

Ubiquitous Computing

Trust Issues for a “Healthy” Society

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The notion of ubiquitous computing (ubicomputing) has important implications for health care. Ubiocomputing scenarios involving the rapid communication of information between interested parties assume that health consumers will be willing to place their trust in agents rather than physicians, but are these assumptions reasonable? This article discusses what is known about the role of trust in health care and ways in which the trust relationship has changed with the impact of new technologies. Differences between the current, predominantly web-based environment and that of ubicomputing are highlighted in relation to health care. A key point to note is the move away from consumers making their own trust judgments toward a scenario in which these decisions become the domain of intelligent agents.

Keywords: *trust; health; ubiquitous computing; Internet; scenarios*

Health and Ubiquitous Computing (Ubiocomputing)

The vision of ubicomputing embraces always-on communication and seamless access to information. But what does this mean for health care? Presumably, systems that act not simply to store health information but to continuously monitor and communicate health status, coupled with intelligent environments that can respond immediately to this information: Restaurants that can screen the food on offer, homes that adjust temperature and lighting in accordance with known conditions, hospitals that are primed with up-to-date information the moment the patient arrives. Such near-future scenarios have been used by a number of researchers to explore the health implications of new technologies, and these typically illustrate the interaction of handheld or implanted devices with intelligent networks and buildings (Hartog, Schmidt, & Vries, 2006; Little, Marsh, & Briggs, 2007).

In one such scenario (Little et al., 2007), Bob uses his personal digital assistant (PDA) to communicate with colleagues working at a different location. Built into his PDA are a number of personalized agents that can pass information seamlessly to relevant recipients. As Bob is epileptic, his health agent monitors his health and can alert people if he needs help. While out at lunchtime, Bob trips over a broken paving slab and falls to the ground. When he fails to respond to his PDA alert, the health agent takes over and contacts the emergency services. The paramedics are able to assess Bob and upload all his medical information direct to the hospital via their handheld devices. Hospital staff are then well prepared for Bob's arrival and can deal with his injuries immediately. Meanwhile, other agents built into Bob's PDA take control of his diary, cancelling appointments and informing his parents of the situation.

Clearly, one aspect of ubicomp allows for the rapid communication of health status and health history between interested parties—presumably by drawing on agent technologies. However, exchanging health information in this way raises important legal and ethical implications, and inappropriate disclosure of health data would constitute a major privacy violation (Stanford, 2002). Many of these scenarios assume that health consumers will be willing to place their trust in agents rather than physicians, but are these assumptions reasonable? To assess this, we need to understand more about the role of trust in health care and the ways in which the trust relationship has changed with the impact of new technologies.

Trust and Health Care

Trust is a key construct for the doctor–patient relationship. We know that trust is usually based on assumptions about the competence and honesty of the physician, his or her respect for confidentiality, and his or her willingness to act in the best interests of the patient (Hall et al., 2002). In fact, the majority of patients do trust their physicians, and this trust directly influences their willingness to seek help, discuss sensitive matters, and adhere to treatment regimes (e.g., Safran et al., 1998).

Physicians, however, are not the only sources of information regarding health. Friends and family provide additional support, and increasingly, patients are turning to the Internet so as to be better informed and better prepared when meeting the doctor or are searching for support, alternative answers, or reassurance (Rozmovits & Ziebland, 2004). More than 70,000 health-related sites can now be found on the Internet (Pagliari & Gregor, 2004), and more than three quarters of all Internet users have searched online for health-related information (Sillence, Briggs, Harris, & Fishwick, 2007). These figures suggest that the Internet is a success story as far as e-health is concerned. However, when issues of patient trust are considered, the picture is more complex. Less than half of the medical information available online has been reviewed by doctors (Pew Research Center, 2000), and few sites provide sufficient information to support patient decision making, with many also heavily jargon laden and difficult to read (Smart & Burling, 2001). There is a large body of research assessing the quality of information available on the Internet (Jadad & Gagliardi, 1998; Wyatt, 1997), embracing diverse topics such as Viagra, rheumatoid arthritis, and diabetes. A systematic meta-analysis of health Web site evaluations noted that 70% of the studies reviewed concluded that quality is a problem on the Internet (Eysenbach, Powell, Kuss, & Sa, 2002).

