# Have digital resources taken a wrong turn on the health 'information journey'?

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## ABSTRACT

This paper discusses the health information needs and drivers of UK patients in terms of a health 'information journey'. This journey is identified from the experiences of both NHS Direct, who provide information services, and patients themselves. 22 in-depth interviews were conducted with patients and information providers at NHS Direct. The findings identify a health 'information journey' for the patient from 'initiating information requirements' to the 'facilitation of that information' and the need for 'contextualized information interpretation' and mediation. We also discuss how NHS Direct uses information resources to support patients' needs by specifying elements of the information journey they do and do not support, and how those needs are supported by other professionals. The study has shown that patients are often confused about how various resources fit into their journey (e.g. can doctors facilitate information retrieval, will they provide barriers to its interpretation). The findings of this paper support health digital library designers in their development of appropriate systems and support for those systems.

## Categories and Subject Descriptors

H1.2: User/machine systems (human factors); H3.7: Digital Libraries (user issues); H5.3: Group and organisation interfaces (organisational design); K4.3: organisational impacts (reengineering).

## General Terms

Human Factors; Design; Management

## Keywords

Health informatics, Patient information, Digital resources, Grounded Theory, Mediation, Information needs.

## 1. INTRODUCTION

Patients are more and more frequently using online and offline health information resources to address their health information needs. Within the UK, one important resource is NHS Direct, which provides both a telephone and web-based service to callers seeking health information. NHS Direct use digital libraries and resources both to provide evidence based support for their patient support systems and to give patients up-to-date, relevant information. Access to such resources is changing the perceived roles, relationships and expectations of patients and health professionals alike. An informed patient may evolve a more equitable partnership with their doctor or may challenge their expertise. It is therefore important to consider how these resources may or may not be fulfilling patients' needs. In this paper, we present preliminary findings of a study of both NHS Direct staff's and patients' perceptions of information needs and uses, in terms of an 'information journey'.

Within and outside the health sector, there is a long history of user-centred studies that inform information system design focussing on user needs and user-intermediary interactions [e.g. 10, 16]. Recently, emphasis has increasingly been placed on understanding information behaviour as it occurs within its natural context [8]. Social informatics has taken information technology research towards the consideration of institutional and cultural contexts [4,9]. However, the importance of users understanding information within the context of their own and others' experiences is not adequately reviewed by these approaches. We consider how electronic information resources relate to patients' changing information needs on their 'information journey', based on two studies of health information seeking.

## 2. BACKGROUND

Digital resources have the potential to positively revolutionize patients' health information interactions by increasing informed health behaviours and effective expert–patient consultations. However, although positive benefits have been reported [13], so too have frustrations [3] and some serious negative outcomes [13].

In a quest to create digital resources to appropriately support users, many researchers have explored the nature of users' information needs and information seeking. Some of this work has focussed on elaborating the inner cognitive structures and processes at the heart of information needs, such as the work of Taylor [16] and Belkin, Oddy and Brookes [2]. Other work has focussed on users' information seeking behaviours [for example, 1 & 7]. What has emerged more recently, however, is an emphasis on more holistic research that locates these issues within their broader contexts [8]. In work specifically concerned with digital libraries, Crabtree *et al* [5] identified two main factors connected to the information searching context:

1. the importance of collaboration between the librarian and the user in the searching activity, and

2. the significance of social context in digital library design.

The importance of user experience and social context in digital library design has gained prominence. Covi and Kling [4] note that there are few high-level theories to aid designers in understanding the implications these issues have for DL design and implementation. However, whilst it is important to review digital resources and information within social and organisational structures, the users' interpretation of their experiences within a personal context is nevertheless often overlooked. Patients' information requirements, in particular, are often couched within strong emotional and social drivers with a need to contextualise information within their own or others experiences. For example, in her book 'Illness as a metaphor' Susan Sontag [14] highlights how, historically, it has been important for patients to objectify some illnesses as socially 'evil' in origin, which in turn affects their behaviour and interpretation of health information.

Recent digital resource research has advanced into the experience elements of these applications [12,17,18]. The importance of interest, enthusiasm, enjoyment, entertainment and appreciation are a few of the elements highlighted by these findings. However, much of this research identifies the hedonistic aspects of these applications rather than the complex interplay of users' emotions within their personal and social experiences. Within the health domain, in particular, the critical nature of information and its associated emotional influence on patients' personal and social experiences are vital.

