

Women Wading Through the Web A Health Toolkit

womenshealthmatters.ca



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CANADIAN COUNCIL ON LEARNING
CONSEIL CANADIEN SUR L'APPRENTISSAGE

IHI The New
Women's College
Hospital

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About the toolkit

Introduction

More and more Canadian women rely on the Internet as a source of health information for themselves and their families. Are you one of these women? Then this toolkit is for you! Whether you are a beginner or an experienced Internet user, the sheer volume of information can be daunting at times.

We created this toolkit to assist the many women who have asked us for help in navigating this often confusing maze of health information on the Web. We hope the toolkit will enhance your ability to find, analyze and understand the information you seek for you and your family.

At womenshealthmatters.ca, we have been helping women wade through the Web since 2000. Produced and reviewed by women's health experts at Women's College Hospital in Toronto, our website provides women of all ages with information, news and research findings on women's health, diseases and lifestyles.

Whether you are new to the Internet or an experienced user, we hope you will use the toolkit to:

- Learn more about search engines and other search tools and strategies.
- Judge the quality of a website.
- Improve your skills in finding and assessing reliable health information.
- Understand medical research.
- Analyze health information from the media.
- Communicate more effectively with health professionals.

How to use the toolkit

You can read the toolkit from beginning to end, or skip to the sections you are interested in. You might want to print it out and keep it by your computer for use as a handy reference tool.

If you come across a term you don't understand, you can:

- Try Answers.com (www.answers.com), a website that searches information from many sources at once
- Type the word "define:" (with colon and no quotation marks or spaces) followed by the word or phrase in your Google search box.
- Look at the glossaries in some of the tools at the end of each section of the toolkit.
- Use Webopedia (www.webopedia.com), an online encyclopedia and search engine for computer technology.
- Right-click on a word in the toolkit, then click on "look up" for a definition from an online dictionary. (This may not work on all computers.)

Before you start

Before you search for online information, think about what you are going to do with the information you find:

- Are you trying to find information about a disease or condition?
- Are you looking for research?
- Is it for yourself or someone else?
- What do you plan to do with the information once you find it?

Answering these questions in advance may help you determine what kind of information is best for you and how to find it.

You and your health-care professional

If you need expert medical advice, you should always seek the services of a competent health-care professional. Keep these points in mind when discussing information you have found on the Internet:

- Do not diagnose or treat any disease or condition yourself.
- Take a printout of information you find to your appointment.
- Think about the best way to present your information.

Did you know?

You can discuss your experiences related to health information on the Internet with other women and the staff at womenshealthmatters.ca in our free moderated discussion group at www.womenshealthmatters.ca/ubbthreads7/ubbthreads.php

1

How to use the Internet to search for health information

When you search for health information on the Internet, you may not find what you are looking for, or you may find too much information. Not everything you find will be useful or reliable. In this section we provide basic information and tips on searching the Internet.

There are three main kinds of search tools on the Web:

1. **Search engines** index the content of websites. Google is the best known search engine, but others such as Yahoo, Live, and Ask are very good. Use them to search across the Web.
2. **Subject directories** group various resources on the Web by topic. Use these to find websites that are about a topic such as women's health.
3. **Specialty sites** are major sites devoted to a particular subject. There are many specialty sites about health: some are very big with a wide range of resources and health topics; others are smaller and deal with a single topic such as breast cancer or arthritis.

When you are looking for health information you will want to use all of these.

Search engines

How search engines work

Search engines crawl the Web, moving from page to page to pick out words and phrases. They store them in a database along with a record of where it was found. Search engines also provide a way to search this database to locate webpages that hold the information the searcher needs. Pages that match the search words best and are the most relevant will be listed first in the results.

Search engines are not all the same. They visit and index different pages and sites at different times. They rank results by different rules and have different features. Therefore, your search results will be different on every engine you use. You might like the way results are displayed better on one search engine compared to another.

Most search engines suggest other search questions you can try. Watch for these suggestions – they can give you good ideas.

Warning: search engines all carry advertisements. They are usually labelled as “sponsored results” or “sponsored links”. Some may be useful but always be aware that they are advertisements.

Leading Web search engines

- Google (www.google.ca) – very large, will show suggestions for refining a health search, is good at returning relevant results.
- Yahoo (www.yahoo.ca) – large, has Yahoo Health, will offer search suggestions.
- Live (www.live.com) – large, has the Health Vault, will offer related searches.
- Ask (www.ask.com) – medium sized, has “smart answers”, helps with narrowing a search, shows other resources such as images and video.

Metasearch engines

A metasearch engine searches other engines – it does not crawl the Web itself. This can be a quick way to see the top 10 results from three or four engines at once. Most metasearch engines have separate metasearch capabilities for the Web, news, blogs, images and video. All have ads or sponsored links:

- Clusty (<http://clusty.com>) will group results into folders. This can help you understand a topic better.
- Info.com (www.info.com) has a large selection.
- Zuula (www.zuula.com) shows results one engine at a time.

Custom search engines

You can create your own custom search engine to search many websites that you have selected in advance – all at the same time. Google offers one; there are many others.

