Preface: Why This Book*

Scope and Target Audience

We wrote *The Medical Library Association Guide to Finding Health Information on the Web* for the informed health care consumer, often known as patients and patient advocates. More precisely, it is written to those health care consumers who want to know as much as possible about their own health issues, and who seek that information independently, assertively, and even sometimes aggressively. We also hope that the information and strategies will be useful to all health care specialists, librarians, and any other professional helping other individuals with their health information needs and concerns. While there are many guides available directing readers to any number of sites and sources available on the Web, our focus is different. We concentrate not so much on specific sites or sources of information, but rather on teaching effective strategies for searching and types of information and sources which are usually available for most health concerns.

The Strategic Approach

This strategic approach is the most useful and significant aspect of the guide. By strategic, we mean learning how to make a range of searching decisions that will positively impact on the quality and usefulness of what you find.

This range covers

- understanding all aspects of questions,
- selecting the best search engines,

* Once upon a time, a number of years ago, back when the World Wide Web was just getting started and there were no commercial web sites, everything you could find on the Web was there because some individual person believed passionately that this was important to share. During those early days, certain standards evolved quickly about how people shared that information. Almost immediately, it became expected, almost mandatory for most web sites in existence at the time to include a statement about why that particular web site had come into being. In keeping with that tradition, we’d like to offer a few words about why this book came into being, why we feel the effort is important, and what we hope you'll get out of it.
employing a variety of information resources,
appreciating background issues and concerns

We examine the nature of questions including
• commonly asked questions,
• question types,
• tools for evaluating and rephrasing your question,
• good models of the questioning process.

We explore the wide variety of search engines including
• types of search engines,
• matching the best search engine with the type of question,
• rethinking your question versus choosing a new search engine.

We investigate other valuable information resources, demonstrating
• how to apply the questioning and searching tools to specific topics,
• what types of resources are usually available for different topics or questions,
• how to decide if the information or web site is trustworthy.

Organization

The guide begins with several chapters dedicated to understanding the essential background of effective searching of health information on the Internet. We begin with “Health Information on the Internet” exploring the history, overview of current trends and unique challenges. Then we move on to delve into “Evaluation and Issues in Using Internet Health Information” where we look at issues of criteria, confidentiality, standards, web site accessibility, and many others. Next we progress into a critical discussion of “Strategies and Strategic Searching” that includes general tips, question types, and putting the pieces together. Finally “Background Information for Health Information Searching” contains general sources, tools, statistics, and standards. The frequently asked questions portion of this section gives ideas for how to find information on general health concerns — drug information, laboratory results, medical procedures, terminology, and more.

In the next section of the guide we show you how to use the strategic approach in a comprehensive series of real-life health situations. We survey five key “Sources by Life Stages,” — including children, adolescents, men, women, and seniors. Next we examine more than a dozen essential “Health and Wellness Issues and Sources” — including sexual and mental health, first-aid and personal safety, living with a chronic illness, and end-of-life care. Following this is an overview of more than fifty topics on specific illnesses. This list ranges from AIDS to autism, dementia to diabetes, sleep disorders to suicides. We selected the top reported causes of death and disability for all major populations in the United States, both by age group and ethnicity, as reported by the US Census. To help address searching for those less common illnesses, we also include a section on searching
for information about rare diseases. The guide ends with a series of handy appendices gathering additional practical references and resources.

For each of the topics, we focus on teaching the search strategy skills and special issues which apply to the topic, along with representative examples of the types of information or Web sites which you should be able to find. For example, in searching for information on issues related to breast cancer, you will learn how to limit your search to find just health information and not pornography. To help with concepts to limit and focus the search, we include background information for the illness topics, such as the anatomical area or medical specialty or specialties usually involved in providing care. While not all topics actually have available all types of information resources, we include information in most topics on Web sites from such types of resources as professional organizations, patient support groups, frequently asked questions, hotlines, and a few good starting places. For these, look for the "Best One Stop Shops."

We do not expect that all these links will still exist or be in the same place by the time the book is in print, so we also include a section on how to find where a site has moved. Remember, though, the purpose of The Medical Library Association Guide to Finding Health Information on the Web is not limited to the links included. Even if the information we selected as an example disappears, you can probably find something similar or better, with the tips and suggestions elsewhere in this book.

