

Turned on or turned off?

Accessing health information on the Internet

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Abstract

It is often claimed that Internet access provides people with more and better health information, resulting in better-informed patients who engage in more reflexive and equal negotiations with their doctors. Counter arguments suggest that Internet information overload will increase levels of anxiety and confusion amongst health care consumers, resulting in their disempowerment. This paper discusses on-going research investigating the ways Internet users and non-users access and manage information about specific health treatments. The paper describes how our research design and methodology is enabling us to avoid the generalisations and tendencies towards technological determinism found in much previous research in this field.

Keywords

Internet, health information, patients, HRT, Viagra

Introduction

In this paper, we describe an on-going research project that examines the validity of claims being made about the role of the Internet in patient/consumer empowerment. Whilst it is widely accepted that developments in information and communication technologies (ICTs) present opportunities for improving access to information about health, very little is known about where and how people do access and manage health information. Recent health policy documents in the UK suggest that the greater availability of health information via the Internet will lead to the emergence of more informed patients who are better able to assess the risks and benefits of alternative treatments for themselves. This is said to lead to the emergence of more equal patient-provider relationships and a more equitable distribution of health care resources (HEA 1998; NHS Executive 1998). In contrast, counter arguments suggest that the increase in the provision of online information sources may be at the expense of offline ones, thereby reinforcing existing patterns of inequality and/or reconstructing new ones, based on differential access to the skills, equipment and services required to take advantage of the information carried by new media (Schiller 1996; Thomas and Wyatt 2000). Concerns have also been raised about the over-abundance of information available online, leading to confusion and ontological anxiety (Beck 1992), as lay users do not have the expertise to evaluate and interpret the appropriateness of the information. This point is partly supported by press reports of 'Internet Print Out Syndrome' (*The Independent* 1999) where patients confidently misdiagnose themselves and put pressure on health care professionals to provide inappropriate treatments.

The project we describe here set out to examine such polarised claims via detailed empirical investigation of the ways both Internet users and non-users access and manage information about specific health treatments. The aim of this paper is to describe how we have drawn upon social science perspectives from both technology studies and medical sociology to inform our research design and methodology. The paper discusses the ways in which particular

innovative aspects of our research design and methodology are enabling us to go beyond the generalisations found in much previous work in this field and, at the same time, avoid the tendency to link technological and social change within such deterministic frameworks.

In the next section, we outline what social science – particularly technology studies and medical sociology – can contribute to the debate about the emergence of the 'reflexive consumer', the 'informed patient' and the role of ICTs in the management of health information by health care consumers. Following that, we describe our research design and methodology that starts with individual 'patient participants' and follows them over a period of time to analyse and understand more about their information practices. Several innovative aspects of our methodology are addressed. We first outline the many advantages of our longitudinal approach. We then outline the rationale for grounding our research in a study of 'users' (including potential and ex-users) of two specific pharmaceutical interventions – HRT and Viagra. We then discuss our emphasis on understanding information as 'discourses' that can be identified in various health information texts. Then we turn to an examination of how our cross-media emphasis enables a comparison both of different media and of users and non-users of the Internet. Finally, we discuss the implications of our approach for understanding more about the processes of social exclusion and inclusion. Wherever possible, we illustrate the successes (and limitations) of our research design through discussion of preliminary results.

The Internet and the reflexive patient: learning from social science

In this section we argue that critical approaches to the study of technology in health care can enable us to challenge the technological determinism and techno-euphoria found in much of the policy and technical literature. Following dominant thinking in technology studies, we start from the assumption that technologies do not determine patterns of use. Instead, technology and social practices are understood as mutually constitutive (see, for

example, Bijker et al. 1987; Mackenzie and Wajcman 1999). From within this technology studies literature, we are particularly interested in that which seeks to better understand the uses and users of technologies. Here, we have been influenced by the work of Woolgar (1991) on 'configuring the user' and of Akrich on 'scripts' (1992). Both of these commentators have emphasised the ways in which particular representations of users become embedded in technological design and how such design then limits the range of users and uses to which that technology can be put. However, other work on the consumption, 'domestication' or 'appropriation' of technologies (Silverstone and Hirsch 1992; Lie and Sørensen 1996) has also been instructive for us. Here, technologies are examined in the context of 'everyday life', with emphasis on the highly contextualised and embedded characteristics of both users and use. In our attempts to compare dominant representations of uses and users of the Internet with actual use and users, we seek to make visible the very different contexts of Internet use or non-use and identify the factors that shape such use practices. We should make clear that, although we have regularly used the terms 'use/r' and 'non-use/r' as shorthand in the design stages of our project, we find the use/non-use distinction largely unhelpful for our overall purpose. This has always been to better understand the many different ways in which people engage with the Internet, alongside other media technologies, in the context of wider health information landscapes. As we hope to show, our longitudinal design is proving particularly appropriate for highlighting the extremely dynamic nature of Internet use in a health information context.

