Why (and how) you should encourage your patients' search for health information on the Web

⭕ 69% of Americans look for health information on the Internet. Don't discourage your patients from this: Instead, empower them to identify reliable advice. Includes a patient handout to aid your efforts.

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CASE **The Internet has (at least) two faces**

Both Patient A and Patient B are 8 weeks pregnant with their first baby. At an office visit, you discuss influenza vaccination.

Patient A tells you: "I was undecided about the vaccine until I read all these horror stories about the H1N1 vaccine. A Web site, organichealthadviser.com, says vaccines and pregnancies don't mix safely.[1] It says that if the flu vaccine isn't safe for a baby less than 6 months old, how can it be safe during pregnancy?[1] I read story after story of women who got the vaccine and miscarried. Why would I want to be injected with a toxin?"

Patient B explains: "I was undecided about the vaccine until I read the information on the Centers for Disease Control and Prevention (CDC) Web site.[2] I didn't know that pregnant women are more likely to get really sick from the flu. The CDC says the vaccine is safe during pregnancy, will not harm my baby, and not only reduces my chance of getting sick from the flu, but will give my baby protection for 6 months after she is born.[2] When and where can I get my shot?"

Sixty-nine percent of Americans (80% of those who have Internet access) turn to the Web for information about their health care, and 23% of people who have a major medical illness or other health condition report that the Internet plays a major role in helping them deal with their health issue.[3,4] They might research symptoms, diagnosis, tests, and therapies before a visit to your office; many come armed with questions, sometimes bringing reams of pages downloaded from various sites. Among women receiving ObGyn care, almost 60% have accessed Web-based information before their visit.[5] Others take to the Internet after their appointment to confirm or refute what they have heard in the office.

Regardless of what a patient researches or when she does it, the *why* is because she wants to be an active participant in her medical care. That is a good thing because participatory medicine (shared decision-making) leads to improved outcomes. However, the

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key to truly informed decision-making is *content*: **A patient can be fully empowered to participate in her health care only if she has information that is accurate, understandable, and current.**

Web-based health information: Entirely factual?

Not only do patients research health online, 60% of people believe what they read to be factual and at least as good as the information they receive from you in your office. In fact, there is evidence that only 6% believe the health information they gather online is lacking in quality.[5,6]

However, studies reveal that the accuracy of medical content on the Web varies greatly from site to site. For example, among women seeking information on the Internet about potential teratogenic agents, 40% found incorrect information, some of which was potentially harmful.[7]

In addition to the problem of potentially suspect content, more than 50% of patients don't disclose with you the information that they find online.[7] Ever encounter a patient you just couldn't sway from a diagnosis she believed she had but you knew she didn't? If your patient tells you where she got the information, you can walk her through the diagnosis and treatment step by step, pointing out where her information might not be accurate (or, sometimes, even medically plausible)—but it's hard to undo what you don't know about.

The ideal scenario. Discuss Web-based information as part of your visit, thereby acknowledging that the Internet is a valid place to investigate personal health care. You can also preemptively provide tools for tracking down the most accurate and understandable content. See, for example, the patient handout on page 41.

Let's face it: Physicians have an advantage when it comes to weeding out the wisdom from the woo. To supplement our baseline knowledge, we can easily research facts on PubMed, check our medical societies for guidelines, or, simply, ask a colleague. Our patients don't have these same resources, but

with some guidance from you, their Internet health experience can be greatly enhanced.

Four tips for evaluating online content

Consider the source

The very first thing to consider is the domain name—e.g., ".gov," ".org," ".edu," ".com," or *.anythingelse*.

.gov sites are owned and maintained by the US government. From a medical standpoint, the .gov designation means that a site contains evidence-based information maintained by medical librarians that is written at a level that most people can read.

It's a common misperception that the .org designation indicates a not-for-profit site that is therefore "looking out for the public's best interest." But anyone can purchase an .org domain. Even if a particular site really is administered by a not-for-profit organization, that status does not ensure that the content is of high quality.

.edu sites are affiliated with academic institutions.

.com and *.anythingelse* are, like .org, free for anyone to purchase.

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Evidence-based medicine tells us that .gov sites are the most accurate for content—anything else is buyer beware (interestingly, .edu sites fared the worst in one study for accuracy).[7,8] This doesn't mean that sites that are not .gov have no value! On the contrary, non-governmental Web sites, blogs, and news articles are often the first place a search starts. That's because current content, such as a new site, is more likely to feature prominently in a search engine response. But non-governmental sites do require an additional level of scrutiny. For example, in one study, only 55% of health information on news Web sites was medically accurate.[8]

Who is the author? Does she have financial ties or bias?

