November 2008

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Recommended Citation

Pinkowski, Patricia (2008) "Trends in Consumers' Health Information Needs and Expectations," *Against the Grain*: Vol. 20: Iss. 5, Article 6.

DOI: <https://doi.org/10.7771/2380-176X.5184>

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Trends in Consumers' Health Information Needs and Expectations

by **Patricia Pinkowski** (Director, Green-Field Library, Alzheimer's Association National Office, 225 N. Michigan Ave., Fl. 17, Chicago, IL 60601; Phone: 312-335-5730) <patricia.pinkowski@alz.org>

Introduction

Many topics related to consumer health information are consistently seen in the literature. This article will look at: the Internet, Baby Boomers, caregivers, complementary and alternative medicine, and literacy issues. The paper will not provide an overview of the library's role in building and servicing consumer collections, but rather, it will highlight some current issues and challenges that affect any library whose mission includes serving in this role. Choice of topics was based on local experience working with consumers in a health library environment and not on research showing which topics are "hot" or widely prevalent. This library is focused on aging related issues, primarily Alzheimer's disease, but with 30+% of the population currently over 50, and those 85+ the fastest growing segment of the population, it is a segment that warrants attention.

Internet Use

Issue: The majority of Americans use the Internet. The majority of Internet users actively search for health information. Libraries have a role both in providing access and in assisting users to assess the quality of the information.

The May 2008 demographic report of the **Pew Internet & American Life Project Tracking Survey** showed 73% of U.S. adults used the Internet.¹ **Harris Interactive** shows 76% of those in the U.S. are online.² **Harris Interactive** has also tracked people using the Internet for health information since 1998. The number of Cyberchondriacs [their term] increased annually until a slight leveling off in 2008. Of the 76% of American who are online, 81% have at one time or another looked for health information. **Harris** also identified that 66% of the total adult population has looked online for health information at some time, even if they aren't personally connected to the Internet.

In December 2007 the **Pew Internet & American Life Project** and the **University of Illinois at Urbana Champaign, Graduate School of Library and Information Science** released a report titled, *Information searches that solve problems: how people use the Internet, libraries, and government agencies when they need help*.³ This report looked at how people use a variety of information sources to help them address some common problems. One of the major findings was that more people turned to the Internet than any other source of information and support when addressing a problem. When specifically looking for health information, people first turned to professionals and family, then to the Internet — but the Internet was still a major source. Of those surveyed who found their way to a library, 39% found what they were seeking related to health matters. We are left to wonder: Doesn't the requested information exist? Didn't the

library have the needed resources? Didn't reference assistance connect the patron with the information?

The "world-wide" nature of the Internet has far-reaching impact. The **Alzheimer's Association's Library** for many years spent time obtaining copies of basic Alzheimer's disease brochures and pamphlets in multiple languages. This is no longer the case. Many countries around the world have associations related to Alzheimer disease and sponsor Websites providing basic information on the disease and caregiving. While these materials may not be culturally appropriate to someone who speaks that language and lives in the U.S., the basic medical information is accurate and up-to-date. We vet the Websites by whether they are members of the organization, **Alzheimer's Disease International**. It saves both time and cost to refer patrons to a Website rather than search out and maintain a collection of brochures.

Since the early 1990's libraries have worked hard to provide access to the Internet to all people and have been generally successful in doing that. But work remains to ensure patrons are able to assess the quality of what they find and go on to find what isn't online. To prevent being marginalized by the Web, libraries must beat the 39% success rate mentioned above.

Boomers

Issue: Throughout their lives, Baby Boomers (born 1946-1964) have been agents of change. This is expected to continue and library services need to predict and meet those changing needs. From the health point of view, Boomers want information on healthy living and mental and physical fitness.

The Boomers have traditionally challenged and changed their environment — from the peace movement and civil rights, the Vietnam draft, the "pill," to some less laudable culture changes such as "greed is good" and "the one who dies with the most toys wins."

Many of the projections on Boomers expect them to also change how society views old age. In 2006 the first of the Boomers turned 60 and now seem to be working on changing the concept of aging. Many don't want to retire, but rather to change careers or to be active volunteers or advocates. The **Boomer Project** is a company that specializes in marketing to Boomers. They found the average 54-year-old considered himself 41. Further testing showed a psychological age of 39.⁴

A study from the **Kaiser Family Foundation** looked at the 50-64 year olds (Boomers) compared to the 65+ (Seniors) and found that Boomers are more than twice as likely to search for information online.⁵ While the same report found that current seniors look for prescription drug information and nutrition and exercise,

the Boomers look for much more. They want information on diseases, insurance, healthcare professionals, and prevention.