There is a need for research that merges findings concerning user needs with social context and personal experiences. In this paper we use constructivism as a basis for interpreting our research findings. Constructivism, which has been adopted as an interpretive framework by other researchers in user-centred information systems research [e.g; 6, 10], is founded on the idea that by reflecting on our experiences we construct our own understanding of the world we live in. Our experiences, in turn, involve continuous actions which are organised according to 'emotional meaning-making processes' centred on the self but understood as a part of social and symbolic systems [11].

## 3. RESEARCH METHOD

This paper draws together results from two studies that investigated patient information needs and the experiences of NHS Direct in supporting those needs. The studies were designed to explore the processes of health information seeking from the two different perspectives of information provider and information user. 22 in-depth interviews were conducted with NHS patients and information providers at NHS Direct. Data from the two studies were then brought together around common emerging themes.

For the information provider study, 6 NHS Direct interviews and several observational studies were conducted over a 6 month period at one of the UK call centres. A representative sample was taken from across the organizational structure (i.e. call handler, nurse advisor, nursing manager, clinical lead, information manager, health information officer). The observational studies reviewed activities and procedures within the call centre and the adjacent library. A wide variety of online and offline resources were found to be used; the main ones mentioned were: leaflets, NHS Direct online, the UK

National electronic Library of Health (NeLH), and internal NHSD resources.

For the information user study, two groups of 8 patients were interviewed. The first group were selected from a Patient Advice and Liaison Service (PALS) patient panel attached to a London hospital. The patient panel holds regular focus group meetings to feed back on various aspects of the hospital's activities including the design of patient information. The second patient group was mature students studying towards an MSc in Human Computer Interaction. The two groups were of contrasting ages with the first group ranging from 43 to 81 years with an average age of 64, and the second group ranging from 25 to 42 years with an average age of 31 years.

An in-depth analysis of respondents' perceptions was conducted using the Grounded Theory method. Grounded Theory [15] is a social-science approach to data collection and analysis that combines systematic levels of abstraction into a framework about a phenomenon which is verified and expanded throughout the study. Once the data is collected it is analysed in a standard Grounded Theory format (i.e. open, axial and selective coding and identification of process effects). Compared to other social science methodologies, Grounded Theory provides a more focused, structured approach to qualitative research. The methodology's flexibility can cope with complex data, and its continual cross-referencing and analysis of emergent themes allows for grounding of theory in the data and the uncovering of previously unknown issues.

## 4. RESULTS

One obvious, but nevertheless often overlooked, finding for information providers from the two studies is that patients' information needs are not static or on one level :

> *"They* (the information providers) *have to think back to where the patient is and the kind of information journey they go through in terms of building up their own understanding plus their coping at stages. People don't want information always they want to be able to take it and put it in a box and they build up information over time"* **[Health information manager]**

The results suggest the decomposition of a 'health information journey' into three broad categories: the initiation of an information requirement, information facilitation and contextual interpretation (Figure 1).
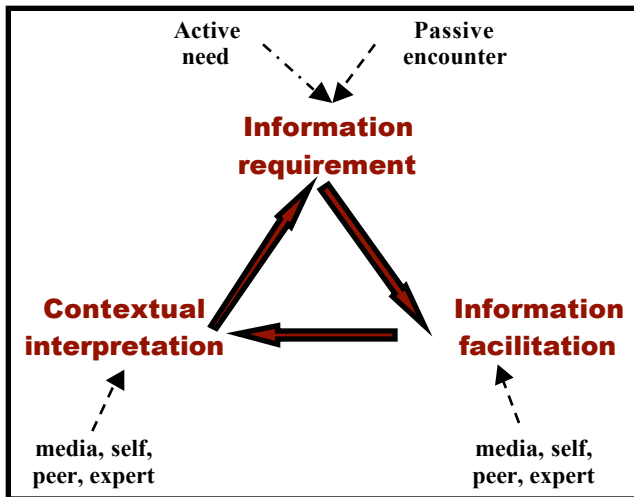
Figure 1: The health information journey

It was found that either an active information need (e.g. 'I need to know more about my complaint) or a passive encounter with information (e.g. a news report on the link between HRT and breast cancer) initiated a patient's information requirements. At this stage, though, information requirements can be vaguely formulated. Information facilitation is a process of exploring and elaborating requirements and obtaining or providing information. Contextual interpretation involves understanding the meaning of information in relation to the user's particular case. At each of these stages the information user can be supported by a third party or otherwise.

