

Consumer Guide to Internet Resources In CAM

Introduction

Health care providers are increasingly treating patients who are bringing Internet printouts to the consultation. These printouts often include information on CAM products and practices. Current estimates on the frequency of this phenomenon vary from 58% (1) to over 70% (2). While the impact of this access to health information on the practitioner-patient relationship has been debated, the (3)Internet is increasingly playing a role in medical decision making and allowing patients to become more involved in their health care decision making.

Use of CAM Health Information

There is limited data on CAM Internet users and the data that does exist suggests that those seeking online CAM information on the Internet are primarily those who suffer from chronic illness and that they are seeking information on CAM and nutritional advice. As trends in user involvement, consumer empowerment, and wide dissemination of information on CAM continue, it will be increasingly more important to understand and address the needs and desires of those who are accessing CAM information on the Internet. With this in mind, following resources have been compiled to help aid patients and consumers who are considering CAM treatments.

Government Resources

The National Center for Complementary and Alternative Medicine, National (NCCAM)

<http://nccam.nih.gov/>

The NCCAM is dedicated to exploring complementary and alternative healing practices in the context of rigorous science; training CAM researchers; and disseminating authoritative information to Health care consumers and patients.

NCCAM Public Information Clearinghouse

As one of its mandates from Congress, NCCAM is charged with "the dissemination of health information. In respect to identifying, investigating, and validating complementary and alternative treatment, diagnostic, and prevention modalities, disciplines, and systems." (Public Law 105-277) The NCCAM Clearinghouse serves this mission. It is the public's point of contact for scientifically based information on complementary and alternative medicine (CAM) and for information about NCCAM. P.O. Box 7923

Gaithersburg, Maryland 20898

Tel: 1-888-644-6226; outside U.S.: (301) 519-3153

Fax: 1-866-464-3616 (Toll-Free)

TTY: 1-866-464-3615 (Toll-Free)

Email: info@nccam.nih.gov

<http://nccam.nih.gov/nccam/fcp/clearinghouse/>

NCCAM Newsletter

<http://nccam.nih.gov/nccam/ne/newsletter/>

NCCAM Fact Sheets

Considering Complementary and Alternative Medicine Therapies?

<<http://nccam.nih.gov/fcp/faq/considercam.html>>

Frequently Asked Questions about CAM and the NCCAM

<<http://nccam.nih.gov/fcp/faq/index.html>>

General Information about the NCCAM

<<http://nccam.nih.gov/an/general/>>

NCCAM Clearinghouse

<<http://nccam.nih.gov/fcp/clearinghouse/index.html>>

NCCAM Research Grants: Information for Researchers

<<http://nccam.nih.gov/fcp/factsheets/information/information.htm>>

Acupuncture

<<http://nccam.nih.gov/fcp/factsheets/acupuncture/acupuncture.htm>>

Cancell/Entelev*

<http://cis.nci.nih.gov/fact/9_13.htm>

Coenzyme Q10

<http://cis.nci.nih.gov/fact/9_16.htm>

Hepatitis C

<<http://nccam.nih.gov/fcp/factsheets/hepatitisc/hepatitisc.htm>>

Laetrile/Amygdalin*

<http://cis.nci.nih.gov/fact/9_3.htm>

St. John's Wort

<<http://nccam.nih.gov/fcp/factsheets/stjohnswort/stjohnswort.htm>>

CAM on Pub Med.

This collection of more than 220,000 citations is accessed through the Pub Med database, which also includes Medline. Sponsored by the National Center for Pub Med can be accessed at: <<http://www.nlm.nih.gov/nccam/camonpubmed.html>>

Combined Health Information Database (CHID)

The federally supported Combined Health Information Database (CHID) is another service in which NCCAM participates, which includes a variety of materials not available in other government databases. CHID aggregates health information for the public on numerous topical areas related to health and disease. < <http://chid.nih.gov/> >

National Institutes National Cancer Institute National Cancer Institute (NCI)

The National Cancer Institute has funded a number of CAM clinical trials, many in conjunction with NCCAM, including evaluation of the value of vitamins and minerals in cancer prevention and treatment, Gonzales nutritional therapy, angiogenesis effects of shark and bovine cartilage, the effects of caratinoid nutrients on human papilloma viral lesions, the effect of natural inhibitors of carcinogenesis, and other types of natural products research.

