APPENDIX B

MEDLINEplus Evaluation

Final Report

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Consumer Health Information Seeking Interviews

P. Zoë Stavri, Ph.D.

with contributions from

Donna Freeman, MLS, MD

and assistance from

Becky Lyon, MLS
Cathy Burroughs, MLS
Robin Sewell, MLS, DVM

Pacific Southwest Regional Medical Library Agreement 5400CBC324

Consumer Health Information Seeking Interviews

Background:

The National Library of Medicine (NLM) has been conducting usability and user satisfaction studies of Medline Plus throughout its development. In addition, the formative and ongoing evaluation of Medline Plus has included systematic assessment of need and discussion with user target groups. Surveys of users and community focus groups have provided useful information to the system developers. As useful as these survey and focus group data are, because they focus on users of Medline Plus, they do not assist in understanding potential users who fall within the stated scope of the site. To this end, a web research agency has conducted studies using potential users of MedlinePlus as well. Understanding the breadth and scope of resources that consumers use to get health information can help in further refinement of a tool that many current users already find to be useful. Information regarding already established means of information seeking can assist in identifying ways in which people who might benefit from the use of MedlinePlus can be made aware of its existence and usefulness, uncover misconceptions about its use, and discover perceived gaps in coverage that may benefit from alternative access points.

Impetus for the study

One of the driving forces for this project was to try to use a qualitative research method (semi-structured or intensive interviews) to obtain data about users of MEDLINEplus to augment already existing quantitative survey data and other techniques such as focus group interviews. **Intensive interviews are appropriate when pursuing in-depth information about feelings, attitudes, beliefs and behaviors and allow the participants discussion to shape the direction of the interview.** This method can uncover feelings and beliefs that would not be revealed in a more public forum such as a focus group or in a static information exchange environment such as quantitative, structured interviews or paper surveys. One of the hallmarks of this method is that an interview guide with probes is used instead of a more rigid interview schedule with ordered, precisely worded questions as the interviewer's instrument. The order of the questions takes a conversational tone with elaboration at the point of mention rather than in a structured order. However, the data collection method does not result in a set of anecdotal narratives but rather a systematically collected set of data from which emergent themes can be teased. When used appropriately, intensive interviews can augment other types of data collection (triangulate with) leading to a richer understanding

of the reason why people answer questions a particular way. As a data augmentation component, it allows researchers to clarify points that are confusing or require elaboration when collected through static means such as surveys.

Thus, this study functioned as a feasibility study for the usefulness of this type of methodology to gather data for the needs of the MedlinePlus development team. As the project progressed, it became evident that the process would be as important a research outcome as the aggregated data. This held true both the in the design, solicitation of participants through the individual sites, and in several instances, training new researchers to use the methodology. Our sample was not large – and this is usually the rule in qualitative methods – and thus inferences to the general population of MedlinePlus and potential MedlinePlus users would not be made. Yet, as is also the rule with qualitative methods, quantity and inferences was exchanged for deeper probes and further understanding of a smaller number of cases.

Instead of randomly selecting participants, since we were very much hoping to understand the feasibility of using this method, we decided to work through the Pacific Southwest Regional Medical Library to try to identify potential users of Medline Plus through libraries in the region who had received library partnership grants. The site contacts greatly influenced the mix of participants in this study and the methods used to solicit their participation.

To reiterate, the overarching goal of this project has been to design and perform a preliminary study of the feasibility and usefulness of using a qualitative method to assess how the public finds health information, and to delve deeper into the usefulness of MedlinePlus for those users who have tried it.

Organization of the report

After a general discussion of the research process, the data will be described and analyzed. Finally, considerations and concerns will be enumerated including how the design evolved and why; and recommendations for further refining the process will be given.

Method

All libraries that had received funding through the public library partnership in the PSRML region were sent an informational email by Heidi Sandstrom who explained that someone might be contacting them to

participate in this study. Key personnel within two partner libraries who had received funding through the PSRML were then contacted by Ms. Sandstrom by telephone, and she further explained the aims of our study. The Tucson Pima Public Library was contacted directly by Dr. Stavri since there was an already established collaborative working relationship established with them through the Arizona Health Sciences Library where she has a part-time appointment. Dr. Stavri followed up with each contact, outlining details of the procedure. For the Tucson set of interviews, after the original contact, Dr. Freeman made further arrangements.

We described not only the aims of the study but also what we would need from the key personnel, in particular a room or other private spot to conduct the interviews, and a way that was best suited to the location to solicit participants.