How to use a search engine

Learn how it works. Spend a few minutes reading the help pages, search tips and FAQs (frequently asked questions).

Ask yourself what you really want to know, then:

1. Try to put that into three or four words.
2. Review the first 10 or 20 results.
3. Identify the ones that seem the most relevant.
4. Note the words that are used on the pages you like.
5. Rerun your search with some of those words.
6. You might do this three or four times before you get the results you want.



Quick search tips for most search engines: Use double quotation marks (“ ”) around words or phrases to ensure they are searched exactly as is, with the words side by side in the same order.

Example: “women’s health”.

Put your most important keywords first.

Example: osteoporosis women treatment calcium

Try natural phrasing—search engines give higher ranking to pages with words in the order you use.

Example: treatment of osteoporosis in women

Combine phrases with other keywords.

Example: “women’s health” journal

Type the word OR (always in capital letters) when you want results for different topics or spellings that might not occur within the same webpages.

Example: cardiovascular OR heart OR stroke

Limit your search to sites in a particular “domain”, such as a country (.ca for Canada), or an organizational grouping (.gov for US government) or .org for non-profit sites although there may be some commercial mixed in. Do this by using a colon in the search after the word site.

Example: “breast cancer site:ca”. (In Google, this will retrieve Canadian websites on breast cancer—including government, non-profit and commercial sites.)

Subject directories

Subject directories lead you to places on the Internet that have information on particular topics. Human editors create and maintain these subject directories, selecting the sites to include and often adding a description.

Examples:

- Digital Librarian (www.digital-librarian.com)
- Google (<http://directory.google.com>)
- Infomine (<http://infomine.ucr.edu>)
- Internet Public Library (www.ipl.org)
- Librarians’ Internet Index (<http://lii.org>)
- Open Directory (www.dmoz.org)
- Yahoo (<http://search.yahoo.com/dir>)

How subject directories work

Most directories have 10-20 top categories, each with more specific sub-categories. You can browse them or perform a keyword search of a directory’s contents. They are most useful when you want to see what’s available in a particular field or area of interest.

Did you know?

The Health A-Z section (www.womenshealthmatters.ca/resources) on womenshealthmatters.ca uses our own search engine to search our database. You can also browse an A-Z list of health topics, or use the detailed (advanced) search feature like a subject directory. We also provide a Google search box to search within our entire site.

Health portals and specialty health sites

There are many specialty health sites. Some are full portals with web search, articles, news, and perhaps some personal search features that will remember what you are interested in, or save your results. Other specialty health sites are smaller and specific to a health topic.

Examples of health portals:

- Healia (www.healia.com) – searches the Web, PubMed/Medline and clinical trials.
- MedlinePlus (www.medlineplus.gov) – news, tutorials, topics from US National Library of Medicine.
- WebMD (www.webmd.com) – health topics, headlines, videos, personal portal.

Example of a specialty health site:

- womenshealthmatters.ca (www.womenshealthmatters.ca)

Trusted websites

You don't always have to use search engines and subject directories to find what you need. Think about which websites might have the information you are looking for. Or use our own list of recommended websites at www.womenshealthmatters.ca/toolkit/recommendedsites.

A note on the deep Web

Accounting for 60 to 80 percent of Web material, the deep Web consists of information search engines can not or will not index, including the contents of some databases.

To find deep Web information, you have to find some kind of direct link to it. Search engine results might turn up websites that contain databases. Once you connect to the site, you can then search the database. Just remember the word “databases” and keep your eyes open.



Tip: To locate your search keywords within a retrieved document or webpage, scroll down to the “Find” command under the Edit menu on your toolbar.



If you want to learn more ...

The following tutorials provide instructions on how to use search engines and find information on the Internet. Some contain comparison charts of different search engines, explanations of Boolean logic, handouts and glossaries.

Bare Bones 101: A Basic Tutorial on Searching the Web, from USC Beaufort Library (www.sc.edu/beaufort/library/pages/bones/bones.shtml), provides 20 basic lessons with related exercises.

Finding Information on the Internet: A Tutorial, from UC Berkeley Library (www.lib.berkeley.edu/TeachingLib/Guides/Internet/FindInfo.html), covers search engines, subject directories and the deep Web.

Internet Tutorials (www.internettutorials.net), maintained by librarian Laura Cohen at University at Albany, SUNY, contains a basic guide to the Internet, a discussion of the major Web protocols and research guides.

Searching the World Wide Web, from The OWL (Online Writing Laboratory) at Purdue University (<http://owl.english.purdue.edu/owl/resource/558/01>), contains a discussion on how the Internet and search engines work and a list of resources to help you search the deep Web.

Web Search Guide (www.websearchguide.ca), by librarian Gwen Harris, has a weblog, a search guide, self-paced tutorials, a newsletter and news items.

2

How to judge the quality of a website

Now that you've found a website, what should you look for to make sure its information is reliable? In this section, we talk about what makes a website trustworthy.

Many websites are excellent, but many more contain information that is misleading, incorrect or even dangerous if you follow their advice. This is because – unlike getting a book published by a commercial publisher – almost anyone can set up a website and claim to offer expert information and opinions.