Despite the fact that the Internet is an unregulated and often unreliable source of medical information, it is rapidly becoming a new “object of trust” (Hall et al., 2002). Surveys of Internet users suggest that trust is an important issue in the health domain (Williams, Huntington, & Nicholas, 2003). Many people searching online for health advice trust the information and advice they find there—believing that it will enable them to better deal with their health and will convey health benefits (Mead, Varnam, Rogers, & Roland, 2003). Time constraints in the consulting room have also led to an increase in online searching. In this short period of time, both the doctor and the patient find it difficult to explain and discuss all their issues. Patients often think doctors do not give them enough information to make sensible choices about how they want to be treated (Carvel, 2005), and they often find it difficult to recall the specifics of their discussions with the doctor after the consultation

(Kalet, Roberts, & Fletcher, 1994). Williams et al. (2003) found that the Internet is used both as a way of enhancing the doctor–patient relationship and as a counterbalance to information (or the lack of it) provided by the doctor.

The Internet allows people to communicate and interact with a far greater variety of people across all walks of life. It provides up-to-date information as well as increased social support (see Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004, for a review). Online social support can reduce feelings of isolation and can provide information and emotional support (Preece, 1999). There are online social support groups for a range of health conditions, including sports injuries (Preece, 1999), irritable bowel syndrome, and breast cancer (Coulson, 2005a, 2005b), and groups specifically designed to provide support for friends, family, and other caregivers (White & Dorman, 2000). The Internet enables information to be shared in the form of text and images and can put people in touch with the most up-to-date information from some of the most eminent sources in the medical profession. The Internet can offer people second and even third opinions and in short can provide people with information and advice that they simply cannot find anywhere else.

Some studies have indicated that information gained from an online search helps the majority of users to understand more about an illness or injury, and in some of these cases, the information is sufficient for patients to act on to improve their health (Nicholas, Huntington, Gunter, Russell, & Withey, 2003). A review of the literature concerning online cancer support suggested that participation in such groups helped people cope more effectively with the disease (Klemm, Bunnell, Cullen, Soneji, Gibbons, & Holecek, 2003). However, other studies have indicated that although the Internet can increase patients' knowledge about their health conditions, they can be left feeling too overwhelmed by the information available online to be able to make an informed decision about their own health care (Hart, Henwood, & Wyatt, 2004). Reviews of quantitative web-based intervention studies have generally indicated beneficial effects of the Internet on health outcomes, although issues concerning the methodological quality of such studies remain (Bessell et al., 2002). A more recent meta-analysis by Wantland, Portillo, Holzemer, Slaughter, and McGhee (2004) concluded that in the majority of studies, knowledge and/or behavioral outcomes improved for participants using web-based health interventions.

Not only are 75% of Internet users searching online for health advice, but they trust the advice they find and are prepared to act on it (Sillence et al., 2007). A large-scale questionnaire study indicated that three of the most important trust markers for online health advice sites are (a) easy-to-use site, (b) advice from a knowledgeable source, and (c) advice that is independent and impartial. In the past 5 years, health consumers have been increasingly turning away from more regulated sites (i.e., those run by government bodies) and toward more personalized sites, often maintained by interested individuals. More personalized, interactive sites raise issues concerning information disclosure and control of personal data, issues that are all the more pertinent in a ubicomp society.

Trust and UbiComp

The examples given above illustrate some of the dynamics of trust in a health care environment. However, these examples do not fully capture the most pressing trust issues for

ubicomp, largely because they depict a situation in which individuals act to select or filter out information they believe to be more or less trustworthy. In other words, they capture what happens when people make their own trust judgments. In the ubicomp context, “mutual trust is crucial for ubiquitous devices, which must share information and work together to present an unobtrusive interface to their users” (Shand, Dimmock, & Bacon, 2004)—in other words, people will not be able to make their own individual trust judgments but will need to pass these decisions on to intelligent agents. This is simply because they would otherwise find it impossible to cope with the sheer volume of information exchanged and the consequent need for moment-to-moment trust decisions.

