THE INTERNET, VIRTUAL COMMUNITIES AND THREATS TO CONFIDENTIALITY

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Objectives. To describe the role of the Internet in building virtual communities of doctors, to identify threats to privacy and confidentiality in this use of the Internet, and to suggest ways in which this threat can be managed.

Summary. The Internet is revolutionising the medical profession. The doctor's role as medical expert is being challenged by patients who have immediate access to multiple sources of information about their diseases. Telemedicine makes use of the Internet to enable doctors to diagnose and treat patients far from their offices or hospitals. Internet list servers and chat groups gather doctors together in virtual space to exchange views on clinical and professional issues. This paper focuses on the last of these Internet applications, beginning with a description of the 'virtual community' that the list servers and chat groups constitute. It demonstrates how various Internet practices particular to virtual communities, namely registration, email lists, and 'cookies', pose a threat to confidentiality. It discusses the conflicting values at stake, especially privacy and confidentiality on the one hand and openness and freedom on the other, and suggests how a balance between these can be achieved.

Conclusions. The proposed resolution of the value conflict necessitates the implementation of effective registration systems, including collection of participants' personal information, and the monitoring of submissions to the chat groups. At the same time, the privacy (anonymity) of participants is maintained, except to the monitor, and the latter can intervene to delete uncivil submissions. Participants are also protected against unauthorised use of their email addresses for advertising purposes and the like.

THE INTERNET AND ITS MEDICAL USES

The Internet is a network of networks through which computers communicate with each other. The World Wide Web

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(www) is one of the major Internet networks. The www has multiple uses. Internet sites (e.g. that of the South African Medical Association (SAMA)) provide any amount of information to potential interested readers. Email allows for almost instantaneous communication between individuals whose computers are connected to the www through a server. People who visit sites ('users') can leave messages on message boards. Two or more people can go on-line at the same time and 'chat' (type) to each other. Sites can host web events, where moderators can show slides, videos or live Webcam to chat users. The site administrator can send email to every person who joins the site's mailing list, and list servers allow email messages and replies to be sent automatically to all users. Users can be asked questions about any issue in on-line polls and surveys, and they can see which of their friends are currently on-line. They can then drop messages directly to those friends, or 'page' them and invite them to a discussion in a chat room. These technologies are revolutionising the communication industry.

The Internet has already had a considerable impact on the practice of medicine in many parts of the world, and this is likely to continue and expand. Innumerable medical web sites (e.g. Medscape) provide doctors and patients alike with a plethora of information about every conceivable medical condition. Much of the information on the Internet is inaccurate, however, and physicians may have to spend time correcting misconceptions. More positively, the Internet provides doctors with ready access to the latest research results and clinical guidelines for improving patient management.

Another potentially valuable use of the Internet is telemedicine, which a World Medical Association document defines as 'the practice of medicine, from a distance, in which interventions, diagnostic and treatment decisions and recommendations are based on data, documents and other information transmitted through telecommunication systems',[1] including, but not limited to, the Internet. Telemedicine applications range from the transmission of radiographic images and pathology slides to interactive consultations between doctors in different locations.

Other applications of the Internet for the medical profession include access to high-quality continuing professional development, especially for doctors in remote areas; rapid, interactive linkage with their professional association (e.g. SAMA's Medigram); and billing/reimbursement mechanisms.

The focus of this paper is on a different application of the Internet, one that is being used increasingly by doctors as well as by many other groups — the development of virtual communities.

THE ROLE OF VIRTUAL COMMUNITIES

As well as being a communications network, the Internet is a place, a 'virtual' place in which many millions of people 'live'. A growing number of Internet sites, including medical ones, have committed themselves to becoming 'virtual communities'. The centre of the on-line, virtual medical community is usually a message board system. Here members of the community post messages for others to see and respond to when they come on-line. Anything from the 'hot news' items of the day to clinical cases is open to discussion. The discussion in this format is asynchronous, somewhat like a speeded up exchange of letters with one's pen pal (with the entire community watching and reading the letters).

The second component of the virtual community is the live chat that takes place on the chat server. This allows text-based real time 'conversations' with whoever else is in the chat room at the time. When new participants arrive they are greeted warmly and then face a barrage of questions: where are they from, what are they doing and what do they think of the issue under discussion. Some stay and return again to chat with people who start off as strangers and slowly become familiar. When the members are comfortable with each other the community will start to mature and interactions will take place at levels other than that of the simple text.

Community building is a long, slow process. The physical medical community already exists in South Africa. Interaction among members on-line provides possibilities, as yet unimagined, for improved communication and trust that can strengthen the community.

