Health information on the Internet: a qualitative study of NHS Direct Online users

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Introduction

Health information has permeated the Internet. Electronic health information is becoming ubiquitous. Quite apart from the Government’s NHS Direct presence on the Internet there exist thousands of health Web sites of commercial, voluntary and individual origin. Medical support/discussion newsgroups have also flourished. For those without Web access touch-screen kiosks can be found in health centres, supermarkets and libraries, and the Internet itself is now accessible on touch-screen systems and digital television. Despite the huge economic and political investment in digital health information-provision there has been little evaluation of the investment in terms of its impact on the health consumer. The CIBER group at City University are working on a major Department of Health (DoH)-funded research project, “Digital Health” (Nicholas et al., n.d.), on the use and impact of the remote health information initiatives mentioned above. This paper reports on one study within this research programme: a qualitative examination of use of the Internet by the general public, using the somewhat novel method of an online survey that attempted to capture qualitative data from a small number of open questions. Much attention is afforded to the methodology, given its comparatively unusual nature.

Aims and objectives

The main aim of the research was to enrich data accrued from both computer transaction log analysis (see, for example, Nicholas et al., 2002a) and questionnaire surveys employing principally closed questions (Nicholas et al., 2001a, b, 2002a, b) measuring the use and impact of the Internet on the general public. The study was interested principally in the extent to which, and in what ways, the Internet was being employed with regard to people’s health. The objectives of the study were to examine:

- reasons behind people’s decisions both to look for health information and to consult the Internet for this purpose, and what drew people to the NHS Direct site in particular;
- how they use the Internet with regard to health (i.e. the number and type of...
Internet sites accessed, and for what kind of health information;  
• possible impacts on dealings with the doctor as a result of finding and using information acquired from the Internet;  
• their perceptions of information in terms of quality, authority and trustworthiness.

Methodology

An open-questioned survey method was employed for this study, posted on to the NHS Direct Web site. It was hoped that the more qualitative data accruing from open questions would, as Silverman (1999, p. 8) states in his review of qualitative research, “provide a ‘deeper’ understanding of social phenomena than would be obtained by purely quantitative data”. Often a qualitative methodology is used when little is known of the phenomenon under scrutiny (Glasser and Strauss, 1967). In the current case, however, the territory is not entirely virgin, as we have a good idea of the “information landscape” by virtue of log statistics and survey-data (Nicholas et al., 2001a, 2002b). However, qualitative research addresses not only relatively narrow questions about the use of and opinions about the particular system or service, but with the full context in which an information need arises and is met. Moore (2000, p. 121, original emphasis) claims that “quantitative data are very good at telling you what is happening, qualitative provide an insight into the deeper question of why?”

Previous research by the group, particularly work on the use and impact of the Internet (e.g. Nicholas, 1996; Nicholas et al., 1999), has confirmed assertions (Dervin 1992; Wilson, 1990) that often the perspectives of information professionals and researchers are not those of the user community. It is vital, therefore, that in researching the needs of those for whom the service – be it an information kiosk, Web site or digital TV initiative – is targeted must be free to describe their situations, needs and experiences, “in terms of their own frames of reference . . . on their own terms” (May, 1997, p. 112). The present research employed a loose, semi-structured questionnaire format. This approach allowed people “to answer more on their own terms”, but still enabled the researcher to work with a topic framework.

An important issue, with regard to the methodology, is that of the quality of responses. Work has been done on this. Kiesler and Sproull (1986) compared response patterns with a paper questionnaire and an electronic questionnaire. They found that respondents who answered the e-survey made fewer mistakes and gave richer answers to open-ended questions.

Research has also shown that online questioning results in fewer items being omitted by respondents (Kiesler and Sproull, 1986; Schaefer and Dillman, 1998; Sproull, 1986). The biggest difference between online and offline methods, however, is that electronic surveys produce richer responses to open-ended questions (Mehta and Sivadas, 1995; Bachman et al., 1996; Schaefer and Dillman, 1998). Responses to open-ended questions in online surveys tend to be longer and more revealing than those generated in standard postal, self-completion surveys (Taylor, 2000).

