

DOCTOR INTERNET®

HOW TO USE THE INTERNET
FOR HEALTH & MEDICINE

(VERSION 1.01 - BASICS TO INTERMEDIATE)

INSTRUCTIONS
AND REFERENCE FOR



- ◆ PATIENTS,
- ◆ FACILITATORS,
- &
- ◆ HEALTH PROFESSIONALS.

CHADD EVERONE, IM., PH.D.
PRINCIPAL INVESTIGATOR

*A structured approach to
using Internet resources*

Copyright © 1999 - 2001

CHADD EVERONE
F.I.S. - FOUNDATION FOR INFINITE SURVIVAL, INC. (Est. 1972)
LIFE-EXTENSION & CONTROL OF AGEING PROGRAM
BERKELEY, CALIFORNIA

<http://www.doctorinternet.com>
<http://www.fis.org>

ALL RIGHTS RESERVED

IT IS UNLAWFUL TO REPRODUCE OR TRANSLATE , WITHOUT THE PERMISSION OF THE COPY OWNER, ANY PART OF THIS WORK BEYOND THAT PERMITTED BY THE 1976 COPYRIGHT ACT, UNITED STATES (TITLE 17, U.S. CODE) SEE [[HTTP://WWW.LOC.GOV/COPYRIGHT](http://www.loc.gov/copyright)]. FOR VARIANCES, CONTACT THE FOUNDATION FOR INFINITE SURVIVAL, INC.

LIBRARY OF CONGRESS CARD NUMBER: 00-191207
ISBN 0-9701066-0-2

IT IS UNDERSTOOD THAT IN PROVIDING THIS INFORMATION, THE PUBLISHER, COPYRIGHT HOLDER, AUTHORS, OR DISTRIBUTORS ARE NOT ENGAGING IN THE PRACTICE OF MEDICINE; NOR ARE THEY LIABLE FOR HOW THE INFORMATION MAY BE USED.

BECAUSE SOME OF THE MATERIAL, SUCH AS LINKS TO COMPUTER SITES AND PAGE DESIGNS OF INTERNET SITES, CHANGE WITHOUT NOTIFICATION TO OR CONTROL BY THE AUTHOR, THE BOOK IS SOLD AS IS. ALL TERMS WHICH ARE KNOWN TO BE TRADEMARKS OR SERVICE MARKS HAVE BEEN APPROPRIATELY IDENTIFIED.

TABLE OF CONTENTS

PREFACE & INTRODUCTION. THE FOCUS OF THE BOOK ♦ BACKGROUND OF THE AUTHOR ♦ REMARKS FOR THE PATIENT, THE FACILITATOR, AND THE MEDICAL PROFESSIONAL ♦ HOW RESEARCH IS PUBLISHED, THE SOURCES OF INFORMATION, AND THE GENERAL STRATEGY	5
PROCEDURES. SECTIONS 1-4 ARE THE BASIC PROCEDURES IN A STRUCTURED APPROACH TO USING THE INTERNET FOR HEALTH AND MEDICAL RESEARCH. THE ADDITIONAL SECTIONS EXPAND THOSE ROUTINES.	
1 - PRELIMINARY SURVEY - MEDLINE - "REVIEW" CITATIONS	24
2 - DEFINING YOUR SEARCH TERM(S) - MeSH	35
3 - SPECIALIZED SEARCH ROUTINES	39
4 - COMMON SEARCH ROUTINES	69
5 - MAKING A RESEARCH REPORT	87
6 - MEDICAL REFERENCES - DICTIONARIES, ENCYCLOPAEDIA	89
7 - PRE-FORMATTED INTERNET LINKS - MEDLINEPLUS.....	97
8 - RESEARCHING A DRUG OR CHEMICAL	104
9 - OTHER RESOURCES OF NLM & NIH	107
10 - PERSPECTIVE ON THE NATIONAL LIBRARY OF MEDICINE	117
11 - RESEARCHING CANCERS	143
12 - EXPERIMENTAL, CLINICAL TRIALS	158
13 - PROPRIETARY, BIO-MEDICAL DATABASES	163
14 - BOOLEAN OPERATORS & THE GRAMMAR OF SEARCHING	165
15 - INTERNET SEARCH ENGINES / SITES FOR BOOKS	168
16 - COMMERCIAL MEDICAL WEB-SITES	176
17 - EPILOG & THE DOCTORINTERNET PROGRAM/WEB-SITE	178
GLOSSARY OF MEDICAL DISEASE	183
INDEX	222
NOTES	226

SPECIAL ACKNOWLEDGMENT TO:

DALE SOBEK
WILLIAM RHETT
DOUGLAS WALSH
INGRID RADKEY
WILLIAM MARTIN
RICHARD STANCLIFF
CHADD ALEX. EVERONE

PREFACE

Things which pertain to computers make their greatest sense when you are actually on the machine and working on a problem. Thus, I will keep the background information to a minimum and move to the Procedures as quickly as possible. In fact, it is likely that you have some immediate, medical interests; and if so, you can jump to the procedures section, which begins on page 24 and come back to these preliminary remarks, later.



