

In Crivelli, B. and Rubinelli, S. eds., *Televisione, stampa e internet tra medico e paziente*, Numero speciale di *Tribuna Medica Ticinese*, 21-27.

Click here for health information/advice: Interaction pathways via the NHS Direct website

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Abstract

ICT (Information Communication Technologies) such as Websites, internet are increasingly being seen as a medium of information exchange in all spheres of life. In relation to health care, the internet has the capacity to create more informed patients and can potentially transform the doctor-patient relationship, accompanied by a shift to preventive medicine, autonomy and self-care. In this overview paper, we examine the recently launched NHS Direct Website in the UK, paying particular attention to the design features of information-organisation, with implied end-users in sight. We suggest that the Website performs two primary roles: first, as a provider of information, and second, as a gatekeeper for further access to NHS services (whether this be NHS Direct or a face to face consultation). We begin with outlining the different pathways for potential users seeking either information or advice. This leads us to invoke the notions of risk and trust which seem to underlie this information/advice dichotomy. We conclude that in light of user profile, organisation of information and advice, and the limits on access to internet technology, the e-health revolution may not quite have occurred.

Introduction: new challenges for modes of healthcare delivery

The long waiting lists, the short duration of consultations, poor access to healthcare in out of hours, lower threshold of medical literacy etc. are some of reasons why the National Health Service (NHS) in the UK is committed to trying out different alternative means of healthcare delivery. NHS Direct is one such alternative, with its

Website, helplines, as are walk-in centres for providing health information and treatment for minor or chronic illnesses and injuries. This drive for greater access to and awareness of public health is also complemented by a reconfiguration of the role of the pharmacists in dispensing treatment. At first sight, all these developments can be seen as a movement away from health care delivery to ownership and empowerment on the part of the patient in an increasingly consumerist market place. It also suggests a move towards preventive medicine, whereby the public takes care of their own health needs through being informed on a regular basis. As Fraser (1997) puts it: "Access to the health knowledge base is essential to the delivery of high quality health care ... [and] should be free at the point of use" (Fraser 1997). This means that the issue of access is paramount in this information provision as a way of minimising health inequalities. It however presupposes that end users have access to telephones and internet services, while being motivated as knowledge consumers. The tension it creates between empowerment and dependency is the topic of a recently concluded research project (www.york.ac.uk/res/ihp/projects).

Although in this paper we confine our discussion to the organisation of information and advice in the NHS Direct Website, it should be recognised that use of technology in the health care setting goes far beyond this, e.g., clinical information services such as electronic transmission of lab results, enhanced diagnostic and screening procedure, peer-conferencing, technology assisted decision making. For our purposes, the interaction between consumerism and patient autonomy on the one hand, and the IT-mediated information provision on the other, constitute, in the words of Kassirer (1995), 'the next transformation in the delivery of healthcare'. What we are presented with is a multi-level communication scenario whereby patients have the possibility of interacting with their doctors, armed with access to medical databases and through participation in relevant patient support networks. This scenario creates new dialogic relations, and can potentially give rise to competing voices and interpretations. Issues of risk and trust thus come to the fore. How, for instance, should certain types of information and advice sequences in the Website be endorsed with expert voices? In order to ensure lasting trust and confidence, how does one go about monitoring the quality of information/advice being posted in the Website? Following the notion of 'clinical governance', one might consider a parallel trajectory of 'cyber governance'.

NHS Direct in context

NHS Direct¹ (henceforth NHSD) is described as a “24-hour nurse advice and health information service, providing confidential information on:

- What to do if you or your family are feeling ill;
- Particular health conditions;
- Local healthcare services, such as doctors, dentists or late night opening pharmacies.
- Self help and support organisations.”

In terms of call volume, the service is extremely successful. This is borne out by the fact that NHSD handles approximately 7.5 million calls a year (Eaton, 2002: 568) and boasts “an extraordinary 90% public approval rating” (Boseley, 2000).

