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Supporting Cancer Knowledge Needs Using Online Information

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Summary and Key Points

1. Healthcare providers require quality, credible, evidence-based information for their oncologic knowledge needs.

2. An understanding of health information literacy is necessary to access and identify websites or databases containing reliable, freely available medical information.

3. There are many free, credible, publicly available resources provided by government departments and health organizations.

4. The National Library of Medicine (NLM) offers services and biomedical electronic information resources searchable by people around the globe.

5. A well-designed clinical question strengthens the search strategy by efficiently retrieving relevant, topic-specific results.

6. Use of search techniques and PubMed tools, such as MeSH (Medical Subject Headings) and My NCBI (National Center for Biotechnology Information), improve search results and support the research process.

7. "Open access" is free, unrestricted, online access to scientific and scholarly research.

Introduction

Information is exploding at an exponential rate. Because there is a flood of medical information on the Internet, it can be difficult to wade through the many resources to determine what information is best to use in practice. The intent of this chapter is to help the health care provider find reliable online cancer information. To help inform clinical decision making, health science librarians continue to address this rapidly growing body of literature by analyzing resources and identifying the highest quality information available on the Internet.

The concept of Evidence-Based Medicine (EBM) is important to understand, as well as the process needed to find literature supporting EBM. Why EBM? EBM is "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients."[1]

Making evidence-based clinical decisions is not about intuition, but finding reliable, up-to-date literature and using it in combination with clinical expertise and patient choice. Once a source for free online quality literature is located, a health care provider can consider the best current evidence to thoroughly answer clinical questions.

Information Literacy

Health information, specifically information about cancer, is available almost everywhere and is especially pervasive on an increasing number of health websites. When a health care provider searches online for information it is critical to retrieve results that contain reliable medical information to use in patient care. Sometimes it can seem challenging to find credible information. Although there are trustworthy free sites, including the National Library of Medicine (NLM), National Guideline Clearinghouse (NGC), Drugs@FDA (United States Food and Drug Administration), and National Cancer Institute (NCI), there are many others, some of which may be questionable. To ensure retrieval of quality information, the validity of the information on such online resources needs to be verified. Websites, and the information presented on the sites, can be evaluated by examining the following criteria: Accuracy, Authority, Bias/Objectivity, Currency/Timeliness, and Coverage of the website.[2]

1. Determine who is sponsoring or creating the website – Look for an "About Us" page to see who runs the site. Is it a government branch, a university, a health organization, a hospital, or a business? Does the site have an editorial board and is information reviewed before it is posted? Does the site contain outdated information?

2. Why are they doing this? Is the site sharing information, educating people, or trying to convince the reader about something, or even selling a product?

To look at websites, journals, or tools with a critical eye, consider five simple words when evaluating free online information: Who, What, When, Where, Why (Figure 1).
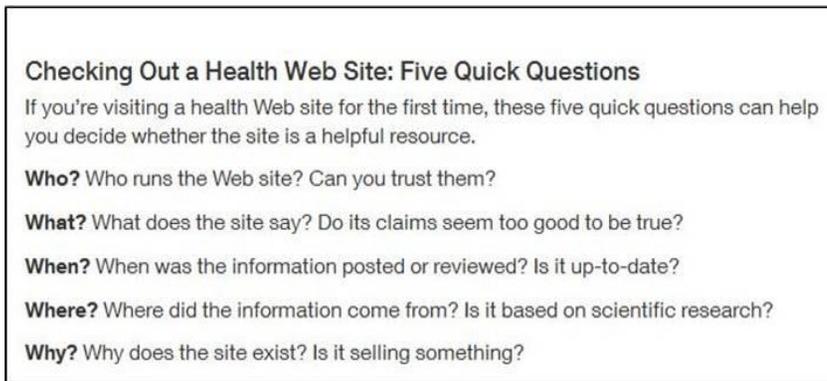
Figure 1. Quick website evaluation questions.[3]

Further information and instructions to evaluate online health information and address health fraud, specifically targeting vulnerable groups, especially people with cancer, can be accessed through the NLM MedlinePlus. The two sections are compilations of comprehensive information suitable for both health care providers and patients.

Cancer Information Resources

Members of the Medical Library Association (MLA) Cancer Librarians Section compiled a list of recommended websites for cancer information, available at the MLA website. Cancer librarians reviewed the websites for quality, confirming the currency, credibility, content, and audience of each resource, and grouped the websites in categories, including Clinical Trials; Government and Organization Websites; News and Current Awareness; Professional Society Meeting Abstracts; Practice Guidelines and Treatment Overviews; Statistics and Epidemiology; Treatment Options: Alternative Medicine; and Treatment Options: Drugs and Biologics. In addition, cancer information websites for patients and caregivers are listed.

