

# Transforming Web-based Patient Education at the University of Washington and Beyond

by Kristen Shuyler, Tracey Wagner, Scott Macklin, Aaron Louie, Brett Shelton, Eric Maddox, Jennifer Turns, and Frederick A. Matsen III, M.D., of the Program for Educational Transformation Through Technology (PETTT)

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“On your web site I feel like there is someone that I can ask questions and they will take time to answer it.”

“Thanks for the information. I have used your web site to gain information and to prepare me to talk to my doctors . . . I was able to become a participant in the process and not just a patient with a problem.”

“Reading this [web site] will change my life. No one has ever explained the facts as simple and straightforward as you do. “

“It [the Arthritis Source] was a source that I enjoyed reading because it seemed to be very comprehensive.”

“If a question comes up all I have to do is go to your web site and it answers my questions for me. It is there for me day or night.”

“Your web site made me a little smarter in order to go back to my physician to ask probably some more appropriate questions.”

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# Transforming Web-based Patient Education at the University of Washington and Beyond

In 1995, the University of Washington Department of Orthopaedics and Sports Medicine began offering patient education materials on its web site (<http://www.orthop.washington.edu>). This site, the Arthritis Source (AS), presented



University of Washington  
Orthopaedics &  
Sports Medicine

static information about arthritis adapted from Arthritis Foundation brochures. In 1999, the University of Washington's Program for Educational Transformation Through Technology (PETTT)<sup>1</sup> began studying and redesigning the Arthritis Source in the context of learner-centered design and patient education. Through an iterative cycle of research, design, and implementation, PETTT has transformed the original Arthritis Source into a highly popular, multimedia, dynamic, database-driven, user-centered health resource on the internet. We are now evaluating the redesign by researching how people use the Arthritis Source and the outcomes linked to use of the site.

The redesigned version of the Arthritis Source offers web-based multimedia information and interactive features for anyone with questions about bone and joint conditions, including arthritis. In addition, the technology and database behind the AS enable the department's medical faculty and web manager to easily create, organize, manage, and archive content on the site. In redesigning the site, we envisioned three broad goals for the AS: it would serve as a knowledge-building community, a knowledge management tool, and a source of information and education for patients (and other lifelong learners, which we call "learners at large").

In this paper, we focus on the Arthritis Source as a patient education resource.<sup>2</sup> First, we explore the context of our work and our assumptions about online health information. Next, we explain our methods for studying and redesigning the AS. We also discuss the implementation of the AS beyond the health information domain. Several groups at the University of Washington are adopting parts of the AS model to meet their educational web site and database needs—in domains such as legal education, sustainable building practices, and engineering education.

## Health web sites and "information therapy"

The internet is an important source of consumer health information.<sup>3</sup> Millions of Americans search for online information to supplement what they learn from physicians or other traditional resources<sup>4</sup> (see "A supplement to a visit with a doctor" sidebar). Web-based health information may be particularly important for people with arthritis and other bone and joint conditions. Because arthritic conditions are often chronic, painful, and not curable, they require patients to learn and apply self-management skills, which may need to evolve as the effects of arthritis change. Many patients are

### A supplement to a visit to a doctor

"Specialists sometimes don't take enough time to explain what is going on. I didn't have time to ask any questions . . . I just had to keep him in there long enough to talk to him. On the Arthritis Source, I feel like there is someone that I can ask questions and they will take time to answer it."

"Well, if my doctor had more time to discuss things with me, I think it would be a wonderful benefit . . . I would rather use [the AS] as a jumping off point and discuss things with my physician . . . They don't have time to sit and discuss all the current research with you but [the AS] is a good supplement to a visit to a doctor."

- Arthritis Source users, 2001

searching for health information to supplement what they learn from their physicians their physicians may not be able to meet these needs due to time constraints or other factors. The number of people who may be searching for online arthritis information is quite large. In the United States, arthritis is the second most frequently reported chronic condition, and is reported by nearly half of all people 65 and over.<sup>5</sup>

#### Day or night

“If a question comes up all I have to do is go to that website [the AS] and it answers my question for me, you know. It is there for me day or night . . . I am new to the computers . . . So this is just really fascinating for me, knowing that you know information that I need is just at my fingertips.”

- Arthritis Source user, 2001

Many people searching for supplementary health information join support organizations like the Arthritis Foundation, but many are turning to the internet as well. According to a recent study, 52 million Americans, or 55% of Americans with internet access, used the web to find health information by 2000.<sup>6</sup> People often use the web to find health information because of its perceived convenience<sup>7</sup> (see “Day or night” sidebar), currency,<sup>8</sup> and anonymity (because some health questions may be difficult to talk about in person).<sup>9</sup>

People looking for health information online may find a huge number of web sites of varying degrees of accuracy and completeness. The number of health-related web sites was estimated to be 20,000 by 2001.<sup>10</sup> Many people sort through these sites by using search engines (as opposed to library or

medical portal web sites).<sup>11</sup> However, a recent study found that 20% of results from English-language search engines led to health web sites with no content relevant to the search.<sup>12</sup> Due to the limitations of internet-based information and searches, it can be difficult for health consumers to find correct, complete, and relevant information.

Despite these challenges to using health information on the internet, recent studies have shown that quality web-based patient education materials may lead to improvements in health status and health care utilization for patients with chronic conditions.<sup>13</sup> These studies have also pointed to the importance of social support in the management of chronic diseases. We recognize the importance of combining information, education, and social support. Indeed, the Arthritis Source is not meant to replace human interaction (such as with a doctor or with a support group), but to supplement traditional patient education materials (such as brochures). When our users want social support, we suggest they call the help line provided by the local Arthritis Foundation chapter or visit the Arthritis Foundation web site. In addition, we have supported the local Arthritis Foundation chapter by donating computers with which they access the AS or other web sites.

By collecting e-mail messages and questions submitted to our search engine, we know that many of our users want social support. However, many of the users simply want answers to their questions (see “Thanks for the information” sidebar), which may be beneficial even without social support. Some claim that the provision of health information can act as a type of therapy—information therapy. Although information may not induce behavioral changes,<sup>14</sup> it may improve self-efficacy, which is a predictor of desirable health outcomes.<sup>15</sup> In addition, information may lead patients to make more informed decisions about their own care.

#### Thanks for the information

“Thanks for the information. I have used your web site to gain information and to prepare me to talk to my doctors about my new experiences with joint roughness. I was able to become a participant in the process and not just a patient with a problem.”

“Reading this will change my life. No one has ever explained the facts as simple and straightforward as you. Many thanks for your help.”

- Arthritis Source users, 2001

For example, a recent that among people who use the web to find health information:

- 70% say that information led them to ask a doctor new questions or to get a second opinion, and
- 50% say that information affected their decision about how to treat an illness.<sup>16</sup>

The goal of the Arthritis Source is to offer patient education materials that support users' self-directed learning and help them answer their questions. We hope users may also improve their general health and quality of life after using the AS. To reach these goals, we aim to provide comprehensive, accurate, and interactive information that is responsive to our users' needs. Evaluating whether we are reaching these goals is our next step with the AS.