NHSD can be seen as part of a broader NHS strategy of re-invention in two significant ways. Operating a round the clock telephone helpline allows continuous access to a service identifiable in some way with the NHS. As such, NHSD can be understood as part of a re-branding of the NHS in public-relational terms as well as part of a technological restructuring of the service. In relation to both of these changes, the NHS is apparently responding to (or arguably changing) the state of health care delivery in the UK. The branding of NHSD as a service maintains its links with the NHS but also stakes out a new field of intervention (cf. Ellerup Nielsen, 2002: 8). The Website under examination here is part of this new role-identity.

Interaction pathways via the NHSD Website

The NHSD Website (henceforth the Website) was re-launched in November 2001. The home page itself is well ordered, and conservatively designed in order to support

¹ . NHS Direct, which was set up in 1998 (DoH 1998), only operates in England, while Wales is served by NHS Direct Wales (though can be accessed through the same number as for England) and Scotland by NHS 24.

version 3 internet browsers (Eaton, 2002: 568). As is routinely the case, the home page presents "individual and/or global elements of the site" (Ellerup Nielsen, 2002: 17). The page consists of a welcome banner ('Welcome to NHS Direct online' under small pictures and a date stamp) at the top of the page with the phone number for NHS Direct in the prominent upper right hand corner.² Down the left side, a column (though not a frame) provides a basic directory of information more or less standard on web pages (about, FAQ, contact from link and so on). The right hand column provides a free text search facility and a variety of 'hot topics'. These borders remain constant in most pages within the site though the right hand column changes to reflect the structure of the section one is in at any point in time. This allows easy modular navigation.

The site contains three main sections, clearly indicated on the home page. The first is a 'health encyclopaedia', the second a 'self help' guide and the third a database providing access to local NHS information such as locations of GPs, pharmacies and so on. Our analytic focus will be on the first two sections: it is suffice to say that the third section provides factual local information about NHS resources through a series of drop down menus and free text boxes.

Organisation of information and advice

The ostensive purpose of this Website is to provide "...high quality health information and advice for the people of England". The Website delivers information and advice and clearly distinguishes between the two.³ The information section, the health encyclopaedia, is identified by a question-answer sequence: the question, "Want to find out more about an illness or condition?", is followed by the answer, "Our health encyclopaedia covers a wide range of health topics" with hyperlinks in both question and answer. In contrast, the advice section is headed "Not feeling well?" with "try our

² The prominence of the NHS Direct logo and banner suggests a close relationship of the Website with the call line. It is worth noting that the Website came after and is in many ways dependent on the telephone service.

³ Researchers analysing face-to-face healthcare encounters find it difficult to keep information and advice sequences separate. See, for instance, Silverman (1997) in the case of HIV/AIDS counselling, Sarangi (2000) in the case of genetic counselling, and Heritage and Sefi (1992) in the case of health visitors interacting with first-time mothers.

self-help guide" offered as a response. We will return to the significance of the permeating question and answer structure of the Website below.

Given that the Website is dependent in some way on the call service, it is appropriate that it is supported by the help-line. This is explicitly flagged in 'About' information for the Website, but it is also clear from the prominent position of NHS Direct's phone number on each page. This is also backed up by the Department of Health, with the comment that users tend to seek information rather than diagnosis (Boseley, 2000).

When one enters the information section, it is possible to navigate alphabetically, by subject or to jump across to the self-help guide. The subject index breaks the encyclopaedia down in terms of body systems, lifestyle choices (sport, alternative therapies) and psychosocial elements (advice, counselling and bereavement). Once into a particular illness or condition, information is organised along the encyclopaedic format. An introduction section provides a definition, with a number of links for other sections in the entry. These do not appear to be stable across conditions. In the entry for 'Shingles', for example, one can choose among complications, symptoms, treatment and selected links. However for 'Thrush' one chooses among diagnosis, symptoms, treatment and causes. The information given in the case of shingles is basic and propositional. The entry tells the reader that "shingles and chicken pox are caused by the herpes zoster virus". It then describes how the virus remains dormant in the system, followed by an etymological treatment of 'shingles'. This type of information would be found in any reasonably good dictionary.