While there may be a multitude of good, free oncology-related resources, the following individual websites represent a sampling of what is currently available and are suggested for health care provider use.

Cochrane reviews are systematic reviews, updated regularly, of primary research in medicine and health, developed by international collaborators and based on all relevant primary research on a topic to assess the efficacy of a treatment, in the form of an answer to a specific question. For questions that have been reviewed, they are a reliable source of data to practice EBM. They are published online as The Cochrane Database of Systematic Reviews, which unfortunately are not Open Access. However, they do publish summaries of each review which are Open Access. In addition, free access is provided for certain emerging nations. Reviews are searchable by topic, or by specific issue. For example, the cancer topic, which is subdivided by organ, is available here: Cochrane cancer reviews.[4]

Drugs@FDA on the U.S. Food and Drug Administration (FDA) website provides information about FDA-approved innovator and generic drugs and therapeutic biological products. This includes finding drug labels, specific ingredients, and approval histories. Another part of the FDA site is a section specifically for health care professionals with resources, activities, and news.

Health on the Net Foundation (HON) is an international non-profit, non-governmental organization offering online health information for both medical professionals and patients. HON provides a selection of services and tools; an overview of the available medical search engines on the website includes HONmedia, a medical image and video repository.

The National Comprehensive Cancer Network (NCCN) provides guidelines useful for the treatment of almost all cancers, age related issues detection, prevention, risk reduction and supportive care and as well as subject compendia from the guidelines, and patient resources. These are very detailed.

National Cancer Institute (NCI) provides free resources for health professionals to find evidence-based information about cancer as well as educational information, training tools, and resources from NCI and NIH.

National Guideline Clearinghouse, an initiative of the Agency for Healthcare Research and Quality (AHRQ), provides objective, detailed information on clinical practice guidelines for physicians and health professionals.

OncoLink, founded in 1994, contains comprehensive information about specific types of cancer, updates on cancer treatments, and news about research advances. The site provides tools and educational materials to support the practice of practitioners. It is maintained by University of Pennsylvania cancer specialists with a mission to help provide accurate cancer-related information at no charge.

OPENPediatrics is an online community of clinicians, caring for critically ill pediatric patients, who share best practices from all resource settings around the world through collaboration and digital learning technologies, such as virtual education and medical calculators. The open access, online educational platform is sponsored by Boston Children's Hospital in collaboration with the World Federation of Pediatric Intensive and Critical Care Societies.

Google Scholar provides another alternative to find oncology literature. A search can be broad across many disciplines, sources, and types of publications, and although the abstracts are usually free, some full-text articles may require subscriptions.

Open access journals are another source for online cancer information. Many of these journals are published entirely online with the expectation all information will be freely available from the first date of publication. Others begin as subscription-based resources that become freely available after an embargo period has passed. The Directory of Open Access Journals (DOAJ) is a comprehensive resource that indexes and provides access to more than 10,000 open access, peer-reviewed journals covering all areas of science, technology, medicine, social science, and humanities. Oncology topics can be searched in both journals and articles.

Although there are a variety of approaches to search DOAJ, one strategy is to choose the heading "Browse Subjects" and enter "cancer" as a keyword in the "search subjects…" box. This will display "Neoplasms.

Tumors. Oncology. Including cancer and carcinogens," (Figure 2) Select the button to "View Journals/Articles" and filter the results by articles, journals, subject, publisher and/or language. Another strategy is to enter a term in the home page search box; retrieve relevant articles and journals, and limit the result by using appropriate filters.
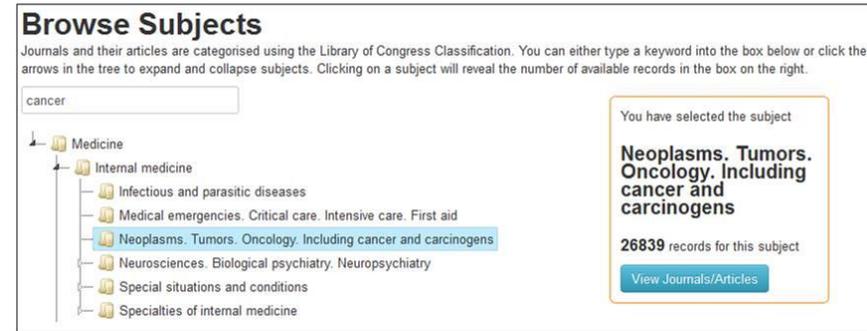
Figure 2. Example of a search strategy in the Directory of Open Access Journals (DOAJ)[4]

The Directory of Open Access Books offers over 2,200 academic peer-reviewed open access books from 70 publishers. Searches can be filtered by subject and date of publication.