DoctorInternet

The DoctorInternet program (in its book form, companion CD, and expanded web-site) provides a structured approach to using the Internet for health and medicine and related subjects. This includes, but is not limited to, finding information about:

- diagnostics
 - state-of-the-art treatments
 - experimental trials
 - risk profiles
 - conventional and alternative therapies
 - preventive measures
 - professional services, and
 - medical research.

PREFACE

The information in this book serves a wide variety of interests; however, it is written mostly with three groups in mind. The first is the patient who wants to play a more active role in deciding and planning one's health and medical strategies and who wants to do so from a scientifically informed position. Second is what we will call the "facilitator", who is someone helping the patient to obtain the most appropriate medicine. Frequently, a facilitator is a relative or associate of the patient; or one can be a paid consultant. And third, the program is directed to health care professionals, including physicians, who see the value of using research databases and other Internet resources in their practice and continuing education. Later, specific comments will be directed to each of those groups.

In addition, the same procedures which apply to patients, facilitators, and physicians will also apply to the interest of science writers, attorneys, educators and students, researchers, investors, and anyone with an interest in the bio-medical sciences. Even those who are interested in veterinary medicine for their pets or livestock will use many of the same databases and search routines that apply to humans.

I want to emphasize the idea of a "**structured approach**" to using the Internet - particularly for medical purposes. We are in the midst of an explosive growth in bio-medical information; and this will continue, at an accelerated rate, into the foreseeable future. Consequently, a new order of medicine is emerging - one which is driven by research and advancing technologies. It will involve a high degree of patient ("consumer") involvement. The time of technology transfer from research to its application will shorten from 10-20 years to 10-20 months; and the clinical environment will, itself, become more of a research environment, in which individual cases can be treated within an experimental/clinical model. Increasingly, advances in knowledge are coming "on-line"; and

PREFACE

the same information, which used to be available only to a small, esoteric group of information specialists (the author being one), who had training in information technology, is now available to everyone (lay person and professional alike) through a computer via the Internet. Much of the right kind of scientific information is still proprietary and available only to paying members; but increasingly those barriers are coming down. Access is no longer the main problem - coherence is. Both the “consumers” of medicine and the providers of medicine, themselves, can easily be overwhelmed and confused. Obviously, much of the information is not relevant to the particular situation of a particular person, and one can easily become side-tracked or lost. So, you must learn to stay focused. Also, one must be discriminating because some of the information is faulty or even deliberately misleading for the purpose of selling products. Mostly, however, the problem is in the massive amount of information and the lack of its organization. There are relatively simple procedures for staying focused, for discriminating, and for making sense out of the chaos; and that is what we will be providing in a structured approach that is consistent with good research methodology and that is the back-bone of the DoctorInternet program.

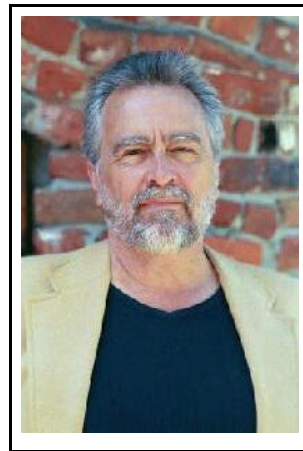
You can, of course, bounce around to various web-sites like some kind of pin-ball video game; and everyone will do that to some extent. That can be entertaining and sometimes informative; but mostly, it is confusing. After you have tried that, and after you have been dispelled of the illusion that all you have to do is to type in your concern and the computer will give you the complete solution, and before you become too frustrated, come back to this structured approach. Go step by step through the procedures, and you will obtain credible scientific information which you can put to use.

To obtain this information, one does not need to be trained in computer technology nor even have a computer. In fact, most public libraries now have access to

PREFACE

the Internet and most librarians know how to navigate through it and employ the procedures in DoctorInternet. So, even if a person were to be completely naive and unequipped, one can use those resources to execute the main routines in this book and obtain meaningful results. Some people will be completely mystified and enervated by the medical terminology and concepts. Even so, at the very least, you can still do the routines in section **1 - Preliminary Survey - MEDLINE - "review" citations**. Print those results, and give the document to your physician, saying that there might be something useful in it for your treatment. If you do nothing more than that, then you will have done a service to both yourself and your doctor, benefiting both. But the potential is far greater!

