information provision make the perceived credibility of health information increasingly complex and uncertain, even as it is increasingly prominent online today.

Miriam J. Metzger
Andrew J. Flanagin
University of California, Santa Barbara

See Also: Digital Divide; Health Literacy, Online; Information Seeking; Internet: Information Acquisition; Media Literacy; Online Health Information Seeking; Online Health Information Sharing.

Further Readings

Eysenbach, Gunter. "Credibility of Health Information and Digital Media: New Perspectives and Implications for Youth." In *Digital Media, Youth, and Credibility,* Miriam J. Metzger and Andrew J. Flanagin, eds., and the John D. and Catherine T. MacArthur Foundation Series on Digital Media and Learning. Cambridge, MA: MIT Press, 2008.

Eysenbach, Gunther and Christian Kohler. "How Do Consumers Search for and Appraise Health Information on the World Wide Web? Qualitative Study Using Focus Groups, Usability Tests, and In-Depth Interviews." *British Medical Journal,* v.324 (2002).

Hu, Yifeng and S. Shyam Sundar. "Effects of Online Health Sources on Credibility and Behavioral Intentions." *Communication Research,* v.37/1 (2010).

Metzger, Miriam J. and Andrew J. Flanagin. "Using Web 2.0 Technologies to Enhance Evidence-Based Medical Information." *Journal of Health Communication,* v.16 (2011).

Online Health Information Exchange and Privacy

The emergence of the Internet as an important source for health information and exchange provides new opportunities and challenges for patients and providers alike. Telemedicine, e-mail, e-health records, and online support groups are all contexts where health information is exchanged in mediated settings. This entry reviews contexts for online health information exchange and addresses concerns related to disclosure, anonymity, and data security that are relevant in these interactions.

Online Health Exchange Contexts

There are several contexts where health information is exchanged through mediated processes. Many of these exchanges access the Internet via traditional computer interfaces, yet others incorporate video technology, and still others utilize mobile communication technology such as "smart" phones or tablets. The first of these contexts is concerned with the doctor–patient interaction. Telemedicine connects patients in health care settings who are physically located separately from the providers, generally by video over Internet connection (phone consultations also occur). This type of medical provision is useful for underserved populations in remote areas and/or for specialists. In extreme cases that would not reflect typical use, consider the example of a researcher stranded in an isolated area who must rely on the Internet or videoconferencing for medical treatment information. In contrast to more specialized cases employing telemedicine, e-mail is increasingly used for everyday, nonemergent communication with health care providers, and this can include mundane appointment reminders or test results. E-mail is often easier, more convenient, and less time-consuming for patients than an office visit or phone call. However, physicians are presently not reimbursed for these e-mail interactions, so this raises questions of balancing time management and effectiveness.

There are also contexts that are concerned with exchanging information via mediated settings. Electronic health records are computerized medical records in a health care organization. By adopting electronic medical records and making information readily available across providers, interactions with patients can potentially be quicker and more efficient. Personal records are online databases in which patients can store, collect, and share their own health information. Although there are several benefits to electronic medical records, current challenges include

difficulty integrating record systems (e.g., cannot easily send scans to another physician using a different system), the expense of the system to the provider, and the absence of "backup" if a computer network is "down" on a particular day. Patients may be concerned about their access to this information and the lack of control over the way information is accessed and used by others.

The final context is related to interpersonal exchanges online. Online support groups are based on a sense of similarity where patients with common conditions can connect with one another. Patients can share information about their condition, providers, and treatment, and provide and receive social support. The types of online support groups vary widely and include, for example, breast cancer survivors, adult children of alcoholics, and parents of children with Down syndrome. Privacy, synchronicity of the channel ("real time"), and varying levels of identity are all relevant concerns in these contexts.

