'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information

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Abstract   In this paper we describe and analyse results from an empirical study designed to provide insight into factors facilitating and/or inhibiting the emergence of the much-heralded 'informed patient' and its sociological equivalent, the 'reflexive patient' or 'reflexive consumer'. In particular, we seek to examine the relationship between information and empowerment in a healthcare context and assess the significance of the Internet in mediating this relationship. The paper draws on data from interviews with 32 mid-life women concerned to know about HRT for the relief of menopausal symptoms. Having analysed these women's 'information practices', we conclude that constraints on the emergence of the informed patient identity exist within both patient and practitioner communities and within the space occupied by both in the medical encounter. In particular, in this paper we identify a tension caused by the emphasis on 'information for choice' in the informed patient discourse which itself obscures the potential conflict between lay and expert/ medical knowledges in the clinical encounter.

Introduction

Recent health policy documents in the UK (Department of Health 1998 and 2001a) 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 different treatments for themselves. The now widely used notion of 'informed choice' is indicative of the greater agency and sense of empowerment said to be experienced by such patients. Such thinking exists within sociology, too, where, following Giddens' notion of the 'reflexive consumer' (Giddens 1991), there is some support for the idea that the overall expansion in medical knowledge via new media technologies such as the Internet will empower patients (see, for example, Hardey 1999 and 2001). The project upon which this paper is based started from a rather different premise. Rather than assuming that the Internet will necessarily and always empower patients, our own position was to remain alert to the important potential of the Internet without making too many prior assumptions about the extent and nature of its use and its relationship to patient empowerment. Our project investigated the ways in which individuals engaged with a range of different media and sources of health information in constructing their understandings about their health problems and treatments.

This paper begins with a brief overview of the debates about the significance of the Internet for health information in the context of debates about the informed patient and the 'partnership' model of practitioner-patient relationships. This is followed by an outline of our methodology and an introduction to our research participants. In our results section, we first report on the 'information landscapes' currently inhabited by our participants. Here, we found that whilst the Internet does now feature in the information landscapes of half of our participants, it is just one of many different sources through which they currently access health information, with more traditional sources and media continuing to be very significant. We argue that there are still a number of serious constraints on the emergence of the 'informed patient' identity in our patient group. First, a significant minority of participants are reluctant to take on the responsibility implied by the 'informed patient' discourse. Second, there is a real problem with information literacy amongst our participants which has implications for the extent to which they are able to become more 'informed' about their health, whatever the media form involved. Third, participants' accounts of their expectations and experiences of information sharing in encounters with healthcare professionals suggests that there are serious constraints operating in the medical encounter itself which further inhibit this process of empowerment through information.

The Internet, health information and patient empowerment

Information and empowerment

Quality information, appropriately targeted, is seen as central to the empowerment of patients and is part of the UK government's agenda, as evidenced by policy documents such as *Information for Health* (Department of Health

1998) and *Building the Information Core* (Department of Health 2001a). In particular, information is understood to be a necessary precursor to the development of new 'partnership' relationships between healthcare practitioners and patients that the government is seeking to promote. The field of 'consumer health information' has become so important that one expert in this field has argued we are witnessing the growth of a new 'information specialism' (Gann 1991). The dominant discourse here is said to be one of 'rights', where patients have a right to information and are 'treated as individuals, not treatment opportunities' (Gann and Needham 1992).

Concern to provide more quality information to the public to help facilitate the emergence of this more informed patient has come from many quarters but particularly from those involved in assessing quality and providing tools for measuring the quality of health information offered to the public. One such UK organisation, the Centre for Health Information Quality (1999), has argued for healthcare practitioners to work in a partnership relationship with consumers to develop information materials and promote shared clinical decision-making. Information professionals, too, are calling for public empowerment through accessible health information (Calvano 1996).

There are many practical limitations on the extent to which this new partnership model can be realised. As one *British Medical Journal* (*BMJ*) editorial argued, there are two important questions to be asked here: how far do patients want to participate and how feasible is it in days of the eight minute consultation? (*BMJ* 1999). Research supports the notion that healthcare practitioners are experiencing new pressures which they associate with the growth of consumerism in healthcare. For example, Weiss and Fitzpatrick (1997), in a report on research into GP (general practitioner/family doctor) prescribing practices, found that GPs were prescribing 'irrationally' as a response to the growing demands and expectations of patients.