Before moving on to discuss our methods, together with some preliminary findings that help illustrate the successes (and limitations) of those methods, we briefly review recent work on health information and the Internet and on the patient-provider relationship in late modernity to better situate our research within current debates in social science.

Health information and the Internet

Internet usage has grown dramatically in most industrialised countries since the development of the World Wide Web in the early 1990s. In

many industrialised countries half or more of the adult population has home Internet access, although in countries such as France, Spain and Italy it remains under one third. The US and Canada with only 5 percent of the world's population account for over 40 percent of the world's Internet users (Pastore 2001a). Within countries, although the exact patterns may vary depending upon local traditions of inequality and exclusion, so-called 'digital divides' exist, between men and women, between young and old, between different ethnic groups (Schiller 1996; Wyatt et al. 2000). It seems reasonable to assume then, that many people continue to obtain health information offline.

In our research, we consider such inequalities of access to the Internet in the context of health information. We do not take for granted the claim that Internet access necessarily confers advantage and that, in turn, non-access results in disadvantage and social exclusion. In addition, we take a broad view of 'access', not seeing it simply as having a home Internet connection or not. Many more people have access via schools, universities, libraries, workplaces or cafés. These different contexts or 'sites' of access and use may also influence the types of information sought and the experience of use. We shall return to this issue in our discussion of research methodology and preliminary findings in a later section.

After pornography, health information is the most sought after material on the Internet (Pinkowish et al. 1999). A survey by the Boston Consulting Group (Pastore 2001b) suggests that 75 percent of all US adults who are online use the Internet to look for health information. Nearly half of these subsequently use that information in their consultations with health care professionals. However, previous research (Wyatt 1999; Eysenbach 2000) suggests that remarkably little is still known about who accesses online health information, if the information is substantively different and/or differently interpreted from information available offline, and how information sourced via different media affects patient-provider relationships and subsequent treatment outcomes.

Our research is primarily concerned with the informational activities and experiences of those

that are commonly referred to as health care *consumers*. However, one of the common claims about the Internet is that it blurs the boundary between consumers and producers (Thomas and Wyatt 1999) – this is certainly true when it comes to health *information* which may then impact on care. The blurring of this boundary in the health area is explicitly addressed by Ferguson (1997). He examined what those he describes as ‘online self-helpers’ are actually doing when they go online for health purposes. He found that roughly 25 percent of the search engine queries on the Web involve people looking for information or advice on health-related matters and that such Internet users were very proactive in their use of the Net. They may be sending email to friends or getting support in dealing with their health problem. They may find and sign up for an email list or USENET newsgroup for their chosen health topic. They may visit a support forum on a commercial network such as AOL and CompuServe which combines asynchronous chat, live chat, database information, and the ability to do searches all grouped around particular areas of concern. They may visit a web site, consult a web directory or use a web search engine. Some consumers are even creating their own health websites.

Ferguson argues that these ‘online self-helpers’ are reshaping the health care system based on their own preferences. For example, many self-help groups create their own ‘Frequently Asked Questions’ (FAQs) and reject traditional patient information created by health care professionals such as a handout or leaflet which is then simply put up on the web in unaltered form. He found that consumers dislike the top-down approach taken in such information and the way it makes the patient ‘the passive recipient of professionally controlled care’ (Ferguson 1997, p. 255). Ferguson further argues that the health care professionals who participate in these online self-help networks have had to shift their role from authority figure to facilitator, generating new roles for consumers and providers. This research illustrates well the co-construction of the technical and the social discussed earlier. The Internet is instrumental in shaping new social relations and social practices in health but, equally, Internet ‘users’ here are, through their information practices, shaping

what the Internet is.

