

Finding It on the Internet: Health Access for Elders

**Oregon Health & Science University,
Portland, Oregon**

**Final Report
November 2001- May 2003**

Submitted by:

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Submitted June 23, 2003

NARRATIVE DESCRIPTION

Summary / Introduction:

The main project goal, development of a health information web site for elders, has been accomplished within the project time frame and within budget.

The project site, The Prepared Caregiver, has a content focus on caregiving for elders. This focus was developed in collaboration with Oregon Health & Science University (OHSU) nursing faculty. The primary target audience for the site is people age 55 and up who are providing care at home for a spouse or parent.

The web site is prepared to move to OHSU's Center for Healthy Aging as soon as the Center's staff is ready.

Geographic region:

The project was designed to provide information of particular use to elders in Oregon. It does this by providing annotated links to caregiving resources in Oregon. The general information on the website has no geographic limit to its applicability.

Collaborations / Partnerships:

The main partnerships were among OHSU entities: the library (Dolores Judkins), the Center for Healthy Aging and the Hartford Center for Geriatric Nursing Excellence (Marna Flaherty-Robb), and the Department of Medical Informatics and Clinical Epidemiology, or DMICE (Mary Devlin). The other major partnership was with RareHeron, a web design company (Andrea Drury and Kayo Parsons-Korn).

Library, DMICE and RareHeron staff all worked together very well. The collaboration is essentially over with the completion of this report, although there is a final piece of work for Rare Heron to do in moving the site to its final host at the Center for Healthy Aging.

The relationship with the Center for Healthy Aging has been an issue. The web site was completed by the end of May but has still not moved to the Center, the site host. The person who we were told would move the site turned out to not have the needed knowledge to do it. The person to whom she turned over that responsibility has been on medical leave. Our current expectation is that the site will finally be moved and publicly available by the end of June 2003.

A more important issue, and one that plagued the project, was the relationship with Marna. In the grant, she had agreed to get original content for the site from her colleagues on the OHSU nursing faculty. Marna either misunderstood or forgot her role in the project. As a result, timely receipt of content for the site was a big problem.

In November 2002 Marna asked Susan Butterworth, a colleague in the School of Nursing, to be the liaison with the faculty. As a result we did receive some content from the nurses between the end of January and the end of March 2003. Some expected content never arrived.

Another difficult collaboration was with the OHSU grants office. There were problems getting permission to begin the grant. Procedures changed and submissions had to be redone. Then there were a series of lost submissions. The grant finally received IRB approval in October 2002.

Other collaborators were the Multnomah County Library, the Elsie Stuhr Center, OASIS, Providence ElderCare at Glendevor, and Calaroga Terrace. The library provided a focus group location and assistance in recruiting focus group members. The Elsie Stuhr Center, a senior center in Beaverton, OR, helped us recruit people for usability testing. OASIS, a senior organization located in the Meier & Frank department store, runs classes and has many other activities. They provided both a location for usability testing and helped recruit testers. Providence ElderCare at Glendevor, an assisted living facility, and Calaroga Terrace, a retirement home, both provided locations for focus groups and helped recruit focus group members. These collaborations are all complete.

There were scheduling challenges associated with the focus groups. The Calaroga Terrace group had to be postponed about six weeks because influenza was prevalent in the home at the initial date, and then the holidays intervened.

The Providence ElderCare at Glendevor group was postponed for several weeks because a new provider training class needed the room we had booked and that took precedence.

I worked with the librarians doing computer training at the North Portland branch of Multnomah County Library to recruit focus group members. That effort only provided one person. I think it would have been more effective if I had had the time to spend at the library and approach prospects myself.

Training:

None.

Training sites:

None.

Exhibits:

Mary Devlin gave a presentation about the project, its process, and the web site on June 4, 2003 as part of the OHSU research in progress series. The talk was at OHSU and about 35 people attended. Attendees came from OHSU (DMICE, the library), Oregon Graduate Institute of Information and Technology (OGI), and Kaiser Research. People were impressed with the web site and its usefulness for the target population.

This presentation will also be given at the University of Washington on June 30th. The audience will come from the regional NLM office and the health sciences library.

A proposal for a poster session at the annual American Medical Informatics Association (AMIA) meeting has been accepted. The poster will be presented in Washington, DC, at the November 2003 conference.

Resource materials:

There were no training materials developed.