No website is perfect. Use the information in this toolkit, and your own judgment, to decide if the website answers the questions we list in this section. If it doesn't, you may want to look elsewhere.

Keep in mind that no website – even womenshealthmatters.ca – is the only definitive information source. When we publish content on our site, we hope it will help women to have more informed conversations with their health-care providers and friends. A health-care provider who knows the details of your health history and concerns will always be the best source of information for helping you make personal health decisions.

Here are six questions you should ask to judge whether a website is reliable:

1. Who is responsible for the website?
2. What is the purpose of the website?
3. Can I understand the website?
4. Is the information accurate, objective and trustworthy?
5. How current is the information?
6. Does the website respect my privacy?

1. Who is responsible for the website?

The website should list its creators, sponsors and funders. Look for a section called “About Us”, “Who We Are”, “Our Company” or something like that.

- **Non-profit organizations** and **governments** often contain more reliable or unbiased information on their sites than commercial sites do. Hospitals or large disease-specific groups like the Canadian Cancer Society are likely to focus on medical information and have access to a lot of medical expertise.
- **Advocacy** and **health promotion organizations** may focus on how our health-care system could serve people better in dealing with a particular health situation. Usually non-profit, they may have some funding from governments or foundations.
- **Commercial sites** can contain reliable information, but you should always find out what they are selling first. You might have to visit several pages on the site before determining this.

- **Sponsors or funders** can play a big role in the creation of the site. For both non-profit and commercial sites, try to find out how the sponsors or funders were involved, and how they influenced the content.
- Some **drug companies** set up separate non-profit sites. Your only clue may be the copyright statement at the very bottom of the webpage. Note: if you see a statement such as “sponsored by an unrestricted educational grant from...”, the information you find on the site may be less biased.
- **Individuals** create websites and blogs for many reasons. Look for information about their training and experience, and about any experts who may support them.



Tip: Be cautious when you read vague statements like, “This site was created by a group of doctors to answer your questions on diabetes.” Be sure to ask: Who are the doctors? To whom do they report? Are they trying to sell you something? Look for clues such as a product that is mentioned frequently, an online store, extravagant claims or a lot of testimonials with little proof behind them.

2. What is the purpose of the website?

Try to find a clear statement about its purpose. Look for:

- A short summary of the purpose on the homepage or in the “About Us” section.
- Headings like: “Our Mission”, “Goals”, or “Our History”.
- The scope of the site: what it covers and what it doesn’t.
- A statement about the intended audience: for which age group, gender, ethnocultural group or educational level is it written? Is it for consumers or health-care professionals?

The purpose of a website may be related to who created it:

- **Non-profit organizations, governments, hospitals and other health-care facilities** often start sites as an extension of their mandate to provide care to their communities and to raise their profile.
- **Researchers and academics** may create websites to share their work with colleagues, other academics and sometimes consumers.
- **Private companies** want to highlight their products and show how they are used.
- **Individuals** may create a site to share their experience about a disease or the health-care system. This type of website often emphasizes personal experience.



Tip: Watch out for people who create websites simply to promote their own ideas about a disease or treatment. They may go against accepted, proven medical research.

3. Can I understand the website?

- If you don't understand the information, it can't be helpful to you, even if it's medically accurate.
- The stated purpose and intended audience of the site should give you an idea of how easy it might be to understand.
- The design should be simple to navigate. You should be able to find your way easily from information about causes, to information about treatment or support.
- When you begin looking for information, keep at it until you find a website that is easy to read and makes sense to you.

4. Is the information accurate, objective and trustworthy?

- Is the information based on research? (See part 3 of this toolkit for more on research.)
- Are the names of authors and their credentials listed?
- Does the site explain the reasons for developing and sharing the information?
- Does the site state that the information should not be taken as health advice or as a substitute for visiting a health professional? (You will usually find this in the "Terms of Use" section.)
- If the site contains advertisements, sponsorships or sponsored links, are they clearly separated from the health information?
- How does the site choose links to other sites? Some sites link to any website that asks for or pays for a link; others link only to those that meet certain criteria.
- If you have to pay a fee to use some or all of a site, does it state why?
- Can you contact people involved with the site if you have questions?
- Are all sides of the issue presented? If not, does the site state this clearly?
- Does the site back up statements with references from reliable sources such as recognized medical journals or authors with academic credentials?
- Is there a seal of approval like the HONcode (Health On the Internet) seal or the US-based HIPAA (Health Insurance Portability and Accountability Act)?
- Is the site mostly free of typing, grammar and spelling mistakes?

5. How current is the information?

On the Internet, content can be published very quickly, but that doesn't mean that everything online is current. In medicine, information changes very rapidly.

- A properly maintained website should be updated regularly. Webpages should show the last time the page was updated or reviewed.
- Links to other sites should be updated regularly, and outdated or dead links removed. A lot of dead links suggests that a site is not being kept up to date.
- Many sites contain events sections or lists of recommended books. If these are not well maintained, it may be another clue that the entire site is not up to date.

