

## 'I need her to be a doctor':

patients' experiences of presenting health information from the internet in GP consultations

### Abstract

#### Background

Patients are increasingly using the internet for health-related information and may bring this to a GP consultation. There is scant information about why patients do this and what they expect from their GP.

#### Aim

The aim was to explore patients' motivation in presenting information, their perception of the GP's response and what they wanted from their doctor.

#### Design and setting

Qualitative study based in North London involving patients with experience of bringing health information from the internet to their GP.

#### Method

Semi-structured face-to-face and telephone interviews using a critical incident technique, recorded, transcribed verbatim, and subjected to thematic analysis by a multidisciplinary team of researchers.

#### Results

Twenty-six interviews were completed. Participants reported using the internet to become better informed about their health and hence make best use of the limited time available with the GP and to enable the GP to take their problem more seriously. Patients expected their GP to acknowledge the information; discuss, explain, or contextualise it; and offer a professional opinion. Patients tended to prioritise the GP opinion over the internet information. However, if the GP appeared disinterested, dismissive or patronising patients reported damage to the doctor-patient relationship, occasionally to the extent of seeking a second opinion or changing their doctor.

#### Conclusion

This is the first in-depth qualitative study to explore why patients present internet information to their GP within the consultation and what they want when they do this. This information should help GPs respond appropriately in such circumstances.

#### Keywords

family practice; internet; patient participation; physician-patient relations; qualitative research.

### INTRODUCTION

The global use of the internet has expanded dramatically in the last 10 years<sup>1</sup> and it is estimated that 70% of UK households have internet access,<sup>2</sup> with large numbers of users searching for health-related information.<sup>2-4</sup> In the UK it is government policy to promote use of the internet by patients for information about health and health care,<sup>5</sup> with investment in websites for patients such as NHS Choices ([www.nhs.uk](http://www.nhs.uk)). Internationally, the proportion of patients who seek health information online and subsequently introduce the information into the consultation appears to be growing,<sup>4,6,7</sup> with most clinicians having experience of this.<sup>8-12</sup> However, the data on what happens when a patient brings such information to a doctor remain sparse.<sup>13</sup>

Several authors have suggested that use of health information from the internet changes the dynamic within the consultation and mirrors a possible shift in the patients' role from a passive receiver to an active participant in the decision-making process with regard to health care.<sup>14-17</sup> There are reports that this shift in access to information has led some doctors to feel devalued, anxious or challenged,<sup>8,17-19</sup> although others report seeing this as an opportunity for a more informed and productive consultation.<sup>18,20</sup> Concerns have been expressed that the internet threatens the doctor-patient relationship<sup>21,22</sup> and that the quality of information found varies widely.<sup>23,24</sup> Data from the US suggest that

health information on the internet can lead to unnecessary, or even harmful, treatments or investigations.<sup>8</sup>

Hence it is important to ascertain why patients take health information from the internet to a consultation with their doctor, what they want from their doctor when they do this, what their actual experiences are, and how this affected the doctor-patient relationship. This study addresses these questions.

### METHOD

#### Design

A qualitative interview study of patients who reported presenting internet information within a consultation with their GP.

#### Setting

People were invited to take part via posters placed in north London GP waiting rooms, in libraries, and community centres. They were also recruited via email newsletters and health-related websites, with the aim of including people from across the country. Interviews were conducted either in person in north London or by telephone.

#### Participants

Interviews were conducted with people who reported presenting health-related information from the internet to their GP. Those who were <18 years or who were unable to give informed consent were excluded from the study. The aim was to recruit a sample with maximum

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### How this fits in

Internet use for health information is increasing. There is anxiety about the impact this may have on consultations, but to date there is little understanding of patients' expectations and experiences when bringing such information to a consultation. This study investigates why patients take internet information to their GP and their experiences in doing so. These data can help doctors to understand the motivation of patients who bring health related internet information to a consultation and to respond constructively in order to strengthen the therapeutic relationship.

diversity in terms of age, sex, ethnicity, educational status, years spent in the UK, and self-defined health status. To do this demographic information were obtained from all volunteers and used to select participants for interview.