## History of the Arthritis Source

The Arthritis Source has been a successful web site since 1995. Before PETTT became involved, thousands of people used the AS every day, and it received many unsolicited compliments in e-mails. Despite its popularity, the site had room for improvement. When PETTT began working with the AS in 1999, we wanted to update the information, address issues from studies of patient information needs, redesign the database for storing the information, and make the information more user-centered.

PETTT's early research with the Arthritis Source discovered who used the site, characterized these users, and identified their information needs (we called these efforts "listening to the learners"). An early research study was a large-scale, web-based survey of AS users, which was followed up by a series of in-depth phone interviews with some of the respondents.<sup>17,18,19</sup>

We aimed to address our research results and the patient education literature in our redesign. In addition, we wanted to create a system that would be scalable (able to grow without significantly increasing the effort required to manage it) and generalizable (able to be transferred to other domains, both within and outside of medicine). We also recognized that if the site was to be useful, it needed to serve the needs of all the parties involved—the users, the site managers, and the content authors:

- **To design a solution that serves the needs of the users**, PETTT conducted research to "know thy users" or "listen to the learners." Through our research, we have learned that although our user population is varied, many of them share some common needs and characteristics. We tried to meet these needs in our redesign.
- **To design a solution that is easy for site managers to use**, PETTT adopted a content management system that was easy to use, customizable, and free.
- **To design a solution that is easy for content authors to use**, PETTT developed strategies and technologies that allow multiple authors to create and manage new content easily and efficiently.

Based on our early research and these three goals, PETTT redesigned the AS and released a new version of it in July 2001, and continue to research and improve the new design. The July 2001 version of the AS tailored the content for the primary audience. In the redesigned AS, the content consists of articles about conditions, surgeries, medications, and coping strategies. Because the majority of respondents to our web-based survey identified as people with arthritis (61%) or friends and relatives of a person with arthritis (8%), these articles were written from templates that we designed

with these users' needs in mind (the templates are discussed further below). The redesign also updated the site's information structure, improved navigation options, modernized the graphic design, and created a database for managing the content.

## Description of the system

The Arthritis Source is more than a health information web site—it is a set of strategies and technologies to support the needs of all who use it. These strategies and technologies, which we developed in response to our “listening to the learners” research and literature reviews, include:

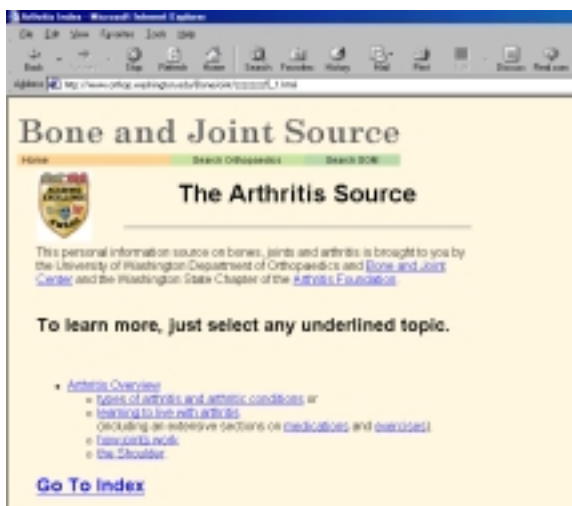
- Research-informed user interface
- Template-based articles to facilitate distributed content creation
- Templates designed in response to research
- Question-based navigation (using natural language processing)
- Multiple mechanisms for user feedback
- Multiple ways to respond to feedback and incorporate user ideas
- Multiple ways to measure and display site usage easily
- Multiple ways to support the community of users
- Permissions to limit or grant access to site content and management
- Ability to easily upload videos, images, and links
- Ability to edit anything in the web site or database with only a web browser
- Database with automatic meta-tagging of content
- Evaluation and assessment strategies (three levels)

These strategies and technologies are explained below, with each heading (such as “User interface”) corresponding to one bulleted item above.

### User interface

The user interface of the redesigned AS is based on two goals: offer information in a straightforward and consistent way, and offer multiple ways to find information.

Old Arthritis Source site design (below) and new site design (right)



The new front page, displayed above, shows our attempt at designing a straightforward interface. Other aspects of the new interface, such as the consistent look of all articles in the site and the organization of other sections of the site, cannot be seen here, but can be seen as one uses the site (at <http://www.orthop.washington.edu>).

Because not everybody finds information in the same way, the AS offers multiple ways users can access or search our content. They can:

- **Browse the site by orthopaedic specialty or body part.** AS patient education articles are divided into ten categories: Arthritis, Pediatric Orthopaedics, Sports Medicine, Traumatology, Tumors & Oncology, Back & Spine, Foot & Ankle, Hand & Wrist, Hip & Knee, and Shoulder & Elbow. Most articles are listed in at least two of these sections to provide multiple pathways to find information. For example, “Shoulder Replacement Surgery for Arthritis” is listed in both the Arthritis and Shoulder & Elbow sections.
- **Ask a question.** Users can ask their question in plain English and the web site suggests similar, pre-answered questions. This feature is discussed in “Question-based navigation” below.
- **Take a poll or quiz.** Users can take a poll or quiz and be directed to specific content in the site based on their responses. Polls and quizzes are discussed in the “Assessment, evaluation, and research” section below.
- **Use a site map.** Users who want to see the full extent of what is on the site can view our site map. A link to the site map is included on every page.
- **Scroll through lists.** Users can scroll through three alphabetical lists of information: all article titles, all QuickTime movies, and all conditions available.
- **Perform a keyword search.** Users can perform a structured keyword search. They can search article titles or the full text of the site, and they can limit their searches by condition.
- **Read about what information we do NOT offer and where else they might find it.** We provide a page that describes information we know users often want, but which we do not offer (e.g. social support, finding doctors not affiliated with UW, or finding a job in the health sciences). We offer what we consider the best links to places where they can find this information.

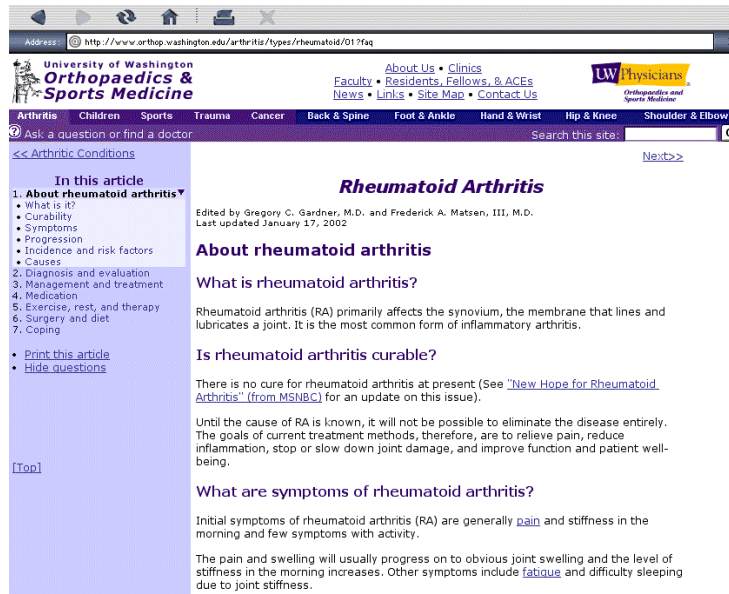
## Template-based articles

Most of the content in the AS was written in a web-based template that covers one of two topics: surgeries or conditions (we will offer others, such as medications, in the future). These templates are sets of questions based on our research about the types (and order) of information that people with arthritis want (see next section).

