

## Consumer Health Information Column

Susan Murray

Some thoughts about the current situation for consumer health information in Canada . . .

Although I officially moved to a position at McGill University in August 2009 (previously I was the manager of the Consumer Health Information Service based at the Toronto Public Library), consumer health information (CHI) is still very much on my mind. In fact, the Life Sciences Library here has a CHI collection that is well used despite our location up the hill. Consumer health information is an important and rewarding area for a librarian – often in a team with other professionals and volunteers – to be working in, but I am concerned about the lack of support from Canadian government officials [who feel that consumers can easily access quality health information on the Internet] and many Canadian health organizations. A number of CHI centres have closed or are fighting for their existence. On the bright side, St. Michael's Hospital in Toronto opened a Patient and Family Learning Centre this summer (<http://www.stmichaelshospital.com/learn/patient-family-learning-centre.php>).

I would encourage anyone working in CHI to join the Consumer Health Information Providers Interest Group (CHIPIG), an affiliate of CHLA/ABSC (<http://www.chla-absc.ca/chipig/>). Although CHIPIG began as a group of CHI librarians in the Toronto-Hamilton area, its membership is now Canada-wide. They have in-person meetings several times a year, and distant members can join in on meetings virtually. There is a list of the top 10 Canadian consumer health websites from 2010 (<http://www.chla-absc.ca/chipig/top-ten-2010.html>), which will hopefully be reviewed and updated regularly. At past CHLA meetings, CHIPIG members have presented posters on topics such as health literacy.

Another resource is the wiki (<http://chis.wikidot.com/start>) that the Consumer Health Information Service (CHIS) began and kept up to date until May 2009: it includes some content added by the staff of the Business, Science and Technology department of the Toronto Public Library (TPL). “Locating Reliable Health Information on the Internet”, a course developed by CHIS, continues, and you can find tips on where to search for information, and evaluate the sites (Note: the most recent course dates can

be found on the main TPL site). There's a link from the TPL page to the Health and Wellness blog (<http://torontopubliclibrary.typepad.com/health-and-wellness/>) where you will find short articles on health topics with lists of related resources, mentions of special health dates, and dates for upcoming talks at TPL.

In the U.S., there is continuing support for consumer health information, and sites such as MedlinePlus (<http://www.nlm.nih.gov/medlineplus/>) have expanded in response to user need. MedlinePlus now features over 900 health topic pages (many of these are also available in Spanish), information from over 1 000 organizations, and over 35 000 links to authoritative health information. You can even find a list organized by state of consumer health libraries' services for local residents. While we had the Canadian Health Network (CHN) web site in Canada until March 2008 – CHN was a national, bilingual health promotion service operated by the Public Health Agency of Canada and major health organizations across Canada – it never had the wealth of information found on MedlinePlus. Currently, there is no “one-stop-shopping” site in Canada for consumer health information. However, there is CHIPIG's list of the top 10 Canadian consumer health websites; these are specialty sites organized by topic. Yes, there is the Healthy Canadians site (<http://www.healthycanadians.gc.ca/index-eng.php>), but as of December 2011, the most recent update was June 2011, and it doesn't provide enough information for consumers to make informed health care decisions. In the area of support for consumer health information, Canadian consumers have been the losers. When you have an opportunity to advocate for the provision of CHI in your institution or to the Government, please do so!

### Interesting Studies/Publications:

1. At the Medicine 2.0'11 Congress at Stanford (<http://www.medicine20congress.com/ocs/index.php/med/med2011>), Susannah Fox from the Pew Internet Project delivered a keynote presentation on peer-to-peer healthcare. “Peer-to-peer healthcare is a way for people to do what they have always done – lend a hand, lend an ear, lend

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advice – but at internet speed and at internet scale.” The talk drew on their research on social networks, smart phones, and health communications, as well as on stories from the front lines, which turned out to be mostly about moms, the power users of both social tools and health care.

One of the most dramatic successes was the example of the mother who posted a photo of her four-year-old son who went to a clinic to be treated for a rash and fever, and was given penicillin. When his condition worsened, the mother posted a photo of him on Facebook. A friend told her to go the hospital immediately because her son with similar symptoms had been diagnosed with Kawasaki disease. The friend was right, and the boy was successfully treated. <http://pewinternet.org/Reports/2011/Medicine-20/Part-1.aspx>

2. According to a recent study by the Center for Studying Health System Change (HSC), funded by the Robert Wood Johnson Foundation, the proportion of American adults seeking information about a personal health concern from a source other than their doctor dropped to 50 per cent in 2010, down from 56 per cent in 2007. A reason for this may be that due to rising health care expenses, there has been a decline in demand for health care which may have reduced some consumers’ need or

motivation to obtain health information on their own. On the other hand, those cutting back on health care because of the cost might be expected to increase their health information seeking, as a substitute for obtaining information from health care providers. (<http://hschange.org/CONTENT/1260/1260.pdf>)

3. The European Centre for Disease Prevention and Control (ECDC) published *A literature review on health information-seeking behaviour on the web: A health consumer and health professional perspective*.

This review by Swedish researchers provides an overview of English-language research studies published from 2006 to 2010 on online health information-seeking behaviour by health consumers and professionals. The articles were drawn from peer-reviewed journals, conference papers, consumer reports and health professional studies, research by recognised independent institutions, as well as systematic and narrative reviews of the various topics. Sources used include Web of Knowledge, Business Source Premier, and searches of the grey literature using Google. <http://ecdc.europa.eu/en/publications/Publications/Literature%20review%20on%20health%20information-seeking%20behaviour%20on%20the%20web.pdf>