### Data collection

Semi-structured interviews were carried out from May to July 2009 using a critical incident technique.<sup>25,26</sup> The majority of interviews were conducted by one author who was introduced as a 'researcher', with two of the interviews conducted by another author who was introduced as a GP. The participant was asked to focus on a specific occasion in which they had brought internet information to a GP consultation, their motivations for doing so, the ensuing perceived response, and how this could have been improved. If this had been positive, they were then asked to focus on a previous negative response and vice versa.

Both face-to-face and telephone interviews were audiotaped and transcribed verbatim. Field notes were taken by the interviewer to ensure that non-verbal cues were documented. All interviews were anonymised with participants allocated a participant identification number, and checked for accuracy by the first author. Recruitment and interviews were continued to saturation point, that is, the point at which no new themes were emerging. The interviews lasted for between 45 and 90 minutes. Participants were given a token of gratitude (£25 plus travel expenses) for taking part in the study.

### Data analysis

Data analysis was performed by a multidisciplinary group consisting of an academic GP, a service-based GP, a medical sociologist (all experienced

qualitative researchers) and an academic foundation year 2 doctor with training in qualitative research methods. Interviews were completed in batches of two to three and then discussed by all members of the team with feedback after each interview. Data quality and richness from interviews undertaken face-to-face were compared with those undertaken on the telephone early on in the analysis, and as both types of interviews yielded data of similar quality and richness, all interviews were treated as a single data set. An inductive approach was used, whereby themes emerged from the data. Emergent themes were identified and coded following discussion within the group. Analysis was conducted concurrently with data collection to allow for emergent themes to be tested in later interviews. The software package NVivo 7 was used to organise the data. For clarity of understanding, occasionally some data have been omitted and are identified by [...]. Quotes are identified by participant identification number, along with the age and sex of the participant.

### RESULTS

A total of 26 participants were interviewed and saturation was achieved. Sixteen participants were female, 19 were white, 20 had lived in the UK for >10 years and 18 had been educated to degree level or higher. Eighteen reported a long-term illness such as diabetes, arthritis, heart disease, or depression (Table 1). Fourteen interviews were conducted face to face and 12 over the telephone. Most of the participants who were interviewed face to face lived or worked in London, while those interviewed by telephone represented a wide geographical spread. Data have been organised according to four main themes:

- reasons for using the internet;
- reasons for discussing internet information with their doctor;
- anxieties about bringing information to their doctor; and
- experiences of bringing information to their doctor.

### Reasons for using the internet

The overarching rationale for using health information from the internet was to make the best use of the consultation. Participants reported using the internet for health information as it was accessible and easy to find relevant information quickly. Many participants used the internet to avoid 'bothering' the doctor or to self-

**Table 1. Demographic characteristics of interviewees**

	Female (n= 16)	Male (n= 10)
Age, years		
18–30	4	3
30–65	10	6
>65	2	1
Ethnicity		
White	13	6
Non-white	3	4
Years in UK		
>10	13	7
<10	3	3
Education		
GCSEs/A-levels/equivalent	7	1
Degree or higher	9	9
Health status		
Chronic illness	12	6
No chronic illness	4	4
Type of interview		
Face to face	7	7
Telephone	9	3

triage to decide whether a GP consultation was necessary, and if so, how urgently. Participants felt that doctors' time was limited and did not want to be seen as attending with trivial complaints.

*'If there's something wrong with me, I will Google® it, to see whether I actually need to bother her or not.'* (P24, 32 years old, female)

Others felt that they were able to extract more from information on the internet than was possible within the time constraints of a consultation or believed that information from the internet would be more up to date than that obtained from their GP.

