

(How) do People Negotiate Online Information into their Decision Making with Healthcare Professionals?

Lauren Bussey

Pact Lab, Department of Psychology
Northumbria University, Newcastle
upon Tyne
UK

lauren.bussey@northumbria.ac.uk

Elizabeth Sillence

Pact Lab, Department of Psychology
Northumbria University, Newcastle
upon Tyne
UK

elizabeth.sillence@northumbria.ac.uk

ABSTRACT

In this paper, we describe how people negotiate and communicate with healthcare professionals (HCPs) about information they have found online for the purposes of making health decisions. Drawing on 55 interviews with people using the Internet as part of their health decision-making we show how online information can be successfully integrated into decision-making leading to decision satisfaction and perceived positive outcomes. We describe what successful integration looks like as well as detail the ways in which integration of information can be disguised during negotiations with HCPs. Finally, we document what happens when integration fails, potentially valuable information resources are lost or the patient decides to bypass the HCP altogether. By exploring successful and unsuccessful integration examples we make three suggestions about how integration of online health information into HCP discussions around decision-making could be improved via (1) improved digital curation tools (2) providing communication scaffolding for the doctor-patient consultation and (3) harnessing the power of collective resources.

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1 INTRODUCTION

Against a background of increased patient involvement in health decision making the Internet, in its broadest sense, continues to provide people with an ever-expanding health resource. Online health information and advice generated via health organizations, charities, commercial entities and increasingly patients themselves, creates new opportunities for people to influence the direction of the decision-making around their health.

Health websites can provide people with new information about their symptoms, diagnosis or treatment and help to generate new ideas, queries and potential solutions to take forward to meetings with the clinicians [1]. Online peer resources, in particular, often encourage people to take an active, thorough approach to their own health investigations although this kind of self-directed online searching is not always welcomed by health care professionals concerned with the quality of the information exchanged in health support groups online [2]. Previous research suggests that HCPs often have mixed feelings about patients bringing the results of their Internet searches with them to the consulting room [3] and time constraints on appointment times are an additional pressure in this respect. However, given the growing use of online resources by patients, their family members and informal carers it is important to know how people are bringing that information to their discussions with HCPs and the strategies they are using to negotiate the online information into their decision making with HCPs.

In this paper, we present examples of how online health information can be successfully integrated into HCP decision making in order to achieve satisfaction around the final decision. We further describe a strategy by which people disguise the process of integration during their discussions with HCPs and finally illustrate what happens when integration fails to occur. We report on three suggestions for improving integration and facilitating smoother negotiations around decision-making discussions with HCPs.

1.1 Background

Given the governmental and professional body drive towards collaborative health decision making, [4] more people, especially active information seekers, are now using online health resources to assist their decision-making [5,6]. Despite the increasing use of online health information, surveys of internet users suggest that HCPs remain an integral part of the decision making process, so how are the two information resources integrated by patients and importantly how do patients negotiate the use of online health information into their discussions with HCPs about their decision making?

The literature regarding information sharing with HCPs in a wider health context - beyond decision-making is a useful starting point highlighting a number of factors that seem to affect the likelihood that people share the information with their physicians etc. Firstly, they may be more likely to share information if they feel a sense of responsibility to do so [7] or if they have been encouraged to do so by a relative or by the online information itself [8]. Secondly, men appear to be more willing than women to discuss their online health information with a HCP [9]. Conversely, people are less likely to share their online information if they are concerned that they may have misunderstood or misrepresented the content or have concerns over personal privacy [8]. Likewise, people refrain from sharing if they fear a negative reaction from the HCP [10] and are reluctant to share if they sense that the doctor may feel insulted by the presence of the online information in the consulting room [8]. This point highlights the importance of the pre-existing patient-physician relationship [11] in terms of acting as both a barrier and a facilitator of shared conversation.

We know that good doctor-patient communication can influence health outcomes, for example treatment adherence, [12-14] and it seems reasonable to assume that open communication around information resources may actually benefit the relationship, as patients are better able to articulate learned information, more confident to ask questions, and are subsequently better equipped to contribute to shared health decision making [15]. Despite this, patients report that HCPs sometimes react negatively to information derived from online sources [16] or believe that the HCP will perceive them to be challenging [14]. If the HCP has a dominant communication style [17] discussing online health information could negatively affect the relationship making it less likely that patients will choose to divulge or discuss online resources [15].

