



## Presenting and Interpreting Health Risks and Benefits: the Role of the Internet

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## RESEARCH FINDINGS

### KEY FINDINGS

Are we seeing the emergence of more 'informed patients'? How do people inform themselves about health problems and treatments generally and about the risks and benefits of HRT and Viagra, in particular? What are the main sources of information and/or advice used? How significant is the Internet for those seeking information about HRT and Viagra? How do people (patients and practitioners) assess the risks and benefits of HRT and Viagra? How do practitioners respond to patients who have sought information for themselves?

Does access to the Internet result in more informed patients?

- Patients have access to a wide variety of information sources but health care practitioners retain an authoritative position
- Informal networks of friends and colleagues and neighbours are an important source of health information for women, in particular
- The mass media (especially TV and newspapers) are another important source of health information but its reliability is often questioned by health care practitioners
- New technologies, including both the world wide web (WWW) and NHS services such as NHS Direct (telephone and online) are increasingly important but these seem to be used to supplement, rather than substitute for, more traditional sources of information
- Efficient use of the Internet is hampered by poor information literacy skills including the ability to understand the information found
- HCPs appear to have ambivalent views about 'informed patients'
- Informed patients do not always disclose what they know to doctors
- Men are less concerned with the 'risks' of Viagra than women are of the 'risks' of HRT
- Women place a good deal of trust in their GPs when deciding whether or not to take HRT, only looking for alternative sources of information and advice when something goes wrong
- Many patients experience a pressure to become more informed (including a pressure to 'get connected') and whilst this is not always welcome, it appears to shape their health information seeking practices

#### RESEARCH TEAM

Dr Flis Henwood, School of Information Management, University of Brighton  
Dr Angie Hart, Centre for Nursing and Midwifery Research, University of Brighton  
Dr Sally Wyatt, Communicatiewetenschap, Universiteit van Amsterdam  
Ms Julie Smith, School of Information Management, University of Brighton

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## Sources of Health Information

Participants drew more or less actively on a range of sources, with the family doctor as the most important source for both men and women. Family members, usually women, were the second most frequently cited source, with friends, pharmacists and alternative practitioners also mentioned. The media used include magazines, television, World Wide Web, self-help books, newspapers and other items such as leaflets from pharmacists or those provided by pharmaceutical companies with drugs. The most striking difference between the women and the men was that the women had much more diffuse social networks, including family, friends, neighbours and colleagues, which they draw upon to talk about their health whereas men talk primarily with their doctors and sexual partners. Nearly all of the men had learned about Viagra via the mass media, whereas information regarding health generally and HRT came from a wider variety of sources.

Just five out of fifteen men were connected to the Internet at home or work, with only two actually using the Net for Viagra-related information activities. Nineteen of the 32 women were connected to the Internet at home or work. Of these, only sixteen actually used it, some more regularly than others. Fifteen of these sixteen 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 of work. Twelve users accessed the Internet at home and three accessed it elsewhere. Of the fifteen who had accessed health information, three had done so only on behalf of others. 11 women had used the Internet at least once to try and access information about menopause or HRT, with very mixed results.

We found almost no interest in online communities amongst participants. The experience of women participants suggests that the menopause and associated health problems can be easily shared with one's established face-to-face network of family, friends, neighbours and colleagues, making online communication unnecessary. Given the difficulties many men experience in discussing their sexuality, one might expect that an online community might provide a safe, easy and anonymous way to do so. However, the barriers to discussing such matters seem to be very high, with very few men discussing their problems with anyone other than medical professionals and partners.

## Constraints on the Emergence of 'Informed Patients'

There are very real constraints on the emergence of 'informed patients'. 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.

A second constraint on the emergence and enactment of the informed patient identity has to do with levels of 'information literacy', which can be defined to include the following aspects, each of which must be considered separately:

- 'information seeking' - general awareness of where to find information
- 'information retrieval' - the tools and techniques for accessing information
- 'sense-making' - understanding the production context and content of the information accessed
- 'information integration' - the interpretation and situated use of information to reflect current health concerns, personal interests, values and lifestyle
- 'information communication' - the communication of information in the context of health care decision-making.