There is a much more fundamental problem with the informed patient discourse and with much of the consumer health information literature, however. As Dixon-Woods (2001) has argued in her analysis of publications about the use of patient information leaflets, the dominant discourse in this literature tends to privilege bio-medical over other forms of information and knowledge, and adopts a rather one-way model of communication. Dixon-Woods' analysis therefore points to a potential constraint on the patient empowerment process, where, in cases of conflict between bio-medical and 'lay' knowledges, for example, 'information for choice' might better be replaced with the more honest 'information for compliance'.

Recent work in medical sociology suggests that there continues to be a gap between the partnership and 'negotiation' models of practitioner-patient relations and the empirical reality of everyday practice. For example, Massé *et al.* (2001), in a qualitative analysis of clinical encounters between peri-menopausal women and women doctors, argue that there are very clear limitations on the enactment of the negotiation model proposed by Katon and Kleinman (1981). They conclude that viewing the clinical encounter

as a transactional process between two rational actors is misleading and reductionist. Massé *et al.* identified two main 'strategies' used by doctors to convince women of the usefulness of hormone replacement therapy (HRT). First, they placed strong emphasis on the positive effects of HRT on the long-term quality of life and a low emphasis on the benefits of modification of lifestyle. Second, the information they provided was not 'neutral' but had itself to be considered as part of the strategy used to convince women to consider taking HRT.

Whilst Massé and colleagues tend to identify practitioner actions as particularly significant in constraining the emergence of more equitable practitioner-patient relations, Lupton (1997) has drawn attention to the fact that patients have agency here, too. Lupton argues that patients do not always act 'rationally' within the context of the medical encounter, in line with notions of the reflexive self of late modernity: 'a self who acts in a calculated manner to engage in self-improvement and who is sceptical about expert knowledges' (Lupton 1997: 373). Having analysed data from 60 in-depth interviews, she concludes that:

> in their interactions with doctors and other health care workers, lay people may pursue both the ideal type 'consumerist' and the 'passive patient' subject position simultaneously or variously, depending on the context (1997: 373).

For Lupton, 'late modernist notions of reflexivity . . . fail to recognise the complexity and changeable nature of the desires, emotions and needs that characterise the patient-doctor relationship' (1997: 373). As we demonstrate in a later section, our own empirical data support this view.

The Internet and patient empowerment

A powerful discourse around new media technologies such as the Internet and their potential for delivering and communicating health information has entered this debate about information and empowerment. Again, the UK government is putting massive resources into developing new media-based information services such as NHS Direct and NHS Direct Online[1], as well as promoting the use of these and other health information services via web kiosks, interactive television and other platforms (Nicholas, Huntington and Williams 2000, 2001). Huge efforts are also being made to encourage the use of new electronic media in the context of the patient-practitioner consultation (Department of Health 2001b, Watkins *et al.* 1999). Other countries are following similar strategies (see, for example, Health Canada 1999).

The potential of such new media in the development of new services and new practitioner-patient relationships is also widely discussed within the emerging field of 'consumer health informatics'. Ferguson (1997), in particular, has argued that, alongside technological developments, we are witnessing the emergence of a new health consumer identity which he terms the 'online

self-helpers' (Ferguson 1997). He argues that the health care practitioners who participate in these online self-help networks are also experiencing an identity shift, moving from authority figure to facilitator.

Eysenbach (2000) also identifies a new and growing concern with the information needs of patients, and 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 . . .* 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 (2000: 1714, our emphasis).

Eysenbach is very careful not to reify the Internet or see it as always the most appropriate means to deliver health information. For example, he argues that consumer health informatics is not restricted to the use of computers and telecommunications but also includes the delivery of information to patients through other media. Despite this conclusion, however, the overall tone of his work is very optimistic about the potential of the Internet, with a tendency for increased consumer control and self-reliance being attributed in some way to this particular information medium. He is also making the normative assumption, like Ferguson, that people want to operate as healthcare 'consumers', to take more responsibility for their own health through 'self-care'.