I, personally, have been doing medical research reports since 1972 (i.e., for over 25 years as of the date of this writing), and I can rightfully claim to be one of the few experts in the world in this field. Literally, I have done thousands of research reports on a wide spectrum of medical problems and subjects in bio-technology. How the information has been used and its degree of benefit always varies in each individual case; however, in every case, the caliber of the information has always been regarded as the best available, by scientific standards. It is not so much that I know a great deal. Rather, it is mostly that I know how to know. "Knowing how to know" seems to be the essence of our present, research driven, high technology, information era. Of course, the expert does accumulate knowledge through experience; but because content is changing and evolving so rapidly, one's knowledge can rapidly become obsolete. The true expert is a person who is well grounded in the process of knowledge acquisition so that one



PREFACE

knows how to obtain the most current information and assemble it to use, in conjunction with one's prior experience, for application to a particular situation. Then, in the next situation, even though it might be the same, one needs to go back and repeat the process, thus, staying in close touch with new developments in that area and making modifications as one proceeds. It is not that knowledge is disposable; but rather, it needs to be continually refurbished.

My own history in doing medical research reports illustrates how radically this field has evolved. As I said, I began doing this kind of work in 1972, when, as the principal of our Life-Extension & Control of Ageing Program, doing research reports became a component of that work. Whenever a participant got a serious medical problem, I would go into the recent scientific literature, retrieve the relevant research citations, and organize it into a bound document so that I, the participant, and the treating physician(s) could review the state-of-the-art procedures for that particular problem and design an appropriate therapeutic strategy. Frequently, the report would confirm that the conventional treatments were all that was available. Sometimes, we would find that a proposed treatment offered no real benefit and that it involved serious adverse effects, such that no medical treatment was the better approach. Frequently, we would find newer refinements to the conventional treatments which would be of some potential benefit; and sometimes, we would find substantially new, experimental approaches that might be worth attempting. That basic scenario remains the same today; but the process of achieving them has radically changed.

Originally, here is what I would have to do to create a medical research report. First, in physical terms, I was confined to using the biology library of the university because that was the only place to obtain the appropriate reference material in the form of books and journals. (Now, much of this material is on-line via the Internet and, consequently, is available from almost anyplace in the world; and

PREFACE

that will be expanding, in depth and breadth, over the years.) There, in the library, they had the principal source of information - a series of reference books called the Index Medicus. This series is published by the National Library of Medicine. It indexes reports in medicine and biology from journals all over the world; and it goes all the way back to 1879. The Index Medicus is still published; it is the progenitor of the computerized database called MEDLINE, which you will be using; and it has been called, justifiably, one of the major contributions to Civilization. Later, I will explain that claim more fully in the sections where MEDLINE is used and in a historical outline of the National Library of Medicine. The Index Medicus contains three principal elements: 1) the title of the scientific report, 2) the name of the lead author, and 3) the journal in which it is published. Citations are categorized according to what are called Medical Subject Headings, which will be important for you to understand - again, in a later discussion. In doing a research report, I would first make sure that I had the proper Medical Subject Heading (a.k.a. MeSH term) for the particular problem or issue. Then, starting with the most recent volumes, I would work my way backwards, chronologically, about 5 years, finding the citations under the MeSH heading, and inserting a piece of paper with reference arrows to identify the sectors which I needed to Xerox, later. The reference librarian, Ingrid, was my constant mentor in this process, as she continues to be today. (There is absolutely nothing comparable to a good reference librarian! And I am eternally grateful to Ingrid, Norma, and Beth.) Once I had tagged all of the volumes, I would then Xerox the appropriate sections. From that point, I would organize the Xeroxed pages with the most recent being first. Because science is a process of continuously refining and up-grading prior knowledge, it is best organized in reverse chronological order. I would then read the citations, looking specifically for “review articles”, which I would then retrieve, in full, from the actual publications in the library stacks and Xerox them. When completed, I would write an over-view with my observations and comments, and bind all of

PREFACE

the material into a report, copies of which I would then give to all parties concerned. That was the “Base Report”, which would then serve as a reference for making decisions about a treatment strategy, including further research into particular areas.

That is the method which any researcher would have had to use in order to do such a report, and the procedures had not changed (with the exception of Xeroxing technology), for over a hundred years, since the beginning of the indexing of the medical literature. The entire process, from the initial research to the final report, would take between several days to several weeks, depending on the medical problem, and sometimes I would have to charge several thousand dollars to justify the work. And it was always appreciated and deemed as worth it. Generically, the procedures remain essentially the same today. What has changed is the implementation methods and consequently the scope, the speed, and the cost.

One day, in about 1983, Ingrid introduced me to the new terminal in the library, saying that Index Medicus was now available on the university computer via a program called MEDLINE. I recall that neither she nor I were very enthusiastic. She commented that nothing would ever replace a large, library table upon which one can place multiple books for a panoramic perspective and the heuristic effects which that offers; and, as it turns out, she has been proven to be correct. Although the computerized database is extremely powerful, it is not at all comparable to a big table and a pile of books, for certain aspects of research. Irrespective of that and although it was an excruciating experience to adapt to receiving the information through a video screen and with the multiplicity of obscure commands to find what one wants and all of the many glitches which were intrinsic to computerized technology during the early stages, I now do virtually all of my initial research via the terminal and have abandoned the book

PREFACE

form of the Index Medicus, except for research prior to the establishment of the electronic databases. The process of generating a medical research report, which used to take me many days and cost a lot of money, can now be done, much more extensively and better, in less than 1 hour at a nominal cost or at no cost, if you do it for yourself, which is the whole purpose of this book. With some practice, most people can develop expertise in doing these research reports; and with more practice, many can qualify as experts in the assembly of medical information for a particular client.

