Health and the internet: Strategies for making sense of electronic health care in the information age.

As internet usage continues to expand, at least by most indicators of usage in the developed world, the phenomenon of electronically mediated health is receiving increased attention in the scholarly literature. This rapidly expanding literature is informed by disciplines as diverse as information science, health informatics, the sociology of health, and specialist literature concerning health professionals themselves. The issues covered range from highly specific measures of usage and information gain to more discursive accounts of what this means for the relationship between health professionals and clients, or indeed what it means for our sense of ourselves as human beings.

From its inception the internet was a prime site for the dissemination of health information. As long ago as 1997 there were 25,000 sites devoted to aspects of health (Ferguson, 1997) and 21st century estimates suggest a much higher number, from 100,000 upwards (Steelman, 2003). Likewise there is some variability in estimates of the extent to which people use these facilities. According to Bovi, (2003), approximately 3 million Americans used the Internet for online consultations with a medical expert. For example, an early 21st century survey revealed that 41% of patients participating in the study were reluctant to spend time in physicians' offices to ask questions that could be answered through other means of communication, such as e-mail. The survey also concluded that 81% of the online population would like to receive e-mail reminders for preventive care and 83% would like follow-up e-mails after a visit to their physicians (Information Technology Association of America, 2001).

However, the sense of continued expansion needs to be tempered with caution. Childs (2004a; 2004b) reports evidence to the effect that the number of publicly available pages on the internet has reached a plateau, and some months, such as March 2004 show a similar plateau or even small downturn in the number of active UK internet users. Expansion on the other hand can be seen in the increasing number of UK households wit their own PC and with broadband access. For example the Office of National Statistics (2004c) reports that in the third quarter of 2004 52% of UK households had access to the internet compared to only 9% in the same quarter of 1998, and in October of 2004 61% of adults had used the internet in the three months prior to interview. Taking internet usage as a whole, the juvenile section of the market seems to be expanding most rapidly according to market analysts Nielsen Net Ratings (2004) with the biggest percentage gains in access and in pages viewed being apparent in the 2-11 age group. Here, as well as predictable favourites such as Disney and Cartoon Network, there were substantial increases in sage of MSN Messenger and AOL Instant Messenger services. Thus, the rising generation is expanding its usage of internet services and it likely to carry this orientation through as it matures.

Internet usage of course, does not occur in a social vacuum and the technology is intimately connected with systems of social relations, norms and persona values (Bloomfield & Vurdubakis 1994, May *et al*. 2001). Thus, consideration of the social implications of Internet use involves understanding individual behaviour along with macro-social analyses of wider institutional and politico-economic factors which both constrain and facilitate behaviour (DiMaggio *et al*. 2001). For example, perhaps Internet access is affected by the availability of privacy and the fostering of social networks (Skinner *et al.* 2003). Moreover it is perhaps mediated also by the kinds of relationships people have with existing flesh-and-blood health professionals in their lives (Rogers and Mead, 2004).

Internet access to health therefore takes place in the midst of a variety of social inequalities, social networks and normative frameworks that inform patters of use and the meaning that usage has for the people concerned. The existing contours of social life, involving variables such as age, ‘race’ gender, geography and social class can be seen reflected in patterns f access and use, yet the experience of internet health information can itself be seen as an agent which changes the landscape of health care. Indeed, this potential has been described as ‘e-scaped medicine’ (Nettleton and Burrows, 2003).

Practitioners themselves are also acutely aware that access to the internet is informed by people's socioeconomic status (Wong, 2001; 2004). For example, a study by Christensen et al (2004) which describes a internet intervention for depression, showed that the people who gained the most from this programme were well-educated women in their late 30s. Thus, groups known to be at particular risk for mood disorders such as the elderly or poor people did not seem to be represented in this study.