The arguments of Ferguson and Eysenbach are very persuasive and many critics of the paternalist model of practitioner-patient relations that has dominated state-provided healthcare systems for so long will have sympathy with these views. However, following the work of Lupton and others discussed earlier, we would argue that some of the assumptions underlying these arguments need further empirical testing. For example, are individuals really moving towards self-care in quite the way suggested by these arguments? Is there a direct link between information access and empowerment? And, most significantly, are Internet access and patient empowerment so inextricably linked?

Optimistic accounts of Internet use can be found in the sociological literature, too. Hardey (1999), for example, has claimed 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' (1999: 820, our emphasis). In more recent work, Hardey (2001) re-affirms that the Internet has the potential to transform doctor-patient relationships by ending

the medical monopoly over information. Drawing on a qualitative study of 10 households who do use the Internet and an online questionnaire sent to people who produced their own home pages about their illnesses, Hardey highlights the emergence of health service users as significant *providers,* as well as consumers of health information and advice.

Similar points have been made by Burrows *et al.* (2000) who explore the use of the Internet for online self-help and social support – what the authors term 'virtual community care'. Like Hardey, Burrows *et al.* draw attention to the rise of self-help groups; the privileging of lay knowledge and experience over the 'expert' knowledge of health and welfare professionals; the nature of professional-client relationships; the quality and legitimacy of advice, information and support; dis/empowerment; and social exclusion. They argue:

> Whether or not the large number of social actors who currently engage in online self-help and social support constitute themselves into virtual communities is a key area for debate. But whatever conceptualisation one favours, there 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, IRC, 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: 101).

Such detailed empirical studies of Internet use can tell us much about the significance of this medium in the everyday lives of specific user groups and about the emergent relations and communities that may accompany such use. Thus, studies of online health communities tell us much about how the Internet can support community building which is valuable and interesting in its own right. They also demonstrate well the point made by science and technology studies (STS) that users of technologies 'shape' those technologies to fit their needs and that the context of use, in particular, is central to understanding the significance of such technologies (Bijker and Law 1992, MacKenzie and Wajcman 1999, Lie and Sørensen 1996, Silverstone and Hirsch 1992). There is, however, a danger that such work will be interpreted and/or used to imply that the Internet is, in itself, empowering of patients, and it is this type of technological determinism that we wanted to avoid in our own study. In the next section, we explain how we designed our study to do this.

The study and its participants

The study focused on a group of mid-life women in the context of their decision-making regarding taking hormone replacement therapy (HRT) for the relief of menopausal symptoms. However, rather than starting with the

Internet as our focus and then trying to recruit users and non-users, we sought, instead, to identify a group of women who would have information needs and therefore be *potential* users of the Internet, and then to examine their information practices across a range of different media and sources.

Why mid-life women and HRT?
Following earlier work on technology and inequality (Wyatt *et al.* 2000), we were interested in examining some of the issues concerning the 'digital divide' and the inequalities surrounding Internet use, and we determined that the health information practices of mid-life and older women would be an appropriate focus. Whilst age and gender are factors that have been shown to affect Internet use, with older people and women being generally underrepresented amongst Internet users, women have been found to use the Internet more than men for accessing health information (Fox and Rainie 2000). We wanted to see, therefore, how far the Internet had begun to figure in the information landscapes of this particular group of women. HRT was thought to be an interesting focus here because almost all women in mid-life face some symptoms associated with the menopause, for which HRT is the most well-known conventional treatment, and were therefore likely to face a decision about its use. Thus, it would be possible to take this particular group and try to identify their information and decision-making practices regarding HRT. In particular, we aimed to map the information landscapes they inhabited and gain insight into the key information sources and media used to access health information as part of this decision-making process.

Hormone replacement therapy comprises a range of treatments that have been available since the 1960s. Such treatments are offered to women during menopause or following a full hysterectomy. At the time that most of our participants were prescribed HRT, it was the dominant conventional treatment for the relief of a range of menopausal symptoms as well as being used in the prevention of osteoporosis, heart disease and bowel cancer. Dangers identified at the time included increased risk of breast cancer and dementia. Thus, the benefits of HRT are potentially huge but so are the associated dangers and uncertainties. More importantly, these risks and benefits are highly contested and always changing[2]. In addition, there are many alternative therapies available for alleviating menopausal symptoms and preventing the onset of osteoporosis, including herbal and homeopathic remedies as well as dietary adjustments; and so the range of information and advice available to women is both enormous and potentially conflicting.