Wikimedia Commons is a free media file repository, which makes available public domain and freely-licensed educational media content (images, sound and video clips) to everyone, in many languages.

The Digital Commons Network brings together scholarship from hundreds of universities and colleges, providing open access to peer-reviewed journal articles, book chapters, dissertations, working papers, conference proceedings, and other original scholarly work. This constantly growing collection of publications is curated by university librarians and their supporting institutions, and represents thousands of disciplines and subject areas—from Architecture to Zoology. Oncology resources can be discovered by entering a cancer keyword in the home search box, or choosing a "Medicine and Health Sciences" discipline, followed by a "Medical Specialties" sub-discipline, and then "Oncology" as the entry point.

Cancer Information on Mobile Apps

A mobile app is another commonly used tool to access health information. Mobile apps are software programs that run on mobile devices, such as smart phones and tablets, and can be purchased or downloaded for free. Health care providers find mobile apps facilitate patient care, while consumers use them to manage their health and wellness. With an increasing number of medical apps becoming available through app stores, it can be a challenge deciding which ones to choose. Generally, it is easier to find a description and a review of an app by searching app stores for a specific topic or device, either Apple or Android. Since this discussion highlights only a few medical apps, the reader is encouraged to consider other information sources, websites and Android or Apple reviews to select apps. These are usually either free or low cost. Additionally apps can often be downloaded from individual or institutional journal subscriptions.

The following is a sample of what is available (Table 1):

Table 1: Available Mobile Apps

AgileMD
Epocrates
Medscape
National Comprehensive Cancer Network
New England Journal of Medicine
PubMedMobile

National Library of Medicine Resources

The National Library of Medicine (NLM)) is an institute within the National Institutes of Health (NIH), US Department of Health and Human Services (HHS). It is the world's largest biomedical library, and offers services and electronic information resources searchable by people around the globe. The following NLM databases provide value to a health care provider searching for different types of oncology information.

MEDLINE/PubMed is an online scientific medical resource with a publicly available database of over 22 million journal citations dating from 1946 to the present. MEDLINE is the NLM journal citation database, which uses the NLM controlled vocabulary, Medical Subject Headings (MeSH), to index citations. PubMed contains over 25 million references and includes those in the MEDLINE database as well as other types of citations.

Included among these other references are citations not yet indexed with MeSH, citations from MEDLINE-indexed journals that are "ahead of print," and citations published prior to 1996 that have not been converted to MEDLINE status.[4] Basic search techniques in PubMed are discussed later in this chapter.

PubMed Central (PMC) is NLM's free electronic, full-text archive of biomedical and life sciences journal literature. In the PMC Journal List, all journals included in PMC are listed by title with data indicating the amount of time following publication when articles become available for free access (embargo). Each title links to all issues of the journals in PMC or to articles in NIH Portfolio journals that deposit all NIH-funded articles and some non-NIH-funded articles into PMC PubMed does not include citations for certain types of PMC material, such as editorial content, which is considered out of scope for PubMed. Therefore PubMed does not index everything that is in PMC. Editorial content, in this context, refers to articles and article-like items, including book reviews, news items and obituaries. PMC also accepts journal cover images and accompanying captions. "Oncology" may be entered into the search box to retrieve all journals with "oncology" in the title. "Cancer" may be searched similarly.

PubMed Health provides information for consumers and clinicians on the prevention and treatment of diseases and conditions. It specializes in systematic reviews of clinical effectiveness research, and includes reviews from the Database of Abstracts of Reviews of Effects (DARE), which are not included in PubMed. Key terms can be entered in the search box to find literature on clinical effectiveness, and results can be limited by using the filter menu.

Two other NLM information services designed for the public, but also useful for health care professionals, are MedlinePlus and ClinicalTrials.gov. MedlinePlus provides consumers with reliable, up-to-date health resources, which cover diseases and conditions, information on drugs and supplements, using tools and videos, encyclopedias, and images. Patient handouts, available in English and Spanish, can be emailed or printed. The entire website is accessible in Spanish. Specific health topics are available in over 45 languages, from Amharic to Vietnamese. as well as some sections in other languages. A search for "oncology" results in over 4,400 articles.