After a great deal of discussion with other researchers in this methodology, it was determined that the benefits of tape recording would be outweighed by the potential reticence of participants to elaborate upon their health information seeking during a relatively short period of time while being tape recorded. We felt that this decision would also allay some of the concerns TPPL staff expressed about client confidentiality. On a design level, since we were not specifically interested in verbatim recording of consumer vocabulary, we further felt that this decision was warranted. In order to facilitate accurate reflection of the ensuing intensive interview, we therefore required that we have two researchers present at each interview. One person would actually ask the initial questions and follow the lead of the respondent to obtain information on all points listed in the interview guide while the second person took notes and asked for clarification at the conclusion of the interview.

We decided to reward each respondent with cash 'token' for participating ($5 or $10) at the conclusion of the interview. While we started the process believing that $5 would be adequate compensation, the length of time each respondent ultimately spent with us felt to warrant an increase to the original $10 we had budgeted for.

Development of the instrument

Resources that work well for librarians may or may not be the same ones that work well for the public. Since one of our primary goals was to elicit experience and opinions from library users rather than from librarians, our first challenge was to get to these people. Before using branches of the TPPL system to recruit volunteers, we sought the understanding and agreement of the TPPL staff. A memo outlining the goals and plans for the

study was shared with the Managing Librarian for Reference and Information at the TPPL Main Branch. We met with her, and she readily agreed to check with her administration to rule out any possible misgivings on their part; she also agreed to contact the branches of the library to see if the staff could connect us with customers who were known to have used library resources to look for answers to health related questions.
The questions we chose to ask of library users came from a combination of brainstorming around the ideas of what stimuli would probably lead people to ask health or medical related questions, ideas derived from the literature, comments of librarians about helping people look for information, and from experience working with people who sought help from the information services desk at the Arizona Health Sciences Library (AHSL). Our questions tended to cluster in a few general areas, and a draft interview structure was blocked out. (See Appendix 1 for the final iteration of the interview intake form). The data collection form was designed to provide sufficient space so that the note-taker could make notes during the conversations. The intention was to have a "semi-structured" encounter so that the interchange could be as naturalistic as possible. Since the interviewer is provided with a set of basic topic areas to cover rather than a structured list of questions, the conversation should flow naturally and jump back and forth between topics if that is how the respondent offers.

Pilot testing

The interview format and data collection forms were pilot tested with four volunteers, all graduate students in Information Resources and Library Sciences. Not surprisingly, this group of respondents was very familiar with looking for information, particularly using computers, and had considerable experience both with computers and the Internet. The test runs were useful in prompting a rearrangement of the general topic sequence to ask questions about computer use "comfort level" and demographics towards the end of the conversation. If asked first, questions about computer use gave the respondent the impression that the only resources of interest were those online. However, we hope to gather information about other potential resources, including other people and print materials, so the computer use questions were moved to follow the main body of the interview.

The pilot testing was helpful in giving an estimate of how long each interview might take and in practicing the mechanics of taking accurate notes while still engaging in a one-on-one conversation. In addition, each pre-test respondent had used the Net to research his or her own health-related questions, and this experience was of interest.

Insights gleaned from pretesting

In originally conceiving this project, we thought we would be able to talk to a range of people, including those comfortable with using computers and the Net and those to whom these information intermediaries were new and barely known. Graduate students in information resources are not typical members of the public in that not only are they experienced computer users and Web searchers, they have greater insight than most into how information may be arranged for easier retrieval, and they tend to be more demanding of quality and credentials for their sources. By the nature of their training, they tend to question what they find and not be satisfied with the first things that come up. In the pilot interviews, each student volunteered experience in looking for health or medical information on line. In one case, the student was very experienced and was able to share several resources that she had found valuable. She was also able to comment on the aspects of the sites that allowed her to find what she wanted and contributed to her sense of trust and satisfaction.

The branch managers in the public library system also shared some interesting insights. Concern about possibly violating the confidentiality of their customers was raised by a couple. Others said they knew people who regularly used the Web looking for health information and would be glad to put us in contact with them, and this approach has been the most productive so far. An observation from several was that they thought that the customers who looked for health information on the Web tended to do it on their own, usually from home, and were not the people who interacted with the library staff. Most of the people who came to the desk for help were not willing to sit down at the computer, but wanted the librarian to get the requested information. Therefore, the library staff could not really identify potential volunteers for us.