6. Does the website respect my privacy?

Health information is something most of us consider extremely private. In fact, many people use the Internet because they feel they are anonymous when asking personal questions. So be sure to find out what kind of information the website may be collecting about you, and

whether they will sell your name to someone else. Even your e-mail address may reveal more than you want others to know.

- Read the site's "Terms of Use" and privacy policies.
- If you have to register to use a site, find out why, and how the information will be used.
- Consider setting up a separate e-mail address just for online registering.
- Be especially careful before giving any personal information to join a mailing list or discussion group.
- If you really want to use a service, but are concerned it is asking for too much information, consider using a false identity to protect your privacy.
- The HONcode (international) and HIPAA (US) seals of approval have privacy rules.



If you want to learn more ...

Evaluating Health Information

(www.nlm.nih.gov/medlineplus/evaluatinghealthinformation.html), from Medline Plus, offers links to a variety of online resources, from basic tutorials to articles that analyze news and research. Some of the links on these pages will be helpful when you read other parts of this toolkit.

Evaluating Internet Health Information: A Tutorial from the National Library of Medicine (www.nlm.nih.gov/medlineplus/webeval/webeval_start.html), provides a virtual tour through two fictional websites, one reliable and one that is suspect. It uses images of the sites to show where to find information to help you decide if the site is reliable.

Is This What I Want? from the Women's Health Care Centre of the Peterborough Regional Health Centre, gives women seven tests that information should pass, and five additional questions to make sure it is useful. You can find the links to this title and a companion title, **Finding Good Health Information on the Internet**, on this webpage: <http://www.prhc.on.ca/womenshealth/healthinfo>.

A User's Guide to Finding and Evaluating Health Information on the Web (<http://www.mlanet.org/resources/userguide.html>), from the Medical Library Association (MLA), includes advice on starting your search, guidelines for content evaluation, links to the MLA's list of top 10 most useful American consumer websites and its recommended cancer, diabetes and heart disease websites.

3

How to interpret medical research

In this section, we discuss different types of medical research, where to find the original research reports, and how to understand and interpret them.

Medical research aims to advance our knowledge of how our bodies work, how illness affects us and how those illnesses can best be prevented and treated.

Credible researchers publish their findings in peer-reviewed medical journals, which means that anything published has been reviewed by other researchers who weren't part of the study. The reviewers make sure the research was done in a logical way and that the author's findings match the information collected.

Medical journals provide a place for researchers to debate ideas. Usually a number of different papers are published on a topic before an idea is accepted. A treatment will be tested in different circumstances and groups of people. Often research may appear to contradict earlier findings, particularly when it is edited for the news. One day you read that hormone therapy is good for you; the next day that it is not. This leaves you wondering which is right. This isn't necessarily a sign of bad studies. It might be related to how the study was conducted, or who was studied.

Researchers and care providers also need ways to make sense of the debate. Medical journals use these methods:

- **Meta-analysis** – statisticians evaluate many papers and pool the findings of the most reliable research together for an overall result.
- **Review articles** – a topic expert writes a summary of what has been learned on a topic and which issues are still being debated.
- **Practice guidelines** – an expert committee reviews all the literature and comes to an agreement about how it should influence medical care.

Types of research studies

You are most likely to hear about intervention studies. An intervention is anything that might prevent or treat a disease. The intervention could be a drug, an herbal medicine or a program such as group therapy to help women stop smoking.

Clinical trials

A clinical trial is the most formal and careful way of testing an intervention. A clinical trial compares what happens when people take a treatment compared to what happens to untreated people, or people using currently approved treatments.

People not taking the treatment are called the control group. The people in the control group should be as similar as possible to those testing the treatment. Drugs, vaccines, medical

devices and some natural products must be tested in this way under strict regulations before they can be approved in Canada. The company that developed the new drug or device usually designs and pays for the trial.

Clinical trials begin only after results from laboratory and animal studies show that the new treatment is safe to test and likely to be useful. Trials go through four phases, or stages. Health Canada reassesses the drug at each phase before it can go to the next.

When the federal government finally approves a drug for marketing, this means that it has proven useful in enough people, and its known side effects are considered satisfactory or not dangerous. It may not mean that the drug is effective or safe for all people at all times.

Here are some other words used to describe clinical trials:

- **Randomized** – trial participants are chosen at random in order to test the treatment on a group that is similar to the people who will use the treatment in the future.
- **Blind or double-blind** – blind means that the people in the trial don't know whether they are in the treatment group or the control group. Double-blind means the researcher involved doesn't know either. Studies are blinded by giving the control group a placebo (a fake treatment). This prevents their expectations (and those of the caregivers) from influencing the trial.

Randomized double-blind controlled clinical trials are considered the strongest form of research evidence, but such studies are not always possible.

You can also learn about interventions through **case reports** and **case-series reports**. These are reports caregivers make about the experiences of one or a few patients. They may not be typical patients (and their experience may not be like yours), but case reports are an important way to find rare side effects for further study.

Observational studies

Some studies help us learn about what happens to people who are exposed to a risk or living with an illness. They compare two groups: one with the disease or risk and a second group that does not have the disease or risk.

- **Case-controlled studies** look back in time to compare the groups.
- **Cross-sectional studies** compare groups at one point in time.
- **Cohort studies** compare what happens in the future to two matched groups.