<<http://www.nci.nih.gov/>>

NCI Office of Cancer and Complementary and Alternative Medicine

The Office of Cancer Complementary and Alternative Medicine (OCCAM) was established in October 1998 to coordinate and enhance the activities of NCI in the arena of complementary and alternative medicine (CAM). The goal of (OCCAM) is to increase the amount of high-quality cancer research and information about the use of complementary and alternative modalities

<<http://www3.cancer.gov/occam/>>

NCI Cancer Trials Database

<http://www.nci.nih.gov/clinical_trials/>

Quality and Safety Issues

The Food and Drug Administration (FDA)

The FDA regulates dietary supplements under a different set of regulations than those covering "conventional" foods and drug products (prescription and Over-the-Counter). Under the Dietary Supplement Health and Education Act of 1994 (DSHEA), the dietary supplement manufacturer is responsible for ensuring that a dietary supplement is safe before it is marketed. FDA is responsible for taking action against any unsafe dietary supplement product after it reaches the market. Generally, manufacturers do not need to register with FDA nor get FDA approval before producing or selling dietary supplements. Manufacturers must make sure that product label information is truthful and not misleading. FDA's post-marketing responsibilities include monitoring safety, e.g. voluntary dietary supplement adverse event reporting, and product information, such as labeling, claims, package inserts, and accompanying literature.

<<http://www.fda.gov/>>

FDA Food Safety Site

<<http://www.cfsan.fda.gov/>>

Dietary Supplements/Food Labeling Electronic Newsletter

<<http://www.cfsan.fda.gov/~dms/infonet.html - fda-dsfl>>

The Centers for Disease Control (CDC)

In the area of CAM, the CDC has taken a role in monitoring herbal supplements and has also analyzed data on nutritional supplements. Although their Web site does not post an area dedicated specifically to alternative medicine, a subject search yielded 40 documents, primarily reports in pdf files. All entries are relevance ranked to the topic. Of the first 20, 19 were published within

the past 15 months. The CDC site also provides excellent up-to-date information regarding infectious disease, outbreaks, and epidemiology.

<<http://www.cdc.gov/>>

The Federal Trade Commission (FTC)

The FTC protects consumers by pursuing organizations that fraudulently market products and services on the Web. Recent enforcement actions have been taken and are currently underway.

< <http://www.ftc.gov/opa/2001/06/cureall.htm>>

Canadian Natural Health Products Directorate

This new office will have the authority to approve natural health products for the Canadian market, ensuring Canadian consumers safe the natural health products

<http://www.hc-sc.gc.ca/hpb/onhp/welcome_e.html>

Health Protection Branch, Canada

<<http://www.hc-sc.gc.ca/hpb/>>

Research Resources in CAM

NCCAM funds and monitors more CAM research than any other institution in the United States. The level of appropriation for NCCAM has been increased twice, to a budget of \$113M for the year 2003. As a result partnering with other NIH Institutes, NCCAM has achieved aggregate funding totaling roughly \$200M for 2002. Table 7.1 provides list of clinical trials that are currently recruiting subjects.

NCCAM Sponsored Clinical Trials

Phase III Clinical Trials	Status	Cosponsoring NIH Institutes/Centers	Target Enrollment	ClinicalTrials.Gov URL
Shark cartilage as adjunctive therapy for lung cancer	Enrolling subjects	NCI	756	http://clinicaltrials.gov/ct/gui/c/w1r/show/NC T00005838?order=1&JServSessionIdzone_ct=mxnx862t1
Ginkgo biloba to prevent dementia	Enrolling subjects	NIA, NHLBI, NINDS	3,000-3,500	http://clinicaltrials.gov/ct/gui/c/w1r/show/NC T00029679?order=4&JServSessionIdzone_ct=mxnx862t1
Acupuncture for osteoarthritis pain	Enrolling subjects	NIAMS	570	http://clinicaltrials.gov/ct/gui/c/w1r/show/NC T00010946?order=2&JServSessionIdzone_ct=mxnx862t1
Glucosamine/chondroitin to treat osteoarthritis	Enrolling subjects	NIAMS	1,588	http://clinicaltrials.gov/ct/gui/c/w1r/show/NC T00010790?order=1&JServSessionIdzone_ct=mxnx862t1
Vitamin E/selenium to treat prostate	Enrolling subjects	NCI	32,400	http://clinicaltrials.gov/ct/gui/c/w1r/show/NC T00006392?order=3&JServSessionIdzone_ct=mxnx862t1

cancer				
Hypericum perforatum to treat minor depression	Awarded	NIMH, ODS	300 (min)	N/A
EDTA chelation therapy to treat coronary artery disease	Under review	NHLBI	1,600 (est)	N/A
Saw palmetto/P. africanum to prevent progression of benign prostatic hypertrophy	Announced	NIDDK, ODS	3000 (est)	N/A

Source: S. Straus, S. Congressional Testimony, 2002

ClinicalTrials.Gov

ClinicalTrials.Gov provides a complete listing of all CAM trials sponsored by the NIH. For a complete listing of clinical studies in CAM search under the Keyword "Alternative Medicine". As of April 2002, there were 147 clinical trials listed.