Interviewers and note takers

Except for some of the Tucson interviews, two people were present at all data collection encounters. P. Zoë Stavri either was present as interviewer or note taker at all the interviews except that Donna Freeman conducted 3 telephone interviews and one on-site interview by herself in Tucson and Dr. Stavri conducted an interview herself. Dr. Freeman was learning this technique and conducted the pre-testing of the interview schedule as part of an independent study under Dr. Stavri, School of Information Resources and Library Science, University of Arizona. She also conducted some of the interviews by phone, as noted, per request of the interviewee. In Honolulu, Cathy Burroughs from the Pacific Northwest Regional Medical Library

accompanied Dr. Stavri for data collection. In Las Vegas, Becky Lyon, National Library of Medicine, took notes for two of the interview days, and Robin Sewell, Applied Informatics Fellow, sponsored by Dr. Stavri, took notes on the remaining interview days.

Information about the locations

Three public library pilot program leaders in the Pacific Southwest Regional Medical Library were used as starting contacts for the data collection: Tucson Pima County Public Library; Honolulu Medical Library (not technically a public library although it is open to the public) and Las Vegas Clark County Public Library. Branches visited in the TPPL system included Woods (North West Tucson); Arivaca (a very small, remote town on the south east periphery of the county); Green Valley (a retirement community south of Tucson). Two branches were visited in LV: Charleston (which houses the free-standing Consumer Health library) and Indian Springs (a small remote town, populated by retirees and employees of the military base, west of Las Vegas. The library shares a small community center with the Senior Center and the Parks Division).

Recruitment

We were referred to the managers of five branches in the TPPL system. They had been contacted by telephone by our original contact at the Main Branch. Each branch manager was then called and asked if she could possibly refer to us any customers known to have been looking for health-related information. The responses of the managers were varied and quite interesting, and will be further discussed in the section on Results. Based on these conversations we were able to make contacts with some volunteers and conduct the first few interviews.

In the remaining two locations, Consumer Health libraries were in place, and the staffs there were very cooperative in setting up appointments and circulating flyers soliciting walk-in participation. Each of the recruitment methods will be reviewed below with emphasis upon the success or failure we encounter in using each method.

Individual referrals

Phone interviews

In a couple of cases, branch managers knew of people who had looked for health-related information on the Net and asked these folks if they would

be willing to talk with us. Receiving permission to give us their contact information, the manager then got back to us with telephone numbers. Three interviews were thus conducted over the phone because it was more convenient for the respondent than to get to the library branch on a scheduled day. While lacking the non-verbal cues and information inherent in a face-to-face interview, each conversation flowed easily and took about 20 minutes to complete.

In person

The manager at one of the smaller, out-of-town branches, Arivaca, said that she knew of several people who would be glad to be interviewed, so we arranged to meet these people at that branch to talk with them at a scheduled day and time. We were able to use a small conference room for privacy, and these conversations went well, tending to last a bit longer than the telephone interviews.

Newspaper ad

At one branch, Green Valley Arizona, the manager could not suggest any individuals but thought that placing an ad in the local paper might work to bring in interested volunteers. This branch is in a community about 40 miles south of Tucson and is the only public library branch there; the local paper is the only alternative to the Tucson paper. We went to this branch at the announced day and time and were able to talk with three people over a three-hour period. All had come to the library in response to the ad, though one had misunderstood what we wanted to talk about.

Recruiting Walk-ins

In one of the larger branches in the City of Tucson proper, one strategy that was tried was simply being at the branch library for several hours during the day hoping to recruit volunteers by posting a sign near the reference desk. Only one interview each was garnered in this way in two attempts at soliciting participation at the Woods Branch.

Appointments

By far the most successful method we used to recruit participants was to have librarians ask their clients, or additionally, in the case of Honolulu Medical Library, people who took a MedlinePlus training class, if they would be willing to talk to us when we came to their location. Several other people signed up based upon a sign placed by the reference desks announcing our imminent arrival. We were fortunate that both Las Vegas

and Honolulu agreed to assist us in the way as our time onsite was thus very effectively spent.

Respondents and non-representative sampling

This study focused on feasibility and methodology rather than representativeness. In light of these primary goals, the opportunistic sampling frame is not seen as a limitation. Respondents were either identified and scheduled in advance by librarians in respective locales or self-identified in response to flyers or advertisement, or were recruited on the spot by librarians.

