

Locating Patient and Consumer Information from U.S. Government Websites

Shifting cultural norms and government priorities in health messaging create challenges for professionals who depend on agencies for timely, science-based, nonpartisan, and inclusive educational materials for patients and consumers. This document provides tips for beginner, intermediate, and advanced level professionals in locating archived patient and consumer information.

For materials that have disappeared:

Many efforts have been made to take snapshots of the internet over time. Consider using an archived version of web resources provided by government agencies. Below are efforts made by non-profit organizations to archive.

Beginner:

Internet Archive's Wayback Machine

web.archive.org

Simply input the URL of the resource you previously used to find a clickable calendar of dates the resource was archived.

Intermediate:

Federal Depository Library Program Web Archive

Archive-it.org/home/FDLPwebarchive

Browse through archived federal websites within archive date ranges.

Advanced:

Common Crawl

commoncrawl.org

Downloadable files of archived federal websites.

For materials that may have changed:

Beginner:

Read it yourself. The best way to assess whether a website is applicable for your population is to read it yourself. This is not always possible with materials written for specific needs or translated materials. However, it is always best to review materials rather than trusting their titles.

Intermediate:

Use a text comparison tool. Many writing software tools (including MS Word and Google Docs) have tools that allow you to compare text and images to see what changes have been made between versions. There are also free tools online such as diffchecker.com where you can upload files or copy/paste text to highlight the differences.

Advanced:

Monitor common websites for changes. There are apps and browser extensions that monitor and report when a website has been changed. Tools include changedetection.io and visualping.io.

Creating Your Own Materials

An advantage of materials provided by US government agencies has been that they met professional standards with respect to health literacy and were updated regularly. Much of this content is free use and is allowed to be repurposed for educational purposes.

However, it is not always the case, and you should consult with your organization's legal and communications departments to determine whether the information can be used. For more information visit:

Learn about copyright and federal government materials (USA.gov)

www.usa.gov/government-copyright

Considerations

With archived materials, it is important to recognize they are not being updated with changes in science and best practices. Always be transparent with the consumer/patient that the materials are aging and the information may need to be updated.

Even if the government priorities return to what they were, it is unlikely that the same materials will return in the short term, if at all.

People who can help

Remember that you are not alone facing these challenges. There are many out there who can help.

Librarians

Librarians have specific skills in accessing and navigating the information environment. Depending on what you are looking for, you may be served by your community librarian, or by one in an academic center.

Many libraries have staff with Consumer Health Information Specialization (CHIS) that have specific skills to help with consumer-focused health information.

Professional organizations

Depending on your professional identity, these are challenges faced by others in similar roles. Check with your professional organizations to learn what guidance they may provide or bring up the conversation in your professional practice forums.

Institute for Healthcare Advancement's Health Literacy Solutions Center and Listserv

IHA's Health Literacy Solutions Center and Listserv can be fantastic resources for navigating this environment. As an organization that serves a multidisciplinary group of health literacy-minded professionals, there are resources and discussions that may be helpful. If you have a specific problem, ask it to the listserv.

Online communities

As many impacted by these challenges are hesitant to use their own organizational resources/identities for discussing these issues, many have turned to social media spaces and communities. You can search for groups on LinkedIn, X, BlueSky and Reddit.