The barriers to information integration for physicians are twofold. Firstly, the time consuming nature of the process in which HCPs report spending more time reinterpreting and correcting misinformed patients [18]. Secondly, HCPs report feeling ill-equipped and lacking the confidence to refer patients to credible and appropriate information websites [11]. The contribution of online resources to health decision making has been noted in the literature [19] as well as the facilitators and barriers to shared decision making [20] but understanding how this information is taken to consultations and integrated in the decision making process with the HCP is not well understood. In this paper we

highlight three strategies relating to information integration by people concerned to use their online resources alongside their HCP to reach a health decision.

2 METHOD

This paper is based on data collected from three UK-based studies all concerned with the use of online health information and decision-making. There were 55 individual interviews in total with 18 focused on participants' use of online support groups and 37 participants describing their broader use of online health resources. The total sample consisted of 15 males and 40 females with an age range of 18-66 years. Interviewees discussed a number of different health issues ranging from cancer, fertility treatment through to sleep difficulties, allergies, vaccinations and medication problems. These issues are representative of chronic, acute and stage of life health conditions and are likely to cover a breadth of decision types from treatment and procedural decisions, through service provision, lifestyle and screening issues. Focusing on multiple conditions allowed a more comprehensive overview of the internet in relation to decision-making and information integration.

2.1 Analysis

All the interview transcripts were read for instances of information integration. Specifically, we identified examples where participants detailed how they had negotiated online health information into their decision-making discussions with health care professionals. The two authors then discussed these sections looking for both examples where integration had and had not occurred. The ways in which participants described these processes or the barriers that prevented successful integration were then compared and three main themes were derived. We remained mindful of the differing contexts of our interviews but upon discussion found that more similarities than differences existed and so decided to analyze and present the results as a whole and to only highlight key differences where appropriate.

3 FINDINGS

When people were engaged in decision-making activities they regularly relied upon online information and advice. People noted ideas, made selections and evaluated decisions via online engagement. However, participants also noted that for the majority of decisions they needed and wanted HCP involvement. Therefore, the issue arose as to how to combine or integrate information and advice from different online sources with the information and advice from the HCP. Below we characterize three ways in which information integration was said to occur (or not), we highlight the key characteristics of these encounters between patients and HCPs and illustrate the benefits for patients in terms of decision satisfaction.

3.1 Successful integration

Participants noted the times they had successfully integrated online material into their decision-making activities with HCPs depended on, *inter alia*, their existing relationship with their HCP, the nature of the health concern and the type of decision they were making. Focusing on the process of integration itself, we

note the importance of a) clear evidence of information searching, selection and evaluation and b) maintaining clear doctor-patient identities.

Participants believed that HCPs were more comfortable with using online resources as part of the decision making process when the HCP remained in control of the information source i.e. they had directed patients to specific, credible online sites or patients were reporting information that came from credible sources.

One participant recalled a time she had to confirm to the doctor that she been looking online to assist her decision:

“Her (the doctor’s) face dropped and then once I said it’s the NHS website don’t worry, she said “Oh brilliant!” and then I kind of led the appointment as opposed to her just asking me a million questions. Once I said “This is what I think what do you think? We were able to discuss it and look through the symptoms together” (P22 internet).

This quote also highlights the idea that framing the online information within the context of the consultation is important.

“My approach is I don’t go to my GP and say the forum or Wikipedia says this it must be right so can I have this drug or this treatment I go and I sort of say I look at it with some balanced judgement and say what do you think and I’ve had several changes of drugs as a result of that that have improved my wellbeing shall we say.” (P15, online forum)

Participants described the importance of having a long-standing relationship with the HCP, having sufficient time in consultations and being careful to introduce the material in a thoughtful manner. For patients this meant demonstrating a commitment to sifting through relevant and irrelevant information, presenting a cautious account of what has been found and acknowledging the potential pitfalls in online information. Interestingly, participants noted the importance of still deferring to the HCP for expert opinion – acknowledging the pervasive attitude “let me be the doctor and you be the patient” (P4 online forum).

Using the online information to assist decision making within the context of the HCP consultation can occur in a number of more or less explicit ways. Several participants talked about the need for persistence and doing your homework so that you could present the HCP with a convincing set of arguments in support of your decision.