While we specified that we wanted to talk to people who looked for health information on the Internet we were expecting that we would be talking to some people who, while they did seek health information, did not necessarily use the Internet to find it. We were completely taken aback, however, by the people who signed up or were recruited to talk to us who flatly denied needing health or wellness information. The flyer mentioned 'token of our appreciation' but no clarification, yet it is our impression that some of the people in Las Vegas came to talk to us just for this reason, especially when one person asked about compensation during our introduction. Yet while the compensation may have motivated some people, several others (particularly in Hawaii) did not want to take the compensation and finally 'donated' it to the library (this also happened after the final interview at the Woods Branch, Tucson). These people were talking to us because they felt passionate about their experiences, for better or worse, in pursuing health information. It was apparent, in Indian Springs, that the recruited people were regular library or community center users, of retirement age or on disability, who the librarian could talk into speaking with us – in other words they appeared to be talking to us as a favor to the librarian.

However**, we do not believe that we have achieved theoretical data saturation,** which is the goal of qualitative research sampling. This occurs when the themes start to repeat themselves and no new themes emerge. While we did begin to find consistency in themes within geographic locations, enough variation occurred between sites that we can only say that the data appear to suggest regional variations within the southwest in terms of individual feelings about web searching and the type of information found online. **More data collection of this type will be needed before we feel that data saturation and exhaustion of themes has occurred.**

Data

A total of 38 respondents were interviewed with a geographic breakdown as follows:

Tucson / Pima County = 10
Honolulu = 11
Las Vegas / Clark County = 17

Two of the interviews (1 in Green Valley and the other in Indian Springs) took place with married couples per their request and thus we had 36 individual sessions to discuss after the demographic section.

Demographic data

The demographic data we collected is reported below in abbreviated form. Some people were concerned with giving us responses in these categories. For example, while we initially began to collect data about educational level and occupation, we abandoned this as it appeared to sensitize some people. We will suggest an alternative to gathering this data in the recommendation section later in this report.

Computer / web experience:

Computer experience

Some computer experience	27
No computer experience	9

Computer experience by Gender

	Married couple	Female	Male
High computer use[1]	1	10	7
Intermediate computer use		2	1
Low computer use[2]	1	2	3
No computer use		5	4

[1] *high computer use was defined as more than 3 years*
[2] *low computer use was defined as less than 1 year*

Computer experience by Age group

	High computer use[1]	Intermediate computer use	Low computer use[2]	No computer use
18-35	4			
36-64	10	3	3	4
Over 65	4		3	5

While nine people had never used the Web, one of these respondents did however have a computer at home but no interest in connecting to the Internet.

Seven people had been using the web for under a year; 3 people were intermediate in their use of the web (i.e. used infrequently or for between 1 and 3 years) and 19 people had been using the web for over 3 years, considering themselves heavy Internet users.

Where people search

Not everyone who used the web, used it to find health information, and in fact 2 of our web users said they had never used it for health information seeking. Of the 23 people who used the library to search the Internet for any reason, 8 people used the library exclusively. 18 people searched the web at home, 5 of them exclusively. 4 people searched the web from their office (only 1 of these exclusively) and 2 people used other places like a Senior Center, but not exclusively. 9 people never searched the web.

English as a First Language

We were originally hoping to find Hispanic participants in the Tucson area, given the demographics of the community, and this was the impetus for asking this question. However, working through the libraries here presented some challenges, as mentioned earlier, and this hope was never realized. This question also disturbed some people in Honolulu, so an off-handed way of asking it was developed.

36 spoke English as their first language
2 spoke other languages first, 1 Vietnamese, the other Arabic

Resources used for health information seeking

Resource	Number of People
Books	25
Dr or other health care provider	23
Web	21
Librarians	17
Magazines	16
Friends or family	12
Medline Plus	8
Drug inserts	7
Pharmacist	7
Newspapers	6
Online support/chat	5
Television	5
Medline	4
Radio	3
Alternative health care provider	2
Drug ads	2

Favorite websites excluding search engines

Mayo	4
WebMD	3
PubMed Medline	2
Cleveland Clinic	2
AOL Health	1
ABC.com	1
"USPDI"	1
DrKoop.com	1
Johnson & Johnson	1
Rand Corp.	1
www.consumerlab.com	1
MSN Healthlink	1
www.er123.com	1
www.symptomorillness.com	1
Queens, Laura's Health	1
www.micropigmentation	1
CDC	1
UCLA	1
Discovery.com	1
e-medicine	1
Healthline	1

Favorite print sources

- Prevention Magazine
- Time Magazine
- Omni Magazine
- Colliers Encyclopedia
- World Book Encyclopedia
- PDR
- Merck Manual

MedlinePlus data

Knowledge or use of MedlinePlus

Knowledge of M+	Use of M+
19	8

Comments about MedlinePlus:

Scope

- Good site when looking for information on symptoms
- "The library is set up to get you there!"