This book stands by itself and can be used without any of the associated websites. It is, however, a part of three such sites. **DoctorInternet.com** is the subscription-based site with the full program, containing all of the procedures in the book and the most recent expanded utilities and features. Access to the ".com" program is provided with this book and to participants in the Life-Extension Program at **fis.org**. **DoctorInternet.org** provides introductory searches, free of charge. Also, we produce a CD ROM, as a companion to the book. It contains an electronic copy of the book, the Internet templates of the program, and an expanded glossary of bio-medical terms.

I trust that this will be an informative and interesting process for you, as it always is for me. More importantly, I hope that it will be of substantial benefit to you, which, obviously, is the main objective.

Best wishes, *C. A. Everone, Berkeley, California*

INTRODUCTION

As was said, the procedures in this book will serve a variety of interests - science writers, investors in biotechnology, students, etc. However, the focus is on the interest of patients, facilitators, and medical professionals. Here, I will direct some remarks to each of those categories.



DoctorInternet

TO THE PATIENT

Increasingly, many people, who have medical problems, want to be more actively involved in the decision process. However, this only makes sense if one is reasonably well informed so that intelligent questions can be asked and a meaningful dialog established with the attending medical professionals. Being properly informed is mostly your responsibility, if you want to be involved. As a patient, whether you are newly diagnosed, already in treatment, or in remission, you will want to know several, basic things.

- First, have you been properly diagnosed? Misdiagnosis does happen, frequently during the early stage of a disease process. Proper diagnosis includes an accurate definition of the “etiology” (i.e., the cause of the problem), an accurate staging of the disease, and an evaluation of its trend.
- Second, you want to know if you are or will be receiving state-of-the-art treatment. The medical procedures which are practiced in the normal clinical environment, “in the field”, can be behind that which is practiced in clinics which are more research-oriented. Frequently, “watchful waiting” or “observational” medicine is more appropriate than immediate treatment. Also, “adverse effects” of treatment must be considered in calculating the merit of a therapy because sometimes the treatment can shorten life-expectancy and decrease the quality of living worse than the disease, itself.
- Third, you should know about appropriate experimental options; and, you will want to stay in touch with the status of relevant research, world wide. It can take 10-20 years or longer for research to be transferred to conventional medicine; and

INTRODUCTION

by knowing about new investigations, one can sometimes accelerate or by-pass the normal process.

These are the three, basic issues which everyone should resolve in any medical situation, and the initial routines which we provide will help accomplish this, in what we will call the Base Report (Procedures 1-4 and, for cancer, 11). Many other issues can be important; and we will also provide the routines for obtaining an array of relevant information.

Untrained, non-technical people can learn to understand the medical literature. I am continuously amazed at how quickly a patient, who is motivated, can become well educated in their problem. Most lay persons are accustomed to receiving their scientific information from second-hand sources such as newspapers, magazines, and newsletters in which the scientific information is translated into the vernacular. However, a lot can be lost in that translation. With some study, persistence, and a dictionary (we will show you how to make your own dictionary), most people can learn to read directly the scientific literature itself; and that is infinitely more interesting and rewarding. You do not have to learn all of medicine, just the medicine which is associated with your particular problem. The Internet is abundant in vernacular material, and we will point to some of the main sources. However, our emphasis will be in showing you how to access the real, scientific literature and learn how to use it. In other words, we want to bring you to the science in preference to trying to bring the science to you.

Again, if this kind of information is new to you, then do not be intimidated by terminology or the technical concepts. It will take some time; but with practice, you can become acceptably fluent. Do not succumb to the phobia of feeling that you might offend your physician by doing your own research and wanting to understand the scientific basis of the treatment strategy. It is natural that you will feel like you might be insulting your physician by doing such research; and, indeed, you may actually be. But ultimately, your body belongs to you, and you are the one who has the right to make the decisions. Even if your decision is to blindly defer to the judgment of your doctor, it is still you who makes that decision. It may happen that your doctor may rebuff you for doing research; thus, you should attempt to train him or her into accepting your involvement. If the resistance persists, then find another doctor. That kind of attitude is inconsistent with good medical ethics and is obsolete in modern, scientific medicine. Even if you are a member of an HMO, you still have some ability to pick your physician. HMOs are required to have procedures

INTRODUCTION

for changing one's physician and appeal procedures for considering innovative therapies. Besides, if you can afford it, you are always at liberty to pay for your own medicine.

