Advice for intrepid internet sleuths looking for credible medical websites, studies and symptom finders

BY HALLIE LEVINE

ardiologist Barbara Roberts, 78, volunteered with the Rhode Island Medical Reserve Corps during the height of the COVID-19 pandemic and vaccinated many hundreds of people. So she was disturbed to learn last April that her cousin's wife, who was also in her 70s, was hospitalized and on a ventilator after contracting COVID.

"I didn't realize she hadn't been vaccinated, but her husband told me that they'd done their research online and decided against it," Roberts recalls. "I was horrified because there's so much health misinformation on the web. People tend to believe anything that supports their own biases—in this case, that it would be dangerous to get the vaccine."

When the woman died, "it made me both very angry and very sad," Roberts says. "It was totally preventable."

Stories like Roberts' are too common these days as more and more of us have turned to the internet to research our own medical conditions and concerns.

According to a 2021 survey, almost 60 percent of all Americans go online to get medical questions answered, and 4 in 5 of us research



our medical recommendations online after a doctor appointment.

Although there are many benefits to doing your own health research, there's a dark side too: "Some people just end up believing everything they read, or they become so cynical about the health information blasted at them online" that they may begin to generally distrust the medical profession, says health care journalist Gary Schwitzer, founder of the former Health News Review website.

The problem could get even worse after the introduction of artificial intelligence-driven text-generating tools called chatbots.

When you ask a chatbot a question, it pulls information from everywhere online to create an amalgam of data, news and opinion, taking from both traditional and unknown sources. Online publishers use these bots to generate content, including in the health space.

We asked some of the nation's top epidemiologists for the fundamentals of doing your own health research, from how to find the most credible sites to evaluating the best symptom checker. We chose three common scenarios you may face at some point to help you find the information you need, safely.

#### **RESEARCH TRIGGER NUMBER 1**

Your doctor just gave you an alarming diagnosis.

If you've been told you could have a particular health condition, your first impulse may be to simply type it into a search engine. That's probably not the best move, cautions Alice Pomidor, M.D., a retired professor of geriatrics at Florida State University. "You might get an ad [that looks official] or other information that's not reputable," she explains. (Look for a "Sponsored" tag; it means an organization has paid big dollars to show up at the top of searches related to that topic.)

Rather than type your diagnosis into a search engine, Pomidor recommends that you go to one of the following sites and search for your diagnosed condition within it:

- National Institute on Aging (nia.nih.gov)
- ► American Geriatric Society (healthinaging.org)
- ► Centers for Disease Control and Prevention (cdc.gov)
- National Institutes of Health (nih.gov)
- ► American Academy of Family Physicians (familydoctor.org)
- ► Mayo Clinic (mayoclinic.org)

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# **Your Health**

#### **CONTINUED FROM PAGE 16**

Each of these sites includes a health information page where you can search topics from A to Z to find your specific concern.

Any health website sponsored by a federal government agency should provide the most upto-date, reliable information. Those sites will end in .gov (you can also visit usa.gov for a list of federal websites).

Other excellent options are well-known medical schools, whose sites tend to end in .edu, as well as large professional organizations.

"But it's important to not just automatically assume that because a website ends in .org, that it's legitimate," cautions Robert Shmerling, M.D., a senior faculty editor at Harvard Health Publishing and member of the faculty of medicine. Though .org usually indicates a nonprofit, it may be an advocacy group that's pushing its own unresearched agenda.

# **RESEARCH TRIGGER NUMBER 2**

# You see a startling health news story or hear a surprising medical claim.

If a headline about a health discovery sounds too good to be

true, it usually is. It's clickbait. The news is based on a new "study," but there are no links to the study and few or no mentions of an author. "That's a red flag," says Jennifer Manganello, a professor of health policy, management and behavior at the School of Public Health at University at Albany.

If there is a link to the study, look for this information:

- ▶ Who conducted the study? Ideally, Manganello says, study authors are affiliated with a large research institution such as the medical school of a highly respected university.
- be trusted? The gold standard is usually a randomized control trial, where people who received a specific treatment are compared with a control group that didn't. Scientists also use good but less reliable observational studies. For instance, such a study may find that people who meditate regularly are less likely to have a heart attack. But the results may be due to their heathier lifestyles in general.
- ▶ Who was involved with the study, and how many participated? Well-done studies often

#### **AARP'S APPROACH TO HEALTH JOURNALISM**

The AARP print and digital content teams are committed to top-grade reporting and writing on all matters health. Here's how we do it.

STAFF EDITORS overseeing our coverage specialize in health journalism and routinely read medical journals, attend conferences and monitor health trends to be on top of the medical issues of the day.

writers are chosen based on their specific health expertise and experience; many of our writers have won national awards for their medical reporting. FACT-CHECKERS verify statistics, facts, quotes and study references within each story, in addition to making sure that information is in context and current.

# PROFESSIONAL REVIEWERS

backread many health stories containing scientific descriptions to make sure they are accurate and fair from a doctor's or researcher's perspective.

PROOFERS review stories as they reach their final form to make sure that the editing and design process has not introduced errors or lost key facts or context. involve hundreds, even thousands, of participants, Manganello says. Notice who they were and if their cases apply to yours.

▶ Is it peer-reviewed? Trust only studies published in medical journals. They typically have strict criteria for inclusion. "Just recently, I stumbled upon a so-called scientist on Twitter," says Marney White, professor of social and behavioral sciences at the Yale School of Public Health in New Haven, Connecticut. The person posted a "study" with a preposterous claim, White says. "I soon found out that this individual hadn't been employed in their field for many years, and they were citing an unpublished paper. But I could see how convincing this person

When reading a study, your initial step is to look at the abstract. This short intro can help you with what the study's about and its main findings.

#### **RESEARCH TRIGGER NUMBER 3**

# You have something strange going on with your body.

First off, try not to self-diagnose. Second, a 2021 study suggests that symptom-decoding tools are accurate only about half the time. Manganello recommends that you stick with symptom checkers that are part of a hospital or medical center website. There are several good-quality, for-profit sites that provide symptom analysis as well. Of course, these checkers should be just one source of information.

If you can't resist searching your symptoms online, here are some things to keep in mind, Pomidor says. Don't go straight to the sources at the top of your search results, since those may be paid advertisements. Also, stay away from forums, review sites or social media, since they can be alarmist.

Start with a nationally known health system's or organization's website, though you will still need to get that strange rash checked by your doctor. "You can take a picture of it with your phone and send it to their office," Pomidor suggests, but she stresses that you should send your information or photo via your doctor's patient portal. If you send it by email or another way, your medical or personal information may not be safe.

Hallie Levine is an award-winning medical and health reporter. Her work has appeared in The New York Times, Consumer Reports, Real Simple, Health and Time, among other publications.

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