Not sures

- Thinks 'probably' has heard of M+, but not sure as she does not bookmark sites.
- Heard of through Honolulu Medical Library but 'not sure what it is'.

Misconceptions:

- “Site where you can ask nurse questions and get answers. They all sound the same”.
- “Cannot tell difference between Medline and MedlinePlus”
- “Where you can get cut-rates on drugs”
- MedlinePlus = WWW (terms used interchangeably, such as “go to Medline Plus to search Yahoo”
- MedlinePlus, “NIH_NLM” and Department of Health and Human Services used interchangeably.
- Confusion about URL: www.nlm.gov and why it did not always work.

Will try after our meeting

- Says will try after our description since it sounds more consumer oriented than PubMed
- Heard of, but did not know where to find, got URL
- Gave them URL; wrote us back to say "wealth of good information"
- Pointed to site by librarian; tried from work and bookmarked but didn't get good sense of it; "looked interesting"; will try again
- Took class and it was suggested that she use this first instead of Google but has not yet. Thinks it is a good idea, just has to do it.
- while has not heard of it, would trust because has "National" in the name; that and similar sounding names (like "National Library Association") an indication of trustworthiness; seems like authoritative producer.
- heard of not used; took url home

Too much or too little

- Tried: good information but confusing. **More medically oriented than needed** for long-term care info. Not sure difference between M+ & Medline. Wanted to download articles and could not.
- Heard about it from library brochure and tried. **Limited information** (not detailed enough) on gestational diabetes so went to search engine (Google) for more detailed information. **Did not have the dosage** specific info wanted.
- **Thinks information is too general** and still needs to be more consumer friendly, consumer oriented, and personal to be useful. teaches M+ to ESL students w/ HS education (Korean & Japanese); sometimes used M+ to mean 'Web'; liked alpha-pick list; not as current as should be (new drug couldn't be found); needs more info on alternative treatments; needs to offer more gray areas & hot topics
- Says: **need to know vocabulary** to use M+; but also used terms 'NIH NLM' and 'Dept of Health & Human Services' as places she searched; said 'DHHS NIH' is too technical; grateful for M+ because **looks like good source, more direct than Google.**
- Was not very satisfied; found it to be **'mostly references'**; gave **too much of an overview** when he needed in-depth information
- "www.nlm.gov" once she knows what something is called; heard through librarian; seemed excellent but **not on target** for tattoo removal but good for drugs like aspirin; used PubMed for tattoos

Computer use problems

- Took class but difficulty getting back in but just learning to use a computer; needs basic more computer instruction; afraid if he linked out somewhere he would get charged. Frustrated no one there to help him.

Web satisfaction

When you have a health question, do you find what you are looking for?

	Frequency
Yes[1]	17
No	0
Sometimes[2]	8
Do not actively seek	11

[1]total includes the following responses:

- Web does not provide enough depth so for details go to books found at bookstores.
- Has librarian do the search on the web
- Only sometimes finds things on the web; mostly gets answers in books

[2]total includes the following responses:

- much of what he finds on his condition (CFS) is not current
- has difficulty finding information about organizations a second time and cannot fine local and national contact people
- can easily find national information but wants more local information

Can you understand what you find on the web? (n=21)

Yes	16
Sometimes[1]	5

[1] total includes the following responses:

- find answer, but do not always understand what it says
- drug inserts contain too much jargon
- understands most except drug names: too complicated
- books are more understandable; the web is too technical
- difficulty interpreting the normal values from a lab test

How long do you spend looking for information?

Less than an hour at a time and only one session	11
Over 3 hours at a time and often several sessions	10

Do you trust the information you find on the web? (includes two who do not use for health information)

	Frequency
Yes[1]	13
No[2]	4
Sometimes[3]	6

[1]Responses include the following:

- Use intuition, or common sense or gut reaction to gauge trustworthiness (6 people used this criterion to evaluate the information they found).
- Trust information because do not know how to evaluate web information: "I am not a doctor", just assume that it is good since it seems okay and of 'pretty good quality (3 people expressed variations on this theme).
- Randomly picks site from search that catches his eye, and then reads more thoroughly if he likes the format and design. All have turned out to be 'pretty good'.