This group is also becoming more evidence based. More and more requests received at the **Green-Field Library** are worded "Can you find me research on...?" or "Can you find me studies on...?" Formerly requests were simply "I'm looking for information on..." This could be a reaction to how news reports on TV and the radio are worded. It could be that some of the training and education around the need to assess quality is paying off. But people, and especially Boomers, are increasingly aware of quality issues. Sites such as **Hospital Compare** (www.hospitalcompare.hhs.gov) and **Nursing Home Compare** (www.medicare.gov) allow you to select up to three facilities and compare them on specific issues.

Caregivers

Issue: A new paradigm is emerging. Caregivers or other interested second parties are taking on the role of information seekers for those too overwhelmed by diagnosis or caregiving responsibilities. Materials and services for these patrons may differ from those for patients.

A **National Public Radio** interview, "Patients Turn to the Internet for Health Information," by **Joseph Shapiro**, quotes **Susannah Fox** of the **Pew Internet & American Life Project** as saying that "half of those online searches are done on behalf of someone else..." "When someone gets sick, people aren't just bringing flowers or a hot dish," **Fox** says, "because it's not always the patient that can handle the research. It's the friends and family who surround them who are able to do that research on their behalf."⁶

Second-person searching on health topics isn't new, particularly with ethnic groups where language can be an issue. But our own experience has shown this is a rapidly increasing phenomenon. Children, grandchildren, non-caregiving siblings, spouses, partners, friends, neighbors are taking on the task of finding the latest research, identifying treatment options, looking into specific caregiving issues.

One aspect of second-person searching we found surprising is related to language. Our association focus groups, caregiver requests, and other reports are seeing an increase in requestors wanting culturally appropriate information in English in addition to non-English for other family members. These individuals are more comfortable in English than in the language of their relatives but still see themselves as part of a specific cultural group.

continued on page 24

The **Center for Medicare and Medicaid Services** saw a need to meet the information needs of caregivers. In September 2008 they launched an initiative designed primarily for caregivers. The initiative, **Ask Medicare**, includes a Website: www.medicare.gov/care-giver, and an e-newsletter. This project was launched in response to the large number of inquiries **The Centers for Medicare and Medicaid Services** receives from caregivers on behalf of **Medicare** recipients. Information and tools are provided to help navigate **Medicare**, deal with billing issues, make informed medical decisions, and cope with caregiving pressures.

Complementary & Alternative Therapies

Issue: Interest in complementary and alternative therapies is not new. But the scientific and medical community is finally paying attention. Reputable information and research in alternative therapies are rapidly increasing.

Once upon a time the only places you could find information on complementary and alternative therapies were in sources that were considered "quack" medicine, or in the ads of questionable magazines. The **National Institutes of Health** now sponsors the **National Center for Complementary and Alternative Medicine** (<http://nccam.nih.gov/>) to provide information, train researchers, and fund research. This is an especially active field for diseases and conditions that have no traditional medical treatment. Clinical trials related to complementary therapies can be found in standard listings such as *ClinicalTrials.gov*.

There is also a broader definition for what is included under complementary and alternative. It encompasses not only herbal supplements but things like art, music, pet, doll, and massage therapies.

Literacy

Issue: Literacy levels have not improved over time implying that "easy to read" and non-print materials still need to be sources of information.

Health information literacy has been a focus since the 1970's. The **Healthy People 2000** and **Healthy People 2010** initiatives define health literacy as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."⁷ This definition is closely tied into the basic definition of literacy as the ability to read. The 2003 **National Assessment of Adult Literacy (NAAL)** (U.S. Department of Education) showed little change from the 1993 survey from the same group. Thirty million people (14%) were below basic literacy skills. Sixty-three million (29%) operated at a basic skill level.⁸ The **American Medical Association (AMA)** has recognized the impact of literacy levels on patient compliance for years and has prepared professional training materials and reports. In 2008 the **AMA**

against the grain people profile

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BORN & LIVED: Born in Evanston, IL; lived in Wilmette, IL; Oxford, OH; Greenwich, CT; Bad Kreuznach, Germany; and Northbrook, IL, in that order.

EARLY LIFE: The area where I grew up was semi-rural — animals, farms, commercial greenhouses — but was still very close to Chicago where we had lots of family. So it was the best of both worlds. No one locked their doors. Car keys were kept in the visor of the car. You knew most people in the village. Most of that changed by the time I was in high school.

FAMILY: I'm single but have a large extended family in this area and have enjoyed watching my nephews grow up.