“So I just printed a load of stuff off that and took that in for my doctor and she did finally relent and went oh ok so yes that actually kind of worked in my favour that

time and within three days of taking the tablets I was fine.” (P12, online forum)

Others expressed the idea that online forums in particular were useful places to gain ideas about the sorts of questions you should be asking HCPs in order to make treatment decisions for example. Below a participant described advising someone to print off the forum members suggested questions to take to the HCP meeting.

“Sometimes people will say ‘that was a good point Heather that’s something I am going to discuss with my oncologist at my next meeting’ so things that people have been helped to think through and we will quite often say to them why don’t you print off this page from the forum and take the notes with you so that you’ve got them to refer to when you’re in the hospital?” (P1, online forum)

3.2 Disguised integration

Many participants expressed the opinion that HCPs were often still reluctant to encourage or condone the use of online health information resources.

“I’ve said to some doctors before that I’ve already looked online and they were like “You shouldn’t look up too much information online because it does scare you” (P35, Internet).

On some occasions participants described the way in which they integrated the information and advice they had found online into their discussions with HCPs without making it explicit how they had encountered that information. For some this meant disguising the source altogether:

“I said I’ve spoken to....., I didn’t mention it was a website, I said I’ve spoken to quite a few other parents who’ve got children with sleep apnea and they’ve recommended this or they’ve said this and then they seemed to listen, as soon as you mention its a website - their eyes glaze over and they think ‘oh yeh you’ve been googling’ do you know what I mean ‘oh no you’re a google mum’ sort of look so I’ve learnt not to say that.” (P14 Online forums)

Whilst others used the information they had found online as a way of corroborating the HCPs message only revealing their own knowledge and its source if the two messages did not align.

“In other cases where I’ve read something online and then I’ve told him (doctor) my symptoms and he’s told me something maybe different to what I expected to hear due to the online information so I may have yeah implicitly suggested something that I might have read online and then he’s gone no don’t worry about it you know don’t read, you’ve probably read too much online or something like that.” (P19 Internet).

"Because you sort of know an answer so you'll deliberately ask it to see if they'll say the same answer or to elaborate on anything..." (P14 Internet)

for that lecture or the embarrassment so I just don't say anything." (P29 Internet)

3.3 A failure of integration

A few people indicated that they did not intend to integrate the online information at all and rather used it to inform decision making directly – bypassing the HCP altogether. In these cases, usually involving a non-serious health issue, participants were happy to rely solely on the online advice and not 'bother the HCP'.

"Yeah in fact some of it if it was just dietary and I couldn't find the information about how much vitamin C I would think what is the point in going to a doctor it's just a waste of the doctor's time to say take one vitamin c drink a day or whatever. Or eat an orange but yeah I feel like that would be a waste of both our, well especially their time so I feel like I'd just wait a while and leave it and not change because of it (P24 Internet)

For other people they were motivated to search for, select and evaluate online material in relation to their decision making but were then reluctant to try and integrate into their discussions with HCPs. Common reasons for this failure of integration were fear of a negative response from HCP and potential embarrassment about misinformation or misunderstanding regarding the information and advice. For some, previous experiences had informed their current behavior and they no longer attempted to integrate the information.

"From past experiences with the medical profession say, you don't mention the internet in any shape or form cos you'll get shut down very quickly and I do understand that to a degree because obviously they think you are just going into Mr Google and believing everything that you see so that is very much that perception from specialists or doctors oh gosh don't go down that route." (P13 online forum)

Unlike the examples of successful integration, a failure of integration can result in delayed outcomes, reduced wellbeing and non-satisfactory decision-making. For example, one participant described how they had researched their symptoms and decided that a sugar test was the next appropriate course of action but felt unable to talk about the online information with the HCP and were left feeling the appointment had been a waste of time.