[2]Responses include the following:

- Mistrust the information on government websites, especially the FDA since they have their own agenda in presenting information (3 people made this kind of statement).
- Distrust commercial sites, especially drug companies (3 people)
- Distrust sites with advertisements (2 people)
- Doesn't trust Q&A forum: how can the doctor respond to someone unknown?
- Credentials not as important as a site that is "interesting", if not, mistrust

[3]Responses include the following:

- Scientific evidence and related studies, peer review, scientific basis

(4 people)

- Western medicine, North American medicine (2 people mentioned this)
- If there is consistency in the treatment of the topic between sites, more likely to trust.
- If it has something like National in the title, then it is trustworthy.

Information needs

A taxonomy of information needs is presented in Appendix 2. Outside of work related searching, people in our sample look for health information for themselves, and their family and friends, especially parents, spouses, and occasionally to address the health concerns of their children. In broad terms, they search for health information to prepare for an appointment with their provider or to understand what was said during a visit. They search for information regarding diseases, conditions, syndromes and symptoms; medications (including over-the-counter preparations); health and wellness information; and alternatives to mainstream Western medicine treatments.

Discussion

We found differences in attitudes towards information resources. Respondents 6 (husband and wife) and 102 were very wary about government resources, especially the FDA.

There was great variety in the desire or tolerance for evaluating the information resources found on the web. Many respondents in Las Vegas / Clark County were not critical of any of the information they found on the web, and discussion with the librarians confirmed that this had been identified as an issue and was a training priority.

Themes:

Local information

Five of the participants elaborated upon the notion that they wanted and expected to find local information. This included directory information (names and addresses), local support groups and local resources.

Confusion about search results versus information

People seem to confuse the information they get from a search engine with the progenitor of the information. For example, one respondent compared the information he got from Yahoo (simpler to understand for drug information) with that he got from PubMed (good for disease information) as if they were equivalent types of data sources.

Passive health information seeking

Some people are satisfied with 'passive' health information such as drug inserts, news, radio, TV, but do not actively seek out information. This has sometimes been called accidental or incidental information seeking.

Evaluation criteria

"I am not a health care professional so cannot evaluate the information" was a common theme but this caveat did not keep people from looking for things. It was simply that they felt they could not tell if the information was good or not. We found that when we explained MedlinePlus to many of these people, they thought that it sounded like a site they would trust especially when we gave an overview of the highly selective material they would find there. This underscores the need for the trustworthiness of the site to be prominently displayed in simple obvious terms to allay the concerns of the people who feel that they are not knowledgeable enough to evaluate the health information themselves.

Many people said they used their 'intuition' to gauge whether or not the information was credible. It may have been that they could not articulate the criteria they used, but some very sophisticated searchers used similar words.

Confusion about MedlinePlus

One person indicated that he thought this was a place to buy drugs and elaborated by recalling the well placed collection of capsules on the website. Another person remembered that this was a place to ask a nurse questions. One person used it loosely to mean a starting point for web searching.

Difficulty in remembering names of sites and how they were found

We only probed for more information regarding MedlinePlus, but it seemed that people did not always remember the names of the sites they visited especially if they were searching from a public place where they could not use bookmarks to return to sites. When people did recall sites (with the

exception of search engines) they were more apt to remember what they found there rather than the precise URL. Only rarely were people confident that they knew how they got to the site (or how to get back) and in many instances reflected confusion about the entire process.

People like coming to the web with known urls

While search engines were popular conduits to health information, people were very apt to try links that had been suggested to them by other people (such as librarians) or the media (such as Oprah, the newspaper, NPR). While no one in our sample mentioned health care providers as conduits for web sites, it was apparent that many people in our sample obtained and trusted health information they received from their health care providers and pharmacists. This seems to open up further possibilities for helping people get to health information they can trust.

Considerations for further study

After conducting these interviews at the 3 locations, we reflected upon what we would do differently if we were to expand this study.

1. Re-consider tape recording interviews. While this would add processing time and expense to the project, some of the wonderful verbatim description could not be captured through note taking alone. It was, on the other hand, very useful to have two people in the interview room as witnessed during the times when only one researcher was present. When two people were present, impressions could be discussed at the conclusion of each interview and clarification could be asked by the note taker. However, one consideration might be that people could be reluctant to speak so freely about their health concerns when being tape recorded. We do not know if this would be a hindrance since it was not attempted. If we do decide to tape record subsequent interviews, Internal Review Board (or its equivalent) permission would have to be obtained.

