


Patient No. 327445-0

7-882-004-1.0



**What Ails Access  
to Government Health  
Information?**

 Biblio Laboratories

Is it science or supposition that is infusing  
the federal approach to medical advice?

BY JENNIFER BUREK PIERCE

**A**mericans in increasing numbers turn to the Internet for health information. According to the 2002 report "Counting on the Internet" by the Pew Internet and American Life Project, 73 million Americans searched the Web in 2001 for information about diet, drugs, or disease. Yet, even as more Americans seek health information online—believing, according to the Pew report, that they will find accurate medical advice there—others are raising questions about the reliability of, and access to, health-related information from a seemingly indisputable source: namely, federal websites.

The federal government produces a range of health information materials, encompassing not only medicine per se, but also broader topics such as environmental health, which address concerns such as the quality of drinking water. In recent years, groups ranging from ALA's Government Documents Round Table (GODORT) to the nonprofit reproductive-rights lobbyists at the Alan Guttmacher Institute have taken issue with the alteration or removal of information from federal health web pages. Others, such as U.S. Rep. Henry Waxman (D-Calif.), have expressed concern about the influence of partisan policymaking on both the availability of information and the funding that determines information dissemination through public health programs. And some freedom-of-information proponents, including a former president of ALA's Freedom to Read Foundation, June Pinnell-Stephens, and Washington, D.C., attorney Thomas M. Susman, indicate that the ongoing accessibility to the public of government-produced information, including health information, should concern librarians.

"There are currently three primary ways the [Bush] administration is restricting access to government information: classification, funding, and ideology," Pinnell-Stephens said. "Although classifying health information is less frequent than other types of material, such as reports about energy infrastructure, it does have at least an indirect effect by removing material that affects public health."

In presentations she has made to a number of audiences in Alaska, where she serves as collections service manager for the Fairbanks North Star Borough Public Library, Pinnell-Stephens has identified other instances in which federally sponsored health information has been compromised. She points to the decision to discontinue funding for the PubScience web-accessible database once produced under the auspices of the Department of Energy and its partners, which contained some health-related information, and to Department of Health and Human Services audits of AIDS organizations that publicly disagreed with the

administration preference for abstinence education to stem the disease's spread. (According to the July 8 *Washington Post*, 33% of the president's \$15-billion global AIDS bill to assist stricken countries in Africa was earmarked for abstinence education; another \$62.5 million was appropriated for HHS grants to abstinence-only sex-education programs in the U.S.)

Other administration actions criticized by some as impeding public access to health and science information include:

- revisions to fact sheets on condom use and on a disputed connection between having an abortion and developing breast cancer;
- removal on national-security grounds of a U.S. Geological Survey CD-ROM about water supplies from depository library collections (*AL*, Apr. 2002, p. 16–18); and
- changes in the accessibility of material about chemical-plant operations collected by the Environmental Protection Agency, including the retention of contact information for patrons of EPA reading rooms.

### *Pinpointing the symptoms*

Rep. Waxman is among the most vocal critics of information policies that reduce public access to government information. As ranking minority member of the House Committee on Government Reform, Waxman has devoted significant attention to identifying withdrawn and modified health information on federal websites, as well as other practices with potential to prevent access to information not sanctioned by particular ideological perspectives.

"HHS includes some of the most respected scientific and public health organizations in the country and has a strong tradition of basing policy decisions on the best available scientific information. I was disturbed by the troubling reports that the Bush administration was undermining this

tradition, and I asked my staff to investigate," Waxman told *American Libraries*. "Their research revealed a pattern of suppression and distortion of scientific information to fit the administration's political and ideological views. Scientific information that does not match the administration's ideological viewpoint was removed from HHS websites."

Material identified by Waxman and his staff as removed or altered includes content by the National

**Defending against terrorism does not adequately explain some recently identified omissions from government health information.**

JENNIFER BUREK PIERCE is assistant professor of library and information science at Indiana University's School of Library and Information Science in Indianapolis and editor of *Indiana Libraries*.



Cancer Institute on lack of evidence between having an abortion and later developing breast cancer, as well as information from the Department of Health and Human Services on protecting one's sexual health through condom usage. Also of concern to Waxman are political appointments to advisory committees, such as the National Center for Environmental Health, whose committee members guide the research and development goals and related policy matters. Appointees to this committee were scrutinized for their ties to industry after scientists wrote an open letter of complaint about conflicts of interest to the October 25, 2002, issue of the journal *Science*. Waxman explained that he and his staff "are currently investigating more than 100 such tips."

Acknowledging that Bush administration officials shield government information from the public eye "for a wide range of reasons, including legitimate national security purposes," Waxman nonetheless asserts that defending against terrorism does not adequately explain some recently identified omissions. "The administration has regularly suppressed scientific information simply because that information conflicts with the administration's ideological agenda," he argued. "Rather than be honest with the American people about pursuing policies contrary to science, it has tried to suppress or even change the science."