## 4.1 Initiating information requirements

The data showed that most commonly information requirements were triggered by the realization that a patient was experiencing symptoms, the receipt of a diagnosis or a treatment prescription and information encounters including health alerts. In the cases where patients reported information requirements arising from symptoms, they usually wanted to know whether a potential diagnosis might be serious enough to warrant visiting a doctor. Where symptoms and conditions appeared mild, many patients described seeking information to enable self-treatment.

Following an expert (e.g. doctor) diagnosis, or a treatment or procedure prescription, many patients described a need for general information to provide an understanding of their condition or the appropriateness of a treatment to their specific circumstances and values. More specific post diagnosis needs included ratifying the diagnosis, exploring the seriousness of a condition, exploring lifestyle implications and finding good specialists. Specific information needs about treatments mostly related to exploring side-effects.

*"Yeah, well especially for things like birth control pills you just check... so that you know you can get erm... thombosises... so you know that if you get y'know arm pain or leg pain ... you have to go to the doctor about it..."* **[Patient]**

Information requirements were also prompted by passive (i.e. unplanned) information encounters received through the media (radio, newspapers, magazines) and conversations with

peers. These usually related to alternative diagnoses or treatments.

*"... the new insulin, Clargine, which has recently come out. I read about that and talked about it before a case was made for me to go on to it"* **[Patient]**

Staff within NHS Direct expressed the view that recently the public have become more driven by peers and press to seek health information, which in turn has increased the number of NHS health alert responses to allay these fears (e.g. Hodgkinsons, Single MMR, HRT & Breast Cancer):

*"because there is a lot of information out there in the media and in the press. People hear about it and they call us because I think they're worried about it, or they think it's going to affect them. I mean we certainly have a lot more health alerts than we ever had"* **[Health information officer]**

*" if, for instance, there was a chemical spill anywhere within our area that we might get calls about then there might be something very briefly there to alert you when you come on the shift"* **[Call handler]**

Although NHS Direct did not take on an active role in initiating public information queries, the health service, via the press, initiated these queries through health alerts. It was also found that NHS Direct adopted the information and advice facilitating portion of the information journey, while the role of mediating and interpreting that information was placed in the hands of other health professionals.

Although some health information calls were re-directed internally from the nurse advisors, a growing number of people are ringing up specifically for health information. Patients' needs were also identified as increasing in complexity and the breadth of information required.:

*"30% of the calls that we do are health information"* **[Clinical lead]**

Most calls were initiated by patients themselves but a growing number of health professionals either called on behalf of the patient or recommended they should call:

*"But we do have quite a lot of health professionals contact us and we treat them the same as we do any other customer, and they ask a question and we research it and answer it."* **[Nursing Manager]**

*"So if they can't answer it then and there they tell the person to call us ..... If they don't have the time to go and start searching things."* **[Health information officer]**

## 4.2 Information facilitation

The findings identified the importance, for patients on their 'information journey', of obtaining information from a variety of sources including books, peers, telephone help lines (including NHS Direct), the Internet and health professionals. These resources contrasted with leaflets, magazines, radio and television which were seen as less suitable for active information seeking.

*"I've been in waiting rooms and just sort of picked up leaflets. They've not necessarily been conditions that I have had... but because leaflets tend to be based in... I mean they're not placed in... They're not there when you need to know about a condition"* **[Patient]**

Many NHS Direct calls entailed frequently asked questions (e.g. infectious diseases, dentist contact details) and general

health queries (health department details, NHS policy documents) that could be dealt with reasonably quickly. However, a growing number of queries are increasing in complexity and the time required to source the information, especially with a growing number of expert patients.

*"I mean I know that one of the HISPs (health information specialists) was doing something on scuba diving and she had to actually wait for the article to arrive, well that could take a couple of weeks."* **[Health information officer]**

*"Particularly with some people who come in with that sort of enquiry you know they've done the basics themselves really they might have had the condition for 20 years and know quite a lot about it but they still want to know what the latest is. They've perhaps heard about a trial and can they get on it please."* **[Health information manager]**

The success of this service has led it to be a central source for all general health queries even those that cannot be answered through their resources (e.g. benefits & social services information, schools public health information).

*"We sign-post people to the right place."* **[Health information officer]**

An element of many of these calls is the increased importance of locally relevant information.

