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An engagement framework for understanding the communication needs of different health groups

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Abstract

Qualitative investigations were conducted with three discrete health groups, involving asthma sufferers, smokers considering quitting, and personal carers of people with multiple sclerosis (MS). The participants searched for and commented on the different kinds of health information that was available online, including discussions and postings about shared patient experiences. Different patient groups clearly showed different communication needs in terms of their online search behavior and this reflected (i) the information available on and offline, (ii) the success of previous patient-clinician communications and also (iii) the complex coping strategies of the patients and carers themselves. We captured these needs in a new engagement framework that can be used to guide the design of new online systems and to support developments in patient-clinician communication.

Author Keywords

online patient experiences; patient-clinician communication; asthma; smoking cessation; MS

Introduction

Patients now find it very easy to communicate directly with other patients via eHealth technologies, but what

do these online communications tell us about patient needs and how can we use this information to improve patient-clinician communication? In the 2011 Pew Internet Survey, 34% of the Internet users had read someone else's experience or commentary about health or medical issues via forums, blogs, case studies and testimonials of various kinds [1]. Preece [2] has argued that "Physicians can provide the facts, but other patients can tell you what it really feels like and what to expect next, in a way that only someone with personal experience can" (p. 63) and Ziebland et al have tried to document the different kinds of support needs that patients have, that are not entirely met by their clinicians [3]. Empirical studies on peer to peer health communication have particularly focused on those chronic conditions considered serious – such as HIV/AIDS [4] - and they have typically focused on a single health condition, and/or multiple conditions considered similar (e.g., degenerative neurological diseases, [5]). Whilst such research is important and insightful, the narrowed focus limits the degree to which comparisons can be made across different types of health conditions.

A large National Institute for Health Research (NIHR) program is currently seeking to explore the role of online patient experience for health decision making in three different kinds of health groups: asthma sufferers, smokers wanting to quit, and carers of someone with multiple sclerosis (MS) – see www.ipexonline.org. These three patient groups were chosen to reflect different types of health conditions (i.e., patients with a chronic health condition, individuals looking for a health behavior change, and individuals who are responsible for someone with a serious life threatening health condition). In collecting data from the groups in three

studies, the researchers noticed engagement disparity with the online health information and patient experiences. This was observed in terms of reaction and interest in the materials shown during the study, participant's engagement with similar material before and after the study, and whether they thought online patient experiences were useful. Of the three groups, the MS carers were the most engaged, with the asthma group and then the smokers showing the least engagement. In order to account for this disparity, we have conducted a secondary analysis of the qualitative data provided in these three groups to draw up an engagement framework that helps us understand different communication and engagement needs across diverse patient groups. In this paper we present this framework and also discuss ways in which it might be used to support patient-clinician communication.

Method

This paper is based on secondary analysis of data from three studies conducted in the UK between 2011 and 2012 by the authors. For this study, qualitative data from focus groups and interviews (including follow-up telephone interview in studies two and three) were used. In total, the pooled-sample comprised of 74 participants, including 29 asthma sufferers, 25 smokers considering quitting, and 20 personal carers of people with MS.

Results

The first point we should note is that the ways that different patient groups engaged with the material was a direct function of the quality and quantity of material available both on and offline. Here there were notable variations between patient groups. For *Asthma Sufferers* good information about the condition was

provided by the individual's clinician. Patients consequently showed high confidence in that information and felt that they understood the condition well enough. As a consequence they were relatively disinterested in peer information available online: *"I got given an information pack from the doctor that was from the NHS, but have not really looked online. Because they just gave me the pack, so I thought that would have all of the information that I needed"*.