Most participants had a broad general knowledge of where to find health information, but the majority had very poor information retrieval and sense-making skills. This was particularly the case with respect to Internet use. We found that search strategies used were very unsystematic with almost no awareness of which individual or organisation was publishing the information being accessed. 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.

The third constraint on the emergence of informed patients concerns patient-practitioner relations in the health care encounter. Here, the study found reluctance on the part of some practitioners to engage in the new relationships implied. Health care practitioners responded in one of two main ways to being faced with more 'informed patients'. The first group saw such patients as over anxious and seeking inappropriate levels of control. The second group took the view that such patients should at least be understood as 'motivated' and 'wanting to get better', as this was likely to produce a more productive exchange and, as several mentioned, increased compliance. Several practitioners alluded to feeling threatened and challenged by patients who came 'armed' with information. Several also mentioned the need for additional training to deal with informed patients.

Health care practitioners had problems with patients informed via the mass media, comparing 'well-informed' and 'accurate' patients with 'media-informed' patients who were considered difficult to deal with. The mass media here were considered to offer only 'one-sided opinions' and one consultant spoke about having to spend time 'undoing the damage of the press'. There was one clear exception - a nurse counsellor who argued that she could work with whatever the patient brought in and that the answer to working with such patients was building trust through open and honest communication.

With respect to Viagra, specifically, health care practitioners' views on the role played by the media were more mixed. All were positive about the role of the mass media in giving a 'voice' to men suffering from erection problems. Viagra was said to have 'revolutionised men and sexual dysfunction' and the Viagra story in *EastEnders* was said to have been 'part of the process of releasing the stigma'. However, the media was also blamed by some for the way in which it implied a 'quick fix' for erection problems, with one practitioner who counsels men with erection problems noting that patients want treatment first, before they agree to 'work'.

All HCPs agreed that, despite the hype, they had only seen a gradual increase in patients coming in with information accessed via the Internet. Again, HCPs offered contrasting views on this with some perceiving it as a threat and others preferring to construct it as an opportunity. The kinds of problems identified by HCPs mirrored those discussed above with respect to informed patients more generally but included some additional difficulties. Several suggested that the Internet can 'feed' the anxieties of patients with hypochondria. There was the suggestion that, for those with erection and sexual problems, the web links to pornography sites might actually be 'making matters worse'. Concern was also expressed about 'odd websites' (examples included those challenging orthodox views on childhood vaccination) and 'individualist accounts' (such as individual experiences of specific illnesses which were not generally thought helpful).

Just three practitioners gave web site addresses to patients. Most appeared to have fairly low level skills in Internet use. All were self-taught and three expressed no confidence in their ability to use the web, in particular. Two consultants were still highly reliant on others (an information professional and a domestic partner) to access journal articles relevant to their research specialisms. Again, a need for training in the use of the Internet, especially in the context of a consultation, was mentioned by several HCPs.

Patient participants also spoke of the difficulty of trying to enact the informed patient identity in the consultation. There were many of examples of women who had informed themselves regarding menopause and HRT but who, upon trying to

negotiate with their GPs, had had their views and opinions quite decisively rejected or dismissed. This seemed to be particularly the case where 'lay' knowledge did not coincide with expert/medical knowledge and where a certain level of compliance with medical opinion is required. Linked to this was some patients' reluctance to disclose to HCPs information they had accessed elsewhere for fear of judgement or denial of treatments. Men had fewer problems with disclosure than women.

### Interpreting the Risks and Benefits of HRT and Viagra

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 in the medical literature at the time included increased risk of breast cancer and dementia, although most participants only recalled being told about breast cancer. Advantages identified by patients included relief from debilitating or embarrassing menopausal symptoms and prevention against osteoporosis. Side effects, such as weight gain and 'bloating', were identified as negative aspects of HRT, causing some women to stop taking it, despite the return of hot sweats and other menopausal symptoms. We conclude that the desire to conform to hegemonic femininity was a major factor in decisions both to take, and to stop taking, HRT.

