BRIEF COMMUNICATIONS

Consumer health libraries: what do patrons really want?

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BACKGROUND

The Consumer Health Library (CHL) at the Methodist Hospital of Dallas (MHD) provided the author experience with and insight into the health information needs of patrons. Because the seeds of inquiry discussed in this brief communication were initially sown in this facility, a description at that point in time will be given. Opened in August 2001, the 900-square-foot library was located in the main hospital lobby near the gift shop, coffee shop, and senior resource center. In the first 6 months, it contained approximately 600 monographs and dozens of pamphlets and brochures and was beginning to acquire health magazine titles. Four computers for patron use provided Gale's Health and Wellness database, as well as Internet access. The budget for non-personnel expenses was approximately $13,000. Usage levels varied widely during the initial months of service, as news was still circulating about the existence of the facility.

From experiences gained in this environment, including the challenges of implementing and evaluating services, a clear question came to mind. Are the information needs of health consumers really being met? To elaborate, do the needs that information professionals perceive really match the needs and wants of the patrons? Professionals naturally feel qualified to determine their patrons' information needs and ways best to meet them. But what needs do patrons themselves demonstrate?

To more adequately evaluate perceived needs versus actual needs, the author posed a series of questions to the email discussion list of the Consumer and Patient Health Information Section of the Medical Library Association (CAPHIS). The discussion list has been active since 1997 and is open to anyone interested in consumer and patient information topics. It has approximately 825 subscribers at present.

DATA COLLECTION

The professional literature includes a 1993 survey asking the general ''why'' of consumer health information requests [1], as in ''why are they asking for this?'' Our current question is about the ''what.'' Members of the CAPHIS email discussion list shared their thoughts in a November 2003 discussion. The following are the list of questions posed and a summary of the nine individual responses received.

What do your patrons seem to need or want most from you?

Answers:

- information on disease conditions
- information on navigating the health care (provider) system
- miscellaneous, nonmedical, ready reference information including travel directions, yellow page access, etc.
- a quiet place to escape
- printed material to share with a patient and the rest of the family
- computer access for email or research
- information about medical tests
- recommendations and evaluations of doctors (something a librarian cannot ethically answer)

What consumer health services do the physicians and medical community seem to need or want most from you?

Answers:

- assurance that we provide a quality service and quality materials
- consultation services on patient education material development, health literacy issues, and resource purchase advice
- a place to refer patients for additional information
- availability or access to the library's resources
- individual instruction in navigating the Internet or intranet

What seems to be lacking most in the patient's health information experience?

Answers:

- focus on health promotion and wellness information
- follow up and evaluation as to how the information impacted a health behavior or treatment decision
- knowledge of where the library is located and that it is available for their use
- comprehension of what the doctor or nurse told them
- understanding of basic human anatomy and medical terminology

What are your most popular services or materials?

Answers:

- computer access (for Internet and word processing)
- quick take-away items such as pamphlets and brochures (listed by several librarians)
- telephone line access and access for laptop computers
- children's area with computer, books, games, etc.
- free delivery of materials on request (to patient's home or to the patient care unit)
- copy machine and fax for patient or family use

- medical databases
- personal, human assistance in locating information

It would be interesting to pose these questions to CHL professionals every ten years. Patron needs may not change as rapidly as technology, but they will definitely fluctuate over time.

DISCUSSION

The responses from the list mirror the author's experience managing the CHL at MHD. Patrons are normally in a hurry. For the most part, they want free information that they can quickly grab and take home. That explains why health brochures, such as those provided by Channing Bete and Krames, are so popular in most consumer health libraries. For the CHL at MHD, a large percentage of the budget was devoted to keeping these materials well stocked. The most popular topics included stress, depression, anger, and sexually transmitted diseases (STDs). The subject areas will naturally vary with the community served. That is one reason it is so important to understand cultural issues in providing health information [2]. Although the MHD facility is in an inner-city neighborhood, similar brochure topics would likely be applicable to many other settings.