HRT receives a great deal of coverage in the popular media in the UK and it may be argued that this would limit women's need to access information via the Internet. However, precisely because of this media coverage, including, at times, some very adverse reporting concerning prescribing practices and side effects, we thought it possible that women would turn to other sources to check and validate media accounts. It was this kind of 'cross-media' practice that we were keen to identify.

Recruitment and interview focus

Thirty-two women were recruited through a GP practice (family doctor) or gynaecological clinic in a city in the south east of England. Women who were taking, had considered taking, or had recently stopped taking HRT were all considered for inclusion in the study. Interviews, each lasting between one and two hours, were conducted between November 2001 and May 2002. All interviews were audio-recorded and fully transcribed. Our sample included participants from a range of socio-economic groups, with varied educational experience and qualifications. Of the 32 women interviewed, the average age was 55, with the youngest being 39 and the oldest 73. Six of these women did not have children. Eighteen were in a relationship. Twenty-six owned their own homes, although 15 had an annual income of less than £20,000. Thirteen had some form of post-secondary education. All were white.

The interview schedule included questions about health information practices in general before going on to ask about HRT-related health information practices. In the results section below, we present a very brief overview of the health information landscapes inhabited by our participants. We then discuss constraints on the emergence of the informed patient under three headings: taking responsibility; information literacy; and the medical encounter. The final section of the paper explores the implications of the study, as a whole, for both theory and policy in this field.

Results

Information landscapes

In order the better to understand how these women located themselves within the landscape of health information, the very first question we asked them was:

> *What, if anything, do you do when you first feel something isn't quite right with your health?*

Not one woman, in reply to this question, stated that she sought information via the Internet as a first move. Results suggest that most women still rely heavily on their doctors as a first port of call for health advice and information. This was confirmed in responses to a subsequent question on other information sources used regularly, where GPs were confirmed as being *the* most important source of health information and advice for 31 of the 32 participants. Family members, usually women, were the second most often cited source, by 23 of the women. Friends, pharmacists and alternative healthcare practitioners were mentioned by 22 participants.

Again, as a result of prompting, the following information 'media' (in order of importance) were cited as having been used by participants to

access health information at some point in the past: the Internet; women's and health magazines; television; self-help books; newspapers; radio; NHS Direct; and 'other' such as leaflets from pharmacists or those that come with drugs.

Of the 32 women interviewed, 19 had access to the Internet. Of these, 16 had actually used the Internet at some point, some more regularly than others. Nearly all users (15 out of 16) had used the Internet to access health information at some time, which appeared to be one of the most popular uses of the Internet outside work, with leisure/hobbies, holiday and travel information and finances also being important. Twelve Internet users accessed the Net at home and three accessed it elsewhere (one only had work access, one preferred work access as her son dominated the home PC, and one had regular access through her daughter's friend at her daughter's friend's home). Of these 15 users, three had sought information about the health of others, but not about themselves.

Thus, results suggest that our participants access a range of different information sources and media, but the interesting questions remain. How keen are they to become more informed about their health? Does access to information necessarily lead to feelings of empowerment? Does access to the Internet enhance information-related empowerment? Below, we explore the constraints on the emergence of the 'informed patient' under three headings: taking responsibility; information literacy; and the medical encounter.

Taking responsibility
The informed patient discourse and its sociological equivalent – the 'reflexive consumer' – assumes that individuals want to take more and more responsibility for their own health and that this involves active information searching, above and beyond the traditional visit to the doctor. In order to assess how far our participants engaged in such active information searching, we therefore asked:

> *Have you ever looked something up for yourself before going to see a doctor, nurse or other health care practitioner?*