Roussos and Moussouri (2004) have explored trust in a ubiquitous e-commerce environment and point out that the users are more comfortable with systems where they know that they can shut down the exchange of information if necessary and where they can interact with systems in such a way that their identity is not revealed. Such elements allow the user to feel in control of what is essentially a very complex data exchange process. Other studies (e.g., Lederer, Hong, Dey, & Landay, 2004) have explored the possibility that the user can set rules to control information exchange by filtering out the identity of the enquirer, the situation at the time of enquiry, or the accuracy of the personal information disclosed:

- *The fair use of personal data*—that is, data that are used within a known context and not exploited elsewhere;
- *personal control over the system*—including the capacity for an individual to shut down the flow of information at any time;
- *anonymity*—allowing interactions with the system where identity is not revealed; and finally
- *branding and reputation*—whereby users had more trust in the capacity of “known” brands to develop robust technology.

Various articles have addressed the issue of how intelligent agents might come to make trust judgments. Some trust models are static, requiring the agent to adhere to a particular policy (often in respect of privacy or security issues), whereas some are dynamic, reflecting, for example, the processes found in recommender systems whereby some kind of collaborative filtering plays a role in profiling those organizations or agents that are well regarded by others (e.g., Abdul-Rahman & Hailes, 2000; Shand et al., 2004). Some models also recognize that trust judgments will move away from a binary trust/mistrust judgment in recognition that an intelligent agent will not simply need to decide whether to trust another agent but instead will need to make a judgment about how much information should be shared with other agents in a range of different contexts (e.g., Patrick, Briggs, & Marsh, 2006).

Relatively rare are the dynamic approaches that consider the evolution of trust throughout time. This is perhaps understandable when we consider that a trigger for much of the research on trust was an e-commerce scenario in which a potential consumer is faced with a decision of whether to buy from a vendor he or she has encountered on the web. Under such circumstances, the initial decision of whether to trust is paramount, but in an ubicomp context, we are exploring richer issues in relation to the transfer of trust over a network of agents and the evolution of that network. The evolution of trust throughout time is in itself a very interesting issue. One of the earliest studies of trust in automated systems (Lee & Moray, 1992) demonstrated that trust is easily lost but is hard to win, and a number of

researchers, considering this asymmetry, conclude that the underlying processes involved in making or breaking trust are different (e.g., McKnight & Chervany, 2001).

Briggs and Marsh (2006) have explored a model of trust that elucidates the dynamics of trust both across networks of individuals and across time—building on Marsh's (1994) widely cited computational model of trust. They argue that such a model requires a more sophisticated understanding of those mechanisms that drive overall levels of trust up or down within a temporal/social network of exchange, and they highlight the importance of constructs such as forgiveness and regret in the dynamic framework.

Trust and Ubicomp in the Health Care Context

The ubicomp health care agenda is relatively new, and although a small number of groups are focusing on the technical aspects of ubiquitous health care applications (e.g., Chakravorty, 2006; Dulay et al., 2005), it is not surprising to find that only a few researchers have explicitly considered the trust issues that are likely to be crucial in this domain. On the basis of the existing literature on both trust and privacy, Van de Garde-Perik, Markopoulos and De Ruyter (2006) have drawn up a set of empirically based guidelines for the designers of ubicomp health care systems. In keeping with the scenario-based research we described earlier, they described a futuristic health system to a number of researchers, asking them to consider the importance of various privacy guidelines (developed by the Organization of Economic Co-Operation and Development). In keeping with the work of Roussos and Moussouri (2004) above, the guidelines explored issues in respect of the relevance, type, and purpose of the data collected; the security aspects of data storage; and users own access to their data. As the authors predicted, people were more concerned about controlling the collection and release of data for specific purposes than they were about the quality of the data, although the authors did identify individual differences in the preferences expressed. Most intriguing, on the issue of trust, age differences applied, whereby younger adults are more concerned about controlling the flow of data than their older counterparts. It is possible that such differences are directly related to risk perceptions—with older adults considering the cost/benefit ratio falling on the side of protecting health irrespective of the risk to privacy. Understanding such judgments is vital if we are to be able to move toward an appropriate and seamless exchange of information that does not violate an individuals civil rights.