Medical faculty from the Department of Orthopaedics & Sports Medicine write AS articles by answering questions about a condition they treat or a surgery they perform. The questions and the doctor’s answers are automatically converted into a web-based article. The article displays headings (e.g. “Curability”) for each section, but the question for each section (e.g. “Is rheumatoid arthritis curable?”) can be displayed if the user wishes to read them (see examples on the next page).

Articles based on these templates are whole entities that can be read in a natural way, not a series of unrelated “frequently asked questions.” At the same time, all articles based on a template have logical and consistent structures based on real questions, facilitating users’ searches and reading comprehension. Users can search the articles by asking questions, because every paragraph in the article is associated with a question.

From a technical standpoint, the templates reduce the workload of both the author and the web manager, because the code to display the articles is automatically created by the templates. In addition, each section of an article is given automatic meta-tags, which facilitates database storage and searches.



Two versions of Rheumatoid Arthritis article: questions for each section (above) and headings for each section (below)

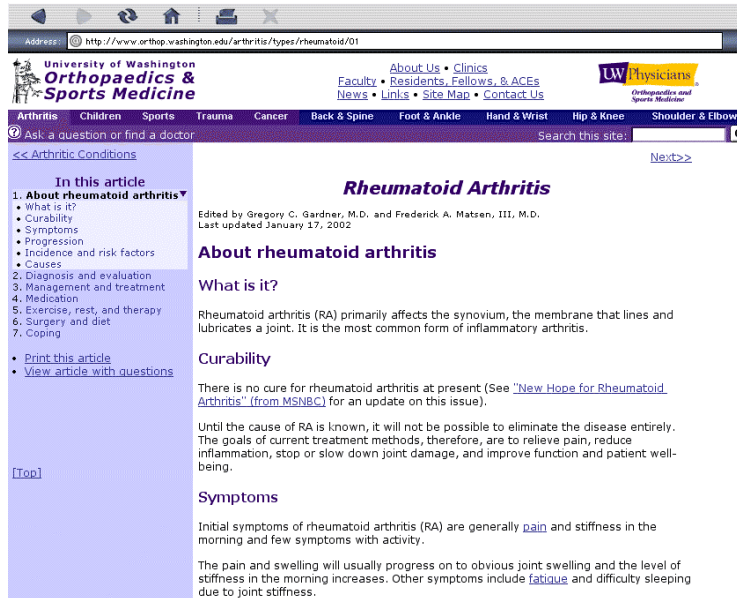
### Research to inform templates

To offer articles with information that patients want or find useful, we conducted three types of research before writing the article templates:

- Literature research to understand what others have discovered about patients’ information needs.
- Consultation with content experts (medical doctors) to discover what types of information they thought patients should know.
- Audience analysis to find out what our users want to know (“listening to the learners”).

### Question-based navigation

Although we hope that AS articles are easy to browse because they were created from research-informed templates, we also recognize that it may be challenging for users to find relevant information in a large web site, particularly as the amount of





### Four ways to search this site:

Ask a question, find a doctor, view lists, or enter search terms

**#1: Ask a question**

Type your question here:

I have back pain. Would exercise help me?

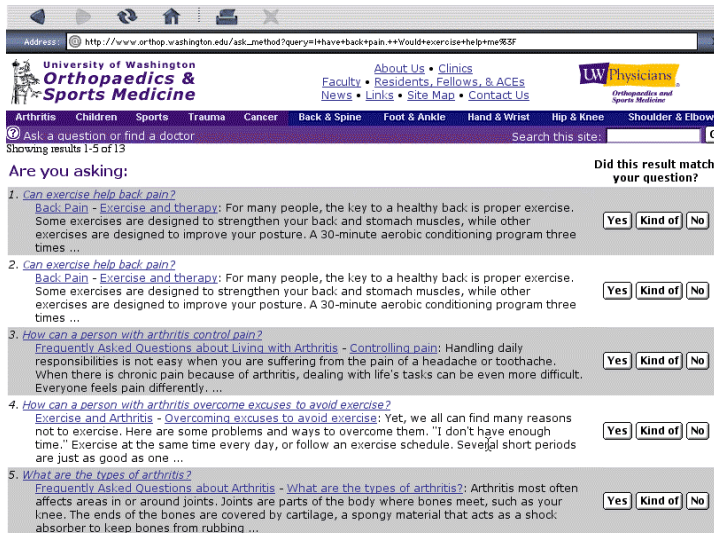
Ask

#### Help with asking a question

If you have a question, just type it in plain English here! Our system will attempt to suggest pre-answered questions that resemble your question.

**Note:** This system is under development, so it may not meet your needs yet. However, with your help, we can make it better. Let us know how well our system matches your question to the pre-answered questions.

“Ask a question” interface on search page (above).  
Results from the question-based search (below).



### Decent answers

“I would like to ask questions and get decent answers to them.”

“If a question comes up all I have to do is go to that website [the AS] and it answers my question for me.”

“On the Arthritis Source, I feel like there is someone that I can ask questions and they will take time to answer it.”

- Arthritis Source users, 2001

content increases. To help users find relevant information, the AS offers multiple ways to find information. The most innovative of these is a system that allows users to ask questions in their own language.

After a user types a question, the search system performs a simple type of natural language processing (NLP) and suggests five similar questions that have already been answered (by a template-based article). When these questions are presented as search results (see example to the left), the user has three options:

**1. Click on the question to read the answer.** The question and answer are embedded in a template-based article. Following the link to an article authored by a UW physician, instead of a single question and answer, may allow the user to find related information that was not part of the original search.

**2. Re-state the question to find different search results.** When restating questions, users can read the five original questions that were returned as search results. We hope that seeing what types of questions are offered by the web site may help the user ask useful questions (See “Evolution of a question” sidebar).

**3. Submit the unanswered question** to the site developers, if none of the results are satisfying or interesting. We have designed a question-management system to help us respond to the high volume of questions submitted, and to record the topics and types

of questions submitted. In addition, the user can rate the questions returned. Next to each search result is a simple poll that asks: “Did this result match your question?” The user can evaluate the search results by clicking **Yes**, **Kind of**, or **No**. We plan to use this data to improve the NLP technology.

This question-based navigation system has grown out of our “listening to the learners” research. We found that many of the people who come to the site already have particular questions in mind. The question-based navigation interface is our attempt to

#### Evolution of a question

At 8:26 am in February 2002, a user searched for an answer to this:

“my husbands leg bone below knee is splinering and knee has moved over it, is there a surgery to save his leg”

At 9:22 am, the same user typed:

“aproximately 6inches below knee cap the long bone is spintering is there a surgery that can cover this and help support the leg bone”

At 10:01 am, the user asked:

“can a femur tibia splintering of the bone be surgicially be repaired?”