TO THE FACILITATOR

A facilitator is someone who helps the patient obtain the most appropriate, best possible care. Frequently, this is a relative, but it can also be a close friend, member of one's church or social group, the public librarian, or a paid professional. The facilitator can be one of the more important members of the treatment team, acting as an intermediary between the patient and the health professional. It is common that the patient is in denial and/or is intimidated by the medical professional; and the neutral facilitator can be more aggressive and play the role of an advocate. Again, the essential requirement for being an effective facilitator is having the right kind of information. A current newspaper article or an article in a magazine or health newsletter may be helpful and may open some possibilities, but that is not a sufficient basis for asking professional level questions and seriously proposing treatment options. You need to know how to assemble and present the scientific information and ask relevant questions. Doing Procedures 1-4 is more than sufficient for a first step.

There is a real need and a growing demand for professional facilitators who can do medical research reports; and we are developing a training and certification program for people who are interested. Patients, who have gone through this process, frequently make good facilitators for other patients.

TO THE MEDICAL PROFESSIONAL

This category includes anyone who is duly licensed to treat medical problems - medical doctors, chiropractors, osteopaths, naturopaths, nurses, and paramedics. Although medicine is highly computerized, most of the technology is used for billing and administration; and, in general, medical professionals are far behind in using the technology for the actual practice of medicine. The same basic procedures which are recommended for the patient and the facilitator are prerequisite for the medical professional. In fact, you may want to consider asking the patient to do various searches for your evaluation, both as an activity for them to do as part of the therapeutic process and to aid you in staying current. Prescribe the Procedure 1 search strategy, designate the proper terms, give it to the patient or facilitator, have them do the retrieval and print out the report for you. If they come to you

INTRODUCTION

with unusual ideas, have them do a research report and present it to you. In addition to the basic search routines, we will provide more advanced strategies that have particular application to professionals.

As everyone knows, medicine is currently in a state of considerable turmoil, due to the convergence of multiple forces. ♦ Third party payors (i.e., HMOs, insurance companies, and government agencies) are increasingly dictating what can be practiced, and their emphasis is not necessarily on good medicine but perhaps more on profitability by cost containment while maintaining customer satisfaction. ♦ The threat of predatory, malpractice litigation imposes a defensive approach to medicine which may compromise the most appropriate care. ♦ A better educated patient population is emerging. They are capable of and require a greater degree of involvement in the decision making process. Further, there is a demonstrable shift in “consumer demand” in favor of “alternative” and more “natural” modalities, many of which are utter quackery; and people need to be better educated in the scientific method. ♦ More aggressive marketing tactics by pharmaceutical companies are creating a patient demand for remedies that are not traditionally in the realm of medicine. ♦ The cost of medicine is now about 20% of the gross domestic product. The benefits are no where commensurate to that cost; and, reportedly, about half of that is spent in the last 6 months of life of terminal patients, when there is no chance of cure or even life-prolongation. ♦ The idea of a “standard of care” used to mean that which you were taught in school and that which is practiced on your local community. Now, it is the continuously revising opinion of some scientific committee for evidence-based medicine. And the notion of “community” is shifting to a consensus of international experts. Further, the politics of professional societies can be another confounding force. ♦ Underneath all of the social, political, and economic machinations, and of much greater consequence, are two substantive factors: 1) the shift in the epidemiology of disease from the acute/crisis type of episodes to the chronic/ageing associated pathologies for which conventional therapies are ill-suited and 2) the rapid progress in understanding the fundamental mechanisms of biological and disease processes, thus causing an acceleration in the evolution of therapeutic modalities. Between those two, the scientific paradigm upon which medicine is based is being forced to change profoundly.

Somewhere in this complex set of forces, there is still the issue of the practice of good medicine - i.e., a trained professional taking the responsibility for attempting to do the best that one can within a set of unique, individual circumstances to manage or, possibly, cure a problem of a particular individual. Integrating computer technology into that practice may

INTRODUCTION

seem like a further complication; and, certainly, it is not a panacea. It can, however, mitigate the vulnerability to malpractice by demonstrating “due diligence”; it can help overcome some of the constraints of parochial “standard of care” criteria; it can build patient confidence in scientific medicine; and mostly, it can help you to stay on top of the evolution of bio-technology and help provide state-of-the-art medicine and best possible care to your patients, which, after all, is the main purpose.

Many professionals will be saying, in their internal dialog, something like; “I spent all of this time, effort, and money to be educated, why can I not just practice what I know and not have to be concerned with continuously revising my practice by staying on top of the research?” But, you know the answer even before you complete your objection, so there is no merit in belaboring the point. There is a whole new order of communications technology which will radically transform all sectors of society, including the practice of medicine. This was forecasted in the early 1970’s; and it is now in full swing. The future belongs to those who can get on top of it and figure out how to use it. Consider the analogy between the impact which the information technology of Gutenberg had on the established theocracy of that age and apply that to what the Internet will be doing to the established orders of today - only shorten the time by a factor of 1,000.

HOW MEDICAL KNOWLEDGE IS PUBLISHED

One of the first things to keep in mind is that, although it may seem like the Internet is the complete repository of all knowledge, still, only a small percentage of medical information is available at this time through this medium. Also, the information which you do obtain must be viewed with some understanding of its limitations, which can be accomplished by having a general idea about how scientific information and medical knowledge is published.