"I just list my symptoms and hope they push me the right way (but) when I went the other day the doctor said 'I will have to check your bloods again' and I was like but 'I am taking iron tablets do you think its my iron' she was like 'we'll take your bloods again it will be fine.' I wanted her to do a sugar test but she didn't but I don't want to be like I have looked online and I have this because they will be like I'm the doctor and I know what I'm talking about, don't look online. I can't be bothered

4 DISCUSSION

In this paper we have shown that successful information integration is taking place as people employ strategies to ensure that online information can be successfully negotiated in decision-making discussions with HCPs. For these people successful integration leads to a better sense of decision making satisfaction, more collaboration or agreement between HCP and patient. On the other hand, for some people open discussion of online health information is still not possible. One strategy is to disguise the source of the information so that it still forms part of the negotiations around decisions (albeit unacknowledged by either party). Despite people engaging in careful and time consuming online research there are cases where they are unable to translate that work into a meaningful part of their negotiations with HCPs and as such are left feeling unsatisfied with their overall decision making. In some cases, completely avoiding a consultation with a HCP was seen as preferable to poor integration attempts. People were able in some cases to comfortably base their health decision making on the basis of online health information alone. In more minor cases this may be appropriate but bypassing the HCP entirely in terms of decision making because of a poor relationship or to avoid time wasting has potentially serious implications. This failure of information exchange and integration removes the opportunity to validate the online information from a professional perspective and may suggest potentially harmful decisions and outcomes on the basis of online resources.

The results of this study paint a picture of variable integration with both the source of the online information and the role of the HCP influencing the outcome. We noted for example that participants felt that online support group information in particular was less well received by HCPs. This supports previous work suggesting that people are sometimes tempted to obfuscate the source when the information has been derived from an online health community [16].

Peer-to-peer resources, however, continue to form an increasingly common online health resource and have been shown to be important across all stages of decision-making activities [19,6]. Traditionally, HCPs have been reticent to encourage their patients to use online support groups [2] but the quality of these resources is growing. Peer resources and curated experiences are becoming embedded within well-moderated, credible and high quality websites and HCPs now have a greater range of options in terms of signposting their patients to appropriate peer resources.

Our interviews described decision-making discussions predominantly with general practitioners but there was a sense that particular groups of HCPs e.g. specialist nurses were more comfortable with the integration process and encouraged people to make use of online resources. It may be that making an assessment of who would benefit from online resources and deciding how best to signpost individuals to credible and relevant health information is something that takes time and is a consequence of a longer-term relationship with a HCP.

On the basis of our findings we introduce three key ideas for improving the integration of online health information into HCP discussions around decision making.

Improve digital curation tools: Providing tools to improve the way patients can search for, select and curate their own set of relevant health resources will improve the usefulness of the resources available and make clear both to the patient and the HCP the key issues around the decision under consideration. Effective tools are needed to help patients focus on the specific decision making activity involved, to reflect on their personal priorities including inter alia, attitude to risk, financial situation and family responsibilities. Finally, these tools could expose contradictions, highlight corroboration points and opportunities and allow easy ways to download, save and share information with relevant others.

Provide scaffolding for doctor-patient communication around online resources: As acknowledged in previous research [12] the extent to which people felt comfortable talking about their online health searches as part of their decision-making depended in part on the relationship they had with their doctor. Whilst corroboration with other resources i.e. friends and family, is actively encouraged as part of the decision-making dialogue there is as yet little acknowledgement of how to advise people to engage with online information. To capitalize on the importance of the doctor-patient relationship improvements to the ways in which open dialogue around online information can occur need to take place. In addition to a set of go-to online resources, HCPs could encourage more targeted discussions by providing patients with a way of structuring or scaffolding their searches, for example, around the different stages of decision-making activity [21]. The intention here would be to encourage patients to reflect further on their 'personal preferences' at each stage thus precipitating improved dialogue within a broader conception of shared decision-making [22].

Harness the power of the collective resource: The leaders and moderators of online support groups are in a position to collect and curate collective responses, information and advice in relation to different health topics. Their domain specific knowledge is invaluable in terms of signposting more robust information whilst also making suggestions for how information can and should be considered and used as part of the decision making process.

This study has focused solely on UK patient perceptions of information integration but we are currently engaged in a study discussing these same issues with HCPs. Going forward it will be interesting to see how these perceptions vary depending on different healthcare models. The strategies and scenarios identified in this patient-led study are proving a useful way of exploring different stakeholder perceptions around the possibilities of information integration. The findings from this study suggest that it is time to rethink common perceptions regarding the use of online health information in the consulting room. The notion of such patients as a-priori information hoarders or cyberchondriacs is outdated and unhelpful. With so many different ways of accessing health information and advice present online now we need to improve education and guidance on both sides of the consulting table to make better use of the resources available.

The authors have declared that no competing interests exist.

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