Cohort studies are considered stronger than the other two types of observational studies because they are better controlled.

A note about research on complementary and alternative medicine

Reliable information and research on complementary and alternative medicine (CAM) can be challenging to find. While the same tools for evaluating mainstream health information also apply to CAM resources, you should keep these points in mind when considering CAM information:

- Federal regulations and standards requiring proof of the safety and effectiveness of natural health products such as vitamins, herbal medicines and supplements are different than those required for putting prescription drugs or over-the-counter products on the market.
- It is more difficult to get research funding to test CAM products and practices.

Therefore, CAM research may be less rigorous and the information may be based on testimonials or individual case studies. When considering CAM, consult highly regarded websites for another opinion.

Guidelines for evaluating research

1. What kind of study was it?

Refer to the beginning of this section for types of research studies.

2. Who conducted the research, and where?

Look for a group of researchers based at a reputable university, hospital or research institution. These have research ethics boards that approve the study design before it starts. Be careful about research done by an individual without clear affiliations.

3. Where was the article published?

An article will be more believable if it appeared in a peer-reviewed medical journal than just on the investigator's website or in a company's brochure.

4. Who paid for the study?

Would the funder make or lose money from positive or negative study results? The study might be partially or fully paid for by the company that will make and sell a particular drug. If the researchers received funding from an independent agency that uses a peer-review process, the findings may be less biased.

5. Was the study conducted in the laboratory, with animals or with people?

Be careful about reports that suggest a link between laboratory or animal results and results in people. Proof of results in people may still be years away.

6. How many people were tested?

A small number of participants does not mean that the study is invalid, but it could lead to questionable results. In many situations researchers need to study a large population over a long time to make sure that findings are not just the result of chance.

7. Did the study include people like you?

Check to see if the people in the study were a similar age, sex, education level, income group

and ethnocultural background as you. Did they have the same health concerns? Studies done on people very different from you may not apply to you.

8. Have the results of the study been repeated by other investigators?

If this is the only study of its kind, more research is needed to confirm the results. A new study that is consistent with other high-quality research is much more convincing than a single study that disagrees with earlier results.

9. Is there more than one side to the story?

Study authors should include information from those who hold a different viewpoint when they report on controversial topics.

What do those numbers and risk factors mean?

Investigators often talk about risk when they report their findings. They might mention relative risk, absolute risk or both. Relative risk is usually shown as a ratio or a percentage. An absolute risk is a number.

An article on the National Research Center for Women and Family's website, entitled *Hormone Therapy: The Risks & Benefits*, discusses the Women's Health Initiative Study's 2002 report on hormone therapy. Approximately 10,000 women received combination hormone therapy (estrogen and progestin) and another 10,000 took a placebo.

Within five years the women who received the treatment experienced changes in health problems. The following table (showing how the treatment changed the health outcomes of the women studied) illustrates just how different results can look when they are reported in percentages vs. absolute numbers. Note that the figures in the left and right columns represent precisely the same results. They are just being reported in two different ways:

Percentages	Absolute numbers
41% more strokes	8 more strokes
29% more heart attacks	7 more heart attacks
Twice as many blood clots	18 more blood clots
26% more breast cancer	8 more cases of breast cancer
37% fewer cases of colorectal cancer	6 fewer cases of colorectal cancer
One-third fewer hip fractures	5 fewer hip fractures

While the percentage increase in some diseases was large, the risk for most patients remained quite small. That does not mean these risks are not important, but seeing the absolute numbers can better help you decide if the risk is worth taking.

Finding research papers

If you want to read medical papers on a topic, review articles or practice guidelines are usually a good place to start. Databases like Medline (see the list on the next page) allow you to search for abstracts (summaries) of research articles and for particular types of articles.

Reviews give you an overview of the topic, and list all of the specific studies mentioned.

Use these additional ideas to follow up on a report you heard about:

- To find the scientific journal where the article first appeared, you can go to a public, hospital or university library. Many libraries have both print and online subscriptions to the complete text of articles that you won't be able to access from your home computer.
- You can search the Internet for the journal or publisher's website, but access to articles is rarely free, especially in the first six months of publication.
- Go directly to an online medical database like Medline. For a specific disease, you could go to a trusted national website.
- Contact the TV station, radio or newspaper where you first heard the report. Ask them for their sources of information. The news organization might have a link on its site to more information about the article.
- Ask your doctor about the report. He or she may have a copy.

Abstracts or full text of research studies: selected websites

The following list includes several open-access journals. This type of journal provides full research articles free of charge immediately upon publication. The other sites in the list may charge for some or all of their articles, but their summaries are free.

The Cochrane Collaboration (www.cochrane.org) reviews different studies on a topic. Plain-language summaries are included.

HighWire Press (<http://highwire.stanford.edu>), a division of the Stanford University Libraries, hosts medical journals and full-text articles. Many are free.

MedlinePlus (www.nlm.nih.gov/medlineplus), a consumer service of the US National Library of Medicine and the US National Institutes of Health directs you to health information. Ready-made Medline searches are included in MedlinePlus, giving easy access to medical journal articles. MedlinePlus also has information about drugs, an illustrated medical encyclopedia, interactive patient tutorials and health news.