2. When subsequent contact is made, summary data should be presented to the site as the data collection arrangements are being made. For some reason, the TPPL was less cooperative even though they initially were enthusiastic about participating. Perhaps if other sites could see that their users would be truly anonymous in the reporting of the data, they would feel more comfortable in helping us find participants.

3. Soliciting participants. We tried a number of different ways of soliciting participation in the study: grabbing walk-ins based upon signage in the library; setting up appointments with 'regulars', identified by the

librarians;, running an ad in a local paper and then showing up at the appointed time. Of these methods, the only one that was truly successful was having the librarians identify regulars who they knew searched for health information. We would suggest that this is the method used in subsequent iterations of the study. While a newspaper ad did have potential, it would have to have been run twice (a week ahead as we did and the day of or the day before the interviews as suggested by one of the people who responded to the ad). The identification of health information seekers by the librarians serves a screening purpose as well since one of the people who showed up as a result of the ad came to voice her opinion about Arizona health care and get an opinion as to what she should do next, not to discuss her health information seeking. On the other hand, one of the people who had signed up for an interview in Las Vegas indicated that he did not seek out health information at all (he volunteered himself and was not suggested by a librarian) and almost all of the people at the Indian Springs branch did not seek health information.

4. Asking for demographic information: we found that some people were sensitive about some or all of the following types of questions: a) occupation b) education level c) first language (especially in Hawaii). One option to asking people these demographic questions is to collect this information at the end of the interview by handing respondents a quarter page questionnaire that merely asks these demographic questions with an id number at the top to associate the responses with the interview itself. We believe, although we did not test it, that people will be less reluctant to answer these questions when we are not maintaining direct eye contact as we do in an interview.

5. Intake form: as we progressed in the data collection phase of the study, significant needed changes became apparent. One was that not everyone used it the same way and that there might be a better way (mentioned above) to collect the demographic data.

6. Include more extensive interviews with site librarians. We talked extensively with the librarians in Honolulu and Las Vegas about their experience with the information needs of their clients. In Las Vegas we followed up on an impression we had that people were not critically evaluating the information that they found on the Web and found that this was not just our outsiders' impression but a perceived training priority. We suggest that interviews with the local librarians be conducted as part of the data gathering process as well as to follow up on impressions.

7. Participation of local libraries. We felt that we would have an easy time dealing with the TPPL since Dr. Freeman and Dr. Stavri are living in the

area and involved in other projects that included the library system. Original discussions with the system head of public services indicated great enthusiasm for the project. As the time drew near for the actual interviews, it became apparent that they were not eager to participate in this project. After much prodding, some unease at identifying 'their' patrons with health information needs was expressed. Yet, one of the smaller branch libraries – Arivaca – was very helpful in setting up interviews. The Woods branch also identified a few people for us but left us to use signage for the most part to recruit. While the Green Valley branch was wiling to have us come to the library, they suggested we place an advertisement in the local paper. While we did not get overwhelming response to either the signage or advertisement, it could have been because we were past the 'snowbird' season in Arizona meaning that many part-year residents had already departed for cooler climates.

Our experience with TPPL contrasts greatly with the reception we received from both the HML and LV. In both locations we were initially 'introduced' by phone and email by Heidi Sandstrom and then Dr. Stavri followed up with email and telephone calls. Once our contact people felt comfortable with what we were trying to accomplish, they very enthusiastically set about to find us their health information seeking regulars and to make sure we had a fruitful visit. The impression we got was that they were proud to have us visit their libraries. Of course, the PSRML and the NLM meant something to both of the locations while TPPL, despite its partnership with the AHSL, did not have the loyal connection to the whole NNO. This is just one explanation for the different reception we received in TPPL but is something to consider if we plan more site visits. Another explanation may be that it was a limited term event for us to visit the libraries and we were perceived as special visitors while in Tucson and its system we were not traveling far enough to make it an event.

Conclusion

This is a labor intensive but detail rich method of gathering information about feelings, attitudes, knowledge, beliefs and motivations surrounding personal health information seeking. Its appropriate use is to try to answer questions in this realm and to probe further when faced with data, gathered using quantitative methods, which are not easily explained. Using the method we used to gather participants through public libraries, it also presents a viable means of getting input from people who do not have home computers but who still use the internet to gather information as well as target users who might not yet feel comfortable searching the internet.