Scientific investigators, throughout the world, work on their projects and present their findings in various forums. They conduct personal conversations and correspondence with collaborators. This is probably the most important mode of communication; and none of those exchanges are available to the public on the Internet. Also, they present their findings at conferences, poster sessions, and symposia; and most of that is not available on-line nor is it available at research libraries. You have to attend. These first two steps are what might be called “unpolished” work, which eventually is targeted for publication. Next, scientists send their individual research reports to journals which publish papers in particular

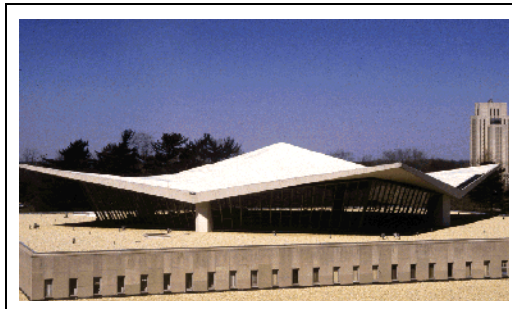
INTRODUCTION

areas of interest. Usually, these journals are published by non-profit societies for their membership and for subscribing libraries. There are also commercial publishers of scientific information. When an editor of a journal receives a paper, if it is of interest, then it is sent to a small group of scientists who have established expertise that is pertinent to the subject. They evaluate the merit of the paper in a process which is known as “peer review” - sometimes rejecting a paper, other times asking for changes or clarification from the original investigator. The idea is to help insure the reporting of only relevant and quality research. If the paper is accepted, then it is scheduled for publication in a printed journal. It must be understood that most of these scientific reports, in their full form, are available only to subscribing members of the society or at research oriented libraries which subscribe to the journals. Increasingly, many of these societies are publishing directly on the Internet; however, the number is still small, and they usually charge for the information.

World-wide, there are about 7,000 bio-medical journals that are published in the life sciences and which (apart from private correspondences, the proceedings of conferences, books, and the minds of the individual investigators, themselves) constitutes the repository of scientific knowledge. How to get to this knowledge and organize it in a meaningful way for a particular person is our challenge. In our structured approach, the focus is on several databases.

THE PRINCIPLE SOURCES OF INFORMATION

The resources the National Institutes of Health (NIH) will be used as the corner stone of our program. NIH is the world’s leading medical research organization, supporting some 35,000 research projects, with a budget of about \$18 billion (fiscal 2000). The agency includes 20 separate health institutes, including the National



The National Library of Medicine - from the roof. Most of the building is underground, thus, protecting the collection from catastrophes. It is an interesting and worthwhile historical footnote that both the Internet and the National Library of Medicine were created initially by the U.S. military. The military is usually regarded as a tremendous economic burden to society; however, it is likely that the Internet, by creating an entirely new layer on the world economy, will, by itself, repay, in short order, all of the expenditures that have ever been made on the military. In addition, the National Library of Medicine has been an integral and necessary component in the “biological revolution”, also creating a new economic order.

INTRODUCTION

Library of Medicine, of which MEDLINE is a product and is a central component for our program.

MEDLINE. The principle database which you will be using for all subjects is MEDLINE. Consider this to be the primary “front-end” to medical information on the Internet. To go about using the general resources of the Internet without first grounding oneself on the information from MEDLINE is somewhat futile. MEDLINE is a professional, bio-medical database which, until about 1997, was available only by subscription to researchers. It is the oldest and most extensive aggregation of citations, embodying over 11,000,000 records, going back to 1966. Over 30,000 new citations are added each month. MEDLINE is created by the National Library of Medicine; and it is supported by the American tax-payer within a total budget for The Library of about \$200 million annually, which is less than \$1 per citizen. There are other, privately published, bio-medical databases such as BIOSIS, Excerpta Medica, and Chemical Abstract Services; but these are less complete and are expensive, being available only by subscription. Of the 7,000 journals which are published in the life-sciences, MEDLINE indexes about 4,800. The MEDLINE indexing is a meticulous process, which is described later, in detail. It is important to understand that the citations in this database are not the full articles but rather are only an abstracting of the articles; and when one finds a report that is particularly relevant, one must still go into the library and retrieve it. This needs to be emphasized because, as a result of the ease of electronic retrieval, many people, including researchers, are now using the abstracted articles alone as a basis for formulating decisions. Although that may be appropriate, up to a point, such truncation can be a major fallacy in many situations.

CancerNet/PDQ. For cancers, in addition to MEDLINE, you will be using a database called CancerNet (also known as PDQ or Physicians Data Query). This is produced by the National Cancer Institute - again, a component of the National Institutes of Health. CancerNet/PDQ is a comprehensive, cancer database, which contains peer-reviewed summaries on cancer treatment, screening, prevention, and supportive care. It contains also a registry of several thousand active, clinical trials for the treatment of all types of cancer at locations from around the world. Further, it contains directories of physicians, genetic counselors, and organizations that provide cancer care.