Medscape (www.medscape.com), from WebMD, offers medical information and educational tools to health professionals. It also includes review articles, book reviews, journal commentary, patient education articles and more. You can perform a combined search of Medscape, Medline and other sources.

Open Medicine (www.openmedicine.ca) is a Canadian peer-reviewed, independent open-access journal of health research.

PLoS Medicine (<http://medicine.plosjournals.org>) is a peer-reviewed, open-access journal published by the Public Library of Science.

PubMed (www.pubmed.gov) and **PubMed Central** (www.pubmedcentral.nih.gov) from the US National Institutes of Health (NIH), provide a single access point to information from a variety of sources. PubMed contains abstracts from thousands of journals. It also includes links to free full-text articles in PubMed Central and to journal websites.



If you want to learn more ...

The Arthritis Society (<http://tinyurl.com/2eu28m>), has an article on clinical trials, how they work, deciding to participate, what happens when you enroll, Canadian regulations and a glossary.

Glossary of Clinical Trials Terms (<http://clinicaltrials.gov/ct/info/glossary>), from ClinicalTrials.gov, a service of the US National Institutes of Health, covers the most common terms used in clinical trials.

Guidelines for Your Health (www.guidelinesforhealth.com), produced by the Guidelines Advisory Committee, an partnership of the Ontario Medical Association and the Ontario Ministry of Health and Long-Term Care, is a consumer website that explains evidence-based practices that doctors follow. The corresponding site for practitioners (www.gacguidelines.ca) contains additional guidelines.

The Inclusion of Women in Clinical Trials: Are We Asking the Right Questions? (www.whp-apsf.ca/pdf/clinicalTrialsEN.pdf) is a report from Women and Health Protection. It discusses how women are more often included in clinical trials today, but shows there is more work to be done – for example, in addressing gender differences that may play a role in how women use and respond to drugs.

NIH News in Health (formerly Word on Health) June 2007 issue (http://newsinhealth.nih.gov/2007/June/docs/01features_02.htm) features an article on understanding medical research and getting involved in clinical research.

Some Things Only a Woman Can Do (www.womancando.org), from the Society for Women's Health Research, is an education campaign about medical research and volunteering for clinical trials.

Those Scary Statistics (www.craighospital.org/SCI/METS/stats.asp) and **Understanding Those Medical & Research Articles** (www.craighospital.org/SCI/METS/articles.asp), from Craig Hospital in the US, explain statistical terminology (such as mean, median, standard deviation and statistical significance) and cover the components of research articles and what you can expect to read in each part.

Understanding Medical Research (www.nlm.nih.gov/medlineplus/understandingmedicalresearch.html), from Medline Plus, is a gateway webpage with links to FAQs on clinical research, understanding risk, dictionaries and glossaries.

4 How to understand media and web-based health information

In this section we discuss how to assess media and web-based coverage of health topics, whether it's news reports about research or articles on the latest miracle food. We also touch on other ways you may get your health information online – such as through e-mail and discussion groups.

Every day we hear or read a story in the news or on the Internet about new medical research findings. We might hear about a new drug to treat osteoporosis, a cure for ovarian cancer or a breakthrough discovery in managing heart disease. Or we might see articles about foods or dietary supplements that promote health or prevent disease.

Sorting through all this is confusing. So is hearing about research studies that contradict each other. But these challenges can inspire you to look at news critically.

First questions

Ask these questions before you decide to investigate a news report further:

- Is the story sensationalized to attract attention?
- Does the story contain background information that helps you to evaluate it?
- Does it give you different points of view from experts not involved in the study?
- When you look closer, is the story actually an advertisement?

Media reports on health information and research studies

Most health issues are complicated. News reports may contain hype about medical breakthroughs. And it's not always easy to tell what stage the research is at, what is known about the risks and side effects of drugs, or their potential benefits. Yet without media reports, most of us would not even hear of the research in the first place.

Unfortunately, reporters rarely have the time to read the full research study and analyze its complexities. They may rely on press releases that do not assess the strengths and weaknesses of the research. They may take stories from publications where ideas and opinions about treatment are still being debated and where readers are assumed to have a scientific background.

Because of limited space, a news report can rarely provide you with all the details you need. When reporters shorten and edit information, they may end up misleading you unintentionally.

A story may change each time it is edited or rewritten. The original researcher may have written, "Bladder cancer in women appears to be related to caffeine." The newspaper could say, "Coffee linked to bladder cancer in women," while a TV news anchor reports, "Coffee causes bladder cancer in women." These are all very different statements.



Tip: When you are evaluating the credibility of media reports, try using the same guidelines we gave you in part 3 for evaluating research.

Web-based reports on health information and research studies

Health information on websites has an added layer of complexity when compared to information in other media such as TV and newspapers. Even if you have already assessed a website as we recommended in part 2, and reviewed the research guidelines in part 3, you should ask the following additional questions about health information published on websites.

1. Who wrote it?

Not only should a site state who is responsible for the entire site, it should say who wrote individual articles and provide their credentials.