Appendix 1

Date/Time **Location** **Interviewer** **Interview ID#**

PHIS	Looked in past 2 months? Y / N Why?	For whom: self? Family? Others
PHIR	Who? Doc – other HCP? Friends?	Web? Books? TV? Magazines?
Web	Kinds of questions? Favorites for health info?	How do you find Web sites? Search engine? Other…
MedlinePlus	Heard of M+? Y / N	Used M+? Y / N
Satisfaction	Find answers on the Web? Y / N / M Feelings about Web info.	How long spent looking? Comprehension?
Internet	Computer location: home / office / library / other	**C**omputer & Web experience: <1yr….1-2yrs….3+ yrs L/M/H
Demographics	M / F Age: ___18-35 / 36-64 / 65+	Engl 1st? Yes / No

Appendix 2
Information Needs

Family or friends

Child

Child health

- chicken pox vaccination
- over the counter ear cleaning techniques

Parent

Disease, condition, syndrome, symptoms

- dementia / Alzheimer's
- diabetes

Health care provider visit related

- help parent understand what doctor said after appointment

Psycho-social information

- help aging parents cope with living at home

Surgery and procedures information

- kidney stone treatment

Other family or friend

Disease, condition, syndrome, symptoms

- diabetes mellitus
- gestational diabetes
- lupus
- lymphoma
- melanoma
- Paget's disease

Surgery and procedures information

- breast reduction
- diet and dialysis
- surgical second opinion

Spouse

Disease, condition, syndrome, symptoms

- arthritis
- diabetes
- emphysema
- heart condition

Miscellaneous

- liquid oxygen information

Surgery and procedures information

hernia surgery preparation
tests for specific conditions

Self

Alternative therapies including vitamins
alternatives to prostate drugs
CoQ10
herbal information
Kambucha
Turmeric
herbs, vitamins, diet, exercise and weight loss
non-western medicine information in general
self-treat without causing more damage
vitamins, minerals, calcium
contaminants in
prevention
wellness, alternative approaches to

Dental information
effect of mercury in fillings
how to deal with a toothache

Disease, condition, syndrome, symptoms
bipolar disorder
breast cancer in men
bronchial problems
bursitis
cancer information, general
chronic fatigue syndrome information specifically for men
cough, recent
diabetes
dosage specific drug information
fibrocystic breast disease
glaucoma and other eye or vision
knee problems: water knee, soft knee, bursitis
lymphedema
pain in the side
plantar wart
“rare” disorders
symptoms, cold versus allergy
thyroid problems beyond prognosis, symptoms, recovery
tinnitus

General interest

- drug abuse information
- laws and legal information pertaining to medicine
- mad cow disease
- soft contact lenses
- tattoo removal
- web support groups

Health care provider visit related

- interpret lab test
- medical definitions
- prepare for visit: “check out protocols”; what to ask
- understand what the doctor said after appointment
- problems with HMO

Local information

- acupuncturist
- directory and local contacts / information
- location of pain management clinics
  - information about director of pain management clinic
- physician who treat.....
- support groups

Medication information

- aspirin
- asthma and medications
- drug ads, additional information
- glaucoma medication
- ingredients: what is ‘really’ in drugs
- off-shelf uses of drugs
- over-the-counter drugs
- Quadramet
- side effects and interactions of medications
  - Accutane
  - drugs leading to liver damage
  - prescription complications from ‘ingredients’
- verify information that comes from pharmacy
- Zocor

Psycho-social information

- caregiver survival
  - crisis management
  - dealing with dementia
- dysthemia and depression in general

personality disorders

Specific item or information source

Body Human

electronic journal articles, locate

'Fit for Life' health maintenance information

Surgery and procedures information

knee surgery information

gall bladder surgery suggestions

scanning technology for colonoscopy

Wellness and life stage information

cholesterol information

exercise and maintenance for health

exercising and breathing to raise metabolism

health and nutrition and preventative medicine

health concerns in SW Asia (travel)

Hepatitis A&B vaccines

lifestyle changes

to lower cholesterol

how to lose weight

physical exams after 50

high blood pressure

menopause

estrogen and risk for breast cancer

hormone replacement therapy

osteoporosis

self-help guides

walking at a brisk pace for exercise and possible injuries

Work related

Alternative therapies including vitamins

alternative therapies to reduce need for hospitalization

herbal supplements

Disease, condition, syndrome, symptoms

Mad cow disease

Medication information

ace and beta blockers

Aleve

Miscellaneous

laws and legal information pertaining to medicine