Another way to assist patrons with this ''grab 'n' go'' desire is to create customized information pamphlets. One adaptation proved very popular with the CHL clientele at MHD. Reference statistics were kept on the questions being asked, and one-page information sheets on those topics were created, much like a simplified pathfinder. To begin, a brief, easy-to-understand paragraph described the disease or topic (in only factual terms with no opinion or advice given), followed by examples of the print library materials addressing that topic. Next, relevant citations of current news and journal articles from the library's databases were given. Finally, local and national support groups, organizations, Websites, and so on were listed for further assistance. Not only were these an inexpensive alternative to the purchased brochures, but also an innovative marketing tool to remind patrons of the available services. Hospital administrators, who had assumed these were purchased materials, were delighted to learn they originated internally.

A critical point mentioned in the survey is the importance of ''second mile'' services, those that go beyond the normal scope of providing health information. Patients, family members, and visitors often need a break from the strain of the medical issues they face. Whether it is providing email availability, a children's play area, or just an ear to listen, the personal touch is vital to a consumer health library. One of the most valuable services provided in this environment is compassion. People often just need to talk as a way to release the tension. Family members dealing with traumatic injuries to their loved ones may find solace while chatting in the safety and anonymity of a consumer health library. The author witnessed one instance when that conversation between two strangers lasted for hours. Whether the comforter is the librarian or another patron, consumer health libraries can often be a ray of hope well beyond any health information that is provided.

Consumer health librarians can best meet their patron's needs by listening to them and providing the services they desire most. Offer an inviting, quiet location staffed by helpful, knowledgeable information professionals. Stock a wide variety and large supply of pamphlets and brochures. Speak to the patron in lay terms, explaining what the doctor said in simpler language (with the normal disclaimers about not providing medical advice). Such a comfortable, down-to-earth environment can begin the emotional healing needed by patients and families alike.

This type of library requires an information professional with extraordinary people skills. In fact, superb bedside manner should be personified in consumer health libraries. Physicians are often perceived as sacrificing attentiveness for a large patient base. Consumer health librarians have a unique opportunity to fill this gap of compassion and service.

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Consumer health information Websites: a survey of design elements found in sites developed in academic environments*

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BACKGROUND

In preparation for redesigning the consumer health information (CHI) Website of the Health Sciences Library System (HSLS) at the University of Pittsburgh, a review of the literature revealed a surprising lack of

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* Based on a poster presentation at MLA '04, the 104th Annual Meeting of the Medical Library Association; Washington, DC; May 24, 2004. A graphic image of the poster is available through the Health Sciences Library System of the University of Pittsburgh Website at <http://www.hsls.pitt.edu/services/instruction/presentations/mla2004/ketchum04.jpg>.

studies of the design or composition of such sites, despite growing interest and development in the CHI area. There are many general resources for Website design on bookstore shelves and online [1–3], instructions tailored to consumer health libraries [4], and recognition of CHI-specific design issues [5, 6] but no record of the current visual or design status of CHI Websites. This study will begin to fill that gap by providing a basic overview of current CHI Website design practices. The goal of this survey is to simply identify features, not to judge the positives or negatives of any particular feature.

A brief literature review of CHI Website design provides a helpful backdrop for this survey. Databases searched included Ovid MEDLINE, PubMed, Project Muse, Scopus, Academic Search Premier via EBSCO, Information Science & Technology Abstracts via EBSCO, and Library and Information Science Abstracts (LISA). Due to the lack of meaningful Medical Subject Headings (MeSH) terms, a search strategy combining an array of potential keywords with MeSH terms was employed covering three main concepts: (1) consumer health information, (2) Websites or pages, and (3) design. MeSH terms included ''Patient Education,'' ''User-Computer Interface,'' and ''Internet,'' as well as the MeSH publication type, ''Patient Handout (pt).''

No studies were found surveying the design features used in CHI Websites. Rather, published studies focus primarily on what should be in a Website, not how it actually appears, giving no indication of current design practices. The three main aspects of CHI Websites covered in the literature can be summarized as:

1. Who are CHI consumers?
2. What do consumers want or need?
3. What do consumers get?

In partial response to the first question, for example, it has been found that visitors to CHI Websites often have similar needs, and those in poor health are more interested in this information than those in good health. Also, the use of CHI Websites decreases reliance on health professionals for information [7]. Detailed consumer profiles based on certain sets of information-seeking behaviors, rather than on population demographics, have been developed to better understand the information and formats sought [8].