Our condition article template features this question: “Can surgery help treat [name of condition]?”

support users in their efforts to find information, by allowing them to explain their needs in the way they are most naturally inclined—in plain English. We have hypothesized that seeing the five questions returned as search results would help users learn how to formulate the type of question that the system can answer. Again, we have not conducted formal research on this, but we have found examples of users’ questions evolving over time to reflect the type of questions the site can answer (see “Evolution of a question” sidebar).

From a technical standpoint, the question system has three parts:

**1. Natural language processing (NLP).** The current NLP is very basic but is becoming more sophisticated. In the current version, users’ questions are parsed into standardized text, processed by a dictionary of medical terminology, and compared to a simple thesaurus that we developed specifically for the AS, based on the types of information offered in the templates.

**2. Semantic matching.** The parsed questions are compared to questions that we have already answered. The system searches the content database and returns the questions that are most similar to the user’s original question.

**3. Evaluation of the system and the content** with various analysis and management mechanisms built into the system.

### Multiple mechanisms for user feedback

The AS offers multiple ways for users give us feedback. They can:

- Rate how useful each page is, by voting on the simple utility tool at the bottom of every page (see “Simple utility tool” in the “Evaluation, assessment, and research” section below).
- Submit questions they felt were not answered by our question-based navigation system.
- Send e-mail to the web manager, who responds to it or passes it on to a content author.

### Multiple ways to respond to and incorporate user feedback

When users give feedback about a web site, site managers must find ways to respond to it (when necessary), summarize it, manage it, and use it to improve the site.

In the case of the AS, we respond to e-mails as quickly as possible, and we use these tools to respond to (or use) the other types of user feedback:

- An automated system to view the simple utility tool feedback, including user comments. Content authors (and site managers) can see how articles rate, read comments, and improve articles as necessary.
- A through-the-web answering template that tracks the topics of the questions received.

### **Multiple ways to measure and display site usage**

To make ongoing evaluation of AS usage possible, we have created two ways to easily visualize AS log file data, both temporally and spatially:

- Easy-to-create weekly and monthly usage graphs and tables.
- Automatic daily and cumulative world maps of usage.

These tools are discussed further in “Assessment, evaluation, and research” below.

### **Multiple ways to support the community of users**

We have designed two new features on the AS to help reveal to users what other users think, know, and believe:

- Quizzes and polls that show aggregate responses and deliver customized content based on each user’s specific responses. These quizzes and polls cover knowledge about arthritis and personal experience with arthritis.
- A system to display cumulative page “usefulness” ratings (from the simple utility tool) to users.

These features are discussed further in “Assessment, evaluation, and research” below.

### **Permissions to limit or grant access to site content or management**

A major feature of the AS is its content management system, Zope (discussed in “Technical profile of the system” below). With Zope, many users can add content, edit content, or manage content. The key to this “distributed content creation” system is that each user can access only certain areas of the AS. For example, authors can edit their articles, but not other authors’ articles. The site manager, however, can edit aspect of the site. These permissions ensure that the multiple content authors do not edit content that is not theirs, and that the site manager can fix problems anywhere in the site.

### **Easily upload videos, images, and links without web programming skills**

Our content management system, Zope, allows authors and managers to easily add videos, images, or links to their articles. Authors do not need to understand web programming or how to use special software (e.g. File transfer protocol or FTP) to add videos, images, or links to their articles.

### **Edit anything in the web site or database with only a web browser**

Another benefit of our content management system, Zope, is that users can edit and update AS content (articles, images, videos, etc.) without any web programming

skills. They need only a web browser on a computer with internet access. In addition, future authors can edit old content (if they are given the permissions to do so), ensuring that the site will never grow inaccurate or inaccessible to new authors.

### Database with automatic meta tags for content

Our content management system, Zope, frees the content authors from having to think of “key words” or other meta tags for the content they add to the site. We have designed the article templates and configured Zope so that whenever a piece of content is added, it is automatically given meta tags to facilitate finding that information in the future.

### Evaluation and assessment strategies (three levels)

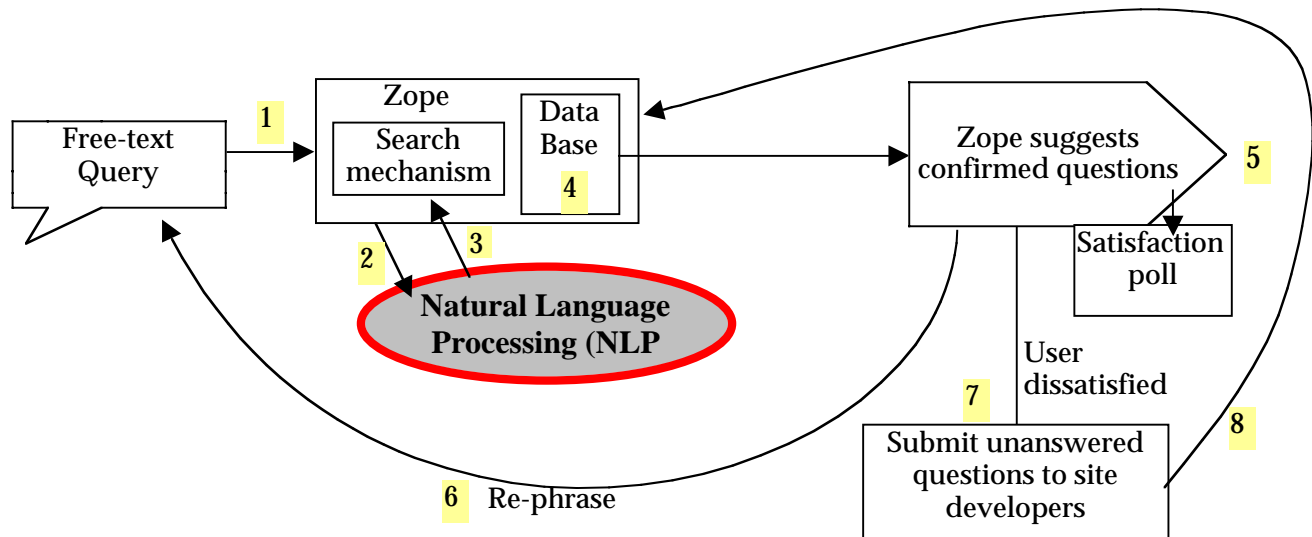
See “Evaluation, assessment, and research” below.

## Technical profile of the system

### Zope

We used Zope (<http://www.zope.org>), an open source, free, and customizable content management system to build the Arthritis Source. We continue to use Zope, in concert with a database, to manage the content and create new features.

Zope is the backbone for our question-based navigation feature. Zope’s internal search mechanism is fairly limited in its ability to parse text. However, it can easily incorporate the functionality of external programs. We configured a shallow natural language processor (NLP) to parse free text and return a structured result, which Zope uses as keywords in its search. This, in tandem with metadata improvements and suggestion-based search results, has approximated our goal of a robust free-text question-and-answer system with meaning-based search. Below is a diagram of this system:



1. User submits free-text question to search interface in Zope.
2. Zope sends the question to external syntactic parser.

3. NLP system parses the text, using internal dictionary, and returns a structured query to Zope's search mechanism.
4. Zope's searches the content database and returns objects (question/answer pairs within articles) that match structured query.
5. If user is satisfied with the results, he or she follows the link to the question within the article (and submit satisfaction data to the question-driven navigation poll)
6. If the user wants to find different results, he or she may re-phrase the question and search again
7. If user is unsatisfied with results, the user may submit his or her unanswered question to the site developers.
8. Site developers use unanswered questions to add to site content.