2. What is the source of the information?

Many health and medical sites post information collected from other websites or sources. If the person or organization in charge of the site did not write the material, the original source should be clearly identified.

3. How do you know the content is valid?

The article should state the evidence upon which the material is based. Medical facts and figures should have references (such as citations of articles in medical journals).

4. How current is the information?

When you're looking at dates on a website, make sure you understand whether the date is the last date the entire article was reviewed or just the last date there was a change to the page.

5. Is it an Internet health myth?

Be wary if immediate, effortless or guaranteed results are promised. Look for telltale words and phrases such as *breakthrough*, *miracle*, *secret remedy*, *all-natural* and *exclusive*. Don't forget that, unlike scientists and health professionals, websites may be selling products that have not been subjected to the scrutiny of real scientific research. If testimonials or case histories from satisfied users are the only evidence a product works, don't buy it.

Did you know?

At womenshealthmatters.ca, we publish news about research and health issues for women several times a week. Our virtual Health Centres contain detailed information on diseases and conditions common to women. Visit our homepage at www.womenshealthmatters.ca/index.cfm.

What else do I need to know?

Identify information that would help you make a better decision

Remember that scientific information is always somewhat uncertain. Think about missing information and unanswered questions. Do not rely on the headlines as a basis for managing your health. And remember that trusted websites contain health information that may not have made the latest headlines, but has stood the test of time.

Learn about clinical guidelines

These are official guidelines of standard, accepted practice that doctors should use to manage your treatment. Not only can they be useful in analyzing what you hear in the media or read on the Internet, but you can also take them to your doctor to discuss your own treatment. Some are written just for doctors but others are “translated” for patients.

Beware of e-mail myths, hoaxes and scams

Don't believe any health-related e-mail without further research, no matter how convincing it may seem. Search google or check the resources at the end of this section to find out if the information is true. If it isn't, your search results will likely show this.

Talk to your doctor or other health-care professional

Show him or her what you have found.



Tip: Be a “cyberskeptic.” Check out a product with your doctor, pharmacist or other qualified health professional. Avoid any online physician who proposes to diagnose or treat you without a proper physical exam or consultation.

Other web-based sources of health information and news

Discussion groups

Many women find it invaluable to be able to talk over health problems with friends, share information and receive support for decisions. On the Web, women can find tremendous value in the wisdom that comes from sharing experiences in online discussions.

When choosing a discussion group, it is best to join a moderated one. This way, the moderator can answer questions, step in if discussions get out of hand, off-topic or are misleading and ban abusers. Moderated discussion groups are safer than non-moderated ones.

Ask the Expert features

Many respected websites have an “Ask the Expert” section where women can send their health questions to a trusted health professional.

Personal stories

Stories are another way to learn how other women cope with health problems in their lives. We recommend reading stories on respected websites such as womenshealthmatters.ca. These are helpful to get a real-world perspective through someone else's eyes. But remember, any

story is just one woman's experience, and may be quite different than yours.

E-bulletins, listservs and RSS feeds

These are an excellent way to keep up with women's health news and research:

- Online e-bulletins or newsletters help you learn what's new on a website by sending you e-mail notices.
- RSS feeds are used to publish frequently updated content such as blog entries, news headlines or podcasts. An RSS document contains either a summary of content or the full text. RSS helps you to keep up with your favourite websites in an automated manner. Look for the RSS icon on sites that provide this feature.
- Listservs are e-mail based notices or discussion groups. Some are moderated and others are not. Health promotion listservs often have active discussions. Some gather news from women's groups and websites. The Ontario Women's Health Network listserv offers a lot of women's health information. You can even sign up for listservs for doctors or warnings from Health Canada about reported problems with drugs and health products.

Blogs

Blogs (short for weblogs) are online journals or diaries. Visitors to blogs can post their own comments. Many blogs are similar to personal websites, and also have features in common with discussion groups, personal stories and e-bulletins.

Social networking sites

Sites like MySpace and Facebook offer their members the ability to share messages, media and other information with each other. Health organizations may use these sites to post information.

Did you know?

You can find many interactive features at womenshealthmatters.ca: discussion groups on several health topics (including one on using the information in this toolkit); an Ask the Expert feature; personal stories (you can even submit your own); and a monthly e-bulletin.



If you want to learn more ...

Health News Review (www.healthnewsreview.org) is an American website that grades media stories on accuracy, balance and completeness.

Media Doctor Canada (www.mediadoctor.ca) is a website dedicated to improving the accuracy of Canadian media reports about new drugs and treatments. Browse it to deepen your understanding of how news stories should be written and what kinds of errors, omissions and misinformation they may contain.

National Research Center for Women & Families (www.center4research.org) reviews research on a variety of women's health topics. The I Saw It on the Internet section debunks Internet health myths.

Quackwatch (www.quackwatch.org), operated by a doctor, combats health-related frauds, myths and fads. It contains information on health fraud and misleading health claims about products, therapies, services, health advice, advertisements and services.

The Skeptic's Dictionary is a book and website (www.SkepDic.com) applying a critical lens to all things supernatural, paranormal and pseudoscientific as well as to medical topics. It helps you think critically about just about anything you read.