#### *Documenting what's disappeared*

These efforts, Waxman said, reflect a broader policy aimed at limiting the availability of information about government actions. "The Bush administration has consistently demonstrated its penchant for secrecy. The suppression of health and scientific information is only one example among many," he contended, pointing to other agency actions such as the Departments of Justice and Homeland Security limiting access to information previously covered under the Freedom of Information Act. In apparent agreement, the American Library Association and the American Association of Law Librarians were two of 75 signatories to an August 27 letter urging Homeland Security Secretary Tom Ridge to hold public hearings on implementing the Homeland Security Information Sharing Act of 2002, lest the law's implementation "preclude public access to information that community residents, parents, journalists, and others in the public currently obtain from or

with the assistance of government in order to make their communities safer, inform the public, and for other purposes."

GODORT is also addressing such issues and has created a working group on Permanent Public Access to Government Information that operates within GODORT's Federal Documents Task Force. The round table's website ([www2.library.unr.edu/dept/bgic/Duncan/PPBmillerchronchart.doc](http://www2.library.unr.edu/dept/bgic/Duncan/PPBmillerchronchart.doc)) includes a chronology compiled by Barbara R. Miller, assistant documents librarian at Oklahoma State University in Stillwater, of both removed information and other government actions with the potential to affect access to government information. Health-related information covered by this listing includes environmental health matters such as water source and quality, as well as steps to take in the event of nuclear emergencies, Miller explained.

"We put that up on the Web so that people could see the sheer amount of information that was disappearing," Miller said. "It was just incredible to see how much stuff was taken off." In particular, she sees the decreased information access impacting scientists' ability to carry out basic research.

"A lot of this has direct and indirect bearing on health," she added.

Concerns about health-related information, as well as other instances of scrubbed information, led GODORT to propose a resolution on withdrawn electronic government information, said Arlene Weible, chair of GODORT's Legislation Committee and head of the Government Documents Department at the University of North Texas Libraries in Denton. The resolution, approved by ALA Council at the Association's 2003 Midwinter Meeting (*AL*, Mar., p. 66), asks government agencies to provide continued access to withdrawn electronic information and calls for a searchable archive of withdrawn information, as well as record schedules indicating changes in site content.

Drafted to "create an awareness of concern" among webmasters about how "the historical record can be removed by a simple mouse click," the resolution was also written "to remind federal agencies that electronic documents and records have an equal status with tangible records and that these are also governed by Title 44 and records retention provisions," Bob Walter, dean of learning resources at Pittsburg (Kans.) State University and chair of the Subcommittee on Government Information of ALA's Legislation Committee, told *AL*. Acknowledging that GODORT members

### **An elected official took issue with the CDC's fact sheets about condom use.**



had also hoped to “express a concern that information is removed from web pages for political reasons without further accessibility to the user,” Walter speculated that, no matter how heightened the public awareness, “If the political advantage is felt to be strong enough, it will occur again.”

### *Blinded by science*

Likewise, some Guttmacher Institute research reports on reproductive health have pointed to federal government actions that are likely to impact public health information. These reports refer to both congressional and administrative acts that have directed resources away from generally accepted public health activities regarding reproduction to fund the dissemination of an abstinence-only approach. One report by Guttmacher senior policy analyst Heather Boonstra observes, “A number of recent moves [by the Bush administration] suggest that scientific decision making is being subverted by an over-zealous commitment to ideology.”

HHS spokesperson Bill Pierce (no relation to the author of this article) refutes these charges. “This is absolutely science based, 100 percent,” he said. Pierce explains that in the case of the more highly publicized controversies—the Centers for Disease Control and Prevention (CDC) condom fact sheet and NCI information questioning links between developing breast cancer and having had an abortion—a member of Congress had requested review of the fact sheets. In each case, Pierce stated, the agency responded appropriately with a literature search and “found that the statements were not supported by scientific data.”

In response to concerns aired by Waxman and other members of Congress, NCI reevaluated its breast cancer research. The institute revised its findings again and

now reports that “having an abortion or miscarriage does not increase a woman’s subsequent risk of developing breast cancer,” according to material posted at Waxman’s website. Yet, according to Boonstra, while NCI has directed messages to the congressman acknowledging this, the agency “has not reposted that fact sheet” at its own website.

CDC spokesperson Kathy Harben offered more details about changes to the condom fact sheet, explaining that the agency is always working “to improve the processes of trying to protect the public health.” In the case of the condom fact sheet, the CDC and other agencies such as the National Institutes of Health and the United States Agency for International Development formed a working group to evaluate messages about condom use because of concerns that existing fact sheets were based on expert opinion instead of research data. “We were challenged on the statements that were on there. It’s true that someone who

was elected called us on it, but the process that was used to modify the language was a scientific one,” Harben said.