SAMA's website (www.samedical.org) and the ethics site developed by the authors (www.ethics.co.za) are two examples of South African medical sites aimed at community building.

THE VALUES AT STAKE

Use of the Internet to create virtual communities raises important ethical issues. We understand the term 'ethical issue' in the following sense: 'An issue involves conflict and controversy. Ethical issues bear upon the rights and wrongs of human decision making and behaviour. They involve conflicting beliefs about how human beings should live, about the values individuals and groups should uphold, and about the values that may be sacrificed when all values in a situation cannot be honoured and maintained'.[2] For the purposes of this paper, we do not need to cover all the ethical issues raised by the Internet. Issues such as 'gender bending' (pretending to be a member of the opposite sex), and the vast power being distributed among the elite, educated, wealthy users of the Internet are fascinating debates that require their own guidelines. This section focuses on the conflicting values at stake in the use of the Internet to build virtual communities, in particular privacy and confidentiality on the one hand and openness and freedom on the other.

Privacy, confidentiality and informed consent

In this context we understand the term 'privacy' to mean a person's right to determine with whom he or she will share information, and to know about and exercise control over use, disclosure and access to any information collected on him or her. Privacy entails the right of consent; non-consensual collection, use, disclosure or access violates privacy, even if such actions are justified. Confidentiality means that information about a person is to be kept secret and not disclosed or made accessible to others unless authorised by that person.

Traditionally doctors have been sensitive to the need to protect the privacy of their patients and the confidentiality of medical information, as evidenced in SAMA's credo, which states that doctors will 'strive to respect the confidentiality of information entrusted to [them]'.

The Canadian Medical Association recently adopted a *Health Information Privacy Code*[3] that states, 'The right of privacy is fundamental in a free and democratic society. It includes a patient's right to determine with whom he or she will share information and to know of and exercise control over use, disclosure and access concerning any information collected about him or her. The right of privacy and consent are essential to the trust and integrity of the patient-physician relationship. Non consensual collection, use, access or disclosure violates the patient's right of privacy. The right of privacy is important and worthy of protection, not just for the good of individuals in society but also for the good of society as a whole.'

In keeping with this respect for privacy and confidentiality, doctors should be suspicious of any attempts to erode these values, whether in the medical or other sectors. They need to be aware that their own privacy, not just that of their patients, is at stake. The Internet raises particular problems in this regard: (*i*) every email that is sent, every exchange on a chat server, is recorded; even if it is deleted, it is usually recoverable, which can result in a major invasion of privacy; (*ii*) many Internet sites are only open to registered users — the personal information that individuals are required to submit when registering can be used for many other purposes, without the consent or even the knowledge of the individuals involved; and (*iii*) many Internet sites automatically record data about the user without the user's knowledge, such as the website the user came from and the country in which the user is based.

These threats to privacy and confidentiality are not easy to combat, both because of the technical capabilities of the Internet and because privacy and confidentiality can conflict with other important values such as openness and freedom.

Openness and freedom

Some virtual communities allow participants to maintain their confidentiality (anonymity) because they value freedom of speech and consider that anonymity guarantees the practice of free speech, however outrageous. Any attempt to control members is met with immediate verbal abuse ('flaming'). Participants in these communities tend to be young, aggressive, intelligent and ever ready to do battle.

These communities value free speech and free information exchange: 'If the Net has any legacy at all, it is one of anarchy, of chaos, of the belief that all information should be free . . . The Net also has a legacy of anonymity . . . Anonymous communication encourages verbal violence. Its far easier to attack someone and question personal motives when the social consequences of face-to-face verbal assaults are removed.'[4]

In order to prevent such abuses, many virtual communities have instituted control measures: 'In on-line communities like The Well (www.well.com) . . . designated 'hosts' monitor discussions, keep participants on the topic, encourage disagreement (discouraging hostility when it crosses certain boundaries), and sometimes even remove ('scribble') the worst personal attacks. Even though some participants use pseudonyms, they cannot hide behind anonymity. Over time, many well users come to know one another and begin to see themselves as part of a community. Monitoring discussions is an inevitable step for any Web site that takes itself seriously or wants to be take seriously. Somebody must provide oversight, be responsible, take charge. When that happens, flamers tend to retreat to the many thousands of places on the Net where flaming is the primary currency of communication.'[5]

Some medical sites openly discourage verbal violence, but in doing so they put limits on the exercise of freedom of speech. Which is precisely where the conflict lies — in order to discourage anonymity, one has to implement registration systems that work (collection of individuals' personal details). One also has to ensure that when people write something on these sites, their (real) names are visible for all to see. Yet this goes directly against the need to ensure confidentiality, and the need to encourage free speech.