*"we are without a doubt advanced in what people have available and on tap to them locally and you know some of that can be lost in the machinery, if you like."* **[Nursing Manager]**

From the patient perspective, not surprisingly, fewer of those interviewed in the older rather than the younger patient group used the internet for health information seeking. As well as increasing information access for callers without internet access or for those who require information out of office hours, NHS Direct also provided help to those with access in finding useful and reliable web sites:

*"I'll say that it's from a web-site and they'll say oh well actually tell me where the web-site is and I'll go and read it myself."* **[Health information officer]**

Among those patients who did search the Internet the outcomes of these searches were variable. Successes included one interviewee who twice discovered that friends' minor symptoms were indicative of something serious. Both subsequently sought medical help resulting in one being hospitalised immediately and the other prescribed drugs for a heart condition. These successes, however, were counterbalanced by reports of failures to find anything useful and the recognition that searching can be "haphazard" and the information "unreliable".

NHS Direct emphasized the importance of imparting high quality information from various different sources to increase patients' knowledge base.

*"And we have the approved web-sites ... they have been checked out by health information and the information is okay to use."* **[Call handler / Nursing advisor]**

*"And it doesn't matter if they contradict each other as long as we sent out 3 we've given them the whole range of opinion in that area."* **[Health information officer]**

The findings also showed that NHS Direct supports callers' needs for information expert skills in identifying and interpreting their needs. It was highlighted that these callers often required the skilled analysis of an information expert to identify their needs:

*"the skills health information staff need are very much communication and negotiation skills. Finding out what people want, what their real worries are and communicating information clearly back to them."* **[Health information manager]**

The importance of helping patients understand, and exploring their information needs, also arose in the patient interviews. One interviewee in particular explained how a telephone call to a back pain charity help desk provided him with a list of key questions to ask about his treatment, which he found very useful.

A clear information role was identified for NHS Direct in the *'information journey'* as that of facilitating information retrieval for later interpretation by the patients, hopefully mediated by health professionals (e.g. doctor, consultant). Reinforcing this idea, many of the patients interviewed commented on the value of resources that allow information to be taken away for consideration (e.g. leaflets, books and internet printouts).

*"Personally, I have increasingly used the internet to access information, erm... and often because... it's so useful to be selective. You find a paragraph, you find a chapter that is really spot-on... And to be able to download, print it off, and give it to the person concerned or just have it for your... just for your own reference, erm... is so good."* **[Patient]**

## 4.3 Contextual interpretation

The role of mediating information interpretation was clearly understood by those within NHS Direct. The nursing advisors highlighted the importance of contextualising their advice according to individual needs.

*"Age specific if necessary, gender specific as well. So I wouldn't be able to use the female breast problem alogorithms because he's a male and also couldn't access things like menstrual problems."* **[Call Handler / Nursing advisor]**

*"Call handler can document in there, 'caller distressed', whatever information they feel will be useful for the nurse when they pick the call up off the queue."* **[Call Handler / Nursing advisor]**

This point was echoed by many of the patients who expressed concern that generic clinical information and knowledge should be interpreted and acted upon in a way that accounted for their own particular circumstances, such as their medical history, other conditions and treatments, and wider aspects of their lives.

*"..it was just after I had come out of hospital... and I was on some drugs which they give to you, and I told him... and at the end of the interview he recommended something which was completely against what it says on my list of the things to take with these heart drugs"* **[Patient]**

*"Because I've gradually come to the opinion that they don't necessarily know what is the best for me as an individual."* **[Patient]**

Despite patients' need for information interpretation, this was seen as outside the remit of the NHS Direct information service and within the role of other health professionals (e.g doctors, support helpers). It was noted that frequently patients tried to

push NHS Direct into an interpretive role by asking for either recommendations or diagnosis.

*"they call up and say… which is the best one, you know operation, and do you think I should go and have this operation. And we can't tell them that we say 'No you have to discuss it with your consultant, what is the best one for you because with everyone it's going to be different."*

**[Health information officer]**

*"We assess the symptoms, don't diagnose and we pass them on if necessary"*

**[Call Handler / Nursing advisor]**

For some the impartial facilitating role is not what they require:

*"it is frightening to some patients as well, because sometimes you'll be doing all the things you should be about offering choice, if the evidence isn't good then you are trying to say that it isn't terribly clear and some people will come back and say I just want an answer I just want a clear answer, and so they are rejecting the range of information they want the clinician to tell them what to do really, and that is their choice as well. So information is quite a burden for people as well."*

**[Health information officer]**

Despite the apparent need for obtained information to be interpreted by health professionals, however, almost all of the patients interviewed expressed a good deal of caution about introducing information that they had obtained themselves into the context of the clinical encounter, particularly where this might be perceived as a challenge to the doctor's clinical judgment.