Eighteen of the 32 participants had never looked anything up for themselves before a visit to a doctor or other healthcare practitioner. Eleven of these offered no explanation for this and many seemed surprised by the question. Two kinds of explanation were offered by the seven other participants. The first suggested a reluctance to take the kind of responsibility for self-care suggested by the 'informed patient' discourse. The feeling here was that it was the doctor's job to know about such matters. This view was evidenced by comments such as: 'that's what they're trained for' (Helen); 'I would just trust a doctor' (Betty); and 'I wouldn't look in anything, I'd just go by what the doctors tell me. For myself I wouldn't look anything up. Ignorance is bliss sometimes!' (Christine). The second kind of explanation suggested a

different kind of constraint on the emergence of the 'informed patient' identity. Here, there appeared to be a fear of being seen to challenge the doctor: 'it might be like telling your granny how to suck eggs really, he might not want to know' (Annie); and 'They don't like to be told you've got X. They like to tell you that you've got X' (Caroline).

Thus, we cannot assume that everyone sees the importance of taking on more responsibility for their health, especially where that involves 'becoming informed' outside of the traditional medical encounter. This particular group of mid-life women felt either that it was a doctor's job to inform patients about their health or that there would be problems in trying to work in partnership with doctors in the way suggested by the informed patient discourse. We return to this discussion later when we discuss womens' accounts of information exchange in the medical encounter.

Information literacy

Becoming informed involves skills and competencies that relate both to the information itself and to the medium used to access that information. Amongst our participants we found women who had very few information literacy skills and others who lacked general computer literacy skills and/or web searching skills. Below, we discuss how lack of competency in these areas can inhibit the emergence of the informed patient identity. To illustrate this point, we compare more and less 'literate' participants, some of whom have access only to the more traditional media, others who have access to the Internet as well.

Annie is interesting to us because, whilst she claimed never to have looked something up before a visit to her doctor, she is clearly an avid information seeker and literate in relation to the health information she accesses through traditional media and sources. At the time of the interview, Annie did not own a computer and had never accessed the Internet herself.

Annie told us how she clipped and saved articles from both tabloid and quality newspapers and magazines, sent off for additional information and collected leaflets from her doctor's practice, from hospital waiting rooms, from the pharmacist, from health food shops and from prescriptions. She regularly bought health books, and used bookshops as a sort of reference library (looking things up in books in shops rather than going to a library). She watched things on television if they caught her eye. She bought popular health magazines every couple of months. Annie talked with friends, colleagues and family, especially her sister, about health matters. She was discerning in her use of information, explaining that when she received unsolicited 'junk mail' on health matters, she tended to ignore it, thinking they were trying to sell her something.

Annie had accessed a range of traditional information media to inform herself about the pros and cons of HRT and the use of alternative herbal remedies to treat menopausal symptoms. In addition, when very concerned about a specific treatment she had been prescribed, she had enlisted a friend

with access to the web to help her find the precise information she needed. She represents our more information-literate participants.

In contrast to Annie, Marge appeared to be far less information literate and really rather uninterested and disengaged from debates about HRT and related health matters. Marge was in her early 50s at the time of the interview. She lived alone in state-subsidised housing, had four children and two grandchildren. She had trained and worked as a nurse but was retired on health grounds. She was registered disabled. She had been taking HRT for about four years since being diagnosed with osteoporosis. She had had a hysterectomy in 1981 but was not offered HRT at the time and was uninterested in why that might have been. She was unaware of any alternative treatments for osteoporosis and had not looked for any.

All Marge's information and knowledge about HRT came either from specialists or her GP. Her first port of call when concerned about her health was always her GP, whom she trusted absolutely. She did not look up health issues in self-help books which she thought can be 'frightening'. She did not actively look for health information in traditional media but might read/watch something if she noticed it. She has had home Internet access, via Sky, for three to four years but rarely used it for health-related matters. Her main use was for accessing digital photos of her granddaughter who lived in another part of the country. She reported using the Internet for health information when she was first diagnosed with osteoporosis but could remember little about this search other than that her son-in-law, who worked 'in computers', had given her a specific web site to go to. Marge showed little awareness of the sources of information (publisher, organisation, etc.) she found on the web and expressed no interest in issues of information validity or quality, tending to trust whatever she found there, regardless of source. She identified no particular advantage to finding information online and complained about getting 'too much information' with no possibility of asking anyone any questions.

