

## **Building a Consumer Health Website from the Ground Up**

According to Patricia Gallagher, the managing editor and content committee chair of New York Online Access to Health (NOAH), surprisingly few of the New York public libraries housed any substantive consumer health information collections in the early 1990s. Even though New York is one of the biggest and most diverse cities in the world, New Yorkers could not find answers to their important health questions and concerns. The city desperately needed a resource that provided accessible, understandable health information rather than complicated, technical medical jargon found in standard scientific resources such as textbooks and journals.

The creators of NOAH set out to change this. Rather than building a large paper library collection no one could afford, they created a virtual collection that has since evolved into an invaluable research tool.

### **NOAH's Beginnings**

In 1994, four New York City library organizations established the NOAH Web site to provide consumers with a portal for finding quality health information. The founding organizations—The City University of New York Office of Library Services (CUNY), the Metropolitan New York Library Council (METRO), The New York Academy of Medicine Library (NYAM), and The New York Public Library (NYPL)—have since been joined by the Queens Borough Public Library and the Brooklyn Public Library. The project was initially funded by a three-year grant from the U.S. Department of Commerce, but today the Web site—which can be found at <http://www.noah-health.org>—is maintained by a network of dedicated volunteers.

“When I came to NOAH seven years ago, our main goal was to assemble information on seven categories of health information that were considered of primary concern to New Yorkers” says Gallagher. “Those topics were AIDS, tuberculosis, heart disease and stroke, sexually transmitted diseases, sexuality, pregnancy and cancer.”

### **Expanding NOAH**

After these initial seven categories were established, the range of new topics added to the NOAH Web site grew quickly. Six months later, Gallagher's director at the New York Academy of Medicine, suggested they add information on neurological conditions. After that, NOAH took off at a rapid pace.

Since that time, Gallagher and her team of volunteer librarians have adapted NOAH as they learn more about how consumers search for health information online. For instance, access to information must be available through a number of different methods. Users must be able to browse broad illness categories, browse word lists, AND still be able to input and search for words within a database. Therefore, NOAH provides multiple access points to the health issues

covered, including a word list, broad health topics page, and a search engine. Research conducted by the original design committee also found that users didn't like having to click around a website; if they had to go further into a site than three clicks, many users just became frustrated. So, NOAH was designed to bring users to full-text information within just three clicks.

### **Finding Content Material for NOAH**

Gallagher and her team find most of the NOAH content material through Internet searches and through familiarity with the websites of full-text providers like Medem, Mayo Clinic, and the National Institutes of Health. She relies on textbooks to help her categorize materials and often reorganizes content pulled from health-related Web sites that are not consumer friendly. Disease organizations, self-help groups, and Web rings all provide outlets for quality information.

For example, when Gallagher created a section on diabetes, she started with the American Diabetes Association's (ADA) Web site (<http://www.diabetes.org>). Some of the information she found was too clinically-based and directed primarily toward physicians, and the consumer information was not always easy to sort out, so she reorganized the information and structured it in such a way that was not overly daunting or complicated for the consumer. At NOAH, consumers will find a section entitled "Information Resources" in which they can follow links that will take them to the home pages of disease organizations and associations such as ADA's.

It takes extensive searching to fill out a category, Gallagher reports. "But sometimes the categories grow quickly. For instance, I initially had a short section on breast feeding, but then I kept adding more links to it because I kept finding more information on breast feeding techniques, benefits, nutrition for the mother and baby, breast pumps and equipment, nursing rules, weaning, and all the different aspects involved. I discovered through this process that even simple topics can be multi-dimensional. Next thing I knew I had an entire Web page full of information that could help people learn and understand all the issues involved in breast AND bottle feeding."

In addition to creating approximately two new pages of information per month, Gallagher and her team refresh the Web links every three months to provide the most up-to-date information possible.

### **NOAH Consumers**

Gallagher conducts research on NOAH's users based on an optional form they can choose to fill out to provide feedback on their NOAH visit. Through this vehicle, she is able to identify the most common search topics and who the most frequent site visitors are. (Students top the list.) She also receives feedback on ways to improve the site.

One of the most important things Gallagher has learned is that simplicity is best. “Too much information on one page scares people away, and pages that are overloaded with different links, graphics and text just doesn’t work,” she says. “I’ve also learned that not everyone speaks or reads English well, so the Web has a definite advantage over books if it’s used correctly.” Certain media formats like streaming videos are helpful for those who do not read well, and the Internet allows for all kinds of alternative reading and learning styles.

Once Gallagher has read the consumers’ queries, she sends them a letter that either contains the answer to their question or a list of other resources where they can conduct further research. She reports that it is difficult to find Spanish-speaking volunteers, but luckily one volunteer has helped her since the program started in 1994. The volunteer is overwhelmed with inquiries in Spanish, but she feels that it is an extremely important and helpful position to fulfill since there are so many Hispanic-Americans who use NOAH’s services.

### **Outreach Efforts and the Future of NOAH**

During its early stages, NOAH was featured in a *New York Times* article and readers were able to learn all about the program. Since then, Gallagher and her team have relied on search engines and occasional publicity announcements to inform consumers about NOAH’s resources.

NOAH does not have volunteers who work exclusively on outreach efforts, but there is a steering committee in charge of promoting the site. In the Beta test stage of NOAH, the committee conducted focus groups in New York to test the site’s staying power and to determine the usefulness of the information. Gallagher plans to hold another round of focus groups in the near future.

NOAH volunteers plan to redesign the Web site within the next year so that its editors can upload data faster and more easily. “We’ve come a long way since we first decided to build a consumer health information Web site,” says Gallagher. “Through our journey, we’ve learned that there is a big difference between providing medical information and providing quality consumer health information.”

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