It simply isn't possible for one book to include everything of importance for your health information needs. More than likely some people will have health concerns we were not able to include for reasons of space or time. With the methodology described above for the selection of topics, we hope that we have at least touched on the most important health topics and issues of concern to most health care consumers. Our focus is on how to find the information relative to those concerns, but there is also the issue of what happens with the information you have found, and how you use it to communicate with your health team and inform your decision-making process. This is touched on briefly in the main text, but there are ethical and philosophical concerns which apply to the presentation and concept of the entire book, and for that reason seem more appropriate to discuss here.

**Introduction**

While the first part of the Preface gives you a rough overview of what we tried to do and how, we would be seriously remiss if we did not acknowledge that there are significant issues relating to this task. First of all, as in any effort of this sort, there is the question of how any author or authors can possibly attempt to address such a seemingly impossible task, no matter how well intentioned and hard working they might be. Next, while
Internet searching for health information is one of the largest areas of growth on the Net, and the provision of what is called e-Health has become highly commercialized, this doesn't necessarily please everyone. As long as the Internet has existed, there have been concerns about how to determine the accuracy, quality, and ethical focus of any given bit of e-Health information found by the search engines. Those concerns have not grown less over the years, despite the enormous efforts of many fine and dedicated people to address them. Since we know that it is not possible to resolve these concerns, why, you might ask, would we feel compelled to make the attempt? A richer discussion of the background of the concerns and issues seems appropriate.

From the beginning of the Internet, people have taken the opportunity to reclaim the intentions present at the historical foundations of publishing and copyright. That is, first, to say what they believed was important, whether or not anyone else agreed with them, documenting their ownership of the ideas. Second, to offer a chance for dialog between the people who were providers of the information or opinions and the people who were consumers of the same. With respect to health information, perhaps more than in any other area, there has been a great deal of debate about whether or not this has been a good thing. One concern was that the most readily accessible information was, at least early on, likely to be the least medically sound. The United States government, state and other national governments, various healthcare organizations, academic medical centers, healthcare corporations, and individual healthcare providers rapidly addressed this issue by making available evaluated and reviewed consumer health information, and offering a variety of options for patients seeking health information.

Despite this, healthcare providers continue to hold strong concerns about the health information available on the Internet in general, and have had strong reactions to the Internet-based information brought to them by their patients. The debate has ranged across both extremes, and has found its way into the day-to-day life of most healthcare providers. We've heard of practitioners who expressed strong gratitude for the information brought to them by an informed patient, and proceeded to act on the information and incorporate it into the treatment plan. We've heard of practitioners who, in front of the patient, took the printout from the pharmaceutical company's web site regarding the prescribed medication and its side effects, and put it in the waste receptacle, solely because it was from the Internet and disregarding the source or quality of the information.

It is because of these vastly different reactions that we want not just to help the patient to find their own information, but also how to determine the information is quality information. Then, how to present the information you have found to your healthcare provider so that they will also know you have found "good stuff." Ideally, we would hope that knowing how to use the Internet effectively will help build trust in the clinician-patient relationship; a trust which, according to other sources, seems to be on shaky ground.
"Professional codes define professional responsibilities with ever-greater accuracy. Huge efforts also go into ensuring trustworthy performance. ... The efforts to prevent abuse of trust are gigantic, relentless and expensive; and inevitably their results are always less than perfect. Have these countermeasures begun to restore trust, or just to reduce suspicion? ... Patients, it is said, no longer trust doctors ... and in particular no longer trust hospitals or hospital consultants. 'Loss of trust' is in short a cliche of our times." O'Neill, Onora. A Question of Trust. (BBC Reith Lectures 2002: Lecture 1. Spreading Suspicion, 6 April 2002, p. 2-3.) URL: <http://www.bbc.co.uk/radio4/reith2002/1.shtml>; PDF: <http://www.bbc.co.uk/radio4/reith2002/pdf/lecture1_text.pdf>

Fundamentally, this book is about personal empowerment in one of the most intimate aspects of our personal lives. It is also about a belief that access to quality information and shared health decision making both nurture the a trust that comes from a sense of what personal control and power is possible in a situation which is by definition unpredictable and filled with personal risk. You may have seen or heard one of the many radio and television advertisements from the National Health Council with their very appropriate slogan: "It's your health. You call the shots." URL: <http://www.nationalhealthcouncil.org/>. In some ways this is an expression of the peculiarly American perspective on the inalienable rights and responsibilities of the individual.