PROFESSIONAL CAREER AND ACTIVITIES: My first profession after college was teaching high school science. After I got my MLS, I started working in health related libraries and really liked it. I've worked at the **University of Illinois at Chicago**, **American Hospital Association**, and the **Alzheimer's Association**. I have been active in the state, regional, and national health sciences library associations and served on the board of one of our state multi-type library systems.

IN MY SPARE TIME I LIKE: The last couple of years I have been clearing out the family homestead and moving into a new place of my own. This has pretty successfully used up any spare time. I hope to get back to traveling, and volunteering at the local botanical garden.

FAVORITE BOOKS: Lately I've been recommending *People of the Book*. I like mysteries and am taking a seminar on the detective novel at the **Newberry Library** here in Chicago. If I find an author I like, I try to read everything they have written, but in chronological order. It is interesting to see how their style develops through the books.

PET PEEVES/WHAT MAKES ME MAD: Bad drivers.

PHILOSOPHY: You can't win if you give up — that's the philosophy, the practice of it is much harder.

MOST MEANINGFUL CAREER ACHIEVEMENT: Starting up a library from scratch for the Alzheimer's Association and have it still be open 18 years later.

GOAL I HOPE TO ACHIEVE FIVE YEARS FROM NOW: Successfully transition to retirement.

HOW/WHERE DO I SEE THE INDUSTRY IN FIVE YEARS: Five years from now I don't think we will be tied down to a desktop or laptop computer. They will be smaller, very portable and multipurpose. There will still be books, AV's, and probably some new media we haven't thought of yet. But the systems to manage them will be less cumbersome. 🐾

Foundation released a report, "Assessing the Nation's Health Literacy," commenting on the health implications of the **NAAL** literacy report.⁹ Those at the lowest end of the literacy range were less likely to use either the Internet or written materials to get health information. They were more likely to rely on information from TV and radio, health care professionals, and what they were told by family and friends.

Since its inception in 1991 our library has experienced a great demand for video and DVD products. The **Food and Drug Administration**, the **National Cancer Institute**, and most of the **National Institutes of Health** now provide "easy to read" materials. The **Alzheimer's Association** has tried to be aware

of literacy levels in our publications, both in print and on the Website. Former wisdom was to write materials at a 5th grade level. Recent comments have been that this is now considered too high and materials need to be written at a 3rd grade level.

Additional Information

No matter if they have longtime experience in serving consumer health information needs, or are just getting started in this area, librarians can still rely on professional colleagues who share their knowledge in the literature and through library association sections.

Library Journal (2004-2005) volume 53, issues two and three focused on "Consumer

continued on page 26

Health Issues, Trends, and Research". The first issue was titled "Strategic Strides Toward a Better Future" and the second "Applicable Research in the 21st Century." The stated goal of the issues was to provide a resource for librarians with an interest in providing consumer health information services. The editor, **Tammy Mays**, selected authors from the medical, academic, governmental and public library arenas to share their research and experience. The second issue, especially, focuses on best practices. **Mary Gillaspys** article in issue three includes mention of increased quality of print materials, including the encyclopedia series from the **Gale Group**, the consumer version of the *Merck Manual*, **O'Reilly's** patient-centered guides, **Marlowe's** "first year" publications, and the *Mayo Clinic* group of books.¹⁰

The **Medical Library Association** has a very active section focused on consumer health issues, the **Consumer and Patient Health Information Section (CAPHIS)**. They provide access to online "core" lists prepared by libraries around the US and Canada (<http://caphis.mlanet.org/chis/collection.html>). **CAPHIS** also has a listing of 100 consumer health Web-sites that are vetted and organized by subject area (<http://caphis.mlanet.org/consumer/index.html>). A quarterly newsletter, *Consumer Connections*, covers topics of interest to a consumer health information operation (<http://caphis.mlanet.org/publications/newsletter.html>). 🌱