In another study of online self-help groups, Burrows et al. (2000) address questions of risk, reflexivity and the emergence of consumers who are also ‘producers’ of health information. They argue that ‘(T)here is no doubt that growing numbers of people across the globe are using e-mail, the World Wide Web, mailing and discussion lists, news groups, MUDs [multi-user domains], IRC [Internet relay chat], and other forms of computer mediated communication (CMC) to offer and receive information, advice and support across a massive range of health and social issues’ (Burrows et al 2000, p. 121). Like Ferguson, Burrows and his co-authors find that such users are very active in contributing to the ever-growing volume of health information on the Internet. This alerts us to the possibility that health care consumers may be active in contributing to Internet discussions, newsgroups, etc. and that, therefore, as well as being recipients of information and advice from others (professional and lay) via this medium, they are also, very often, ‘producers’ of information. This is an important starting point for our research in which we view health care consumers as active rather than passive in their management of health information – that is, as ‘producers’ as well as ‘consumers’ of information, whatever the media form involved.

A related debate about the role of the patient/consumer in the management of health information has emerged from medical sociology and it is to this literature that we now turn.

The patient-provider relationship in late modernity

Much has been written in medical sociology recently about the changing nature of the patient-provider relationship in late modernity. One set of debates draws attention to the emergence of the ‘informed patient’ and the perceived decline in medical authority resulting from the wider diffusion of medical information to the lay public. For example, in the late 1980s, the ‘contractual model’ of the patient-provider relationship emerged in medical sociology, which contains an idealised notion of that relationship and of the informed patient more generally. Bury describes the model’s

assumptions: 'The doctor would provide clear information about treatment options and about the risks and benefits involved. The patient, in turn, would offer to assess the information, be willing to ask pertinent questions and accept a greater level of responsibility in accepting or refusing treatment' (Bury 1997, p. 98).

Giddens (1991), too, whilst acknowledging that such active decision-making could pose a 'dilemma' for patients who no longer had any 'overarching authority' to whom they could turn, nevertheless concurs that the overall expansion in medical knowledge in late modernity can empower patients. He illustrates this point with his now well-cited fictional account of a woman with back pain who finds information from a variety of sources until she is in a position to make 'a reasonably informed choice' (Giddens 1991, p. 141). This is one example of Giddens' 'reflexive consumer', a concept that has been very readily taken up within the social sciences and within medical sociology in particular. Its apparent link to the empowerment of patients has led some commentators to apply and interpret Giddens' concept in exclusively positive terms, often with the Internet being seen as the means by which such empowerment occurs. For example, Hardey claims that, 'the Internet forms the site of a new struggle over expertise in health that *will* transform the relationship between health professionals and their clients' (Hardey 1999, p. 820, our emphasis). In this construction, we see a conflation between information and empowerment with the Internet being the medium through which this empowerment takes place. An important goal of our own study is to research and analyse the relationship between information and empowerment, rather than simply assuming that access to information results unproblematically in such shifts in power towards patients. Furthermore, we want to identify the significance of different information media and sources for strengthening and weakening the link between information and empowerment.

The medical informatics literature contains similar deterministic assumptions to those discussed above. For example, Eysenbach (2000) highlights how, until very recently, medical informatics was concerned almost

exclusively with the needs of health care professionals. He identifies a new and growing concern with the information needs of consumers and highlights two factors driving this change. The first is the emergence of evidence-based medicine and the second is a growing awareness of the need to equalise relationships between health professionals and lay people. These trends are partly the result of an effort to cut healthcare costs by improving patients' ability to help themselves and make informed choices. Eysenbach attributes a specific role to new interactive technologies such as the Internet in this shift of emphasis towards consumers' information needs:

"The increasing availability of interactive information that is accessible to consumers, most notably through the Internet and related technologies such as digital TV and web television, coincides with the desires of most consumers to assume more responsibility for their health and the pressures of costs on health systems, the emphasis on the health of populations and on prevention, and the growing desire of health professionals to realise the potentials of patients and their families. Information technology and consumerism are synergistic forces that promote an "information age healthcare system" in which consumers can, ideally, use information technology to gain access to information and control their own health care, thereby utilising health care resources more efficiently" (Eysenbach 2000, p. 1714, our emphasis).

