

eHealth as a challenge to 'expert' power: a focus group study of Internet use for health information and management.

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Summary

The potential effects of ehealth have been well documented. However, the use of the Internet for health is an ever increasing phenomenon, with an estimated two-thirds of web users having searched for a specific health problem. To investigate current ehealth use amongst adults, focus groups were conducted to explore participants' attitudes to and reasons for health Internet use. The focus group data were analysed and interpreted using thematic analysis. Three superordinate themes were identified exploring ehealth behaviours: *Decline in expert authority*, *Pervasiveness of health information on the Internet*, and *Empowerment*. Results showed participants enjoyed the immediate benefits of ehealth information and felt empowered by increased knowledge, but they would be reluctant to lose face-to-face consultations with their GP. Our findings illustrate changes in patient identity and a decline in expert authority with ramifications for the practitioner-patient relationship and subsequent implications for health management more generally.

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Introduction

The nature of the Internet and its plethora of sites mean that health information on a whole host of topics can be accessed at literally the touch of a button. The normalisation of household Internet has meant journal articles, medical information and medical libraries are increasingly accessible. The World Health Organisation (WHO) identified over 100,000 health related websites in operation¹, with other generic sites totalling 60 million.²

The NHS Expert Patients programme³ advocates patients' active involvement in their healthcare by educating them and helping them to understand specific conditions, their implications and possible treatments; its aim is to create fully informed and consenting individuals. However, there is a discrepancy between the proposed 'expert patients' and willingness of health professionals to work with them, highlighting the need to educate health services staff about the potential benefits of the programme.⁴ Although information for patients is available from the NHS and associated charities, increasing political awareness among patients, current NHS finances and media publicity of, 'health scares' (e.g., MMR, SARS, BSE) are swaying public attitudes toward being cynical of Government and more trusting of the mass media to educate them on health issues.⁵

However, in this lie problems. Complex scientific research is often summarised for the purpose of news reporting or posting on the Internet, which can lead to misinterpretation if findings are not presented in their entirety. Medical research obviously deals with participants who vary by age, ethnicity, gender and social economic status⁶ which can potentially cause individuals to misapply and over generalise the evidence. Internet health information also can lack authority cues that enable people to assess the validity of the information source.^{7,8} Indeed, we agree with Rennie and colleagues⁹ that more research is needed to understand how patients use the Internet and to evaluate the quality of information retrieved.

Potentially, the Internet is a medium that can address health inequalities. We know that young men are less likely to visit their GP than women of a similar age¹⁰ and men are higher frequency users of the Internet; women too are beginning to use it more particularly for communication purposes.¹¹ Internet health users are generally considered to be of higher socio-economic status, education, income, and job status;¹² whereas GP attendees are ethnically diverse¹² and belong to lower social class and employment groups.¹³

Expert authority

The theory of expert authority as described by Paterson,¹⁴ refers to the power afforded to an individual who has greater knowledge and experience than another, in this case, the doctor-patient dyad. However, with the push for partnership in health management the strength of this authority is under threat. Historically, the power awarded the medical profession has enabled it to define what constitutes medical knowledge¹⁵ and it has controlled access to it by favouring a didactic relationship in which patients are passive recipients of treatment.¹⁶ Increased availability of information via the Internet may also contribute to this challenge of authority and that is one of the questions we addressed in this study

Our first aim was to establish whether individuals use the Internet for health purposes and if so, how. We were interested to explore how the Internet would function as a resource for health information alongside existing mechanisms (e.g., GPs, NHS direct) and within the context of the Expert Patients Programme. Finally we asked whether the Internet would change the way people manage their health.

Method

Data collection

Ethical approval was granted by the University Ethics Committee. We conducted four focus groups with eight men and eight women aged between 19 and 62 years (mean age 37.5). Participants were healthy volunteers and were recruited through quota convenience sampling. All participants described themselves as white British with

varying levels of educational qualifications and occupations (including three health professionals). One participant was diagnosed with diabetes and another with irritable bowel syndrome. (See Table 1 for details.)

Focus groups were considered appropriate in this novel area of investigation because of their interactive nature which enables participants to bounce ideas off each other, compare attitudes and to explore their shared and unshared experiences.¹⁹ An open-ended schedule was used to guide the discussions but the facilitator was keen to prioritise participants' stories so that any unanticipated ideas were heard.¹⁹ The schedule included such questions as 'what do you use the Internet for?', 'is there anything specific you look for on a health website?' and 'can you trust the information you read?'. Focus groups were digitally recorded and transcribed verbatim. Each lasted between 60 and 90 minutes.