"Liberty cannot be preserved without a general knowledge among the people. ... The preservation of the means of knowledge among the lowest ranks is of more importance to the public than all the property of all the rich men." Adams, John. "Dissertation on the Canon and Federal Law." 1765. American Letters, Speeches and Documents On-Line Library. URL: http://www.ashbrook.org/library/18/adams/canonlaw.html

The concepts of liberty and pursuit of happiness are inextricably interwoven with the personal, and there is little more personal than our health. What John Adams says connects those core issues with access to the necessary knowledge to make informed decisions, and applies to all general topics. Health information certainly cannot be excluded. With the availability of Internet access in public libraries throughout the United States, the vision of universal access to needed information has come closer than at any time in our country's history. David Brin has widely discussed the broader implications of this general concept for empowering our contemporary society.

"What has worked - the foundation of our liberties - has always been openness and candor. Especially the ability to force the mighty out in the open where we can hold them accountable. All three of the greatest human inventions - science, democracy and free markets - depend on open information flows." Brin, David. "The Value - and Empowerment - of Common Citizens in an Age of Danger." The Futurist. 2001. URL: <http://www.futurist.com/portal/future_trends/david_brin_empowerment.htm>

The expression of similar concepts is not rare on the Internet. Indeed, free flow of almost any kind of information seems to be at the conceptual foundation of the Web, a kind of operating assumption. It is not difficult to find this assumption expressed in terms perhaps less noble and more targeted toward a kind of information guerilla warfare.
"Information wants to be free. / Access to computers and anything else which may teach you something about how the world works should be unlimited and total. / Always yield to the hands-on imperative. / Mistrust Authority. / Do It Yourself. / Fight the Power. / Feed the noise back into the system. / Surf the edge." Branwyn, Gareth. Cyberpunk Cut-and-Paste Manifesto: A "C-Word" Sampler. URL: <http://www.streettech.com/bcp/BCPgraf/Manifestos/Cut&Paste.html>

It is this conceptual foundation, underlying both American democracy and the Internet, which has created the environment in which many healthcare consumers feel not just allowed but obligated to share information about their health issues and concerns. This is the same environment making possible a free dialog between healthcare professionals and healthcare consumers such as has never before occurred. Now, the type of patient called a "Clinic Cynic" by the Path Institute can freely flourish, and even be respected and integrated into the generation and review of health information. It seems fitting, given the immediacy and intimacy of health to the human condition and quality of each person's life, that health information has become one of the foremost arenas for resolving the variety of issues besetting this new information environment. A few of these issues, which will be discussed later in the book, include accessibility of the information, privacy, standards, ethics and guidelines for how the information is provided. Across all of these lies an unstated assumption of the right of the individual to choose to make their own informed health decisions, a concept also sometimes referred to as "informed consent."

The concept of informed consent is somewhat at odds with a much older concept in the medical literature, that being that the physician or healthcare provider knows best. Another way of stating this second concept, which has resulted in substantial discussion and concern both within and without the professional healthcare community, is the phrase "noncompliant patient." In short, this is basically a patient not doing what they were told to do by their healthcare provider. Charles Atkins, a physician who admits to being a noncompliant patient himself, in his brilliant editorial for the American Medical Association, gives some richer insights into the complexity of the concept.

"As I approach my 40s, I can just imagine what my response would be to a physician trying to push a drug that would make me fat, bald and stupid. Yet if I were to be recommended such a pill ... and then neglected to take it, I would be branded as noncompliant. ... So I start with Stedman's Medical Dictionary to ascertain whether this is even a word. I find compliance: "The consistency and accuracy with which a patient follows the regimen prescribed by a physician or other health professional. Adherence." Still, I don't care for the sound of noncompliance -- as if not following the doctor's advice is a sign of moral turpitude. The term hides a bigger issue: Why is this person not doing what the doctor said?" Atkins, Charles. "Patients usually have reasons for being noncompliant." American Medical News. April 9, 2001. URL: <http://www.ama-assn.org/sci-pubs/amnews/ann_01/edca0409.htm>

The concept of noncompliance is so ingrained into the past of our medical system to be represented in the medical dictionaries, as above. It can be traced back into medical history to the Prayer of Maimonides, including references to concern over the quality and source of information the patient acquires.
"Grant that my patients have confidence in me and my art and follow my directions and my counsel. Remove from their midst all charlatans and the whole host of officious relatives and know-all nurses, cruel people who arrogantly frustrate the wisest purposes of our art and often lead Thy creatures to their death." Maimonides Daily Prayer of a Physician. [Either written in the 12th century by Moses Maimonides, or 1793 A.D. by Marcus Herz, depending on the expert source.] URL: <http://www.MedTerms.com/script/main/art.asp?articlekey=4247&rd=1>

Despite, or perhaps because of this long history, there does seem to a recent trend in the medical community to question the concept and its validity, Dr. Atkins being far from the first. Dr. Warner Slack discusses noncompliance at length in several places of his book, Cybermedicine, reiterating the following conclusion.