Eysenbach concludes his article by suggesting that computers are not always the most effective means of communicating health information (Eysenbach 2000, p. 1719) and his more recent work is concerned with the important question of the quality of health information on the Internet (Eysenbach 2002). However, the overall tone of his work continues to be very optimistic about the potential of the technology. It is here that our research seeks to enter the debate and ask: How far do the assumptions embedded in the quote above hold true and for whom? Are interactive forms of information necessarily and always superior? Which consumers are 'assuming more responsibility for their health'? How far do health care professionals welcome the more informed and responsible patient? Is

the technological determinism in the latter part of the statement borne out by experience? These are some of the questions that our research is designed to investigate.

Eysenbach (2000) discusses a specific ICT development that is designed to enhance consumer choice. These 'decision aids' are said to help clinicians integrate a patient's preferences with scientific evidence, the patient's history and local constraints. They can be used by patients with or without the physical presence of health care professionals and are seen to be potentially valuable in those situations when different treatments may lead to different risk/benefit scenarios (Eysenbach 2000, p. 1715). For example, with contraceptive choice, the decision aid would allow for patients to place values on outcomes such as unwanted pregnancy versus venous thrombosis. Such tools for use by consumers sound very interesting insofar as they recognise, and allow for, consumer preferences and values to be incorporated into the health care decision-making process. What counts as risky to some consumers will be considered less of a risk to others, depending on the wider context within which they live their lives. Our research should enable us to throw more light on the processes by which health care consumers come to assess the risks and benefits of specific pharmaceutical interventions and to understand such decision-making processes within the wider context of their everyday lives.

We are, then, concerned with consumer health information and its management and are convinced by the argument that the widespread availability of health information via new media, such as the Internet, offers great opportunities for enhancing patient empowerment and choice. However, drawing on insights from technology studies, we seek to avoid technological deterministic thinking, both in its technophobic and technophobic forms. Just because a potential for such a development exists does not mean it will occur in all circumstances and for all people at all times. The real world is much more complex and fragmented that such scenarios would lead us to believe. Our research sets out to examine what is actually taking place on the ground, in the everyday lives of real people seeking and

generating information about specific health problems and treatments. In this endeavour, we aim to keep the technology to the fore without reifying it or treating it as a determinant of patterns of social and cultural change. Our chosen research design and methodology aims to produce findings that will contribute to the debates in the field of consumer health informatics by detailing the range of information practices used by health care consumers which may or may not be currently supported by information and communications technologies.

Our study: presenting and interpreting health risks and benefits – the role of the Internet

Informed by the debates summarised above, we are currently engaged in research, which brings together technology studies and health studies with the explicit aim of developing new theoretical frameworks and methodologies for exploring the technology-society relationship in the context of health care settings. Building on our recent work on 'technology and inequality' (Wyatt et al 2000), we also attempt to explore whether and how 'Internet inequalities' apply specifically to the field of health information.

We have argued above that it is important to examine optimistic claims about the Internet and the challenge to medical expertise through detailed empirical study of both on- and offline users of health information from a variety of social, economic and cultural backgrounds. We aim to identify the factors which facilitate and/or inhibit the emergence of the 'reflexive consumer' in the health care setting by examining the processes by which patients seek health information both on- and offline, employ that information to assess health risks and benefits and to negotiate with health care professionals regarding treatment. Using this approach, our research assesses the extent to which more equal patient-provider relationships are emerging in late modernity and to what extent such patient empowerment is determined by access to, and deployment of, particular sources of on- and offline information. In this way, we situate our work within debates about online health information firmly within wider debates about health inequalities and relations

of knowledge and power in patient-provider relationships (Annandale and Hunt 2000).

Objectives of the study

The central objectives of our research are to:

- assess the ways in which patients access health information concerning two specific pharmaceutical interventions – hormone replacement therapy (HRT) and Viagra - both on- and offline;
- assess the ways in which the risks and benefits of these pharmaceutical interventions are interpreted by a range of patients, both on- and offline;
- explore the implications of information sourced both on- and offline for knowledge/power relations in patient-provider relationships and for subsequent treatment outcomes; and,
- analyse the above in the context of patterns of social inclusion/exclusion in relation to both health care and the Internet.