Analysis

Focus groups were analysed using thematic analysis.²⁰ The analysis aimed to examine the meanings of participants' experiences of ehealth and to extrapolate what those experiences mean in terms of their own health management and the function on the Internet within that. Transcripts were read several times to identify patterns including similarities and differences in participants' experiences and opinions. The primary analyst (LD) independently identified and defined a number of emerging themes. She then met with co-researchers (RS and OA) to review the themes and ensure they represented the broader story of the whole corpus.

Results

Three superordinate themes were identified: *Decline in expert authority*, *Pervasiveness of health information on the Internet*, and *Patient empowerment*. These will be discussed in turn using data extracts from the focus groups.

DECLINE IN EXPERT AUTHORITY

This superordinate theme, *decline in expert authority*, comprises two subthemes: *demise of meritocracy*, and *concerns about the NHS and the breakdown of trust* in Government bodies, politicians, and civil servants.

The authority afforded to health professionals, and doctors in particular, has in the past led to the doctor being considered as a deity amongst men. However, the Expert Patient programme is encouraging patients to take a more involved and proactive role in their healthcare. Consequently, we are seeing an effect on power dynamics between health professionals and patients, with patients becoming regarded as the expert with regards to illness experience.²¹ With this new found knowledge comes a new power, the power to negotiate treatment.

Demise of meritocracy

The availability of health and illness information through journals, books and in particular the Internet has lead participants to doubt the authority of health professionals.

Sam: I think the doctors can feel like if you're trying to do

Kevin: like override them

Sam: yeah, if you self diagnose then they tend to think, when I've said things about the things I've found on the Internet to a doctor before they, you can just tell that they frown upon it a little bit some doctors, and think your just clutching at straws or your being er

Kevin: it's 'cause they think that they know best and you doubting them in someway

Ronin: oh yeah, personal ego isn't it.

Many of the volunteers in this study were highly educated, particularly in science and medicine, and felt they possessed the knowledge and capability to correctly interpret Internet health information. As 'lay' knowledge increases, the perceived gap between them and their GP appears to close; patients may begin to question their GP's authority in ways they would not have done previously. Below, Pam talks of her experience of visiting her GP for hormone replacement therapy:

Clare: and it's horse oestrogen in the early HRT

Pam: so I went back to him and told him all about it and he says "don't worry, I understand. I'll put you on something else". I got home, checked that one, it was exactly the same again [Horse urine]. So I went back and I absolutely flipped.

Lauren: it was probably because it was cheap

Pam clearly feels misled and potentially patronised by her GP's apparent assumption that she will not discover the truth about the hormone s/he has prescribed. Another possibility is that the GP was unaware that the second hormone also contained horse urine.

Concerns about the NHS and the breakdown of trust

Participants displayed deep concerns about the current state of the NHS and the implications for their future healthcare. Comments tended to be linked to and reflective of media coverage of incidents of malpractice which influenced participants' judgement of the health service and health workers. Clare indicates that current health professionals are less passionate about their role compared to the health professionals of several decades ago.

Clare: no, they [health professionals] don't really want to be doing it. So it's that plus the fact you can't underestimate the fact that the whole nation has been shocked rigid by people like Beverly Allitt, Harold Shipman, there's Alder Hay, Bristol, I mean all these scandals over the last 10 years have done irreparable damage to these people who the nation has always held with great trust and very high esteem

Participants' view of these isolated incidents reflected negatively on their view of the Government, which filtered through to an overall cynicism of the individuals and groups who work in the NHS.

Paul: you can go on the National Health Service, but I think there's a two year waiting list.

Jonah: it shouldn't be, 'cause what did Tony Blair say the other day that waiting lists have been cut to 26 weeks

Paul: but he's going now so he could say anything.

This scepticism toward the Government, NHS and health professionals appears to reinforce the lack of trust in the doctor-patient relationship, and fuels the drive for complementary and alternative health information.