Disclosure Concerns

There are several privacy concerns that are highlighted in online settings that are related to disclosure or sharing private and personal information. One concern raises questions about who can access patient health information. Does the Health Insurance Portability and Accountability Act (HIPAA) protect patients' online information in the same way as in a hospital or a physician's office? As technology develops, regulations shift and change to increasingly protect emerging applications of patient privacy. Patients should be aware that health care personnel other than the primary physician have access to their information including, but not limited to, data entry specialists, technicians, and administrators, beyond the medical team. Because this information is identified or specifically linked to the patient's name or possibly an identification number, there is added sensitivity to privacy issues. Disclosure concerns increase for certain kinds of sensitive information (e.g., stigmatized or genetic). For electronic health records, access control by the medical provider is different from personal health records for which participants grant access.

Another concern deals with who is present on the medical provider's end. For example, in telemedicine, is the provider present or are other nonvisible health care personnel present for the interaction? In e-mail interactions, are physicians responding, or is a nurse or physician assistant responsible for replying to patients (and is this person required to confirm information with the physician)? The reduction of available cues makes it difficult to discern which health care personnel have access to the exchange and may increase uncertainty for patients. This feature of online health information is different from face-to-face health interactions, in which more provider information is available.

Other online health concerns are related to unauthorized interception of information (e.g., filling out an online questionnaire or faxing test results). If an unauthorized physician or health care employee accidentally accesses information, how is this handled? Similarly, what happens if a doctor discloses information inappropriately or in an unauthorized setting? This concern is not unique to an online interaction except that the potential risk increases based on the number of times people send or exchange information online. Medical personnel may also be accessing health records remotely, and they must be sure that information is not accessed or disclosed to unauthorized others (e.g., log out of a home computer).

Although there are several concerns related to disclosure, the perception of anonymity and increased privacy may facilitate more disclosure online. In mediated settings there could be a perceived decreased risk of disclosure, particularly for rare or stigmatized health conditions. For example, if patients seek social support for a new HIV diagnosis, they may choose to join an online support group as opposed to a face-to-face support group where disclosure concerns are magnified because individuals are identifiable. It might also be easier for people to report less socially desirable health behaviors online (e.g., smoking, alcohol consumption, or past sexual partners) compared to answering in person.

Anonymity Concerns

There are several challenges related to anonymity that emerge in mediated settings. The lack of anonymity can be troubling in video interactions such as telemedicine, in which information is identifiable (and perhaps recorded). These concerns,

however, are similar to face-to-face health care interactions in which the patient's identity is known, albeit to a limited extent and primarily to the medical team. In isolated circumstances, patients' information may be de-identified or separated from their names, such as in the case of anonymous HIV testing.

Anonymity is more protected in some mediated contexts than in others. For example, patients in online support groups can often log in without providing much—if any—identifying information. In some instances only a username is required to join these groups. Some people create online user names that are not associated with their identity (e.g., Patient10 or User101). Online support groups provide the opportunity to present and also misrepresent an online image. If patients are seeking support, particularly for a stigmatized condition, they may choose to mask their identity in these settings. Some people exercise even greater caution by creating an alternate e-mail address, for example, not using an employer's e-mail system or even a work computer for personal information such as health information. Depending on the information, a patient may be highly motivated to ensure that an employer or partner does not find out.

Data Security Concerns

There are data security concerns that surface in mediated interactions. First, logistics are a concern. What happens if information is accidentally sent to the wrong physician or even a mistaken carbon copy in an e-mail? How do providers keep patient data confidential and protected from hacking? There are instances in which celebrities' health information has been accessed and leaked to news sources. Are there safeguards in place that protect patients against identity theft and insurance fraud?

These concerns relate to storage of medical information but often unrecognized are issues related to transmission of information. Unless encrypted, many e-mail transmissions can be intercepted, and many widely used wireless networks are not secured. The emphasis in these data security discussions is often on physical servers or networks, but a portable device such as laptop or flash drive containing identifiable patient health information can also increase risk.

Much of this research focuses on the provider's end or how medical information is stored after collection. Also relevant but not often discussed are data security issues on the patient's end. Patients may be seeking treatment (e.g., for substance use or mental health services) that they do not want known to others. In this case, patients must be vigilant about clearing browser histories and ensuring that e-mail is secure. Examples of securing e-mail would be using complex passwords, logging out of systems (and not saving passwords), clearing Web history, and avoiding use of public computers, such as those belonging to an employer, when accessing anything sensitive.