*"I think I've… I haven't sort of gone with a printout in my hand and been conscious that erm… that I know something, and perhaps I haven't readily let on that I know"* **[Patient]**

*"I think I go into the doctors with the attitude that I'm just the patient here not… you know, so anything I do know I just sort of block it out, and I'll just sit down and I'll describe my symptoms… Maybe its just because of this thing about authority kind of people and they're dismissive and you just accept what they say."* **[Patient]**

However, many said that the potential seriousness of an issue and their level of certainty about their information would increase the likelihood of them discussing received information with their doctor.

# 5. CONCLUSION

We have discussed how patients' information needs and the type of support they require changes as they progress along the 'information journey'. Digital resources have taken a wrong turn on this journey through a lack of clarity of their role as integrated within the wider context of the patient's 'information journey'. NHS Direct call centres explicitly identify their role as intermediaries in the facilitation of information. However, the ambiguous roles and the poor hand-over to other bodies and people means that patients' 'information journeys' are often disjointed (e.g. NHS Direct are sometimes slow to respond to press health scares that in turn initiate information needs, thus frustrating patients and call centre operatives alike; patients passed on to other professionals to support information interpretation are uncertain how to approach this without damaging important

relationships). Similarly digital resources often do not relay to patients how the information fits into the 'information journey' or where intermediary support can and should be used. This lack of integration means that, for patients and practitioners alike, the position of digital health resources within healthcare remains uncoordinated, awkward and, undoubtedly, underexploited.

Users' *information requirements* are not always active needs but are sometimes spurred on by passive encounters with information (e.g. press alerts, local health problems). The health department has more frequently used NHS Direct as a 'mouthpiece' for NHS responses to these changing health fears. This tactic of quick responses to current health issues means a continual up-dating of relevant up-to-date and often local information which is often lacking in many digital libraries. Applications that relay continually up-dated information and locally relevant information may have a higher cost but can also increase their usefulness and applicability according to user needs.

Patients were found to use a wide variety of sources to *facilitate* their access to health information. A clear distinction was made within both studies between general information or 'frequently asked questions' and the more focused specific health queries. Although some digital resources do provide these distinct functions, they are often hidden within the interface design and as such are not evident as a key information requirement which should be quickly apparent to the user.

Digital resource designers should also understand that patients are not always clear about what their information requirements are, but instead are driven by vague fears. These drivers can lead to very specific personalised questions with loaded personal attributes and emotional repercussions that are hard to answer simplistically.

For example: 'if I take drug **A** for a diagnosed *minor* problem **B** while I partake in *greatly enjoyed* activity **X** will this increase the probability of producing *minor* symptoms **Y** yet *greatly feared* effects on lifestyle **Z**'

Of clear importance to patients within both studies was the quality and trustworthiness of the information and its providers. When this information has been correctly identified it can save patients time and highlight timely interventions by health professionals. However, the research also identified the importance of providing support in *interpreting* this information according to individual needs. With an increasing use of the Internet there is a growing risk that even high quality trustworthy information can be misinterpreted, by the average lay-person, with regard to their personal experiences and needs. As an anecdote from one respondent highlighted:

*"I remember a really really distressing inquiry where somebody had lost a baby and they got information off the internet and basically they had misunderstood the medical meaning of abortion i.e. what we would call a miscarriage and they thought that somebody had aborted their baby and it was just really really distressing and it was just how a misunderstanding of the medical terminology can lead to enormous distress. So the Internet is brilliant but it is also worrying."* **[Health information manager]**

Ultimately, the findings revealed that, for various reasons, there is a growing need for patients to access a wide variety of high quality health information outside the doctor / patient

consultation. However, the social and personal contextualization and flexible interpretation of this information needs to be increased so as to adequately support patients. Digital health resource providers are on the verge of realising their huge potential or dropping into the depths of damaging possibilities, and the burden of this responsibility must not be taken lightly.

# 6. ACKNOWLEDGMENTS

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