## Assessment, evaluation, and research

PETTT's research cycle includes characterizing (or creating) an exemplar project (in this case, the Arthritis Source), researching the exemplar in a real setting, refining the exemplar based on the research, and then researching the refined exemplar project. This iterative cycle allows us to apply the lessons we have learned from research, prompts us to ask new

research questions on each iteration of the cycle, and provides a research opportunity for groups and students on campus who would like to research a real tool in a real setting.

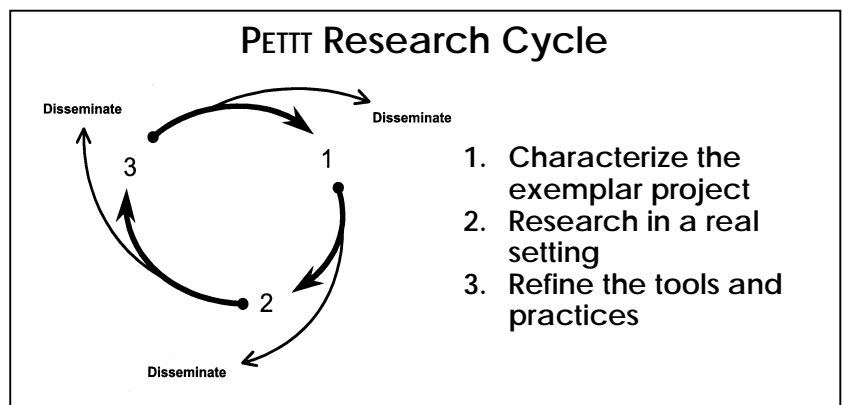
In our first round of research with the AS (or "Step 2" of the research cycle), our main research questions were: *How effective is the Arthritis Source?* and *What are important characteristics of the users?*

We use the phrase "listening to the learner" or "know thy user" to describe our efforts to explore user characteristics and needs. We explored a variety of mechanisms for addressing these two questions, including:

- conducting a content analysis of discussions in arthritis chat rooms,
- analyzing AS log files,<sup>20</sup>
- analyzing patient-physician email correspondence,
- observing the questions asked a public education forum about arthritis,
- conducting a large-scale online survey on the AS,<sup>21</sup>
- offering quick polls on the AS,
- conducting in-depth phone interviews with people who have arthritis,<sup>22</sup> and
- exploring how one group of users adopted the web site into their practice.<sup>23</sup>

From these efforts, we have been able to:

- gain a better understanding of the demographics of our users,
- collect a large number of questions (over 200 a month) asked by AS users,
- begin to understand the background knowledge and conceptions or misconceptions that learners bring to their interactions with the AS, and



- identify design implications that we could use to improve the AS.

The development and research on the AS has traveled through one full rotation of the “PETTT research cycle” (see figure above). We are now entering the next cycle of research, in which the refined AS becomes the object of study. Our current research questions are: *How do people use the Arthritis Source? What are the effects of using the Arthritis Source?* and *How effective has the redesign been?*

In approaching these two broad questions, we have begun to think about three levels of evaluation of the site:

- “Level one” represents the least interaction with the user. It comprises data gathering tools that are built directly into the web site and invisible to users.
- “Level two” requires a small amount of user participation. This level of research includes actions that users choose to take with a single “click” (e.g. voting or responding to a poll).
- “Level three” asks for more involvement and participation from the user. This level of research includes in-person usability studies, telephone interviews, or long web-based surveys.

## “Level one” research

Our “level one” research is unobtrusive and aimed at discovering who uses the site, how they use it, what parts of the site are being used, and how they find the site. Our research efforts at “level one” include basic log file analysis, visualization of log file data, and search engine research.

### Basic log file analysis

We investigate the AS log files to see weekly, monthly, and yearly trends in:

- Number of visits
- Number of users
- Average visits per day
- Average pages viewed per visit
- Average visit length
- Average time per page
- Most viewed articles
- Search statistics
- Countries of origin of visitors
- US extensions of visitors (e.g. com, net, edu, org, mil, gov)
- Pages that send visitors to our pages (referrer pages)
- What page users see first (entrance pages)
- What page users see last (exit pages)
- Web browsers used to visit the site (e.g. Netscape, Internet Explorer)

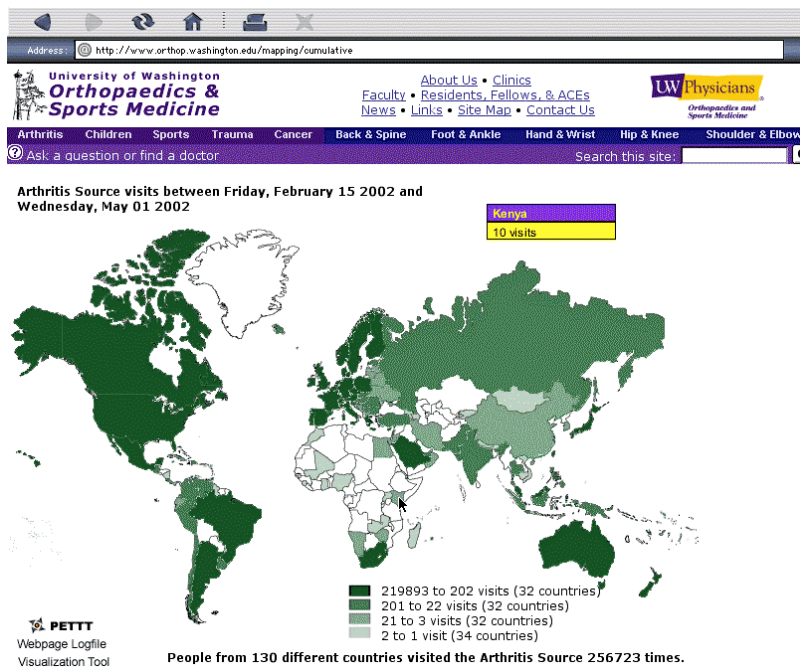
These statistics allow us to continually update the site to meet the basic needs of our users (e.g. making sure that the site works in each of the top browsers). In addition, they inspire new research questions (e.g. why is one article more popular than another?). Our site statistics are available at <http://www.orthop.washington.edu/stats>.

## Visualization of log file data

Sometimes graphics tell a better story about data than the pure numbers can. We have created two automatic statistics visualization tools that help us:

- Understand site usage at a glance.
- Demonstrate the international reach of the website.
- Show users the worldwide community they are joining when using the site.

The first visualization tool is an interactive world map that shows the location of AS visitors (see map below). This is automatically generated every day, and is available in daily and cumulative maps. The second visualization tool shows site visits over time in a graph that is easily generated from the log files (see next page). Both of these visualization tools are available at <http://www.orthop.washington.edu/dept>.