A flyer announcing The Prepared Caregiver has been developed. Once the site is publicly available these flyers will be sent to hospital, public, academic and community college libraries in Oregon, and to the Oregon State Library.

Web sites:

The web site created for the project is currently housed at <http://www.ohsu.edu/library.test.caregiver>. Once it is moved to its permanent host, the Center for Healthy Aging, we expect the URL to be <http://www.ohsu.edu/caregiver>.

The Center will host and maintain the site. OHSU library staff will assist with maintenance and ensure that it happens.

Document delivery and reference services:

Neither of these are services associated with this project. However, the OHSU library provides a link from The Prepared Caregiver to their health information by mail and e-mail service. This service is available to OHSU patients and to people living in Oregon.

There are no use statistics since the site is not yet available to the public.

APPROACHES AND INTERVENTIONS

Identifying and scheduling sessions:

Mary Devlin did recruitment and scheduling for the focus group sessions. Pat McAleer recruited usability test subjects. She also scheduled the test sessions.

Promotion / Marketing:

A flyer announcing the site will be mailed to hospital, public, academic and community college libraries in Oregon, and to the Oregon State Library. A cover letter asks that library staff post the flyer in a prominent location so library customers will see it. It also asks that reference staff be apprised of the new web site.

The site will be announced on appropriate library listservs.

An announcement will be sent to newspapers in Oregon.

State agencies and other organizations whose services affect elders will be notified of the site. They will be asked to link to The Prepared Caregiver.

The OHSU library will provide a prominent link to the Prepared Caregiver from its consumer health area. Multnomah County Library will be asked to do the same.

Training:

None.

Personnel / Staffing:

Mary Devlin (MAT, MLS), NLM Library Fellow in DMICE, was the project manager. She also did information and link research for the site and assisted in re-writing content for web publication.

Dolores Judkins (M.LS), Head of Research and Reference Services at the OHSU Library, was the project coordinator.

Marna Flaherty-Robb, Assistant Professor and Associate Dean for Practice Development and Integration, The John A. Hartford Foundation Center of Geriatric Nursing Excellence, was the nursing faculty liaison.

Andrea Drury (MLS), Rareheron Web Design, was the information architect for the site. She also did information and link research, and re-wrote content to make it suitable for web publication.

Kayo Parsons-Korn, Rareheron Web Design, developed the site's graphic design.

Frank Spillers (MS) and Daniel Loewus-Deitch, Experience Dynamics, did the expert usability review of the site.

OHSU faculty nurses who contributed information to the site were Pat Archbold (RN, DNSc, FAAN), Teresa Harvath (PhD, RN, CNS), Karen Lyons (PhD), Deborah Messecar (PhD), Karen Talerico (PhD, CNS), and Victoria Warren-Mears (PhD, RD, LD). Susan Butterworth was the contact person who got eventually material from them for the site.

Others contributing information were Bruce Devlin (RPh), Kathy Devlin (RN, CNOR) and Sue Morey, freelance medical writer.

Dianna Andes, OHSU Library, managed the project budget.

Kathy Drew transcribed the focus group tapes.

Pat McAleer confirmed and scheduled usability test subjects.

Web site development:

The site was developed using an iterative process involving the RareHeron team, Andrea and Kayo, and Mary. After laying out a conceptual framework and potential content areas, Kayo did a draft design. All this work was informed by the focus group usability discussions and generally accepted good design principles.

Examples of focus group information that was used in site design include:

- Color choice

Group members liked colors that were not vibrant and that created a background that made reading easy. They were also particularly opposed to the use of pink, purple and violet.

- Metaphor

It was important to have a metaphor for the site. The metaphor that emerged was that of a trusted, knowledgeable friend. Language choice and writing style reflected this metaphor. In addition, we included photographs of all contributors to the site to help users get a sense of the people involved.

An expert usability review was done when the site was nearing completion. Many of the review suggestions were incorporated; others will need to wait for later site updates since there was not the time nor money to include them by the end of May.

People to do usability testing were recruited from OASIS, the Elsie Stuhr Center and through personal networks. A recruiter, Pat McAleer, was personally hired by Mary to find, screen and schedule testers. All the testers were at least age 55. Some had quite a bit of web experience; some had very little.

The purpose of the usability tests were to find out if users could easily navigate the site to find information, and what obstacles prevented them from doing this.