Think about who is running the Web site, why they are doing it, and what they are trying to achieve. Is the author a doctor, a health reporter, an advocate, or a drug company? The credentials of any physicians associated with the site should be listed as well as credentials and affiliations of authors, if they are non-physicians. Sites that list physician credentials tend to rate higher in accuracy of content.[7]

Talk with your patients about the importance of financial ties. The sponsor of the Web site should be listed (drug company, university, or a physician blogging without reimbursement). Bias and money go hand in hand, so be careful in evaluating whether the information provided favors the sponsor. If there are products for sale that are recommended by the medical content, bias is implied and, in my opinion, that site is not informational but commercial.

Bias can also be non-commercial, which is why authors of academic papers are not only supposed to report financial ties but also any real or perceived conflict of interest. This can be hard to discern at times, but the Web site should disclose why it exists. If the message is muddied by advertising and other commercial content, it's best to just move along.

How current is the content?

We all know that new studies constantly reshape the way we practice (and sometimes guidelines from professional societies seem to change with the wind), and what is new quickly becomes out of date. The good and bad with online information is that it is always there. A permanent record is in many ways a good thing, but content from 2004 may not be applicable in 2011. This is a particular issue with news sites. They may report on a fascinating study in 2007, but if a retraction later appears or a new study refutes the findings, that information may not warrant an article on the Web. A good rule of thumb: Anything older than 2 years requires an additional level of scrutiny.

Be wary when the subject is complementary and alternative medicine

Online content related to complementary and alternative medicine (CAM) should be approached with a higher degree of caution. One study found that 25% of CAM sites presented information that could cause physical harm if acted upon, and almost all CAM sites omitted vital warnings, such as drug interactions, contraindications, and adverse reactions. The quality of CAM sites doesn't improve even when they meet three or four of the *JAMA* benchmarks for information quality (see page 40).[9] In one study of breast cancer sites, Web pages with CAM content were 15 times more likely to contain inaccurate content, compared with sites without CAM content.[7]

Instruments and tools for evaluating online content

Three tools are available to help patients and providers judge the quality of written online information:

Discern is a 16-question tool designed to assess the quality of online health information. You will find it at http://www.discern.uk/discern_instrument.php. I recommend that you mention this tool to patients, even if you are uncertain whether they will use it. Certainly, any patient wedded to what seems like questionable content from a specific Web site should be encouraged to evaluate

the site using the Discern tool. In addition, if you have Web sites other than .gov sites that you like to share with patients, it might be wise to personally review them with Discern so that you can reaffirm that you are directing patients to reliable content rather than a quagmire of misinformation.[10]

The Health on the Net Foundation (HON) is an independent, seven-person, Geneva-based panel that evaluates accuracy of medical Web sites based on specific guiding principles. It can be accessed at http://www.hon.ch/. Web sites that meet these criteria are awarded seals of approval. Only one problem: Not all sites that carry the seal are compliant with HON, and sites that don't carry the seal can nevertheless be complete and accurate.[11,12]

JAMA **benchmarks** are four disclosures intended to help ensure the quality of a Web site: authorship, references, conflict of interest, and currency of content. Some research suggests that sites that have three or four of the benchmarks are more likely to have accurate content, but there is also evidence to suggest that *JAMA* benchmarks may not always reliably identify inaccurate information.[7,13]

Recommend a mini-course

Because these tools may be difficult to use or unreliable at identifying quality content, I recommend that every patient spend time on the National Medical Library Web site learning how to look up information. The other benefit of this site is that it lists top 10 Web sites for content, so it is a great launching point for a multitude of searches. It can be found at http://www.mlanet.org/resources/userguide.html.

If the patient finds the information at this portal too dry, there is a fantastic 16-minute tutorial about evaluating online health information; it's a service of the National Library of Medicine and the National Institutes of Health. I recommend that *every* provider do this tutorial. Why? So you can better educate yourself on how to use the Internet and so you can tell your patients how great it is. It's available at http://www.nlm.nih.gov/medlineplus/webeval/webeval.html.

FAST TRACK

The four *JAMA* benchmarks of quality are authorship, references, conflict of interest, and currency of content

Take the bull by the horns

Discuss the Internet with *every one of your patients*. Specifically, ask if she has read any information online and, if she has, how it stacks up with what you have just discussed during her office visit. That's what I do. Explain that accurate content is critical in health-care decisions, guide your patient to sites that are more likely to be accurate, and teach her how to maximize the Internet to enhance her health care.