Whilst the benefits of HRT are potentially huge, so are the associated dangers and uncertainties. More importantly, these risks and benefits are highly contested and always changing. However, most participants had no access to a discourse of risk that recognised the provisional nature of biomedical knowledge. Exceptions here were women who had some knowledge and experience of complementary medicine. Here, knowledge of the alternative therapies available for alleviating menopausal symptoms and preventing the onset of osteoporosis (including herbal and homeopathic remedies as well as dietary adjustments) exposed these women to an alternative to biomedical science and introduced the notion of contested knowledges, if only implicitly. Another group was generally sceptical of hormonal interventions. This position seems to be related to their being of the generation that were persuaded to take the contraceptive pill, which later proved quite controversial.

HRT received extensive coverage in the media in the UK between the first and second round of interviews, following the abandonment of clinical trials of combined HRT in both the US and UK. Whilst most women we spoke to were aware of this development, only a few sought further information and, again, most relied on their usual sources of information: their own embodied experiences and those of their friends and family, and health professionals.



Viagra has a relatively short history. It was made commercially available in 1998 and has since become Pfizer's best-selling drug. Viagra is contra-indicated with most drugs prescribed for heart problems. In addition, it can result in fever and blurred vision. Thirteen of the fifteen men had tried Viagra, and only five of these reported unequivocal and unproblematic success. Most men did not think of Viagra in terms of risk and were only interested in Viagra as a 'technical fix', and whether or not it would work for them. As a result of the extensive media coverage of Viagra since its introduction, most men felt they were quite well informed about it, at least about its existence. The Internet was used either to confirm existing knowledge, to buy cheaper Viagra, or to look for pornography as an alternative solution to erection problems. In some cases, where erectile dysfunction was associated with prostate problems or diabetes, men did look for information about those wider conditions. Men were relatively unaware of alternative forms of treatment.

### **The Internet and Patient Empowerment**

Access to and use of the Internet is not a necessary, and certainly not a sufficient condition to ensure patient empowerment through increased access to health information. The study found evidence of informed patients who used the Internet and others who did not. Information literacy skills - broadly defined to include general awareness of where to find information plus the skills to navigate and retrieve information through the appropriate media and to be able to judge that information's validity and relevance to the individual case - are all much more important than access to the Internet, per se. However, even these skills will be insufficient to guarantee empowerment where negotiation with health care professionals who are, at best, still ambivalent about the shifting relationship with patients, is required to ensure appropriate treatments and care.

## **About the Project**

The project is one of 31 ESRC/MRC-funded projects in the 'Innovative Health Technologies' Programme, a number of which are concerned with evaluating claims about the transformative potential of the new information and communication technologies increasingly being

used in health care.

This research was concerned with the claims about the transformative potential of the Internet in a health information context and therefore sought to examine the significance of the Internet in the overall information landscapes of our patient sample. For this reason, the study did not take Internet use and users as its starting point but, instead, sought to identify people with potential health information needs and followed their journeys through their particular health information landscapes. The 2 groups selected for study were women needing HRT information and men needing Viagra information.

The research involved a longitudinal study of the information practices of a group of 32 women and 15 men. The aim was to identify their information needs, the sources and media used to access health information and the significance of the Internet in their overall information landscapes. In particular, the study examined the relationship between information and empowerment and sought to identify factors facilitating and constraining the emergence of informed patients.

Women participants were recruited through a GP practice and a Gynaecology Clinic and men were recruited through Urology and Diabetes clinics and a psychosexual counselling service. All were interviewed once with half the sample being interviewed a second time 9-12 months later. Ten interviews with health care professionals (including GPs and specialists in Urology, Gynaecology, Sexual Health and Diabetes) were also undertaken. Three observations of consultations between key participants and HCPs were carried out and 13 other observations were also undertaken in Urology and Gynaecology clinics.

The analysis of data collected suggests the need for a much more sceptical response to the claims about the link between information and empowerment and, in particular, about the Internet as a tool for empowerment, in a health information context. More research is needed regarding how information literacy skills might be enhanced and how health professional-patient relations might be improved through better training and reflection on the role of information, knowledge and power in the health care encounter.

**For further information contact:**

**Professor Andrew Webster, IHT Programme Director**

**Department of Sociology, University of York, Heslington, York YO10 5DD**

**Tel: +44 1904 43 3064/4740 ♦ Fax: +44 1904 43 4702/3043 ♦ E-mail: [iht@york.ac.uk](mailto:iht@york.ac.uk)**

**Web site: <http://www.york.ac.uk/res/iht/>**