PERVASIVENESS OF HEALTH INFORMATION ON THE INTERNET

Participants talked openly about their use of ehealth information, describing seeking health information online as a normalised, almost daily activity. Internet use for these participants plays an active and multifaceted role in their daily lives. When asked to give an example of what she used the Internet for in the context of health, Gertrude replies:

Gertrude: I was doing lipotrim [a diet programme for weight loss] recently to lose weight so I actually joined an internet forum where you could chat to other people who were doing lipotrim and get advice about like you know, you can ask cus it's like a very low calorie diet. Um so I was just using that as a form of support and also for information

The many roles of the Internet as specified by the participants embody, create and develop a consumer identity, which has the potential to not only affect their purchase choices but also their choices when it comes to healthcare, especially when combined with a greater knowledge of health and medicine.

A crucial concern that has been highlighted in recent medical literature of this extensive Internet use for healthcare is the validation of ehealth information.⁹ Participants explored this issue in depth, explaining exactly what they look for as a marker of good quality health information. The participants demonstrated a knowledge of criteria that constitutes grounded and 'safe' information. For example, they discussed the trustworthiness of websites endorsed by a Government department, i.e., the NHS, and the need to investigate the origins of other ehealth information.

Gertrude: I think you can get Internet sites, 'cause I've looked at one that I think is particularly good which the mouth cancer foundation and it was set up by a restorative dental consultant um and its like a registered charity and all the rest of it they've actually got some Internet award.

Ronin: erm, there's plenty out there but a lot of these are just bullshit, you've gotta be careful, you've gotta kind of half know what your looking for to make sure you don't get caught off in any pseudo-science or any sort of crap.

Despite their 'web literacy', the next theme shows us that participants did not view ehealth information as a replacement for standard health services. Rather it was seen as a complementary information source alongside information or treatment from their GP.

EMPOWERMENT

The participants advocated the Internet as an empowering tool in their healthcare. It not only can be used as a complementary information source but also afforded individuals the power to learn how to conduct their own health checks if not for self-diagnosis and treatment then just to ease their minds whilst waiting for a doctor's appointment.

Sam: I was covered in a rash all over my body and I looked at pictures on the Internet and erm thought mainly to check that it wasn't completely life threatening like it wasn't gonna be some horrible disease, see if it was something like measles or something erm, just for piece of mind before going to the doctors.

This tactic did not work, however, in more serious instances:

Bernardette: So I got the consultant to write down what it was [Breast cancer] and straight away Googled it and it came up with a Google Scholar erm two main research articles that were cited a lot. One of which said prognosis is really good, the other said that prognosis is terrible. So at that point I just thought "you should know better than to go straight to the Internet for advice like that" so I sort of stopped it.

Bernadette's experience demonstrates the point made earlier that scientific research can be complex. Despite her experience as a health professional (CBT therapist) and having the skills to systematically search for research evidence on the Internet, in this

instance Bernadette felt swamped by her emotional response, which prevented her from behaving in a rational way.

The immediacy of the Internet was advantageous to these participants because they felt unable to get an immediate, or convenient, appointment to see their GP. The Internet appeared to be a solution to this dissatisfaction.

Morag: Yeah, I picked up on what you [Gertrude] said though the convenience of it. Like sometimes you get in and it's turned 6 o'clock at night and you just want to "oh I'll have a look at that on the Internet" the doctors aren't accessible then and the NHS helpline is useless half the time anyway (laughs)

Despite this, participants still preferred to see a doctor as and when needed.

Nathan: I think as good as the Internet is and the way we're moving on in the future and you've got all these you know diagnose yourself, I still don't think you can beat personal contact. However futuristic we've got and whatever means we've got I still think the old fashioned way, you speak to somebody who's professional, you can't beat that

The Internet features highly in these participants' lives and they clearly describe ehealth as a beneficial and potentially empowering resource, given the skills to appropriately interpret information retrieved. The accessibility of ehealth information was compared favourably to GPs which again highlights the need for 'out of hours' surgeries for professionals and those in full time education. Nevertheless, participants did not view their GP as redundant but fundamental in the role of gatekeeper to further and more specialised treatment which the Internet cannot replace.

Discussion

We have heard participants' accounts of their own ehealth behaviour and where this fits within their wider health management. Despite their different educational and professional backgrounds, the overall message from participants converged around several issues. First, participants enjoyed the immediacy of ehealth information which compensated for the perceived lack of availability of GPs. Second, their 'web literacy'

enabled participants to retrieve and, more significantly, assess the validity of health information on the Internet. Thirdly, the availability of ehealth information empowered participants to make sense of their own experiences of health and illness which could act as a comfort whilst awaiting advice from a health professional. However, when searching for ehealth information which has personal relevance, it is possible that an emotional response will compound an otherwise rational and competent individual's ability to interpret what is found.