Methodological issues and preliminary findings

The starting point for our research is people's own experience of finding information on a particular topic, using a 'follow the user' approach. The success of our research depends on the establishment of long-term relationships with users of health information about the potentially sensitive topics of sexuality and ageing. For this reason, patient participants are being recruited at an early stage in their reflections and negotiations regarding the appropriateness of Viagra or HRT for their particular health problems and are then followed up over a period of 6-9 months or whilst such negotiations continue. Initial recruitment takes place via two main routes: General Practice and specialist clinics (Gynaecology and Erectile Dysfunction Clinics). Follow-ups are conducted by telephone, letter and/or email, as appropriate and with prior consent from participants. We are currently in this 'follow-up' phase for the HRT part of the study, having completed the first round of interviews with 32 women. For the Viagra part of the study, we are still at the recruiting stage as securing the participation of men for this part of the study had proved

extremely difficult. For this reason, examples drawn from our preliminary analyses, which we use here to illustrate the success (and limitations) of our methodological approach will, necessarily, be drawn from the HRT part of the study.

There are several advantages associated with the longitudinal design of our research. First, it is proving particularly important for overcoming the user/non-user distinction, which implies a very static model of the relationship between the social and the technical, and for capturing the dynamic processes of Internet use. For example, through our longitudinal approach, we are able to observe and monitor the processes of 'becoming' a user (Bakardjieva 2002) and are able to identify and explore a range of user identities: first-time Internet user, disillusioned user, experienced user, etc. We are also able to explore how user identities shift and change over time and in relation to context- whether use be for professional or private purposes, whether access sites are public or private, whether use is an individual or shared experience and so on. For example, one woman (Respondent 5) who had a PC with Internet access in her home described herself at the first interview as not knowing how to use it. However, she also stated her intention of taking an Internet training course for the over 50s in the coming months. In our follow-up interview, we are able to ask her to reflect on the experience of the training and examine if and how her new skills have been used in relation to health information seeking. Another participant (Respondent 8) might be described as a 'reluctant' user of the Internet for health information. Although she has been using the Internet at home, on her television via Sky, for 3-4 years, her main use is for keeping in touch with her son and granddaughter (especially to view digital photos of her granddaughter) who live at the other end of the country. Although she has consulted the Internet for health information, she goes directly to sites recommended by her son and has no real awareness of the sources of the information she is accessing. She identified no particular advantages to finding information online and complained about getting too much information and having no-one to talk to about it. Another participant (Respondent 9) is a regular Internet user but rarely uses the Web. Her main use of

the Internet is for communication as her lifestyle (living on a boat, away from family and friends) for most of the year, means that she needs to find ways of keeping in touch. She connects to the Internet via her mobile phone and uses this medium to send sections of her on-going diary to family and friends. When seeking out health information, she prefers face-to-face consultation to computer- or telephone-mediated forms of exchange. With this participant, the Internet has played a significant role in her participation in the project, with regular emails being exchanged between her and one of the researchers regarding changed health status and treatment regimes.

A second advantage of the longitudinal design is enabling us to assess the significance of changing health status for the shaping of information practices more generally. For example, we ask our women participants if, where and how they have actively sought out health information about the risks and benefits of HRT. Here, early findings suggest that many women are relatively passive concerning information about the risks associated with HRT until they experience negative side effects. It is this change in health status, often associated with increasing health problems, that then prompts them to become more active information seekers. The longitudinal design has also offered the unanticipated advantage of being able to monitor participants knowledge of, and reactions to, media coverage of new research findings regarding HRT. In mid July 2002, during our 'follow-up' phase with the HRT sample, part of a US clinical trial for hormone replacement therapy was halted prematurely as findings suggested an increased risk of breast cancer, heart attack and stroke amongst those taking a particular combined HRT treatment. We are able to take advantage of this development in our follow-up interviews with women, noting if and how they came to be aware of the research findings, whether and where they undertook any active information seeking for themselves, what information media and sources were used.

Another advantage offered by the longitudinal approach is the opportunity to observe consultations between our patient participants and their doctors or other health care

practitioners. Consent for this, in principle, is sought (and in most cases obtained) at the first interview and the long-term nature of the research relationship enables a suitable appointment to be identified and attended by a member of the research team. The consent of the appropriate health care practitioner is sought prior to the appointment. At these consultation appointments, we are able to observe the communication and exchange of information between patient and doctor. The aim is to begin to assess, for ourselves, the relationship between information and empowerment and the significance of different information media and sources for the process of becoming informed and/or empowered. We have several accounts, from interviews, of women having information about their health problems and treatments that they intended to discuss with their doctors and yet were prevented from so doing for a variety of reasons. These included lack of time, feelings that the doctor would not listen, actual rebuttal by doctors. We are keen to understand more about these attempts at information exchange in the clinical encounter and to be able to reflect on their significance for the debate about empowerment. Follow-up interviews with both patient participants and health care professionals are planned to reflect on the exchanges we have observed.