Other Databases and Sectors of the National Institutes of Health (NIH). The NIH maintains many databases which contain bio-medical information that has been “peer reviewed” for scientific validity. These contain a wealth of good information upon which a

INTRODUCTION

person should ground one's understanding before venturing into the wilderness of the Internet.

The INTERNET itself. The next database which you will be using is the Internet itself. The Internet is a telecommunications network which integrates any and all servers that are plugged into it; thus, making the contents of those servers potentially available to you. This ranges from small, individual servers, to larger main-frames and distributed networks of universities, corporations, and government agencies, such as MEDLINE and CancerNet/PDQ, above.

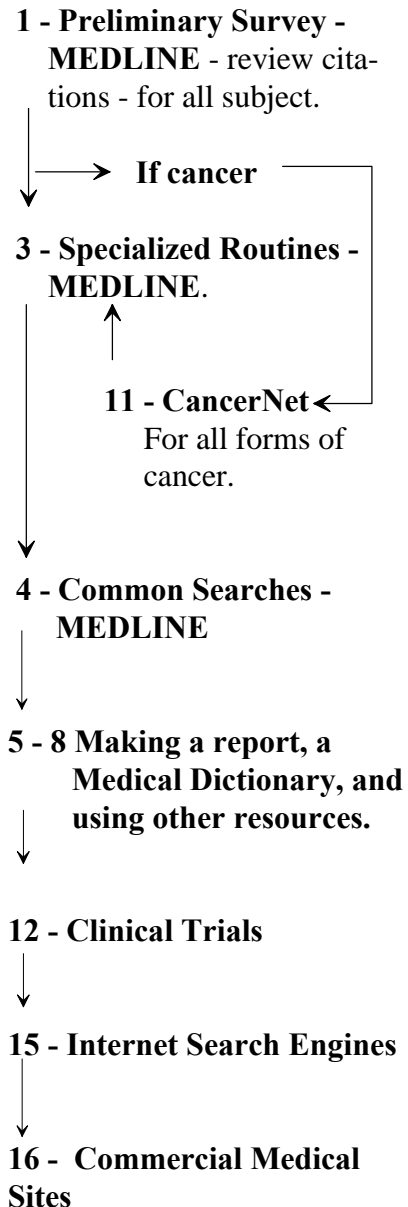
To use the Internet as a database, one employs the various Internet directories, search engines, news groups, and other functions; and we will provide some of the basic guidelines for "navigating" through this complex environment. Also, we provide direct links to various sites which we find of interest.

AN OUTLINE OF THE RESEARCH STRATEGY

From this point forward, you will be dealing with the details of the retrieval procedures and the research information. Although they will appear to be complicated, at first, the procedures are fairly simple if you will just follow the instructions, one-by-one.

It may be useful to have an over-view of the research strategy. The initial procedure will use some of the resources of the National Library of Medicine. The first procedure, **1 - PRELIMINARY SURVEY - MEDLINE - "REVIEW" CITATIONS**, will be used in almost all initial searches. Retrieve the most recent 200, "review" citations. Print this search, read the

Schematic of Search Strategy



INTRODUCTION

citations, mark the ones of particular relevance to your interest, and mark the important terms for **5 - MAKING A PERSONAL DICTIONARY**. Next, if you are dealing with a cancer, bypass, for the time, procedures **2-8**; and go to **11 - RESEARCHING CANCERS - CANCERNET/PDQ**. There, you will retrieve the monographs for the Patient and the Physician, and the listing of the Experimental Trials. Also, there are other sectors which might be relevant.

These first two steps are what constitutes a “Base Report”.

Then, proceed to **2 - DEFINING SEARCH TERMS AND 3 - SPECIALIZED SEARCH ROUTINES - MEDLINE**. You will probably only want to do some of these specialized searches. Again, print and read the information, marking noteworthy items. Subsequently, in the other sections, we will use other medical functions of the National Institutes of Health and other sources. The various procedures which follow, expand your search capabilities from the principle sources of information out into the larger Internet.