#### **Reasons for discussing internet information with their doctor**

There were a number of motivating factors for patients to discuss internet information with their GP. The principal reason was to 'make the most' of the consultation by enhancing and facilitating the communication with the GP. As this participant put it:

*'You're trying to communicate something to this person and you want the communication to be as effective as possible, so if you can show, if you can demonstrate that you understand something then that's going to move the whole process.'* (P3, 29 years old, male)

Many felt that the information would show that they had invested time, thought, and energy into the consultation and therefore both they and their problem should be taken seriously. Internet knowledge was used to lend credibility and gravity to a presenting problem by showing the GP that the problem mattered to the individual:

*'I feel that, that, there was never a time that she didn't take me seriously in any consultations, but I really do feel that the internet [...] made that go so much easier. It rendered a credulity[sic] to what I had to say ...'* (P23, 33 years old, female)

Some participants felt that demonstrating their knowledge and prior research indicated a willingness to take responsibility for their health and would lead to greater equality between themselves and their GP:

*'Because the fact that I actually go and research things on the internet, indicates to my GP that I'm actually serious about my health and I have an interest in it myself and*

*I'm willing to take a bit more responsibility rather than just going in like a child, listening and being told what to do. I think it means that she's more willing to treat me as an adult.'* (P24, 32 years old, female)

It was suggested that information from the internet enabled them to ask 'intelligent' questions signaling both an ability and desire to engage in discussion and self-care:

*'I guess I like to be knowledgeable and let the doctor know that you know I know more than perhaps the layperson [...] you only have you know, so much time with the GP so you want to ask good questions and I wouldn't just go in and then to feel as if the doctor just sort of talks down to me who thinks I don't know anything and you know just tell me something to do so then, because then I will ask a question back.'* (P25, 32 years old, male)

Most participants hoped for some discussion regarding the internet information, in particular participants wanted reassurance, clarification, further information or for the doctor's opinion, with this discussion acting as a mechanism enabling patients to feel they had been taken seriously. Occasionally patients hoped to be directed to other sources of internet information. Importantly, most participants wanted their doctor's professional opinion about whether the information applied to them; valuing and trusting their GP's opinion over the internet source as long as there was adequate discussion:

*'I need someone who's not me, who's not involved, who doesn't have anything at stake in it, I need the person who sees lots of people, who sees bigger pictures and broader trends and isn't caught up in my individual symptoms [...] I mean I need her to be a doctor.'* (P2, 34 years old, female)

Participants discussed using the internet to access appropriate management and treatment information and to find out about novel therapies, with the aim of making the doctor's role easier and the consultation more productive. Patients recognised that their doctor may not have all of the answers or up-to-date information on all medical conditions partly due to their role as a generalist, and partly due to time constraints. However, they wanted to know what their doctor thought and trusted their opinion:

*'I wanted his opinion on it. I thought he*

*may not have realised that this research had been published and this information was available now but if I brought it to his attention we could discuss it and he would have, of course, a much ... Once he had read the information, he would have a much better medical background to understand the significances of it than I would because I'm just a layperson.* (P9, 59 years old, male)

#### **Anxieties about bringing information to their doctor**

Some participants, in trying to manage their relationship with their doctor, struggled with the perceived double bind placed on them of being a patient who is actively involved in their own care while allowing the doctor to act as an authoritative figure. There was an anxiety that gathering internet information may make the doctor feel undermined or challenged, hence participants reported being careful about how they presented information:

*'You have to appease them, to humour them to make them feel they've told you what you've got wrong with you, when you already know.'* (P11, 73 years old, female)

*'I didn't just waltz in there blindly and thrust them at him because I wanted a cooperative approach to it rather than alienating him. And although I didn't think he was the sort of person, necessarily, that would not be open-minded, because I had read that doctors were fed up of patients coming in with this information and demanding that they answer it, I wanted to start it off in the right way[...] I think that sort of sensitivity to their professional status is useful, not because doctors any longer I think necessarily are seen as gods but because they're human beings, that's all.'* (P9, 59 years old, male)