The agency’s message now is that “condoms are very effective, but there’s no guarantee,” she explained. The fact sheets also offer more details about sexually transmitted infection while indicating the role of abstinence in prevention. “It’s more breaking it down by STD [sexually transmitted disease]; not one message suits all STDs,” she said. “There’s still information on condoms on the website,” Harben added.

Nonetheless, Boonstra maintains that the changes “seem to be politically motivated because there had been a letter from members of Congress right before it disappeared.” Explanations about disease-specific condom effectiveness, while technically correct, do not warrant changing messages about condom use, Boonstra said. “It has to do with usage, and correct us-

**“We must always be concerned with accuracy of information and the credibility of sources.”**

**—June Pinnell-Stephens,  
Fairbanks, Alaska**

### **Online Resources Concerning Access to Health and Science Information**

■ *Critics Charge Bush Mix of Science and Politics Is Unprecedented and Dangerous.* Guttmacher Report on Public Policy (May 2003). [www.guttmacher.org/pubs/journals/gr060201.pdf](http://www.guttmacher.org/pubs/journals/gr060201.pdf)

■ GODORT Bibliography on Removal/Elimination of Government Information. [sunsite.berkeley.edu/GODORT/legislation/#removal](http://sunsite.berkeley.edu/GODORT/legislation/#removal)

■ GODORT Chronology of Disappearing Government Information. [www2.library.unr.edu/dept/bgic/Duncan/PPBmillerchronchart.doc](http://www2.library.unr.edu/dept/bgic/Duncan/PPBmillerchronchart.doc)

■ Politics and Science: Investi-

gating the Bush Administration’s Promotion of Ideology over Science. [www.house.gov/reform/min/politicsandscience/](http://www.house.gov/reform/min/politicsandscience/)

■ Project on Government Secrecy, Federation of American Scientists. [www.fas.org/sgp/index.html](http://www.fas.org/sgp/index.html)

■ *Public Health Advocates Say Campaign to Disparage Condoms Threatens STD Prevention Efforts.* Guttmacher Report on Public Policy (March 2003). [www.guttmacher.org/pubs/journals/gr060101.html](http://www.guttmacher.org/pubs/journals/gr060101.html)

■ ALA Resolution on Withdrawn Electronic Government Information

(January 2003). [www2.library.unr.edu/dept/bgic/withdrawn.html](http://www2.library.unr.edu/dept/bgic/withdrawn.html)

■ Congressional Research Service’s “Sensitive But Unclassified” and Other Federal Security Controls on Scientific and Technical Information: History and Current Controversy (July 2003). [www.fas.org/irp/crs/RL31845.pdf](http://www.fas.org/irp/crs/RL31845.pdf)

■ U.S. House of Representatives Committee on Government Reform Minority Office. [www.house.gov/reform/min/inves\\_admin/admin\\_hhs\\_info.htm](http://www.house.gov/reform/min/inves_admin/admin_hhs_info.htm)

age, not with the condom itself," she said.

HHS's Pierce contends that complaints about access to federal health information are based primarily on concerns about the condom and cancer fact sheets, which he characterizes as "old news." "This is six to eight months old," he said. "Someone is continuing to stir this up."

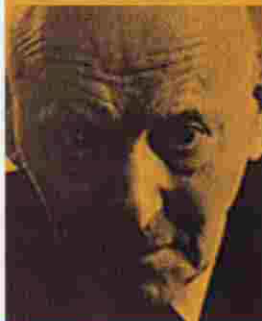
Others following the issue disagree that the concern is passé. Attorney Susman—known for his freedom-of-information expertise—acknowledges that the federal government's electronic information practices have shifted since the terrorist attacks of 2001. "If in doubt, take it out" is the new policy regarding access to information via the Web, Susman said, adding, "When it comes to information involving homeland security, there is no question that the government is putting out less information."

As to whether political ideology or security determines changes in the nature of what government information is available online, Susman observed, "Administrations use agencies and the media as ways of promoting their views." He added that while "it shouldn't surprise anyone that in an administration that is interested in promoting abstinence instead of contraception, that [perspective] should be a part of a message from HHS. Using websites to promote a point of view is not unexpected."

"To remove factual information from websites goes a step beyond that," Susman added.

Echoing this sentiment, Fairbanks librarian Pinnell-Stephens remarked, "We must always be concerned with accuracy of information and the credibility of sources we make available to our users. When government-supported research and reports are compromised by politics and ideology, we can no longer trust their validity. This subversion of the scientific process has the potential of causing great harm and should be protested as loudly as any other form of censorship." ❖

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