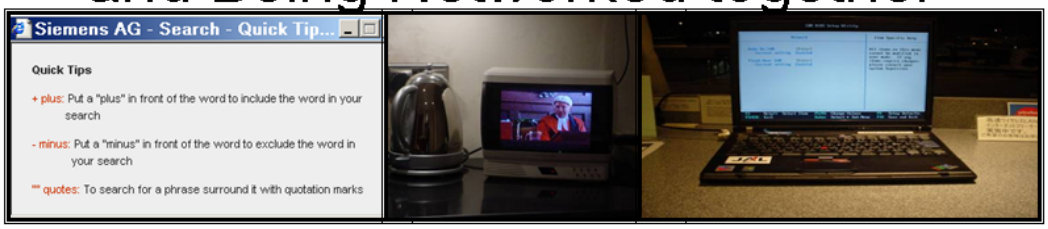
Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

Wireless and Broadband

- People who have grown up using mobile phones regard a phone number as theirs rather than something that belongs to a house or a facility (it is individual not collective)
- Rapid growth in broadband penetration and speed.
- By the end of this year (2005) there will be in excess of 2 billion mobile phones switched on world-wide.
- As we become more connected to everyone and everything (through the increased use of mobiles, email, WiFi etc) we will become more and more susceptible to virus attacks.

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

On-Demand TV, Fragmentation, and Being Networked together



- The average (Australian) couple spends 3.5 hours watching television but only 12 minutes talking each other every day.
- Today there is 24/7 Multi-channel availability of TV
- In the foreseeable future you will be able to access every television program and every film, documentary ever made, when you want it and how you want it
- Nearly the entire world gets to hear and see real-time news events.
- In the future there will be little or no privacy since everything is connected and shown to others
- Innovations are copied as quickly and news about diseases spreads quickly
- For many populations television is the primary medium for education about Medical Information

Will this trend influence the Medical / Health Care Field?
If yes, how?
How will you and your peers access and use information as a result?

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