Given our argument that scientific research needs to be understood in context, our own research also needs to be considered in terms of both its objectives and limitations. Participants were recruited as Internet users because the nature of the study required some first hand experience. It may be that changes in identity or potential breakdowns of trust do not resonate with patients who do not access ehealth information. We do feel our study was robust involving systematic methods of data collection and analysis. Engaging multiple researchers in the analysis process, in particular, provided opportunity for reflection and to monitor our interpretative activities.²⁷ Like most qualitative researchers, we did not aim to generalise our findings 'vertically' to the wider population but we feel the themes we have identified are 'horizontally' transferable to other settings, i.e., they help further our knowledge about patient identity and the implications of a related decline in expert authority.^{28,29}

More fundamental is the impact ehealth appears to be having on the identity of the patient. Participants' use of ehealth information clearly demonstrates that resources are available for patients to become more proactive in their health management, which fits the ethos of the Expert Patients programme, yet also challenges the authority awarded historically to the medical profession. However, the benefits of ehealth cannot be considered universal as individuals may be limited by ehealth literacy and access to the internet.

As summarised above, our findings highlight both risks and benefits associated with this. In short, the key issue is power. The traditional 'sick-role' dyad²² of the all-knowing doctor and submissive patient renders patients powerless. By endorsing self-management programmes, for example in diabetes care,²³ NICE, and Government, are moving toward a model of concordance which empowers patients to make their own

health care decisions.²⁴ While our findings confirm that this can happen, they also corroborate earlier research which emphasised that patient decision-making, particularly self-care acts, are influenced by context (e.g., the nature of information source) and the fact that patients do not always feel they have the power to make decisions.²⁵ Previous research has also indicated that self-management, particularly of chronic disease, can have social and emotional effects, which we found can impact on rational decision-making.²⁶

Further research with other groups (such as minority ethnic groups, young people, older people, and people with acute or chronic conditions) would clearly benefit the evidence base on this dynamic process. We also need to expand knowledge about the function of ehealth information, and its potential links to behaviour change.

In short, this research has identified that patient identity is changing and that this process is aided by the accessibility of ehealth information. Internet use continues to rise and around two-thirds of Internet users have searched for a specific health problem.³⁰ Participants were attracted to the Internet because of its immediacy and because of its convenience. This has clear implications for GP surgery opening hours, currently on Government's agenda,³¹ it questions the expert authority of the health practitioner, and it impacts on the power dynamics within the practitioner-patient relationship.

Competing Interests

All authors state that they have nothing to declare.

Contributors

Louise S Donnelly: Conception and design of study, collection, analysis and interpretation of the data. Responsible for writing the original draft of the paper, revising it and approved the final version to be published.

Rachel L Shaw: Guarantor. Conception and design of study, analysis and interpretation of the data. Involved in the critical revisions of the paper, and approved the final version to be published.

Olga B A van den Akker: Conception and design of study, interpretation of data. Involved in the critical revisions of the paper, and approved the final version to be published.

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Table 1: Participant information

Participant	Focus Group	Age	Highest educational qualification	Occupation
Ronin	FG1M ¹	26	BSc	PhD Student
Kevin	FG1M	24	MSci	PhD Student
Steve	FG1M	24	MSci	PhD Student
Sam	FG1M	24	MSc PGCE	Secondary teacher
Bernadette	FG2F	36	MSc	CBT Therapist
Gertrude	FG2F	45	MSc	Nurse
Morag	FG2F	34	MSc	PhD Student
Pam	FG3F	54	None	Homemaker
Lauren	FG3F	19	A-Levels	Undergraduate student
Holly	FG3F	19	A-levels	Undergraduate student
Clare	FG3F	56	CQSW	Homemaker
Helen	FG3F	56	Diploma	Nurse
David	FG4M	62	None	Shop worker
Paul	FG4M	62	Maths Credit	Clerk
Jonah	FG4M	29	A-Levels	Shop worker
Nathan	FG4M	31	BA	Graphic designer

¹ FG1M: Focus group 1 included all male participants; FG1F: Focus group 2 included all female participants.