"I believe that patients who want to should be encouraged to make their own clinical decisions ... and that noncompliance should be regarded simply as disagreement with the doctor. Our data indicate that patients who elect to make their own medical decisions will be faithful to them, that they will do what they tell themselves to do." Slack, Warner V. Cybermedicine. Rev. & Upd. Ed. San Francisco, CA: Jossey-Bass, (c) 2001, p. 42.

In Dr. Slack's discussions of noncompliance he is explicitly confronting the issue of patients looking for information on the Internet to help them make health decisions. Our personal belief is that it is neither realistic nor ethical to attempt to control or proscribe access to health information. Nor is it realistic or ethical to legislate or prescribe what healthcare consumers do with health information once they find it. In this book, our struggle has been balancing this belief with an equally urgent concern for those health care consumers who do not find the best of the information available. This is through no fault of their own but simply the nature of the Internet and Internet search engines, however it heightens the possibility of making health decisions based on this less than ideal information, placing their health and/or quality of living at unnecessary risk.

"A confused health care consumer is a dangerous patient. He or she may seek inappropriate alternative treatments, which may have adverse health effects." Chandra, Anish. "Potential Influences of the Web on Health Care Patients and Professionals." Health Care on the Internet 5(3) 2001:59-67.

This confusion mentioned by Anish Chandra comes in part from the sheer enormous variety of information available on the Web, in part from perhaps lacking the context to know what information should be possible to find, in part from struggling with what questions to ask and how to ask them. No one even tries to pretend, for example, that all information on the Internet is of equal quality, accuracy, or currency. It can be a challenge even for a healthcare professional to decide which information is preferable for a given situation.

"Overall, the results suggest that there is a fair degree of disagreement between medical experts when they are asked to rate medically-related postings from the Internet." Craigie M, Loader B, Burrows R, Muncer S. "Reliability of Health Information on the Internet:

If there is a lack of consensus among healthcare providers as to what constitutes quality information, then what is the role or expertise of the healthcare consumer in this search, discovery and decision making process? The obvious -- they are the truest and only expert on their own body, its quirks and eccentricities, and how the disease process expresses itself in their personal experience.

"There is no life without illness, no day without healing. What we can do best is what doctors and medicine cannot do for us at all: develop an active sense of the balance of health and illness within ourselves, and develop tactics for tilting that balance more and more against illness." Konner, Melvin. Medicine at the Crossroads. NY: Pantheon, 1993, p. xxi.

It is that process of "tilting the balance" through information with which we hope to assist. That is the personal empowerment of which we spoke earlier in this section. We hope to help health care consumers better understand what kinds of questions can be asked and answered with Web resources, the scope and variety of information available, offer some tools and strategies to help in finding the information. The very nature of information on the Internet means that we cannot guarantee that the information on a recommended site will remain the same, or that the site itself will continue to exist. In every section of the book, we make no attempt to be comprehensive, since to be comprehensive is neither a feasible nor logical effort. Instead, we focus on examples of types of information and types of web sites one may reasonably expect to find. Remember many wonderful and excellent sites are not included in this book. This is just a beginning place. The emphasis of the work is on the strategies and techniques used to locate those representative sites.

Then, once the questions have been asked and searched, and hopefully good quality information found, we hope that you will use this information in collaboration with your healthcare provider as partners in making the best possible health decisions for you. We have seen no one who expresses this better than Tom Flemming in his disclaimer for his "Health Care Information Resources," a site which, not coincidentally, resides on a server named Tiohnhe, a Mohawk name meaning "That which gives life."

"Health Care Information Resources makes information about health and disease accessible in the belief that the informed consumer is a more satisfied consumer of healthcare. This service does not offer advice about health or healthcare and cannot substitute for a healthcare practitioner. Only personal contact with the qualified healthcare practitioner of your choice -- who knows your health history, who can examine you, and who can bring expertise and experience to bear on your situation -- can yield advice about how you ought to handle any of the information you obtain from sources accessed through this service. Decisions regarding your healthcare should always involve the assistance of a trusted healthcare practitioner." Flemming, Tom. Health Care Information Resources. URL: <http://www-hsl.mcmaster.ca/tomflem/top.html>