As for what consumers want or need, one qualitative study using focus groups and usability tests recommends a clean, uncluttered, easy-to-use interface with minimal clicking, reliable sources, links to recommended sites, and illustrations, among other details [9]. A quantitative study analyzing Web server logs shows that users begin and end on the home page, and pages displaying lists of links must be easily navigated [10].

Ultimately, what are CHI Website visitors actually getting? One such study points out some expected benefits, such as increased knowledge and decreased anxiety, but continues into deeper implications: What happens when consumers find that their doctors' advice is contradicted by a published medical source [11]?

Although necessary to understanding the larger picture of CHI and its impact on health care, these studies do not describe what the pages look like, only how users react to them, measured either qualitatively or quantitatively. They give details about the users, rather than details about the appearance of the pages.

The only article found that even hinted at CHI Website appearance is from Taipei Medical College, describing ''the current status of CHI Websites and pages in Taiwan'' as a first step toward developing a reliable system for rating the quality of CHI Websites [12]. However, even this paper does not actually describe basic design details but only refers to the need for a ''cleanly designed site,'' accurate attributions, and frequent updates.

So, what are the current building blocks of design for CHI Websites? To find out, a survey and analysis of CHI Websites originating from academic environments was performed, resulting in a rudimentary inventory of design components to consider during development, as well as a broad overview of existing CHI Websites, illustrating a range of possibilities.

METHODS

In early November 2002, a visual survey of 33 CHI Websites was conducted to identify prevalent format and content. A Google search for ''university ''consumer health information'' '' produced approximately 20,000 results. After viewing the first 10 returned pages, 33 Websites were selected from 16 US states and Canada. The sites were primarily from academic settings but included two public libraries, two hospital libraries with formal relationships to universities, one regional governmental resource, and one consumer health advocacy site from a law school. A few of the Websites had ties to commercial entities, such as insurance companies (Table 1). Some of these sites have moved, disappeared, been updated, or redesigned since the original survey.

A Microsoft Access database was created to collect and analyze content (18 fields) and structure (10 fields) for each of the 33 Websites (Table 2).

FINDINGS

A composite Web page of the five most common content and structural features would yield a one-page scrolling column of links organized by type of information resource (i.e., dictionaries, newspapers, Websites), with contact information, a last update notice, disclaimer, and a site search box. Content would include links to medical news and alternative medicine. The Augustus C. Long Health Sciences Library at Columbia University <http://library.cpmc.columbia.edu/hsl/sg/sgdisplay.cfm?subid=7> is an example of a site incorporating these content and structural features. This approach is very straightforward, with its purpose of presenting information clearly and quickly.

Table 1
Thirty-three consumer health information Websites included in survey (November 6, 2002)