Elderly and poorer people in Australia, where Christensen et al's study was undertaken may well be under-represented amongst internet users, just as they are in the UK Here, as Wong (2004) highlights, old and poor people have less internet access. Of those over 65 years of age, only 7% have ever accessed the internet (Office of National Statistics 2004a). Similarly, of the poorest 10% of the United Kingdom's population, only 12% have ever accessed the internet (Office of National Statistics , 2004b), As Wong concludes, the internet has the potential to offer much, but access to this resource continues to minimal amongst those who most need it. This leads to concerns amongst both theorists and practitioners that particularly needy segments of the population will be missed out in the internet health revolution (Nettleton and Burrows, 2003; Wong, 2004). Of mental health in particular, Wong (2004, p. 1201) says: 'Until access issues are addressed, it is hard to imagine that it will ever replace more traditional face to face services, and mental health service providers must resist the temptation to use it as a cut price way of providing their psychological treatments'.

The present UK government sees digital exclusion as an important aspect of social exclusion which it is keen to overcome. An important aspect of this policy is to prevent a gulf developing between the 'information rich' and the 'information poor', a concern which has attracted a good deal of political and social scientific attention amongst those seeking to ameliorate this 'digital divide' (inter alia Graham, 2002; Hellawell, 2001; Keeble and Loader, 2001; Tambini, 2000).

Policy makers, practitioners and health educators therefore have devoted a good deal of attention to who is getting what out of the internet and how the playing field between rich and poor can be levelled. What is far les clear, and rather less debated is the relationship between ‘e-scaped health care’, language, culture and how we think about ourselves and our place in nature.

Nettleton and Burrows (2003) argue further that the kinds of information that are being privileged in this information revolution are largely based on facts and information whilst what they call ‘discursive knowledge’ is pushed into the background. The fundamental patterns of inequality which are found in UK society will not be disrupted by increased electronic access to health. The authors predict that those who access the electronic information will continue to be more likely to be younger, and come from households whose main wage earner is in one of the professional or managerial occupations. The changes they forecast are concerned instead with some shifts in how medical expertise is localised. No longer will it solely reside in the hands of a specially trained and qualified elite but instead will be shaped by a more diffuse network of consumers, researchers web designers and concerned member of the public as well as doctors themselves. In connection with this, De Mul (1999) writes of ‘the informatization of the worldview’, it has ‘escaped’ into the networks of contemporary infoscapes where it can be accessed, assessed and reappropriated. Rather than being concealed within the institutional domains of medicine, knowledge of the biophysical body seeps out into cyberspace and may be accessed and assessed by non-‘experts’. Furthermore, such knowledge may mix with alternative views or knowledges of the body, disease and illness, with the effect that new conceptualizations may emerge.

Thus there is a tension between the potential for novelty and liberation and the equally strong possibility that the new technologies and ways of communicating will enable things to stay pretty much the same. According to Koerber (2000, p. 66), from a feminist perspective scholars have been acutely aware of this very tension, noting how new technologies are frequently believed to be liberating but rapidly lose this potential once they become established parts of our lives. This happens because in order for technologies to be designed, produced and marketed, they are almost invariably appropriated into existing institutions, industries and practices. Thus they tend to reify and reinforce the status quo and sustain phenomena such as race, class and gender divisions rather than fostering new meanings. As Copeland (2002) adds, although new computer technologies can potentially blur the boundaries of social categories such as gender, race, and class by hiding many of the social cues that indicate these categories, in practice, people very often use technologies so as to perpetuate traditional gendered communication styles. Thus, she argues that men still tend to make use of an adversarial style that distances them from other participants; women tend to interact with cooperative, polite exchanges. In Copeland's own research , drawing on interaction in the chat forum of a website catering to the relative of prisoners in the United States, it appeared that men were likely to contribute most of the material in the chatroom and it was only when women outnumbered men that the gender ratio of contributions was apt to even up. This confirms the suspicions of many feminist scholars of language that men tend to assume positions of dominance in conversations and secure the 'floor' more readily (Cameron, 1998; Saul, 2003; Spender, 1985). The pre-existing patterned inequalities of hetero-patriarchy therefore, spread out onto the new surfaces.