As already mentioned, site development was significantly delayed. We could not begin realistic work on navigation design without having a sense of the content. As a result all the site design, build and review work was more compressed than anticipated. This work began the end of January 2003 and was completed by the end of May 2003.

An additional problem was receiving less content than expected. We did a stickies exercise with content areas we were expecting and discovered a lot of gaps. As a result, the team did research and added much more content and links. This work was done in March and April 2003.

We also had been told that the material would be written in lay language and that it would be suitable for web publication. Both turned out to be untrue. A huge amount of editing was needed to make the material suitable for the audience and venue. This was an issue for some of the nurses because they had asked for assurance that their material would not be changed in any way. They reviewed the site and luckily no one asked that their content be withdrawn.

EVALUATION

Evaluation methods:

Site goals included:

- Compliance with Federal accessibility guidelines

The Prepared Caregiver meets Section 508 guidelines. It also meets Bobby guidelines.

- Elapsed time to load pages

The site was designed to load quickly even with a modem connection. In usability tests, about half of which were done in testers' homes with their modem connection, there was never an issue about load speed.

- Ability to locate certain information within established time

Usability tests counted the number of clicks to find information rather than elapsed time. The target population, at least as represented by the usability testers, often read everything on the screen. This slowed things down, but made them very successful at finding information. We saw that finding the information was more important than how long it took to find, as long as people did not become frustrated in the process.

Initial usability tests pointed out several areas where navigation improvements would be helpful. Changes were made and subsequent tests showed the site was easier to use.

Frank Spillers and Daniel Loewus-Deitch, Experience Dynamics, did the expert usability review. Their report made useful suggestions, many of which were incorporated in the site. Since the review was done before the site was completed, some of their recommendations were for things that had not yet been done but were underway.

Results:

An easy-to-use web site with useful information about caregiving was developed. It includes links to resources in Oregon, and additional links to national resources. People who have seen the site like it, find it helpful, and are looking forward to using it.

Problems / Barriers:

Problems included:

- Time delay in getting content
- Content written at an academic rather than lay person level
- Content written for paper rather than web publication
- Time to get the project through the IRB
- Lack of communication with a significant member of the team
- Delay in getting the site loaded at its permanent host

Continuation plans:

The web site will be maintained by the Center for Healthy Aging and the OHSU library.

The site will be advertised via Oregon libraries and newspapers.

Links to the site will be requested.

Mary plans to write two papers based on this work. One will be a general process paper citing lessons learned that might be valuable for others. The other will be a methodology paper on focus groups with seniors.

In addition, a poster session about The Prepared Caregiver and usability issues will be presented at AMIA in November 2003 and a presentation about the project process will be given at the University of Washington in June 2003.

IMPACT

Once The Prepared Caregiver is available to the public, the OHSU library may get more requests for information from Oregon residents and OHSU patients. There is a link from the web site to the library's information request form.

RECOMMENDATIONS FOR IMPROVEMENT

With the exception of the difficulties getting content and the need to do unanticipated amounts of research and re-writing, the project went well. Having experts in web navigation, design and usability issues participate in the project was a key factor in its success.

Another key factor was the willingness of several key players to work well beyond their expected scope to find content and to edit content for the web. Without that additional work the web site would not have had enough content to be worth using. It was especially important that Mary was able to devote almost full-time to the project for several months.

FOLLOW-UP QUESTIONS

1. Were original projects goals and objectives met?

The original project goals were to:

- Design and produce an easy-to-use web site with quality health information for elders, including local health resources
- Research the overlap between generally accepted best practice for usability and elders' stated requirements

The first goal has been accomplished.

The second goal is partially complete, with analysis of the data continuing for the next few months. Information elicited from elders during the focus groups informed the site design, as did experts' recommendations. The time budgeted for content issues subsumed data analysis.

Project objectives were:

- Research usability criteria to determine current best practice
- Elicit input from elders' focus groups on content and design
- Develop an easily used site based on usability research and input from elders
- Select links that are quality health web sites aimed at elders
- Provide original content on best practices for senior health from the OHSU School of Nursing, Hartford Center for Geriatric Nursing Excellence, and the Center for Healthy Aging
- Provide a list of agencies and organizations that are involved with health issues for elders in Oregon
- Request that Oregon state agencies, libraries, and organizations that work with elders include a link to this page on their web site

- Announce the availability of this web site to news agencies throughout Oregon

All these objectives have been met save the last two.