ClinicalTrials.gov provides the public with information about all types of human clinical research studies around the world. The database includes information about current trials, the results of studies, and studies about specific conditions. The category of "Cancer and Other Neoplasms" can be further searched by topic.

Search Techniques

The search strategies described above are suggestions to find evidence on specific websites, where the information is contained in one place. Depending upon the circumstance, it may be necessary to delve more deeply in the existing literature to find cancer information. In this case, a specific database, like PubMed, may be a better choice to find the needed evidence, but a database search requires a focused approach to retrieve relevant, topic-specific literature. It is instrumental to carefully consider the clinical question – why is it being asked, what outcome is expected? Answering these simple questions can help determine what key words should be searched and how the search results might be filtered. Can the question be broken into parts to find specific key words to enter into a search box? Using a well-focused question saves time identifying appropriate resources and searching for relevant evidence. To define the problem and create an efficient search strategy, one framework that can be used is the PICO model, which has morphed to PICOTT for clinical questions.[5] Following the PICOTT and even the PICOTT(T) structure can help a health care provider quickly find the right evidence to answer questions.

Once a clinical problem has been identified, use the PICOTT formula to articulate the most important parts of the question:

- **P**=PATIENT – Who is the patient? Or the population? Or what is the problem?

- **I**=INTERVENTION – Is there an intervention for treatment? Is there an index for a diagnosis? Is the intent to learn about a prognosis?

- **C**=COMPARISON – Is there a control? Placebo? A "gold standard"?

- **O**=OUTCOME – What is hoped to be accomplished, measured, or achieved? The best treatment? Decreased mortality?

- **T** = TYPE OF QUESTION – Does the question determine the best intervention for a therapy? The accuracy of a diagnostic test? The prognosis of a condition? The harm or etiology? The prevention measures? The cost-effectiveness of an intervention? The quality of life for the patient?

- **T**= TYPE OF STUDY – What type of study would best answer the question? A systematic review, meta-analysis, randomized clinical trial, cohort study, comparative study, economic analysis, or qualitative study?

- **T**= TIME – Would the desired outcome be realized in hours, days, months, years?

When the searcher understands the concepts of breaking the clinical question into parts, it may become less necessary to complete each part of the framework to achieve satisfactory results. Some questions do not fit neatly into the format, but if the key concepts can be identified and combined, the search results should be sufficient.

Clinical Queries is a PubMed tool designed to efficiently answer health care questions by using built-in filters to find literature in three research areas. The clinical study category, probably the most useful for health care providers, includes sub-categories for etiology, diagnosis, therapy, prognosis and clinical prediction guides. The Systematic Reviews section encompasses systematic reviews, meta-analyses, reviews of clinical trials and guidelines. When a searcher enters key terms into a search box, the results in the clinical study category may be further sorted by sub-category and focused by scope to retrieve either sensitive/broad or specific/narrow results, depending on the clinical question and the needs of the researcher (Figure 3). If a comprehensive search is desired or many terms are required in the search, a general PubMed search is recommended.

Figure 3. Screenshot of the results from a Clinical Queries Search[7]

PubMed

Most databases provide step-by-step instructions and often video tutorials to answer questions and guide researchers through the main strategies of running a good search. Because PubMed is a free resource, accessible around the world, and includes an increasing number of free full-text articles, a brief summary of basic search terms, tools, and techniques will be introduced. All aspects of PubMed can be accessed on PubMed Help including FAQs, YouTube tutorials, and an overview, as well as more detailed instructions, of how to search PubMed.

When entering key terms into the search box, PubMed directions recommend simply adding the terms without combining them with an "AND" or "OR" between the concepts. This simplifies the search strategy, although there may be times the search string will be more understandable and less ambiguous by using these Boolean terms. Click the Search button to retrieve results from the search (Figure 4). The researcher can choose to review the list of citations by displaying them in a summary or abstract view, and sorting by most recent, relevance, publication date, first or last author, journal, or title. Results may be limited by using the filter menu on the left side of the page, and choosing a number of options including article type, publication date, or age. Another useful tool is My NCBI, which allows an account holder to save citations and search strings, customize the results display, create email alerts to stay current with relevant topics, and review the search history. A My NCBI account is free; use the Sign in to NCBI link on the top right of the PubMed screen to register or sign into an existing account.