These findings illustrate the very beginnings of a new research literature in which we can model individual preferences in respect of releasing sensitive health information to a network of trusted agents. Preferences may vary according to age, gender, ethnicity, disability, educational attainment, and technical stance, and current work by Little and Briggs (in press) seeks to contribute to this picture, by establishing individual preference profiles for the release of health information based on the variables listed earlier—but the task of categorizing both information and recipient is not trivial. The ongoing research by Little et al. seems to indicate a complex pattern of disclosure relationships whereby people engage with different trusted agents (e.g., physician, partner, friend, employer), potentially disclosing sensitive health information. Individuals may feel comfortable disclosing information to a certain recipient or alternatively may disclose information only under duress. In other situations, individuals are happy to disclose information to a trusted agent yet currently are not

required or expected to do so. This approach to modeling preferences can only add to our understanding of the issues surrounding trust and ubicomp in a health care context.

References

- Abdul-Rahman, A., & Hailes, S. (2000). Supporting trust in virtual communities. In *Proceedings of the 33th Hawaii International Conference on System Sciences* (pp. 1769-1777). Piscataway, NJ: Institute of Electrical and Electronics Engineers Press.
- Bessell, T., McDonald, S., Silagy, S., Anderson, J., Hiller, J., & Sansom, L. (2002). Do Internet interventions for consumers cause more harm than good? A systematic review. *Health Expectations*, 5(1), 28-37.
- Briggs, P., & Marsh, S. (2006, May). *Trust, forgiveness and regret: A psychological model?* Paper presented at Workshop on Trust, Privacy and Identity Issues for Ambient Intelligence, Pervasive '06, Dublin, Ireland.
- Carvel, J. (2005, February 21). Lack of information worries NHS patients. *The Guardian*, p. 10.
- Chakravorty, R. (2006, March). *A programmable service architecture for mobile medical care*. Proceedings of the first workshop on ubiquitous and pervasive health care, Pisa, Italy.
- Coulson, N. (2005a). *Coping with breast cancer in cyberspace: Understanding the role of the online support group*. Galway, Ireland: European Health Psychology Society.
- Coulson, N. (2005b). Receiving social support online: An analysis of a computer-mediated support group for individuals living with Irritable Bowel Syndrome. *CyberPsychology & Behavior*, 8, 580-584.
- Dulay, N., Heeps, S., Lupu, E., Mathur, R., Sharma, O., Sloman, M., et al. (2005, September). *AMUSE: Autonomic management of ubiquitous e-health systems*. Proceedings of the U.K. e-Science All Hands meeting, Nottingham, United Kingdom.
- Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *British Medical Journal*, 328, 1166.
- Eysenbach, G., Powell, J., Kuss, O., & Sa, E.- R. (2002). Empirical studies assessing the quality of health information for consumers on the world wide web, a systematic review. *Journal of the American Medical Association*, 287(20), 2691-2700.
- Hall, M., Zheng, B., Dugan, E., Camacho, F., Kidd, K. E., Mishra, A., & Balkrishnan, R. (2002). Measuring patients' trust in their primary care providers. *Medical Care Research and Review*, 59(3), 293-318.
- Hart, A., Henwood, F., & Wyatt, S. (2004). The role of the Internet in patient practitioner relationships: Findings from a qualitative research study. *Journal of Medical Internet Research*, 6(3), e36.
- Hartog, F., Schmidt, J. R., & Vries, A. (2006). On the potential of personal networks for hospitals. *International Journal of Medical Informatics*, 75(9), 658-663.
- Jadad, A. R., & Gagliardi, A. (1998). Rating health information on the Internet: Navigating to knowledge or to Babel? *Journal of the American Medical Association*, 279(8), 611-614.
- Kalet, A., Roberts, J. C., & Fletcher, R. (1994). How do physicians talk with their patients about risks? *Journal of General Internal Medicine*, 9, 402-404.
- Klemm, P., Bunnell, D., Cullen, M., Soneji, R., Gibbons, P., & Holecek, A. (2003). Online cancer support groups: A review of the research literature. *Computers, Informatics, Nursing*, 21(3), 136-142.
- Lederer, S., Hong, J. I., Dey, K., & Landay, A. (2004). Personal privacy through understanding and action: Five pitfalls for designers. *Personal and Ubiquitous Computing*, 8(6), 440-454.
- Lee, J. D., & Moray, N. (1992). Trust, control strategies and allocation of function in human-machine systems. *Ergonomics*, 5, 1243-1270.
- Little, L., & Briggs, P. (in press). Ubiquitous computing and disability: Exclusive or inclusive systems? *Information, Technology and People*.
- Little, L., Marsh, S., & Briggs, P. (2007). Trust and privacy permissions for an ambient world. In R. Song, L. Korba, & G. Yee (Eds.), *Trust in e-services: Technologies, practices and challenges* (pp. 259-292). Hershey, PA: Idea Group Publishing.
- Marsh, S. (1994). *Formalising trust as a computational concept*. Unpublished PhD thesis, University of Stirling, Scotland, United Kingdom.