In my experience, patients are thrilled to be pointed in the right direction. ⏻

References
1. H1N1 vaccine and pregnancy. Organic Health Adviser. http://organichealthadviser.com/archives/h1n1-vaccine-and-pregnancy. Accessed November 12, 2011.
2. Pregnant women and influenza. Centers for Disease Control and Prevention. http://www.cdc.gov/flu/protect/vaccine/pregnant.htm. Accessed November 12, 2011.
3. Fox S. The social life of health information, 2011. Pew Internet and American Life Project. http://pewresearch.org/pubs/1989/health-care-online-social-network-users. Accessed November 12, 2011.
4. Horrigan J, Rainie L. The Internet's growing role in life's major moments. Decision-making, Communities, Health. Pew Internet and American Life Project. http://www.pewinternet.org/Reports/2006/The-Internets-Growing-Role-in-Lifes-Major-Moments.aspx. Accessed November 12, 2011.
5. Neelapala P, Duvvi SK, Kumar G, Kumar BN. Do gynaecology outpatients use the Internet to seek health information? A questionnaire survey. J Eval Clin Pract. 2008;14(2):300–304.
6. Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' use of the Internet for medical information. J Gen Intern Med. 2001;17(3):180–185.
7. Bernstam EV, Walji MF, Sagaram S, Sagaram D, Johnson CW, Meric-Bernstam F. Commonly cited website quality criteria are not effective at identifying inaccurate online information about breast cancer. Cancer. 2008;112(6):1206–1213.
8. Scullard P, Peacock C, Davies P. Googling children's health: reliability of medical information on the Internet. Arch Dis Child. 2010;95(8):580–582.
9. Walji M, Sagaram S, Sagaram D, et al. Efficacy of quality criteria to identify potentially harmful information: a cross-sectional survey of complementary and alternative medicine web sites. J Med Internet Res. 2004;6(2):e21.
10. Charnock D, Shepperd S, Needham G, Gann R. DISCERN: an instrument for judging the quality of written consumer health information on treatment choices. J Epidemiol Community Health. 1999;53(2):105–111.
11. Hardwick JC, MacKenzie FM. Information contained in miscarriage-related websites and the predictive value of website scoring systems. Eur J Gynecol Reprod Biol. 2003;106(1):60–63.
12. Khazaal Y, Chatton A, Zullino D. HON label and DISCERN as content quality indicators of health-related websites [published online ahead of print May 2011]. Psychiatr Q. doi: 10.1007/s11126-011-9179-x.
13. Meric F, Bernstam EV, Mirza NQ, et al. Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. BMJ. 2002;324(7337):577–581.

Are your searches on the Internet turning up *reliable* health advice? Watch for these 10 red flags of bad information

1. **Sensationalized content** Is the information on the site presented in an alarmist tone? Is it loaded with scary stories and extreme outcomes? Are the issues presented in terms of black and white, with no shades of gray? If the answer to any of these questions is "Yes," the author may have an axe to grind or a hidden leaning. Suspect the accuracy of the information you obtain!

2. **No date** This may seem like a minor problem, but the world of health care moves swiftly. Treatments and approaches that are reliable one day can be discredited in the blink of an eye. If the site does not date its content, or indicate when it was last updated, you have no way of knowing how current it is. Move on!

3. **No author credentials** The author or authors of material on the Web site should clearly, and visibly, present their credentials—that is, their education and training, their title, and where they work. If they do not, it is impossible to judge their expertise—in fact, expertise may be lacking.

4. **Buzz words** The use of quasi-scientific buzz words such as "toxins," "heavy metals," and "detoxification" should draw your attention. These words have no meaning, so they should lead to you question what else on the site might be fiction.

5. **Patient testimonials** Three people may have improved with a particular drug, but what about those who haven't? Using unverified personal experiences is a sign of advertising, not good medicine.

6. **For sale sign** If you can't easily tell the difference between the medical content and products for sale, move along. Even when products don't appear prominently, chances are that the bottom line of the Web site is profit, not education.

7. **All benefits and no risks** Sites that have a stake in a particular treatment—be it monetary, emotional, or some other involvement—usually provide a lot of information on benefits but not so much about risks. Every treatment has risks.

8. **No sources** When physicians scrutinize an article or study, they make it a point to check the list of sources at the end, to ensure that it contains legitimate information, such as reports from a medical journal or government publication. A Web site that presents detailed medical information without providing links to the references or comparable detail about the sources of that information is highly suspect.

9. **Conflict of interest** Most reputable health sites not only provide information from experts, they list any so-called potential conflicts of interest that those experts may have. For example, if a medication made by XYZ Pharmaceuticals is recommended by Dr. Smith, who is also a consultant to XYZ, you should know. Articles and presentations at scientific meetings require these disclosures for a reason: Financial ties can produce bias.

10. **The Web site or product is listed on QuackWatch** This Web site is dedicated to exposing unproven and scientifically questionable medical claims (http://www.quackwatch.com).

Where can you turn for help?

- An excellent starting place is the National Medical Library Web site at http://www.mlanet.org/resources/userguide.html, which provides resources for obtaining reliable health information.

- The National Library of Medicine and National Institutes of Health also provide an outstanding 16-minute lesson on how you can evaluate online health information. Find it at http://www.nlm.nih.gov/medlineplus/webeval/webeval.html.

- healthfinder.gov is a Web "encyclopedia" offering entries on more than 1,600 health topics.