Endnotes

1. **Pew Internet & American Life Project**, April 8 — May 11, 2008 Tracking Survey. http://www.pewinternet.org/trends/User_Demo_7.22.08.htm (accessed September 3, 2008).
2. **Number of "Cyberchondriacs" — Adults Going Online for Health Information — Has Plateaued or Declined** (Rochester, NY: **Harris Interactive**, July 29, 2008), (http://www.harrisinteractive.com/harris_poll/index.asp?PID=937) (accessed September 3, 2008).
3. **Leigh Estabrook, Evans Witt, and Lee Rainie**. *Information Searches that Solve Problems: How People Use the Internet, Libraries, and Government Agencies When They Need Help*. (Washington, DC: **Pew Internet & American Life Project**, 2007), (http://www.pewinternet.org/pdfs/Pew_UI_LibrariesReport.pdf). (accessed August 21, 2008).
4. **Beth Dempsey**. "PatronSpeak: What Boomers Want: They're Changing Old Age and Library Service with It." *Library Journal* 132, no.12 (July 15, 2007): 36-39, (<http://www.libraryjournal.com/index.asp?layout=articlePrint&articleID=CA6457208>). (accessed August 7, 2008).
5. **Victoria Rideout, Tricia Neuman, Michelle Kitchman, and Mollyann Brodie**. *e-Health and the Elderly: How Seniors Use the Internet for Health Information: Key Findings from a National Survey of Older Americans*. (Menlo Park, CA: **Henry J. Kaiser Family Foundation**, 2005), (<http://www.kff.org/entmedia/upload/e-Health-and-the-Elderly-How-Seniors-Use-the-Internet-for-Health-Information-Key-Findings-From-a-National-Survey-of-Older-Americans-Survey-Report.pdf>). (accessed September 4, 2008).
6. **Joseph Shapiro**. "Patients Turn to the Internet for Health Information." *NPR Morning Edition*, Recorded October 11, 2007, (<http://www.npr.org/templates/story/story.php?storyId=15166387>). (accessed August 7, 2008).
7. **U.S. Department of Health and Human Services**. *Healthy People 2010: Understanding and Improving Health*. 2nd ed. (Washington, DC: **US Government Printing Office**; November 2000).
8. **National Center for Education Statistics**. "National Assessment of Adult Literacy — Demographics," (original source of data is **U.S. Department of Education, Institute of Education Sciences, National Center for Education Statistics, 1992 National Adult Literacy Survey and 2003 National Assessment of Adult Literacy**). (http://nces.ed.gov/naal/kf_demographics.asp). (accessed September 4, 2008).
9. **Sheida White**. *Assessing the Nation's Health Literacy: Key Concepts and Finding of the National Assessment of Adult Literacy (NAAL)*. (Chicago: **American Medical Association Foundation**, 2008), (http://www.ama-assn.org/ama1/pub/upload/mm/367/hl_report_2008.pdf). (accessed September 5, 2008).
10. **Mary L. Gillaspys**. "Factors Affecting the Provision of Consumer Health Information in Public Libraries: The Last Five Years." *Library Trends* 53, no.3 (Winter 2005): 480-495.

Additional Resources

Personal communications to the author from **Mary Ann Urbashich** and **Patricia Yuen**, **Green-Field Library**, **Alzheimer's Association**.

eBooks in Health Sciences Circa 2008 — What Have We Got For Our Journey Now?

by **Meg White** (Director, Technology Services, Rittenhouse Book Distributors, Inc.;
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This article will discuss the recent developments and current landscape for eBooks in health sciences and the relevant implications for education, clinical care and research in these fields.

After years of promise and some false starts, health sciences books in electronic format have finally begun to gain some traction as an information resource. Reviewing past *ATG* articles as far back as 2001,¹ readers can see some innovative librarians who began to imagine the potential of "virtual" libraries: available 24/7/365 and integrating a full complement of scholarly materials, journal articles, databases, full-text monographs and reference books. If only innovation could be achieved with the germination of an idea. The reality is much more complex and usually messier.

In 2008 we are fortunate to have the beginnings of a more longitudinal view of the evolution from print to digital. With enough experiments combined with hard data, trends are starting to emerge that can

help further eliminate barriers as well as inform next steps.

Overcoming Barriers

A 2002² survey of primarily academic health sciences librarians reported that 99% of respondents provided access to eBooks as part of their institution's resources. Given this overwhelming reported availability more than five years ago, why have eBooks continued to lag behind journals and databases as a source of information in health sciences? A further review of this same survey data two years later in 2004 identified the following barriers: availability, discovery, and functionality. Reviewing these barriers and subsequent developments can help to illustrate progress to date.

Availability

Perhaps the largest barrier to adoption, availability of titles, has been the most significant shift in the market in the last four years. Early experiments in eBooks followed in

much the same path as early experiments in electronic journals. Migration from print occurred in a sporadic fashion, gradually building to critical mass. Initial eBook platforms were publisher-centric and tended to cluster around specific disciplines or collections of books. Publishers imagined that electronic delivery would disrupt existing sales and distribution channels; creating a more direct relationship between the user (physician, student) and the publisher, thus disintermediating other stakeholders, such as re-sellers, distributors and libraries. The result was products that were small in scope and not integrated into the existing information fabric that serves the typical academic environment. Librarians reported being frustrated at the lack of access to full collections as well as multiple

continued on page 28