#### **Experiences of bringing information to their doctor**

Patients reported a wide range of responses by the GPs to health information from the internet. The majority of participants attended without a pre-determined desired outcome and the outcome of a consultation was dependent on whether the GP engaged with the information and was seen to take it seriously. Positive experiences involved the doctor listening, acknowledging their concerns and the internet information, offering further discussion, and providing a professional opinion and support. Patients were tuned in to their doctor's body language in response to mentioning internet information and described many non-verbal cues from an early point within

the consultation such as leaning forwards, smiling, nodding and eye contact:

*'She smiled at me, she sort of sat there kind of just listening to everything, everything about her body language was just, you know, she was leaning forward, everything about it was just like really encouraging, really like, I'm here for you, I understand, I do recognise it, but don't worry, don't worry and she was able to tell me about her experiences as well.'* (P7, mid 20s, female)

By contrast, closed or dismissive body language was perceived negatively:

*'As soon as I said I looked it up on the internet, he sort of leaned back, and sort of, [sigh] his shoulder dropped, and he, I didn't feel that he was paying as much attention to me any more.'* (P21, 30 years old, female)

Leading on from this, many participants also hoped for some acknowledgement of their efforts to identify relevant information and engage in self-care. Ideally, participants would have liked the doctor to appreciate their efforts to help, rather than implicitly criticising them for being antagonistic or challenging:

*'Well I suppose it would be nice if they, perhaps encourage me or perhaps even compliment me for making the effort to do so.'* (P25, 32 years, male)

Negative experiences were reported when the doctor disregarded the information, were unwilling to admit their lack of knowledge, or when participants believed the doctor had felt threatened or undermined and had adopted a patriarchal, 'doctor knows best' response:

*'I would have much preferred an answer like, well, I don't really know about it, or I haven't read the literature about it, or I don't ... Do you know what I mean? Rather than just go, well, that's just not true, is it? Is what, was the response that I got. It's not true at all.'* (P15, 24 years old, female)

*'She wasn't even interested really in putting me right, it was just very very dismissive.'* (P8, 45 years old, female)

Participants were accepting of their GP not being familiar with the content of the information, as long as they were honest about their level of knowledge and were prepared to read up and give an opinion at a follow-up:

*'If she'd said to me, right, I don't know much about this at all. I think it's something that I need to go and read up about and maybe find out who else is involved within the NHS that would be able to provide the service and, you know, just maybe get a bit more background, and let's make an appointment for you, maybe, in 2 or 3 weeks' time, and once I've had time to read up you come back again and we'll have another discussion about this.'* (P13, 44 years old, female)

The effect of the GP response was most significant where the consultation had not gone well. Most participants who had perceived a negative response on the part of their doctor (even if this meant the GP agreeing with the information but failing to engage with it), said they would avoid that doctor in future. A minority reported changing practices, disregarding their GP's advice, seeking a second opinion privately or gaining medication via the internet:

*'I just know that that's a GP that I won't go and see.'* (P1, 41 years old, male)

*'I think I mean it's interesting cos I manage my health now, I manage the condition by actually having a consultation with the professor who is retired from his research, not by going to GPs.'* (P8, 45 years old, female)

Alternatively they reported continuing to use the internet without disclosing this.

In contrast most participants with positive experiences reported that their relationship with their GP had either been strengthened or confirmed as a result of taking information from the internet into the consultation:

*'I feel cared for. I know that they're trying to do the best for me. I trust them and it makes me feel valued.'* (P17, 36 years old, female)

*'I think it improved our relationship, in that ... because she ... it showed that she was open-minded to her patients' ideas about their treatment and also the kind of respect to their view that they're not all idiots who don't know anything just cos they're not medically qualified.'* (P24, 32 years old, female)

## DISCUSSION

### Summary

This is the first in-depth individual interview study to investigate UK patients' experiences of taking internet information to their GP.

The data show that patients use the internet with the goal of maximising the benefit obtained from a consultation. They wanted the GP to acknowledge the effort they had invested, and engage seriously with the information. Most patients would accept GP advice even if it contradicted the internet information, as long as the GP respected the information and explained the reasons for their opinion. However, a disrespectful response by the GP could have a seriously deleterious effect on the doctor–patient relationship, leading in some cases to a change of doctor or practice.

### Strengths and limitations

The conduct and reporting of this study conform to the guidance provided for the Health Technology Assessment Board in 1998.<sup>27</sup> Experienced qualitative researchers were involved throughout this study. The critical incident approach was well suited to the task and rigour was ensured through purposive sampling, continuing data collection until saturation had been reached, and adopting a process of iterative analysis and data collection. Each interview was read and discussed by the whole team, with this process of critical reflection allowing emergent themes to be explored in subsequent interviews. Purposive sampling combined with using two methods of interviewing (face-to-face and telephone) enabled the inclusion a range of participants both in terms of background and geographical location, promoting the transferability of the findings. There are two important limitations. First, only people with direct experience of taking internet information to their GP were interviewed. This was necessary to obtain data on lived experience, but it is likely that the study population were more 'internet-literate' than the general population. This is also suggested by the high proportion of the study sample with a university degree despite efforts to recruit a diverse sample. It is possible that these findings may not transfer to a less well-educated population. Second, these data are limited to participant reports — there is no way of ascertaining whether the words and behaviours ascribed to GPs really occurred. However, participants believed that they had occurred, and this belief impacted on their subsequent behaviour.

### Comparisons with existing literature

These data build on previous questionnaire studies which have suggested that patients go online to learn more about their health and healthcare options, are often wary of

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### Ethical approval

This study received ethical approval (08/H0723/33) from the North Central London Research Consortium. All participants provided written informed consent before participation in the research.

### Provenance

Freely submitted; externally peer reviewed.

### Competing interests

The authors have declared no competing interests.

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taking information to the doctor,<sup>28,29</sup> but that when they do take the information to the doctor, the doctor's reaction and communication skills are crucial.<sup>30-32</sup> A positive reaction, defined as engaging with the information, is associated with improved therapeutic relationships and increased satisfaction, while negative or dismissive reactions are associated with damage to the relationship and potential reduction in adherence to medical advice. There are also data to suggest that the pre-existing doctor-patient relationship is important, with dissatisfied patients more likely trust internet information over their clinician's opinion.<sup>33</sup> Previous qualitative work has indicated the importance patients place on face-to-face consultations and how they see internet information as complementary to the consultation.<sup>20,34-37</sup> Perhaps for this reason, patients are sensitive to their doctor's feelings and careful not to be seen as challenging the doctor's authority.<sup>20,28</sup> These data demonstrate that previous findings on the importance of consultation skills with patients wanting 'doctors who appear interested, listen well, explain clearly and are open to discussion'<sup>38</sup> are equally applicable in relation to the internet.

### Implications for practice

These data should reassure GPs that patients who bring internet information to a consultation are not intending to challenge their authority, rather, they are demonstrating a desire to make good use of GP time and be actively engaged in self-care. GPs already have the necessary communication skills to demonstrate respect for, and engagement with information brought by patients but these data suggest that not all doctors are applying them consistently. Applying these skills and acknowledging the effort that patients have put into identifying this information should help GPs meet patient expectations in such consultations, and hence lead to improved therapeutic relationships. GPs should not fear disagreeing with information from the internet, but they should be prepared to explain their reasons for disagreeing. Demonstrating disrespect and failing to engage with information is likely to lead to dysfunctional consultations and can seriously damage the doctor-patient relationship. This is an area that medical educators may wish to address through under- and postgraduate education and continuing professional development.



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