< <http://www.clinicaltrials.gov/> >

In addition to funding individual clinical trials NCCAM has funded or provided co-funding to 15 research centers across the US. Each program concentrates on prevention and treatment of at least one major disease condition or on the health issue of a particular population. These centers in turn have the ability to fund pilot studies called "development-of-feasibility projects." Given the focus of each of these centers, they are in a position to conduct, assess and stimulate research within their field. There are now quite a few research organizations focused on complementary medicine; most often these are academic medical schools that are involved in performing research and teaching medical students. A number of them have also developed integrative clinics where patients are treated. Some institutions such as the University of Maryland include a focus on informatics, research, education and clinical care.

MedlinePlus

Designed for both health professionals and consumers MEDLINEplus has extensive information from the NIH and other trusted sources on about 500 diseases and conditions including CAM. There are also lists of hospitals and physicians, a medical encyclopedia and dictionaries, health information in Spanish, extensive information on prescription and nonprescription drugs, health information from the media, and links to thousands of clinical trials.

<<http://www.nlm.nih.gov/medlineplus/alternativemedicine.html>>

Healthfinder.gov

The Government Healthfinder is a massive directory that provides links to Web sites. It is essentially a searchable health portal linked to pre-selected quality government and private health-related sites, including those on complementary therapies. The Healthfinder can be searched by broad topic, by diagnosis, and by therapy, linked primarily to Web resources and organizations.

-A search on the keywords "alternative medicine" produced 150 web resources and 66 organizations.

<<http://www.healthfinder.gov/>>

White House Commission on Complementary and Alternative Medicine Policy

President Clinton formed this commission to make recommendations on public policy and legislation pertaining to complementary and alternative medicine. Web site contains the Full White house Commission Report and transcripts of Town Hall meetings.

<<http://www.whccamp.hhs.gov/>>

Cochrane Collaboration

Consumer Summaries of Cochrane Systematic Reviews

Therapy	Summary Title	URL
Acupuncture	Acupuncture does not appear to help smokers who are trying to quit	http://www.cochraneconsumer.com/ .
Acupuncture	Acupuncture might be able to provide short-term relief from tennis elbow, but more research is needed	http://www.cochraneconsumer.com/ .
Acupuncture	Acupuncture seems to be able to help relieve headaches and migraine, but more reliable research is needed	http://www.cochraneconsumer.com/ .
Acupuncture	Not enough evidence about acupuncture for asthma, and more research is needed	http://www.cochraneconsumer.com/ .
Alexander Technique	No evidence that the Alexander technique can relieve asthma symptoms or reduce the need for medication, and more research is required	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000013
Herbal Therapies	No evidence that the Alexander technique can relieve asthma symptoms or reduce the need for medication, and more research is required	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000013
Herbal Therapies	Not enough evidence to show the effects of spinal manipulation for painful period cramps	http://www.cochraneconsumer.com/Content.ASP?ID=CO0000000684
Herbal Therapies	Title: 'St John's wort for depression'	http://www.cochraneconsumer.com/Content.ASP?ID=CO0000000684

		000000797
Herbal Therapies	The herbal remedy feverfew might be able to prevent migraines, but more reliable research is needed	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000322
Herbal Therapies	Title: 'Herbal Therapy for treating rheumatoid arthritis' Vitamin B1 and magnesium may both help reduce the pain of dysmenorrhoea	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000959
Herbal Therapies	Title: 'Chinese medicinal herbs for chronic hepatitis B'	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000939
Herbal Therapies	Not enough evidence on whether Methenamine (hexamine) salts can prevent urinary tract infection, but they have few adverse effects and might help	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001313
Herbal Therapies	Herbal medicines used in combination with interferons for people with hepatitis C have not been shown to be effective	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001230
Herbal Therapies	Extracts of the traditional South Pacific plant remedy and recreational drug, kava, may provide effective relief from anxiety (although health authori...	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001223
Herbal Therapies	Extracts from the African prune tree (<i>Pygeum africanum</i>) may be able to help relieve urinary symptoms caused by enlarged prostate (benign prostatic hyp...	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001329
Herbal Therapies	Title: 'Herbal Therapy for treating osteoarthritis'	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000958
Herbal Therapies	There is weak evidence that some Chinese medicine may help reduce hepatitis B in symptom-free people carrying the virus, but more research is needed	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001018
Homeopathy	Homoeopathic Oscillococcinum does not prevent influenza, but probably shortens the length of the illness	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000368