Map of Arthritis Source visits between Friday, February 15, 2002 and Wednesday, May 1, 2002. People from 130 different countries visited the site 256,723 times in this time period.

Address: <http://www.orthop.washington.edu/stats/aveDailyMonthVisits>

University of Washington  
**Orthopaedics & Sports Medicine**

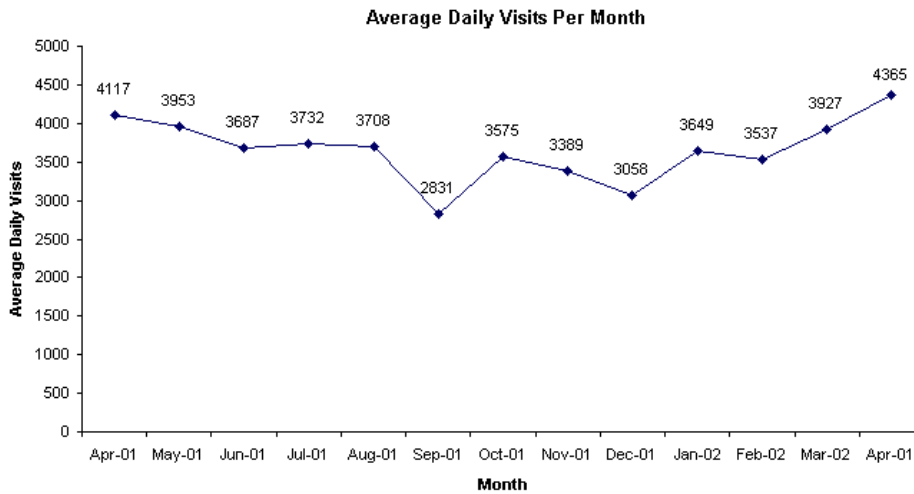
About Us • Clinics  
 Faculty • Residents, Fellows, & ACEs  
 News • Links • Site Map • Contact Us

**UW Physicians**  
 Orthopaedics and Sports Medicine

Arthritis Children Sports Trauma Cancer Back & Spine Foot & Ankle Hand & Wrist Hip & Knee Shoulder & Elbow

Ask a question or find a doctor Search this site:

[Main Statistics Index](#)



Graph of average daily visits to site by month, April 2001 to April 2002

### Search engine positioning

One of PETTT’s early research projects with the AS was to study search engines and their relation to how often the AS is visited.<sup>24</sup> People find web sites in several ways: directory web sites, personal references, links from other sites, advertisements, or search engines. Search engines are the primary way most people find web sites, and are the most common way for users to find the Arthritis Source (the top three search engines that send users to the AS are Google, MSN, and Yahoo). Because of the popularity of search engines, if a health information website is not listed in popular search engines, users may not find it. Even if health information web designers submit their sites to search engines, they may not have designed these sites with the search engines’ measures of merit in mind. Without a working knowledge of current design heuristics, web site designers may find their sites under-visited.

In the search engine research project, PETTT researchers proposed a list of design heuristics to improve the search engine position of informational web sites (search engine position refers where a website appears in the list of search results returned by a search engine). We implemented these heuristics on a set of test web pages in the AS and measured the search engine rankings and hit rates (how often the pages were visited). Our results suggest that the search engine position of web sites can be improved by implementing our design heuristics. Web designers can also increase their rankings by changing their meta data and by submitting their sites to search engines, but these interventions were not as successful as the design interventions. Our results also showed that the improvements of search engine position are correlated with increased hits.

## “Level two” research

Our “level two” research involves users by asking for their feedback. These feedback mechanisms help the site feel more interactive and interesting to the users. These feedback mechanisms are also a type of data collection, because users may not realize that we use their feedback to improve the site and understand its use. Our research tools and methods at level two include web-based quizzes and polls of knowledge and experience, a simple utility tool, and a question-driven navigation poll.

### Web-based quizzes and polls of knowledge and experience

We have developed quizzes and polls that ask users about their knowledge of various arthritis topics and about their experience. The poll shown to the right, for example, asks, “What’s your diagnosis?” After a user checks one or more of the responses, he or she is shown a graph of all users’ responses, and is directed to information in the web site that might be interesting to a person with that condition. For example, if a user selects “Osteoarthritis,” he or she will see that 24% of the web site users also have osteoarthritis. Links are also offered to relevant articles in the AS.

The most popular answer to this poll (26%, n=1044 on 22 April 2002) is “I think I have a condition but I haven’t been diagnosed yet.” We plan to use these data in an upcoming research project. In addition, we are thinking of ways we can respond to these data in our content (by adding information about the diagnosis process, for example).

Quick poll - Get customized information

What's your diagnosis?  
(Check all that apply.)

- Rheumatoid arthritis (RA)
- Osteoarthritis
- Polymyalgia rheumatica (PMR)
- Sjogren's Syndrome
- Fibromyalgia
- Other
- I think I have a bone or joint condition but I haven't been diagnosed yet
- I don't have a bone or joint condition, but I know someone who does
- I don't have a bone or joint condition

Answer

#### Experience poll (above) and what the user sees after answering “osteoarthritis” (below)

What's your diagnosis? (Check all that apply.)

**You answered: Osteoarthritis**

Osteoarthritis, or degenerative joint disease (DJD), is a form of arthritis characterized by the loss of joint smoothness and range of motion without major joint inflammation. DJD probably affects almost every person over age 60 to some degree, but symptoms are often mild. Osteoarthritis is NOT the same thing as [osteoporosis](#).

If you have been diagnosed with osteoarthritis, you might find helpful information in these articles:

- [Osteoarthritis](#)
- [Understanding Osteoarthritis](#)
- [Diagnosis of DJD in the shoulder](#)
- [Frequently Asked Questions about Living with Arthritis](#)

Questions? Comments? Let us know: [orthoedu@u.washington.edu](mailto:orthoedu@u.washington.edu)

**How other people answered:**

- Rheumatoid arthritis (RA) 233 (20%)
- Osteoarthritis 276 (24%)
- Polymyalgia rheumatica (PMR) 68 (6%)
- Sjogren's Syndrome 40 (3%)
- Fibromyalgia 102 (9%)
- Other 92 (8%)
- I think I have a condition but I haven't been diagnosed yet 297 (26%)
- I don't have a bone or joint condition, but I know someone who does 20 (2%)
- I don't have a bone or joint condition 21 (2%)

## Simple utility tool

We ask users to evaluate every page on the AS. At the bottom of each page is a poll (a simple utility tool, or SUT) that asks, “How useful was this page?” and offers five possible responses as well as a text field for comments (see graphic below). In addition, we display the average rating for each article, so that users can see how useful other users felt it was, and to encourage more people to take the poll.

This article is rated ★★☆☆☆ out of 5 stars (1371 ratings).

How useful was this page?				
<input type="radio"/> Not useful at all	<input type="radio"/> Not very useful	<input type="radio"/> Useful	<input type="radio"/> Very useful	<input type="radio"/> Extremely useful
★	★★	★★★	★★★★	★★★★★
Comments: <input type="text"/>				<input type="button" value="Submit"/>
<input type="button" value="Erase Form"/>				

Simple utility tool, available at the bottom of every page of the AS

We recently created a web-based tool for authors and site managers to view users’ page ratings and comments. We will use this SUT data-viewing tool to help authors improve their articles and to research the effectiveness of the content.