Snopes (www.snopes.com) is a website concerned with myths, hoaxes and urban legends.

Women's Health: Reading Between the Lines

(www.cwhn.ca/resources/gba/reading.html), from the Canadian Women's Health Network, is an article that encourages women to make sure all sides of information about research are covered. Several examples of poor research drive their message home.

5

Recommended websites

Visit www.womenshealthmatters.ca/toolkit/recommendedsites for our list of recommended:

- general health websites for women
- major websites covering specific diseases that affect women.

We chose these sites according to the collection development policy we use when selecting resources for the Health A-Z section at womenshealthmatters.ca. Visit our Health A-Z section at www.womenshealthmatters.ca/resources for detailed descriptions of all our websites, books, audiovisual and multimedia materials, as well as articles we have written ourselves on a wide variety of women's health topics.

And remember to check the *If you want to learn more* section at the end of each part of our toolkit for tools, tutorials and further reading on the topics discussed in each part.

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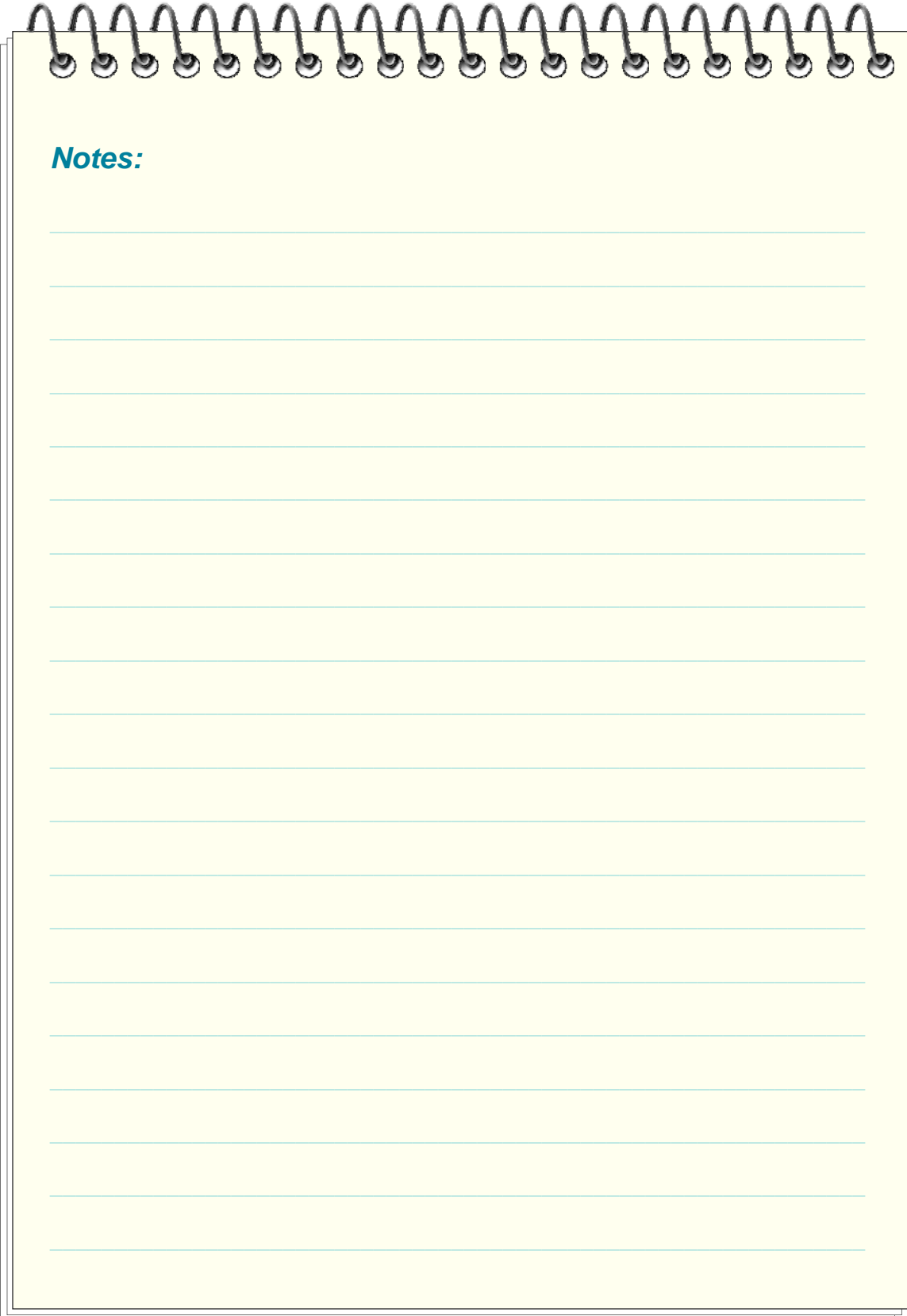
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A graphic of a spiral-bound notebook with a yellowish cream-colored page. The spiral binding is at the top. The page is mostly blank, with the word "Notes:" written in blue at the top left. Below it are approximately 22 horizontal light blue lines for writing.

Notes: