

Research Council adopting similar mandates, openly accessible bio-medical research results promise to become a substantial resource.

It will be apparent from this review that most OA activity has so far occurred within the higher education research sector, leaving other sectors such as healthcare relatively unaffected. This situation appears to be changing, with signs that OA is being espoused to serve political agendas in health information, as seen in calls for clinical drug trial data to be made openly accessible,<sup>3</sup> and in the launch of *Open Medicine* <[www.openmedicine.ca/](http://www.openmedicine.ca/)>, a new journal founded by staff who left the *Canadian Medical Association Journal* in an argument over editorial independence.<sup>4</sup>

But for the NHS, perhaps the most significant development is the news that the Department of Health, already part of the eight-member consortium that funded UK PubMed Central, has introduced its own mandate<sup>5</sup> with effect from April 2007. This mandate requires deposit of papers supported by DH funding in a move that heralds a new era for dissemination of NHS research outputs and suggests official endorsement of Open Access as a principle to be embraced by the NHS more widely.

### Acknowledgement

This paper is an updated version of a talk given at the CILIP HLG Annual Conference, Eastbourne, 11 July 2006.

### References

[All accessed 24 May 2007]

1. Crow R. The case for institutional repositories: a SPARC position paper. SPARC, 2002 <[www.arl.org/sparc/bm-doc/ir\\_final\\_release\\_102.pdf](http://www.arl.org/sparc/bm-doc/ir_final_release_102.pdf)>.
2. Swan A, Brown S. Open access self-archiving: an author study. Key Perspectives, 2005 <[www.keyperspectives.co.uk/openaccessarchive/reports.html](http://www.keyperspectives.co.uk/openaccessarchive/reports.html)>.
3. Adams M. The health care reform legislation that Congress should pass, but won't. News Target, 15 February 2007 <[www.newstarget.com/021610.html](http://www.newstarget.com/021610.html)>.
4. Talaga T. Fired editors launch online medical journal. Toronto Star, 2 April 2007 <[www.thestar.com/article/198412](http://www.thestar.com/article/198412)>.
5. Statement on DH/NIHR-funded research and UK PubMed Central <[www.nihr.ac.uk/files/pdfs/OpenAccessPolicyStatement.pdf](http://www.nihr.ac.uk/files/pdfs/OpenAccessPolicyStatement.pdf)>.

## Looking for medical information on the Internet: self-disclosure, privacy and trust

Tom Buchanan

Department of Psychology, University of Westminster, UK

buchant@wmin.ac.uk

Adam N. Joinson and Carina Paine

Institute of Educational Technology, The Open University, UK

Ulf-Dietrich Reips

Department of Psychology, University of Zurich, Switzerland

*Internet-based health information may be easier for people to access than traditional sources, in part because it can be found more privately. However, there are threats to this privacy. Awareness of this, and loss of trust in Internet search technology, may reduce willingness to look for information online.*

### Looking for health information online

The Internet continues to grow in importance as a valuable source of information, both for healthcare professionals and consumers. While the quality of freely available information is sometimes debatable, there is considerable evidence that non-professionals are using the Web to access health information that is relevant to them.

The 2006 Online Health Search survey by the Pew Internet and American Life Project <[www.pewinternet.org/PPF/r/190/report\\_display.asp](http://www.pewinternet.org/PPF/r/190/report_display.asp)> found that 80% of American Internet users have looked for health information on the Internet; on a typical day in 2006, around 8 million American adults looked for healthcare information online. It appears that access to free medical information online is empowering for at least some people with health problems, who are able to research their conditions and sometimes access information more easily than through traditional means. In the UK, the success of NHS Direct which provides information and advice via a Web site <[www.nhsdirect.nhs.uk/](http://www.nhsdirect.nhs.uk/)>, telephone and interactive digital television to over 2 million people each month is a clear example of this.

Much of this activity is likely to be due to the convenience of accessing information online: one can research a medical condition at one's desk, or even via a browser on a mobile phone, much more quickly and conveniently than

through contact with the traditional medical establishment. Convenience is likely to be a major motivation for many online healthcare consumers.

### Psychological factors

As well as convenience, there are also psychological reasons why some individuals may prefer to access information online. This is especially true in the case of conditions that may be stigmatised or embarrassing. In the first instance, when people are concerned that they may have a particular problem, many may turn to the Web as a source of information before contacting their doctor. One reason for this is likely to do with the fact that researching a condition through traditional means (e.g. contact with a healthcare professional) involves disclosing information that may be sensitive, distressing or threatening to the self.

For example, imagine you are worried about the possibility you have a sexually transmitted disease (STD). Consulting a doctor would necessarily involve describing the symptoms, your sexual history and so on. This is self-disclosure of highly personal information: just by asking about STDs, you are essentially revealing that you are worried you have one, and have engaged in activities that could lead to infection.

If one asks about STDs on the Internet, however, the situation is somewhat different. If, for example, one searches for STD information on Google or another search engine, one is only

disclosing the personal information to a computer system, not a person. Even if one were to ask about STDs in an online support group or discussion forum, one can still hide behind the veil of anonymity and ask with no fear of embarrassing social consequences, no violation of privacy. There is considerable evidence that people will disclose sensitive, personal information more readily over the Internet than they would in person-to-person situations. As an example, Joinson and Banyard<sup>1</sup> reported in 2002 that the seeking of cancer-related information on the WWW closely matched actual prevalence, while information seeking on telephone helplines tended to avoid socially embarrassing cancers (e.g. prostate or testicular cancer). There is a close parallel with the work of Nicholas *et al.*<sup>2</sup> who coined the phrase 'search disclosure' to explain their finding that people searched for more sensitive health information at information kiosks located in private, as opposed to more public, locations.