Homeopathy	Not enough evidence from trials to determine whether or not homeopathy can help improve asthma	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000367
Homeopathy	There is not enough evidence to show the effect of homeopathy for inducing labour	http://www.cochraneconsumer.com/Content.ASP?ID=CO000001212
Prayer	<u>Title: 'Intercessory prayer for the alleviation of ill health'</u>	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000412
Tai Chi	Interventions to prevent falls in elderly people can be effective	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000432
Yoga	No reliable evidence to support the use of yoga as a treatment for control of epilepsy	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000914
Yoga	Not enough evidence about the use of breathing exercises (including yoga and the Buteyko method) by people with asthma	http://www.cochraneconsumer.com/Content.ASP?ID=CO000000126

UK-Bandolier - Complementary and Alternative Therapies

Bandolier strives to gather the best evidence available about complementary and alternative therapies (CAT) for patients, consumers and professionals, and to update this information as better evidence becomes available.

<http://www.jr2.ox.ac.uk/Bandolier/booth/booths/altmed.html>

OMNI

OMNI (Organising Medical Networked Information) is a gateway to evaluated, quality Internet resources in health and medicine, aimed at students, researchers, academics and practitioners in the health and medical sciences

<http://omni.ac.uk/>

CAM Directories

The Rosenthal Center

A comprehensive and authoritative listing, from Columbia University, NYC, of complementary and alternative medicine resources.

<http://cpmcnet.columbia.edu/dept/rosenthal/>

University of Pittsburgh

Alternative Medicine Home Page

<<http://www.pitt.edu/~cbw/internet.html>>

McMaster University Alternative Medicine Resources

A comprehensive Canadian directory of web sites on the Internet.

<<http://www-hsl.mcmaster.ca./tomflem/altmed.html>>

New York Online Access to Health (NOAH)

Complementary and Alternative Medicine

www.noah-health.org/english/alternative/alternative.html

Yahoo Alternative Medicine

Contains a listing of over 500 CAM sites

<http://dir.yahoo.com/Health/Alternative_Medicine/>

HeathWell

Features comprehensive information regarding alternative health and integrative medicine

www.healthwell.com

Popular Health Sites with Good CAM Information

Ask Dr. Weil

DrWeil.com is a leading provider of online information and products for optimum health and wellness.

<http://www.drweil.com/app/cda/drw_cda.php>

InteliHealth

A comprehensive CAM site with a broad range of timely information.

<<http://www.intelihealth.com/IH/ihtIH/WSIHW000/8513/8513.html?k=navx408x8513>>

MedWeb Plus - Alternative Medicine

Extensive directory of CAM sites organized using the same “Alternative Medicine” Medical Subject Headings used by the National Library of Medicine.

< http://www.medwebplus.com/subject/Alternative_Medicine.html >

WebMD/Medscape

WebMD/Medscape—is quite a comprehensive site offering Internet based medical information for consumers and professionals. Site includes extensive content on alternative and complementary medicine resources for patients. Registration is required.

<http://www.medscape.com/>

WholehealthMD

WholeHealthMD.com is a partnership between leading companies in the health-care field: American WholeHealth and Rebus..

<<http://www.wholehealthmd.com/>>

Topical Sites and News

The value of news for researchers is its topical nature, reporting on what is being published in the scientific and medical literature. These sites may also report on utilization, new developments, and trends in the field. To stay abreast of complementary medicine, it can be important to scan topical sources of media, including newspapers, magazines, newsletters, and the Web for new therapies and new research. Just because there has not been a controlled clinical trial does not represent proof either that a therapy does, or does not, work. Epidemiological data and trends are other types of information available from news sources. In the context of how one gathers and synthesizes information, topical content has relevance.

HealthWell Natural News

< <http://www.healthwell.com/news/index.cfm> >

Natural Health Line

< <http://www.naturalhealthvillage.com/> >

Alternative Health News Online

<http://www.altmedicine.com/FrameSet.asp>

USA Today Health

<<http://www.usatoday.com/life/health/health.htm>>

Science Daily News

<<http://www.sciencedaily.com/index.htm>>

Health Watch Web Site

<http://www.trifax.org/menu/health1.html>

Medscape Medical Research News

<http://www.medscape.com/medscapetodayhome>

CNN Daily Updates on Health Topics

<http://www.medscape.com/Home/Topics/multispecialty/multispecialty.html>

Reuters Health Information Services, Inc.