The self-help guide, as the heading suggests, offers basic advice for people to use without further consulting a medical practitioner. If, as has been mooted, NHSD is increasing pressure on the finite resources of the NHS, the Website appears to be attempting to alleviate it. There are two ways to activate the self-help guide which are described in the "How to Use Guide" accessed immediately after choosing the self help guide from the home page. Then, the user can access information through the 'body key' or an index. The body key breaks down the body into four parts; head and chest, abdomen, limbs and skin. A further choice based on symptoms or cause (for example vomiting or food poisoning) is then given. At this point, the guide adopts a yes or no dialogue with a series of questions that cascade down the screen as answered. This is evidently powered by an expert system in the background. The

final result will be one of three things; self-care, call NHS Direct or dial 999. These three options are outlined in the how-to-use guide. However, because this opening section is reasonably long, one has to scroll down to see this information. Because of this, one may not be aware that three options exist. Indeed, in some random conditions we accessed, the only option that ever appeared was self-care.

The questions are extremely straightforward, to the extent that defining temperatures for fever are given when asking if this is present. For example, "Do you or they have a fever, are you or they feeling flushed, hot and sweaty (is the temperature over 38°C or 100.4°F)?" Here it can also be seen that the interface uses the second person with a disjunctive third person. The assumption is that an individual would consult this guide on their own behalf or of someone they can observe. Pictures are provided to help answer questions about symptoms. The question stream is only invoked if one accesses the self help module through the body map.

If one accesses self-help through the index, and thus from condition as opposed to symptom, a great deal of information is presented on a single screen. In the case of shingles, symptoms, causes, prevention, complications and self care are provided in a single frame. The mass of information as well as the order contrasts to that provided in the encyclopedia. Most significantly, in terms of the distinction between information and advice, the self help module provides symptoms and a picture of shingles at the start. However, it seemed to be impossible to access shingles through the Body Module.

There are some striking differences between the text given in information and advice sections. Let us consider the case of shingles and in relation to this condition two common sections from information and advice: symptoms and complications. For symptoms, these are provided first in the advice section but not in the information section. This follows along what one might call a principle of relevance. In the information entry, symptoms are listed in sentences referring to 'some people' or 'a person'. It contains more information than in the advice section. For example it notes that one can "pass on the virus" which may cause chicken pox in another person. This is not mentioned in the advice section, not even in the 'prevention' advice. The symptoms in the advice section are listed in bullet point style with reference only to shingles as 'it'. There is no patient pronoun in this specific section.

Complications in the information section are listed in bullet points. A variety of medically identifiable complications are described and then given their technical name (cf. Askehave, 2002: 279). For example, the first complication is "Persistent pain in the area of the rash, long after the infection has healed (postherpetic neuralgia)". In all, eight complications are given which range from scarring to deafness and facial paralysis. In contrast, the advice section provides a short paragraph about complications noting only that "If it spreads onto the tip of the nose it may affect the eye and you should see your doctor immediately".

Elements of trust and risk

It seems to us that using the Website as a means to health information and advice is bound up with notions of trust and risk. Accessing health information generally can be seen as a strategy to deal with risk. "The meaning of information is precisely a reduction of uncertainty" (Arrow, 1979: 307). As Giddens notes, we seek out systems of experts when we are unsure about something; "...*the nature of modern institutions is deeply bound up with the mechanisms of trust in abstract systems*, especially trust in expert systems" (1990: 83). The Website comes across as an expert system in light of how information and advice is discursively presented. It engenders trust because it is institutional. Notwithstanding recent fiascos with respect to health information and the public (notably BSE, MMR) the health service (as distinct here from the government) is still the initial port of call for most people. Given the proliferation of knowledge and information in contemporary life, particularly with respect to health, it is important that one can trust the information given. Slevin (2000:9) notes that "the internet can be understood to bring new burdens but also to offer new opportunities for dealing with risk in an active way". Following our earlier discussion, it is possible to argue that the Website encourages risk avoidance by its informed users in a climate of preventive medicine and self-care.