Name	Uniform resource locator (URL)
Aetna, InteliHealth: Harvard Medical School's Consumer Health Information	http://www.intelihealth.com
Arizona Health Sciences Library, Consumer Health	http://www.ahsl.arizona.edu
Charlottesville (VA) Community Web, Consumer Health	http://hsc.virginia.edu/hs-library/outreach/consumer.html
Chautauqua-Cattaraugus Library System, Consumer Health	http://www.cclslib.org/consumerhealth.html
Columbia University, Augustus C. Long Health Sciences Library, Consumer Medicine	http://cpmcnet.columbia.edu/library/subguides/consumer.html
Cooper Health System, Medical Library	http://cooperhealth.medicallibrary.medem.com/medlib_entry.cfm?m1=http://cooperhealth&flag=geturl
Crozer-Keystone Health System, Crozer-Keystone Virtual Library	http://www.crozer.org/Crozer/Health+Information/default.htm
Dartmouth Biomedical Libraries, Consumer Health Resources	http://www.dartmouth.edu/~biomed/resources.htmld/conshealth.htmld/
Duke University Medical Center Library, Consumer/Patient Health Information	http://www.mclibrary.duke.edu/respub/refres/consumer.html
Emory Health Sciences Center Library, Emory MedWeb Subject Index for Consumer Health	http://www.medWeb.emory.edu/MedWeb/
Emory University, Robert W. Woodruff Health Sciences Center Library, Consumer Health Resources	http://www.healthlibrary.emory.edu
Exempla Lutheran Medical Center, Consumer Health Libraries	http://www.saintjosephdenver.org/yourhealth/libraries/
Indiana University School of Law, Consumer Information (health law/consumer advocacy)	http://www.iulaw.indy.indiana.edu/programs/CLH/consumerinfo.htm
Indiana University School of Medicine, Consumer Health	http://www.medlib.iupui.edu/ref/consumer.html
Loyola University, Consumer Health	http://libraries.luc.edu/cfpages/subjectpg.cfm?sid=52
McGill University, Selected Consumer Health Resources	http://www.health.library.mcgill.ca/resource/consumer.htm
McMaster University Health Sciences Library, Health Care Information Resources	http://www-hsl.mcmaster.ca/tomflem/top.html
National Network of Libraries of Medicine, New England Region, Consumer Health Information	http://www.nnlm.nlm.nih.gov/ner/ConsumerHealth.html
New Haven Free Public Library/Harvey Cushing/John Hay Whitney Medical Library, Consumer Health Information Network	http://www.cityofnewhaven.com/library/healthnetwork/
Northern Virginia Community College Libraries, Consumer Health Resources	http://www.nvcc.edu/library/BOW/elechealth.htm
Stanford University Medical Center, Lane Medical Library, Consumer Health	http://lane.stanford.edu/toolkits/consumer.html
University of Cincinnati, The Ohio State University, Case Western Reserve, NetWellness Consumer Health Information (partnership)	http://netwellness.org
University of California Davis Health Sciences Libraries, Consumer Health Resources	http://www.lib.ucdavis.edu/healthsci/conshealth.html
University of Iowa, Hardin Meta Directory of Internet Health Sources	http://www.lib.uiowa.edu/hardin/md/
University of Iowa, Virtual Hospital Information for Patients, Iowa Health Book	http://www.vh.org/Patients/Patients.html
University of Maryland Health Sciences and Human Services Library, Consumer Health Links	http://www.hshsl.umaryland.edu/resources/consumer/
University of Maryland Libraries, Consumer Health	http://www.lib.umd.edu/MCK/GUIDES/consumer_health.html
University of Toronto, Patient and Consumers	http://www.stmichaelshospital.com/content/programs/hslibrary/consumerhomepage.asp
University of Wisconsin–Madison Health Sciences Libraries, Consumer Health and Medical Information	http://www.medsch.wisc.edu/chslib/consumer/
Utah Library Association, Utah Consumer Health Information Network	http://www.ula.org/organization/rt/heart/heart-uchin.htm
Virginia Commonwealth University, VCU Libraries, Consumer Health Resources	http://www.library.vcu.edu/tml/bibs/consumer.html
Washington Hospital Healthcare System, Washington Community Health Resource Library	http://www.healthlibrary.org
Yale University Harvey Cushing/John Hay Whitney Medical Library, Consumer Health Resources	http://www.med.yale.edu/library/consumer/

Note: Some of these sites have moved, disappeared, been updated, or redesigned since the original survey.

The *least* typical Website would include multiple columns, frames and/or tables, navigation tabs, a site map, a site index in a page border, and content organized by subject. This site would offer search tips, referral services, and interactive tools such as child development timelines and self-assessment tests. These least typical CHI Websites are those with commercial influences. For example, Harvard Medical School has partnered with Aetna to produce Intelihealth.com <http://www.intelihealth.com>, an extremely dense, colorful, interactive site using frames and tabs, among other complex design features. However, the site also features advertisements and a shopping catalog and is a "wholly owned subsidiary of Aetna, Inc." Although this Website design has a sense of entertainment value, it is also notable that many navigation tools are built in, highlighting a concern for easy and flexible navigability.

CONCLUSION

Although this survey was never intended as anything more than a quick snapshot of design examples, a few questions did emerge for further investigation. For example, the most surprising finding was that twenty of the thirty-three sites (61%) were organized by resource type or format, while sites organized by subject were in the minority, with only thirteen of the thirty-three sites organized this way (39%). Is this organizational choice a response to patrons' actual requests or needs? Does organization by resource type better reflect a physical library? Why was this choice made in so many cases? As for broader questions, why are some features chosen frequently and others not? Who is making those decisions? To what extent does a budget affect design decisions? To what extent do technological limitations impact those decisions?