Informed consent, policies, and laws that protect patients are additional concerns. Informed consent is required by the American Medical Association before patients can e-mail physicians so that patients are aware of potential risks of online health information exchange. What might be less explicit are the policies and laws that protect patients. Another consideration is who has access to the information. Do employers and insurers have access? If so, how are they using this information, and what information is available to them?

If insurers are using patient records for payment, concerns about control and ownership of electronic medical records may arise. Questions such as the legal protection of data and patients' rights may emerge. An additional ethical concern could be about doctors selling health information to marketing companies. Safeguards must be in place to limit access, for example, of patient notes from a psychiatrist or psychologist.

Amanda Carpenter
Kathryn Greene
Rutgers University

See Also: E-Health: Defined; Information Sharing; Internet: Information Acquisition; Online Health Information Seeking; Online Support Groups; Patient Privacy.

Further Readings

Anderson, Paige Laura and Kaye. "The Therapeutic Alliance: Adapting to the Unthinkable With Better Information." *Health Communication*, v.25 (2009).

Masters, Ken. "For What Purpose and Reasons Do Doctors Use the Internet? A Systematic Review." *International Journal of Medical Informatics*, v.77 (2008).

McGraw, D., et al. "Privacy as an Enabler, Not an Impediment: Building Trust Into Health Information." *Health Affairs*, v.28 (2009).

Online Health Information Seeking

The nature of the Internet has brought about a change in the health information landscape. Based on a sequence of nationwide studies conducted by the Pew Internet & American Life Project from 2002 to 2010, it is apparent that about eight in 10 U.S. adult Internet users have consistently gone online to seek out health information. The most common topics that online surfers have looked on the Internet for information include health problems, health remedies, health care professionals, and health facilities. Other studies have also shown that the Internet is often drawn on to garner information before or after consultation with a doctor and to obtain common information such as drug dose. Notably, the Internet has become one of the most trusted health information sources (including online advice from peers), right behind doctors, nurses, and other health professionals. Overall, over two-thirds of the U.S. public believed that reliable and accurate health information could be found on the Internet.

The Internet offers unique features such as privacy, anonymity, immediacy, a wide variety of information and perspectives, widespread access, potential for interactivity and social and emotional support, and the function of going directly to the source of information instead of relying on a gatekeeper such as a doctor or other health professional. In fact, online health information is now primarily accessed through health Web sites, online support groups, and online interactions with health professionals. Online support provides information through the sharing of experiences and behaviors and through exposure to an increased range of opinions and expertise, and can empower a patient to manage health-related uncertainty and to better adjust to a disease. Online discussion forums offer users an avenue to exchange health information and receive social support from one another.

With these e-health features, advocates believe that the Internet can empower patients in managing their own health. Instead of being passive and dependent on traditional health care providers, patients have become more active and autonomous in the sense that they can now make informed decisions, influence treatment decisions, and engage in their own health care. Based on the health information sought on the Internet, patients can develop useful questions for discussion with their health providers, understand the reason behind the use of recommended medications, explore health care assistance options, and gain assistance from other people who had similar health problems.

Research

Several U.S. health authorities have funded research into online health information seeking. One of the most prominent projects is the Health Information National Trends Survey (HINTS) commissioned by the National Cancer Institute. Starting in 2003, the HINTS survey has been conducted every two to three years in the United States. The nationally representative surveys were conducted on adults 18 years and older. In 2009, the survey was replicated in Puerto Rico. The project yielded publicly available longitudinal survey data that allows scholars and researchers to assess how Americans seek, use, and comprehend health information from the Internet and other communication channels, for themselves and others, among other objectives. Since its inception, many scientific research publications have been generated from the survey data and have contributed to the understanding of why people seek health information online and the implications of this behavior to the health care sector.

Other more specialized projects about online health information seeking include the Comprehensive Health Enhancement Support Studies (CHESS) in the Department of Psychiatry at the University of Wisconsin-Madison. Headed by David H. Gustafson, CHESS is a nonprofit interactive e-health system that provides cancer