Essentially, self-disclosure is an integral first step in looking for information about one's own health status. This disclosure appears to be easier online than in more personal encounters.

## Mediators of self-disclosure

However, it is not the case that people will always be more ready to disclose personal information online. Recent work by Joinson and colleagues<sup>3</sup> has examined influences on whether people disclose personal information to Web sites (e.g. electronic questionnaires). Findings indicated that there are two key independent influences on the likelihood of self-disclosure online.

The first influence comprises characteristic privacy-related attitudes and behaviours, where some individuals are characteristically more privacy-concerned than others. The second influence, which is most pertinent to the current discussion, comprises temporary state-like factors – perception of current level of privacy, and trust in the agency requesting disclosure. The influence of perceived privacy on disclosure appears to be mediated by trust.<sup>4</sup>

Joinson *et al.*<sup>5</sup> used a behavioural measure of self-disclosure to examine responses to an online questionnaire asking sensitive personal items (including salary and sexual history). The sur-

vey was hosted on a Web site that was experimentally manipulated to vary the impression given of: (i) the level of privacy respondents could expect (high or low); and (ii) how trustworthy the research team was (high or low). The lowest level of self-disclosure was found in the low-privacy/low-trust condition. However, disclosure levels did not substantially vary across the other three conditions. In the other low-privacy condition, disclosure levels were still high. This is likely to be because trust in the research team was high.

This suggests that, even in situations where we know we have low privacy, we may still disclose personal information because we trust the person we are disclosing to. The corollary of this is that if one does not trust the target of disclosure to protect one's privacy, the likelihood of disclosing personal information to it is reduced. This in turn implies that people may be less likely to search for healthcare information through mechanisms or agencies that they do not trust.

## Why this matters: privacy and trust online

In August 2006, the Internet company AOL released data on over 19 million Internet searches performed by over 650,000 of its members. While the data were released to academics for research purposes, and contained no direct information about the identities of individuals, it soon became apparent that, when examined in combination, some of the search data contained sufficient information for named individuals to be identified.

In March 2007, against a backdrop of pressure from the US Government to surrender its search database for security reasons, Google announced that entries in its search database would be anonymised after 18–24 months. This is in line with EU data protection legislation that requires retention of data for a period of 2 years. Privacy advocates, while welcoming Google's action, have called for the anonymisation to take place even sooner.

Given the expansion of Google into other areas of our online lives (e.g. the introduction of the Gmail email system; the Froogle shopping site; online calendars and office applications such as word processing), the potential for threats to privacy increases as more data about individuals are amassed and

potentially linked up. Google's CEO, Eric Schmidt, was quoted in 2005 as saying the company was moving towards 'a Google that knows more about you'. As individuals we may not know what is known about us, or who has access to that information. While Google is making attempts to protect the privacy of users, the very fact that data are retained in server databases threatens that privacy.

The implication of such events is that privacy on the Internet is becoming increasingly endangered. The simple act of using a search engine to look for information on a medical condition is much less private than one might imagine. Presently, the illusion of privacy still obtains. However, as Internet privacy issues become more salient and widely reported by the media, it is questionable how long this will last. It is entirely possible that public trust in the search engine companies may be eroded.

If privacy – or at least the impression that our online actions are private – is reduced, there is a possibility that people will be less keen to conduct searches that may disclose personal information. While there is clearly a need among consumers for online medical information, it remains to be seen whether increased awareness of privacy issues will affect healthcare search patterns in the future.

## Acknowledgement

Funding from the UK Economic and Social Research Council E-Society Programme (RES-341-25-011) supported the preparation of this article.

## References

1. Joinson AN, Banyard P. Psychological aspects of information seeking on the Internet. *ASLIB Proc: New Info Perspect* 2002; **54**: 95–102.
2. Nicholas D, Huntington P, Williams P, Gunter B. 'Search-disclosure': a concept to aid the understanding of digital information platform preference and location in a health environment. *J Document* 2003; **59**: 523–557.
3. Paine CB, Joinson AN, Buchanan T, Reips U-D. Privacy and self-disclosure online. In: Grinter R, et al. (eds) *Proceedings of the SIGCHI conference on Human Factors in computing systems 2006*. Montreal, Canada. New York, USA: ACM Press, 2006; 1187–1192. <<http://portal.acm.org/citation.cfm?doid=1125451.1125674>>.
4. Paine CB, Joinson AN, Reips U-D, Buchanan T. Privacy, trust, disclosure and the Internet. *Internet Research 7.0: Internet Convergences*; Brisbane, Australia, September 2006. <[http://elsa.open.ac.uk/presto/prisd/Files/AOIR\\_SLIDES.ppt](http://elsa.open.ac.uk/presto/prisd/Files/AOIR_SLIDES.ppt)>.
5. Joinson AN, Paine CB, Buchanan T, Reips U-D. Privacy, trust and self-disclosure online. 2007; Submitted.