USE YOUR PRINTER

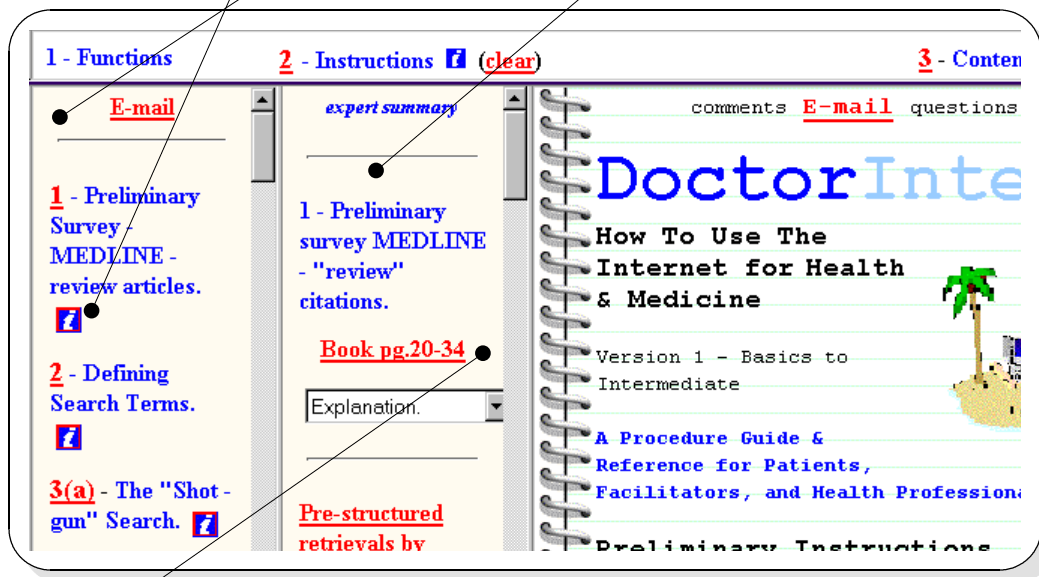
Be liberal with your printer! It is difficult, if not impossible, to read and understand technical information on a computer screen. Printers are cheap. They take a lot of wear and tear and last a long time. Further, printing materials (ink and paper) are also cheap, costing about 2 cents per page, which would be \$4 for a 200 page document. Finally, as confirmed by Dr. Tom Friberg of the Weyerhaeuser Company, one of the largest timber companies in the world, the use of paper does not destroy forest stock (at least in the U.S.): “Today, most all of the wood based fiber used in the US to make paper comes from three sources: 1) recovered paper, 2) wood residuals from the production of lumber and 3) trees grown specifically for pulp production.” (e-mail of June 28, 1999) Also, print on one side. This allows you to make notes on the opposing, blank sheet. See additional comments in Section 5 for suggestions about how to structure a report for presentation to physicians, if your are a patient or facilitator, or vice versa.



INTRODUCTION

THE DOCTORINTERNET PROGRAM & WEB SITE

Again, the procedures in this book stand by themselves and do not require the program functions on the CD or the web-site. However, if you do use the CD and web-site, a cursory introduction is helpful. The DoctorInternet Program, in the CD templates and the web-site, uses three frames for navigation. **Frame #1** (1- Functions) is a complete table of contents of the procedures. Many of the procedures are referenced directly to the relevant Internet site; and the procedure number is an active link. Also, each procedure is explained briefly by selecting the **icon** and is displayed in **Frame #2** (Instructions). A more detailed explanation of each procedure may be obtained by selecting the link entitled



Book pg.... Frame #3 is for the display for the content of Internet sites and chapters of the book. Frames #2 and #3 may be cleared in order to decrease visual clutter, and the size of the frames may be narrowed or expanded to increase visibility by selecting the frame with your cursor and dragging it.

INTRODUCTION

ABOUT THIS BOOK

Again, keep in mind that this book stands by itself and does not need either the CD nor the attendant web-site. Indeed, it is probably best to indoctrinate yourself first with just the book before using the Internet templates. That might help avoid some confusions. We have deliberately keep the book to a manageable length and used a larger font size which is easier to read. It would have been possible to include an extensive amount of diversified information. Although to have done so might have made the initial appearance more impressive, it would have increased the cost unnecessarily and decreased the usefulness. Mostly, what a person needs is to have some professional help with the basics and some guidance with more difficult procedures, and then the degree of extensiveness and diversification should be left to each individual user. In the graphic representation of this book, we have elected to use dotted lines from the text to the relevant graphic images. Aesthetically, this looks somewhat crude; however, the purpose here is instruction, and for that purpose, this is the best mode. Also, the graphics and photographs have been left in the resolution in which they are delivered via the Internet. Thus, they are not high quality, but that is what you get in this medium for the present.

THE DOCTORINTERNET PROGRAM IS EASY TO USE

Of course, nothing is easy until after you already know how to do it. And this is true particularly in regard to computers. However, the procedures in the book and the routines of the program are fairly straight-forward. Just follow the steps, one-by-one; and if you get lost, start over. After a few passes, you will probably not need the instructions at all. In debugging this manual, we used a 17 year old who was completely naive about the system and not very adept at computers. He was able to do a Basic Report on a cancer (i.e., procedures 1 and 11) in less than 15 minutes, making only a few mistakes, which were caused by trying to jump ahead of the written procedures or by clicking on the wrong icon. He self-corrected his mistakes and was able to obtain the exact same information which the most advanced researcher would have obtained, within the constraints of the preliminary search strategy.

Web pages change. If you have an older version of the book, do not be surprised if you find that some of the web-pages have been modified. The databases will remain constant, but the designers keep tinkering with interfaces. Changes are incorporated in the DoctorInternet web-site and in the latest version of the CD ROM.