Information literacy skills are crucial when searching on the web. Awareness of sources (individual or organisation publishing the information) is one means by which one can begin to assess the validity of the information found on the web. While Marge is our least information-literate Internet user, many others were similarly uninterested in information source and validity issues, displaying low levels of information literacy.

When asked about source, some clearly felt that the Internet was itself the source, and a trustworthy one at that. Others, whilst recognising that the web, in particular, offered access to many different sources of information, still seemed relatively unaware of the importance of checking the source. For one woman, repetition was a sufficient indicator of information validity:

> . . . there are so many different sources that you can go to, so many different sites and you are able to compare them with and you find, 'oh yes it said that on the last site so that must be right' (Sharon).

Perhaps surprisingly, there was little awareness of commercial interests on the Internet with only two participants being overtly critical of commercial sites. Jane was one of them. However, Jane demonstrated a rather low level of information literacy being apparently unaware that she was, herself, making use of what others would consider commercially-biased information. As a vegetarian, she was interested in using the web to find alternatives to dairy products as a source of calcium. She explained her search strategy:

> I mean you could put in there 'dairy products' or something, or you could go the opposite way like I do . . . I could look up 'soya'.

Jane explained how this search strategy took her to the site of a well-known soya products company and that here she found out about 'the benefits of soya in your diet'. She continued:

> . . . so you go backwards actually, you find out the benefits, or not the benefits of dairy produce, by looking up something that's actually opposite. . . . I mean you could put in 'dairy products' but it might not tell you what you want to know, so you think there might be another way, so I go round the back door and go to 'soya milk' and then it tells you about that.

Clearly, Jane is unwilling to trust the information about dairy products from producers of dairy products but is, at the same time, more than happy to accept what producers of soya products say about the benefits of soya. As she says herself at one point, a particular site 'might not tell you what you want to know'. For her, this was confirmation that many humans are not able to tolerate cow's milk and that soya is a good substitute.

Perhaps surprisingly, only four participants thought medical sites more trustworthy than other sites. Two women who worked in the health sector specifically mentioned using medical sites as their preferred sources of health information but both seemed relatively lacking in confidence about their use of the web. Carol had access to the Internet both at home and at work. She spoke about looking for something on abortion with a colleague at work and looking for information about a specific health problem of her own. When asked about specific sources she accessed, she described herself as 'quite discerning' in her use but was unable to name any sites she particularly trusted. Barbara, who worked in health administration, mentioned using *Medline*, the medical database, but disliked computers and had few computer or web-related skills and always worked through an intermediary – a health librarian.

Another woman who claimed that she trusted medical sites above others also failed to name any specific sites she used, and seemed unaware of the existence of NHS online information services:

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 (Phoebe).

These Internet users contrast well with our most information-literate user – Janet, who worked in the information profession. Janet had been prescribed HRT following a hysterectomy but had reacted badly to it and had ceased taking it. She used the Internet to find out about alternatives to HRT, among other things. She described her web search strategy:

I go straight to a search engine and put in some terms and in that way then you get the mix of sources that you might want to go for. You're not just targeting medical journals for example and that's not what I want to do. I want to find more of a serendipity kind of approach really and see what comes up and then skim through it because there's usually thousands and thousands but just do it that way.

Janet understood that most people would probably be more trusting of medical sites but explained that she was more sceptical, as she was aware of medical links with the pharmaceutical industry:

I know what the conventional thinking is which is that something in the *British Medical Journal* or something is meant to be reliable – its backed up by conventional research. Then the other me says 'that's funded by pharmaceutical companies, they've got an axe to grind, they know what they want and there are other natural things that you can do' and so I don't consider either more reliable. I consider all of it.

Clearly, whilst medical sites are a signpost to trustworthiness for some, this is not a universal experience. The same sign will be 'read' or interpreted quite differently by different people. In particular, those with an interest in alternative or complementary therapies may well find conventional medical sites restrict and circumscribe their 'informed choice', just as some health-care practitioners were reported to have done in the context of the medical encounter, discussed next.