Along with these familiar findings, there are equally strong suggestions that electronic media facilitate new patterns of sociality, help seeking and healing. There is for example, some evidence that online support from groups the individual engages with via the internet is considered to be preferable or more valuable than that given by a physician (Grandinetti, 2000) because of the convenience, anonymity, cost effectiveness, the quality of emotional support and the ability to retrieve in-depth information. However, Cline and Haynes (2001) caution that there are many pitfalls for health consumers who may be confronted with sites whose information is partial, tendentious oversimplified and is often in hard-to-navigate and may well be impermanent.

As a consequence of this, there have been a number of initiatives designed to promote quality, from prizes and points awarded to particularly exemplary websites through to attempts to develop a means of quality assuring the website content so that visitors can be mad aware that the site has been judged by other professionals to be of a high standard. For example Childs (2004) advocates the use of 'webs of trust' for sites to link reciprocally with a guarantee that the content has been carefully designed to be up to date and informative. Childs also advocates the value of linking together web pages of statutory and voluntary service providers in a locality as well as using the web to make people aware of support groups and other non-statutory services which service users and patients may find useful.

The effect of this diffusion of information along the relatively new electronic pathways afforded by expanding internet usage is already being felt by many health care providers who are increasingly likely to be greeted by patients who have informed themselves via the internet. Malone et al (2004) sought to discern the impact of this on health professionals and their consultations with clients. Whereas their survey disclosed that three quarters of the health professionals questioned had been consulted by a patient bearing information obtained from the internet, only a minority (5%) had experienced this more than six times a month. However, there were some powerful mixed feelings about patients bringing such information to the encounter. In many cases, especially when patients had hazarded a diagnosis of their own and investigated possible courses of treatment, this was seen as a bad thing. Health professionals often had to admit their relative ignorance to Internet-informed patients and offered them follow-up consultations later; yet this was unsatisfactory because it meant more work. Admitting ignorance in the consultation itself amounted to a professional ‘loss of face’ and a feeling of being ‘disempowered’ or even ‘professionally insecure’ (Malone et al., 2004, p. 191). Childs (2004a) on the other hand reports a somewhat more favourable picture, where some survey evidence can be found which suggests that the majority of patients and about half of professionals found it helpful to discuss material on the internet. This then offers a new potential for health care providers to be co-explorers of the electronic landscape with the client.

Despite the growing likelihood of clients surfing the web for information about what is troubling them, at the same time it does not seem that the role of the primary care physician is being entirely supplanted by electronic resources. Harris Interactive (2003) has been tracking the people who search information on health topics (‘cyberchondriacs’) in the USA, France, Germany and Japan for four years. Their number has doubled during this time (54 million in 1998, 110 million in 2002). Most people say that they look for information on their own, but rely on it only if their doctor confirms the quality (60% in the USA and 47% in Japan). Another group tends to judge the information without consulting doctors (37% in Japan, 46% in Germany). Only in some cases (particularly in Japan) do people look for information only if their doctor tells them to do this. A Swedish survey reported by Garbenby and Husberg (2001) found that higher credibility was attributed to health information from healthcare staff and family than to the same information on the net. Thus internet based information, whilst seen as moderately trustworthy, still has some way to go in the hierarchy of credibility compared to face to face sources such as doctors and relatives.