<http://www.reutershealth.com/>

ABC NEWS.com: Health & Living News Index

<http://www.abcnews.com/sections/Living/>

New York Times Daily Health News: Your Health Daily

<http://yourhealthdaily.com/>

Newsletters

The Internet meets an important need in the provision and disseminating of information on alternative therapies. Links between the publishing industry and the internet reflect the breadth of the technology transfer that is taking place, through books and content that include medical textbooks, texts used in the training of CAM professionals, quality CAM journals, full-text journal articles available online, quality trade paperbacks geared toward consumers, and newsletters written for clinicians, administrators, or consumers. An extensive range of online newsletters are available, geared to every conceivable audience and most all the various types of Web sites listed here develop and tailor content for their readers on a continuous basis.

CAM Newsletters

Newsletter	URL
Townsend Letter for Doctors and Patients Published by Jonathan Collin, MD, Port Townsend, Scientific and anecdotal information from researchers, health practitioners and patients.	http://www.tldp.com/
Complementary Medicine Field Newsletter: The Cochrane Collaboration: Karen Soeken executive editor.	http://www.compmed.ummc.umaryland.edu/Compmed/Cochrane/Cochrane.htm >
Bandolier: Andrew Moore, executive editor, NHS R&D Directorate. Contains bullet points (hence Bandolier) of evidence-based medicine and covers CM topics.	http://www.jr2.ox.ac.uk/Bandolier/ >
Natures Herbs: Jim Duke: editor. A Detailed description of herbs commonly used in the U.S.	http://www.naturesherbs.com/nh/index14.html >
Integrative Medicine Consult: Leonard Wisneski, editor.	http://www.onemedicine.com >

This site provides impartial, up-to-date, science-based information about alternative therapies and botanical medicines in short summaries and discussions tailored to the needs of practicing physicians.	
Queensland Herb Society Newsletter: Australian newsletter that contains links to herb resources	< http://www.powerup.com.au/~sage/ >
Natures Herbs: Jim Duke: editor. A Detailed description of herbs commonly used in the U.S.	< http://www.naturesherbs.com/nh/index14.html >
HerbClip: Herb Research Foundation.	http://www.herbs.org/green_aper.html >
HerbalGram: Herb Research Foundation	< http://www.herbs.org/pubHG.html >
Integrative Medicine Consult: Leonard Wisneski,	< http://www.onemedicine.com/ >

CAM Associations

Association	Modality	Country	URL
Complementary Medicine Association	Complementary Medicine	UK	< http://www.the-cma.org.uk/ >
American Academy of Medical Acupuncture	Acupuncture	US	< http://www.medicalacupuncture.org/ >
British Medical Acupuncture Society	Acupuncture	UK	http://www.medical-acupuncture.co.uk/ >
American Association of Naturopathic Physicians:	Naturopathic	US	< http://www.naturopathic.org/ >
American Chiropractic Association	Chiropractic	US	< http://www.amerchiro.org/ >
The Canadian Chiropractic Association	Chiropractic	Canada	< http://www.ccachiro.org/ >
British Chiropractic Association	Chiropractic	UK	< http://www.chiropractic-uk.co.uk/ >
The American Herbalists Guild	Herbal Medicine	US	< http://www.healthy.net/herbalists/ >

American Herbal Products Association	Herbal Medicine	US	< http://www.ahpa.org/ >
British Herbal Medicine Association (BHMA)	Herbal Medicine	UK	http://info.ex.ac.uk/phytonet/bhma.html >
American Holistic Medical Association	Holistic Medicine	US	< http://holisticmedicine.org/ >
American Massage Therapy Association	Massage	US	< http://www.amtamassage.org/ >
The Association of Physical and Natural Therapists		Herbal and Manual Therapies	< http://www.apnt.org.uk/ >
British Homeopathic Association	Homeopathy	UK	http://www.trusthomeopathy.org/trust/tru_over.html >
National Center for Homeopathy	Homeopathy	US	http://www.healthy.net/nch/ >
Touch For Health Association	Therapeutic Touch	US	< http://www.tfh.org/ >

References

1. Wilson SM. Impact of the internet on primary care staff in Glasgow. J Med Internet Res 1999;1(2):E7.
2. Hjortdahl P, Nylenna M, Aasland OG. [Internet and the physician-patient relationship--from "thank you" to "why"?]. Tidsskr Nor Laegeforen 1999;119(29):4339-41.
3. Gerber BS, Eiser AR. The patient physician relationship in the Internet age: future prospects and the research agenda. J Med Internet Res 2001;3(2):E15.