The medical encounter
When discussing the first constraint on the emergence of the informed patient – 'taking responsibility' – we found that 14 of the 32 women had, at some point, actively searched for information about their health prior to a visit to the doctor. These women were asked whether they disclosed what they already knew. As with those who did not look up information for themselves, there was, amongst the more informed participants, still a great concern about appearing to over-step the boundary between 'expert' and 'patient' here. The following examples illustrate this point well:

I wait . . . I'm old-fashioned. I go in for them to tell me what's wrong with me . . . I wouldn't teach them how to do their job, I would defer to their greater knowledge on whatever subject (Peggy).

No, because I think he's got to make his own diagnosis. It's not very helpful if I go in there and say, 'Look, I feel that I have –' I think that's very inappropriate (Carol).

You have to be very careful because they come back with – and I don't blame them at all – they say, 'don't believe what you read in the paper, you're here with me now and I'm telling you this'. I don't blame them, because it must be very hard, when you go and say, 'Oh, I read this in the paper'. It's not easy for them . . . (Pat).

The last example is particularly interesting for the way in which the patient, here, feels the need to protect the doctor from the 'informed patient' who she sees as exerting extra pressures on an already busy professional. Clearly, there is a distinction to be made between informing oneself about one's specific health conditions and treatments and being prepared, or feeling able, to disclose what one has found out to one's doctor. This point is supported by our analysis of participants' accounts of medical encounters during their HRT decision-making.

First, we return to Annie whom we have described as information literate and highly engaged and motivated to take responsibility for her health. However, when it came to her relationship with doctors she appeared not to perform the informed patient identity at all. In the interview, she mentioned, many times, her concern about the weight gain which, according to women's 'lay knowledge', is widely thought to be caused by HRT. She claimed, however, to have been 'reassured' by her doctor when told that menopausal women on HRT gain less weight, on average, than those not on HRT. Despite being very active in relation to information, Annie was very reluctant to engage with her doctor about this. She is clearly slightly intimidated by doctors and claims she would be more likely to disclose what she knows to an alternative/complementary practitioner because 'they are not on such a high level' as medical professionals. Annie shows us that it is perfectly possible to be very engaged with one's own health and informed about treatment options through traditional information media and sources but, at the same time constrained in the full development of an informed patient identity because of a reluctance to challenge the doctor.

Barbara is a good example of participants who seem to have been denied their right to make an 'informed choice' about HRT. She describes being given an implant following a hysterectomy. She told us that she understood that she had no choice – if she did not take it, her doctor told her, she would develop osteoporosis. She suffered many ill effects, including migraines, from the HRT and yet claims she was told nothing about the possible

negative side effects, only later discovering that oestrogen is linked to migraines. After trying many different HRT preparations, Barbara eventually came off it altogether, citing migraines and weight gain as the main reasons. Barbara described her experiences of trying to share information with doctors:

> I kind of researched it a little bit myself, looked it up, came up with suggestions and they don't like it or they'll say 'well, you might have heard that, you might have looked that up but that's not the case.
> The case is this'. And you can see them getting uptight, shoulders going up, arms crossing . . . I mean they might be right sometimes, I'm not saying they're wrong, they might well be right but they're not open. It's a closed door all the time, It's closed. It's black and white and you have got to be out of that [place] as quick as possible . . .
> there is no negotiation.

Other women described feeling similarly dismissed when seeking to become more actively engaged in decision-making. Liza was concerned about being prescribed HRT after only a 10-minute consultation, particularly as her sister had died of breast cancer. She took the prescription and had it filled but never took the pills. She subsequently consulted a colleague at work (a nurse) about alternative ways of taking HRT. She had been offered only pills or patches but wanted to explore nasal spray and cream options so suggested this to the doctor:

> I asked if I could have the creams and he just said, 'no' because nobody else had asked for them, so they'd never prescribed them, so they weren't sure of their efficacy.

She continued:

> I decided not to use anything . . . In the end [I] came away with a prescription which I didn't use.

In Liza's story, it appears no-one was empowered. Liza felt that she was denied her right to an 'informed choice' and her doctors failed to get the compliance they sought when prescribing HRT.

Another woman, Sharon, described how she was concerned that taking HRT might well be making her fibroid grow. She had found this information in a book she had obtained from her local library and took this knowledge to her GP, who dismissed her concerns. She never did find out if there was any relationship between HRT and fibroid growth but believes that prevarication and uncertainty on the part of her doctor resulted in an eventual hysterectomy to remove the fibroid growth. Sharon was frustrated about her attempts to engage more fully with her GP.