These last two objectives should be met by the end of June. Once The Prepared Caregiver is moved to the Center for Healthy Aging its availability will be announced and we will request that suitable organizations link to the site.

2. What lessons were learned? Which strategies were most effective?

One lesson – which is not news – was that it is always more difficult to recruit focus group participants than one thinks. In the end I let go of all but the most important criteria for participants: age, some degree of familiarity with web sites and the Internet, and the ability to speak, read and write English.

I intended to have the focus groups generally reflect the ethnic composition of Portland. This would have meant that over the four groups there would have been about four non-Caucasians, with one person who was Hispanic, one African-American, one Native American, and one Asian. I was fortunate to have two Native Americans.

I did research on the question of having mixed gender focus groups. There was nothing conclusive; the most common statement was that mixed groups could be an issue, without elaboration. I decided to have mixed groups because the content – web site usability – was not anything that I thought would be gender specific nor was it something uncomfortable to discuss in a mixed group. In addition, it was hard enough to find focus group members and get them scheduled into groups without the limitation of groups of one gender. Having mixed groups worked well, and there was no sign of a peacock effect at work. (The “peacock effect” can occur in mixed groups. Sometimes men will do a “knowledge display” to the detriment of group process.) Over the four groups there was an almost even mix of men and women.

Another question was whether it would be effective to have spouses in the same group. The literature suggests this may be an issue, with one spouse deferring to the other. When this happens, it can be a challenge for the facilitator to draw out the quiet spouse. Also, one spouse may suppress their actual opinions so as to agree with the other.

For a practical reason, that of getting enough people for the groups, I decided to allow spouses. I was careful to monitor their respective contributions. There did not appear to be either deference or suppression.

The four focus groups yielded a composition of:

- Age range from 56 to 85 (minimum age was 55)
- 13 women and 12 men
- 8 completed high school / 6 completed college / 11 had postgrad or graduate degree
- All spoke English as their first language
- 23 Caucasian / 2 Alaskan natives
- 20 retired / 5 still actively working
- Internet experience
 - 4 new users
 - 6 casual or infrequent users
 - 13 experienced users
 - 2 non-users
- Physical situations affecting their use of the Internet
 - 20 – nothing
 - 1 – ADD
 - 1 – mouse difficulty
 - 1 – vision and mouse difficulties
 - 1 – very low vision
 - 1 – no answer

Before the focus groups could be held, the project had to get approval from the IRB. Since the IRB rules and forms are set up for human subject research that involves interventions and/or taking samples, many of the hoops that were navigated were not relevant to this project. Approval was obtained October 18, 2002, and it was only then that money could be spent and focus group work could begin.

The approval process went about as badly as it could go, short of being denied approval. Evidence of training in IRB procedures was lost by the IRB and some training had to be redone. Paperwork went astray several times. It ended up taking months to get the project through the system; it should have taken weeks. The lesson here is to always personally walk every paper through the process, and to pay close attention to every step.

3. If the project could start over, what would change about goals, plans, etc.?

If I knew then what I know now...

- Clarification

Make sure that all the major players have the same set of expectations regarding the project and their role in it.

- Agreement in writing.

Do not assume that because something is in a proposal or because it has been discussed, that it will happen. Capture clarification about roles and expectations in writing, signed by all parties.

- Intense and active follow-up

I let myself believe that the Center for Healthy Aging representative was doing what she was supposed to do for too long a time. In retrospect, it would have been very helpful to start reminding her of her responsibility some months before I did. If I had pestered her early and often enough she may have done her part just to shut me up.

- Pay close attention to the IRB process

Insofar as possible, keep your hands on the papers and personally walk them through each step.

4. What advice would be helpful to someone considering a similar project?

Collaboration can be the most challenging part of a project. Know the people with whom you intend to collaborate, and in particular, know whether they are going to follow-through with their part of the plans. If you have doubts, develop a plan for dealing with their lack of follow-through.

Double the amount of time and effort you think it will take to organize focus groups.

When relying on others for content, triple the amount of time you expect it to take to receive material. Do not assume it will come in the format you request and be prepared to do significant rewriting and editing.

Work with people you enjoy and have fun!

Background material:

Focus group / usability test participant information form

Focus group questions

Usability testing recruitment script

Usability test scenarios

Usability test evaluation data sheet

Web site rating sheet

OHSU caregiver site expert usability review

The Prepared Caregiver flyer and cover letter