Figure 4. Anatomy of the Summary Results[8]

Open Access and Copyright

Freely available, online resources are the subject of this chapter. In PubMed, free full-text articles, books, and documents are identified in citations as "Free PMC article," "Free Article," "Free Full Text," or "Free Books & Documents." These can also be selected specifically by using the "free full text" filter on the left menu bar. However, it may be useful to view the abstracts before choosing the (free full-text) or (open access) filter to avoid eliminating and, therefore, missing relevant studies that are not free. Open access research can be obtained directly through two primary vehicles: open access journals, and open access archives or repositories. eScholarship@UMMS is an example of an open access repository; this guidebook, *Cancer Concepts*, is an open access eBook within the institutional repository. Moving beyond one institution, the Digital Commons Network brings together a collection of free, full-text

articles from over 450 college and university repositories to allow a single search for journal articles, book chapters, dissertations, working papers, conference proceedings and other original scholarly work. Opening access to research throughout the world, the Registry of Open Access Repositories (ROAR) provides a means to search specific repositories for content across the whole Registry.

Copyright

Since there is such a rapidly growing body of open access literature, a brief understanding of copyright is essential before reusing the readily available number of articles, images, and photographs. In some journals, before articles are available as open access, they are in an embargo period. Depending on the publisher, original research may not be available in the public domain for an embargo period, typically lasting six to 24 months after publication. However, the NIH Public Access Policy requires that all peer-reviewed journal articles resulting from NIH-finded research must be made available to the public via PubMed Central within 12 months of publication[9]. Other types of publications, for example editorials, may never be released as open access. Some publications make unrestricted online access free or at low cost in developing countries[10]. Post publication and access policies can be obtained from the publisher.

Copyright restrictions need to be observed when reusing online information. Images are ubiquitous and very easy to copy. The key to reusing images in educational and research materials is to respect the rights that are associated with the image. Unless there is an indication the work is in the public domain and free for reuse, assume it IS under copyright and follow these guidelines for reuse. Remember permission can always be requested, if in doubt. For the reuse of copyrighted online material, create a link to a permanent URL rather than making a copy. Anything produced by or for the government exists in the public domain and is free to use. For example, NIH Image Gallery, the CDC Public Health Image Library (PHIL), and National Cancer Institute's Visuals Online all provide materials that exist in the public domain. Other sources for free images include Wikimedia Commons and MedPix, a new free online medical image case database released by the NLM. However, before reusing any image, review the reuse information on the website to ensure there are no copyright restrictions on specific images.

Conclusion

Health information is abundantly accessible on the Internet. If equipped with the right tools, the search for oncology information can be efficient, successful, and comprehensive. Having an awareness of the variety of online resources will permit health care providers to access reliable cancer information from almost anywhere and be assured they are retrieving the best cancer health care evidence possible.

Thought Question

1. How does a health care provider respond to a patient who, after a diagnosis of cancer, reports finding a "miracle" cure on the Internet and insists on trying this approach?

   Your answer:

Expert Answer.

Assuming the patient searched the Internet for a cancer cure, the first websites to appear will probably be advertisements. Following those, there may be links to news stories, and then many websites. One rule to follow when searching for credible information is to avoid any site selling a product or service. If a website includes advertisements, there is a risk either of information bias from the influence of the advertising dollars or of the distracting, persuasive nature of the advertising claims. Both may affect health care decisions. Although information on such a site may not be harmful, it also may not be as robust or as current as information on another site.

Share information about evaluating a website by considering the five information-gathering questions, "Who, what, when, where, and why"? Be aware of these points and consider the mission of a website. Is it for sales, entertainment, information, or a combination of all three? If practical, steer the patient to credible consumer-oriented website, for example, MedlinePlus or one listed on the cancer section of the MLA website, where they can do their own searches for health information. The people working on both these websites are not creating content, but instead are finding good resources to list and add to the content.

Finally, in answer to the patient, the healthcare provider could perform an evidence based search related to this miracle cure on PubMed or PubMed Health. This would be an opportunity for the provider to guide the patient to valuable online health resources and demonstrate the value of assessing medical websites.

Glossary

Boolean terms (operators)- Simple words (AND, OR, or NOT) used as conjunctions to combine or exclude keywords in a search, resulting in focused and productive results.

Copyright- A form of protection provided by U.S. law to creators of original works of authorship.

Embargo period- The period of time (delay) during which a publication is between official publication and in the public domain with open access status.

Open access- Free**,** unrestricted**,** online access to scientific and scholarly research.

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