In an effort to begin examining the UK's patterns of internet-mediated health care, Nicholas et al (2001) undertook a survey of visitors to the site 'SurgreryDoor', receiving completed questionnaire returns from over a thousand users. The aim was to investigate why the site was consulted and discover whether the information obtained was believed to be useful or had any health outcome. The majority of respondents (around 80%) were women and tended to be middle aged. Doctors were usually the first port of call for information. However 50% of respondents cited the Internet as one of their top three information sources. Most people had come to the site without a particular illness or medical condition. Two thirds of users said that the information found had 'helped a lot' in being better informed. Generally, those who used the internet more often were more likely to say it had changed the way they thought about health issues. Just under half felt that the information they found had helped in their dealings with the doctor, while just over half felt that information found had changed the way they felt about their condition. Interestingly, over one-third of respondents said that their condition had improved after having visited the site and more than one in four said that the information they had gained from the site had deferred or even replaced a visit to the doctor, thus highlighting the possibility that some kinds of health care visits at least can be substituted by web based activity. Perhaps this might especially be the case for frequent and experienced web users.

Health professionals themselves remain largely sceptical of the use of the internet in their own practices (Anderson et al 2003) and sceptical about the use of the internet for patient education. Yet there is an increasingly minority of professional voices calling for greater acceptance of this phenomenon ‘It is time to embrace the concept of the informed patient and use their websurfing skills’ said Pemberton and Goldblatt, (1998) in the vanguard of the recent softening of professional attitudes toward the ‘overinformed’ e-patient. Indeed, as Anderson et al (2003) argue it is time for health professionals to welcome the ‘empowered consumers’ rather than see them as intruders trespassing onto sacred turf. The information age, they say, demands a new dimension of ‘consumer responsiveness’.

This apparent disempowerment of physicians has also yielded some interesting new developments on the part of patients. The patients (or ‘informed consumers’) on the other hand find their role transformed from that of a passive recipient of care to that of an active citizen taking some kind of responsibility for their own health needs (Anderson et al, 2003). This is seen by patients as an antidote to the sense that specialist care was delivered in a rather impersonal manner and that the pattern of care they received was dominated by doctors’ economic interests. As Anderson et al note too, the sense of despair tat can sometimes result from a physician’s statement that nothing can be done is difficult to accept, so internet surfing can provide a valuable source of knowledge about alternatives.

The involvement of consumers or patients in the design and planning of research is increasingly modish and the internet can facilitate this enormously. Anderson et al (2003) report how the Cochrane Collaboration has lately identified consumer involvement as one of their crucial pillars. The authors set up an experimental consumer feedback page (http://dermis.net/cgi-bin/cochrane/question.htm) for the Cochrane Skin Group so as to compile a database of ‘frequently asked consumer questions’ which could be addressed in future systematic reviews. After only 2 months, more than 500 consumers made contributions. There is thus some degree of enthusiasm amongst some groups of consumers for this kind of involvement and it may well be that greater alignment between the public's priorities and researchers activities can be fostered through such initiatives.

Thus, as well as those who visit the sites which have specifically been created to cater to the general public, there are a great many who visit sites designed for health care practitioners and scientists. For example London (1999) describes a phenomenon he calls 'if it's there, they'll find it'. London was instrumental in the design of the academic cancer website, Kimmel Cancer Center (http://www.kcc.tju.edu), which originally provided information directed at healthcare professionals and researchers. He quickly found that the database listings of currently open clinical trials, targeted at cancer physicians, were being frequently accessed by members of the public too. Following this discovery, the site developers began to include lay descriptions in their trial listings. Similarly, Eysenbach *et al*. (1999) found that a dermatology website, intended for medical practitioners, was used more by lay consumers than healthcare workers.

For those clients who are in remote or rural areas, the internet may have a great deal of potential for service delivery Walkerman, (2004). Where telephone access can be arranged, there is the potential for web based health to address the problems of rural populations which as Walkerman notes are often characterised by relatively higher morbidity and mortality and poorer socioeconomic indices.