Table 2
Content and structure analysis of thirty-three consumer health information Websites

Content fields (18)		Structure fields (10)	
List of links	32	Columns (as in newspapers)	33
Contact information	26	Site search box	22
Last update	18	Index = links	21
Disclaimer	16	Organized by resource type	20
Medical news	12	Scroll one page	19
Alternative medicine	12	Site index in border	15
Demographic groups	10	Organized by subject	13
Guides	9	Site map/guide	6
Privacy statement	7	Tables	4
Ask a librarian	6	Navigation tabs	2
Today's date	5		
Quality tips	4		
Non-English language	3		
Search tips	2		
Ask the Doc	2		
Commercial affiliation	2		
Referral service	2		
Interactive tools	1		

For now, this survey will at least provide an initial menu of design options for beginning a Website planning process along with a selection of Websites to browse.

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Growth and decentralization of the medical literature: implications for evidence-based medicine

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Evidence-based medicine rests on the shoulders of the peer-reviewed literature [1]. MEDLINE, maintained by the National Library of Medicine (NLM), is the largest and most widely used index of the medical literature [2]. As such, it contains the vast majority of the ''evidence'' that is the foundation for evidence-based medicine.

This study examines trends in the volume, authorship, content, and funding of MEDLINE articles between 1978 and 2001, a time of great change in medical research and medical practice. The authors examine these trends as a means of identifying opportunities and challenges for using this information to guide practice

METHODS

The current study examined data for all journal articles published from 1978 through 2001 and available in MEDLINE in 2003. These years were the earliest and latest for which all fields were available and indexing was complete. We included only full journal articles and excluded editorials and letters.

Analyses compared the number and characteristics of articles published across three 8-year eras: 1978 to 1985, 1986 to 1993, and 1994 to 2001 (Table 1). Relative risks, calculated as the ratio of each value from 1994 to 2001 divided by the corresponding number for 1978 to 1985, were used as the indicator of effect size. Because of the extremely large sample size, even minor changes were likely to be statistically significant.

Table 1
Trends in MEDLINE journal articles, 1978–2001 (n = 8,123,392)

	Time period			Relative risk for change between 1978–1985 and 1994–2001*
	1978–1985	1986–1993	1994–2001	
Article and page count				
Mean number of articles per year	272,344	344,303	398,778	1.46
Mean number of pages per year	1,884,905	2,344,862	2,790,399	1.48
Study characteristics				
Human subjects	62.6%	65.6%	68.8%	1.10
Randomized controlled trial	1.9%	3.1%	6.2%	3.3
Authorship (number of authors)				
1	26.4%	20.3%	15.6%	0.59
2–4	56.1%	53.3%	48.0%	0.86
5 or more	15.6%	25.1%	35.1%	2.25
Median	2	3	4	2.00
Funding source				
Public only	9.1%	6.9%	6.8%	0.75
Private	10.7%	19.5%	27.0%	2.5
Public and private	5.4%	8.1%	8.7%	1.6
None	74.7%	65.4%	57.7%	0.77

* All statistical comparisons across time periods highly statistically significant ($P < 0.001$) due to the extremely large sample size.

Therefore, a relative risk of at least 1.1 between the 1st and 3rd eras was preestablished as an effect size denoting meaningful change over time.

RESULTS

A total of 8.1 million journal articles were published in MEDLINE between 1978 and 2001. Between 1978 to 1985 and 1994 to 2001, the annual number of MEDLINE articles increased 46%, from an average of 272,344 to 442,756 per year, and the total number of pages increased from 1.88 million pages per year during 1978 to 1985 to 2.79 million pages per year between 1994 to 2001.

The growth in the literature was particularly concentrated in clinical research, with an increase in the proportion of studies with human subjects and a change in Medical Subject Headings, which shifted away from basic science headings toward topics related to clinical care and public health (Table 2). The proportion of randomized clinical trials tripled from 1.9% during the 1st time period to 6.2% in the final era. This combination of increasing numbers of articles and increasing proportion of randomized trials resulted in a dramatic increase in the total number of randomized controlled trials (RCTs) over the 3 eras, from 5,174 annual RCTs during the first 8 years to 24,724 RCTs per year by the final era.