Finally, online research may also be effective in addressing sensitive issues. Respondents seem to be more willing to reveal information about their experiences with sensitive conditions (e.g. anxiety disorders, ovarian cancer, incontinence, erectile dysfunction) in online surveys than face-to-face. Moon (1998) found that consumers revealed a great deal of personal information when completing a computer-mediated survey. Illingworth (2001) asserts from her research on the Internet that the familiarity developed “is, at times, difficult to relinquish”. The questionnaire for the present study did not seek to obtain specifically intimate or sensitive information about respondents’ health information needs, although, of course, openness and honesty were desired, and a certain level of intimacy, if necessary, with regard to topics researched.

The questionnaire was posted on the NHS Direct site for three weeks in November 2002. It began with an introductory and explanatory paragraph, which explained the research and indicated that respondents could interpret “health” in as wide or narrow a way as they wished. Seven “open” questions followed, which addressed the objectives outlined earlier (i.e. “Why do you turn to the Internet for health information?”). Subjects’ age range, gender and occupation were also requested. Questionnaire responses were received by e-mail, via a “mailto” link. In
many cases (24 of 42) subjects were asked follow-up questions to clarify or expand on initial answers. Only seven people, however, entered into this dialogue, presumably feeling that they had said all they wished to say on the subject.

E-mail texts were “framework”-analysed (Richie and Spencer, 1994). This approach involves a systematic process of filtering and sorting material into themes, and has been used often in health/medical research (e.g. Buckland and Gorin, 2001; Leydon et al., 2000). As the questionnaire had already pre-determined seven main themes that interested the researcher, the process was relatively easy, although, of course, some respondents strayed from the question theme or did not address it.

Two researchers independently coded and sorted the data and compared their resulting “frameworks”. There was little disagreement. Indeed, the only discrepancy was with regard to the issue of displacement of sources. Reports of visiting doctors less often were described as a displacement of source by one coder and as an impact on dealings with the doctor by another. It was agreed that the coding depended on the definition of displacement, and that the researchers would honour respondents in that those who discussed this in response to the section on displacement would be cited in that section, whilst views of those who saw it in terms of dealing with the doctor would be discussed there, with appropriate cross-references.

Sample

Unlike postal or face-to-face questionnaires, respondents are not targeted with an online questionnaire posting, beyond the fact that they will be users of the particular site chosen. A total of 42 people responded to the questionnaire. This was not considered sufficient to generalise answers in terms of age, gender or occupation, although it did generate over 50 pages of qualitative word-processed data. For the record there were 25 male and 17 female respondents, the modal age groups being 30-39 (female) and 40-49 (male). Most respondents declined to reveal their profession. Those who did included four health professionals, an information professional, and two journalists.

Results

Reasons for using the Internet

A great number of reasons were given for turning to the Internet for health information. Respondents answered in terms of:

- the advantages of the Internet over other sources of information;
- the role of the Internet in their information seeking; and
- the topics they researched.

The most popular advantage of the Internet was its perceived convenience: “It’s open 24/7 and right in my own home. I don’t even need an appointment. No waiting!” Part of this convenience was the use of health information to circumvent the need to visit a GP: “people may feel less inclined to visit the doctor, if they have access to accurate health info [sic] from home”. Although this purpose was only specifically mentioned by three respondents, others referred to this in answer to a later question looking at the effect of information on respondents’ dealings with their doctors.

“Convenience” seemed to be interchangeable with “anonymity” for some respondents, in the sense that anonymity is, itself, one of the conveniences: “It is extremely convenient to use my own PC in the privacy of my home.” and “A readily available (24/7 at home) and anonymous source of information.” Apart from the linkage of the home with privacy, those who mentioned anything concerned with anonymity or confidentiality did so in somewhat general terms (such as simply stating that one could look up information privately). One person confirmed that this was for information about which he felt “unable to ask doctors”.