## Question-driven navigation poll

To evaluate the technology behind our question-driven navigation system, we implemented another poll. This poll appears on the search results page shown after a user has entered a question. Next to each search result is the survey question, “Did this result match your question?” and three answer options. We hope to use the data from this poll to improve our natural language processing technology.

<b>Are you asking:</b>	<b>Did this result match your question?</b>
<i>I. <a href="#">What are some strategies for coping with stress related to back pain?</a></i>	
<i><a href="#">Back Pain - Stress</a>: Every day of our lives is filled with some kind of stress. In fact, any situation can cause stress such as work, personal relationships, raising children, paying bills, the death of a loved one or a new experience. Even very happy occasions such as ...</i>	<input type="button" value="Yes"/> <input type="button" value="Kind of"/> <input type="button" value="No"/>

Question-driven navigation poll, available on search results page

## “Level 3” research

In our language, “level three” research indicates methods that require a high level of involvement from the user, whether it is research done in person, on the phone, on in a web-based environment. This research allows us to delve deep into the thoughts of our users, and to begin to understand how people use the AS and the effects of using the AS. Recent and upcoming “level three” projects include a web-based survey, phone interviews following up on the survey, studying the use of the AS in a help line environment, and a long term study of user learning, goals, and outcomes.

## Web-based survey

PETTT team members implemented a large-scale web-based survey on the AS in 2001.<sup>25</sup> The survey asked users about their current visit to the Arthritis Source, their cumulative past experiences with the AS, their relationship to arthritis (e.g. patient, physician, etc.), the information sources they normally use, demographics, and their opinions about the site. The results of the survey were used to evaluate the effectiveness of the AS, make design recommendations, and understand the users.

One of the measures of AS effectiveness was the success of users' current visits. In response to the question about success, 36% said they were successful in achieving their goal, 23% said they had some success, 8% said they were not able to achieve their goal, and 33% said they did not know whether their visits were successful (n=186).

In learning about the users, we found that the most common reason for visiting the AS was to get information about a condition. The second most common reason was to find information about pain management. Needs for emotional support were implied, but not explicitly stated in many responses. In terms of the user population, 61% of users identified themselves as patients with arthritis, 8% as friends or relatives of an arthritis patient, 4% as medical professionals, 2% as other students, 2% as researchers, and 1% as medical students (n=192).<sup>26</sup>

The AS design recommendations indicated by the survey results included suggestions to:

1. Address patient-centered issues on the site.
2. Help visitors find the site and the information in the site.
3. Acknowledge and address visitor efforts to find social/community support.
4. Provide support for users asking very specific questions.
5. Address visitors' interest in interactivity.
6. Address visitors' interest in up-to-date information.
7. Find ways to address user frustration with site responsiveness and reliability.
8. Address users frustration with page layout.

We addressed these issues, to varying degrees, in the July 2001 relaunch (and in recent updates) of the AS.

## Phone interviews

Following up on the web-based survey, PETTT team members conducted phone interviews to explore how patients think about their arthritic conditions.<sup>27</sup> We focused on two arthritic conditions (rheumatoid arthritis and osteoarthritis), identified ten AS users with each condition, completed structured interviews over the phone, transcribed the interviews, and analyzed the patients' concepts of their conditions.

Knowing visitor concepts can help us develop a more useful information resource. First, we may learn how to bridge information gaps by analyzing misconceptions. Understanding how and why certain concepts or misconceptions are formed may help influence the topic

**Quick Quiz - Do you know the facts?**

**Osteoarthritis involves low bone density.  
True or false?**

True  
 False

**Answer**

First question of a seven-question quiz developed in response to phone interviews

selection and presentation style on the AS.

We used the results of this study to create an osteoarthritis quiz that offers the correct answers (thereby dispelling misconceptions) immediately after the user answers each question (see graphic on previous page). Since the quiz was implemented in late 2001, 1,642 users started this seven-question quiz and 306 completed it.

### Studying the use of the AS in a help line environment

See “Technology adoption” in the Implementation and adoption section below.

### Long-term study of user goals and outcomes

Currently in development is a study that will follow AS users over time, keeping track of what they do on the site and how they answer a series of surveys. This research will explore:

- the goals of AS users,
- whether the AS helped them reach their goals,
- how these goals change over time,
- how reaching these goals affects their self-assessed overall health, and
- whether users learn from the AS.

Our data will be collected entirely online, giving us access to the real-time actions of a group of AS users over three months. Our analysis will focus on how the users’ interactions with the site relate to the goals they ascribe themselves. We will track users’ goals, overall health ratings, and problem-solving abilities over time, comparing these data to their uses of the site. This research will help us understand the effects of informational websites. In particular, this case study will suggest how web-based health information resources may help people reach their self-defined goals, help them learn, and/or help them improve their overall health.

### Research opportunities for University of Washington students

In addition to the three “levels” of research discussed above, PETTT has worked in various capacities with a number of students on campus. Some of these students were pursuing their own research projects on the AS, and some worked directly with us in designing and carrying out their research. Our University of Washington student collaborators have included:

- **Jake Burghardt, an undergraduate student in Technical Communication and Psychology**, helped with early studies of AS users and with search engine research. He presented at the 2000 UW Undergraduate Research Symposium.<sup>28</sup>
- **Crystal Chin, an undergraduate in Technical Communication**, is working on AS usability issues and international issues for her senior project in Spring 2002.
- **Julianne Fondiller, a graduate student in the College of Education**, helped in the initial research about the AS.
- **Kristin Knight, a first-year medical student in the School of Medicine**, will be exploring the questions that patients are asking on the AS in summer 2002, as part of the UW Medical Student Research Training Program (MSRTP).
- **Kristina Liu, a graduate student in the College of Education**, worked as a PETTT researcher, contributing to the online survey and phone interviews, and other research efforts.

- **Aaron Louie, a graduate student in the Information School**, is a PETTT researcher working on the development of the AS and the Northwest Justice Project (discussed in “Conclusions: Extending the AS model to other domains” below).
- **Kate Mobernd, a graduate student in Technical Communication**, is studying reading comprehension and link styles on the AS for her masters thesis research.
- **Paula Roberts, an undergraduate Technical Communication**, ran a pilot usability study on the AS for her senior project in Fall 2001.
- **Laura Schultz, a graduate student in Technical Communication**, is studying heading styles, reading comprehension, and user anxiety on the AS for her masters thesis research.
- **Brett Shelton, a graduate student in the College of Education**, is a PETTT researcher working on AS technology adoption and data display issues.
- **Alice Tanada, an undergraduate studying statistics and engineering**, performed statistical analyses of our online survey results. She will present at the 2002 UW Undergraduate Research Symposium.

## Implementation and adoption

The development and research cycle of any new technology (or strategy for using technology) must include time to work within existing administrative infrastructures. In addition, it must include time for technology adoption within the user population.