- McKnight, D. H., & Chervany, N. L. (2001). Trust and distrust definitions: One bite at a time. In R. Falcone, M. Singh, & Y.-H. Tan (Eds.), *Trust in cybersocieties* (pp. 27-54). Berlin, Germany: Springer-Verlag.
- Mead, N., Varnam, R., Rogers, A., & Roland, M. (2003). What predicts patients' interest in the Internet as a health resource in primary care in England? *Journal of Health Services Research and Policy*, 8(1), 33-39.
- Nicholas, D., Huntington, P., Gunter, B., Russell, C., & Withey, R. (2003). The British and their use of the web for health information and advice: A survey. *Aslib Proceedings*, 55(5/6), 261-276.
- Pagliari, C., & Gregor, P. (2004). *Literature review of traditional research databases*. Retrieved January 10, 2005, from www.sdo.lshtm.ac.uk/ehealth.html
- Patrick, A. S., Briggs, P., & Marsh, S. (2006). Designing systems that people will trust. In L. Cranor & S. Garfinkel (Eds.), *Security and usability: Designing secure systems that people can use* (pp. 99-127). Sebastopol, CA: O'Reilly & Associates.
- Pew Research Center. (2000). *The online health care revolution: How the web helps Americans take better care of themselves*. Available at <http://www.pewinternet.org>
- Preece, J. (1999). Empathic communities: Balancing emotional and factual communication. *Interacting With Computers*, 12(1), 63-77.
- Roussos, G., & Moussouri, T. (2004). Consumer perceptions of privacy, security and trust in ubiquitous commerce. *Personal and Ubiquitous Computing*, 8(6), 416-429.
- Rozmovits, L., & Ziebland, S. (2004). What do patients with prostate or breast cancer want from an Internet site? A qualitative study of information needs. *Patient Education and Counselling*, 53, 57-64.
- Safran, D. G., Taira, D. A., Rogers, W. H., Kosinski, M., Ware, J. E., & Tarlov, A. R. (1998). Linking primary care performance to outcomes of care. *Journal of Family Practice*, 47(3), 213-220.
- Shand, B., Dimmock, N., & Bacon, J. (2004). Trust for ubiquitous, transparent collaboration. *Wireless Networks*, 10(6), 711-721.
- Sillence, E., Briggs, P., Harris, P., & Fishwick, L. (2007). Going online for health advice: Changes in usage and trust practices over the last five years. *Interacting With Computers*, 19, 397-406.
- Smart, J. M., & Burling, D. (2001). Radiology and the Internet: A systematic review of patient information resources. *Clinical Radiology*, 56(11), 867-870.
- Stanford, V. (2002). Pervasive health care applications face tough security challenges. *Pervasive Computing*, 1(2), 8-12.
- Van de Garde-Perik, E., Markopoulos, P., & De Ruyter, B. (2006). On the relative importance of privacy guidelines for ambient health care. In *Proceedings of the 4th Nordic conference on human-computer interaction: Changing roles* (pp. 377-380). Oslo, Norway: ACM Press.
- Wantland, D., Portillo, J., Holzemer, W., Slaughter, R., & McGhee, E. (2004). The effectiveness of web-based vs. non-web based interventions: A meta-analysis of behavioral change outcomes. *Journal of Medical Internet Research*, 6(4), e40.
- White, M. H., & Dorman, S. M. (2000). Online support for caregivers. Analysis of an Internet Alzheimer mail-group. *Computers in Nursing*, 18(4), 168-176.
- Williams, P., Huntington, P., & Nicholas, D. (2003). Health information on the Internet: A qualitative study of NHS direct online users. *Aslib Proceedings*, 55(5/6), 304-312.
- Wyatt, J. C. (1997). Measuring quality and impact of the World Wide Web. *British Medical Journal*, 314, 1879-1881.

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