Despite nearly half the women in our sample being willing and able to look things up for themselves prior to visits to healthcare professionals, in no instance did it seem to be the case that disclosing what was already known about their particular health problems and their treatments was a completely straightforward process for these women. Exceptions might be the one woman who stated that she would feel confident disclosing to a complementary therapist (though not to her GP), and another who felt that 'a lot of doctors now know that some people know their bodies better than what [the doctors] do' and that things were, therefore, getting better over time. In general, however, for this particular group of mid-life women, it seems that the boundary between the expert healthcare professional and the patient is still fairly robust.

Conclusions

The research we have reported on here sought to locate the Internet in the overall information landscapes of a specific group of health service users – mid-life women – and to analyse the significance of different information media in the development of the 'informed patient' or 'reflexive consumer' identity. In the ideal types of patient and practitioner, patients take it upon themselves to become informed about their own health conditions and the treatment options available, and doctors agree to listen to patients and nego-tiate regarding treatments, taking patients' interests and values into account. We conclude that there appear to be very real constraints on the emergence of the informed patient identity for this group of patients, at least.

First, many patients do not want to take responsibility or seek out information for themselves – they are more than happy to trust their GPs and leave decisions to them. There may be many different reasons for this as Lupton (1997) has suggested but it is important that the patient perspective is acknowledged nevertheless. This finding is particularly interesting in terms of the 'rights' agenda inherent within the consumer health-information literature discussed at the start of this paper. 'Rights' carry 'responsibilities' and, whilst many commentators in the consumer health-information and consumer health-informatics fields may believe that increased consumer/patient responsibility for health is the way forward, some patients are clearly not yet convinced. The arguments of consumer health-informatics experts such as Ferguson (1997) and Eysenbach (2000), discussed earlier, might need to be revised to accommodate such findings.

A second constraint on the emergence and enactment of the informed patient identity has to do with skills and competencies in what we might call 'information literacy'. These skills involve general awareness of where to find information, information retrieval, understanding the context of the information being provided, and interpretation and communication of that information in the context of health-care decision-making. This point

becomes all the more pertinent when we come to look at Internet use. Although almost half of our participants had used the Internet for accessing health information, we found that the search strategies used were very unsystematic. In addition, we found, as did Eysenbach and Köhler (2002) in their qualitative study of health information searching on the Web, there was almost no awareness of who or what organisation was publishing the information being accessed. Indeed, for some, the information 'media' and 'source' were collapsed and the Internet was itself considered a source of health information and, for many, a good one at that.

The third constraint in the emergence of informed patients and partnership relations comes from the apparent reluctance of practitioners to take on this new role. Our analysis found plenty of examples of women who *had* informed themselves regarding their particular health condition and its treatments but who, on trying to negotiate with their GPs, had had their views and opinions quite decisively rejected or dismissed. This seems to be particularly the case where 'lay' knowledge does not coincide with expert/ medical knowledge and where a certain level of compliance with medical opinion is required. These findings reflect the arguments made by Dixon-Woods (2001) and Massé *et al.* (2001) and suggest that there are real limits to the 'information for choice' agenda, embedded within the notion of the informed patient.

What is clear is that the informed patient will not emerge naturally or easily within existing structures and relationships. Constraints exist within both practitioner and patient communities and within the space occupied by both in the medical encounter. Analysis from data collected during a later stage of this project will explore practitioner views and experiences of working with informed patients and will be reported upon in due course. More research is needed into how this encounter can be re-designed to enable a more equitable exchange of lay and expert knowledges. Further, more time and resources need to be allocated for reflection on the necessary changes that are needed in both consumer health and medical education to facilitate such fundamental shifts in the balance of power implied in the informed patient discourse.

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Notes

1 These are National Health Service initiatives. NHS Direct is a telephone-based service, NHS Direct Online is an Internet-based service, both offering health information and advice direct to patients and the public.
2 Indeed, the abandonment of a US HRT trial in July 2002, which received extensive media coverage, changed the balance of risk factors. A planned publication will report on how our participants reacted to this new information in the context of their own HRT decision-making.

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