A further advantage of the longitudinal design is the opportunity it offers to see how the research process itself affects participants' practices. By drawing attention to the role of information and different information media and sources in their health decision-making processes, we necessarily influence information practices. For example, at the end of the first interview, we set up the means to facilitate follow-up: gaining further consent, agreeing times and means for further contact etc. In addition, we ask participants to keep a record of any information searching they do. When using the Internet, participants are asked to 'bookmark' or at least make note of particularly helpful or unhelpful websites. With offline searching, participants are asked to keep copies of leaflets, newspaper and magazine articles, etc., where they found information to be of interest. These notes or records then form the basis of a follow-up interview, where we ask participants to talk us through the process by which the particular

information was accessed, its significance to the participant at the time and the ways in which the text is interpreted and used by the participant in later encounters with friends, colleagues and/or health professionals.

In addition to the longitudinal design, the research has four other innovative aspects. First, the research is 'grounded' through its focus on two specific health treatments, Viagra and HRT. For reasons we have already explained, we were keen not to focus solely on Internet 'users', even if complemented by a 'non-user' group. Our next option was to focus on a health condition or treatment about which people might need or want information and look at the use of the Internet in the wider context of health information seeking amongst the relevant patient groups. Focusing on HRT and Viagra has enabled us to focus on the sensitive issues of gender, sexuality and ageing. These are all contested areas in health and therefore amenable to an analysis of the different discourses in health information texts accessed and identified by research participants. Furthermore, the potentially very sensitive issues giving rise to the need for, and the search for, information about Viagra and HRT are likely to have an impact on where, how and why particular searches were made or not made. This relates to the question of 'access', discussed again later. Of course, the focus on these two particular health treatments determines, to a large extent, the participant sample groups. The women recruited have an average age of 55, with the youngest being 39 and the oldest being 73. It is important then that we analyse our data in the context of information practices of mid-life women. Similarly, as erection problems are associated with ageing, we are not surprised to have a majority of older men in our small Viagra sample so far.

Another innovative feature of our research is our intention of using discourse analysis to examine the representations of the body, gender, sexuality, ageing, etc. in different information texts as well as the diverse meanings given to those texts by users/consumers. Assumptions about the nature of the 'patient' (i.e., passive patient versus active, empowered consumer) and expert/lay knowledge will also be analysed, with a focus on how consumers produce, resist

and/or reappropriate meanings/negotiate discourses in their assessment of the risks and benefits of Viagra and HRT. Here, we agree with Lupton about the importance of analysing,

"the ways that the discourses on the human body, medicine and health care that may be identified in such sites as mass media, medical and public health literature and policy documents are recognised, ignored, contested, translated and transformed in the context of everyday experience" (Lupton 1997, p. 108).

This brings us to the third innovative feature of our research – namely, our emphasis on presentation and interpretation of information *across different media*. As our study begins with the experiences of patients, we go beyond the Internet to examine the ways in which people construct health risks and benefits within a broad information landscape, where a range of different media and sources are employed and where individuals are actively engaged in making meaning relevant to their own circumstances. We recognise that participants' behaviour is being influenced by taking part in the study but we are able to gain insight into the very real potentials and problems associated with different information sources and media as experienced by different individuals, over time. We aim to locate this understanding in the wider context of these people's everyday lives. Our preliminary analysis of data from the first interviews with the HRT sample shows that, whilst half the sample had used the Internet at least once to access health information, very few did so regularly and GPs are still the most important source of health information for these women, with 31 out of 32 citing GPs as an important source. Family members, usually women, are the second most cited source, by 23 women. Friends, pharmacists and alternative health care practitioners were all cited by 22 women. There is certainly widespread awareness of the potential of the Internet as a means to access health information but, at the same time, the Internet is just one of many routes used by these women to access the information they need. Furthermore, our more detailed analysis of actual Internet use by these women showed a relatively low level of search skills amongst this group with several relying quite heavily on what we might call

'information intermediaries' (a family member, friends and a health librarian were all mentioned) to guide them through their search. Perhaps surprisingly, when asked about useful sites, no-one explicitly mentioned the UK National Health Service (NHS) accredited sites, such as NHS Direct Online, although one woman stated:

If there was probably an NHS site or something like that on there, that's probably the one I'd go to first, because you trust the NHS. I don't know why but you do! Because that's what they're there for (Respondent 18).