Surprisingly, only three respondents (in a sample that included health and information professionals, journalists and company directors) mentioned currency as a possible attraction of the Internet.

Perhaps, also surprisingly, the depth and breadth of information on the Internet were only cited in the first instance by two people. It may be that, these days, this aspect of the Internet is so well-known that it was not considered worth mentioning. However, those prompted for more details on answers such as “the Net is a good source of information” did make reference to the quantity in follow-up messages.
The roles of people using the Internet for health included those of being professional (nurses, journalists etc.), intermediaries (i.e. to research information on behalf of another) and patients. Some respondents used the Internet in more than one of these roles, indicating usage both when ill (i.e. as patients) and in good health, out of general interest. Using the Internet in terms of information seeking naturally depended on the role and context of the seeker. The following uses were elicited:

- **Professional reasons**
  - The four health professionals all seemed to use the Internet for a large amount of information. One said she used the Internet “to look at government documents, national guidelines, policy documents etc. Also to keep in touch with professional nursing organisations.” Similarly, “I used the Net for searching my local GPs, dentists, hospitals; I also use specialist Web sites for anatomical images, notes on ECG interpretations, some specific medical conditions, medical procedures, prescription-only drugs . . .” Perhaps, unsurprisingly, the health librarian respondent uses the Internet extensively for professional purposes: “I . . . use information which is useful and relevant to students and staff at the School of Nursing and Midwifery, e.g. free e-journals, academic sites, DoH, NMAP, NMC, etc . . .”

One development seems to be the signposting by health professionals to their patients of Internet resources, despite the claim in a recent British Medical Journal editorial that some doctors have gone so far as to warn their patients, “Whatever you do, don’t go on the Internet” (Ferguson, 2002). In one case this encouragement was for them to “use, in particular, NHS Direct”, for self-care and other information. Another respondent directs patients to online support groups or official sites for various conditions. In a follow-up e-mail she added that “often, people who use the Net for information would not bother to go anywhere else, and it makes our job easier if patients have some knowledge”. This represents an interesting development following the well publicised phenomenon of patients using the Internet to challenge or complement information provided by the GP (see, for example, Rumbelow, 1999). Of course, the particular sample here were Internet-using respondents, so there might be a natural propensity amongst them to champion the system.

- **Self-care**
  - Self-care was another reason for turning to the Internet, including researching symptoms and self-diagnosis. This is encouraging, as the Government hopes that information provision will reduce the number of unnecessary visits to the doctor and therefore alleviate the burden on the NHS (Wanless, 2002). Eight of the respondents mentioned looking for information on symptoms, but only four of these said this was to avoid visiting a GP or medical location:
    - I recently found I had shingles and obtained advice on self-help – not needing to visit my GP, as appointments often take several days to arrange. It saves the time of the GP and it is easier to ask questions of a PC than a busy doctor!

A health psychology student considered that: . . . many people do frequently visit their GP for minor probs such as colds, when in reality there isn’t a lot they can do to help. In these cases I suppose that people may feel less inclined to visit the doctor if they have access to accurate health info from home.

Another respondent mentioned using self-diagnosis flowcharts, as can be found on the NHS Direct site, who used sites “that will allow me to input symptoms [which] then give a list of ‘possible’ causes”.

- **To complement information from a medical professional**
  - In addition to self-help, respondents also mentioned using the Internet as a complementary information service to that of the medical professionals. A wide range of views was forthcoming; some may be considered as neutral, others either positive or negative. The “neutral” comments are exemplified by a housewife, who said that the Internet helps her:
    - . . . understand treatment options and find out where to get further information and help (and) to carry out research to enable me to get the best out of an appointment with a doctor. Before an operation or other medical procedure: to
understand what is going to happen, and how to prepare for it.

Others made the point that the GP could not give as much information as was available elsewhere or that there were time constraints on the doctor that precluded a comprehensive information exchange. One registered disabled respondent felt that by using the Internet she saved the doctor’s time: “appointments are shorter, as I am not spending long periods of time asking for information”. Another said that she had “even printed out material to ask my doctor about. And it’s given me questions to ask that I would not have thought of before.” The issue of how the Internet is helping people in their dealings with medical professionals is discussed later in this paper.

Intermediary usage
Using the Internet in the capacity of intermediary – that is, researching things for other people – was mentioned by several (eight, or nearly 20 per cent) respondents. This is a large percentage when one considers responses were “open” – there was no prompting or options from which to choose. A good example comes from a (female) company director, who cited no fewer than four members of her family, of whom one suffered from cancer, another was an alcoholic, a third required inoculation and other travel advice, and the fourth had bouts akin to epilepsy, which the Internet helped show the respondent was a misdiagnosis. At the end of her e-mail she says, perhaps understating the case: “... so I think I can say I have a lot of uses and found lots of help/ information”.

Peer support
Peer support (i.e. patient-to-patient), often touted as a great advantage of the Internet, was cited by only three of the 42 respondents (5 per cent). One mentioned the “ability to get in touch with other patients”, and another “chatting with other people with the same condition”. In a follow-up e-mail the latter mentioned specifically Addison’s Disease Self-Help Group. The third respondent was the lady with polycythaemia rubra vera. She wrote of an e-mail group for sufferers[1] “which I also found very useful on practical advice, e.g. self-help treatments for symptom relief, recommended hospitals, latest research”.

General interest browsing
Only five (12 per cent) described activities that could be coded as “general interest”, and even one of these – a journalist – used the Net in this way for professional reasons, to research for possible stories. Other “browsers” looked for information on “general healthy living”, “lifestyle”, or “information on any random thing I come across, be it news reports, or, well, wherever!” The apparent lack of interest shown in serendipity by the majority of respondents has not been reflected in other findings by the authors. A questionnaire on the site of SurgeryDoor (Nicholas et al., 2001a, b) found that 45 per cent of the 1,068 respondents sought advice about keeping fit and healthy, and another 20 per cent just came out of pure curiosity. Of course, qualitative research identifies the various qualities of an activity, and does not concern itself with the quantities involved.

Topics sought
A number of respondents named specific topics in which they were interested, which they used the Internet to research. There was no apparent pattern to these. Several people mentioned only one topic: “Alternative medicine”. One respondent “would like to know what works and what doesn’t but [it is] hard to find impartial advice”. Four other respondents mentioned the phrase “alternative medicine” and three others the word “homoeopathic”, making a total of eight respondents, or nearly 20 per cent.

A minority of people (five, or 8 per cent) said they use the Internet as a kind of directory or reference guide – to find, for example, medical location addresses, opening times, etc. One wrote, “Today my daughter wanted to find a dentist that provided NHS treatment in our area before she travels.” Some went further than this, using the Net to “establish the guidelines and parameters of NHS treatment”, or to “find out more about the consultant”. A female accountant said she:

... was looking at the NHS Direct Web site, as I want to be treated at Guy’s and St Thomas’s, which is where polycythaemia research is done in the UK. I am unsure if the NHS allows me to specify which hospital I want and thought this Web site would tell me.
The Internet in dealing with the doctor

Clearly, many of the uses cited above (seeking information in addition to that provided by doctors, attempting self-diagnosis, and exchanging peer support) may have an effect on one’s dealings with medical professionals. The questionnaire sought views on the extent to which there has been any such impact. There was some indication that the Internet had enhanced the doctor-patient encounter:

I visit the surgery less often, often discuss the alternatives with the GP, and, on occasion, arrive at an agreement with the GP that I will try [an] alternative remedy first rather than taking an allopathic drug. Sometimes the condition disappears with the alternative approach and there is no need to see the GP again.

Another said:

My GP has been positive about my use of the Internet. He freely admits my condition is very rare and he has never treated it and he has appeared interested in the information I have.

These are interesting comments, in that they reflect the Government’s vision for the future, as expressed in the Wanless report, where the aspiration is that patients will work in partnership with medical professionals.

There were many comments, on the other hand, which suggested that the Internet was used as a counter-balance to information (or lack of it) provided by the GP, and that there was some hostility or disapproval on the part of the doctors.

The most dramatic account was that from a 38-year-old accountant who has a condition named polycythæmia, who said she had: lost confidence in the hospital, as my diagnosis and treatment have differed on many counts from what appear to be the standard procedures” and “if the Internet had not been available to me, the consultant would have made life threatening omissions [sic] in my case”.

Quality and authority of information

A major issue when considering information found on the Internet is, of course, that of information quality and accuracy. Respondents were asked: “How do you look at the issue of ‘information quality’ regarding material you find on the Internet? Does it make any difference to you from where you get the information?” Of course, it needs to be stressed that the very act of asking people about quality may possibly itself prompt them into thinking about an issue about which they may not hitherto have been overly concerned. For example, only one of 20 users evaluating an Internet health information Web site mentioned quality or authenticity issues (Williams et al., 2002). The responses on this occasion, albeit prompted, show a very real concern for the issue. One user said, “quality and quantity of information are paramount.”

Another stated:

Information quality is obviously important especially in relation to health information; it could be potentially damaging physiologically and psychologically to receive incorrect information regarding specific conditions or symptoms.

Unsurprisingly, the medical professionals who answered the questionnaire had a good deal to say on this subject. One of the nurses said:

Quality is so important and sometimes one gets the impression that the search for “innovation” is prized by the DH above everything else. Some nursing sites can be misleading when innovations are mentioned, but are not evaluated, so who knows if they’re any good?

This is interesting, as it suggests that not even so-called “authoritative” sites are always correct. This is evidenced in the literature too. Coulter et al. (1999), for example, point out that even “official” information published by the NHS and other government bodies can be of dubious quality.

The free-lance health writer takes a different stance. She said:

I try to choose sites that are recommended by people I trust, whether they be professionals or friends. . . . if someone doesn’t share my philosophy or just gives me a bad feeling, I don’t really listen. It definitely matters who gives the information.

In other words, this user is imbuing “trusted others” with the authority – rather than the site producers. Amongst those in the health field, however, this view was an exception. More common was this, offered by a “health professional”:

I always look for health info from Web sites set up by known professional bodies or medical schools or colleges, or from NHS and government Web sites where info was provided by registered health-care professionals.

The “general public” also showed a great concern over the issue of quality and authority (although, as mentioned above, the extent to which this was as a result of prompting is not clear). A retired 71-year-old summed up what appeared to be a general feeling amongst this group: “obviously I would tend toward a
reputable organisation to provide ... information”. Others wrote: “I think it’s important to access sites of reputable organisations. Some health sites can be out of date, biased or misleading”; and “I would only rely on information from an accountable and authoritative source such as the NHS, company Web sites, professional or academic institutions”. In total, 12 of 33 replies (36 per cent) to this question indicated a preference for accessing information from “official”, “reputable” or “well-known” sites. One person cautioned, however, that “any information that you are unsure about should be checked with your GP/Dr and should not be the basis for important decisions”.

Of course, perceptions of quality and authority often depend on the viewpoint and beliefs of the information seeker (Nicholas, 2000). Of interest to the present writers are people who take or approve of so-called “alternative” medicine, as they may regard the NHS as not being an authoritative voice when it comes to this kind of treatment. Typical of this group was the lady who said:

Mostly I go to the Net to find alternative medicine approaches to dealing with issues of health care, especially herbal remedies. I also practise yoga, so I will often check out those sites for possible solutions to problems.

In a questionnaire survey posted on the SurgeryDoor Web site (Nicholas et al., 2001a, b) we found alternative medicine users were more likely to use information found on the Net to replace a visit to the doctor, perhaps indicating a disenchantment with orthodox remedies and perhaps even with the NHS itself. Indeed, work undertaken in evaluating health initiatives on digital interactive TV indicated that those interested in alternative medicine were less likely to trust the NHS than other groups (Nicholas et al., 2003).

There was some indicative evidence of this phenomenon, although it was not a prevalent theme, as, of course, the recruits by definition all used the NHS site. Nevertheless, one respondent claimed, “I guess I never just trust what the NHS says”, having offered her view that:

Western medicine in general is myopic in its approach to the matter of health ... there is too much of the notion that current medical practices can “heal” you and too little on the concept of responsibility for one’s own state of health ... What the NHS offers is just one part of the whole. ... I always research their diagnosis as well as their proposed remedy before using it.

Tactics for validating information included checking the organisation responsible, in one case to see if it is “transparent and not hiding anything about their credentials or the sources of the info they provide”, and in another to see “whether it is a recognisable source”. Of course, for those interested in alternative remedies, particular kinds of orthodox treatments, or in specific conditions these “recognisable sources” will be different.

Further work is required to delve into this topic at a deeper level. Regarding the present sample, one person said he asked himself:

Is it complete, factual, provable, first-hand and truthful? Is it up to date, current and from a reliable source? ... Should I equate the information [sic] gleaned in UseNet with that obtained from NHS Direct? No, but with some understanding of those sources a judgement can be made and inferences drawn.

There was an indication from some that Internet-hosted information was unregulated and emanated from a vast number of different sources: “all information on the Net is uncensored and could have been tampered with”.

Trust was an issue that came out in the replies to questions on authority and quality and, in one case, in reply to a question on sites visited. Six respondents (14 per cent) gave answers that were coded as being related to “trust”. These people were generally supportive of the NHS. One respondent, a 35-year-old housewife, said:

In terms of published information, I have a positive view of the NHS (i.e. I trust the information they publish). In other areas, such as trusting my health or that of my family to the NHS, I have a balanced view based on realistic expectations and personal experience (both good and bad).

Others mentioned trusting the NHS “to a large extent” or “on the whole”, but “also look elsewhere for the information”. This echoes a constant theme of Internet usage – that people now will look at several Internet sites (and, therefore, consult several organisations) for information. This appears to be true even when people “trust” one site, or when they go to predefined site types, such as “academic” etc. The ease of information access seems to have made Internet users connoisseurs.
Another issue was raised regarding trust. One respondent considered that the information was:

... trustworthy in the sense that the info present will be accurate on the whole

but went on to say:

... but biased in the sense that there is an economic consideration with health-care provision and the NHS is representing the DoH policies and may not promote treatments that are not available widely on the NHS.

Conclusions

This paper has reported on a study which, unusually, attempted to capture qualitative data from a questionnaire, which, accordingly, used only open questions. A total of 42 people responded to the survey, providing over 50 pages of observations, opinions, and rich accounts of practices and the motivations behind them. Respondents were forthright and open, reflecting findings from previous studies, which found that online communication yielded substantial and high quality data. Only a disinclination to engage in more than one communication exchange disappointed the researchers. It may be that too much information was sought in the initial questionnaire, and hence respondents felt they had little more to offer. Social science researchers have indicated the long time required to gradually establish rapport and trust with research subjects.

With regard to the survey results, the survey showed that the Internet is exploited, in a wide variety of ways, by information seekers acting in a number of roles. Often the same individual uses the system in different capacities – as a patient, an intermediary or a professional.

Indicative evidence is offered that some health professionals are now embracing the Internet to the extent that they direct patients to appropriate Web sites such as those of support organisations and the NHS. Lay users showed a high level of understanding of issues such as quality and authority. In some cases this manifested itself in an interesting (and healthy?) scepticism towards the NHS and its information agenda.

Overall, the survey was a success in terms of its methodology and in the amount and richness of the data accrued. As always with qualitative research, more questions are posed from the results than are answered. Follow-up work will explore further issues such as authority (and “trusted others”) and the complex relationship between patient, information and medical professional.

Note

1 http://members.aol.com/mpdsupport/index.html

References