### Administrative support

PETTT has worked with the University of Washington Computing and Communications (C&C) group to get our content management system (Zope) supported on one of their servers. Because of the amount of traffic on the AS, it was important for the University to host the server. We continue to work with C&C to scale Zope to an enterprise-wide solution. Other groups on campus want to take advantage of the technologies we have developed for the AS, and they will need access to Zope one of the University of Washington servers.

### Departmental involvement

The UW Department of Orthopaedics & Sports Medicine initiated the AS (and continues to run it), and medical faculty create the AS content using our web-based templates. Thus, PETTT has worked very closely with Orthopaedics. Teaching the faculty to use these templates (and offering institutional incentives to spend time on them) has been a slow process, but has taught us about technology adoption and the use of the templates.

### Technology adoption

To better understand how people use the AS, PETTT studied the technology adoption of a group of users not affiliated with the UW. In 2000-2001, PETTT researchers conducted a study to examine how educators (volunteers at an arthritis help line based in Bellingham, Washington) made use of the AS. People from all over the Pacific Northwest call the help line to ask questions about arthritis. Questions cover a variety of topics, including surgery, pain management, doctor-patient relationships,

disease prognosis, and medications. In January 2001, we gave the help line volunteers a computer with high-speed internet access and instructions on how to use the AS.

For two months after the introduction of the computer and the AS, we made numerous trips to Bellingham to explore issues of technology adoption. In addition, we investigated how the volunteers used the Arthritis Source as a resource in their interactions with callers and in their own learning efforts.

We proposed that the AS would help the volunteers in their work by educating them about previously unknown arthritis information and providing them with a resource authored by arthritis experts.

We also wanted to discover what factors influence the adoption of a technological tool into an existing teaching practice. Therefore we first analyzed the “existing teaching practice.” The two pedagogical duties of the volunteers were realized in nearly every observed interaction between the volunteer and the caller. First, each volunteer offered comfort to the caller by providing personal experience and empathy through learned listening skills. Second, each volunteer identified as ideally being able to anticipate additional informational needs that arose with each caller.

The conclusions from this study, in brief, were that each person will adopt technology into teaching practice in his or her own way. In addition, we observed that the volunteers’ use of the AS increased over time, and they said it was quite helpful in some instances (see “Comments from a helpline volunteer” sidebar).

#### Comments from a helpline volunteer:

“Normally when I go to the Arthritis Source, I am looking for information to give to other people, people who call on the helpline . . . I have the URL up above my desk at the Arthritis Foundation and almost every call I ask the person if they are online. And if they say yes, I give them your URL. And tell them that it is a good source of information.”

#### Successful technology adoption in an adopter’s words:

“The Arthritis Foundation, North Puget Sound Branch in Bellingham is very proud to have had the opportunity of working with the PETTT team. It was a very rewarding learning experience for all the helpline volunteers and staff. The Arthritis Source is now a valuable tool used daily. For many volunteers the Arthritis Source was in introduction to web browsing. It is now our standard place to search for answers to difficult arthritis-related questions. We appreciate the reliability and authority of the Source. We find it extremely helpful to be able to answer questions by email.”

- Barbara Osen, Branch Director,  
Arthritis Foundation,  
Washington/Alaska Chapter

This research helped reach people in the communities outside the University of Washington and improved the help line volunteers’ teaching methods through the introduction of technology. It also gave us valuable feedback about the AS design and information presentation.

## Conclusions: Extending the AS model to other domains

The Arthritis Source represents an important way to reach learners beyond traditional academic boundaries, and to help patients find answers to their questions about bone and joint conditions. In addition, the AS has been designed to meet the needs of everyone who interacts with it—the users, the content creators, and the site managers. Our iterative cycle of evaluation, design, and research helps us ensure that people are successfully using the site and that the site changes in response to the users’ needs.

We hope that the technologies and strategies developed for the AS have the potential to be of service to many information domains on campus and many types of users (not only patients). Our next step is to help groups on campus, such as the Northwest Justice Project and the Center for Engineering Teaching and Learning (these and other collaborations are described in the table below) learn from our research, design, and implementation so they can create information sources that serve the needs of their users and authors. Thus, the Arthritis Source model will move beyond the bone and joint patient education domain to help people with diabetes, university educators, people in Washington searching for legal information, or people anywhere in the world looking for sustainable building information.

<b>Name of group</b>	<b>People in group</b>	<b>Type of information offered</b>	<b>PETTT's role in working with group</b>
Northwest Justice Project	Faculty and students from UW Law School, UW Information School, and other groups.	Legal education information authored by students, aimed at the public in Washington.	PETTT is developing the interface and Zope structure for the site, based on our work with the AS.
Center for Engineering Teaching and Learning (CELT)	Faculty and students from UW Department of Engineering.	Solutions and strategies for teaching engineering, authored by engineering graduate students and an engineering teaching consultant, aimed at engineering faculty and teaching assistants.	Jennifer Turns, one of PETTT's research scientists, is the PI of the NSF grant funding this project. It will be based on technologies and strategies developed in PETTT's work with the AS.
Design-build projects in Mexico, India, and Montana	Students and faculty from the UW College of Architecture and Urban Planning.	Sustainable building information authored by students and faculty, aimed at the public worldwide.	PETTT will work with the faculty and students to develop their database, which will be similar to the AS database.
Living with Diabetes group	UW medical providers.	Patient education information authored by doctors, aimed at diabetes patients.	Several PETTT team members consult with this group regularly.

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## Notes

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<sup>2</sup> A forthcoming PETTT paper will explore the knowledge-management tool perspective. A previous PETTT paper explored the knowledge-building community perspective. See Turns, et al. 2002.

<sup>3</sup> Lorig, et al. 2002.

<sup>4</sup> Fox, et al. 2002.

<sup>5</sup> Praemer, et al. 1999.

<sup>6</sup> Fox, et al. 2000: 3.

<sup>7</sup> Fox, et al. 2000: 10.

<sup>8</sup> "On the Net, RX-rated Beats X-rated" 2000.

<sup>9</sup> Fox, et al. 2000: 5, 15.

<sup>10</sup> Metz, et al. 2001.

<sup>11</sup> Eysenbach, et al. 2002.

<sup>12</sup> Berland, et al. 2001.

<sup>13</sup> Lorig, et al. 2002; Wilson, et al. 2001.

<sup>14</sup> Cohen, et al. 1986; Goepfinger, et al. 1987.

<sup>15</sup> Wallston 1993; Taal, et al. 1996; Daltroy, et al. 1993; Strecher, et al. 1986.

<sup>16</sup> Fox, et al. 2000: 19.

<sup>17</sup> Turns and Liu 2001.

<sup>18</sup> Turns and Wagner 2002.

<sup>19</sup> Liu, et al. 2001.

<sup>20</sup> Turns and Shelton 1999.

<sup>21</sup> Turns and Liu 2001.

<sup>22</sup> Liu, et al. 2001.

<sup>23</sup> Shelton 2002.

<sup>24</sup> Louie, et al. 2000.

<sup>25</sup> Turns and Liu 2001; Liu, et al. 2001.

<sup>26</sup> More data about our users are available in Turns and Liu 2001.

<sup>27</sup> Liu, et al. 2001.

<sup>28</sup> Burghardt 2000.