The difference between the advice and information sections on shingles can be understood exactly as trust and risk strategies. When someone is actually unwell with shingles, to inform them that they may suffer facial paralysis will likely result in them seeking urgent medical attention. The Website thus minimises the perception of risk

around the condition. However to withhold this information from the information section would erode trust. It is commonly found on other information sites about shingles. This connection between risk perception and trust is managed in part by withholding information in the advice section. But trust especially is effected by choice of appropriate language. Those looking for information are given technical terminology; those seeking advice are not required to deal with such medical language. These language choices seem appropriate to the immediate aims of the user. The plain language of advice is arguably calming in its transparency; the technical terminology in information is reassuring in its thoroughness.

Confidence in particular GPs may vary between individuals and practices. However the information on the Website is standard nationally. Further, the Website does not require any identifying information from the user. Unlike routine calls to NHSD⁴ and surgery consultations the computer is (or at least appears to be) utterly private (Bogard 1996: 131). Further, should one have trust in NHSD, one is likely to trust the information provided on their Website. Whether the same people or systems provide the information is not made clear. But the strength of brand bonding is such that faith in the telephone service would normally lead to faith in the Website. There is however very little research in this area to support such a view.

Participation design

According to Light and Wakeman (2001), web pages and their associated functions “anticipate activity from both the user and the site”. They see this interaction as approximating a person to person relationship, “even though they may know they are addressing software”. This is not hypothesis, but derived from analysis of talk elicited from people conducting various activities on line. Ellerup Nilsen (2002: 9) also remarks on the internet being a “pull medium which means that the user/receiver is in an active position of information seeking”. This relationship appears to have been taken into consideration in designing this Website. Further, the capabilities of the internet in terms of being able to handle sound, pictures and applications increases possibilities for interaction (Brügger, 2002: 16).

⁴ It should be noted that one is not compelled to provide personal information; however it is routinely asked for.

The use of pictures, especially for skin rashes and the like, is extremely useful in terms of diagnosis. Certainly it takes advantage of the multimedial character of the medium (Ellerup Nielsen, 2002: 11). This can be read as substituting for the co-presence of an expert. The picture allows an individual to perform as expert, comparing their own condition to that provided by the Website. The expert system substitutes for co-present expert in a different way. Instead of a doctor asking questions (or gathering information from a patient's initial narrative) the expert system embedded in the Website performs this function. As each question answered generates another appropriate question, there is something of an attempt to simulate interaction in terms of immediacy and salience. Such expert systems are said to be 'intelligent' because of this. Thus rather than providing lists of symptoms and characteristics, these are elicited in a way that requires user participation.

Indeed the use of question answer structure permeates this Website. The home page divides the Website into three sections using questions, as noted above. Rhetorical though they are, they invite at least an interior response from the user and create a simulated dialogue with the Website.

Interface with the telephone

The Website is attached to the telephone in many ways. Most fundamentally, despite the advent of broadband, many people access the internet through standard telephone lines with the aid of modems. Secondly, the Website is dependent on the helpline, although it is difficult to ascertain if people normally visit the Website prior to or following a call to NHSD. It is assumed that branding and awareness of NHSD would direct people to the associated Website. As awareness of the information on the Website grows, people may well turn to the Website for routine information gathering (either about conditions or NHS resources) rather than call NHSD. The pressures on the call line should only increase, meaning that in terms of time saved the internet is an attractive alternative. Finally, the Website is attached to the telephone for purposes of escalation of advice.

Conclusion: Websites a gateway or a gatekeeper?

In terms of an audience profile for the Website, without actual empirical evidence it is naturally impossible to determine exactly who does use the site and for what reason. There are many reasons why an individual might call NHSD having used the Website. As noted earlier, the information provided is very basic and is need of elaborating/qualifying. It is very likely that the information call handlers have access to is more sophisticated and supported by expert algorithm systems. Secondly, the Website positions itself as an intermediary, a first step, in accessing NHSD, thus adding another layer to negotiate access. As regard the design of the Website, however, there are some key indicators. Firstly, because of the close association (in terms of branding and in terms of next step action) with NHSD, someone accessing the Website has probably used or is at least aware of the telephone service. The second characteristic is linked fundamentally to technology. Just as the Website is designed to be viewed by low resolution browsers and monitors, the information and advice given is also guided and structured in a transparent way. This suggests that the user is not expected to have a great deal of knowledge either about an illness or condition or about the technology being used to access such information.

It seems reasonable to assume that the potential end-user would be one who has experience of and has reason to trust NHSD, but has little knowledge either about biomedical issues or about internet technology. This profile would suggest that access to health care will be improved by the Website. There are two hurdles, however. The first is the gate-keeping function of the Website. Let us return to the three options listed in the self-help guide. As mentioned, the first is actually self-help advice in terms of basic treatment and monitoring of the situation.⁵ The most extreme option is to call 999 for an ambulance. The final option is to call NHS Direct for further guidance. Thus while "The government denies that new technology spells the demise of the family doctor" (Boseley and Ward, 1999) there is a clear gate-keeping function implied in the self-help guide results. NHSD has proven an effective way of dealing with out of hours situations, but the implication is that one should be cleared by the service before seeking an appointment with a GP. While a company's internet site would usually encourage purchasing or some kind of further interactive action, the Website discourages (or at least monitors) it (Ellerup Nielsen, 2002: 8). However if

one considers the Website to be creating new “forms of action and interaction” (Slevin, 2002: 10) we are dealing with not so much a delay in delivery of health service but a radical transformation of it.

In terms of access, information is certainly made more widely available. Especially with the advent of public kiosk style access points for NHSD Website. However access to face to face interactional health care may even have been reduced. The information available is also non-final as any information accessed over the web is recommended as a “springboard for discussion” (Bower, 1999). Indeed, such provision of information while creating informed patients also creates demanding ones. Taken positively, this means that patients equipped with information may require interaction at a level not usually required. Their informed questions and queries may well require more face-to-face interaction time than less. How this might average out over a whole population (taking into account those individuals who did not require face to face interaction because of information provision) is a question for empirical research. Taken negatively, we may be seeing the rise of a cohort of new welfare scroungers. There remains the issue of the already well-informed middle class becoming better informed about their health status, thus widening both the information gap and the health gap.

The second hurdle is constructed by what we already know about people who seek health information on the internet. Miller (2001: 268) in his analysis of web use for health information concludes that biomedical literacy is “the strongest predictor of looking for health information on the Web” with “educational attainment” (high school or further education) as the second strongest predictor. If this is coupled with information about who has access to internet technology, we find that “the Web serves the best educated and best prepared adults in our society” (p.270). The materiality of the internet as media, at this point at least, works against access. In the UK, studies show that “27% of women and 15% of male users of the internet access health information at least once a week” (Boseley, 2000). However, this is a percentage of internet users as opposed to the general population.

In terms of improving access, the internet would not seem to be doing so at this point. It is notable that various marginalised groups – the elderly, the ethnic

⁵ For example, keep the patient warm, administer pain killers and insure fluid intake.

minorities, the lower income groups, the single parent – may still not be using the NHSD resources. However, given that individuals accessing the NHSD Website are more likely to be attracted to the site because of prior experience with the call line, in fact the Website may be opening up the internet to a group of people not usually involved in health information seeking on the Web. Further, should the provision of public access internet kiosks specifically providing access to NHS Direct (Guardian, 2000) continue, a new set of non-traditional internet users will be able to access trustworthy health information.

A final point concerns the (lack of) relationship between information and communication. In what ways does information which is not mediated on a contingent basis by an expert as is the case in the doctor-patient consultation fall short of communicating risk, reassurance, coping etc? Communication researchers working in an interactionist paradigm would probably claim that web-based information lacks a meta-frame – i.e., instructions about how to interpret what is said – which is characteristic of face-to-face encounters. So, what compensatory devices at the rhetorical, discursal and multi-modal levels can be used in the web-based design that would guarantee accurate uptake of information and advice? In other words, how can one ensure synergy between a click of the mouse and a click in terms of quality of life of individuals and society at large?

References

- Arrow, K. (1979) The Economics of Information. In M. Dertouzos and J Moses ed., *The Computer Age: A Twenty-Five Year View*. Cambridge, MA: MIT Press, 306-17.
- Askhave, I. (2002) Drug Information for Laymen: Good or Bad Medicine. In C. N. Candlin ed., *Research and Practice in Professional Discourse*. Hong Kong: City University of Hong Kong Press, 279-292.
- Bogard, W. (1996) *The Simulation of Surveillance*. New York: Cambridge University Press.
- Boseley, S. and Ward, D. (1999) Blair Launches NHS Website for Patients. *The Guardian*, 8/12/99 www.guardian.co.uk [accessed 2/9/03]

- Boseley, S. (2000) Click Here for Treatment. *The Guardian* 24/3/00
www.guardian.co.uk [accessed 2/9/03]
- Bower, H. (1999) "Open Wide and Say @h. *The Guardian* 12/1/99
www.guardian.co.uk [accessed 2/9/03]
- Brügger, N. and Bødker, H. eds. (2002) *The Internet and Society?* Århus: The Centre for Internet Research.
- Brügger, N. (2002) Does the materiality of the Internet matter?. In N. Brügger and H. Bødker eds., 13-22.
- Department of Health (1998) *The New NHS*. London: Department of Health.
- Eaton, Lynn (2002) NHS Direct Online explores partnerships with other health organisations. *British Medical Journal* 324: 568.
- Ellerup Nielsen, A. (2002) *Rhetorical Features of the Company Website*. Århus: The Centre for Internet Research.
- Fraser, V. (1997) *NHS Guidelines on Library and Information Services*. Leeds: NHS Executive.
- Giddens, A (1990) *The Consequences of Modernity*. Cambridge: Polity Press.
- Heritage, J. and Sefi, S. (1992) Dilemmas of advice: aspects of the delivery and reception of advice in interactions between health visitors and first-time mothers. In P. Drew and J. Heritage eds., *Talk at Work: Interaction in Institutional Settings*. Cambridge, Cambridge University Press, 359-417.
- Kassirer, J. P. (1995) The next transformation in the delivery of health care. *New England Journal of Medicine* 332: 52-54.
- Lemke, J. L. (1999) Discourse and Organizational Dynamics: Website communication and institutional change. *Discourse and Society* 10(1): 21-47.
- Light, A and Wakeman, I. (2001) Beyond the Interface: users' perceptions of interaction and audience on Websites. *Interacting with Computers* 13(3): 325-51. [accessed via Elsevier Direct]
- Miller, J. D. (2001) Who is using the Web for science and health information. *Science Communication* 22(3): 256-273.
- Sarangi, S. (2000) Activity types, discourse types and interactional hybridity: the case of genetic counselling. In S. Sarangi and M. Coulthard eds., *Discourse and Social Life*. London: Pearson, 1-27.
- Silverman, D. (1997) *Discourses of Counselling: HIV Counselling as Social Interaction*. London: Sage.

- Slevin, J. (2002) "The Internet and Society: central themes and issues" in N. Brügger and H. Bødker (eds.): 7-12.
- Tae Kim, Sung and Weaver, D. (2002) Communication Research about the internet: a thematic meta-analysis. *New Media and Society* 4(4): 518-38.
- The Guardian (2000) Public Access Terminals to give Health Advice Online. The Guardian 18/10/00 www.guardian.co.uk [accessed 2/9/03]
- Winseck, D. (2002) Illusions of Perfect Information and Fantasies of Control in the Information Society. *New Media and Society* 4(1): 93-122.