There may be demographic characteristics that predispose people to using web based resources more frequently. As we have seen it is fairly well established hat those who are younger (or young middle-aged) and more middle class are more likely to use web based resources, but additional findings have been added to this mix by several researchers. For example Eriksson-Backa (2003) discovered that respondents with diabetes and those who were pregnant tended to have different patterns of internet usage compared to control participants with neither condition. The groups of pregnant women and diabetics were generally more active Web-users than the control group and used discussion forums and health portals more while members of the control group read online newspapers more actively than the others did. This suggests that usage of web resources is focused by the kinds of illnesses or health issues that people feel they have, and this might be associated with greater participation in interactive facilities. People who believe themselves to the healthy on the other hand might browse more general interest material.

The concern with social support and how the internet might enhance this for people in a particular predicament is illustrated by a study from Copeland (2002) who investigated the users of a site for relatives of prisoners in the US www.penpals.com and the uses they were gaining from the site. In particular, she was interested in the use the site's visitors made of the online 'chat' facilities and the social support offered by participants to one another. The potential public health benefits of this may be significant, especially as the participants were often suffering from stress, obesity, and contended with lifestyle issues such as smoking and lack of exercise. The participation in online forums was identified by Copeland as valuable, because following Lauver (2000) she believed that "When women's experiences with stressful events such as harassment, violence, or abuse are listened to and responded to by groups or communities, women's health is improved" (Lauver, 2000, p. 81). This is especially so with the families of incarcerated offenders who are often isolated and at greater risk of emotional physical or financial victimization. This social support from web based facilities might enhance the users' wellbeing across a variety of fronts, therefore.

The idea of enhancements in wellbeing, knowledge and a subjective sense that one is understood or supported presupposes that the information is read and comprehended. This highlights the necessity of examining what people do with the information they find on the web. Such an investigation was conducted by Eysenbach and Kohler (2002) using focus groups to look at how people conducted searches and gained information. Participants said that when assessing the credibility of a website they primarily looked for the source, a professional design, a scientific or official touch, language, and ease of use. However, in the authors' observational study, participants did not check any "about us" sections of websites, disclaimers, or disclosure statements. In the post-search interviews, it emerged that very few participants had noticed and remembered which websites they had retrieved information from. This kind of finding leaves policymakers, health educators and practitioners with some concerns about the effect of especially id f the information is tendentious, partial or taken out of context by the person browsing.

Kiley (2002) argues that there is a mounting number of anecdotal reports of incidents – involving laypeople and health professionals – where patients have been harmed through the use of inappropriate treatments which they learned abut from websites. Equally, people are, for example, raising money for trips abroad for treatments which are advertised on the internet but for whose effectiveness there is little evidence.

On the other hand, there are a number of reports of modest benefit from internet based information and education initiatives. Bessell et al (2002) attempted as thorough a review as they could of studies of relevant initiatives. They found 10 comparative studies completed at the time of their literature search, evaluating issues such as the effectiveness of using the Internet to deliver a smoking cessation programme, cardiac and nutrition educational programmes, behavioural interventions for headache and weight loss, and pharmacy and augmentative services. Whereas all studies showed some positive effects on participants' health outcomes, Bessell et al were extremely wary of the methodological quality of many of the studies they reviewed.

Finally, there are a great many people who are reluctant to use electronically mediated health resources. A study by Rogers and Mead (2004) investigated a small number of clients to see why this might be the case. According to their findings there were several who had little confidence in the use of the Internet and its potential for positive impact on health outcomes. Several factors appeared to be connected with this reluctance to engage with e-information. Electronic resources were not seen as an effective means of managing one's health overall; neither did it have the potential to achieve a desired outcome. Interestingly, this reluctance seemed to be associated with a particular way of thinking about health professionals. That is, amongst these reticent individuals, health professionals and their services were viewed as being largely predetermined and not amenable to lay influence. Participants in this group did not see themselves as having an influential role in negotiations over health matters or their outcome through the use of information. Information could also induce anxiety, as it was seen as interfering with established coping mechanisms and with the efforts of health professionals. Where problems were encountered with the face-to-face services, or gaps in knowledge were identified, there was a fatalistic attitude that these things happened and were irreversible, at least by them (Rogers and Mead, 2004)

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