SEEKING A BALANCE

Is it possible to safeguard the privacy of participants in Internet communities and their freedom of speech while maintaining civility? A reasonable compromise might require participants to register with the site and to identify themselves automatically to a monitor when they sign in. Once registered, the users could still be allowed to choose whether or not to make submissions in their own names or to use aliases. In this way the privacy (anonymity) of participants can be maintained, except to the monitor, but the latter can intervene to delete uncivil submissions. Sites that seek to implement this balance should also develop and display strong privacy statements that warn users of the danger of invasion of privacy. This will result in a balance between the need to encourage freedom and participation, and the need to protect confidentiality.

PRACTICAL APPLICATIONS

Registration

Many sites have a registration option, with a privacy clause similar to the following: 'Wired Digital Inc . . . believes that strong electronic privacy is crucial for the ongoing success of the Internet as a service, commercial, and entertainment medium. To this end, unless you designate otherwise, the information you enter here will be known to only two parties: you and Wired Digital Inc. We pledge that Wired Digital Inc. will not release your personal data to anyone else without your consent — period. You may change the status of whether you wish to receive Wired Digital offers and communications at any time. When we do present information to our advertisers, unless you tell us otherwise, it is in the form of aggregate statistics compiled among all of our visitors' answers to survey questions as well as grouped on-site behaviour . . .'[6]

Standards have been developed for website privacy statements and organisations have been established to monitor compliance (e.g. TRUSTe[7]). Doctors should be suspicious of medical websites that do not have a privacy statement or have one that is not backed up by a monitoring organisation.

Email lists

Registration data are used to generate email lists. That is to say, names and email addresses can be sold by the owners of the sites to advertisers or other commercial interests. This can constitute an invasion of privacy unless an individual has consented, or at least has not objected, to such use of his or her personal information. Responsible websites allow users to make informed choices about such matters. For example, Wired Digital informs potential users that 'When we do present information to our advertisers, it is in the form of grouped statistics compiled from all our participating Members' answers to survey questions and on-site behaviour. Wired Digital will not disclose the contact or demographic information of any individual user or Member to advertisers or any other outside organization without the express permission of the individual. If a user wants to receive information from other reputable organizations whose products or services Wired Digital thinks he or she might find interesting, he or she can so indicate during the Membership registration process. In this case, user information will be shared. Wired Digital will never disclose individual Member contact or demographic information without user consent . . . .'[8]

Here, too, doctors should be wary about registering with Internet sites if they have concerns about receiving unsolicited mail or other forms of communication.

Cookies

Cookies are tiny files of text that many websites put on a user's computer for future reference. Only the website that put the cookies on in the first place can read them at any time in the future. Users need not be concerned that sites will be able to read cookies from other websites and in this way find out something about them that they do not want known. There is currently an outcry against the Pentium III chip, which has a unique user number that serves as a permanent cookie. Public reaction has been so strong that Intel has disabled the feature.

All cookies are put in a special directory on the personal computer called 'Cookies'. The cookie files cannot be put anywhere else and cannot damage one's computer. A number of sites make use of cookies to recognise readers as they come back to the site, as well as for various other administrative functions. In time cookies will be used to customise and individualise the experience of the website.

The problem with cookies is that no informed consent is given by the user as to their allocation. There is a sense in which 'blanket consent' is given, since all PCs will automatically reject cookies unless otherwise disabled by the user. But blanket consent is a dubious practice, since it is usually accompanied by ignorance of the implications, and hence does not constitute informed consent.

Given that cookies are harmless and that information gleaned from them is not sold or disclosed to anyone, it is fair to suggest that sites of this nature are not acting irresponsibly as long as they inform users that they are in fact using cookies. One can, however, set up one's Web browser either to ask whether one is prepared to accept a cookie, or to reject it entirely.

CONCLUSION

The Internet has great potential for the medical profession, not least in terms of its contribution to the development of virtual communities of doctors. However, it also poses a threat to doctors' privacy and confidentiality. The technology exists to manage this threat satisfactorily if websites commit themselves to the principle of informed consent, abide by industry standards of privacy and submit to monitoring by reputable oversight organisations. However, websites can also abuse the confidence of their users by making data available to other groups without the user's consent or even knowledge. Doctors who make use of the Internet, for whatever purposes, should carefully consider the potential loss of privacy that can occur and assure themselves that any such loss is justified in view of the benefits provided by their use of the Internet.

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