This statement is interesting for several reasons. First, despite widespread publicity about such online services by the NHS, this participant remained unaware of such services. Second, the statement would suggest that her search skills were relatively poor – given her trust in the NHS, one would expect that she had looked for the NHS sites but had failed to find them (this is being followed up in a subsequent interview). Third, the trust she displays in the NHS is, itself, fairly typical amongst our sample of mid-life women and this may have significance for their use of information sources and media other than their GPs, their main route to NHS services. Indeed, several described themselves and their relationship to their GPs in ways that suggested a 'generational effect'. For example, one described herself as part of *'the generation where you always thought the doctors were sort of gods'* (Respondent 19). Another suggested that looking up information to share with the GP would be *'like telling your granny how to suck eggs'* (Respondent 7).

The final issue we seek to address through our research is that of 'access', linked, as it so often is, to debates about social inclusion and exclusion. Social exclusion is often thought to be overcome by improving access, to information in general or to particular information media such as the Internet. But what does access really mean and how can we determine whether access has really been improved for particular individuals and groups? Our own approach to 'access' seeks to distinguish between the following elements:

- the site of access – the geographical place or location where information is accessed;

- the source of information accessed – such as the publisher or producer of the information; and,
- the media form used in accessing information – books, leaflets, TV, radio, consultation with medical professional or friends and family, Internet.

For each of these elements, different access issues arise. For example, physical access may be an issue in terms of the site of access – can an individual physically access the site (geographical distance may be a problem as may building or workstation design)? For example, preliminary analysis suggests that home access does not in and of itself confer advantage. This depends on the would-be-user's relationship to the home and the social relations in the household more generally. Thus, one woman (Respondent 2) described how she cannot access her home PC because her son dominates it and she is forced to do all her Internet searching at work. The confidential nature of the searching means that she often stays late at work and works in her office alone.

Different kinds of access issues arise when it comes to the *source* of information. Literacy and educational experience may be of primary importance here with particular difficulties associated with judging the validity and authority claims made by different information sources. When it comes to the information *media*, access issues concern the possession or acquisition of the skills, and knowledge necessary to use particular media, ranging from basic literacy through computer literacy to high level web-searching skills. Our research is throwing light on the limits to access to quality health information by paying attention to the experience of participants across all these elements. For example, very few participants seemed aware of the source of the information they were accessing, especially when the Internet was the medium used. Some were concerned about this but others deemed the Internet itself to be a source, and a trustworthy one at that. There are important policy implications arising from these types of findings which we will continue to analyse. In particular, there appears to be a real need for information literacy skills to be developed more widely so that the public are able to be aware of the

relevance of information sources, to ask critical questions about information they access and to make judgements about the validity and quality of the information accessed. In short, becoming a 'reflexive consumer' or an 'informed patient' requires a degree of social learning, a development that is as important as the informational and technological developments themselves.

Conclusion

In this paper, we have described an on-going project that seeks to understand more about the use of the Internet for accessing health information by members of the public. We first criticise the technological determinism found in many policy and academic texts on this subject, particularly those that suggest that the Internet strengthens a pre-assumed link between information and empowerment, leading to the development of a new social identity: the 'informed patient' or 'reflexive consumer'. We attempt to show how our methodology is enabling us to go beyond such deterministic frameworks to map out a more complex picture of both information handling and Internet use. We have suggested that our longitudinal design is enabling us to explore the changing practices associated with both access to, and communication of health information as new information sources and media become available to users. Our longitudinal design is also enabling us to observe change and development in user identities over time. Through this process, we should be able to identify more clearly than ever before the factors that facilitate and/or inhibit the emergence of reflexivity in particular patients/consumers and the significance of different information sources and media in this process, in order to produce a more nuanced understanding of the relationship between information, the Internet and empowerment in late modernity.

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