The median number of authors per publication doubled between 1978 to 1985 and 1994 to 2001, from 2 to 4, with the proportion of articles written by 5 or more authors increasing from 15.6% in the 1st era to 35.1% in the 3rd. The proportion of articles funded only through private sources increased 2.5 times from 10.7% during 1978 to 1985 to 27.0% during 1994 to 2001. This increase was accompanied by a rise in the proportion of articles funded jointly through public and private sources (RR = 1.6), a decline in articles funded only through public sources (RR = 0.75), and a decline in unfunded studies (RR = 0.77).

DISCUSSION

The study period was characterized by a major growth in the literature indexed in MEDLINE, particularly in randomized trials and other sources of information that might be used to guide evidence-based practice. At the same time, sources providing that information decentralized with an increase in the number of authors per paper and a shift from public toward private funding.

The growing number of articles, the shift toward clinical topics, and the growth of randomized trials point to an increasingly rich source of information available for guiding treatment decisions. However, this stunning growth in medical information also

Table 2
Top 5 Medical Subject Headings (MeSH)

1978–1985	1986–1993	1994–2001
Mammals	Mammals	Public Health
Proteins	Proteins	Proteins
Diagnostic Techniques/Procedures	Public Health	Quality of Health Care
Public Health	Diagnostic Techniques and Procedures	Epidemiological Methods
Pathological Processes	Quality of Health Care	Mammals

brings challenges and risks. While much appropriate attention has been drawn to the need for more evidence to guide practice, the sheer magnitude of that evidence can at times serve as a barrier to its effective use. Nearly 200,000 RCTs were published in MEDLINE-indexed journals between 1994 and 2001 alone.

Furthermore, MEDLINE-indexed journals represent an increasingly small portion of the broader universe of medical information. NLM estimates that currently about 14,000 biomedical journals are published and that it selects only about one-quarter of new submissions for indexing based on quality and relevance to biomedical topics [3]. These biomedical journals, in turn, represent only a small fraction of the growing array of information sources on the Web [4].

The growth of information was accompanied by a broad pattern of decentralization, both in sources of funding and in authorship. While the funding source category in MEDLINE does not distinguish between for-profit and not-for-profit private funders, industry support is by far the largest and fastest-growing source of nongovernmental funding in medical research [5] and likely the primary driver of the sharp growth in privately funded articles seen in the current study.

The rising number of authors, which supports and expands on earlier research noting this trend in particular journals [6, 7], also highlights potential tensions between increased diversity and reduced accountability. In part, the increase in multiple authorship represents a shift in the research paradigm toward multidisciplinary research teams and multicenter trials. However, editors and researchers have expressed growing concern that, as the number of authors rises, identifying contributions of and assigning responsibility to each of the contributors becomes increasingly difficult [8, 9].

How are clinicians, researchers, and librarians to make sense of this growing quantity and range of sources of clinical information? The study's findings suggest the importance of three related approaches. First, it is critical for all users of the literature to develop active reading skills that allow them to efficiently search this enormous body of literature, to identify potential biases, and to sort the wheat from the chaff [1].

Second, as the size and scope of information continues to grow, ''prefiltered'' sources such as reviews, clinical guidelines, and the Cochrane Library are becoming increasingly indispensable for clinicians and researchers seeking to synthesize the literature. As these sources become increasingly important, it will be essential to ensure their continued accessibility, integrity, and quality [10].

Finally, ensuring the accountability and impartiality of the articles published in the peer-reviewed literature is essential. The growth of multiple authorship highlights the importance of supporting and expanding collaborative editorial efforts to ensure explicit role definition and responsibility among contributors [11]. The expansion of privately funded research underlines the importance of transparent and full disclosure of competing financial interests [12].

This study's findings should be interpreted in the light of at least two limitations. First, while MEDLINE is the largest index of biomedical literature, it is, by design, a peer-reviewed subset of the universe of biomedical information. The main study findings, including both the increasing quantity and decentralization, would be expected to be substantially more pronounced in that broader environment. Second, most of the fields in MEDLINE rely on authors and/or indexers for accurate coding. This reliance might lead to underreporting certain fields, such as funding sources for journal articles.

The study's findings at once present challenges and opportunities for evidence-based medicine. The growth of published clinical research during the past quarter century suggests an enormous potential for using that information to improve care. However, transforming this information into useful evidence will require vigilance on the part of the researchers who produce it, the clinicians who use it, and the editors and medical librarians who serve as translators between research and clinical practice.

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