For *Smokers* there was a consensus that health information about smoking and quitting could be found from various sources without the need to go looking online: *"I don't think you need to look for on the Internet. It's on buses. It's on the TV. You don't need to go looking for it they tell you every time stop smoking it's bad for you..."*

In contrast, *MS Carers* felt that clinicians, charities, support groups, friends or family provided insufficient information and as a consequence were keen to go online for further information and advice. Participants felt they could compensate for the absence of physician led material by seeking information online and the first port of call for finding out about symptoms of the conditions and other people's experiences: *"I've used the Internet ... because we'd had very little information from the hospital..."*
"No, not the doctor, he was as much use as a chocolate fire guard ... we used to get two copies of MS Matters, which is the in house magazine from the MS Society... And so I used to send one down to the doctors surgery and it has improved her appreciation of the illness. But that was the case pretty much."
"Yeah, yeah I think nowadays it [the Internet] tends to be kinda a first port of call. I think we kind of resolved

that we, the experience we get at the yearly consultants appointment. Usually a 10-15minute conversation with the consultant where she basically tells them what their symptoms have been so far and give it another year. We don't get any more information"

However, where there was interaction with online information – across the three patient groups – it became clear that there were many different types of patient engagement with the material (Figure 1) and these are captured in a new engagement framework that better helps us understand patient needs.

The framework comprises the three stages – *gating, engagement* and *outcome* - that users appear to move through when interacting with patients experiences online. In Phase I, the patient makes a swift judgment about the look and feel of the site, preferring a clean, professional design that is easy to navigate. He or she also notes the organization behind the site: Is it known? Does it have a good reputation? Is it impartial and free from commercial overtones? In Phase II, they begin by attend to the *'who'* and the *'what'* of the experience. They explored the relevance in relation to their own understanding and situation by *comparing* themselves to the online patient voices and by assessing the ways in which patients were able to *share* their experience. In Phase III, patients anticipate the costs and benefits of further engagement with patient experience and in some cases begin to experience those outcomes directly. Benefits include an increase in participants' knowledge, motivation, and feelings of being supported, but costs can include reduced motivation and disengagement if the stories are too graphic or if the content is overly commercial.

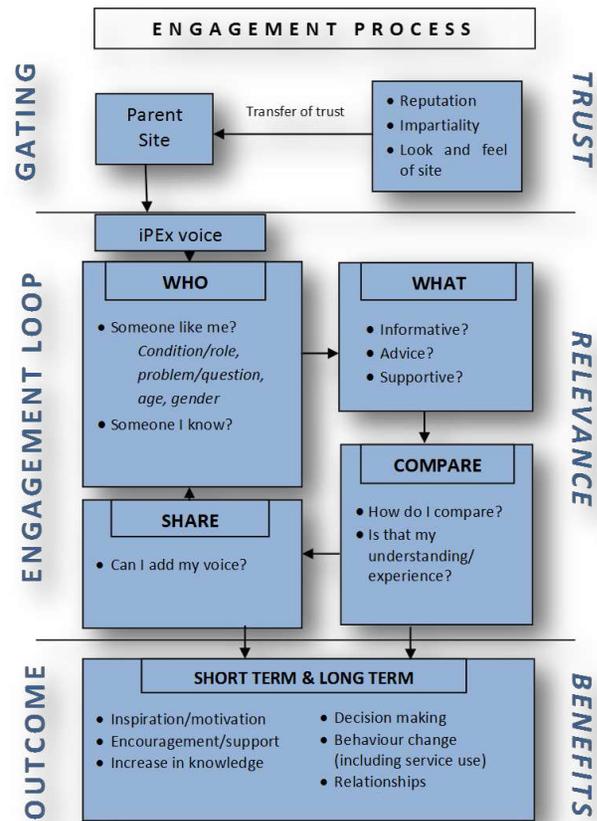


Figure 1: A framework that captures patient engagement with peer information online

The separation of components in each of these stages is useful to our further understanding of patient communication needs, allowing us a chance to understand which types of information are engaging for which type of patient? In terms of patient-clinician communication, we know patients vary in coping strategies and have health needs around anticipation

(finding out all about it, making sense), coping by emotional/social support, and coping by action. This framework will help us map these coping strategies onto the information available more systematically, i.e. it can be used by clinicians as a means of categorizing the different kinds of peer information, advice, and support available and matching these to patient needs in the clinical setting.

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